

Remote self-testing for sexually
transmitted infections, within
online care pathways:

How could this intervention deliver
public health benefit?

Formative research using chlamydia as an exemplar

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Declaration:

I, Catherine Rhiannon Helen Aicken, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signed: 

Abstract

Sexually transmitted infections (STIs) remain a public health challenge in England, despite free, confidential testing/treatment services. The eSTI² Research Consortium is developing a diagnostic self-test for STIs, to be deployed within online care-pathways. Should this intervention lead to increased STI detection and prompt effective treatment, it could reduce transmission and morbidity. Through a scoping review and three studies I explored its potential to benefit public health, thus informing the intervention's ongoing development.

The review (2013) found diverse uses of internet/electronic communications in STI care-pathways, but little research was transferable to remote self-testing or management.

Current internet-use for sexual health may predict use of the proposed intervention, so I estimated its prevalence, and identified associated factors, using British probability survey data (2010-12). Among sexually-experienced 16-44-year-olds (n=8926), internet-use for STI testing/treatment was rare (<0.5%), but available services were limited. 4.5% women and 4.6% men reported internet-use for information/support with their sex-lives, elevated among the better-educated and some STI risk-groups including young people.

In qualitative interviews, 25 young people at risk of STI expressed enthusiasm for a (hypothetical) STI self-test within online care-pathways. Findings informed colleagues' development of eSTI²'s Online Chlamydia Pathway (OCP). For people requiring chlamydia treatment, this included: online automated medical assessment, a helpline, and community pharmacy treatment collection or facilitated clinic access.

I undertook and thematically-analysed 40 qualitative interviews with OCP users, within pilot studies. Participants valued the rapid, convenient and discreet treatment access, increased control over their healthcare, and optional professional support by telephone, enabled by the OCP. Offline parts of the

pathway (pharmacy/clinic attendance) risked compromising its perceived advantages, and require further development.

Recommendations derived from an iteratively-developed understanding of this complex intervention's use and appeal, can enhance its potential to enable STI detection and treatment, promptly, effectively and acceptably. Future evaluation must consider impacts on health inequalities.

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Glossary

aAOR	Age-adjusted odds ratio
AOR	Adjusted odds ratio
app	Application: a computer programme or piece of software designed to perform a particular function (distinct from software which supports the device's operating system) ¹¹
BASHH	British Association for Sexual Health and HIV
BBVs	Blood-borne viruses (e.g. HIV, hepatitis C)
Britain	England, Wales and Scotland
CAPI	Computer-assisted personal interview – in which an interviewer inputs a research participant's responses to survey questions into a computer
CASH	Contraception and sexual health
CASI	Computer-assisted self-interview – in which the research participant inputs their own responses to survey questions into a computer
care pathway	See p58
Checkurself	One of the services commissioned to provide postal home-sampling kits which are ordered online or via text message, within the National Chlamydia Screening Programme (NCSP)
Chlamydia-OCCP	See OCP
CI, 95%CI	confidence interval, 95% confidence interval
co-infection	In the context of this thesis, simultaneous infection with multiple STIs, e.g. gonorrhoea and chlamydia
community pharmacy	Pharmacies which deliver services in community settings (vs. hospital/clinic settings), e.g. high-street/retail; part of primary care. Colloquially known as 'chemists'
complex intervention	See p135
contact tracing	See PN
CTAD	Chlamydia testing activity dataset, Public Health England's surveillance dataset programme for chlamydia testing
DCE	Discrete choice experiment, a health economics <i>'quantitative technique for eliciting individual preferences [which] allows researchers to uncover how individuals value selected attributes of a programme, product or service'</i> ¹²

DH	England's Department of Health
digital literacy	<i>'the capabilities which fit someone for living, learning, working, participating and thriving in a digital society'</i> ¹³
DNA	Deoxyribonucleic acid, molecules which store genetic information Also, 'did not attend' (in the context of patients' missed medical appointments)
eHEALS	The e-health literacy scale, ¹⁴ a self-reported survey measure of e-health literacy
e-health	See p53
e-health literacy	See p349
epidemiological treatment	<i>'[T]reatment given to named [sexual] contacts after a history of exposure [to an STI] but without or in advance of confirmatory pathological findings – namely, treatment in advance of diagnosis'</i> ¹⁵
epididymo-orchitis	Inflammation of the epididymis and/or testicles
e-prescribing	Electronic prescribing
eSHC, eSexual Health Clinic	See OCP
eSTI ²	<i>Electronic Self-Testing Instruments for Sexually Transmitted Infection Control</i> , the Research Consortium to which this doctoral research is attached
FE	Further Education. FE colleges provide post-compulsory education for those aged 16 and older, often vocational, and are distinct from Higher Education institutions (universities) which provide degree-level academic qualifications
GCSEs	General Certificates of Secondary Education, qualifications typically taken at age 14-16 in England, Wales and Northern Ireland
gender	In this thesis I use 'gender' to mean female or male. The way I use the term 'gender' allows me to use 'sex' to refer to sexual intercourse, avoiding confusion. (I recognise that 'gender' is used elsewhere to refer to feminine or masculine social and cultural roles, or personal identification, as distinct from a person's sex which is defined biologically. However, 'sex' and 'gender' are often used interchangeably in recent academic literature ¹⁶)

GP	General practitioner
GUMCADv2	Genitourinary medicine clinical activity dataset (v2), Public Health England's STI surveillance programme, in place during this doctoral research
GUM clinic	Genitourinary medicine clinic; sexual health clinic
HA	See 'Sexual Health Adviser'
HBM	Health Belief Model
HCI	Human Computer Interaction, a field of research on the design and use of interfaces between human users and computer technology
health literacy	<i>'the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health'</i> ¹⁷
HTI	Human-Technology Interaction
HIV	Human immunodeficiency virus
HPV	Human papilloma virus
ICT	Information and communications technologies
IMD	Index of Multiple Deprivation, a measure of area-level socioeconomic deprivation ¹⁸
index patient, index case	<i>'[A] patient with an STI whose partners need to be notified'</i> ¹⁹
IPN	Internet partner notification, see chapter 2, section 2.3.6
IQR	Inter-quartile range
IRAS	Integrated Research Application System (for approval of research within the NHS)
ISSTD	International Society for Sexually Transmitted Diseases Research
MHRA	Medicines and Healthcare products Regulatory Agency
MRC	Medical Research Council
MSM	Men who have sex with men
Natsal	Britain's National Survey of Sexual Attitudes and Lifestyles, described and analysed in chapter 4
NAAT	Nucleic acid amplification test, described in chapter 1, p51
NCSP	England's National Chlamydia Screening Programme, which targets sexually-active people aged under 25 years

near-patient testing	Testing of a sample close to the patient, without sending it to a lab
negative cases	In qualitative analysis, cases which do not seem to fit the patterns observed in the rest of the data, ²⁰ and which can be used to help refine explanations generated in the analysis. ²¹ (Also known as ‘deviant cases’)
NHS	UK National Health Service
NICE	National Institute for Health and Care Excellence (formerly, National Institute for Health and Clinical Excellence)
ns	Not statistically significant
NS-SEC	National Statistics Socioeconomic Classification
OAC	Output-area classification, a categorisation of demographically similar localities based on census data
OCP	eSTI ² ’s Online Chlamydia Pathway, described in chapter 6. [Synonymous with: ‘Chlamydia Online Clinical Care Pathway’, ‘Chlamydia-OCCP’, terms which were used by the eSTI ² team in early publications. eSTI ² publications also use the term ‘eSexual Health Clinic’ (eSHC), a broader term reflecting the potential to incorporate additional sexual health services, in future. However in this thesis, I use OCP, as the more specific term]
ONS	Office for National Statistics
OR	Odds ratio
partner	Used in this thesis to mean sexual partner (see sexual partner)
partner notification	<i>‘[T]he process of contacting the sexual partners of an individual with a sexually transmitted disease and advising them that they have been exposed to infection. By this means people at high risk of an STD [STI], many of whom are unaware that they have been exposed, are contacted and encouraged to attend for screening and treatment’²²</i>
patient referral	Partner notification (defined above) in which the index patient is encouraged to inform their past and current partners of exposure to STI ²³
PC	Personal (desktop) computer
PCR	Polymerase chain reaction
PHE	Public Health England, the body responsible for England’s national public health surveillance, within the Department of Health.

PI	Principal Investigator
PID	Pelvic inflammatory disease
PIS	Participant Information Sheet
PN	Partner notification; see also patient referral, provider referral
POCT	Point-of-care test, defined on p52
PrEP	Pre-exposure prophylaxis: anti-retroviral medication which can be given to people at high risk of HIV infection, in order to reduce their risk of becoming infected with the virus if exposed to it
provider referral, provider-led PN	Partner notification (defined above), where health professionals notify the partner of their exposure to STI without disclosing the identity of the index patient ²³
RCT	Randomised controlled trial
reactive	Some rapid tests give either 'negative' or 'reactive' results. A reactive result is preliminary, and further confirmatory tests need to be performed
remote	In the context of this thesis, away from traditional healthcare settings, e.g. in the patient's home
RHA	Research (Sexual) Health Adviser, a Sexual Health Adviser (see below) in a research role
RNA	Ribonucleic acid
SD	Standard deviation
self-sampling	Self-sampling involves a person taking their own sample (e.g. urine, vulvo-vaginal swab), either for self-testing or to be tested by others, e.g. in a laboratory
self-testing	I define self-testing as testing which involves the user taking their own sample, and operating testing technology themselves (in the research literature, this term is sometimes used unclearly, to refer to self-sampling where the user does not actually test their own sample)
sensitive, sensitivity	The sensitivity of a diagnostic test is ' <i>the proportion of true positives that are correctly identified by the test</i> ²⁴ '; if its sensitivity is high, there will be few false-negative results
serovar	A variation within a species or sub-species of virus or bacteria, classified by surface antigens
Sexual Health Adviser	<i>'Sexual health advisers work in Departments of Genitourinary Medicine (GUM clinics) in the UK and Ireland. [...] The role of</i>

*the sexual health adviser varies enormously from clinic to clinic. It involves working with individuals and groups affected by issues related to sexual health in general and sexually transmitted infections (including HIV) in particular. Their role will commonly embrace the following features: partner notification/contact tracing; sexual health promotion; teaching/training; counselling; research and audit'*¹⁹

sexual partner	In this thesis I use the definition of (sexual) partners used in the Natsal-3 questionnaire: <i>'People who have had sex together, whether just once, or a few times, or as regular partners, or as married [or cohabiting] partners'</i> ²⁵
SHA	Sexual Health Adviser, see above
specific, specificity	The specificity of a diagnostic test is <i>'the proportion of true negatives that are correctly identified by the test'</i> ²⁴ ; if its specificity is high, there will be few false-positive results
STD	Sexually transmitted disease, synonymous with STI (the preferred term)
STI	Sexually transmitted infection (in this thesis, use of the term 'STI' excludes HIV)
UK	United Kingdom of Great Britain and Northern Ireland
US	United States of America
VD	Venereal disease, an archaic term for sexually transmitted infections
VVS	Vulvo-vaginal swab
webcam	A video camera which can be used to stream (transmit) live images, online
WHO	World Health Organization
WS	Workstream (of the eSTI ² Research Consortium)
WSW	Women who have sex with women

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Publications and conference presentations

Peer-reviewed journal articles presenting findings from this thesis

Aicken CRH, Estcourt CS, Johnson AM, Sonnenberg P, Wellings K, Mercer CH. Use of the internet for sexual health among sexually experienced persons aged 16 to 44 years: evidence from a nationally representative survey of the British population. *Journal of Medical Internet Research*. 2016;18(1):e14.

Chapter 4 (thesis objective 1)

Aicken CRH, Fuller SS, Sutcliffe LJ, Estcourt CS, Gkatzidou V, Oakeshott P, Hone K, Sadiq ST, Sonnenberg P, Shahmanesh M. Young people's perceptions of smartphone-enabled self-testing and online care for sexually transmitted infections: qualitative interview study. *BMC Public Health*. 2016;16:974.

Chapter 5 (thesis objective 2)

Aicken CRH, Sutcliffe LJ, Gibbs J, Tickle LJ, Hone K, Harding-Esch E, Mercer CH, Sonnenberg P, Sadiq ST, Estcourt CS, Shahmanesh M. Using the eSexual Health Clinic to access chlamydia treatment and care via the internet: a qualitative interview study. *Sexually Transmitted Infections*. Published Online First, 7th October 2017. doi: 10.1136/sextrans-2017-053227

Chapters 6 and 7 (thesis objective 3a)

Appendix 14 provides full texts of the above articles.

Peer-reviewed journal article integrating qualitative findings from chapter 7 (section 7.2.2) with data from colleagues' quantitative research

Gibbs J, **Aicken CRH**, Sutcliffe LJ, Gkatzidou V, Tickle L, Hone K, Sadiq ST, Sonnenberg P, Estcourt CS. Mixed-methods evaluation of a novel online sexually transmitted infection results service. *Sexually Transmitted Infections*. Published Online First: 11 January 2018. doi: 10.1136/sextrans-2017-053318

Conference oral presentations presenting findings from this thesis

Aicken C, Sutcliffe L, Gibbs J, Tickle L, Shahmanesh M, Sonnenberg P, Sadiq ST, Estcourt CS. 0010 Use and perceptions of the Online Chlamydia Pathway (OCP): findings from qualitative interviews among people treated for chlamydia. British Association for Sexual Health and HIV (BASHH) conference, Oxford, July 2016.
Abstract published in *Sexually Transmitted Infections*. 2016;92(Suppl1):A4-A5.
Chapters 6-7

Aicken C, Fuller S, Sutcliffe L, Gibbs J, Tickle L, Estcourt CS, Sonnenberg P, Mercer CH, Johnson AM, Sadiq ST, Shahmanesh M. Online care for sexually transmitted infections: using qualitative research in intervention development and evaluation.
Society for Social Medicine Annual Scientific Meeting, York, September 2016.
Abstract published in *Journal of Epidemiology and Community Health*. 2016;70(Suppl1):A23.
Chapters 5-7

Conference posters presenting thesis findings and doctoral research plans

Aicken C, Sonnenberg P, Estcourt C, Johnson A, Mercer C. Who uses the internet for sexual healthcare? Evidence from a nationally-representative survey of the British population.
UCL Festival for Digital Health, London, 23-25th June 2014. Chapter 4

Aicken CRH, Sutcliffe LJ, Estcourt CS, Gibbs J, Tickle LJ, Sonnenberg P, Sadiq ST, Shahmanesh M. Getting your Chlamydia care online: Qualitative study among users of the Chlamydia Online Clinical Care Pathway (Chlamydia-OCCP), in a proof-of-concept study.
International Society for Sexually Transmitted Diseases Research (ISSTD)
World STI Congress, Brisbane, Australia, September 2015.
Abstract published in *Sexually Transmitted Infections*. 2015;91(Suppl2):A185.
Chapters 6-7

Aicken CRH, Estcourt CS, Gibbs J, Sonnenberg P, Mercer CH, Tickle L, Sutcliffe LJ, Sadiq ST, Shahmanesh M. 001 PP: Online clinical management pathways for chlamydia treatment: enriching formative evaluation of a complex e-health intervention.
UCL Qualitative Health Research Symposium. 18th February 2015.
Abstract published in *BMJ Open*. 2015;5:UCLSymposiumAbstracts12.
Chapters 6-7

In Appendix 13 I list further co-authored eSTI² Consortium publications which are related to this doctoral research, but which do not present findings directly arising from it.

Chapter 1: Introduction

1.1 Introduction

Sexually transmitted infections (STIs) are a major global public health problem, even in high-income countries with widespread availability of testing and treatment.²⁶ New diagnostic technologies to enable self-testing, and online clinical care pathways to enable patients to receive treatment without attending medical facilities and without a face-to-face clinical consultation, are being developed. Remote STI self-testing within online care pathways is a novel and complex e-health intervention. It offers a means for patients to engage with sexual healthcare which is radically different to that offered by conventional face-to-face, clinic-based services.

My doctoral research addresses the potential for a remote self-test for STIs, deployed within online care pathways, to deliver public health benefit. The context is England's publicly-funded National Health Service (NHS). My research contributes to the ongoing development and evaluation of this complex intervention, and to the wider evidence-base on internet-enabled healthcare. This PhD is attached to the eSTI² Research Consortium, which was established to develop a diagnostic test and care pathway, within a wider remit to conduct basic and translational research to enable enhanced STI diagnosis and management, using internet and mobile communication technologies.

This introductory chapter sets the scene for my research. I first describe the size and nature of the public health challenge caused by STIs in England, and identify demographic groups which are particularly affected (section 1.2). I then explain principles of STI epidemiology and transmission dynamics, which form the theoretical basis for how this novel intervention may contribute to STI control, and thus benefit public health (section 1.3).

By providing an overview of sexual healthcare in England and barriers to sexual healthcare-seeking (section 1.4), I describe the health service context for this novel intervention, and the limits to existing STI control activities. I explain

diagnostic advances, and political and financial pressures which shape NHS sexual healthcare, including future services such as the proposed remote self-test and online care pathways.

I describe the eSTI² Consortium in section 1.5, and then describe the proposed intervention in detail, including why the self-test is being developed for use within an online care pathway (section 1.6). As its use is reliant on information and communications technologies (ICT), I outline the evidence on access to and uptake of the internet and smartphones, including for healthcare (section 1.7). This chapter ends with an outline of the structure of this thesis (section 1.8).

1.2 Sexually transmitted infections: impacts, distribution and prevalence

This section describes the public health challenge of STIs. My thesis focuses on STIs other than HIVⁱ (and so use of the term ‘STI’ in this thesis excludes HIV). In my research, I use chlamydia, England’s most commonly-diagnosed bacterial STI,^{27,28} as an exemplar (justified in section 1.6.5). However, in this chapter I discuss STIs in general, because of their shared mode of transmission, and because the eventual self-testing device is envisaged to test for multiple infections. In this thesis, ‘chlamydia’ refers to genital infections caused by *Chlamydia trachomatis* serovars B and D-K,²⁹ unless otherwise stated.

1.2.1 What are sexually transmitted infections?

Sexually transmitted infections (STIs) are caused by pathogens (bacteria, viruses, protozoa) which are transmissible by sexual contact (oral, vaginal and anal sex, and for some viral STIs, by direct contact) between an infected, infectious person, and an uninfected, susceptible person.

STIs have relatively long infectious periods, and many prevalent STIs are asymptomatic for all or some of this time.³⁰ This means that they are often undiagnosed, and can be unknowingly transmitted.

1.2.2 Impacts on individuals’ health and well-being

Sexual health is defined broadly by the World Health Organization (WHO)³¹ as *a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity.* Reflecting this broad definition, in this section I make general points about the physical and psychosocial impact of STIs, with examples largely concerning chlamydia.

ⁱ HIV is a chronic infection requiring complex long-term monitoring and treatment, and with historic high mortality, and related to this, fear and stigma. It would not be possible or appropriate for people living with HIV to receive all their care remotely, online.

Morbidity

STIs can cause long-term morbidity, even in the absence of symptoms.³² Chlamydia can give rise to pelvic inflammatory disease (PID) in women,³³ which increases the risk of ectopic pregnancy^{34,35} and infertility.^{35,36} Chlamydia also causes morbidity in males (epididymo-orchitis), with some evidence for an effect on male fertility.³⁷ If untreated, genital chlamydial infection can cause painful conditions affecting other parts of the body, e.g. the joints (reactive arthritis) and liver (hepatitis).³⁸

Most bacterial STIs, including chlamydia, gonorrhoea and syphilis, can be cured (although antibiotic resistance is a particular problem for gonorrhoea).^{39,40} Early diagnosis and treatment reduce the likelihood of morbidity (for chlamydia, reducing the risk of PID-related infertility⁴¹ and ectopic pregnancy.⁴²) However, effective host immunity does not develop for curable STIs, so individuals are susceptible to repeat infections. People previously diagnosed with an STI are at increased risk of subsequent infection,⁴³⁻⁴⁵ because of reinfection from untreated sexual partner(s), continuing sexual risk behaviour,⁴⁶ and assortative sexual mixing patterns and clustering of STIs in certain populations (see section 1.2.3), which render exposure to STIs more likely among people whose partners are from these populations. Risks of PID and ectopic pregnancy increase with repeated chlamydial infection.⁴² Repeat positive test results following chlamydia treatment may also be due to persistent infection, i.e. treatment failure.⁴⁷

Due to their shared mode of transmission, individuals may be infected with more than one STI. Therefore, people diagnosed with (e.g.) chlamydia are advised to test for other STIs and HIV.⁴⁷

Psychosocial issues

A range of psychosocial issues are associated with STI diagnosis, which may affect patients' health-seeking behaviour (discussed in section 1.4.2) and what they want or need from sexual healthcare services.^{48,49}

Being diagnosed with an STI can be distressing, and may cause concerns about the medical implications of infection, stigma and implications for patients' relationships.⁴⁹ Therefore, patients may need psychological support^{50,51} and support with interpersonal issues^{50,52} (including partner notification, described in section 1.3.3). However, the stigmatising nature of STIs can affect who, among friends and family, patients feel able to call upon for support with their diagnosis.⁴⁹ Stigma can also lead to changes in the ways individuals diagnosed with STIs view themselves.⁵²⁻⁵⁶ This applies to chlamydia⁵⁷ even though it is a typically short-lived and curable infection. Based on research with women who had been diagnosed with chlamydia, and the work of the sociologist Bury, Duncan *et al.* discuss the implications of chlamydia's unpredictable effects on fertility, and its often asymptomatic yet stigmatised nature. They explain how, because of these characteristics, individuals' management of their chlamydia may primarily involve the management of 'meanings and risks to meanings',⁴⁹ i.e. its psychosocial consequences. (Notably, most research on stigma and STIs other than HIV, is among women, and much less among heterosexual men).

Other impacts

Impacts on individuals include time taken off employment and other responsibilities due to ill-health or to attend health services, the monetary cost of this, and transport costs. However, STI testing and treatment is free at the point of use within the NHS.

1.2.3 STIs in England: prevalence and distribution

Surveillance data and national probability survey estimates together provide evidence of the changing size and nature of STI epidemics, and inform the design and targeting of treatment and prevention strategies (outlined in section 1.4). In this section I describe the prevalence and distribution of STIs, including the STI 'risk groups' which I refer to in this thesis. I also describe the sources of evidence, because I refer to them in later chapters (STI surveillance: chapters 3, 5-7; Natsal surveys: chapters 3, 4).

Evidence from STI surveillance data

Rates of new STI diagnoses have increased since the mid-1990s,^{27,28,58-60} having previously fallen (perhaps due to reduced sexual risk behaviour in response to the HIV/AIDS epidemic and HIV prevention campaigns of the 1980s and early 1990s⁵⁹). Approximately 435,000 new STI diagnoses were reported in England in 2015, with chlamydia accounting for over 200,000 of these.⁵⁸ Rates of STI diagnosis are calculated from data provided by the NHS testing services which contribute to Public Health England's (PHE) STI surveillance programmes. These data show elevated STI diagnosis rates among young people aged 16-24 years, people of Black ethnicities, and men who have sex with men (MSM).^{28,58} Higher rates of STI diagnosis in urban areas⁵⁸ are partly explained by demographic variability: inter-ethnic differences in rates of STI diagnosis are attenuated once area-level deprivation (measured by Index of Multiple Deprivation, IMD) is taken into account,⁶¹ indicating that deprivation is also associated with STI.

Surveillance data can indicate changes in rates of diagnosed infection over time and their distribution across the population, but they do not accurately measure the true incidence or prevalence of STIs, for several reasons. First, undiagnosed infections are not counted; England's STI surveillance data are dependent on the number of people testing, and their characteristics. Therefore, increases in diagnoses can result from increased testing, and do not necessarily indicate rising prevalence or incidence. Second, surveillance and reporting practices can change, including which services contribute surveillance data (see section 1.4.1). Finally, testing practices and test accuracy have also changed over time.

Evidence from nationally-representative surveys

Representative population surveys which collect biological samples avoid these issues (except test accuracy) and can be used to estimate the population prevalence of STIs, whether or not people have tested through health services. Britain's decennial national probability sample surveys, the National Surveys of Sexual Attitudes and Lifestyles (Natsal-2 and Natsal-3), provide reliable prevalence estimates for selected STIs (Table 1).

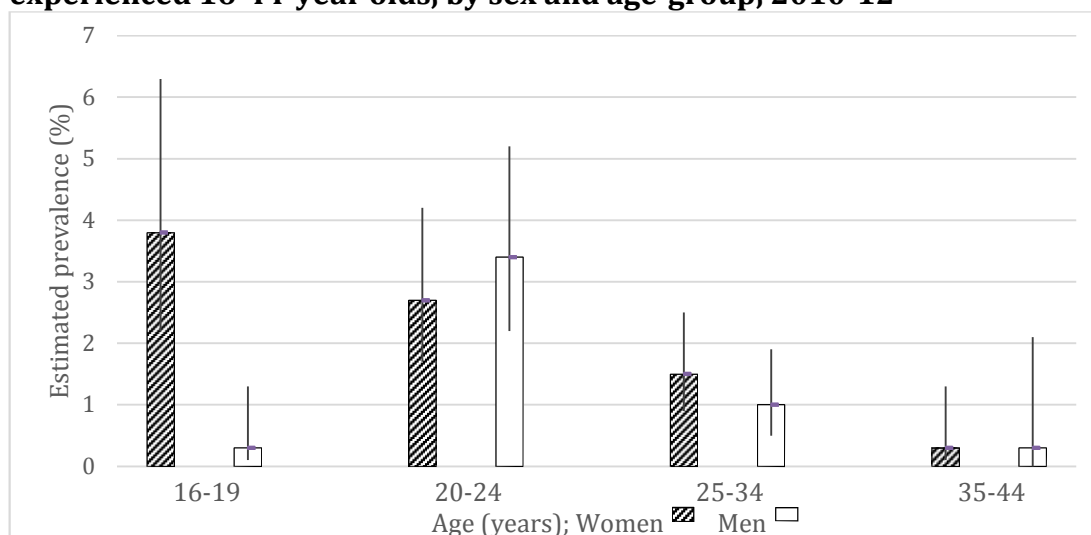
Table 1: Prevalence estimates of selected STIs in urine among sexually-active 16-44-year-olds in Britain, by sex, Natsal-3, 2010-12

	Women % (95% confidence interval, CI)	Men % (95%CI)
Chlamydia	1.5% (1.1-2.0)	1.1% (0.7-1.6)
Gonorrhoea	<0.1% (0.0-0.1)	<0.1% (0.0-0.1)
HIV*	0.1% (0.0-0.4)	0.2% (0.1-0.6)

Data from ⁶². *Test was for presence of HIV antibody.

Figure 1 shows estimated chlamydia prevalence by age, which is highest among 16-24-year-olds. Chlamydial infection is associated with reporting greater numbers of recent sexual partners, reporting condomless sex with multiple recent partners, and deprivation.^{62,63} Sexually-experienced 16-44-year-olds living in the most deprived areas (IMD quintiles 4 and 5) are considerably more likely to be infected with chlamydia than those living in the least deprived two quintiles, after adjusting for age and number of sexual partners in the previous year (adjusted odds ratio, AOR among women: 4.01, 95%CI 1.67-9.63, $p < 0.01$; AOR among men: 3.42, 95%CI 1.28-9.16, $p < 0.005$).⁶²

Figure 1: Estimated prevalence of chlamydia in urine among sexually-experienced 16-44-year olds, by sex and age-group, 2010-12



Natsal-3 data,⁶² showing 95% CIs for prevalence estimates.

In Natsal-2, conducted in 2000, elevated proportions of Black Caribbean men and women, and Black African men, reported having been diagnosed with an STI within the last five years, relative to the White population.⁶⁴ (Natsal-2

provides the most recent reliable estimates for Britain's largest ethnic minority groups). Surveys among sexual health clinic attenders^{65,66} have found larger inter-ethnic differences in the probability of diagnosis, but as a method for measuring the distribution of STIs in the general population, these suffer from selection bias.⁶⁴

Natsal data have many strengths (further discussed in chapter 4) in their potential to estimate the population prevalences of STIs and risk behaviours (little behavioural data is collected in PHE's current STI surveillance). Relevant to chapter 4's analysis, the surveys record reported sexual healthcare use and STI testing, so can be used to explore the extent to which those at high risk of STI are 'reached' by services (discussed in section 1.4.1). However Natsal studies also have limitations. First, representativeness: the sampling frame consists of residential addresses, and so excludes homeless and institutionalised people.⁶⁷ Second, in common with other national surveys, participation has decreased over time, however Natsal-3's sample is weighted according to gender, age and region, and comparison of the weighted data with census data revealed few differences with other key demographic variables.⁶⁷ Third, statistical power considerations limit the potential to explore associations with uncommon infections (e.g. HIV) or to estimate STI prevalence accurately among minority groups. Fourth, periodicity: it is not possible to examine changes in between the surveys or over shorter timeframes (which continuously collated surveillance data allow). As a final point, Natsal-3 data are representative of the British resident population (England, Scotland and Wales), but PHE surveillance data refer to England alone, because health is a devolved matter in the UK. However, according to census data,⁶⁸ England accounts for over 85% of Britain's population.

STI prevalence and distribution: Summary

Together, Natsal surveys and surveillance data justify continued efforts to control STIs, and a focus on STI prevention, testing and treatment among: young people, people of Black ethnic minority groups, men who have sex with men (MSM) and socioeconomically deprived populations (the key population groups

identified by England's Department of Health for targeted STI/HIV prevention.^{69,70}) Natsal data also support a focus on those with greater numbers of sexual partners, although as these people are not confined to any particular sociodemographic group, they are more difficult to identify.

1.3 STI transmission at the population level, and control strategies

Principles of STI epidemiology and transmission dynamics (section 1.3.1) form the theoretical basis for STI control strategies (outlined in section 1.3.2). Thus, they inform an understanding of how a novel intervention may deliver public health benefit, in terms of STI control. In section 1.3.3 I explain the public health roles of the STI control activities which are most relevant to my doctoral research: STI testing, treatment and partner notification.

1.3.1 Principles of infectious disease epidemiology, applied to STIs

STI transmission at the population level is operationalised in the basic reproduction number R_0 , the average number of new infections resultant from each primary case (each person who becomes infected) in a totally susceptible population, early in an epidemic (Equation 1). Where R_0 is greater than one, an infection can persist in the population; if below one, it is likely to die out.⁷¹

Equation 1: The basic reproduction number for STIs

$R_0 = \beta CD$	
Where:	β = probability of transmission per sexual partnership
	C = effective rate of sexual partner change
	D = duration of infectiousness

β , the probability of transmission per sexual partnership, is influenced by the number of times sexual contact occurs between an uninfected and an infected person, the type of sexual contact and whether condoms are used.⁷² It is also influenced by biology: the infectivity of the STI, the infectiousness of the infected person (varying by phase of infection and whether co-infection is present), and the uninfected person's susceptibility (also influenced by co-infection).⁷² C , the effective rate of partner change, is influenced by the mean rate (and variance) of partner acquisition, and patterns of 'sexual mixing' over time (e.g. serial or concurrent partnerships) and between population groups.⁷² D , the duration of infectiousness, differs between STIs and between infected individuals depending on their immune systems; it is influenced by co-infection,

curative treatment of curable STIs such as chlamydia, and suppressive treatment of non-curable STIs.⁷² (Suppressive treatment also reduces the transmissibility, β , of HIV⁷³⁻⁷⁵ and herpes⁷⁶).

D and β differ between STIs, but their durations of infectiousness are typically months or years, if untreated.⁷⁷ Therefore, transmission through the population can be maintained despite most people ‘acquiring’ new sexual partners relatively rarely.⁶⁰ However, sexual behaviour (represented by **C** and β) is the key determinant of STI transmission,⁷⁸ exemplified by the strong associations between chlamydia positivity, and reporting: higher numbers of recent sexual partners. and condomless sex with multiple recent partners.⁶²

1.3.2 Principles of STI control

STI control efforts rely on interrupting STI transmission by reducing β , **C**, and/or **D**, i.e. by influencing the ecology of pathogens and the behaviour of populations, in order to impact on STI incidence (Figure 2).⁷² The Figure also shows how STI control activities, like the epidemics they seek to curb, take place within a social context which can enhance or inhibit their effectiveness.⁷² For instance, structural factors and social stigma influence the uptake of STI services (discussed in section 1.4.2, and later in the thesis).

Figure 2: Transmission and control of STIs

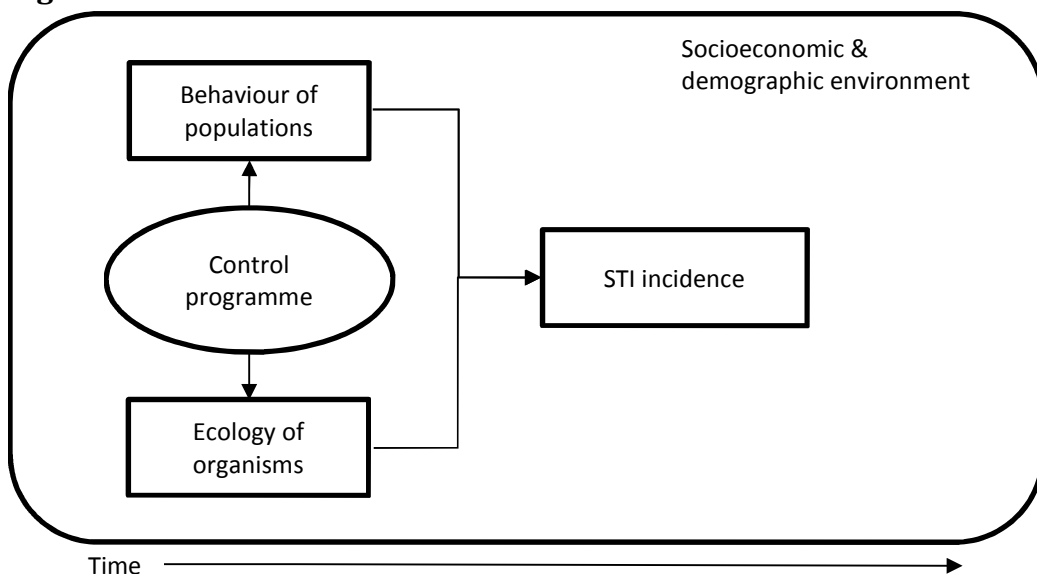


Figure adapted from ⁷². (Widely used in lectures by the authors; used here with their permission.)

Different STI control activities may be adopted depending on whether an infection is widespread within the general population (e.g. chlamydia, for which a screening programme exists), or largely restricted within 'core groups'⁷⁹ within which prevalence is high (e.g. gonorrhoea⁵⁸).^{80,81}

1.3.3 Public health role of STI testing, treatment and partner notification

STI testing, treatment and PN reduce the duration of infectivity of curable STIs, **D**, by case-finding and curing those infected, thus reducing onward transmission and **R₀**. By explaining this, and the role of STI services in providing one-to-one health promotion interventions, this section describes how STI services can benefit public health. I apply this understanding to the proposed novel intervention in chapter 3.

STI testing

Section 1.2 has explained how testing people at risk of STI, regardless of symptoms, is necessary because of the asymptomatic nature of many prevalent infections. Where present, STI symptoms are often non-specific (e.g. vaginal discharge, abdominal pain), and so diagnostic testing is normally still necessary.

Efficient STI case-finding is reliant on those at risk of infection being tested, and so health promotion messaging advises people with multiple sexual partners and those in risk groups to test regularly (young people are advised to test for chlamydia, and MSM and Black African people to test for HIV and STIs.²⁸) Of particular relevance to the thesis, STI testing services must be accessible to these groups, in terms of, e.g., their location, confidentiality and non-judgemental staff.^{82,83}

Treatment

Treatment of people infected with an STI reduces the risk of long-term morbidity and prevents onward transmission of infection, as discussed. Prompt receipt of diagnosis and treatment, enabled by prompt access to clinic,^{84,85} play a public health role by reducing transmission probabilities,⁸⁵ because patients

may continue to have unprotected sex before and during care-seeking.^{86,87} Chlamydia is treatable by oral antibiotics, but post-treatment, a person remains infectious for a short time, and so is advised to abstain from sexual contact during this period.⁴⁷ The threat of antimicrobial resistance – a particular problem for some STIs – makes it especially important that patients receive correct, complete treatment.⁸⁸

Partner notification

High reinfection rates, their consequences, and prevention of onward transmission, provide a strong rationale for notifying and treating sexual partners^{47,89} (PN, see glossary). PN reduce the duration of infectiousness (**D**) of curable STIs, because of the high likelihood that current and recent sex-partners of those diagnosed are also infected; prompt treatment of partners may therefore prevent further STI transmission.²² The population-level impact of PN on STI transmission has been demonstrated through mathematical modelling.^{90,91} The clinical effectiveness of supporting index patients (see glossary) with PN has been demonstrated empirically.²³

The likelihood of successful PN varies by partnership type,^{92,93} with patients being more likely to notify their 'main' or 'regular' sexual partners with whom they expect to have sex again, than 'casual' partners. Notifying, testing and treating regular partners helps prevent reinfection, but notifying casual partners may have greater potential public health benefit, because they are more likely to have other partners than are regular/cohabiting partners.^{80,94} PN for casual partners may be challenging and resource-intensive, due to index patients' reluctance or lack of contact details,⁹⁴ and so requires specialist support.

Other health interventions delivered by STI services

One-to-one health promotion interventions, delivered at testing, diagnosis or alongside a PN discussion, may encourage people to reduce risky sexual behaviour,⁹⁵ and the experience of STI testing or diagnosis may provide a 'teachable moment' for such interventions.⁹⁶ From a health perspective,

desirable behavioural changes include: consistent condom use (reducing **β**), limiting partner numbers (reducing **C**), and regular testing (reducing **D** through earlier diagnosis and treatment of subsequent infections).

Broader sexual health needs regarding, e.g., contraception, sexual assault, or sexual dysfunction, may be addressed directly or through onward referral. Accessing sexual healthcare also presents an opportunity to engage patients in relation to health and social needs that cluster together with sexual risk behaviour, e.g. alcohol and drug abuse,⁹⁷⁻¹⁰⁰ poor mental health,^{99,101,102} and sexual exploitation.¹⁰³

1.4 Sexual healthcare for STIs in England: services and policies

In order to contextualise e-healthcare for STIs, and describe the need and political support for it, in this section I describe existing services which are referred to throughout this thesis, their reach, barriers to their use, and relevant policy. I outline patients' care pathways through these services, for comparison with the novel intervention (described in section 1.6), and describe how progress in diagnostic technologies shapes the delivery of existing and future STI testing services.

1.4.1 Sexual healthcare in twenty-first century England: current services

Until relatively recently, almost all STI testing and treatment occurred in GUM clinics:⁸¹ specialist, publicly-funded clinics which still play a major role in sexual healthcare. GUM clinics are accessible without referral, and provide free STI testing and treatment (without the prescription charges which normally apply in the English NHS), confidentially (patients do not have to reveal their identity, and medical records are kept separate from other NHS records). These features reflect a long-standing recognition that STIs are stigmatised, and that barriers to service use could delay STI treatment access.¹⁰⁴ (Appendix 3 gives a brief history of GUM clinics).

The National Strategy for Sexual Health and HIV

In 2001 the government produced England's first National Strategy for Sexual Health and HIV,⁶⁹ heralding an expansion of access to STI services through increased testing and treatment outside of GUM clinics, faster access to GUM clinics, and a national screening programme for chlamydia, the NCSP.¹⁰⁵

The National Strategy defined three levels of sexual healthcare provision (detailed in more recent guidance¹⁰⁶). For STIs, GUM clinics are defined as 'Level 3' services, primary care services with expertise in STIs as 'Level 2', and 'Level 1' is basic sexual health service provision, e.g. that provided in ordinary general practices. Young people's clinics and other combined contraception and sexual health clinics tend to provide Level 2 STI services (sometimes Level 3). Commissioning of services has not strictly adhered to Levels 1-3, but I refer to

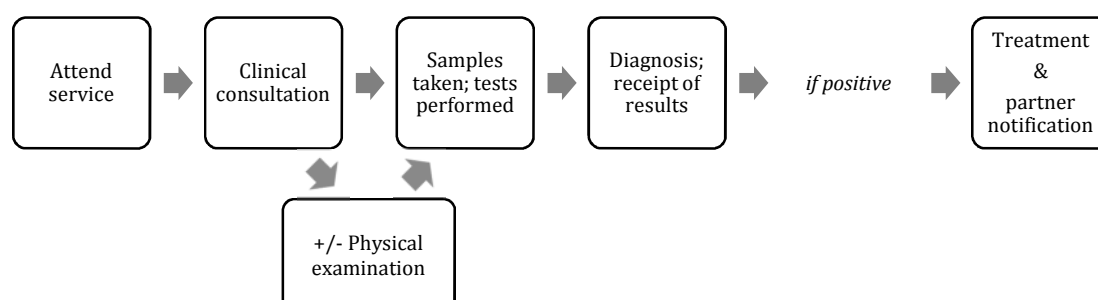
them because they illustrate the diversity of NHS sexual healthcare. (Contraceptive and reproductive health services are often provided within STI services, but are not discussed here, reflecting this thesis' STI focus.)

Level 3: GUM clinics

GUM clinics offer comprehensive STI testing and treatment, and account for the majority of reported STI diagnoses.¹⁰⁷ Typically, patients are offered diagnostic testing for chlamydia, gonorrhoea, syphilis and HIV, and, where appropriate, physical examinations and testing for additional infections.¹⁰⁸

Figure 3 shows a simplified care pathway for STI service provision in GUM clinics. At an initial clinic visit, a patient typically completes a paper or electronic form, and has a face-to-face clinical consultation. A sexual history is taken. Information collected serves to: document the patient's attendance, allow a medical assessment of symptoms or reasons for attendance; determine which tests/investigations are necessary; determine appropriate treatment and any further investigations; facilitate PN should the patient be diagnosed with an STI; enable communication of test results and follow-up, if necessary; and contribute to disease surveillance. Usually men provide urine samples, and it is not uncommon for women to take their own vulvovaginal swabs (VVS; 'self-sampling') for chlamydia and gonorrhoea testing. Depending on the patient's reported sexual behaviours, samples may be taken from other sites (pharynx, rectum). Clinical staff take blood samples for testing for HIV, syphilis and relevant blood-borne viruses (BBVs), and offer patients a physical examination where medically indicated.

Figure 3: Simplified care pathway for STIs: traditional service, e.g. GUM



In some services, clinic attenders reporting no symptoms, and who are determined to be 'low risk', may be offered a fast-track screening service, with self-sampling, and blood samples taken by staff. This may be offered as a 'no talk' service, involving minimal interaction with healthcare staff, if patients wish.^{109,110} Such initiatives are prompted by increasing patient numbers, pressure on staff time and resources, and by acceptability to some patients.¹⁰⁹

Patients are informed of their results by various methods (see chapter 2), approximately a week after testing, and must return to clinic to receive any necessary treatment.

GUM clinic patients who test positive are routinely offered PN support (for most STIs, including chlamydia⁸⁹). PN may be carried out by healthcare staff contacting partners ('provider referral'), but typically patients notify their partners themselves ('patient referral'), with services providing information, support and advice. Supporting patients with PN is a key role of GUM clinics' Sexual Health Advisers (see glossary). For many STIs, current and recentⁱⁱ sexual partners of the diagnosed person may be offered treatment based on their likely STI exposure,⁸⁹ without waiting for their own test results ('epidemiological treatment'), although samples may still be taken for surveillance, and because notification of partners' partners may be necessary.⁸⁹

GUM clinics deliver behaviour change interventions, and address broader sexual health needs (see p37).

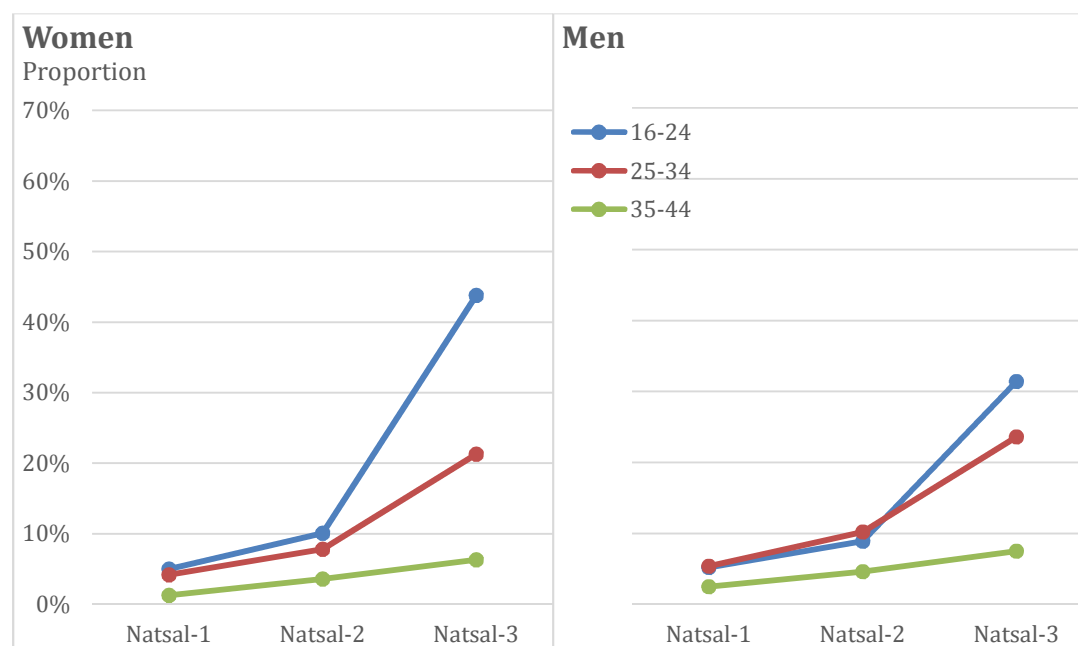
GUM clinics' reach and evaluation

The proportion of Britain's population reporting having used GUM clinics increased between 1990 and 2010-12 (Natsals 1-3), particularly among young people and those reporting higher numbers of sexual partners (Figure 4).⁶² This likely results from clinics' increased accessibility: prompted by the National Strategy, a target for patients to be offered to be seen within 48 hours of

ⁱⁱWithin a defined 'look back period', which varies by infection, presence of symptoms, and biological sex.

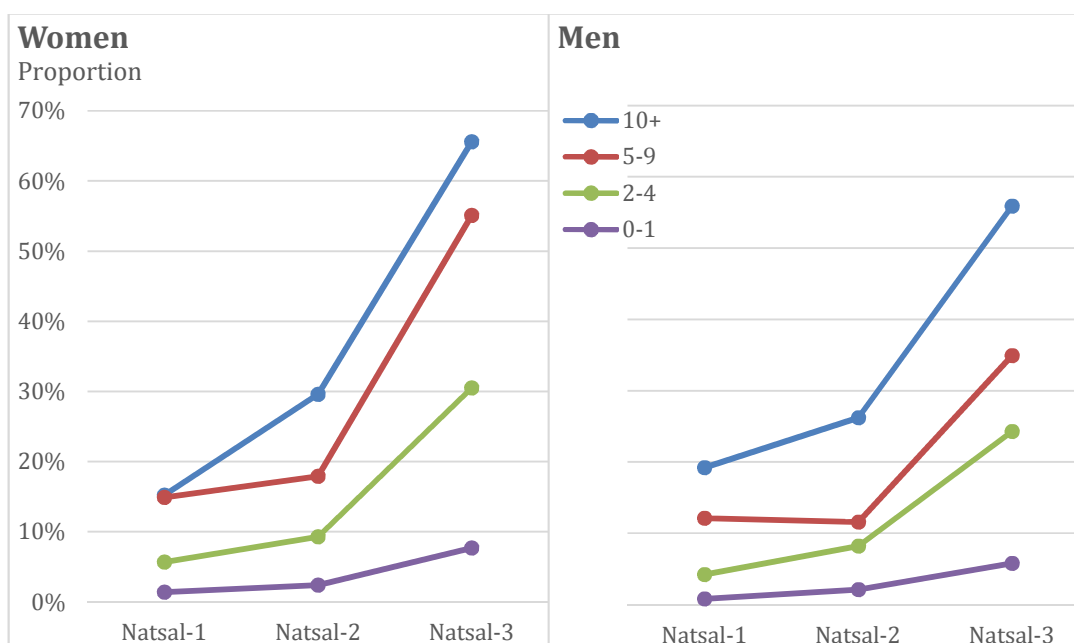
contacting a GUM clinic¹¹¹ was by various means¹¹² achieved for almost all patients by 2011.¹¹³ Clinic surveys found that, compared with 2004/5, patients in 2009 accessed GUM quicker, waited less time before seeking care, and symptomatic patients were less likely to report sexual activity since recognising their need to seek sexual healthcare.¹¹⁴ The 48-hour access target, and routine monitoring of waiting time data, ceased in 2011.¹¹⁵ A 2014 national audit suggested that access subsequently worsened,¹¹⁶ and in the same year it became a recommendation to offer access within 48 hours to 98% of those contacting GUM,¹⁰⁶ but with no requirement to monitor this.

Figure 4: Change over time in reported GUM clinic attendance within the previous five years, by age and reported number of sexual partners
GUM clinic attendance, by age:



(Figure 4, continued)

GUM clinic attendance, by number of sexual partners in the past 5 years:



Adapted from ⁶². Denominator: 16-44-year-old individuals reporting at least one sexual partner ever. Dates of survey administration: Natsal-1: 1990, Natsal-2: 2000, Natsal-3: 2010-12.

However, even in 2010-12 (with good access to GUM) significant proportions of people infected with or at risk of STI, were not testing, according to Natsal-3. For example, among 16-44-year-olds reporting ten or more partners in the previous five years, a third of women and a slightly higher proportion of men had not attended a sexual health clinic in this timeframe, and substantial proportions with prevalent STI reported no recent testing.⁶²

GUM clinics' auditable outcomes for PN refer to the number of partners per index case who are reported by the index case or by healthcare workers to have attended any sexual health service (Level 1-3), and the number per index case verified as having done so, within four weeks of the first PN discussion (for chlamydia and gonorrhoea, minimum targets range between 0.4 and 0.6 partners per index case, depending on infection and clinic location).¹¹⁷ Audits demonstrate that these outcomes are inconsistently recorded, and that there is wide between-clinic variation in how successfully they are achieved.^{118,119} However, the varied nature of sexual partnerships poses challenges to PN and its evaluation (including between-clinic comparisons): namely, the creation of

auditable measures of its impact (e.g. including partnership type⁹⁴ and number of exposed partners).¹²⁰ (This is discussed in chapter 2 in relation to internet-PN.)

Level 2 services

The care pathway for patients in Level 2 services is similar to that of GUM patients (Figure 3). Evidence from one area of England (Cornwall, 2009-2010) suggests that despite being less likely to report symptoms and sexual risk behaviours, patients using Level 2 sexual health services in general practice were as likely as GUM patients to be diagnosed with an STI, but waited longer to seek and receive care, with possible implications for STI transmission.¹²¹

Level 1 services within general practice

Since the National Strategy, general practitioners (GPs) have been encouraged to take on greater roles in sexual healthcare provision. GPs provide primary healthcare to local populations, and so are geographically accessible throughout the country. However, as healthcare professionals who do not (normally) specialise in sexual health, they report various organisational, personal and structural barriers to addressing it.¹²²

Despite this, general practice accounts for a substantial proportion of reported recent chlamydia testing (41.1%, 20.7%, among women, men respectively, in 2010-12,¹²³ including NCSP testing in general practice). In Natsal-3, people tested for chlamydia in general practice were less likely to report sexual risk behaviours than those tested in GUM, but a substantial minority reported unsafe sex and therefore may have been at risk of other STIs.¹²³ Those diagnosed with chlamydia outside GUM were less likely to report recent HIV testing, even though this is advised for everybody diagnosed with an STI.¹²³

GPs do not always manage STIs appropriately.¹²⁴ For instance, nationally-representative data demonstrated that a substantial proportion of people treated for gonorrhoea in general practice during 2000-2011 were prescribed antibiotics which were not recommended (65% in 2011), although incorrect

treatment of chlamydia was less common (1.5% in 2011).¹²⁵ As explained, this risks promoting antibiotic resistance, and may be less effective. The same study showed that chlamydia and gonorrhoea patients diagnosed in general practice were often referred to GUM for treatment,¹²⁵ and although they may be more likely to be managed appropriately there, their pathway to treatment may be extended¹¹⁴ and some may not attend.¹²⁵

PN in general practice varies, as some GPs may not consider it their role.¹²⁶ Indeed, the National Strategy did not list it as a role of Level 1 services,⁶⁹ although NICE later recommended that all sexual health services have arrangements for PN.¹²⁷

The National Chlamydia Screening Programme

England's NCSP, for sexually-active people aged under 25 years, began in 2003 and was implemented nationally by 2007-08. It promotes and provides opportunistic chlamydia screening, advised annually and upon change of sexual partner. Free self-sampling kits, for urine or VVS, are offered in healthcare, institutional and community settings, and can be ordered online or via text message in many areas (see chapter 2). Participants post samples to laboratories for testing,^{128,129} receiving their results some days later, typically by telephone or text message. Management of those testing positive occurs in healthcare settings or by phone, with treatment accessed in healthcare settings (e.g. clinic, GP, pharmacy – varying by locality). Figure 5 shows a simplified care pathway. No consultation takes place for people who test negative.

Figure 5: Simplified care pathway for chlamydia screening



Chlamydia screening: reach and evaluation

Screening coverage reached one-third of the target population in 2010, but declined to 23% in 2015 (32% of young women, 13% of young men).⁵⁸ In a

2013 audit, 94% were notified of their results within 10 days.¹³⁰ The NCSP has a target for at least 95% of those testing positive to be treated within six weeks of testing, but audits show that this was achieved for only 91%.^{130,131} Such timeframes are long, in terms of the potential for chlamydia transmission.

In Natsal-3, 16-24-year-olds reporting known risk factors (e.g. greater recent partner numbers) were more likely to report recent testing for, and to be infected with, chlamydia.^{62,63} However, three-in-ten women and over half of men aged 16-24 years and reporting multiple (2+) partners in the past year, had not tested during this period, and those at greatest risk of chlamydia infection were not always reached.⁶³ For example, residents of the most deprived areas were equally likely to report recent testing, but more likely to be infected, compared to residents of the least deprived areas; and young men aged 20-24 were less likely to report recent testing, but more likely to be infected, than 16-19-year-old men.⁶³

As they are locally commissioned, NCSP activities vary, e.g. by the presence and nature of internet-based services,¹²⁹ and whether there is testing for gonorrhoea^{132,133} (such 'dual testing' of low-prevalence community samples is questionable given the risk of false-positive results.^{133,134})

PN in the NCSP falls below national standards, based on audit data from 2015. 92% index cases were offered a PN discussion (vs. 97% standard). Within four weeks of this discussion, 0.53 contacts per index case were reported to have attended sexual health services (standard: 0.6) and 0.29 contacts per index case were verified as having done so by a healthcare professional (standard: 0.4).¹³⁵

STI surveillance programmes have expanded as services have diversified. Currently, GUMCADv2 covers all commissioned Level 2/3 services,¹³⁶ and CTAD includes all NCSP and non-NCSP chlamydia testing commissioned by Local Authorities and NHS-commissioned laboratories, including chlamydia testing in primary care¹³⁷ (acronyms are explained in the glossary). However,

surveillance programmes still have incomplete coverage, excluding non-chlamydial STIs managed in primary care, and private sector activities.

1.4.2 Healthcare-seeking for STIs, and barriers to engagement with STI testing and treatment services

Once a patient recognises a need to seek sexual healthcare, they may face various barriers to using existing STI services. Understanding these barriers, and sexual healthcare seeking behaviour, can help inform the development of accessible novel services.

Barriers to using sexual healthcare services

STI testing^{138,139} and attending dedicated STI clinics^{140,141} can be perceived as stigmatising^{142,143} (stigma is discussed overleaf). This can negatively impact upon patients' expectations and experiences of clinic attendance:¹⁴¹ they may perceive waiting rooms to be too 'public', or staff to be judgemental or unfriendly.¹⁴⁴ Feelings of embarrassment can deter sexual healthcare-seeking, with some patients particularly concerned about face-to-face consultations,¹⁴⁵ and the healthcare professional's gender.¹³⁸ However, previous sexual health clinic attendance may positively influence decisions to re-attend,^{123,145} suggesting that some barriers to clinic attendance are reduced by familiarity.

Young people report embarrassment¹⁴⁶ and stigma¹⁴⁷ associated with accepting offers of chlamydia screening, even though this requires no consultation.¹³⁹ Receiving chlamydia home-sampling kits by post, and home-self-sampling, has potential advantages for access to testing,¹⁴⁸ and avoids face-to-face interactions, but can compromise privacy from household members.¹³⁹ Home self-sampling also risks loss to follow-up and possibly poor index case management, compared with sampling by clinicians.¹⁴⁹ A systematic review comparing home self-sampling with sampling by clinicians, for chlamydia and gonorrhoea, found similar proportions of people were tested, diagnosed and treated, but harms associated with home-sampling were not evaluated in any of the RCTs included.¹⁴⁹

Patients attending non-specialist services (e.g. general practice) for sexual healthcare can avoid their reason for attendance being known to other patients. However, GPs may be perceived to offer lower-quality,¹⁵⁰ less confidential sexual healthcare.^{139,145} Some MSM may be disinclined to seek sexual healthcare from their GP, who may be unaware of their sexual orientation,¹⁵¹ and GPs may be reluctant to discuss sexual health with lesbian and gay patients.¹⁵²

GUM clinics tend to be attached to hospitals, in urban locations, so travel time and transport may be an issue for some, e.g. patients in rural areas. To address this, some GUM services run 'satellite' clinic sessions, or operate from community settings. Once in clinic, waiting times for walk-in sessions can be long (hours), such that patients may leave before being seen¹⁴⁴ (although changes to access, described in section 1.4.1, may have reduced this).

Concerns about procedures (e.g. physical examinations, methods for obtaining samples) may also deter people from seeking sexual healthcare.^{138,153} Although sampling methods have become less invasive (related to diagnostic advances, section 1.4.3), some people may be unaware of this, or have misconceptions.¹⁵³

Stigma as a particular barrier healthcare-seeking for STIs

Stigma related to STIs can deter people from using sexual healthcare or lead them to delay care-seeking; it influences how healthcare services are experienced and how they need to be delivered,^{48,49,53,57,138,141,154-156} primarily in terms of the need for privacy and confidentiality. Sociological theory on stigma helps to explain this.

Stigma has the dictionary definition of 'a connotation of disgrace',¹⁵⁷ and is understood by contemporary sociologists as occurring through a social process.^{158,159} Link and Phelan^{159,160} conceptualise stigma as the result of a process of interlinked components: the identification and labelling of socially-significant human differences; stereotyping of the labelled person (associating them with undesirable characteristics, e.g. 'promiscuity'); separation of 'them' from 'us', by group doing the labelling; the stigmatised individual/group's

experience of discrimination and loss of status; and the exercise of power (for stigma to exist, the former elements must 'occur together in a power situation that allows them to').^{159,160}

Sociological thinking on stigma was pioneered by Goffman, who noted how individuals with 'discrediting' attributes manage other people's impressions of themselves.¹⁶¹ For a person with a (suspected) STI or a history of sexual risk behaviour, these 'discrediting' attributes are not necessarily obvious or known to others: in Goffman's terms, the person is 'discreditable' (vs. 'discredited').¹⁶¹ Impression management involves concealment of the discrediting attribute,¹⁶¹ which contributes to delayed care-seeking for stigmatised health conditions.¹⁶⁰ Jones *et al.*, building on Goffman's work, identified six dimensions of stigma: how concealable the stigmatising characteristic is, its perceived origin, the danger others perceive it poses to them ('peril'), its disruptiveness to social interactions, aesthetics, and whether its presence is constant or changes over time.¹⁶² Applying some of these dimensions to STIs, their stigmatised nature reflects that they are contagious, 'perceived to be related to controllable and avoidable behaviours',¹⁶³ that they may disrupt sexual/romantic relationships, and, where symptomatic, may evoke disgust.

Goffman also described 'stigma cues', which can indicate to others the presence of a stigmatised and otherwise concealable characteristic.¹⁶¹ Engagement with STI testing, or GUM clinic attendance, can be stigma cues, because they may be perceived to indicate the presence of an STI, or that the person testing has engaged in risky, socially-sanctioned (or indeed, any) sexual behaviour.¹⁶⁴ People seek to avoid or conceal stigma cues,¹⁶¹ thus they may avoid engaging with STI testing services,¹⁶⁵ to avoid being judged as sexually promiscuous.¹³⁸ Different norms surrounding sexual behaviour, e.g. by gender, influence individuals' experience of stigma^{53,166} (see also chapter 6, Box 5), despite the liberalisation of attitudes towards sex which occurred during the last century.

Scambler and Hopkins distinguished between 'felt stigma' and 'enacted stigma' in their work on epilepsy: 'enacted stigma' refers to overt discrimination as a

result of having the condition, and 'felt stigma' to the fear of enacted stigma and sense of shame felt by those with the condition.^{158,167} They found that felt stigma had a greater impact on the lives of people with epilepsy, than did enacted stigma.¹⁶⁷ The concept of felt stigma helps explain how stigma can influence sexual healthcare-seeking in the absence of judgemental behaviour by healthcare staff, and where discreet access to confidential services is available.

The way sexual healthcare services are delivered may inadvertently increase stigma, or seek to reduce it and its impact. Targeting of certain population groups to encourage STI/HIV testing, e.g. through media campaigns, can reinforce sexism, racism or homophobia,¹⁶⁸ by implying that the targeted groups bear responsibility and accountability for STIs¹⁶⁹ or HIV.¹⁷⁰ Attempts to 'normalise' STI testing/chlamydia screening (e.g. through health education campaigns¹⁷¹) may aim to reframe testing behaviour as healthy and 'clean',¹⁶⁴ rather than dirty¹⁴¹ or indicative of 'promiscuity'.¹⁶⁴ Nevertheless, the confidential nature of the UK's GUM clinics, and provision of discreet access to non-judgemental services, remain important, helping patients conceal their diagnoses and sexual behaviours, and thus reducing the impact of stigma on patients' engagement with sexual healthcare.

Conclusion of sections 1.4.1 and 1.4.2

The reach of existing sexual healthcare provision is incomplete, and there is a role for novel services which address barriers to engagement with sexual healthcare. Novel services should enable comprehensive testing, prompt effective treatment, PN, and STI surveillance data collection to take place, and should enable related health needs to be identified and addressed.

1.4.3 Progress in diagnostic technologies and implications for service delivery

I provide an overview of diagnostic testing technologies, in order to explain how these technologies enable STI testing outside of specialist settings, and to situate the proposed self-test within this technological progression. Where

relevant, I focus on chlamydia, and distinguish between ‘self-sampling’ and ‘self-testing’ (see glossary).

Different STIs are detected in different ways, and by testing samples of urine, blood, or swabs (e.g. endocervical, urethral, VVS). Diagnostic advances influence service provision by changing which samples can be used to detect STIs reliably, and by changing requirements for sample transportation, equipment and staffing. For instance, at the end of the twentieth century, testing for many STIs relied on culture, and ELISA (see glossary), which detects pathogen-specific antibodies. Testing methods had relatively low sensitivity, and required invasive sampling. Culture requires the presence of live organisms, and is especially challenging for chlamydia, which survives only within living cells.¹⁷² Light microscopy, requiring specially-trained staff, can be used to detect of some STIs (but not chlamydia¹⁷²), with greater sensitivity if samples are cultured first.¹⁷³

In the early 2000s, testing for many STIs moved to highly-sensitive nucleic acid amplification tests (NAATs), which amplify (create copies of) and detect ‘target’ sequences of a pathogen’s genetic code. NAATs and other ‘molecular’ methods require tiny amounts of genetic material, and do not require the presence of viable organisms, so can be used to test urine (and other body fluids) and self-taken samples, with less stringent requirements for sample transportation (enabling postal sampling kits to be used for chlamydia testing). Self-sampling, in healthcare settings, patients’ homes or community venues, is acceptable¹⁷⁴ and produces accurate results.⁴⁷ NAATs revolutionised the diagnosis of many STIs, and they rapidly became the ‘gold standard’ due to their high sensitivity and specificity.

Point of care tests (POCTs) are used close to the patient and outside a laboratory. There is no agreed definition, but they are described in the 2013 WHO STI diagnosis manual as:

*tests that are simple and can be performed at all health care settings, especially at primary health care settings, with minimal training and [minimal] equipment.*¹⁷³

Such tests ideally meet 'ASSURED' criteria: affordable, sensitive, specific, user-friendly (requiring minimal training), rapid and robust, and delivered to those who need them.¹⁷⁵ Rapid, in this context, means provision of results within 30 minutes,¹⁷³ i.e. during a clinic visit.

Laboratory-based testing, by incurring delays in generating results (of approximately one week¹⁷⁶), risks loss to follow-up, and delays to treatment and PN, related to needing to re-attend clinic.¹⁷⁷ In contrast, POCTs and other rapid tests, deployed in clinical settings, can enable prompt treatment^{178,179} and can reduce or prevent loss to follow-up (i.e. patients not receiving results or not returning for treatment).^{180,181} This reduces onward transmission of infection can be, because sexual risk behaviour may continue during an interval between diagnosis and treatment.^{86,87} However, delayed treatment and loss to follow-up are risks if POCTs are deployed remotely from healthcare settings, as self-tests.

eSTI²'s proposed self-test is discussed in section 1.6.1. No accurate, rapid POCT or self-test for chlamydia is available within the lifetime of this PhD (those available online have performed badly in terms of accuracy^{182,183}), but progress in diagnostic technology is summarised in chapter 8.

1.4.4 Financial pressures on NHS sexual healthcare, and NHS reorganisation

Economically- and politically-motivated reorganisation of the NHS occurred during my doctoral research. A Conservative/Liberal Democrat coalition government was elected in 2010, during a recession (beginning 2008). Reforms were tabled which constituted a major reorganisation of the NHS, culminating in the Health and Social Care Act 2012. In 2013, commissioning of public health services, including sexual health services, moved from NHS Primary Care Trusts (which were abolished) to Local Authorities (councils).¹⁸⁴ Sexual health, including HIV testing, accounts for around 25% of this public health funding.¹⁸⁵

In chapter 8, I describe the situation at the end of my doctoral research; it suffices to say here that financial pressures on NHS sexual healthcare were apparent early in my research, and grew as it progressed.

1.4.5 Policies relating to e-health

This section provides an overview of the most relevant policy support for e-health, up to 2012. E-healthⁱⁱⁱ is defined by the WHO as:

*the use of information and communication technologies (ICT) for health. Examples include treating patients, conducting research, educating the health workforce, tracking diseases and monitoring public health.*¹⁸⁶

In 2010 the UK's new government issued a White Paper, 'Equity and Excellence: Liberating the NHS'.¹⁸⁷ Within a wider political agenda which sought to reduce government funding for public services, this paper promoted individual responsibility for health, and called for an 'NHS information revolution' and a 'patient-centred NHS'. It mentioned patients' use of internet technology to engage with NHS services, but for monitoring and self-management of long-term conditions, and to aid communication with clinicians (avoiding patients having to repeat information, if medical records were available online). It stated that the NHS

*lacks a genuinely patient-centred approach in which services are designed around individual needs, lifestyles and aspirations. Too often, patients are expected to fit around services, rather than services around patients*¹⁸⁷

thus presenting e-health as enabling a convenient, personalised service. The White Paper postulated that better access to health information and more convenient communication between clinicians and patients would increase efficiency. It noted the importance of equity in access, but made no mention of how this would be maintained or monitored, nor how health inequalities would be reduced. Later, the Innovation Health and Wealth commissioning guidance made an explicit commitment to support innovation within the NHS.¹⁸⁸ It briefly mentioned the potential convenience to patients of enabling some consultations

ⁱⁱⁱ 'm-health' and 'i-health' refer to healthcare enabled via mobile communications technologies and the internet, however I use 'e-health' as the more inclusive and widely-used term.

to take place online or by phone, and discussed how innovations could be rapidly evaluated and adopted ‘under tight surveillance and monitoring’.¹⁸⁸

Subsequent documents present similar ideas. In 2012, England’s Department of Health published ‘The power of information’, which focussed on communication with health professionals, electronic records, and access to health information,¹⁸⁹ and a ‘Digital Strategy’, which discussed how e-health could increase convenience for patients by reducing unnecessary face-to-face contact with healthcare professionals.¹⁹⁰ That year, the government’s digital strategy proposed ‘Digital by default’, which went a step further, challenging public services to consider online service provision in the first instance, and claiming cost savings would result,^{191,192} although with no clear basis for this assertion.

1.5 Research context: the eSTI² Research Consortium

This PhD was funded as part of the Electronic Self-Testing Instruments for STI Control (eSTI²) Research Consortium.

1.5.1 Aims and overview of the eSTI² Research Consortium

The eSTI² Consortium was a collaboration between several universities, Public Health England and commercial companies. It was funded as a United Kingdom Clinical Research Collaboration Translational Infection Research Initiative (UKCRC-TIRI) Consortium, for a five-year programme of research (February 2011 to January 2016). It aimed to reduce the public health impact of STIs by developing, testing and implementing rapid, accurate and affordable diagnostic polymicrobial tests (i.e. tests for multiple infections). Its research comprised four ‘workstreams’, each delivered by a team. Workstreams 1-3 concerned the development and validation of the diagnostic testing device (Appendix 1). My research was within Workstream 4: Clinical, Public Health and Economic Impacts (detailed below).

The diagnostic device being developed was envisaged to be deployed within the NHS, but with the potential to be used in various settings, e.g. community or healthcare settings, or wherever users chose to operate it, and with or without the presence of a health worker. My research focuses on the remote self-testing context, involving implementation of the self-test within an online care pathway (as will be described and justified in section 1.6).

1.5.2 Research team: Clinical, Public Health and Economic impacts

Workstream 4’s multidisciplinary team had expertise in public health, epidemiology, human-technology interaction (HTI), clinical genitourinary medicine, health economics and health services research. The scope and nature of my research were influenced by the team’s research activities.

Goals for Workstream 4 included the development of a prototype online clinical care pathway for people with chlamydia, and the care pathway’s ‘online interface’ (what users see on the screen, and the ‘back end’ visible to health

professionals involved in the delivery of care). Workstream 4 colleagues' research also addressed: the ethical, legal and regulatory framework within which the testing device and care pathways were being developed; what surveillance and clinical information needed to be collected and how this could be securely conveyed to NHS clinical services for patients' medical records, and to PHE for surveillance; the development of an online automated medical consultation; electronic prescribing; cost and distribution; and software design (contracted to a software company). Formative research to inform the development of the self-test and online care pathways included the study reported in chapter 5.

Building on this formative research, Workstream 4 colleagues developed and piloted the Online Chlamydia Pathway (OCP) in Exploratory Studies, to gain preliminary evidence of its feasibility, acceptability and safety,⁹ in advance of the availability of a self-test. Within these studies I conducted qualitative research to explore the use and appeal of the OCP (chapters 6-7), and to contribute to its refinement and evaluation.

1.5.3 eSTI² Consortium's objectives, their evolution and fit with my doctoral research

The eSTI² Consortium's objectives evolved over its five-year programme, and this influenced the scope, topic and timetable of my research. The most significant change was that we initially expected a remote self-testing device to be ready for a trial by early 2016. My own and Workstream 4's research activities were initially shaped by this expectation: the team anticipated evaluating the self-testing device within its online care pathway soon after. Mid-way through the five-year programme it transpired that this was unrealistic. A rapid-testing device might be feasible within this timeframe, but as a larger, desk-top machine, operated (e.g.) in a pharmacy. The goal of developing of a remote self-testing device for the accurate diagnosis of multiple STIs appears not to have been achieved by any other group, and development is ongoing.¹⁹³

1.6 What is remote self-testing within online care pathways?

Remote self-testing for STIs within online care pathways is a complex intervention,^{iv} the development of which began at the start of the eSTI² Consortium and this doctoral research. It is a novel proposal, in that:

- the test would be self-operated by lay-people (self-testing), without an initial consultation, 'remote' from healthcare settings and with minimal supervision; and
- the majority of the care pathway could be online.

Results would be received on the spot, and for those testing positive:

- treatment and care could be received 'remotely' (for some users), without seeing a healthcare worker or attending a clinical setting.

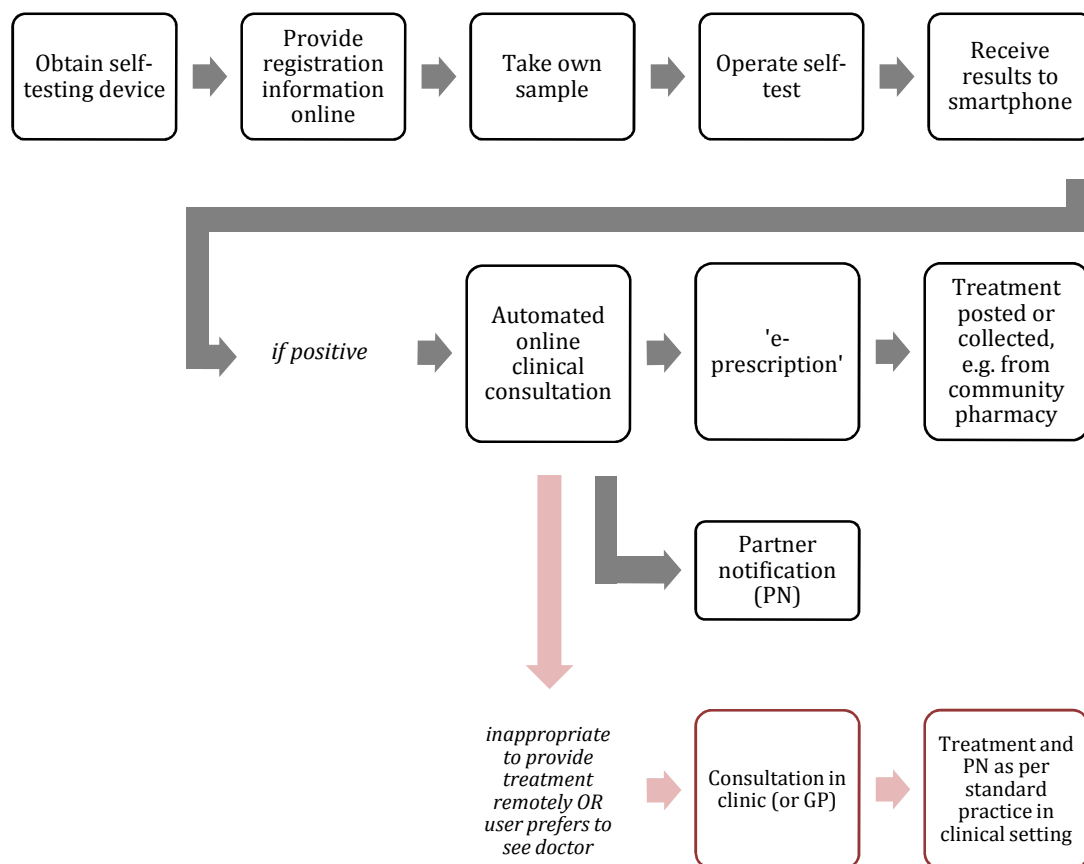
The novelty of the proposed intervention meant that research evidence was lacking, and made it a particularly interesting topic.

An accurate diagnostic self-test for STIs was postulated to reduce the barriers to STI testing described in section 1.4.2, although we lacked evidence about potential users' views on unsupervised self-testing (I addressed this in chapter 5's study). However, it is the online, remote care pathway which represents a radical departure from how health services have been delivered to date. Remote online clinical care pathways have not been available for any STI, nor any acute infection, within the UK or elsewhere, as far as the eSTI² team are aware.

Figure 6 shows the care pathway within which the proposed self-test would be used. In the remainder of section 1.6 I describe the self-test and the rationale for implementing it within an online care pathway.

^{iv} Complex interventions are further discussed in Chapter 3, p155.

Figure 6: Simplified care pathway including remote self-testing for STIs
(Compare with: Figure 3, p40; Figure 5, p45).



1.6.1 The remote STI self-test

The self-test is envisaged to be a 'lab-on-a-chip', accurate diagnostic self-testing device for multiple infections, operated alongside a smartphone (i.e. it would communicate with or be 'read' by the phone in some way). It would be a rapid test, operable by patients with minimal, remote supervision from healthcare professionals (e.g. a helpline). Using this device, lay-people could self-test for STIs at home or wherever convenient, and receive diagnoses electronically. Self-testing requires self-sampling, which, as explained in section 1.4, is already common in sexual healthcare.

1.6.2 The online care pathway

A care pathway (or clinical (care) pathway) is:

*a complex intervention for the mutual decision making and organisation of care processes for a well-defined group of patients in a well-defined period of time.*¹⁹⁴

Care pathways operationalise ‘patient-focussed care’¹⁹⁵ by organising what is required for each patient in the appropriate order. For STI testing and management, a care pathway must include: being tested, receiving results, and, if infected, receiving treatment and support with PN.

Online care pathways, in the current context, constitute a process by which users of the STI self-test could provide registration information to NHS services securely, online, using an application (‘app’). They would then operate the self-test, and receive results electronically. If diagnosed with (e.g.) chlamydia, they could undergo an automated online clinical consultation, leading to provision of appropriate treatment. They would input information, used for clinical and disease surveillance purposes, and would be able to access support if necessary, e.g. by telephone and/or face-to-face. Underlying the automated consultation, a clinical algorithm would check the safety and appropriateness of providing standard treatment, and a means of obtaining treatment would be provided (e.g. post, collection from a specified location). Health promotion information could be provided to all users, and PN would be supported by provision of information online (at a minimum).

Access to clinic-based care could be facilitated as part of the pathway, because it will be inappropriate for some patients diagnosed with an STI to receive the standard treatment, without a face-to-face consultation or physical examination (e.g. due to allergies/contraindications to standard treatment, symptoms suggestive of other health conditions, or the need for healthcare professionals to administer treatment for some STIs, in person). Furthermore, some patients may prefer to attend clinic, and facilitating this may reduce time to treatment and the risk of loss to follow-up. A route to face-to-face, clinic-based care is integral to the pathway (bottom of Figure 6, p58), however I refer to the entire pathway as an ‘online care pathway’, reflecting that it is internet-based, despite having ‘offline’ elements.

1.6.3 Why is an online care pathway needed?

An STI self-testing device could be marketed privately (for-profit), or distributed within the NHS as envisaged by eSTI². In the latter context, it could be deployed within or separately from care pathways. I (and eSTI² researchers) believe it should be implemented within online care pathways, for three main reasons relating to ethics and public health: patient safety, infection control, and public health surveillance.

In terms of patient safety and infection control, NHS services have a duty of care over their patients, responsibilities for clinical care quality and safety,^v and a public health role, which includes antimicrobial stewardship.¹⁹⁶ Home self-tests risk loss to follow-up if those testing positive do not present for treatment and are not contactable by services, in a context where prompt, effective treatment is important for individual and public health (as explained). Collecting registration data via an online pathway, prior to self-testing, enables test results to be communicated to services and patients, such that provision of appropriate treatment and care can be facilitated, including follow-up in case of delays or problems. Without this facility, users of self-tests, who may experience barriers to using conventional services, may not seek treatment, or may search elsewhere online. Treatments available commercially online may be inappropriate,^{197,198} and can be harmful if they are not genuine or if inappropriately prescribed¹⁹⁹ (potential harms of incomplete or ineffective STI treatment are described on p36). Data collected online can also be used to inform PN support, and targeted medical care and health promotion in relation to other needs (e.g. follow-up of those who may be being sexually exploited²⁰⁰).

In terms of public health surveillance, concern already exists about increased testing outside of GUM clinics and the NCSP, and its impact on the completeness of surveillance data,⁴ which could limit PHE's ability to provide accurate, up-to-date information on the size and nature of STI epidemics, and thus to inform

^v Regulatory issues and clinical care quality are addressed by another eSTI² PhD student.

public health responses. For STI surveillance, demographic and behavioural data are required from all those who test, whether or not an infection is detected. Collection of registration information, including identifiers (e.g. mobile phone number, date of birth), could increase the accuracy of surveillance data by preventing 'double-counting' of people who test repeatedly within a short time period.

Furthermore, it seems apt to provide an online pathway with a self-test, because the ability to engage with healthcare whenever and wherever users wish to, without attending healthcare settings, may be an important advantage to self-testing. The proposed online care pathway is envisaged to include automated elements (and not to be completed via instant messaging or webcam with a health professional), meaning that it could be used at any time, and making it easier to manage levels of use and staffing. More complete, standardised data may also be collected. Automation does not preclude 'human' elements, e.g. a helpline.

1.6.4 Implications of an online care pathway

The care pathway concept originated in the mid-1980s²⁰¹ from industrial management, where it was used to decrease the length of hospital stays and reduce costs, with care quality unaffected or improved.²⁰² From an epidemiological perspective, a care pathway's emphasis on rapid through-put and minimising drop-out – such that every patient receives results, and any necessary treatment and care, promptly – is desirable for designing STI services. However, it becomes perhaps less easy online and with minimal supervision, to ensure adherence to a pathway, compared to in a hospital context. Patients do not necessarily wish to adhere to any particular service or pathway, and therefore it is important to understand their behaviour and, as far as possible, to address potential problems during care pathway development (discussed in chapter 3).

1.6.5 Chlamydia as an exemplar infection for remote management

In my doctoral research, I use chlamydia as an exemplar STI. I do not discuss the public health implications of testing people who are at risk of STIs for chlamydia alone (and potentially missing other STIs and HIV), because the eventual eSTI² self-testing device is envisaged to test for multiple infections.

Clinical colleagues considered chlamydia an ideal candidate for proof-of-concept of remote management, delivered largely online, because most chlamydia cases are ‘uncomplicated’ and treatable with a single oral dose of a well-tolerated antibiotic, azithromycin.⁴⁷ In contrast, current recommended treatment for gonorrhoea requires administration of antibiotics orally and via intramuscular injection,²⁰³ meaning that treatment must be delivered in person, by an appropriately-qualified health professional. Furthermore, related to gonorrhoea’s epidemiology, people testing positive for this infection are candidates for more intensive health promotion and risk-reduction interventions, which had not yet been developed for online use.

As the most commonly-diagnosed bacterial STI, chlamydia contributes substantially to the public health burden of STIs, and is most prevalent among 16-24-year-olds.⁶² Young people are frequently characterised as ‘early adopters’ of new technologies, and the following section (1.7) evidences their high levels of engagement with ICT.

My research does not lose sight of the possibility of self-testing and online management for non-chlamydial STIs. I discuss the implications of my findings for other STIs in chapter 8.

1.7 Uptake and use of the internet and smartphones

Uptake and use of the internet and smartphones provide context, and delineate the population which could, in theory, adopt internet- and smartphone-enabled healthcare.

Access to the internet, and smartphone ownership, have increased dramatically in recent years.²⁰⁴⁻²⁰⁷ Among adults of reproductive age (16-44 years), the age-group amongst which most STI diagnoses occur, internet access is nearly universal (98% 16-34-year-olds, 93% 35-44-year-olds in the UK in 2013).²⁰⁸ Smartphone ownership is highest among the 16-24-year-old age-group (Figure 7). Thus, smartphone-enabled online sexual healthcare could make use of young adults' relatively high use of internet²⁰⁹⁻²¹¹ and smartphone technologies^{212,213} to reach the age-group(s) at greatest STI risk.

Figure 7: Smartphone ownership, by age-group

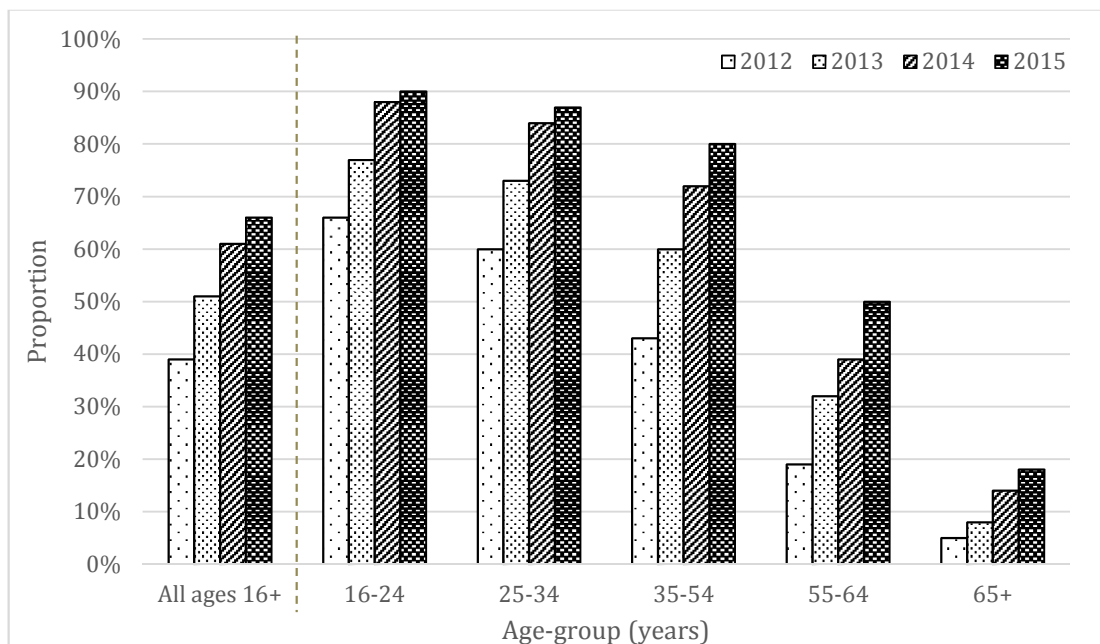


Chart adapted from²⁰⁷, Ofcom Technology Tracker 2015, quarter 1. Survey question wording: 'Do you personally use a smartphone?' reported as 'smartphone ownership' in the original report.

Internet use for finding health information has also grown: from 17% adults in Great Britain reporting this within the previous three months in 2007, to 49% in 2015.²¹⁴ In 2013, over a third of the adult population regularly used the

internet for health information,²⁰⁸ although a breakdown by health topic was unavailable.

‘Digital divides’ have been documented (e.g. by socioeconomic status²⁰⁸), with e-health a specific area of concern.^{215,216} Evidence regarding correlates of sexual health need other than age, is not so promising for internet-enabled sexual healthcare, or is lacking. A 2005 European survey found that people with greater education, those in ‘white collar’ professions or unemployed, those with ‘good’ self-rated health, and those with long-term illness or disability, were more likely to report using the internet for health purposes (including health information).²¹⁷ More recent UK data show that internet access was lower among people with less education²¹⁸ and lower incomes.²⁰⁹ There is scant evidence in relation to ethnicity, from this country; recent government agency publications do not report estimates by ethnicity^{207,214,219} or urge caution around use of the data they present.²²⁰ Evidence from the US suggest that ethnic minorities have lower internet use in general,²²¹ and in relation to health,²²² but these observations may not be generalizable to the UK or English context.

1.8 Structure of this thesis

This dissertation continues with a scoping literature review (chapter 2) about the use, acceptability and effectiveness of internet and related communications technologies in the delivery of sexual healthcare. It supplements chapter 1, providing relevant background information for the thesis.

Chapter 3 details the thesis' three objectives, which correspond to three studies. It explains how they fit together to address the research question, and outlines and justifies the studies' methods.

Chapters 4-7 present detailed methods, results and discussions of the three studies:

- a complex survey analysis about use of the internet for sexual health, in the British general population (chapter 4);
- two qualitative studies, concerning:
 - the conceptual acceptability of STI self-testing within online care pathways (chapter 5)
 - the use and appeal of an online care pathway for chlamydia management (chapters 6-7).

Chapter 8 draws together my studies' findings, discusses them in the context of an evolving healthcare, policy and technological landscape, and presents my conclusions.

Chapter 2: Scoping literature review: email, text messaging, apps and other internet communications in the delivery of STI services

2.1 Introduction

To understand the extent to which the proposed remote online STI care pathways built upon established practice and evidence, I conducted a scoping literature review. The review focussed on the use, acceptability and effectiveness of text messaging, email, internet communications, and apps which serve a communication function, in the delivery of STI services to patients and their partners.

For this review, the literature was first searched early in my doctoral research (2011), and this was repeated in 2013 for my MPhil to PhD upgrade. This is reflected in my use of the past tense to describe the studies' results.

2.1.1 Description and rationale for using a 'scoping' approach

'Scoping' is a method of research synthesis, used to provide an overview of research relating to a particular topic. Scoping reviews aim for breadth of coverage of evidence, with depth varying according their purpose.^{223,224} They can include a range of study types^{224,225} and non-research sources,²²⁴ often without systematic appraisal of quality²²⁵ (i.e. strength of evidence). In contrast, systematic reviews answer specific, narrow questions, and are often restricted to high-quality, peer-reviewed research. With the pace of change in this field, a narrow topic focus or restriction to high-quality research might miss research reports of novel uses of ICT, about which the evidence base may still be weak, but which could be particularly relevant to informing my research on the proposed internet-enabled STI self-test and care pathways. Scoping reviews are also suitable when a research area is 'complex or has not been reviewed comprehensively before';²²⁶ here, existing reviews have rarely searched the literature systematically, and where they have, have concentrated on a narrow topic. Furthermore, the exploratory nature of scoping reviews²²³ makes them well-suited to informing empirical research.²²⁷⁻²²⁹

2.2 Methods

This scoping review used the framework developed by Arksey and O'Malley.²²³ After identifying and defining the research question, relevant research was identified (through a search strategy, see section 2.2.1) and then selected for inclusion (screening, section 2.2.2). Then, the data were charted (i.e. a means of presenting results was developed) and finally, results were collated, summarised and reported (section 2.2.3).

This review covers STI care pathway stages from accessing testing through to receiving treatment, and PN. Searching and screening for inclusion were systematic. The diverse studies were not subject to standardised appraisal for levels of evidence, because their objectives, methodologies and outcome measures were so varied. I present narrative and tabular summaries (including brief comments on quality).

2.2.1 Search strategy

Bibliographic database search

Bibliographic databases were searched on 18th June 2013, using OvidSP, a search engine which enables searching of a wide range of health and medical research databases. Relevant databases searched (Table 2) include Ovid MEDLINE® which includes all of PubMed (with a short delay between inclusion in PubMed and inclusion in MEDLINE®).

Table 2: Bibliographic databases searched for scoping review

Database	Version (selected from limited available options)
Embase	1980 to 2013 Week 24
Health Management Information Consortium	1979 to March 2013
Ovid MEDLINE®	daily update: 1946 to June 17, 2013; in-process and other non-indexed citations: 1946 to present

I used the multi-field search function which allowed me to conduct the search in one step, using the following query (Box 1) conducted across all fields (title, abstract, keywords, *etc.*) Terms for specific types of communications technology

were used instead of the term 'e-health' (or 'ehealth'), because several relevant studies of which I was already aware did not use this term.

Box 1: Search query for bibliographic database search

[genito*urinary OR GUM OR sexual health OR sexually transmi* infection* OR sexually transmi* disease* OR STI OR STIs OR STD*]
AND
[internet OR online OR web* OR e*mail OR text message* OR SMS OR short messag* service OR app OR apps OR mobile*app*]

Hand-search of conference abstracts

Recent (2011-July 2013) conference abstract publications were hand-searched, and abstracts were included if they met inclusion criteria and had not already been located via the database search.

Table 3: Conferences included in abstract search

Conference	Location	Date
BASHH	Newcastle, UK	May 2011
ISSTD	Quebec, Canada	July 2011
BHIVA	Bournemouth, UK	April 2011
BASHH-ASTDA	Brighton, UK	June 2012
BHIVA	Birmingham, UK	April 2012
CDC STD Prevention	Minneapolis, USA	March 2012
IUSTI-Europe	Antalya, Turkey	September 2012
BASHH	Bristol, UK	May 2013
ISSDTR-IUSTI World	Vienna, Austria	July 2013

Conference organisations and associations: BASHH: British Association for Sexual Health and HIV; ISSTD: International Society for Sexually Transmitted Diseases Research; BHIVA: British HIV Association; ASTDA: American Sexually Transmitted Diseases Association; CDC: US Centers for Disease Control and Prevention; IUSTI: International Union against Sexually Transmitted Infections. **NB:** Abstract books for the following potentially relevant conferences were not searched because abstract books were not located in time for my MPhil/PhD upgrade, and/or conference websites no longer worked: IUSTI World 2011 (New Delhi, India); IUSTI Europe date unknown (Riga, Latvia); IUSTI World/Australasian sexual health conference 2012 (Melbourne, Australia); BHIVA 2013 (Manchester, UK; no abstracts from BHIVA 2011 or 2012 conferences met inclusion criteria).

2.2.2 Screening

Inclusion and exclusion criteria (Table 4) serve to focus this review on uses of communications technology most relevant to remote STI care pathways.

Included documents concerned communications between services and patients or patients' partners, and also ICT facilities provided by services to enable

patients to notify their partners ('patient referral') electronically.

Communications within the health service (e.g. between health professionals), and communications to promote testing and re-testing, were excluded. Since many prevalent STIs are asymptomatic, and the diagnostic device would detect pathogens (rather than diagnosing based on symptoms), pictures, videos and information for self-diagnosis were excluded. Online risk self-assessment was excluded, as were remote consultations, unless they led to provision of STI testing or treatment. HIV treatment/care was excluded, as it is substantially different to the management of curable STIs, such as chlamydia, for which entirely remote care is proposed.

Table 4: Inclusion and exclusion criteria

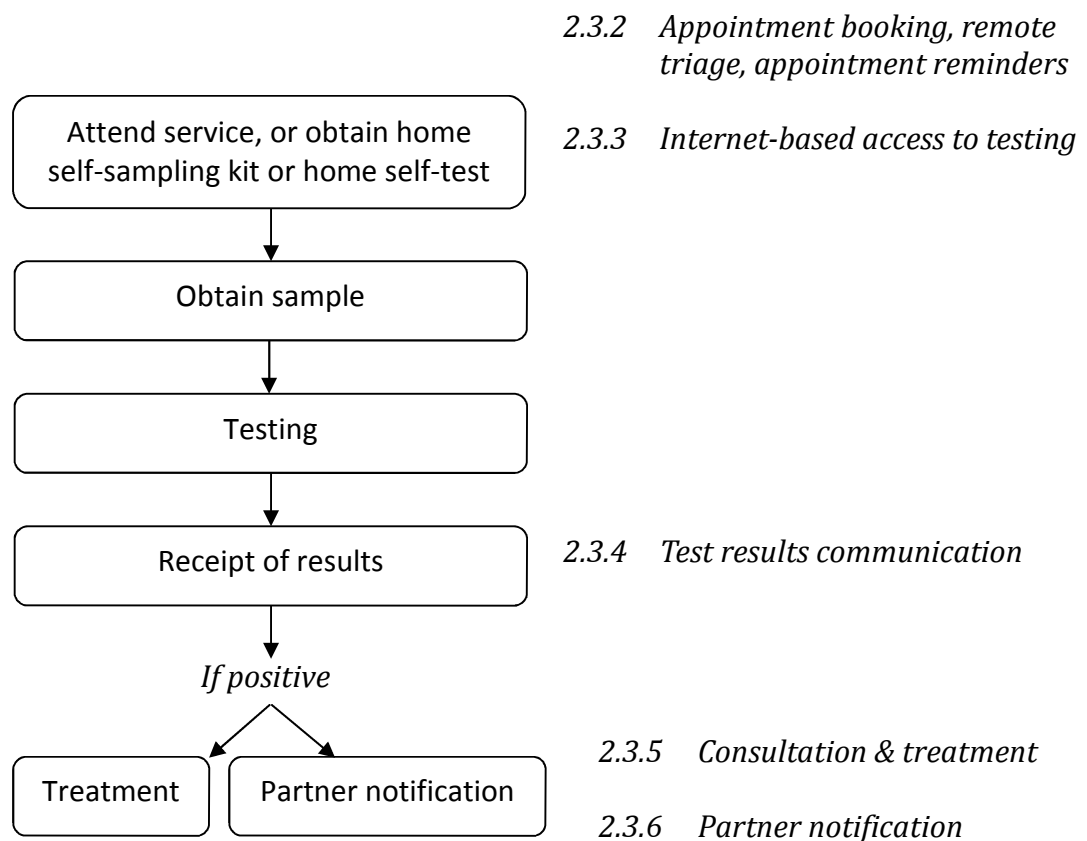
Inclusion criteria		Exclusion criteria
Communication technology		
Any of the following: <ul style="list-style-type: none"> • Text message (SMS) • Email • Internet communications (websites facilitating communication, instant messaging) • Apps (applications) serving a communication function 		<ul style="list-style-type: none"> • Communication by (mobile) phone call, or by other means. • Websites which do not provide individualised communication.
Type of service delivery		
<ul style="list-style-type: none"> • Accessing STI/HIV testing (including booking appointments, ordering testing devices, ordering home-sampling kits) • Clinical consultations regarding provision of STI treatment/care (but not for HIV) • Partner notification 		<ul style="list-style-type: none"> • Health promotion consisting of primary prevention information/advice, or promotion of testing • Treatment/adherence/care for HIV • Consultations limited to provision of advice/information, or signposting to services, but not treatment • Access to free STI/HIV testing as an incentive for research participation • Risk assessment for STI/HIV • Re-testing/re-screening reminders; re-screening services • Condom purchasing/request, contraception & abortion services
Communication type		
<ul style="list-style-type: none"> • Communications between individual patients and healthcare or laboratory services, remote from healthcare settings • Automated systems (e.g. patient provides information to healthcare services via an automated app) • Partner notification (either provider- or patient-led) 		<ul style="list-style-type: none"> • Communications aimed at population groups (e.g. health promotion, service information: clinic locators, opening times) • Non-remote communication technology use: use within healthcare settings (e.g. for sexual history-taking or risk assessment) • Communications between professionals (e.g. for clinical training, clinic management, surveillance, maintenance of patients' health records)
Publication date		
Documents published 2000 onwards		Documents published before 2000

Inclusion criteria (continued)	Exclusion criteria (continued)
Type of research	
<ul style="list-style-type: none"> • Primary research reporting service-related, acceptability, or clinical/public health effectiveness outcomes • Reviews of primary research described above, with clear search strategies and specific outcomes 	<ul style="list-style-type: none"> • Opinion pieces and overviews of the field without clear search strategies and/or without clear outcomes • Case studies • Studies using communication technologies for research recruitment, but not as the object of study • Studies of communication technology use by the public or patients, in general, or (e.g.) to seek sexual partners
Outcome measures reported	
<ul style="list-style-type: none"> • Acceptability to users/potential users, preferences • Measures of uptake, use, and clinical, service-related or public health effectiveness 	<ul style="list-style-type: none"> • Other outcomes unrelated or more distantly related to uptake or effectiveness (e.g. proportion of patients with a mobile phone; proportion of partners contactable by email) • Views of health professionals or providers
Miscellaneous	
	Colleagues' rapid analysis of interviews conducted for the study reported in chapter 5 ²³⁰

2.2.3 Results presentation

Methods for presenting results evolved as the included documents were read and organised. Research reports were categorised according to the sequence of events in an STI care pathway (Figure 8). Within each section, results were described and tabulated (except where otherwise specified).

Figure 8: Simplified STI care pathway, and headings for presenting scoping review results



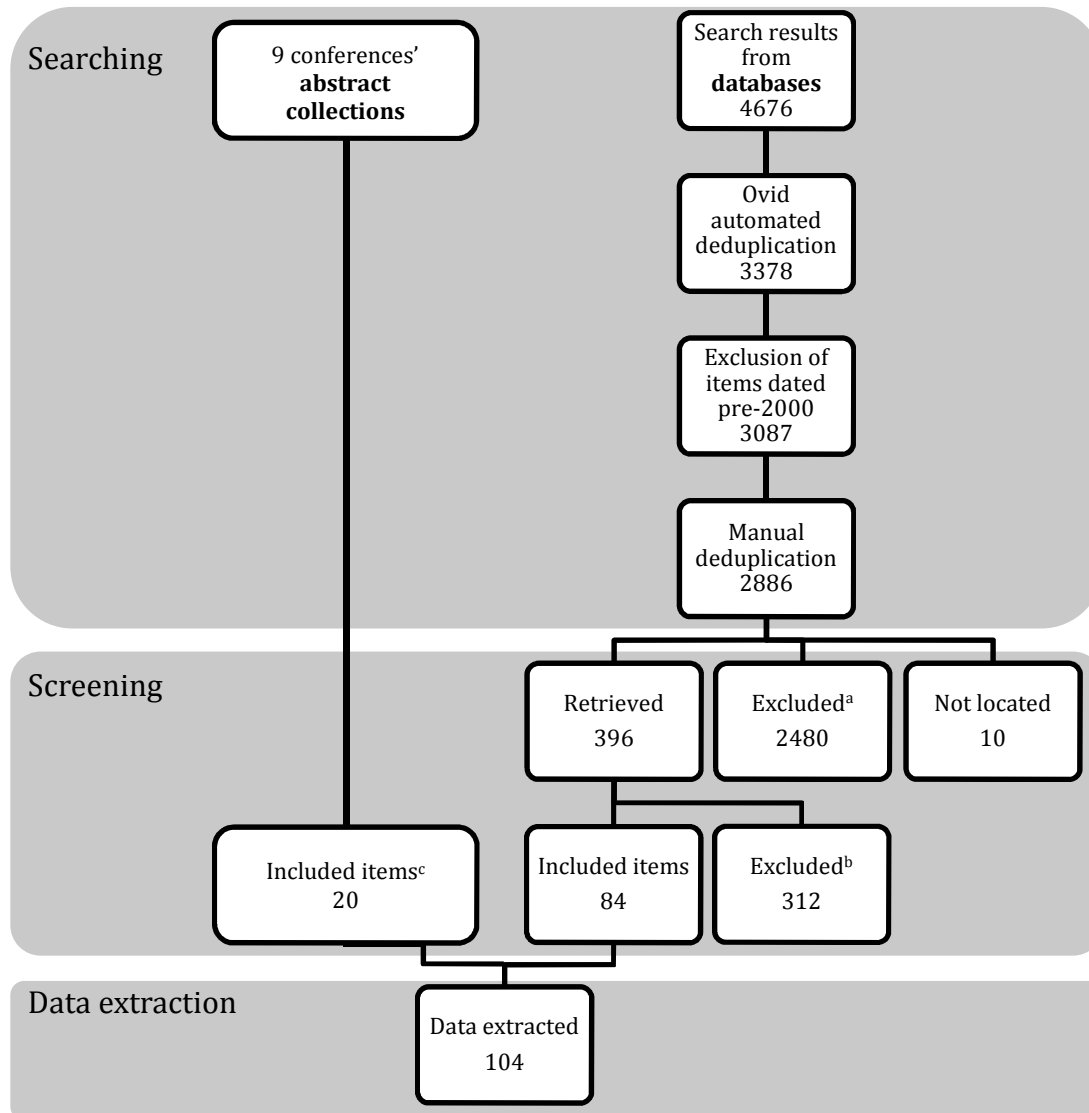
Note: Activities which are outside the scope of this review (e.g. provision of health information) are not shown.

Where details in documents were missing or unclear, authors were not contacted, due to issues with standardising the information collated from studies with diverse designs and outcomes, and due to the large number of included studies.

2.3 Results

From the database search, 84 documents were included. The conference abstract book search located 20 additional documents (abstracts).

Figure 9: Flow of literature diagram



^aExcluded based on the reference obtained from the database search, which included: title, keywords, and sometimes, abstract.

^bExcluded based on full text or abstract.

^cNot including those already identified and included via the database search.

The 104 included documents are listed in Appendix 4. (It would be preferable to report the number of studies as the unit of interest, instead of the number of documents/research reports,²³¹ but this was not straightforward for

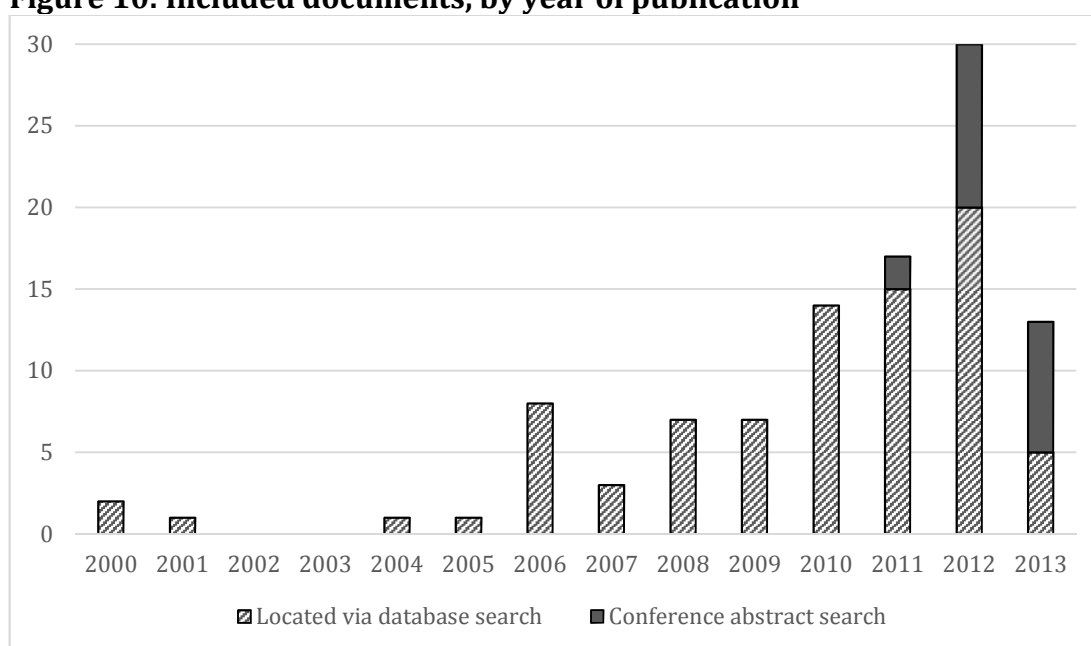
observational studies using audit data, which sometimes re-analysed the same data, e.g. multiple articles by Gaydos *et al.* concerning iwantthekit, section 2.3.3).

Several non-systematic literature reviews and editorials provided overviews of the field (e.g. use of the internet in relation to sexual health). These fell outside inclusion criteria, and all of the relevant literature cited in these documents had already been identified through this review's search strategy.

2.3.1 Overview of studies and documents included in this review

The majority of the 104 included documents was published since 2005 (Figure 10).

Figure 10: Included documents, by year of publication



Note: The literature search was conducted mid-way through 2013, hence the lower number of documents in this year; the conference abstract search included conferences from 2011.

Included studies were commonly observational and without comparison groups (for example audits and cross-sectional surveys; see Table 6 and Table 8-Table 14). It was often unclear whether new interventions, or changes in clinic practice, had been subject to formative research before implementation.

Few experimental studies were found, and only three used randomisation (thus reducing the risk of selection bias). One evaluated the Dutch internet-based chlamydia screening programme, using randomised stepped-wedge design (p85, Table 8 p87).²³²⁻²³⁶ RCTs compared internet-PN with standard partner management (Kerani *et al.*,²³⁷ p116-117), and compared different means for notifying patients of their STI test results (Reed *et al.*,²³⁸ p107, p112.)

Topics of two systematic reviews^{174,239} overlapped with this review (unsupervised HIV testing,²³⁹ home-sampling for chlamydia/gonorrhoea which was sometimes internet-based¹⁷⁴). A review of apps for STI/HIV prevention and care²⁴⁰ met inclusion criteria, but located no apps which individually met criteria for this review: apps regarding HIV treatment/care were found, but none for other STIs, and PN was not mentioned.

Table 5 shows the number of included documents which addressed each topic (see also Appendix 4).

Table 5: Number of documents concerning each topic

Topic (results section number)	Number of documents
2.3.1 Appointment booking, remote triage, appointment reminders	12 ^a
2.3.2 Internet-based access to testing: home-sampling, testing, downloadable forms for free testing without a face-to-face consultation	46 ^b
2.3.3 Test results communication	27 ^c
2.3.4 Consultations following positive test results, and provision of treatment	2
2.3.5 Partner notification	26
Total number of included documents	104^d

^aIncluding two documents which report identical data.

^bIncluding an erratum to an article.

^cIncluding two documents which report identical data.

^dSome documents concerned more than one topic, so the numbers above do not sum to the total.



2.3.2 Appointment booking, remote triage and appointment reminders

All documents located on these topics concerned UK GUM clinics and presented quantitative data.

Appointment booking

Three studies²⁴¹⁻²⁴³ consisted of surveys which asked patients and/or the public their views on services which were not yet available (internet booking, and for one study, email booking). Their findings, summarised in Table 6, are difficult to compare because they were conducted at different times, in different populations, and asked questions in different ways. In two studies,^{241,242} authors noted differences by ethnicity, with lower acceptability and accessibility among Black Caribbean patients. In one of these studies, internet-booking was observed to be more popular among young people²⁴¹ (the other study was conducted exclusively among this age-group²⁴²).

A further study explored uptake of an electronic booking system (internet and text messages), which increased in popularity with time since implementation, but was still used by only 16% patients in January 2008.²⁴⁴ In combination with other changes to clinic practice, authors reported a positive impact on clinic access, but it was not possible to establish the extent to which this was attributable to the electronic booking system.

Booking, remote triage and reminders

‘eTriage’, a web-based system in which patients enter information for remote triage and appointment booking (with automated appointment reminders), was audited by the clinic in which it runs. 86% concordance was found between signs/symptoms reported online and in clinic, and a survey of its users found it to be highly acceptable.²⁴⁵



Appointment reminders

Three surveys among GUM clinic patients (one restricted to patients who missed an appointment²⁴⁶) asked their views on a (hypothetical) appointment reminder system using text messages or email. Text message appointment reminders were acceptable to most,^{246,247} and emails less so (proportions not reported²⁴⁷).

Three audits of text message reminder services²⁴⁸⁻²⁵¹ explored the impact of these on non-attendance at GUM clinics (and one, at HIV clinics too),^{249,251} all reporting reminders to be beneficial. One compared people who chose to use the service with those who did not (with risk of bias by other factors that influence choice to use reminders and non-attendance), one compared non-attendance before and after implementation of a reminder service,^{249,251} and the other piloted reminders among some patients (it was unclear how these were chosen).²⁵⁰ The latter (a non-peer reviewed letter to a journal) also included: a cost-benefit analysis, illustrating that where text-reminders facilitated cancellation, cancelled appointments could be re-used, contributing to a high 'return' from implementing reminders; and results of a survey among users (more than 95% respondents reportedly found the reminder service helpful).²⁵⁰

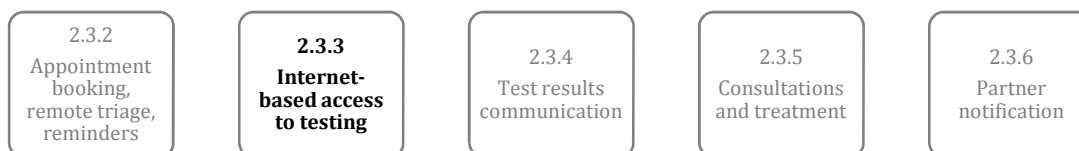
Table 6: Booking, remote triage and appointment reminders

Study	Setting, population	Study type	Sample size, response rate	Communications technology	Relevant outcomes	Relevant findings	Comments
BOOKING							
Ross <i>et al.</i> 2000 ²⁴¹	5 UK GUM clinics, patients with internet access	Survey	n=499 with internet access (41% of a survey of n=1204 respondents)	Internet	Acceptability – if internet booking were available	64% (317/499) indicated they would use the internet to book an appointment (if this facility was offered) Authors also report how internet access varies by ethnicity, age and between clinics	No response rate given; patients with internet access were a minority of survey respondents
Ross <i>et al.</i> 2007 ²⁴²	UK GUM clinic and community samples – all aged 16-25	Survey	Community: n=542, response rate 92% Clinic: n=202, response rate 43%	Internet, Email	Preference* for booking method – if it were available (*communication method specified as first or second choice)	<i>Internet</i> : preferred* by 9.6% community vs. 26.7% clinic sample (p<0.001). <i>Email</i> : preferred* by 7.0% community vs. 11.4% clinic sample (p=0.07). Overall 21% (157) preferred* internet/email for booking. Variation by ethnicity (p=0.05 after adjustment for 'other factors' – N.B. sub-groups small). OR for preferring* internet/email for booking among clinic (36%) vs. community (16%) = 4.54 (95%CI 2.56-8.06)	Clinic sample has low response rate
Lawton & Andrady, 2011 ²⁴³	4 UK GUM clinics	Survey	Not provided	Internet	Acceptability – if internet booking were available	67% would like to be able to book online	No numbers or response rate reported (abstract)

Table 6, continued	Setting, population	Study type	Sample size, response rate	Communications technology	Relevant outcomes	Relevant findings	Comments
Menon-Johansson <i>et al.</i> 2010 ²⁴⁴	3 UK GUM clinics	Audit	n/a	Internet, text messages	Uptake of electronic appointment booking	Uptake increased over time (% patients using electronic appointment system): 8% January 2007, 16% January 2008 <i>Authors report positive impact on clinic access, in combination with other changes, but do not quantify effect of internet-booking separately</i>	Difficulty in attributing change in clinic access to electronic booking
APPOINTMENT BOOKING, REMOTE TRIAGE AND APPOINTMENT REMINDERS							
Jones <i>et al.</i> 2010 ²⁴⁵ (see also DH ¹¹²)	UK GUM clinic	Audit (case-note review; analysis of 'eTriage' database) and survey	Audit: case-notes of first 175 patients who booked via eTriage; database analysis: n=909 initial eTriage appointment requests compared to n=9041 regular clinic attendees Survey of patients using eTriage: n=223, response rate not reported	Internet (for booking, triage), email and text message (for reminders)	Uptake, acceptability among users, concordance between symptoms/signs reported on eTriage and consultation	<i>Case-note review:</i> 150/175 (86%) concordance between eTriage & case-notes. (Concordance adjusted to 97% (170/175) due patients' lack of awareness/resolution of symptoms; selecting 'ulcer' to refer to rash). <i>eTriage database analysis:</i> Patients booking by eTriage differ from other patients; 56% female vs. 51%, p<0.001 (<i>Differences in mean age, diagnosis reported; unclear if stat. significant.</i>) 592/909 (65%) selected text message for appointment reminder. <i>Survey:</i> 96% would use eTriage again; 70% liked website; 70% found it easy to use; 7% felt too much information requested; 94% understood language used; 92% felt process clear; 94% would recommend it. 92% received appointment message in <1day.	Authors' rationale for adjusting the concordance is unclear, and appears not to reflect how patients used/would use the system

Table 6, continued	Setting, population	Study type	Sample size, response rate	Communications technology	Relevant outcomes	Relevant findings	Comments
APPOINTMENT REMINDERS							
Cohen <i>et al.</i> 2008 ²⁴⁷	UK GUM clinic	Survey	n/N =304/350 (87%)	Email, text message	Acceptability – if it were available	Text message reminders acceptable to 67%; email less acceptable (% not reported) (<i>N.B. 88% considered (any) appointment reminder a good idea</i>)	Lack of details e.g. % reporting email as acceptable
Swarbrick <i>et al.</i> 2010 ²⁴⁶	UK GUM clinic patients who DNA'ed	Survey (phone interview)	n/N=182/383 (response rate 48%)	Text messages	Acceptability – if it were available - among patients who DNA'ed	84% (152/182) would find text message reminders useful	Low response rate
Lawton & Andrady, 2011 ²⁴³	4 UK GUM clinics	Survey	Not provided	Email or text message	Acceptability – if it were available	77% would be happy to receive reminders by text or email	No numbers or response rate reported (abstract)
Nair <i>et al.</i> 2008 ²⁴⁸	UK GUM clinic	Audit	n=204 (response rate not applicable)	Text messages	Uptake Attendance at booked appointments	148/204 (72.5%) chose and were sent a reminder. Attendance 80.4% among those sent reminder (n=148) vs. 71.4% not sent one (n=56), p=0.023. No statistically significant association between reminders and cancellation.	Letter; not peer-reviewed. Differences between those who chose vs. did not choose to get reminder may explain difference between groups.

Table 6, continued	Setting, population	Study type	Sample size, response rate	Communications technology	Relevant outcomes	Relevant findings	Comments
Price <i>et al.</i> 2009 ²⁵⁰	UK GUM clinic	Audit/ observational study (criteria for being sent a reminder vs. not being sent one – not reported) Survey Cost-benefit analysis	Pilot: n=1879 booked patients, of which 727 sent a text reminder Survey: n=158, response rate not reported	Text messages (<i>with option to cancel</i>)	Attendance and cancellations of booked appointments Acceptability Cost-benefit	<i>Pilot:</i> Cancellation: 19.7% (143/727 sent a reminder); vs. 0% (0/1152 not sent a reminder), p not reported. DNA: 10.6% (77/727 sent a reminder); vs. 20.7% (239/1152 not sent a reminder), p<0.001. No reduction in non-attendance (DNA & cancellation). <i>Survey:</i> 96.8% found text reminders useful; 22.1% would have forgotten time/date without it; 94.9% would have used service to cancel if necessary; 18.4% felt that their use of this might be affected by the charge for cancellation. <i>Cost-benefit analysis:</i> Return of 18,197%. (Cost of text messages, benefit of re-used appointments due to cancellation.)	Letter, not peer-reviewed. Lack of detail on cost-benefit analysis, which excludes call-centre costs of delivering service and dealing with cancellations. Unclear criteria for not texting reminder to 1152 patients.
Brook <i>et al.</i> 2013 ^{249,251}	UK GUM/HIV clinic	Audit, before and after implementing routine text message reminders	n=768 (before) n=699 (after) response rate not applicable	Text messages	Attendance at booked appointments	<i>After intervention</i> , DNA rate decreased by 35%: from 26% (203/768) to 17% (119/699), p<0.0001. <i>Breakdown:</i> Male sexual health appointments: 46% decrease [28% (56/200) vs. 15% (24/165), p<0.004] Female sexual health appointments: 30% decrease [23% 69/302) vs. 16% (43/273), p<0.02] HIV appointments: 31% decrease [29% (78/266) vs. 20% (52/261), p<0.001]	Limited information (abstracts)



2.3.3 Internet-based access to testing

Internet-based access to testing encompasses downloadable laboratory requisition forms, internet-ordered self-sampling kits and internet-ordered self-tests. These are defined and compared in Table 7.

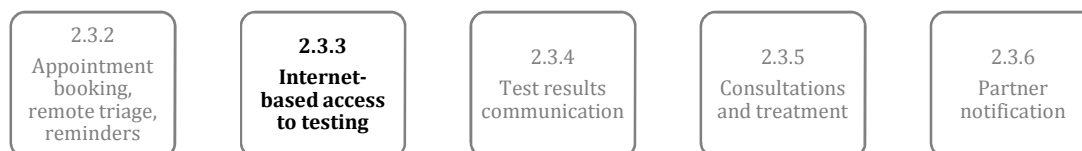
Table 7: Comparison of methods of internet-based access to testing

	Access	Taking samples	Submitting samples	Obtaining results
Internet-ordered self-tests	Self-test ordered online by user	Self-taken	n/a	Test is operated and read by the user
Internet-ordered self-sampling kits	Self-sampling kit ordered online by user	Self-taken	Posted to laboratory	Results are communicated by lab/clinic to user
Downloadable laboratory forms	User inputs information online, receives downloadable form specifying testing regimen, and attends lab for testing	Taken by lab staff	Attend laboratory (no face-to-face consultation needed)	

NB. Self-testing/-sampling are also known as home-testing/-sampling, where they occur outside of healthcare settings. There is inconsistent use of terminology in the literature, e.g. 'self-testing' is sometimes misleadingly used to refer to self-sampling where testing is laboratory-based.²⁵²

Rationales for implementing internet-based access to testing include: its feasibility, the aim of increasing access and reach to 'non-clinic' populations²⁵³⁻²⁵⁷ and rural populations,²⁵⁸⁻²⁶² and the potential for targeting individuals (via online self-risk-assessment)²⁶³ or groups, based on criteria such as age and/or place of residence. Downloadable laboratory forms have low marginal costs for each test, unless costly promotion is needed; in contrast, unused self-sampling kits can be wasteful,²⁶⁴ and this is a consideration for publicly-provided services.

Below I summarise the literature on different types of online access to testing. First, I discuss commercial internet-based home-tests and commercial home-sampling services, together, as they were studied in similar ways (documenting



provision/availability but without providing audit data). No retrieved documents concerned publicly-provided home self-tests for STIs. Then, I discuss internet-ordered home-sampling, followed by downloadable laboratory requisition forms. The latter two models of screening/testing provision are heavily influenced by health service context,¹⁷⁴ limiting comparability of findings between countries, and so where possible I note the countries where studies took place.

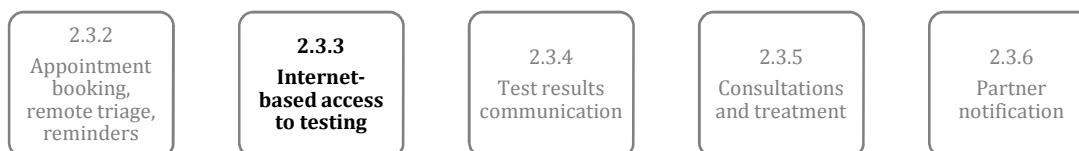
Commercial internet-based home self-testing and sampling (not tabulated)

An online convenience survey of French-speaking MSM (n=9169, conducted 2009) found that 30% were aware of online HIV self-tests, but among these, few who were not already HIV-positive had accessed one (n=82), and still fewer (n=69) used it themselves.²⁶⁵ As use was associated with recent unprotected anal intercourse, and living one's sex-life with men in secrecy, authors suggest online self-testing may reduce barriers to testing in a vulnerable population.²⁶⁵

Various surveys of commercially-available internet home-sampling and testing for STIs note lack of regulation¹⁹⁷, use of tests which are inadvisable,^{129,266} inaccuracy,¹⁹⁷ non-return of results,¹⁹⁷ provision of limited or poor-quality health advice,¹²⁹ and varying follow-up/treatment options for positives.¹⁹⁷

Non-commercial internet-ordered home-sampling kits

Some STI screening or testing initiatives which used internet-ordered home-sampling kits (Table 8) were wholly or mostly internet-based (e.g. Netherlands chlamydia screening, US *iwantthekit*), while for others, the internet was one of several means of accessing screening (e.g. NCSP). Treatment and management of those testing positive typically occurred through traditional services (clinic, general practice). In general, internet-based access to testing can be replicated relatively easily to serve different regions.^{129,233} However, this was not done within England's NCSP, where more than 58 websites were known to provide an



internet-ordered home-sampling service (in March 2010), and details of how it was provided varied between websites.^{129,267}

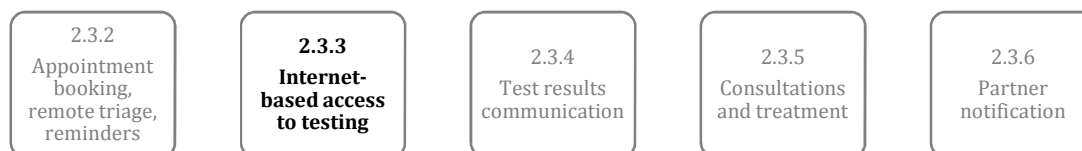
Uptake and impact on STI control

The largest bodies of research concerned the US *iwantthekit* and the Dutch chlamydia screening programme, which I describe and compare below.

Iwantthekit was established in 2004 for free chlamydia testing for women in Maryland.²⁶⁸ It later expanded to include men,²⁶⁹ gonorrhoea and *T.vaginalis*,²⁷⁰ rectal self-sampling kits²⁷¹ and other localities.^{272,273} Test results were communicated by telephone call.²⁷⁴

Observational studies of *iwantthekit* found: high positivity (females: 10%, males: 13% for chlamydia);^{268,270,272,274,275} high proportions reporting previous STI,^{268,269} symptoms,^{269,270,272,275} and risky sexual behaviour^{268-270,275} including among repeat-users;²⁷⁶ and higher usage of *iwantthekit* in deprived areas, among women.²⁷⁷ Higher chlamydia positivity than local family planning clinics,²⁵⁶ and higher proportions of male participants than conventional services^{268,270} led authors to conclude that it may reach a different and underserved population. However, uptake was low: 1171 women participated in Maryland/Baltimore, 2004-2008, compared to 168,360 chlamydia screens through family planning.²⁵⁶ Pilots in rural and university settings found low uptake^{260,273} and costly marketing,²⁶⁰ which limited *iwantthekit*'s feasibility.

Dutch online, register-based annual chlamydia screening started in 2008, for ages 16-29. The programme was implemented with a randomised stepped-wedge design to distinguish the impact of screening rounds from secular trends.²³⁵ Emails or text messages informed participants that their results were ready, which they then accessed online. The programme found 4% positivity, and was evaluated for its potential to interrupt transmission,²³⁴ with data collected on: duration of care pathway stages,²³³ repeat participation,²³⁴ and



treatment rates.²³³ Despite screening over 79,000 people (10-16% of the eligible population in successive screening rounds), Dutch trial authors concluded ‘low’ participation to be the greatest barrier to interrupting transmission.²³⁴ Without evidence of an impact on prevalence, they stated that their results do not support roll-out, despite feasibility.²³⁴ Participation was far in excess of iwantthekit, both in absolute terms and relative to the local population size.

In contrast, lack of data (e.g. time to treatment) for iwantthekit limited the potential to estimate impact on transmission.²⁷⁸ Though it cited this limitation, an economic analysis comparing iwantthekit to clinic-based sample-collection concluded the former was more cost-effective, using an economic model of 10,000 iwantthekit participants,²⁷⁸ far exceeding numbers that had ever used iwantthekit.

England’s NCSP, within which chlamydia self-sampling kits are offered via healthcare and community settings and online, has been described in chapter 1 (section 1.4.1). In national research about internet-based self-sampling, NCSP areas did not always record ‘internet’ as a distinct source of self-sampling kits,¹²⁹ which hindered evaluation of the internet-based aspect of the programme. The available data suggested that internet-ordered kits accounted for 5.7% of NCSP tests in 2010, and were used by a higher proportion of women than men, but with less difference by gender compared to kits obtained via general practice or sexual and reproductive health services.¹²⁹ Within the NCSP the positivity rate of ‘internet’ tests was 8.1% among males and 7.3% among females, comparable to NCSP tests via sexual and reproductive healthcare settings and higher than those via general practice; however internet-based testing reached similar proportions of residents by quintile of deprivation, whereas these healthcare settings were better at reaching those in the most deprived areas.¹²⁹

Table 8: Internet-based home-sampling: positivity and uptake/population coverage (grouped by intervention/programme)

Study	Setting, population	Type of study	Sample size, response rate	Main relevant outcomes	Main relevant findings	Comments
DUTCH INTERNET-BASED CHLAMYDIA SCREENING PROGRAMME: REGISTER-BASED SCREENING (SELECTIVE IN LOW-PREVALENCE AREA)						
van den Broek <i>et al.</i> , 2010 ²³⁵ van Bergen <i>et al.</i> , 2010 ²³³ van den Broek <i>et al.</i> , 2012 ²³⁴	Amsterdam, Rotterdam, South Limburg – Netherlands, 16-29 year olds	Controlled trial with randomised stepped-wedge design. ²³³⁻²³⁵	n=79,173/421,820 individuals (18.8%) (102,283 samples) Survey of positives: 43% response rate	Chlamydia positivity ²³³⁻²³⁵ Participation rate (uptake) ²³³⁻²³⁵ Estimated chlamydia prevalence ²³⁴ Treatment rate ²³³	<i>Chlamydia positivity</i> : Year 1: 4.2%. ^{233,235} In successive intervention blocks, 4.3%, 4.0%, 4.2%. ²³⁴ Higher among women than men (4.2% vs. 3.8%, OR: 1.12 (1.04-1.21) ²³⁴ <i>Participation rate</i> : 16% in year 1, (lower where selective ²³⁵). Participation declined in successive screening rounds: 16.1%, 10.8%, 9.5%. ²³⁴ Higher among women(21%) than men(10%). ²³² Participation higher among 25-29 yr olds than 16-19 yr olds. ²³⁴ <i>Treatment rate</i> : Estimated at 90%, based on self-report ²³³	Study designed with specific aim of measuring impact on chlamydia prevalence; high quality, large RCT. Limitations include reliance on self-reported data about treatment.

Table 8, continued	Setting, population	Type of study	Sample size, response rate	Main relevant outcomes	Main relevant findings	Comments
op de Coul <i>et al.</i> , 2012 ²³²	<i>As above (year 1 participants and non-participants in screening programme)</i>	Audit, survey	n=261,025 for audit (all invitees, response rate n/a) n=31,466/261,025 for survey (response rate 12.1%)	Positivity (breakdown by demographics, sexual behaviour) Participation rate, adjusted to the sexually active population (breakdowns by demographics, sexual behaviour)	<i>Positivity:</i> Higher among: younger people, those of non-Dutch origin, those with a non-Dutch steady partner, those resident in high risk areas, lower education, those with history or symptoms of STI <i>Participation:</i> Adjusted to sexually active population: 19.5% [95%CI: 19.4%-19.7%] Lower participation among: males, younger people, those of non-Dutch origin, lower education, lower socioeconomic status and high community risk level, those in long-standing relationships and those without history or symptoms of STI	Low participation rate to survey, but methods are sound and appropriately applied.
Koekenbier, Dokkum <i>et al.</i> , 2011 ²⁷⁹	<i>As above (those who requested but did not return a test-kit)</i>	Audit to explore effect of participation reminders (by email/text message)	Not reported (but see above for overall study size)	Proportion providing email/mobile number Sample return rate	99% provided an email address, 72% provided a mobile number. Proportion returning a sample increased 10% to 16% after email/text reminder (in round 2 of screening, from 7% to 17%). Also: “email/SMS reminders resulted in more men returning a sample. Persons with a higher sexual risk more often returned their sample before these reminders” (but data not presented to support this)	Limited details (abstract)

Table 8, continued	Setting, population	Type of study	Sample size, response rate	Main relevant outcomes	Main relevant findings	Comments
ENGLAND: INTERNET ACCESS TO SELF-SAMPLING KITS VIA THE NCSP						
Woodhall <i>et al.</i> , 2012 ¹²⁹	England, within NCSP, sexually-active people aged under 25	Audit of national NCSP data	n=59,719 (in 2010) Data from 71/95 NCSP areas with available data	Proportion of all NCSP screens which were from internet home-sampling Positivity	Proportion of NCSP screens which were from internet-testing rose from <0.05% in 2006 to 7.1% in 2009; 5.7% in 2010. Higher proportion of men (36%, no comparator provided), White people (females: 92% vs. 84%; males: 91% vs. 81%), 20-24yr olds (females: 65% vs. 44%, males 68% vs. 42%) screened via internet, compared to all NCSP screens. Internet screening reached fewer residents of the most deprived areas compared to GP and sexual & reproductive health screens, within the NCSP (p-values not reported). <i>Positivity:</i> Females 7.3%; males 8.1%. Higher than NCSP screens in general practice (5.6% females, 5.7% males), lower than sexual & reproductive health clinics (8% females, 9.9% males).	Largely limited by the inability of 24/95 programme areas to provide separate data for internet-testing.
Woodhall <i>et al.</i> , 2011 ²⁶⁷	<i>As above</i>	<i>As above</i> , and structured interviews with NCSP co-ordinators	96 programme areas; 58 websites; NCSP co-ordinators in 26 areas	Proportion of NCSP sites offering internet home self-sampling; Audit/process data	95/96 programme areas offer internet home self-sampling, through 58 websites. Websites varied in information provided. Range: 1-7days for despatch of kit; 2days – 3weeks for results notification.	Quite low response rate for NCSP co-ordinator interviews. Few details (abstract).

[illegible]

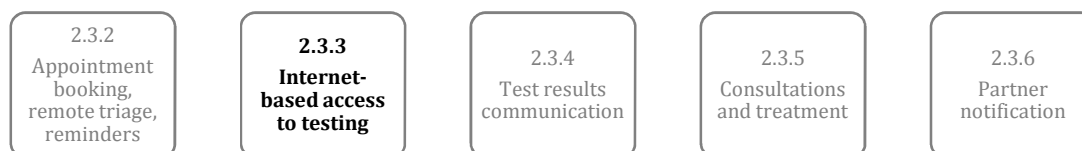
Table 8, continued	Setting, population	Type of study	Sample size, response rate	Main relevant outcomes	Main relevant findings	Comments
US iwantthekit WEBSITE: TESTING FOR VARIOUS STIs						
Gaydos <i>et al.</i> , 2006 ^{268,281} , 2009 ²⁷⁵ ; 2011 ²⁷² [journal articles] 2011 ²⁷⁴ [abstract]	Women 14+, Maryland, ²⁶⁸ , ²⁸¹ Washington DC, West Virginia, ²⁷⁵ & Illinois, Denver, ^{272,274} USA	Audit/observational study	n=400 ^{268,281} n=1203 ²⁷⁵ n=1525 ^{272,274} (response rates/ population sizes not reported)	<i>Among females:</i> Chlamydia, gonorrhoea, Trichomonas positivity	<i>Among females:</i> Chlamydia 10.25% ^{268,281} Positivity higher than in local family planning clinics; similar to the prevalence in high schools, particularly among 14-19 year old participants ^{268,281} Chlamydia 9.1% ²⁷⁵ Chlamydia 10%, gonorrhoea 1%, Trichomonas vaginalis 10% ^{272,274}	No attempt to compare participation with population size, nor establish population prevalence or impact on prevalence. Participation likely low relative to population size.
Gaydos <i>et al.</i> , 2009 ²⁶⁹ [abstract] Chai <i>et al.</i> , 2010 ²⁷⁰ [journal article]	Men 14+, Maryland, Washington DC & West Virginia, ²⁶⁹ & Illinois, & Denver, ²⁷⁰ USA	<i>As above</i>	n=270 ²⁶⁹ n=501 ²⁷⁰ (response rate/ population size not reported)	<i>Among males:</i> Chlamydia positivity Gonorrhoea positivity Trichomoniasis positivity	<i>Positivity among males:</i> Chlamydia 13.4% ²⁶⁹ Chlamydia 13%, gonorrhoea 1%, Trichomonas 10% ²⁷⁰ <i>Positivity comparators: Chlamydia:</i> Higher positivity than in high risk groups: e.g. incarcerated young men, male inner city youth. <i>Gonorrhoea:</i> much lower than in STI clinics, similar to community samples. <i>Trichomonas</i> slightly lower than in STI clinics. ²⁷⁰	

Table 8, continued	Setting, population	Type of study	Sample size, response rate	Main relevant outcomes	Main relevant findings	Comments
Muvva <i>et al.</i> , 2012 ²⁷⁷	Women 14+, Baltimore, USA	Comparison of Census Block Groups where women have and have not ordered kits	710 census blocks (response rate n/a)	Characteristics of areas from which kits were ordered vs. areas where kits were not ordered	<i>Areas where kits were requested (vs. not):</i> higher proportion 'below poverty' (24.7% vs. 20.1%); lower home ownership (51.3% vs. 58.9%, $p<0.01$); much more likely to have higher than average proportion of Black female population (70.1%, vs. 39.6%, $p<0.001$); more likely to have higher chlamydia rates than Baltimore rate (58.4% vs. 48.4%, $p<0.05$), but ns difference for gonorrhoea	Limited details (abstract)
Gaydos <i>et al.</i> , 2011 ²⁵⁶	Women aged 14 and older, Maryland, USA	Comparison of participants' data, with family planning clinics' routine screening	n=1171 (and n=168,360 in family planning clinics)	Chlamydia positivity	Chlamydia 10.3% - higher prevalence than 3.3%-5.5% found in family planning clinics. Younger mean age, more likely to be resident in Baltimore (city) than Maryland (remainder of the state), and of Black race, compared to family planning clinic participants (all $p<0.05$)	Minimal discussion of low numbers screened compared to clinics
Ladd <i>et al.</i> 2011 ²⁷¹	Women using rectal swab kits, region(s) not specified, USA	Audit/observational study (including surveys)	n=1084 submitting vaginal swabs; n=205 submitted rectal swabs with consent forms	Uptake and return of rectal sampling kits Positivity for anal chlamydia, gonorrhoea, trichomonas	<i>Uptake:</i> Among iwantthekit users submitting vaginal swabs, 17.9% (194/1084) reported anal sex in previous 90 days. Of these 58.2% (113/194) ordered & returned a rectal sampling kit. A further 95 rectal kits were returned by women who did not report recent anal sex (n=90) or did not return a vaginal swab (n=5). <i>Positivity:</i> 18.5% (38/205) prevalence of anal STIs (including chlamydia, gonorrhoea and/or trich.) Of these 38, 34 had vaginal samples tested and 70.5% (24/34) tested positive. Of those testing positive for rectal STIs, 67.7% reported no symptoms, and 12.0% no rectal partners in the previous year	(Abstract)

Table 8, continued	Setting, population	Type of study	Sample size, response rate	Main relevant outcomes	Main relevant findings	Comments
Simons <i>et al.</i> , 2012 ²⁶¹ , 2013 ²⁶²	'Alaskan natives' aged 14+, USA	Audit/observational study	n=55 ²⁶¹ n=161 ²⁶²	Positivity	<2% positivity (STI not specified). ²⁶¹ Chlamydia 8.6% (14/161), gonorrhoea 2 cases, Trichomonas 4 cases. ²⁶²	Small n, limited details (abstracts)
Jenkins <i>et al.</i> , 2012 ²⁷³	Men and women university students, Illinois, USA	Comparison of self-sampling kit provision, vs. direction to iwantthekit website to order kits	Total 596 students in two study arms (for uptake, see findings)	Uptake of testing and chlamydia positivity in each study arm	<i>Uptake</i> : Kit study arm: 3.5% (n=12); website study arm: 1.2% (n=3). <i>Chlamydia positivity</i> : Kit study arm: 0% (0/3); website study arm: 16.7% (2/12).	Low uptake in both study arms
Jenkins <i>et al.</i> , 2011 ²⁶⁰	Men and women aged 14 and older in rural Illinois, USA	Observational study: rural pilot of iwantthekit	n=138, response rate not reported	Chlamydia, gonorrhoea positivity. Comparison of treatment rates with other settings. Comparison of participants with those at other screening sites.	Males (n=52): Chlamydia 3.8%; gonorrhoea 0%, Trichomonas 9.6%. Females (n=86): Chlamydia 7%; gonorrhoea 1.3%, Trichomonas 17.4%. (Female Chlamydia positivity comparators: 5.7% in family planning clinics, 12.4% STI centres.) 8/9 chlamydia/gonorrhoea infected individuals were treated (89%), compared to Illinois STI Centres 77%, family planning clinics 79%, hospitals & school-based clinics 89%, private physicians 91%, universities 99%. Total tests through iwantthekit: n=138 vs. n=35,842 in traditional screening venues during same year. Internet-testers more likely to be male (37.7% vs. 23.4% traditional screening sites, p<0.05).	As above. High costs reported but costs analysis methods unclear.

Table 8, continued	Setting, population	Type of study	Sample size, response rate	Main relevant outcomes	Main relevant findings	Comments
Huang <i>et al.</i> , 2011 ²⁷⁸	Women aged 14+	Cost-effectiveness analysis comparing iwantthekit to clinic-based sample collection, chlamydia	No n for primary data used to create model	Cost-effectiveness PID cases prevented (& similar medical outcomes)	US\$41,000 'direct medical costs' saved by internet screening, vs. clinic-based screening. 35.5 Pelvic Inflammatory Disease (PID) cases prevented, based on 10,000 women screened.	Lack of time-to-treatment data and transmission modelling. Model is for 10,000 women screened, but far fewer had ever been screened.
Notes on iwantthekit, above: Study findings (positivity, uptake, <i>etc.</i>) include kits ordered by phone, but the large majority of mailed kits are ordered online (97.2% in the earliest study, 2006). Kits were also placed in the community in this first study, ²⁶⁸ but numbers distributed this way are not reported. Subsequent studies used mailed kits (i.e. mostly internet-ordered). Observational studies of iwantthekit, with the exception of those by Jenkins <i>et al.</i> ^{260,273} successively re-analyse some of the same data. As the programme changed in setting, population and infections tested for, data are presented in separate rows, to make clear the differences between studies.						
US 'I KNOW'						
Rotblatt <i>al.</i> 2012 ²⁸²	Females 12-25, Los Angeles county, USA	Audit/observational study	n=2032 testable specimens returned to lab	Positivity (chlamydia/gonorrhoea combined)	'Most orders were made online' (no figures presented) 8.9% chlamydia and/or gonorrhoea positive (n=181)	Limited details (abstract)

Table 8, continued	Setting, population	Type of study	Sample size, response rate	Main relevant outcomes	Main relevant findings	Comments
US: ONLINE STI TESTING AND TREATMENT						
Spielberg <i>et al.</i> 2013 ²⁸³	Females, 18-30, 4 San Francisco Bay area health depts., USA	Demonstration/feasibility study over 3 months	n=256 eligible; n=213 mailed a kit; n=143 returned kit.	Proportion of those eligible who 'enrolled'; proportion of those mailed a kit who returned it; proportion positive (chlamydia/gonorrhoea/trichomonas).	217/256 (85%) 'enrolled' (unclear whether this means they requested a kit); 143/213 (67%) returned kit; 5.6% positive	Limited details and small n (abstract)
DANISH CHLAMYDIA SCREENING PILOT						
Andersen <i>et al.</i> 2001 ²⁸⁴	Men and women aged 21-23, Aarhus county, Denmark		n=36 ordered online, of total eligible population of 30,000	Test kits ordered (kits returned and positivity were also reported, but not separately for internet-ordered tests)	36 kits ordered online to addresses within study area (vs. 306 via answerphone)	Small n; study period 14 weeks. Evaluated for effect of mass media campaign, not for public health impact, nor effect of internet vs. by answerphone.



Acceptability

Evidence from surveys suggests high acceptability of internet-based home-sampling among users of these services,^{268-270,275,276,281,283,285,286} but no surveys measured acceptability among the general population (Table 9). Research on acceptability sometimes focussed on the home-/self-sampling aspect of internet home-sampling,^{268,269} also found to be acceptable in a systematic review.¹⁷⁴

Formative research with women about proposed chlamydia self-sampling services, has used focus groups (US)²⁸⁷ and online surveys (Australia).²⁸⁸ Concerns were expressed about how to receive kits in a way that protected confidentiality,^{287,288} and about the accuracy of testing this way.²⁸⁸ Receiving sampling kits by internet/post was popular in both studies.^{287,288}

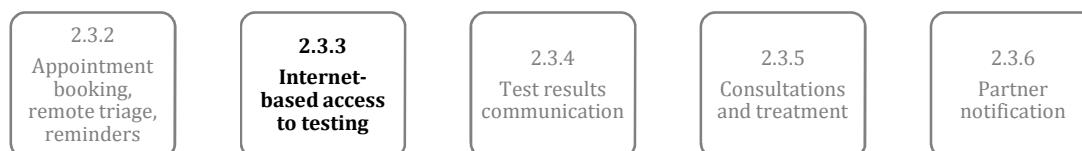
In a case-control study of women using iwanthekit, those who had used the service before (17% of 1747) were more likely to perceive the service as accurate, and as confidential, than were new users.²⁷⁶ No comparison was made with repeat users' perceptions at first use of the service. Therefore it is unclear whether repeat users trusted the service more, or whether users' views changed after they experienced using the service.

Table 9: Internet-based home-sampling: acceptability

Item	Population, setting, STI	Study type	Sample size, response rate	Main relevant outcomes	Main relevant findings	Comments
Graseck <i>et al.</i> , 2011 ¹⁷⁴	Various Chlamydia, gonorrhoea	Systematic review of home- vs. clinic-based specimen collection	Aggregate sample size not provided	Acceptability of home-sampling (not exclusively about internet-based sampling)	Home-based specimen collection (including via internet-ordered kits) is generally acceptable.	Acceptability findings are summarised narratively
Gaydos <i>et al.</i> , 2006, 268,281	Female iwantthekit participants, USA Chlamydia	Surveys with kit users, and among people who requested kit but did not return it	N=400 kit-users; N=108 who requested kit but did not return it – question-specific non-response rates provided, see findings	Preference for self-sampling; perception of safety of self-administered swabs; whether would iwantthekit again	89.5% (358/400) kit-users ‘preferred self-sampling’ (14/400 provided no response). 92.6% non-users who requested kits preferred self-sampling (8/108 no response). 87.5% (351/400) kit-users considered self-swabs safe (35/400 no response). 99/108 non-returned (5/108 no response) 86.3% (345/400) kit-users would use the internet/self-sampling again (37/400 no response). (<i>Question non-responders included in denominators</i>).	Questions seem poorly worded (and no pilot of questionnaire mentioned) Way of dealing with item non-response differs between studies, so percentages difficult to compare.
Gaydos <i>et al.</i> , 2009 ²⁷⁵	As above Chlamydia, gonorrhoea, Trichomonas	Surveys with kit users	n/N=1093 to 1162, out of 1203 (question non-response varied)	As above, and: Ease of self-sampling	90.9% preferred self-sampling; 94.5% considered self-administered swabs safe; 91.7% would use internet/self-sampling again; 96.7% considered self-sampling easy or very easy (<i>question non-responders not included in denominators</i>).	
Gaydos, Barnes <i>et al.</i> , 2009 ²⁶⁹ (abstract)	Male iwantthekit users, USA Chlamydia	As above	N=270 (survey response rate not reported)	Preference for & ease of self-sampling Hypothetical repeat use	86.7% preferred self-sampling, 87.5% would use internet/self-sampling again, 88.9% considered self-sampling easy or very easy.	

Chai <i>et al.</i> , 2010 ²⁷⁰	As above Chlamydia, gonorrhoea, Trichomonas	As above	n/N= between 376 and 400/501 (varying by question)	Perception of safety of penile swabs Hypothetical repeat use Ease of self-sampling	86% considered penile swab safe (342/396), 89% would use internet/self-sampling again (357/400), 89% considered self-sampling easy or very easy (336/376). <i>(Question non-responders not included in denominators).</i>	
Gaydos, Hsieh <i>et al.</i> , 2011 ²⁷⁶ (abstract)	Female iwantthekit users, USA Chlamydia, gonorrhoea, Trichomonas	Case-control: comparison of surveys from repeat-users of iwantthekit, with first-time users (controls)	n not provided by authors: '17% of 1747' (=297) repeat users, double the number of matched controls	Perception of internet-based screening	Repeat users more likely to perceive internet-testing as confidential (OR: 1.98, 95%CI 1.32-3.44) and results from self-administered swabs as accurate (OR from multivariate analysis: 2.49, 95%CI 1.61-3.87) vs. first-time users – <i>no proportions provided.</i>	
Spielberg <i>et al.</i> 2013 ²⁸³	Females, 18-30, 4 San Francisco Bay area health depts	Feasibility study over 3 months; follow-up survey	106 of 143 those returning kits completed follow-up surveys	Ease of use, acceptability - among users	98% reported easy to use, 98% would recommend to friend, 94% preferred online service vs. clinic-based care.	Limited details (abstract)

Table 9, continued	Population, setting, STI	Study type	Sample size, response rate	Main relevant outcomes	Main relevant findings	Comments
Greenland <i>et al.</i> , 2011 ²⁸⁵	Dutch internet-based chlamydia screening participants and non-responders	Surveys with random samples of screening participants, and non-responders to screening invitations	Participants survey: n/N= 3499/5569 (response rate 63%) Non-responder survey: n/N= 2053/13,724 (response rate 15%)	Ease of use Acceptability Reasons for non-participation	<i>Participants:</i> 94% agreed that packaging the sample for posting was easy; 92% agreed instructions were clear; 89% agreed method easy to use. Little variation by ethnicity or gender, but among urine-kit users, Turkish participants were more likely to find vaginal swabs 'unpleasant' (73% vs. 42% p<0.001). <i>Non-responders:</i> No/limited internet access reported by 2.5% as reason for non-participation. Internet participation reported as a disadvantage among non-participants aged 16-19 (26.1%) and risk groups including: non-Dutch (20.2%), those with low education (22.8%), and multiple recent sexual partners (24.4%). <i>Both groups:</i> Using internet for screening reported as advantageous (93% participants, 56% non-participants).	Sampling and statistical methods good, but survey of non-responders achieved low response rate.
Koekenbier, Kalma <i>et al.</i> , 2011 ²⁸⁶	<i>As above</i> , those requesting but not returning test-kits	Qualitative interview study	n=25 (response rate/refusals not reported); saturation reportedly reached	Reasons for requesting but not returning test-kit	Motives for requesting kit: perceived personal risk for chlamydia, and advantages of screening programme compared to conventional testing, including anonymity and avoiding clinic/GP invasive testing. Barriers to returning kit: low personal risk-perception, recent testing, lack of clarity re: screening procedures, fear positive result, privacy worries, finding method of sampling unpleasant.	Difficult to assess quality given limited details (abstract)
Ahmed <i>et al.</i> , 2013 ²⁸⁸	Women aged 16-25 recruited facebook, Victoria, Australia	Survey	n=278, 65% participation rate (of 426 who clicked on advert & were contactable)	Conceptual acceptability of internet-based chlamydia screening	76.3% (209/274) reported willingness to participate in internet-based chlamydia screening (using VVS). Greater willingness among those with lower education, and those living outside major cities. Free-text responses included concerns about the online nature of the service, privacy, and trust in results accuracy.	No response rate. No multivariate analysis



Downloadable forms for free testing without consulting a health professional

Programmes in two countries have enabled MSM to download laboratory requisition forms, which they could take to laboratories where they could have blood-tests for syphilis, anonymously (Netherlands²⁵⁷) or confidentially (US^{254,255}). Very low numbers of cases were found in these small audit studies, but high positivity rates were reported^{254,255,257,289} (Table 10). Authors concluded that this model of testing reaches ‘non-clinic populations’, complementing existing service provision,^{254,255,257} but presented no evidence for an impact on transmission.

In Western Australia a similar model was implemented, but for chlamydia testing.²⁸⁹ Low uptake (377 tests) compared to regional chlamydia notifications (n=10,249)²⁸⁹ suggests limited impact on prevalence.

Acceptability (not tabulated)

Qualitative studies among Canadian youth, clinic-attenders and MSM, explored internet-based STI testing hypothetically.²⁹⁰⁻²⁹² Although it was viewed positively, the need to print forms was perceived as outdated,²⁹⁰⁻²⁹² MSM and clinic-users expressed an interest in continuity of online care (i.e. for other aspects of STI care to be provided online),²⁹² and MSM wanted the service to be anonymous.²⁹¹

In a small Canadian survey (n=99), 76% of sex-workers and their clients expressed interest in internet testing,²⁵³ but no distinction was made between these two groups in the reporting of results.

In a user-survey of the Australian chlamydia internet-testing service described above, ‘almost all’ (n not reported) would recommend the service. However, the response rate was very low (17%, 55/332),²⁸⁹ and so results may be biased.

Table 10: Downloadable forms for free testing without consulting a health professional: summary of audit data

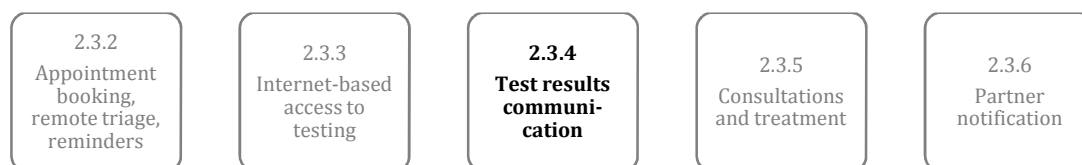
Item	Infection	Setting, population	Tests performed	Results accessed	'Positivity': Number and percentage of those tested requiring treatment ^a	Proportion of diagnosed and treatable infections treated	Comments
Klausner <i>et al.</i> , 2004 ²⁵⁴	Syphilis	MSM, San Francisco, USA	n=140	Not presented	6 (4.3%)	All	Small numbers achieved, lack of evidence of population-level impact, although evidence presented (see text) of reach to non-clinic populations.
Levine <i>et al.</i> , 2005 ²⁵⁵	Syphilis	MSM, San Francisco, USA	n=218	Not presented	6 (2.8%) Comparators: 2.2% at gay men's health centre, 3.0% among MSM at municipal STD clinic	All	
Koekenbier <i>et al.</i> , 2008 ²⁵⁷	Syphilis ^b	MSM, Amsterdam, Netherlands	n=93	90/93	7 (estimate) ^c (7.5%) Comparator: 5.5% ^d in STI clinic	Not presented ^b	
Kwan <i>et al.</i> , 2012 ²⁸⁹	Chlamydia	General population, Western Australia	n=377	Not presented	66 (18%)	All	No sampling frames or response rates available

^aAs a positive test result for syphilis antibodies can indicate current or past infection, confirmatory testing is required to identify current infection requiring treatment.

^bSince the study took place, authors report that asymptomatic testing for other STIs and HIV is included in the service.

^cAuthors report that 4/7 did not attend confirmatory testing, of which 1 did not collect results.

^dCalculated based on figures presented in the article: 319/5852.



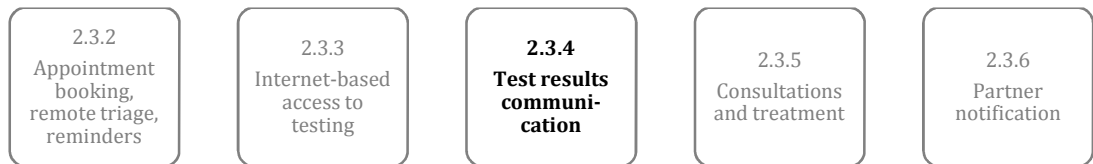
2.3.4 Test results communications

This section includes research about electronic messages which either contained STI test results, or which notified patients that test results were ready (prompting them to contact services or to log in to a website to receive the actual result). The division between the two was blurred by the fact that negative ('all clear') results were sometimes provided electronically, but the same results service might alert patients to contact the clinic/testing service in the case of a positive test result. Research literature did not always clearly state the content of results communications.

Conceptual acceptability and preferences

Several studies (Table 11) explored the conceptual acceptability of means for communicating results electronically or preferences for how to receive results. Study designs included surveys with healthcare users and/or community samples,^{241,275,293-300} and one survey consisting of a Discrete Choice Experiment (DCE) in which participants were asked to rank different combinations of features of a proposed service, including how results were received.³⁰¹ One qualitative study, using focus groups with a predominantly female sample of users of an adolescent health centre in the US, explored the broad topic of use of ICT for sexual healthcare and sexual health education.³⁰²

What stands out from the survey research is that prior to implementation of text message, email or internet services for results communication, participants preferred to receive their results by other methods, for example, phone call. Acceptability of electronic results communications was, in some studies, lower if the proposed message would include results²⁹⁶ or if it communicated positive results.²⁹⁴ Lower conceptual acceptability was found among some risk groups,²⁹⁹ females,^{294,299} and with increasing age.^{295,301} However, the limited details provided (including about the nature of the messages, how the survey questions were asked and their response options) make these studies difficult to compare. The only study which compared preferences to the methods



actually chosen by patients, found that only 0.2% chose an electronic method (email) for results notification (text messaging appears not to have been offered).²⁹⁵

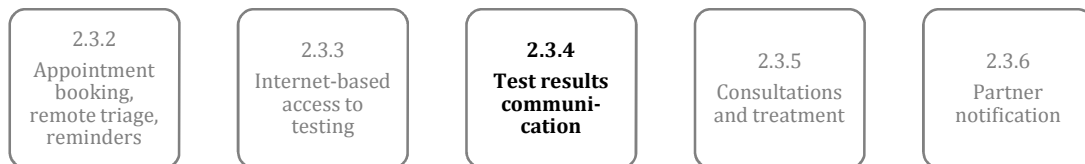
Few details were reported about the qualitative study (described in an abstract). Participants predominantly wanted to receive text messages to indicate a need to return to clinic regarding their results, but not to receive the actual result (diagnosis) in the message.³⁰²

Table 11: Text messages, email and internet test results communication: conceptual acceptability and preferences

Item	Setting, population, STI	Study type	Sample size, response rate	Main relevant outcomes	Main relevant findings	Comments
Brown <i>et al.</i> , 2008 ²⁹³	16-25 year olds, GUM and community surveys, UK, STIs	Survey	Clinic: 92% (202/220) Community: 43% (542/1260)	Hypothetical preference (as first choice)	Overall less than 5% gave text message, email or internet as their first choice (vs. telephone, face-to-face).	Response rate for community survey is low
Brugha <i>et al.</i> , 2011 ²⁹⁴	18-29 year olds, healthcare settings and students, Ireland 2009 Chlamydia	Survey	n=6085 (5685 students, 400 healthcare attendees, response rates not reported)	Hypothetical preference (as first choice)	Email preferred by: 14.5% students, 8.0% healthcare attendees for positive results; 24.8%, 15.8% for negative results. Texts preferred by: 5-7% for positive results, 8-10% for negative results (alternatives: call to landline, call to mobile, patient calls clinic, letter). Email more popular among men than women, for positive and negative results.	No response rate reported
Challenor & Deegan 2009 ²⁹⁵	Patients attending GUM clinic, UK 2008 Infections not specified	Survey; responses compared with audit data on actual method chosen for results communication	n=1000, response rate not reported; n=977 for actual results notification method chosen	Hypothetical acceptability; method actually chosen	Mean rating (scale: 1-9): text message 5.8; email 4.9; internet 3.8; mobile phone call 7.7. No news is good news 3.7 (i.e. results only notified if positive). Email chosen by 0.2%, text message apparently not offered.	Response rate not reported
Cook <i>et al.</i> , 2010 ²⁹⁶	STD clinics, Florida, USA 2009 Infections not specified	Survey	n=397, response rate 83%	Hypothetical acceptability	Comfortable with text message, email message saying results are ready: 41%. Comfortable with text or email giving actual result: 18%.	Good response rate. Limited details (abstract)

Table 11, continued	Setting, population, STI	Study type	Sample size, response rate	Main relevant outcomes	Main relevant findings	Comments
Gaydos <i>et al.</i> , 2009 ²⁷⁵	Users of iwantthekit internet-based home-sampling. Chlamydia; later, gonorrhoea & Trichomonas	Survey	N=1179 (response rate not reported)	Preference (hypothetical?)	Email 35.5%; internet 9.8%. More than one answer possible.	Response rate not reported
Lawton & Andradý 2011 ²⁹⁷	4 UK GUM clinics	Survey	Not reported	Hypothetical acceptability	Reported happy to receive results by: text message 36%; email 22%; website 16%. <i>Numerators, denominator not reported.</i>	Limited details (abstract)
Malbon <i>et al.</i> , 2012 ³⁰²	Adolescent Health Centre, USA 2010 STDs	Focus group study	n=31 in 7 groups (response rate not reported) 30/31 female	Hypothetical acceptability/preference	General preference to be notified by text message if result was abnormal. Unanimously did not want the actual result sent by text.	Limited details (abstract)
Miners <i>et al.</i> , 2012 ³⁰¹	Diverse STI testing centres, UK 2010 STIs	DCE survey	n=3358, response rate not reported	Hypothetical preference	Study compared various characteristics of service provision. Preferred method for receiving results was 'text or call to mobile phone' but lack of borderline significance of this and 'email', suggest other characteristics were more important to patients. (Alternatives: phone up test centre, post).	Survey response wording means results cannot distinguish preference for text message vs. mobile phone call

Table 11, continued	Setting, population, STI	Study type	Sample size, response rate	Main relevant outcomes	Main relevant findings	Comments
Ross <i>et al.</i> , 2000 ²⁴¹	GUM clinics, UK 1999 Infections not specified	Survey	n=1204, response rate not reported	Hypothetical acceptability	Email acceptable to 52% of the 41% (n=499) with internet access; internet acceptable to 63% of those with internet access (315/499). Some ethnic groups at higher risk of disease may also lack internet access.	Lack of response rate
Saadatmand <i>et al.</i> , 2012 ²⁹⁸	African American adolescent men, high morbidity neighbourhood, USA 2010, STD	Survey	n=108 of 193 (193 approached includes people who may have been ineligible)	Hypothetical preference	Website: 11.1%, text or email 12.0% (alternatives: telephone, letter, clinic, 'would not do' – <i>i.e. would not test</i>).	Small n, likely moderate response rate
Tripathi <i>et al.</i> , 2012 ^{299,300}	STD clinics, South Carolina and Mississippi, USA 2009-10 STD	Survey	n=2719, response rate not reported	Hypothetical acceptability	Prefer results by text message only if negative: 35.8% agree, 64.3% disagree; prefer results by email only if negative: 29.8% agree, 70.2% disagree; prefer results by email whether positive or negative: 41.9% agree, 58.2% disagree. Combined preference to receive results whether positive or negative: both text message & email 29.2%; email only 12.7%; text message only 21.0%; neither text message nor email 37.1%. Multivariable analysis: Higher acceptability of email and text messages for results with younger age, and daily use of email and text messaging; lower acceptability associated with female gender. Lower acceptability of text messages for results associated with college-level education compared with less than high-school.	Results reporting confusing and at times unclear, large n but no response rate given



Uptake, use and effectiveness

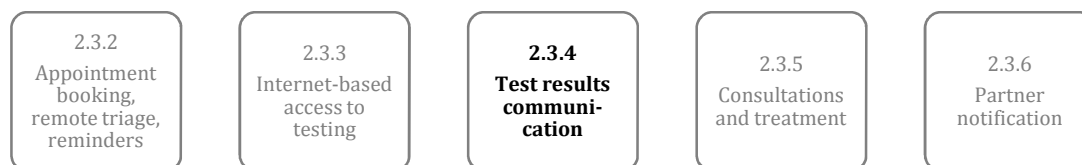
In practice, online and text message based results services appear acceptable. However there has been little evaluation of their impact on clinical outcomes.

Text messaging

When text message results services were actually implemented, they appeared to be more acceptable than the research on their conceptual acceptability suggested, although possibly this reflects changing norms over time. Clinic audit data showing an increase (2004-2008) in uptake of results by text, suggested growing acceptability in some clinics.²⁴⁴ GUM audits also report positive impacts of text message results notification on clinic running (namely, staff-time^{244,303}).

Two studies assessed the effect of text message results systems on time to treatment for chlamydia. Neither named diagnoses in results; instead they provided negative results or (if positive) asked patients to contact the clinic. A before-and-after study (n=596) of the impact of a text message results service on median time to treatment in a New Zealand clinic, found no statistically significant effect (3-4 days),³⁰⁴ while a small (n=49) lower-quality UK study comparing patients who were and were not texted results, did find a favourable effect (9 vs. 15 days, p=0.005).³⁰⁵

Text message 'transmission rates' (proportion of messages reaching patients' phones) have been reported as 93-95%.^{303,304} In a randomised study of communication of STI results to emergency department patients (in the US), comparing phone call only, text message only, and call plus text message, those in the latter group were more likely to receive their test results within 7 days, but there was no difference between the call only and text only groups.²³⁸



Online results services

The proportion of patients who access test results online has ranged from 74-100%^{283,306,307}; notably online access to results has sometimes been offered as the default, and sometimes on an opt-in basis, which may affect uptake.

In a large survey (n=3499) of a random sample of Dutch internet chlamydia screening participants, 96% rated the online results service favourably, with little variation by positivity.²⁸⁵ In a study in the UK, among the 11.5% who took up the offer of chlamydia home-sampling with online registration, 82% (n=3401) chose to receive results online.³⁰⁸

A large US clinic study explored the effect of a new online results service on receipt of results and proportion of those testing positive who were treated within 30 days, comparing the period before implementation with the period during which the results service was provided on an 'opt-in' basis, and then as the default option for receiving results. No statistically significant effect was found for either receipt of results or proportion treated, although those choosing the online results service were more likely to be notified compared to those not doing so (who the clinic attempted to contact via telephone call).³⁰⁶ It is difficult to interpret these findings due to non-experimental design.

Table 12: Results communication: summary of studies about uptake, use and acceptability

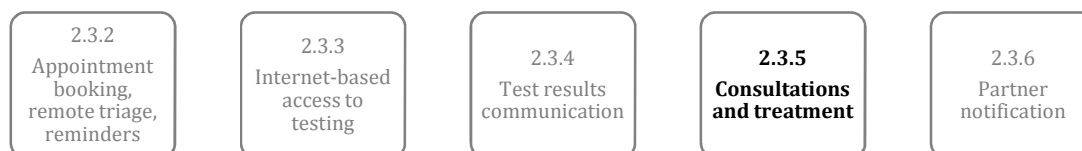
Item	Setting, population, STI	Study type	Sample size, response rate	Main relevant outcomes	Main relevant findings	Comments
TEXT MESSAGING: Negative results in message; in case of positive results, message asks patients to contact clinic, or return to clinic						
Dhar <i>et al.</i> , 2006 ³⁰³	GUM clinic, UK 2003-04 STI/HIV (except for those at high HIV risk)	Audit; Survey among users and non-users of text message results service	n=6451 were texted results message (69%) n=150 survey responders, response rate not reported	Acceptability; Staff time; Failure rate of message transmission	100% users pleased with text message results service; 'the majority' found it quick, safe, confidential. Estimated reduction in staff time spent conveying results: 19-20hrs/week for negative results phone calls; by text message 8hrs/week (for all results). Non-users cited 'wanting to hear results personally' as main reason for declining results service [figures not reported]. 5% failure rate in message transmission.	Unclear reporting of relevant methods and results
DH ¹¹²	UK GUM clinic	Audit, survey	Sample size not reported	Staff time Acceptability	Text messages (stating that results were negative or asking to return to clinic) led to reduction in demand for nurse-led telephone results service (saving 30 hours/month). 80% survey respondents felt text results service 'was the best option available' (vs. returning to clinic, or receiving results by telephone or letter).	Limited details (grey literature)
Lim <i>et al.</i> 2008 ³⁰⁴	STI clinic, New Zealand, people diagnosed with uncomplicated chlamydia	Audit before and after implementation of text message results service	Chlamydia cases: before: n=303; after n=293 of which 237/293 were texted results. Response rate n/a	Median time to treatment; proportion of text message delivered	No statistically significant difference in median time to treatment, before and after: all patients: 3 days vs. 4 days; among patients not treated immediately: 7 days vs. 7 days. 93% (of 237) text messages were delivered. Authors checked for and found no significant differences in gender, age, ethnicity, and number of patients treated immediately.	Well-designed observational study

Table 12, continued	Setting, population, STI	Study type	Sample size, response rate	Main relevant outcomes	Main relevant findings	Comments
Menon-Johansson <i>et al.</i> 2006 ³⁰⁵	STI clinic, UK, people diagnosed with chlamydia	Audit of selected cases	Text group n=28 Comparison group n=21 (response rate n/a)	Median time to treatment	Text group vs. comparison group: Contact to treatment: 1 day vs. 1 day, p=0.756 Test to treatment: 9 days vs. 16 days, p=0.005 (NB text messaging was offered to those at low HIV risk).	Small sample size. Groups demographically comparable, but may differ in other ways
Menon-Johansson <i>et al.</i> 2010 ²⁴⁴	3 GUM clinics, London, UK Infections not specified	Audit	Unclear	Uptake of text message results service Impact on number of sexual health screens performed	After 1 year of text message results service, 40% patients received their results this way. Number of sexual health screens increased 10% over first year of text message results service.	Numbers not reported. Text results service introduced alongside other changes to clinic practice; difficulties with attributing change in screens to results service
Platteau <i>et al.</i> , 2012 ³⁰⁹	Outreach testing for MSM, Belgium, STI and HIV	Pilot study	138 MSM tested	Proportion of messages received; rating of various results notification methods	137/138 received their test results (one incorrect phone number). Text message rated best method for receiving results (median rating 9/10).	

Table 12, continued	Setting, population, STI	Study type	Sample size, response rate	Main relevant outcomes	Main relevant findings	Comments
ONLINE RESULTS SERVICES						
Bracebridge <i>et al.</i> 2012 ³⁰⁸	Systematic postal Chlamydia screening, in one NCSP area, ages 18-24. Participants were asked to register online	Evaluation of systematic screening with online remote clinic access	n=3401/3431 (proportion of Chlamydia screens where method of contact was recorded)	Uptake of online results among those using the service	82% users registered and requested results online (the remainder contacted the service).	Few details on this aspect
Greenland <i>et al.</i> , 2011 ²⁸⁵	Netherlands Chlamydia screening programme	Survey	n/N= 3499/5569 (response rate 63%)	Acceptability among users	Receiving results by internet rated as: very good: 76.8% men, 76.5% women; good: 19.4% men, 19.6% women (ns gender difference). Chlamydia positives (n=261) vs. negatives (n=3238): very good: 83.7% vs. 76.3% p<0.001; good: 12.8% vs. 19.9% p<0.001.	Random sampling of participants
Koekenbier <i>et al.</i> , 2013 ³⁰⁷	Netherlands online Chlamydia screening for low-risk young people	Audit	n=388 kits requested, 86% returned; n=135 requested appointment	Uptake of online results	All checked their test result online (n not reported – unclear if includes clinic attenders).	Good response rate but unclear reporting and few details (abstract)
Koekenbier <i>et al.</i> , 2008 ²⁵⁷	Netherlands, downloadable lab referral letter for MSM, syphilis	Audit	n=93	Uptake of online results	'Ninety percent (90 of 93)' [sic] checked results online.	Results unclear

Table 12, continued	Setting, population, STI	Study type	Sample size, response rate	Main relevant outcomes	Main relevant findings	Comments
Ling <i>et al.</i> , 2010 ³⁰⁶	US STD clinic, online results service	Audit over period when online results service was (1) unavailable, and then provided as (2) an 'opt-in' service, (3) 'opt-out' service. Survey (during (2))	Audit: n=12,494 unduplicated new patient visits in study period. Survey n/N=429/442 (97%)	Proportion receiving results Proportion treated within 30 days. While the service was opt-in: Uptake; Reasons for accepting/declining service	Non-significant differences over study period in: % gonorrhoea/chlamydia cases untreated on day of visit, proportion receiving results (66%, 66%, 75%); and proportion of those receiving results treated within 30 days (81.3%, 82.1%, 70.9%). Those choosing online service more likely to receive results (74% vs. 62%, p<0.0001). While the online results service was 'opt-in', 36% signed up to it. Main reasons for accepting: ability to access results any time of day (75%); believing they would receive results faster than if phoning clinic (37%). Main reasons for declining: preferring to call clinic (43%); limited internet access (32%). Most important reasons for declining: limited internet/computer access (47%).	Large n; observational study. High response rate for survey
Reed <i>et al.</i> , 2013 ²³⁸	Emergency department, US, females 14-21 years, STI	Randomised intervention: comparing call, text message or call+text message	n=386, response rate not reported	Proportion receiving results within 7 days of testing	Call+text message study arm: 94% Call+text significantly more likely to receive result compared with call only (OR: 3.1, 95%CI 1.4-6.7), but no significant association with text only.	Experimental design, but few details, e.g. no power calculation, response rate (abstract)
Spielberg <i>et al.</i> , 2013 ²⁸³	Women 18-30, San Francisco, chlamydia, gonorrhoea, Trichomonas	Analysis of data from study of home-sampling	n=143 people returning a kit	Time to results access	80% (115) accessed results online the same day; 86% (122) within 2 days; 92% (131) by study end (duration 3 months).	No sampling frame and limited details (abstract)

Table 12, continued	Setting, population, STI	Study type	Sample size, response rate	Main relevant outcomes	Main relevant findings	Comments
van Bergen <i>et al.</i> , 2010 ²³³	Netherlands internet-based chlamydia screening programme	Audit of screening programme data (see Table 8 for details)	261,025	Proportion checking results online	95% checked their results online, 90% within 7 days of notification by email that results were ready.	Large sample size and good study design overall, but few details reported on results notification
VARIOUS						
Buhrer-Skinner <i>et al.</i> , 2009 ³¹⁰	Australia, within a pilot of chlamydia home self-sampling kits	Pilot study	92 participants who provided contact details (of 100 returning a sample)	Proportion choosing various methods for being contacted regarding results	21.3% (n=18) chose text message, 9.5% (n=8) chose email (alternatives: mobile phone, landline phone, mail).	Small study, message content unclear

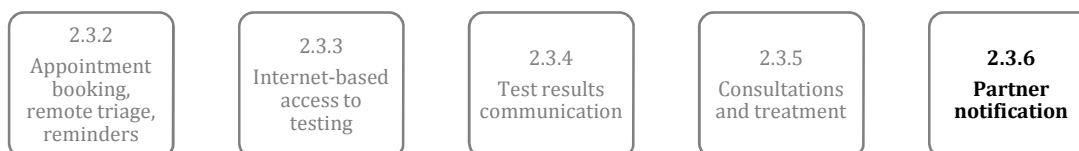


2.3.5 Consultations following positive test results, and provision of treatment

Only two articles concerning these topics were located and met the review's inclusion criteria.

One study, conducted in 2008-09, consisted of a pilot of chlamydia screening which involved home-sampling kits being sent to all 18-24-year-olds registered with GPs in North East Essex, UK ('systematic postal screening').³⁰⁸ Those testing positive completed an online clinical questionnaire which was reviewed by a doctor, and could choose whether to receive their treatment by post or to collect it from a local pharmacy. If the doctor had concerns they telephoned the patient. The main objective of the study was to evaluate systematic postal screening, including its cost, and no further details were presented about the questionnaire, or about treatment provision. Of 152 index patients, 131 were treated remotely (95.4% requested treatment by post and 4.6% from a local pharmacy), and 5 were referred to GUM, with treatment outcomes not recorded for a further 21 index patients. In addition, 26 partners registered online, and all were sent treatment by post.

The second paper reported the findings of a systematic online search of internet-available STI treatments, undertaken in 2007.³¹¹ 77 treatments were provided by 52 companies, and study authors surveyed information available on the companies' websites, but did not attempt to obtain treatment. Websites stated that a consultation was offered for 3/5 chlamydia treatments, 3/4 gonorrhoea treatments, 13/39 genital herpes treatments, and 6/29 genital warts treatments; the same or lower proportions recommended users to seek medical advice.³¹¹ Prior to purchase, only 10 of the 77 treatments were named in the information available and were recommended by UK guidelines (3/5 treatments for chlamydia, 3/4 for gonorrhoea, 0/39 for genital herpes, and 4/29 for genital warts), and information regarding side-effects, contraindications, PN and prevention was often poor or absent.³¹¹ (At the time, oral antibiotic treatment was recommended for gonorrhoea,³¹² potentially deliverable online).



2.3.6 Partner notification

This section concerns use of ICT for ‘provider referral’, and for ‘patient referral’ (see glossary) where the latter is supported by services which enable online messages, emails (including e-cards) or text messages to be generated and sent, anonymously or otherwise.

‘Internet-PN’ (IPN) is use of the internet to facilitate notification of sexual partners. IPN is used (though not exclusively) to notify sexual partners whom index cases met online. By using email addresses or chatroom names, IPN can reach partners whose real names and contact details are unknown.³¹³⁻³¹⁸ The legitimacy of anonymous messages may be questioned by recipients,^{314,319} however little malicious use of IPN services is reported.^{316,320}

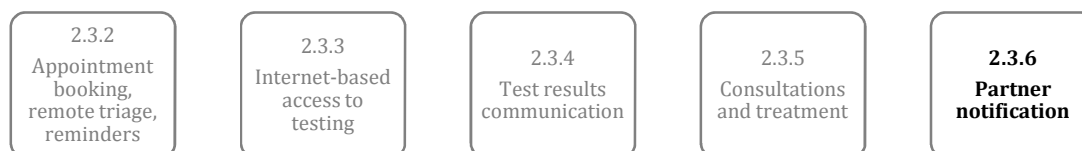
Use and effectiveness

Provider-led PN

The first documented provider-led IPN concerned a syphilis outbreak investigation among US MSM internet sex-seekers, where ‘screen names’ (online aliases) of cases’ partners were emailed.³¹⁵ Provider-led IPN and text message PN has since been documented for syphilis and HIV in various US localities.^{317,321-326} Authors report that high numbers of partners were tested/treated per index case (e.g. 5.9 partners medically-evaluated per case;³¹⁵ 53 partners examined/treated, among 27 cases who ‘named’ 381 email/online partners³¹⁷). This reflects PN efficacy, but also high numbers of partners among the populations of online sex-seekers among whom IPN has been used. IPN may result in significant increases in overall PN activity for syphilis^{317,326} (and HIV,³²⁶ though this is outside this review’s scope). However, systematic data collection has not always occurred³¹⁸ and outcome measures vary.

Patient referral

In an Dutch evaluation of IPN, 14% (n=160) of index-cases used the service to notify a median of 2 partners, and 86% notifications were non-anonymous.³²⁷



Heterosexuals with one recent partner were less likely to use IPN; and MSM with syphilis were more likely to do so than those with other STIs.³²⁷

The US ‘inSPOT’ IPN website was evaluated in a RCT, among MSM, for gonorrhoea/chlamydia, with low enrolment, and low use in inSPOT arms (1/27), such that the study was terminated.²³⁷ Study design was criticised for randomising patients for whom IPN may be unsuitable.³²⁸ Two studies measured reported use/receipt of inSPOT messages among clinic attendees (as part of evaluations of local promotion of inSPOT), assuming most contacts notified would attend large local clinics.^{329,330} Reported use/receipt of inSPOT PN messages was low^{329,330} (but although these promotion campaigns may have reached risk-groups, to be effective they needed to do so at a particular time, i.e. when recently diagnosed with an STI.³³¹) As in the Dutch evaluation discussed above, InSPOT data show syphilis to be overrepresented among messages sent, perhaps reflecting user-populations (largely MSM).³¹⁶

An Australian chlamydia IPN website, targeting heterosexuals, reported that SMS were sent more commonly than emails (2727 vs. 108) but did not report PN outcomes.³²⁰

Internet-PN: evaluation issues

Partners for whom internet is the only means of contact (by services or by index patients) are likely to remain untreated otherwise.^{321,332} Therefore, instead of comparing IPN with other types of PN, it may be more useful to consider that IPN can reach partners unreachable by other means, thus meeting a need unmet by conventional PN.^{333,334} A 2007 review noted weak IPN study designs.³³⁵ Some subsequent research constitutes an improvement, but methodological difficulties remain, and more evidence of IPN’s effectiveness is required.

Table 13: Uptake and effectiveness of partner notification by text message, email and internet

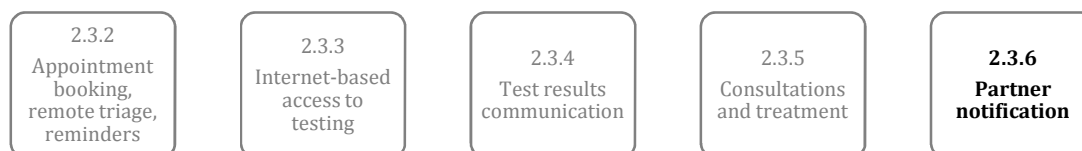
Item	Population, setting	Study type	Means of notifying, STI	Sample size	Main relevant outcomes	Main relevant findings	Comments
INTERNET-PN WEBSITES WHICH SEND NAMED OR ANONYMOUS E-CARDS, EMAILS, OR TEXT MESSAGES							
Bilardi <i>et al.</i> , 2010 ³²⁰	Hetero-sexuals, Australia	Audit/evaluation	'Let them know' Patient-led PN for chlamydia	n=2835 messages sent	Uptake (PN messages sent), Reports of misuse	2727 text messages and 108 emails sent over 11 months period (excluding 6 week period when data was lost due to server malfunction) Increase in monthly uptake over time (85 to 369, p<0.01). 4/14 comments reported hoax use of the site.	Lack of PN outcomes
Götz <i>et al.</i> 2013 ³²⁷	STI clinic patients Rotterdam and Amsterdam, Netherlands	Audit	'Suggest-a-test' (SAT) Patient-led PN. Website generates email, text message, letter or 'gay dating site' [sic]. Various STIs	n=1184 index patients	Uptake, Proportion of partners notified, Positivity by method of notification	160/1184 (14%) of indexes used SAT; 588 notifications sent (median 2), of which 82% by text message, 16% email. 86% messages were non-anonymous. Heterosexuals more likely <i>not</i> to use if only had one partner; MSM more likely to use if diagnosed with syphilis. Rotterdam data (67 indexes used SAT): 56% (225/402) partners notifiable, 95% (213/225) notified using suggest-a-test. STI positivity was lower in those notified by suggest-a-test (28%, n=116) than those with contact cards (45%, n=152; p<0.001).	Good study design, details sometimes unclear (abstract)
Kerani <i>et al.</i> , 2011 ²³⁷	Washington State, USA, MSM	RCT of referral to inSPOT (& <i>Patient Delivered Partner Therapy</i>)	'inSPOT' Patient-led PN for gonorrhoea and chlamydia	n/N= 53/318 (16.7%) enrolled & completed study	Uptake, Partners notified, treated & tested	1/27 in inSPOT study arms used inSPOT website. PN outcomes ns different between study arms, but fewer partners HIV-tested among inSPOT study arms: ratio of unadjusted mean number of partners tested per index 0.42 (95%CI: 0.18-0.99).	RCT ended due to low enrolment. Likely under-powered.

Table 13, continued	Population, setting	Study type	Means of notifying, STI	Sample size	Main relevant outcomes	Main relevant findings	Comments
Levine <i>et al.</i> , 2008 ³¹⁶	Various localities, USA	Audit	'inSPOT' Patient-led PN, various infections	23,594 e-cards sent (in 2006-07)	Uptake, Recipients per e-card	Average recipients per card: 1.6. 23,594 e-cards sent (2006-07), 15.4% for gonorrhoea (3631); 14.9% for chlamydia (3519); 9.3% for HIV (2736); 48.8% (11,505) for other STIs.	Lack of PN outcomes
Plant <i>et al.</i> , 2012 ³²⁹	Large local STD clinic, Los Angeles, USA, MSM	Observational evaluation of inSPOTLA promotion: audit and surveys of MSM in the community	'inSPOTLA' Patient-led PN, various infections	Audit: n=1287 STI/HIV contacts; Baseline survey: n/N=203/707. 28.7% agreed & eligible; Follow-up survey: n/N=306/627 48.8% agreed & eligible	Proportion of patients attending clinic as contacts notified by inSPOTLA; Surveys of use and awareness	<i>Audit:</i> 0.2% (2/1287) of those attending as contacts reported attending because of receiving an inSPOTLA card (over 3 years). <i>Surveys:</i> before vs. after: aware of inSPOTLA: 15.8% vs. 14.4%, p=0.76; ever sent an e-card: 0.5% vs. 1.3% p=0.39; ever received an e-card: 0% vs. 1.0% p=0.25.	Low response rate
Rietmeijer <i>et al.</i> , 2011 ³³⁰	Denver, Colorado, USA, all sexualities	Observational evaluation of inSPOT Colorado promotion: website data; STI clinic surveys	'inSPOT Colorado' Patient-led PN, various infections	1 st survey: n=453 2 nd survey: n=481 (response rates >95% in both surveys)	Surveys of use and awareness	<i>Baseline vs. follow-up:</i> Ever heard of inSPOT: 4.9% vs. 5.8% ns difference; ever sent inSPOT e-card 0.2% vs. 2.0% 'p>0.05' [<i>sic; perhaps should be p<0.05, based on CIs</i>]. Ever received an e-card 0.4% vs. 1.0%, ns difference. Of the 10 in the second survey who reported having sent an inSPOT e-card, 7 had misunderstood the survey question.	Lack of PN outcomes

Table 13, continued	Population, setting	Study type	Means of notifying, STI	Sample size	Main relevant outcomes	Main relevant findings	Comments
van Bergen <i>et al.</i> , 2010 ²³³	Dutch internet-enabled, register-based chlamydia screening programme	Audit data on internet-enabled PN (within broader study of screening programme)	Website for anonymous PN, chlamydia	1745* index cases; 382 partners notified by IPN <i>(*calculated from figures provided in the paper)</i>	Uptake: email addresses provided; proportion of partners requesting test kit; proportion of these testing positive	95% of 1745* accessed their test results online. They provided email addresses of 382 non-regular sex partners of the previous 6 months. 125 of the notified partners (33%) requested a test kit, of whom 107 (86%) sent in a sample for chlamydia testing. Twenty-nine of these samples (27%) tested positive.	Low uptake of anonymous IPN was expected by authors as patient referral is most common
OTHER USE OF INTERNET, TEXT MESSAGE OR EMAIL FOR PN							
Klausner <i>et al.</i> 2000 ³¹⁵	California, USA	Audit/ account of practice	Chatroom PN for syphilis	n=7 early syphilis cases linked to an online chatroom	Partners medically evaluated per index; proportion medically evaluated	Interviews with 2 index cases resulted in 5 related cases identified (n=7). Among these: 'partner index' (number of uniquely named partners divided by number of cases): 12.4. Mean number of partners medically evaluated per index: 5.9 (42% of 'named' partners).	Very small n. <i>First report of internet-PN.</i>
Vest <i>et al.</i> , 2007 ³²¹	STD clinic patients, Texas, USA	Comparison of patients with pseudonymous partners (only contactable by email) with unmatched controls	PN including via email/ online, various STIs and HIV	n=53 patients with pseudonymous partners; n=265 unmatched controls	PN outcomes for index patients with and without pseudonymous sex partners	Cases (reporting ≥1 pseudonymous sex partner) vs. controls: 49.7% (88/177) vs. 69.7% (372/543) partners notified (p<0.001); 80.7% (71/88) vs. 95.4% (355/372) notified partners evaluated (p<0.001). No difference in proportion infected (26.8%, 29.9%, p=0.601). <i>(Cases more likely to be White, MSM, to have multiple partners, partners with multiple partners, prior STDs).</i>	

Table 13, continued	Population, setting	Study type	Means of notifying, STI	Sample size	Main relevant outcomes	Main relevant findings	Comments
Ehlman <i>et al.</i> , 2010 ³¹⁷	People diagnosed with early syphilis, Washington DC, USA	Audit of provider-led PN	Provider-led PN via email (including messaging e.g. on sex-seeking website)	n=27 patients with early syphilis who provided email/ internet contact details for 1+ partner	PN outcomes for index patients with and without at least one partner contactable by email/ internet	<p><i>Indexes:</i> 71% (381/535) PN investigations were internet-based.</p> <p><i>Partners:</i> 381 internet partners emailed, of which PN outcomes ascertained for 17% (65/381), of which: 9% (6) infected and treated; 38% (25) preventatively treated; 6% (4) already treated; 34% (22) tested & uninfected).</p> <p>29% (110/381) contacted service and were provided with information, of which: 48 self-reported having been examined and treated; 30% (116/381) opened email; 24% (90/381) email not received or unknown whether or not received.</p> <p><i>Effect of email PN on overall PN activity:</i> 75% increase in partners investigated; 8% increase in indexes with at least one partner treated; 26% increase in patients examined & treated if necessary; 83% increase in partners notified of STD exposure.</p>	Low n. Appropriate design to estimate impact of email PN on overall PN activity.
Mendez & Maher 2012 ³²⁵	Portland, Oregon, USA	Audit and anecdote	Provider-led PN: text message is sent after an unanswered phone call	n=149 contacts	Proportion responding to PN message	<p>56% contacts phoned back after receiving the text message.</p> <p>Most respond within 10-15 minutes, vs. 3-4 days for responses to letters (anecdotal reports from providers).</p>	Letter; not peer-reviewed. No data on PN outcomes.

Table 13, continued	Population, setting	Study type	Means of notifying, STI	Sample size	Main relevant outcomes	Main relevant findings	Comments
Bernstein <i>et al.</i> 2013 ³²⁶	San Francisco, USA	Audit	Provider-led PN for syphilis and HIV	n=645 syphilis contacts, n=691 HIV contacts with only internet contact information	Proportion of partners contacted who had internet-only contact info; proportion of those contacted tested/treated	Of partners with internet-only contact information: 47.1% syphilis contacts and 46.6% HIV contacts successfully contacted. Of these: 42.4% (129) syphilis internet partners presumptively treated or brought to treatment (7.2% increase in 'successful PN outcomes'). 17.1% (55) tested for HIV (7.9% increase in 'successful partner outcomes').	Lack of detail in results (abstract)
Hightow-Weidman <i>et al.</i> 2012 ³²²	North Carolina, USA	Audit before/after 'collaboration' to improve IPN	Internet PN (email, sex-seeking websites) for syphilis, HIV	n=288 internet contacts	PN outcomes before and after collaboration	95/155 (61%) successfully notified vs. 34/133 (26%) in earlier period.	Few details (abstract)
Jackson 2012 ³²³	Louisiana, USA	Audit	Provider-led internet PN for HIV and syphilis	n=75 partners referred	Proportion of partners reported as tested/treated	35.8% (14/75) partners referred to the service agreed to seek or already sought testing and/or treatment.	Small n. Few details (abstract)
Mettey <i>et al.</i> , 2012 ³²⁴	Philadelphia, USA	Audit	PN for male syphilis and HIV cases, through the internet	n=104 male index patients reporting internet-use to seek sex partners	Proportion of online contacts <u>not</u> notified Number of new cases found Number treated presumptively	17 men named 70 online contacts. 29/70 (41.4%) could not be notified due to spelling errors, change or deletion of online profile. No new syphilis/HIV cases found; 11 contacts treated presumptively for syphilis; 7 contacts, who had never been tested before, received negative HIV test results.	Some unclear reporting, few details (abstract)



Conceptual acceptability (Table 14)

The majority of research on conceptual acceptability of electronic PN concerned patient-referral, but the nature of PN communications was not always clear (for instance, notifying partners using websites which generated email ‘e-cards’ could be described as PN by internet, or email). Research about the conceptual (hypothetical) acceptability of notifying partners by electronic means was sometimes conducted with those diagnosed with an STI, or notified of STI exposure using conventional means,^{319,336,337} and sometimes broader groups^{330,338-345} among which the idea of notifying a partner of STI exposure, or being notified, may be more abstract. One study surveyed GPs.³⁴⁶ Most research used surveys, but there was also some qualitative research.

Acceptability of notifying partners online/electronically may differ by partnership type,³⁴⁰ message content,³⁴³ infection,³³⁷ HIV status and STI history.³⁴¹ Personal contact was generally preferred.^{319,343} Comparisons of studies among heterosexual populations³³⁶ and MSM^{338,339} suggest possible lower acceptability of IPN among the former. However, most MSM in a mixed-methods study (65%, n=118) had not heard of PN, and expressed greater concern with being notified at all, than the method of notification.³⁴² Levels of awareness of PN *per se* may pose a barrier to formative research about new PN methods.

One survey of MSM, recruited from sexual health clinics and a private medical practice, presented them with various scenarios of PN, including via an anonymous e-card informing them of gonorrhoea exposure.³³⁸ If notified by e-card (compared to by a partner), fewer reported that they would seek HIV testing (86% vs. 78%, $p < 0.0001$, HIV-uninfected men only), and fewer reported that they would seek care in the absence of symptoms (64% vs. 84%, $p < 0.0001$).³³⁸ Authors suggest that this represent risks of IPN relative to patient-referral by other methods.³³⁸ However in practice, as I have discussed earlier, without IPN some internet-contactable partners will remain un-notified.

Table 14: Partner notification: conceptual (hypothetical) acceptability

Item	Study population	Study type	Means of notifying, STI	Sample size, response rate	Main relevant outcomes	Main relevant findings	Comments
RESEARCH AMONG PEOPLE RECENTLY DIAGNOSED WITH AN STI OR RECENTLY NOTIFIED OF STI EXPOSURE							
Bilardi, Fairley <i>et al.</i> , 2010 ³³⁶	STD clinic patients recently-diagnosed with Chlamydia	Survey	Website for anonymous PN via email/text message, Chlamydia	n/N=202/286 response rate 71%	Hypothetical usefulness; Current PN practice	47% would have found a website for anonymous PN useful. 34% of 94 who had not contacted all contactable partners said that they would have contacted more partners with this. Heterosexual men less likely than women, MSM to say that they would use web-based tools if available (4% vs. 12%, 16% p=0.02). Few had emailed/texted their partners for PN, preferring to notify face-to-face/by phone call.	
Hopkins <i>et al.</i> 2009 ³¹⁹	Chlamydia patients, Australia 2006-07	Semi-structured telephone interviews	Text message, email; Chlamydia	n/N=40/66 (60.6%)	Hypothetical acceptability, impressions	Text message/email generally less favoured than face-to-face notification, but could be acceptable where contacts were not otherwise reachable, or patients wished to avoid direct contact. Text/email PN could be considered rude, impersonal or 'gutless'. Privacy could be compromised by messages being shown to others; anonymous messages might avoid this. SMS may be problematic due to message length.	
Scott <i>et al.</i> , 2010 ³³⁷	GUM clinic patients who were STI contacts or newly diagnosed	Survey	Text, 'Patient initiated, provider enabling PN' various STIs and HIV	n=106 (response rate not provided)	Hypothetical acceptability	60% considered PN by text message acceptable and 25% unacceptable. 80% newly-diagnosed patients chose patient referral (41/51), among 17%, by text message (unclear if this refers to notifying or being notified). Acceptability varied by infection.	small n, no response rate. Unclear reporting (abstract)

Table 14, continued	Study population	Study type	Means of notifying, STI	Sample size, response rate	Main relevant outcomes	Main relevant findings	Comments
RESEARCH AMONG CLINIC ATTENDEES							
Kerani <i>et al.</i> , 2011 ³³⁹ [abstract]; Kerani <i>et al.</i> , 2013 ³³⁸ [article]	MSM, STD clinic and private medical practice, USA (49% with experience of PN; 56% previous STI)	Survey	Anonymous e-cards; message to partner, via inSPOT (can be anonymous), 'STD'	n=198 (no response rate reported)	Hypothetical acceptability and preferences for sending an inSPOT e-card; reaction to receiving a hypothetical e-card	<i>Sending</i> : 56% said they would use inSPOT e-card to notify a partner if they had an STD. When given multiple options 38% chose an e-card. <i>Receiving</i> : If asymptomatic, 62% reported that they would seek medical care; 98% if rectally symptomatic; higher proportions if the email/e-card was signed.	No response rate reported
Rietmeijer <i>et al.</i> , 2011 ³³⁰	Denver, Colorado, USA, clinic attendees	Survey	Text message, email/ internet STI	Survey: n=481 (response rate >95%)	Hypothetical means of notifying partners, if diagnosed	11.0% text message; 4.8% email/internet (89.4% face-to-face/in person; multiple responses possible). <i>Part of inSPOT evaluation</i>	High response rate
Apoola <i>et al.</i> , 2006 ³⁴³	GUM clinic patients, UK	Survey	Text message, email from clinic; content varied 'an STI'	n=2544, response rate not reported	Hypothetical acceptability of being contacted (rating as a good or bad method)	<i>Text message</i> : asking you to contact clinic: rated 'good' by 31.1%, 'bad' by 42.3%; informing you that you may have an STI: 17.0% good, 61.4% bad <i>Email</i> : asking you to contact clinic: 23.9% good, 45.3% bad; informing you that you may have an STI: 9.1% good, 67.1% bad. Higher acceptability of text/email among those with access to mobile phone, email; among men; among Asian/Black respondents. Patient referral: good 65.%, bad 14.7%.	Large n but response rate not reported

Table 14, continued	Study population	Study type	Means of notifying, STI	Sample size, response rate	Main relevant outcomes	Main relevant findings	Comments
RESEARCH AMONG OTHER POPULATIONS							
Mimiaga, Fair <i>et al.</i> , 2008 ³⁴⁰ Mimiaga, Tetu <i>et al.</i> 2008 ³⁴¹	MSM recruited online via US partner-seeking websites, 2005	Survey	IPN/email message; STI/STD	n=1848, no response rate	Hypothetical acceptability and preferences for notifying partners	Participants selected one preferred option: 32.2% Public Health Specialist (with profile on sex-seeking website) emails partners; 37.9% tell/email regular partners, and Public Health Specialist emails other partners anonymously; 22.3% notify partners themselves (4.5% do nothing; 3.2% something else). ³⁴⁰ 92% would notify partners by email (sent themselves or by Public Health Specialist). ³⁴¹ HIV uninfected/status unknown respondents more likely to say that they would use IPN than HIV infected respondents (p<0.05); differences in acceptability by STD history. ³⁴¹	No response rate. Terms IPN/email appear to be used interchangeably
Mimiaga <i>et al.</i> , 2009 ³⁴²	MSM, Massachusetts, USA	Qualitative semi-structured interview survey	Various, STD/HIV	n=118 (response rate n/a: respondent-driven sampling)	Features of an ideal PN system	For 'a number of participants' an ideal PN system would be internet-based, on a sex-seeking website. Few had heard of PN and expressed more concern about being notified, than the method of notification. <i>Percentages reported are not repeated here, see comments (right).</i>	Questionable reporting: heavy use of %s to report 'qualitative' findings

Table 14, continued	Study population	Study type	Means of notifying, STI	Sample size, response rate	Main relevant outcomes	Main relevant findings	Comments
RESEARCH AMONG OTHER POPULATIONS, continued							
Ladd & Gaydos 2012 ³⁴⁵	18-25 year olds, USA	Online survey which randomised participants to scenarios	n=343 (response rate not provided)	Provider-led and patient referral; (sender or recipient of PN; varying PN options)	Hypothetical acceptability	For senders and recipients, provider-led PN by phone more acceptable than provider or 3rd-party email (p<0.001), which were more acceptable than: provider texts, anonymous e-cards, anonymous texts and provider visits. Available options significantly impacted upon acceptability.	Unclear what '3rd-party' signifies; lack of detail (abstract)
Wohlfeiler <i>et al.</i> 2012 ³⁴⁷	US, online dating/sex-seeking website users, website owners & 'HIV/STD directors'	Focus groups	Website users n=4062; owners n=18; 'HIV/STD directors' n=82	E-cards for PN	Hypothetical acceptability	'A majority' of all groups supported providing e-cards to notify partners of potential STD exposure.	Not credible that focus groups were conducted with >4000 people. Few details (abstract)

2.4 Discussion

2.4.1 Main findings

Internet, email and text message communications have been used at diverse stages throughout STI care pathways, but I found few examples of delivery of STI clinical care by these means. These communication technologies were therefore used largely as adjuncts to clinic-based care, and adopted for only part of STI care pathways. Often, research took the form of audits of service changes which had already been adopted, with little published formative research, and few well-designed evaluations which aimed to assess the impact of these technologies on individuals' health or public health.

Based on the literature located in this scoping review, internet-ordered postal home-sampling kits appear to be the closest existing services to the remote self-testing device within online care pathways proposed by the eSTI² Consortium. Similarities were that users: provided details online (at a minimum, their address and contact details) before testing, took their own sample without supervision, and in many cases received test results – or notification that results were ready – electronically. However, users waited days or weeks for their results (because their self-taken samples were posted to a laboratory for testing) and clinical management of those testing positive for STIs including chlamydia tended to take place face-to-face in healthcare settings or by telephone. One pilot study within the NCSP was an exception,³⁰⁸ but few details about this aspect were reported. The proposed self-testing device within online care pathways is therefore novel.

Internet-based home-sampling programmes such as *iwantthekit* and the Dutch chlamydia screening programme attained relatively low coverage, and high-quality research on the latter found that there was insufficient uptake to impact upon transmission.²³⁴ These services are highly acceptable among those who use them, but there is a lack of evidence from the wider population.

2.4.2 Strengths and limitations

‘Scoping’ enabled me to survey a wide range of literature relevant to internet-based STI testing and management, and to identify and document diverse innovations in e-healthcare for STIs and their supporting evidence. I did not contact study authors for details where these were missing, reflecting the balance between depth and breadth in the design and conduct of scoping studies.²²³ The number and diversity of topics and study designs precludes an assessment of the weight of evidence²²³ in relation to any particular outcome or use of ICT, including comparable appraisals of the diverse studies’ quality.

Rising numbers of relevant publications over time support my decision to include conference abstracts in this review, thus documenting research and service innovations which might not yet have reached publication as journal articles by the time this review took place. However, innovations in sexual healthcare may have occurred without being researched, or with research undertaken but unpublished, and these will have been missed. Publication bias is a risk with all literature reviews, which may be lessened by this review’s inclusion of grey literature and abstracts to medical conferences (within which audits and small studies may be more likely to feature). Incomplete inclusion of new (at the time of the database search) research is also a possibility, because Medline® includes all of PubMed but with a ‘short’ delay (the length of which is not publicised). Bibliography searches and citation-tracking of included articles were not systematically undertaken, which may have identified further relevant documents. However, a search of the bibliographies of review articles (which were not themselves included) did not lead to the identification of any additional relevant studies.

Chlamydia was not used as a search term (nor were other STIs, e.g. gonorrhoea, syphilis) reflecting that at the time of this scoping review, my doctoral research focussed on STIs in general. However, relevant literature located since this review has universally included the general terms which I used in the search

strategy (e.g. STI, sexual health, GUM), and so relevant articles seem unlikely to have been missed.

Dates of data collection were not extracted from the documents, because they were often not reported, although this information would assist interpretation of the studies' findings given the pace of change in technology adoption (section 1.7). No attempt was made to estimate how widespread or common each usage of communications technology had become; this was not the focus of this review.

2.4.3 Meaning and implications

This scoping review found limited transferable examples or evidence to inform the development of eSTI²'s remote self-testing within online care pathways. The proposed intervention was unique in its intentions to use ICT throughout an STI care pathway, and to incorporate a self-test. The paucity of much of the formative research that I located contrasts with its recognised importance in the development of complex e-health interventions (discussed in chapter 3, section 3.3). Most of the included studies did not consider the public health impact of the interventions and changes in practice that they examined, which may reflect that they often concerned only small parts of clinic-based STI care pathways. Where care pathways represent a more radical departure from existing practice, as eSTI²'s does, formative research and eventual evaluation of public health impact is clearly even more important.

These findings confirmed the importance of my thesis' research question, which is to explore the potential public health impact of remote self-testing within online care pathways. The findings also informed my decision to conduct qualitative formative research from a very early stage in development of the self-test, and of the online care pathways within which the self-test would be embedded (this formed objective 2 of this thesis, see p142; the study is described in chapter 5). I extended this formative research with further qualitative research with users of a pilot online care pathway for one STI,

chlamydia (objective 3, p142; study described in chapters 6-7). This second qualitative study aimed to develop an understanding of how the online care pathway was used and its appeal.

Evidence suggests that internet-based access to testing (section 2.3.3) may result in a higher proportion of positives diagnosed than clinical services, but low uptake²⁵⁷ may affect public health impact and cost-effectiveness. This low uptake, relative to what is required for these services to impact on infection rates, raises questions about the potential reach of the proposed self-test within online care pathways. It also raises concerns about the acceptability of these services in the general population. Several studies suggested that while some risk-groups may be well-served by these e-health initiatives, others could be underserved if alternatives are unavailable. From a health systems perspective, an internet-based service can be considered one of several complementary means of providing STI testing and management. In this case, such services do not need to be acceptable to, or be used by, all sexual health patients. However, this scoping review suggested that evidence about the potential user-population for internet-based sexual healthcare was limited. Objective 1 of this thesis (p142) addressed this gap.

Lack of evidence on the acceptability of internet-based home-sampling among non-users, or in the general population, meant there was little indication of what could deter people from using these services (therefore acceptability was explored as part of objective 2).

Since this review (2013) there have been further increases in the availability and use of internet and smartphone technology (documented in chapter 8) which suggests a growing scope for internet-based services. Chlamydia positivity for internet-based screening within the English NCSP, at 11%, has been shown to be high compared to other healthcare and community settings, and equal to that for chlamydia testing in GUM in the NCSP's target age range³⁴⁸ (supporting findings about internet-based home-sampling from a US healthcare

context²⁵⁶). Chapter 8 documents recent relevant changes and innovations in STI service delivery and their evidence, to contextualise this thesis' findings.

Chapter 3: Research strategy, aims and objectives

3.1 Introduction

The primary research within this thesis consisted of one quantitative study and two qualitative interview studies. The quantitative study (chapter 4) was a complex survey analysis, and provides evidence about the population who may use internet-based sexual healthcare. One qualitative study (chapter 5) concerned the conceptual acceptability of a hypothetical remote self-test within online pathways. The other qualitative study (chapters 6-7) concerned the use and appeal of a newly developed online care pathway for the management of chlamydia.

In this chapter, I

- explain the epistemological and ontological assumptions that underlie my research strategy (section 3.2),
- define remote self-testing for chlamydia within online care pathways, as a complex intervention, and describe the nature of formative and process evaluation for such an intervention (section 3.3),
- define public health benefit in relation to my research question, and the scope of my research (section 3.4),
- explain my objectives and how they contribute to answering my research question, justify the methodology and outline the methods for each study (section 3.5; methods are described in detail in chapters 4, 5 and 6),
- explain the role and value of reflexivity in my research (section 3.6).

3.2 Epistemological and ontological position

Methodological choices in research are underpinned by epistemological and ontological assumptions³⁴⁹⁻³⁵¹ which shape how research ‘problems’ are conceived and understood, and therefore how they could be addressed. An ontological position concerns what exists, that we can know about, logically preceding an epistemological position, which concerns how and what we can know about it.³⁴⁹ Social research can employ a variety of ontological and epistemological perspectives,³⁵⁰ but within a piece of research these should be consistent (i.e. within my thesis as a whole).

My research concerns an applied topic: I seek to understand by whom, and how, remote self-testing for chlamydia within online care pathways might be used and experienced, in order to make practical recommendations to inform this complex intervention’s design and to gather evidence of its potential to benefit public health, or otherwise. I assume that people have views, beliefs, emotions, motivations, perceptions, behaviours and experiences (ontological properties³⁵⁰), which exist (a realist ontological assumption), and about which we can make inferences through research.^{352,353} I consider that research findings are always influenced by the researcher³⁵⁴ and understood through socially-constructed meanings³⁵⁵ (an interpretivist epistemological claim).³⁵³

I also assume it is possible to draw tentative inferences about mechanisms that may underlie ontological properties (views, experiences, *etc.*). In so doing, I acknowledge the potential for research to develop theories, and to test them. This fits with the role of my research, which iteratively contributes to the intervention’s ongoing development and evaluation (as outlined in chapter 1 and discussed further in section 3.3 below). My approach can be described as ‘critical realism’ (as described by Maxwell³⁵³ and Ormston *et al.*³⁵⁵). Critical realism allows interdisciplinarity (appropriate to public health and health services research, which span disciplines, e.g. epidemiology, clinical sciences, psychology, sociology) and the use of multiple research strategies (quantitative and qualitative).

3.3 Approach and context of the research: development of a complex intervention

3.3.1 Defining remote self-testing within online care pathways as a complex intervention

I consider remote self-testing for chlamydia within online care pathways to be a complex intervention, and I refer to it throughout the thesis as an ‘intervention’ (vs. ‘model of service provision’, ‘service’, *etc.*) As explained in chapter 1, care pathways are themselves complex interventions,¹⁹⁵ and e-health interventions tend to be particularly complex.³⁵⁶ According to the UK Medical Research Council’s descriptions of complex interventions,³⁵⁷ the proposed intervention has several further features which make it especially complex. It requires users to operate new technologies (the self-test and online interface), and to perform multiple potentially difficult behaviours, with minimal supervision from healthcare staff. It needs to have built-in flexibility; it is not delivered in the same way for every user. For example, not all of those with an STI can safely be managed online (explained in chapter 6), and some may prefer to see a clinician in person. For these people, there could be a means of facilitating access to face-to-face clinical care, so as not to ‘lose’ them, which could cause treatment delays and an increased risk of morbidity and onward transmission (as explained in chapter 1).

3.3.2 The methodological context: formative and process evaluation

My research contributes to the formative evaluation, and the early part of the process evaluation, of remote self-testing with online care pathways. This intervention is being developed and refined within the lifetime of this PhD. Developing a complex intervention can require moving iteratively between development, piloting and feasibility testing, and evaluation,³⁵⁷ as the eSTI² Consortium has done; it is not a linear process of discrete phases.

Formative evaluation is research to develop and refine interventions with a view to improving the prospects of their success. Process evaluation concerns how an intervention works (or does not work). It is required to understand

causal mechanisms, contextual factors that influence outcomes, and implementation.³⁵⁷ It can be carried out alongside outcome evaluations, but also ‘within feasibility testing phases’ (p10 in Moore *et al.*³⁵⁸), as in this research.

The effectiveness of the proposed intervention in delivering public health benefit is dependent on how it is designed and implemented, and whether and how patients use it. Uniquely within e-health in the NHS, it will remotely support people from testing and receipt of a new diagnosis, through to treatment, for chlamydia (and in future, perhaps other STIs), a stigmatising infection which has psychosocial as well as medical consequences (as has been described in chapter 1, section 1.2.2), and for which partner notification and management is necessary. Several features make it particularly important to conduct detailed research with users and potential users to inform the intervention’s development, which I explain here.

First, as has been explained (chapter 1), people with chlamydia require treatment promptly, but the online care pathway is to be implemented remotely and with minimal ‘supervision’ from clinicians, and perhaps with no previous contact with sexual health clinicians or sexual health services. Progress along online care pathways therefore may be more patient-led than service- or clinician-led. Clinicians may be less well able to encourage prompt treatment remotely than in a clinical setting, and there may be a greater risk that patients misunderstand or are unable to follow the care pathway. Second, health-seeking behaviour cannot be assumed to be rational,³⁵⁹ perhaps particularly following a potentially upsetting new diagnosis. Nor can we assume that patients using remote care pathways wish to adhere to them throughout, or share the priorities of clinicians and health service providers who developed them (e.g. regarding the desirability of: providing accurate information, promptly accessing results, and if positive, promptly accessing treatment, and notifying their recent sexual partners). Third, formative research is recognised as particularly important in the development of complex interventions,³⁵⁷ including e-health interventions,³⁶⁰ where qualitative and mixed-methods

research can enable understanding of user-behaviour, and issues affecting intervention success.³⁶¹ Engagement with target audiences is recognised as an important challenge to e-health interventions for sexual health,³⁶² which may be aided by incorporating potential users' views throughout development. The need for qualitative research with patients to improve the development of new diagnostic technologies is also recognised.³⁶³

3.4 Defining public health benefit, in the context of this thesis

This thesis explores the potential for STI self-testing within online care pathways to treatment and PN, to benefit public health. As the research took place alongside intervention development, it is not yet possible to measure definitive outcomes (e.g. infections averted), nor to obtain sufficient data to model impacts on STI transmission (as could be done by an impact/outcome evaluation). Instead, I gathered indicative evidence:

- to contribute to an understanding of the intervention's potential to deliver public health benefit;
- to inform the intervention's ongoing development and evaluation, for public health benefit.

The concept of remote, smartphone-enabled self-testing linked with online care pathways, as envisaged in the eSTI² Consortium's original grant application, was essentially technology-driven: an opportunity was recognised for new and emerging diagnostic and communications technology to benefit individual and public health. Precisely how it might do so was not defined or operationalised in a conceptual model, beyond that remote smartphone-enabled self-testing might reach underserved or hard-to-reach populations, possibly by increasing the accessibility or acceptability of STI testing and routes to treatment among these groups, and/or by saving the health service money. MRC guidance advises that the development and evaluation of complex public health interventions should be informed by theory – a conceptual model of how they will bring about change – but also recognises that conceptual models can be developed or identified alongside intervention development.³⁵⁷ Doing this can involve bringing together existing evidence, new primary research and relevant theory,³⁵⁷ as eSTI²'s Workstream 4 did, and my own research within it. I describe my conceptual framework in the following section.

3.4.1 What would make a chlamydia testing and treatment intervention successful, in public health terms?

As outlined in chapter 1, early detection and treatment of chlamydia, through appropriate testing of those at risk and PN, could reduce chlamydia incidence, and morbidity associated with long-term and repeat infection.

I identified the following ways in which remote self-testing within online care pathways could deliver public health benefit, i.e. health benefit for the population as a whole, and which I could explore at an early stage in intervention development. This forms the conceptual framework for my research.

- **Testing:** Increasing detection of undiagnosed infection (which can then be treated) by:
 - Providing accessible and acceptable chlamydia testing which overcomes (all/some) barriers to testing via existing services, in order to increase testing among those at risk of chlamydia.
- **Treatment:** Increasing rapid, effective treatment of those diagnosed with chlamydia by:
 - Shortening the time between receipt of positive test results and treatment of those testing positive, and
 - Increasing the proportion of those testing positive who receive appropriate, effective treatment and take it correctly.

Together the above would benefit public health by reducing **D** (the duration of infectiousness) thus reducing the basic reproduction number **R₀**, and by reducing sequelae of long-term infection. As has been discussed, diagnostic testing of those infected is necessary to identify those unknowingly infected, in order to provide appropriate treatment.

As secondary concerns to testing and treatment, I considered evidence of the intervention's potential to support the notification and management of partners (as part of a wider service which supports PN), in order to reduce onward transmission; and to provide timely, accurate epidemiological information to

inform public health action (to a similar or better standard than existing services).

Remote self-testing within online care pathways is envisaged to complement (not replace) existing sexual healthcare, therefore all of the above can be qualified: ‘...as a complement to existing sexual healthcare’. Given that equity is an important principle in public health I also consider evidence for the intervention’s potential to reduce or widen inequalities in sexual health (by education, ethnicity, socioeconomic status, *etc.*)

I apply this conceptual framework loosely, recognising that it is not yet possible to explore complexities (e.g. whether overall public health benefit will be achieved if some of the above are achieved and others are worsened; the impact of reducing the ‘burden’ on clinic capacity if some of their patients use self-testing and online care pathways instead).

3.4.2 Aspects outside the scope of my research

Some aspects which could influence the intervention’s impact on public health are unknown at this stage in intervention development, or are being addressed by other researchers, and so were outside the scope of my doctoral research. These are listed in Table 15, where I also list some assumptions made for the purposes of my research.

Table 15: Aspects outside the scope of my doctoral research

Aspect	Notes	Assumptions for my thesis
Cost to the NHS of the device and care pathways	Within the scope of another PhD student's work on health economic aspects of eSTI ² device and care pathways. Influenced by the (unknown) production cost of the self-test.	n/a
Costs and savings to the user	The intervention is being developed for use within the NHS but costs have not yet been determined. In the NHS STI treatment is provided without charge. Savings to the user (e.g. reduced time off work and travel costs) are not being measured.	Cost to users of the testing device is assumed to be nil or low. Treatment assumed to be free to users, as it is currently.
Impact of delivering services online on clinic capacity	Unascertainable at this stage in eSTI ² 's research.	n/a
Distribution of the testing device	Unknown; influenced by cost of the device and other factors, so not currently being explored by eSTI ² .	n/a
Impact of self-testing and remote care pathways on sexual risk behaviour	Behaviour change aspects, and the possibility and comparative effectiveness of remote or automated health promotion vs. standard care, in health behaviour change, are not yet being explored.	n/a
Diagnostic accuracy	The testing device is still being developed. ¹⁹³	Assumed to meet regulatory standards and to be as accurate as existing clinic-based tests
Clinical care quality and safety (including training and supervision of staff)	Addressed by another PhD student ² and by colleagues, during the development of the Online Chlamydia Pathway (OCP).	Assumed to be safe. Preliminary evidence of clinical safety was obtained in the OCP's Exploratory Studies (see chapter 6).
Infections tested for	Envisaged (in eSTI ² grant application) to test for multiple STIs. The OCP was developed only for chlamydia treatment access.	The device is assumed to test for chlamydia in the first instance.
Design of the user-interface	Colleagues conducted qualitative research to inform the design of the online care pathway's user-interface. ¹	n/a

3.5 Thesis aim, objectives and methodology

I aimed to explore the potential for remote self-testing for chlamydia within online care pathways to benefit public health, thus informing ongoing intervention design and evaluation.

To fulfil this aim I examined three objectives (described in detail in the following pages), corresponding to three studies:

- 1 To estimate the prevalence of use, and factors associated with, use of the internet for sexual health in Britain, as indicative evidence about future users of internet-based STI services;
- 2 To explore perceptions and acceptability of a hypothetical remote self-testing device for STIs within online care pathways, among a potential user population, in order to inform intervention development;
- 3 (a) To explore how people diagnosed with (or exposed to) chlamydia used an online care pathway from chlamydia results notification, to treatment and PN (the Online Chlamydia Pathway, OCP) in order to identify aspects for improvement; and
(b) to develop a detailed understanding of the nature of and limits to its appeal to them, and offer interpretative explanations for this.

Table 16 maps these three objectives and their three studies onto my conceptual framework. The following sections of this chapter describe and justify the objectives, and outline and justify the methods for each study.

Table 16: How remote self-testing within online care pathways could deliver public health benefit, showing scope of this thesis to provide indicative evidence, and aspects addressed by other researchers

Aspect	Desired effects, in order to deliver public health benefit (which could be measured in a future trial / evaluation)	Addressed in this thesis by:			Not addressed in this thesis (indicating responsible eSTI ² workstreams, WS)
		Obj. 1: Survey analysis, Ch4	Obj. 2: Qualitative study 1, Ch5	Obj. 3: Qualitative study 2, Ch6-7	
Testing	Increase uptake of testing among those at risk of STI	Potential user populations	Acceptability to potential users		Design of diagnostic testing device (WS1,2,3) Design of online user-interface (WS4)
	Provide an accessible testing service which overcomes barriers to testing in existing services		As above		
Treatment	Shorten the time between receipt of results and treatment		As above	Use and appeal of Online Chlamydia Pathway	Design of online user-interface; Safety and clinical care considerations (WS4) WS4's Exploratory Studies of an Online Chlamydia Pathway – quantitative components**
	Increase the proportion of those testing positive who receive effective treatment and take it correctly				
*Partner notification	Enable recent sexual partners of those testing positive to be brought to care		As above	As above	WS4's Exploratory Studies of an Online Chlamydia Pathway – quantitative components**
*Disease surveillance	Provide timely, accurate information, to inform public health action		As above	As above	Which data will be collected; Secure data capture and transfer (WS4)

*Explored as a secondary consideration in both qualitative studies (chapters 5-7). **In the Discussion (chapter 8), quantitative findings from this quantitative research are integrated with my findings.

3.5.1 Context to qualitative studies

My qualitative studies took place within the research of eSTI²'s Workstream 4, which I describe (and Appendix 2 provides a timeline for this and for my research). The first qualitative study (reported in chapter 5) took place early in the development of the self-test and online care pathways, and was part of the formative research in the complex intervention's development. Studies concerning user-interface design¹ and clinical care quality and safety² also took place.

Together, this formative research informed the development of the Online Chlamydia Pathway (OCP)⁵ which was led by my colleagues. It was developed to support users from the point of online communication of a chlamydia test result. If positive, it provided information together with the diagnosis, treatment and support with PN (also enabling sexual partners of those diagnosed with chlamydia to be assessed and treated). The OCP could be used with results from conventional testing, in the absence of a validated self-test (which is still being developed by other eSTI² workstreams¹⁹³). Further details about the OCP are provided in chapter 6.

The OCP was piloted by the eSTI² team in Exploratory Studies (see chapter 6), in order to obtain preliminary evidence of its feasibility, acceptability and safety, among 221 people who were diagnosed with chlamydia after testing in GUM or via an internet-based home-sampling service within the NCSP, and their partners. This presented an opportunity for me to develop further the qualitative findings I had generated in chapter 5, this time among people who had experienced a chlamydia diagnosis (or exposure), and had experienced an online care pathway for chlamydia management. This qualitative study is reported in chapters 6-7, and it also forms the main qualitative element of the Exploratory Studies, informing the OCP's ongoing development and future evaluation.

Figure 11: Relationship between key eSTI² activities (coloured boxes), and my thesis' research activities (white boxes)

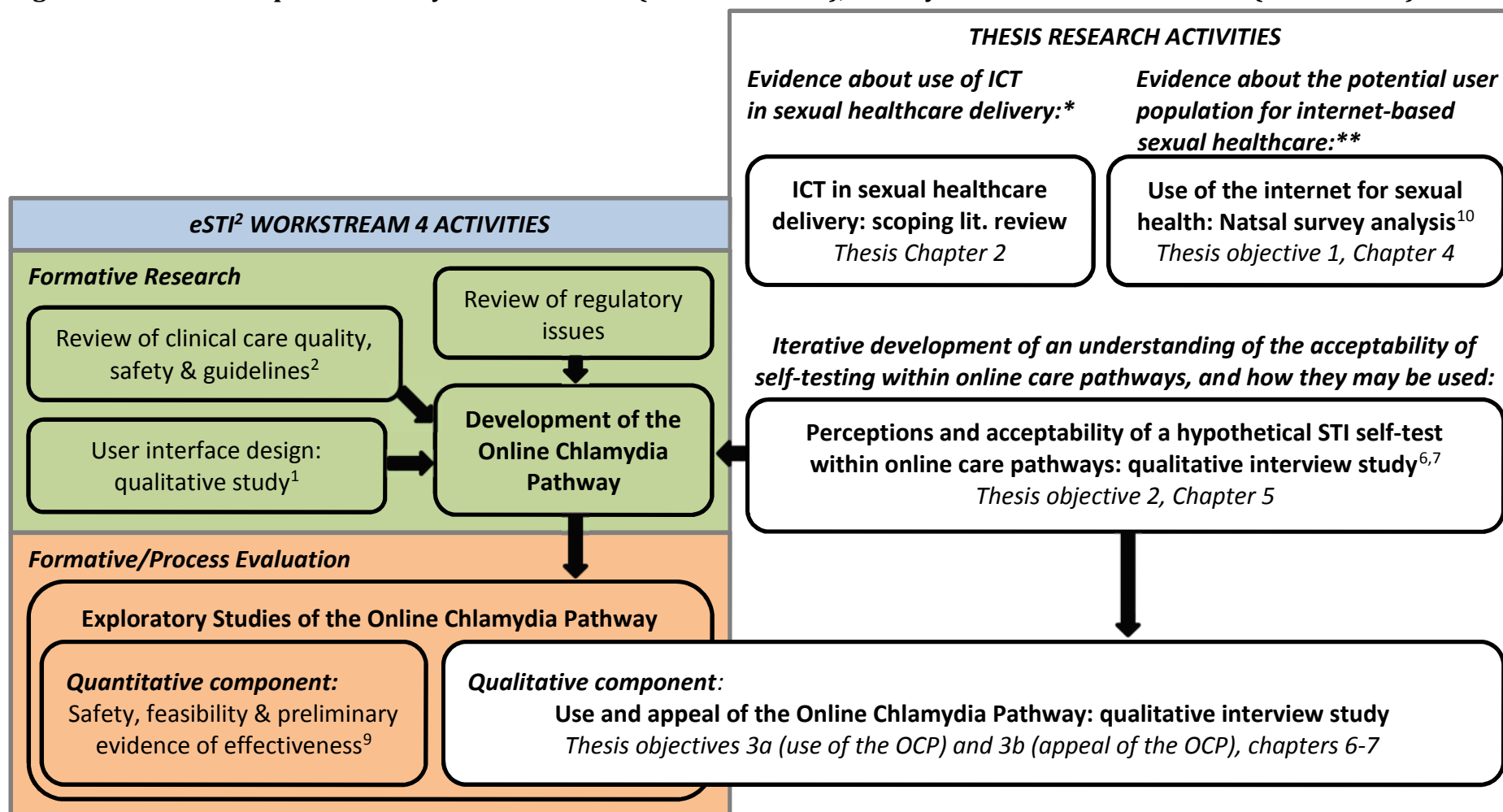


Figure adapted from eSTI² Research Consortium conference presentation slides (unpublished). *To 2013, i.e., early in intervention development. **Data collected 2010-12.

3.5.2 Objectives, justification, methodology and rationale

Objective 1: To estimate the prevalence of, and factors associated with, use of the internet for sexual health in Britain

Justification: Although new internet-based sexual health services continue to be developed, both for STIs and sexual health more broadly,^{2,230,364-366} there are no general population estimates of the number and characteristics of people who use the internet for sexual health in Britain (or elsewhere). I generated these estimates, in order to obtain indicative evidence of the size and characteristics of the population to whom internet-based STI testing and care may appeal (the potential user population). For this I conjectured that those reporting use of the internet for sexual health might represent a population likely to take up internet-enabled sexual health services which are currently being developed.

Methodology: Complex survey analysis of Britain's third National Survey of Sexual Attitudes and Lifestyles (Natsal-3^{67,367}), Britain's national probability sample survey of sexual behaviour, conducted 2010-12.

Rationale for methodology: Nationally-representative data were required, so this objective was approached quantitatively using the most recent (at the time of writing) national survey data.

Natsal-3, a probability sample survey, asked a number of questions about sources used for various types of sexual healthcare and advice/help with one's sex-life (including the internet). At the time the survey took place (2010-2012), the range of online STI services available was very limited (see chapter 2). I therefore decided to explore use of all internet use for sexual health covered by Natsal-3, conjecturing that those who use these services may have need for, and may use, future internet-based STI services. The study's focus was on the year prior to the survey interview, providing a contemporary picture in a rapidly changing field.

Natsal-3 also asked detailed demographic and behavioural questions. As STI prevalence varies by demographic characteristics and by sexual behaviour (see chapter 1, sections 1.2 and 1.3), I could explore use of online sexual health services by these indicators of need for STI testing and care, as well as previous STI diagnosis and use of conventional sexual healthcare. This helped inform whether internet-based sexual health services could reach populations that underutilise conventional sexual health services, relative to their need for sexual healthcare. It could also help inform the development of internet-based sexual health interventions by identifying potential user-groups, thus informing targeting of such interventions.

A 2015 search of the UK Data Service (UKDS),³⁶⁸ which houses data from many national surveys and enables searching by question topic, found just one other survey which asked about sources of sexual healthcare: the Health Survey for England (2010 and 2012). Though it contained detailed demographic questions, this survey lacked Natsal-3's detail on sexual behaviour, and provided no more recent data, so was not analysed.

Chapter 4 presents methods and results of this study.

Objective 2: To explore perceptions and acceptability of a hypothetical remote self-testing device for STIs within an online care pathway, among a potential user population

Justification: The public health benefit that the proposed intervention, STI self-testing linked to an online clinical management pathway, can deliver depends on its acceptability. Chapter 2 demonstrated that the proposed intervention was unique and there was limited applicable evidence from other studies. Although some examples of online STI care exist,^{129,197,265,266,308,311,365,369} these only represent parts of the proposed remote online care pathway, with limited information on acceptability. Qualitative research on the acceptability of home self-testing for STIs³⁷⁰ and internet-accessed STI testing^{290,292,371,372} suggests that potential users have reservations around safety, test reliability, online privacy and confidentiality. Much of this research was conducted in the US and

Canada,^{290,292,370,371} i.e. differing health service contexts, and findings may not be transferable to the UK context, or to the proposed remote self-test within online care pathways.

Methodology: Qualitative in-depth interviews were undertaken among young people recruited from Further Education colleges (see glossary) in an Inner-London locality with high rates of STIs³⁷³ and large populations of Black Caribbean and Black African ethnic origin. I conducted a thematic analysis,^{351,374} informed by existing research evidence.

Rationale for methodology:

Methodological approach

I chose a qualitative methodology for several reasons. First, it allows exploration of issues unanticipated by the researcher, which was important given the limited evidence on this topic, as explained. Second, the intervention is complex and does not yet exist (is hypothetical), making it difficult to describe to participants in a standardised way (as would be required for a survey), and requiring ‘unpacking that is necessary to formulate a position, view or belief’ (p38 in Ritchie *et al.*³⁷⁵). In a qualitative interview, the interviewer could describe the intervention to participants, use appropriate methods to help them imagine it (see chapter 5) and through subsequent facilitative questioning, could examine perceptions of it, including detecting misunderstandings or providing further clarification (which could also provide useful information about participants’ assumptions). Third, I conjectured that perceptions and acceptability would be influenced by beliefs, experiences, and the imagined context of using of the proposed, novel intervention. Therefore it was suited to in-depth contextualised exploration. Fourth, when discussing the proposed intervention with other researchers and friends, I had observed that it could provoke strong initial reactions (e.g. admiration, or scepticism) which might change a great deal over the course of a conversation. I sought to move beyond such initial reactions and to obtain a nuanced understanding of the intervention’s acceptability.

Data collection method

I chose individual in-depth interviews primarily because I considered these most appropriate for discussing private, sensitive topics, including experience of sexual healthcare and STI. I sought to explore these topics in order to explore participants' understanding of STI testing *per se*, and how previous experiences may have shaped their views on the acceptability of the proposed intervention. I was specifically interested in exploring the views of those who had and had not tested before, both of which experiences could be difficult for young people to disclose and discuss among peers. Focus group discussions are effective at exploring normative views (which my study sought to do), and the group context can facilitate exploration of decision-making processes³⁷⁶ which would be desirable for this study. However, I felt that these potential advantages were outweighed by the potential disadvantages.

Study population

The study population was at elevated risk of STI, based on their young age (16-24 years), ethnicity and recruitment from an urban, deprived population²⁸ in Inner London, thus they are a key target group for provision of STI services for reasons of equity and public health need.⁶ Urban populations³⁷⁷ and young people (based on their ICT use, see section 1.8) may be 'early adopters' of new technologies, so I considered them potential users of the intervention. Eligible students were aged 16-24 years and sexually-experienced, in order that the topic of STI testing would not be too abstract for them to imagine.

Analysis

Thematic analysis is a method of qualitative analysis, which can be applied in ways which range from predominantly inductive (data-driven, or 'grounded' in the data) to predominantly deductive (where identification of themes is driven by pre-existing evidence and theory).³⁵¹ The approach I used lies between the two. Thematic analysis is theoretically-flexible, which allowed me to draw on the wide range of theories and evidence which can apply to sexual healthcare seeking, the acceptability of novel diagnostic technology, and the acceptability of a smartphone- and internet-enabled care pathway (discussed in chapter 5).

Chapter 5 presents methods and results of this study.

Note: I designed this study but interviews were conducted by a colleague during my maternity leave, since the data were required for a rapid analysis (not part of my thesis) to inform the development of the care pathway. I conducted a detailed analysis on my return which further informed intervention development. Appendix 6 further defines my role in this study.

Objective 3:

3a: *To describe how people diagnosed with (or exposed to) chlamydia used an online care pathway to treatment and partner notification (the Online Chlamydia Pathway, OCP);*

3b: *To develop a detailed understanding of the appeal of the OCP to its users, and the limits to its appeal; and to offer interpretative explanations for this.*

Justification: The Online Chlamydia Pathway is unique within the NHS and, until this study, had never before been used by patients. Addressing these objectives helps to inform its refinement and future evaluation, and to identify and understand challenges and opportunities to its implementation and potential to benefit public health.

Methodology: Qualitative follow-up telephone interviews were conducted with people who were recently diagnosed with chlamydia and who consented to use the Online Chlamydia Pathway, within Exploratory Studies (which are described in chapter 6). One Exploratory Study was conducted amongst people who had tested in GUM clinics, and the other amongst people who had tested using internet-based home-sampling (within the NCSP).

Two separate thematic analyses^{351,374} were undertaken, addressing objectives 3a and 3b. A mixed inductive-deductive approach was employed, with the topic guide informed by relevant theory and research evidence, but allowing themes

to emerge in the analysis. Findings from these complementary analyses were interpreted with reference to relevant theory.

Rationale for methodology:

Methodological approach

My use of a qualitative research strategy reflects how, despite the previous study, we still knew very little about how people would actually use this complex and remotely-delivered online care pathway, nor in what contexts. I also sought to identify what about it appealed to them and the limits to this appeal. Existing evidence and qualitative understandings of what helps conventional services deliver public health benefit (e.g. reduce their time to treatment), and what makes them acceptable to users (e.g. friendly, approachable staff) are not automatically transferable to this novel context. Qualitative research is particularly well-suited to what Mason calls 'mechanical' intellectual puzzles (p18 in Mason³⁵⁰), about how processes work (e.g. use of the OCP) or are constituted (e.g. its appeal), in context. Evaluation requires understanding the mechanisms and contexts in which an intervention works or does not work,³⁵⁷ and for whom,³⁷⁸ and evaluative qualitative research can play an important role in this.³⁷⁵ Through the interviews, use and appeal of the online pathway could be explored in the context of potential users' prior experiences, including by comparing those who had tested in GUM clinics with those who had tested 'online' via the NCSP.

A further reason for conducting qualitative research is that although interactions with the OCP were time-logged and recorded as part of the Exploratory Studies, they could not be directly observed and therefore the contexts of use would not otherwise be recorded (e.g. circumstances surrounding any delays, or disengagement). Use of other services, and sources of health information and support, would otherwise be missed entirely. Thus the qualitative interviews provide information which complements the Exploratory Studies' quantitative data, to increase further an understanding of OCP use (although detailed integration of quantitative and qualitative data is beyond the scope of this thesis).

A qualitative approach also allowed me to build upon findings of the previous qualitative study, about a hypothetical intervention (explained in section 3.5.3).

Data collection method

I chose in-depth interviews primarily because of the inappropriateness of discussing recent STI care in a group setting, and secondarily due to the feasibility constraints to convening such a group. Also, the study's focus was on individuals' experiences and views, which needed to be explored in depth, including the unique contexts of individuals' chlamydia diagnoses and care.

Interviews were conducted by telephone reflecting the remote and 'faceless' way in which the intervention was received. The literature on in-depth interviewing has traditionally favoured face-to-face interviews,³⁷⁹ but recent research suggests that different interview 'modes' have different strengths and may be appropriate in different contexts,^{380,381} depending on research aims, population and topic. The 'relative anonymity'³⁸² of telephone interviewing may make it particularly appropriate for researching sensitive topics,^{382,383} including sex,³⁸⁴ and interviewees who are in familiar surroundings may feel more empowered to express themselves.³⁸⁵

Analysis

I chose to use thematic analysis for the reasons described for objective 2 (p149); similarly I used a mixed inductive-deductive approach. I sought to allow themes to emerge from the data but also to build on existing theory and evidence, including my previous qualitative study (objective 2, chapter 5).

Framework³⁸⁶ was used for data management (and my use of it is described in chapter 6). This data management method assisted with navigating a comparatively large (n=40) qualitative dataset and enabled me to code my dataset by different parts of the care pathway, so I could easily retrieve data about a particular aspect (e.g. collecting treatment from a pharmacy).

In both of these thematic analyses, I derived themes from this ordered data. I then interpreted these themes with reference to relevant theory and research on sexual health and healthcare use (which played a particularly important role in objective 3b's more interpretative analysis).

Chapter 6 presents methods for this study and sample characteristics.

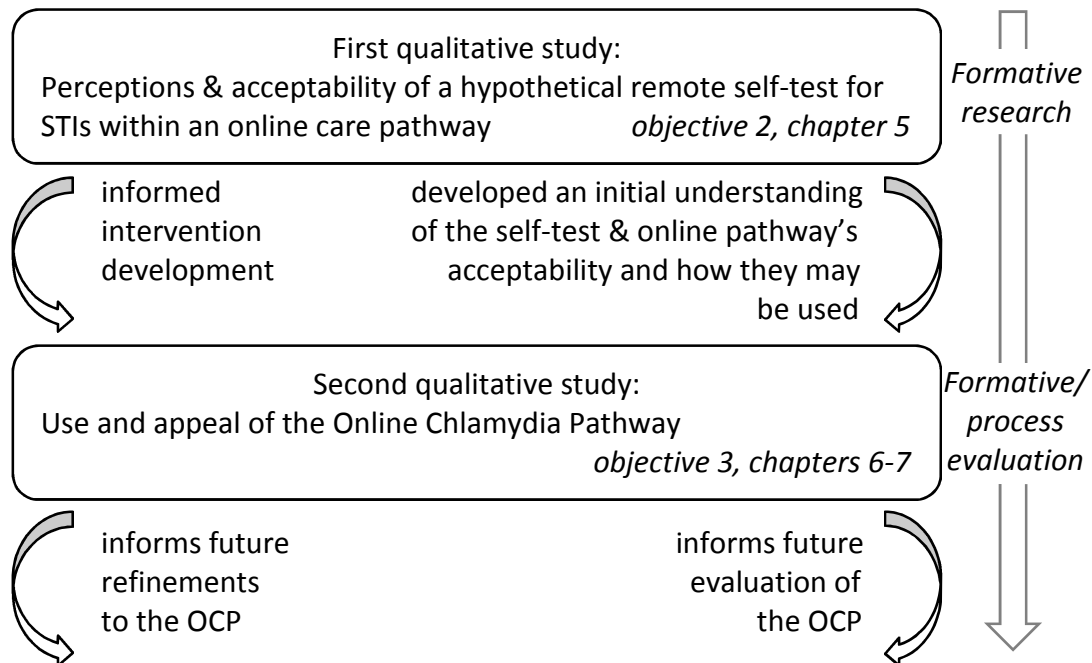
Chapter 7 presents its results, addressing objectives 3a and 3b.

3.5.3 Relationship between the two qualitative studies

Figure 12 outlines the relationship between the two qualitative studies. In terms of intervention development, the first qualitative study's findings informed the development of the Online Chlamydia Pathway (and the future self-test). The second qualitative study's detailed, experiential understanding of the use and appeal of the OCP will inform the OCP's refinement (left of Figure 12). In terms of evaluation (right of Figure 12), the first qualitative study was used to develop an initial theoretical understanding of the self-test and care pathway's conceptual acceptability, which included identifying issues needing further exploration. The second qualitative study built on the findings of the first, and was used to develop further a theoretical understanding of how people go about using such an online care pathway, and its appeal. This can inform its future evaluation.

Figure 12: Relationship between the two qualitative studies in terms of intervention development and evaluation

(My studies contributed to intervention development and evaluation within the context of eSTI²'s programme of research)



Key differences between the two qualitative studies are described in Table 17 (further details are in Appendix 8).

Table 17: Key differences between the two qualitative studies

	1st qualitative study (objective 2, chapter 5)	2nd qualitative study (objective 3, chapters 6-7)
Intervention discussed (main topic of interview)	Self-testing device, within online care pathway	Online care pathway from receipt of results onwards
Infection	STIs in general; chlamydia as an exemplar	Chlamydia
Nature of interview accounts	Hypothetical	Experiential
Interview mode	Face-to-face	Telephone
Study sample		
Sample size	25	40
Age (years)	16-23	18-35
Ethnicity	All non-White	Diverse
Social/educational background	Further Education college students, inner London	Diverse, across South London
Experience of STI diagnosis	Disclosed by 2/25	All

3.5.4 Note on the use of mixed methods

In this thesis, quantitative and qualitative research methods are used to address distinct thesis objectives, in separate studies. The second qualitative study (chapter 7) builds on the findings of the first (chapter 5). The findings of my qualitative studies are integrated in the Discussion (chapter 8), together with key quantitative findings from the Exploratory Studies within which Chapter 7's qualitative research took place. (The quantitative components of the Exploratory Studies were not part of my doctoral research; Figure 11, p145).

3.5.5 Note on the use of reported data

All three studies relied on participant-reported data, generated through a survey and in-depth interviews. I regard well-conducted survey research to produce valid and reliable data, that is, data that closely reflect participants' actual behaviour. I regard qualitative interviews and the data they generate as windows into participants' worlds (representations of their views, experiences, behaviours, *etc.*) and also as close reflections of interviewees' experiences and views. For both surveys and interviews, I recognise that the data generated are influenced by the researcher and by how the research is presented and conducted (reflexivity is discussed in section 3.6, p157).

These assumptions are not unproblematic, and are subject to issues such as recall and social desirability bias. Steps taken to maximise the validity or 'truthfulness' of these data vary between studies with different research designs, and so are discussed in the Methods sections of chapters 4, 5 and 6. I critically engage with these issues in discussing the strengths and weaknesses of each study (in the Discussions of chapters 4, 5, and 7).

3.5.6 Note on the selection and presentation of quotations

There is debate about the use of quotations in qualitative research reporting,³⁸⁷ which can serve various functions.³⁸⁸ In chapters 5 and 7, I used quotations to illustrate themes, to deepen readers' understanding, give voice to my interviewees, and as evidence for my interpretations. I was careful not to privilege the words of my more eloquent interviewees, nor select particularly

dramatic quotations (a criticism of some research reports³⁸⁷), although I agree that quotes need to be sufficiently ‘vivid and compelling’ (p251, Braun and Clarke³⁵¹) to express my findings.

In qualitative public health and health services research, quotations are commonly presented as evidence for points made. This rationale has been expressed by researchers in disciplines where qualitative research was late in gaining recognition, and among those with quantitative research training, in Corden and Sainsbury’s study of senior qualitative researchers.³⁸⁷ However, as some of these researchers explained, quotes could be found to represent almost any view, and evidence lies ‘in the conceptualisation and thematic analysis of all the data, the linkages made and interpretations’ (p12, Corden and Sainsbury³⁸⁷). While I agree with this interpretation, I present quotations to support my points, and to ensure credibility to a multi-disciplinary audience.

I have not edited quotes for grammar or language, even for non-native speakers of English (of whom there were several). Some authors (e.g. Braun and Clarke³⁸⁹) recommend using minimal punctuation in order to reduce the likelihood of changing interviewees’ meanings. However, I considered that lack of punctuation might be more likely to lead to misinterpretation, and so I used punctuation, including speech-marks where interviewees reported verbatim what others had told them. This was done with great care, by listening to the recordings, and where there was ambiguity, punctuation was omitted. For brevity and clarity I sometimes removed parts of quotes (indicated by: ‘[...]’). In each case I took care to preserve the original meaning, and the excerpts removed were short.

I use initials as unique identifiers of qualitative research participants. These are fictitious. I did not use (fictitious) names because participants in both studies had diverse ethnicities and nationalities. To give them all traditional English names seemed wrong; to give them names which I associated with their backgrounds could seem crude, and might in some cases enable their identification to people who knew they had participated in the research.

3.6 Reflexivity: role, value and how it is achieved

3.6.1 Role and value of reflexivity

Qualitative research traditions recognise the inevitable influence of researchers' values, presumptions and perspectives,^{351,390} throughout study design, data collection and interpretation, such that no entirely neutral, objective knowledge is attainable.^{355,391} Reflexivity, an 'essential requirement of good qualitative research', involves the researcher critically reflecting on the research process, their own role in this, and implications for their findings.³⁵¹ I further explain here the role of reflexivity, and how it is achieved.

Writing reflections throughout the research process is a way for the researcher to make explicit and to examine their own assumptions, in order to be aware of these, and not to skew research findings. Therefore it can be considered a form of quality control,³⁹² which enables the researcher to look back on how their thoughts and feelings towards the research changed over its duration. Following advice of qualitative research experts,^{20,351} I kept a diary throughout my PhD which I drew on to write up my research, particularly the qualitative chapters (5-7).

Spencer *et al.*³⁹³ distinguish between reflections on the researcher's own impacts on the data and interpretation, and reflections on research conduct and process, both of which I address in chapters 5-7. A third form of reflexivity has also been identified: disciplinary reflexivity (related to the field of enquiry),³⁹⁴ which I have addressed in this chapter. Reflexive accounts are also tools for those reading research reports, for transparency and to increase the credibility of findings,^{395,396} so that readers can judge for themselves how the researcher's perspective and the disciplinary and methodological approach could have influenced the research. These 'self-reflective attempts to 'bracket' existing theory and [researchers'] own values allow them to understand and represent their informants' experiences and actions more adequately than would otherwise be possible' (p216 in Elliott *et al.*³⁹⁰).

3.6.2 Use of first-person reporting

I wrote this thesis in the first person ('I'), which is standard practice in qualitative research reporting, in recognition of the issues discussed above. It also allows me to make explicit my roles in the conduct of the studies.

Chapter 4: Use of the internet for sexual health in a general population sample: complex survey analysis

Aicken CRH, Estcourt CS, Johnson AM, Sonnenberg P, Wellings K, Mercer CH. Use of the internet for sexual health among sexually experienced persons aged 16 to 44 years: evidence from a nationally representative survey of the British population. *Journal of Medical Internet Research*. 2016;18(1):e14.

4.1 Introduction and objectives

The overall objective of the study reported in this chapter was to estimate the prevalence of, and factors associated with, use of the internet for sexual health in the resident British population. This was in order to obtain indicative evidence of the population to whom internet-based STI testing and care may appeal, and thus contribute to an understanding of its potential to deliver public health benefit.

Specific objectives were:

- to estimate the prevalence of reporting recent (in the previous year) internet-use in relation to sexual health reasons addressed in the survey (chlamydia testing, HIV testing, STI treatment, condoms/contraceptive supplies and help/advice with one's sex-life from information/support websites), among sexually-experienced men and women;
- to describe how the prevalence of this outcome varies by various demographic, behavioural and other characteristics (described in section 4.2.4);
- to estimate the proportions reporting a preference for online sexual healthcare.

4.2 Methods

4.2.1 Natsal-3 survey design and administration

Britain's third National Survey of Sexual Attitudes and Lifestyles (Natsal-3^{67,367}) was conducted in 2010-12 among the resident British population aged 16-74 years (n=15,162). Natsal-3 asked detailed demographic and behavioural questions, and a number of questions about sources used for various types of sexual healthcare and advice/help with one's sex-life (including the internet). Detailed methods have been published by the study team;^{67,367} in brief, Natsal-3 used a multi-stage, clustered and stratified probability sample design, with a boost sample of those aged 16-34 years, and used the Postcode Address File as its sampling frame. An interviewer visited each randomly selected household, and randomly selected one person in the eligible age-range to participate, with oral informed consent. Participants completed the survey using a combination of computer-assisted personal interview (CAPI) conducted face-to-face, and computer-assisted self-interview (CASI) for the more sensitive questions.^{67,367} Natsal-3 achieved an overall response rate of 57.7% and a co-operation rate (of eligible addresses contacted) of 65.8%.^{67,367} The Natsal-3 dataset and supporting documentation are available from the UK Data Service.³⁶⁸

Variables used in this study are based on self-reported responses to closed-ended survey questions. Exceptions are Index of Multiple Deprivation (IMD) quintile¹⁸ and Output Area Classification (OAC) 2011 supergroup (OAC 2011 categorises census output areas into eight supergroups, based on population characteristics).^{397,398} In the Natsal-3 dataset which I obtained, these had already been established from participants' postcodes. National Statistics Socioeconomic Classification (NS-SEC), derived from responses to standard questions,³⁹⁹ had also already been assigned.

4.2.2 Population of interest: sexually-experienced 16-44-year-olds

Several survey questions relevant to these analyses were not asked to survey participants aged 45 and older. The denominator for this study was therefore limited to 16-44-year-olds, which is the age-group in which most STI diagnoses

occur,¹⁰⁷ and which approximates to women's reproductive age. I further limited the denominator to sexually-experienced people, defined as those who reported ever having had any opposite- or same-sex sexual partners, as those most likely to require sexual health services.

4.2.3 Outcome variables

Questions used to create outcome variables are described in Table 18 and Table 19 below (and the full survey is available online²⁵). Outcome variables for this study include reported use of internet services for key sexual health reasons (Table 18) and reporting the internet as a preferred source of contraception, or for STI treatment/diagnosis if an STI was suspected (Table 19). The wording of these survey questions is described in the tables. Of relevance to the question about help/advice with one's sex-life (first question in Table 18), shortly before this question participants were presented with the following broad definition of 'sex life':

An individual's sex life includes their sexual thoughts, sexual feelings, sexual activity and sexual relationships.

In terms of timeframe, the question on sources of contraceptive supplies referred to the last year. Questions on HIV testing, chlamydia testing and STI treatment referred to the last occurrence. For comparability, the variables on these topics were restricted to the previous year, based on responses to other survey questions.

Table 18: Details of Natsal-3 survey questions used as outcome variables

Question wording	Number of responses permitted	Response options (listed in the order they were presented in the survey interview; internet response options are underlined)	Participants eligible for each survey question	Number of participants eligible for each question (unweighted, weighted)
'Have you sought help or advice regarding your sex life from any of the following sources in the last year?'	Multiple	'family member/friend' ' <u>information and support sites on the internet</u> ' 'self-help books/information leaflets' 'self-help groups' 'helpline' 'GP/family doctor' 'sexual health/GUM/STI clinic' 'psychiatrist or psychologist' 'relationship counsellor' 'other type of clinic or doctor' 'I have not sought any help'	Entire sample eligible for the current study	8926, 7400
'Have you got contraception from any of these sources in the last year?'	Multiple	'a doctor or nurse at your GP's surgery' 'sexual health clinic (GUM clinic)' 'family planning clinic/contraceptive clinic/reproductive health clinic' 'NHS antenatal clinic/midwife' 'private doctor or clinic' 'youth advisory clinic (eg, Brook clinic)' 'pharmacy/chemist' ' <u>internet website</u> ' 'supplies from school/college/university services' 'over the counter at a petrol station/supermarket/other shop' 'vending machine' 'mail order' 'hospital accident and emergency (A&E) department' 'any other type of place (please say where)' 'I have not got contraception in the last year'	Those reporting use of any contraceptive method ^a in the last year	7182, 5862

'When you were last tested for Chlamydia, where were you offered the test?'	Single	'GP surgery' 'sexual health clinic (GUM clinic)' 'NHS family planning clinic/contraceptive clinic/reproductive health clinic' 'antenatal clinic/midwife' 'private non-NHS clinics or doctor' 'youth advisory clinic (eg, Brook Clinic)' 'school/college/university' 'termination of pregnancy (abortion) clinic' 'hospital accident and emergency (A&E) department' 'pharmacy/chemist' ' <u>internet</u> ' 'other non-health care place (eg, youth club, festival, bar)' 'somewhere else'	Those reporting chlamydia testing in the last year	2387, 1545
'Where were you tested? (the last HIV test if more than one)'	Single	'GP surgery' 'sexual health clinic (GUM clinic)' 'NHS family planning clinic/contraceptive clinic/reproductive health clinic' 'antenatal clinic/midwife' 'private non-NHS clinic or doctor' ' <u>internet site offering postal kit</u> ' 'youth advisory clinic (eg, Brook clinic)' 'termination of pregnancy (abortion) clinic' 'hospital accident and emergency (A&E) department' 'somewhere else'	Those reporting HIV testing in the last year	802, 562
'Where were you last treated for [STI ^b]?'	Single	<i>Response options identical to those for the question above, except for internet response option:</i> ' <u>internet site offering treatment</u> '	Those reporting having been told by a doctor/ health professional that they had an STI, in the last year	178, 117
Study population size, and denominator for analyses				8926, 7400

^aIncluding condoms. ^bSeparate questions were asked about the following infections: chlamydia; gonorrhoea; genital warts (venereal warts); syphilis; Trichomonas vaginalis (trich, TV); herpes (genital herpes); NSU (non specific urethritis) or NGU (non gonococcal urethritis).

Table 19: Details of Natsal-3 survey questions about preferred sources of sexual healthcare

Question wording (use of bold indicates how questions were presented in the survey interview)	Response options (listed in the order they were presented in the survey interview; internet response options are underlined)	Participants eligible for each survey question	Number of participants eligible for each question (unweighted, weighted)
'If you thought that you might have an infection that is transmitted by sex, where would you first go to seek diagnosis and/or treatment?'	'general practice (GP) surgery' 'sexual health clinic (GUM clinic)' 'NHS Family planning clinic/contraceptive clinic/ reproductive health clinic' 'NHS Antenatal clinic/midwife' 'private non-NHS clinic or doctor' 'pharmacy/chemist' ' <u>internet site offering treatment</u> ' 'youth advisory clinic (e.g. Brook clinic)' 'hospital accident and emergency (A&E) department' 'somewhere else'	Those reporting any lifetime sexual partners	8858, 7338
'If all of these different types of service were available in your area and easy to get to, which one would you prefer to get contraception from?'	'a doctor or nurse at your GP's surgery' 'sexual health clinic (GUM clinic)' 'family planning clinic/contraceptive clinic/ reproductive health clinic' 'youth advisory clinic (e.g. Brook clinic)' 'pharmacy/chemist' ' <u>NHS or Department of Health website</u> ' 'none of these' 'not needed'	Those reporting use of any method in the last year	6909, 5524

4.2.4 Explanatory variables

The following categories of explanatory variables were used:

- Participants' sociodemographics
- Internet access
- Area-level measures
- Sexual behaviour
- Sexual healthcare use
- STI diagnosis

Variables for sexual behaviour and service use were selected to match the timeframe of the primary outcome measure (the year prior to the survey interview). Some measures corresponding to the five years prior to the interview were included (number of sexual partners, having had same-sex partners, sexual health clinic attendance and STI diagnosis). This reflected the greater prevalence of these behaviours over this longer period (in the case of 'number of sexual partners', the greater prevalence of reporting multiple partners⁶⁰), thus it improved statistical power.

4.2.5 Statistical methods

Data were analysed using Stata 12's complex survey functions to take account of clustering, stratification and weighting of the Natsal-3 sample. Weights were applied to adjust for unequal probabilities of selection for participation in the survey (weights were provided in the Natsal-3 dataset^{67,367}). All analyses were conducted separately by sex. Participants with missing data for a given variable were excluded from analyses using this variable, as item non-response in Natsal-3 is low (typically below 0.5% in the CAPI, and 1-3% in the CASI).³⁶⁷

Among uses of the internet for the sexual health needs addressed in this study, only use of information/support websites for advice/help with one's sex-life was sufficiently prevalent to explore associations. Logistic regression was used to obtain crude odds ratios (ORs) to compare the odds of reporting this outcome, by each explanatory variable. Multivariable logistic regression was also used, adjusting for age (as a continuous variable), as a potential confounder of

associations with: NS-SEC code, which contained a 'full-time student' category; Output Area Classification (OAC 2011), which was based on population characteristics including age; recent STI diagnosis; and sexual behaviour variables (as young people report greater sexual partner change: greater numbers of recent and new sexual partners, than older adults⁶⁰). Statistical significance was considered as $p < 0.05$ for all analyses.

All analyses were stratified by gender, in recognition of differences in men and women's sexual behaviour^{400,401} and health-seeking behaviour.⁴⁰²⁻⁴⁰⁴

4.2.6 Ethical approval

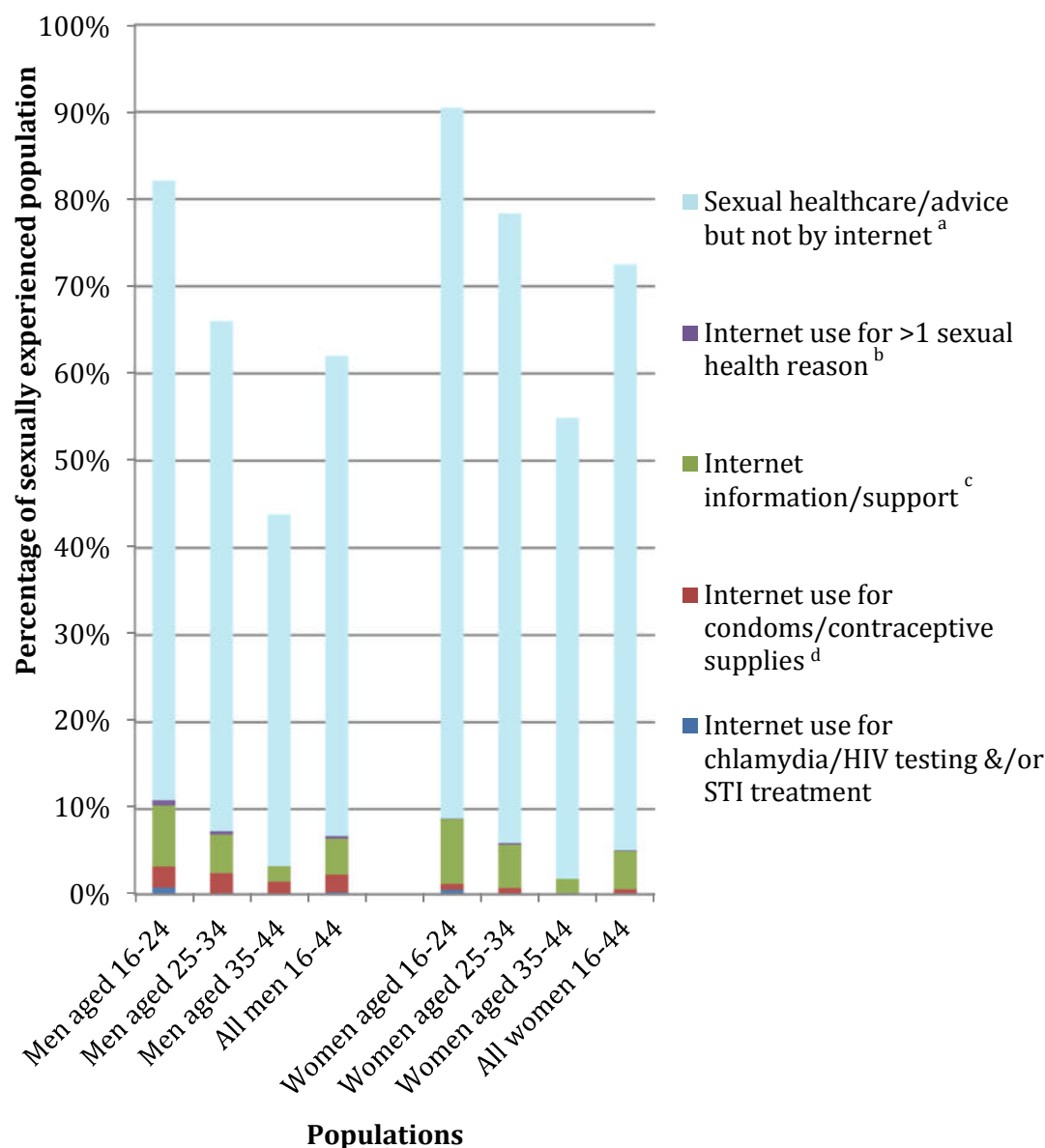
The Natsal-3 study was approved by the Oxfordshire Research Ethics Committee A [Ref: 10/H0604/27].

4.3 Results

4.3.1 Prevalence of reported recent use of the internet for selected sexual health reasons

Among sexually-experienced 16-44-year-olds, internet-use for chlamydia testing, HIV testing, or STI treatment (combined) in the previous year, was reported by 0.3% men, and 0.2% women (Figure 13). No-one aged 35-44 years reported this; among younger people, mostly it was chlamydia testing, with no-one in the sample reporting internet treatment for STIs other than chlamydia. Use of internet sources of contraception/condoms in the past year was a little more common, at least among men (2.4% men, 0.5% women). Use of information and support websites for advice/help with one's sex-life (based on the first question in Table 18, and hereon referred to as 'internet information/support' for brevity), in the past year, was more common still, reported by 4.5% men and 4.6% women. Overall, use of the internet for any of these sexual health reasons, in the past year, was reported by 6.9% men (95%CI: 6.0-7.8%) and 5.2% women (95%CI: 4.5-5.9%). In contrast, 60.2% men (95%CI: 58.2-62.1%) and 71.7% women (95%CI: 70.2-73.2%) reported using non-internet sources of sexual healthcare or advice/help with their sex-lives in the past year.

Figure 13: Percentage reporting seeking sexual healthcare and advice/help with their sex-life in the previous year, and specifically using the internet to do so, among sexually-experienced 16-44 year olds



Notes: The height of the stacked bars shows the total reporting any internet or non-internet sexual healthcare or advice/help: 62.0% sexually-experienced men and 72.5% sexually-experienced women. Those who reported using the internet for sexual health, and use of non-internet sexual healthcare/advice, were categorised by type of internet sexual healthcare/advice used.

^aUse of any of the following, from non-internet sources: chlamydia/HIV testing, STI treatment; condoms/contraceptive supplies.

^bInternet use for more than one of the following three categories: chlamydia/HIV testing &/or STI treatment; condoms/contraceptive supplies; advice/help with sex-life.

^cUse of information and support websites for advice/help with one's sex-life.

^dParticipants were not asked which method they obtained online, but it is likely that this was mostly condoms: 114/122 men and women reporting obtaining contraceptive supplies online in the past year reported use of male (n=113) and/or female (n=2) condoms in this period.

4.3.2 Factors associated with reporting use of information and support websites for advice/help with one's sex-life

Sociodemographic factors

There was no statistically significant difference between the prevalence of reporting 'internet information/support' between men and women (4.5% and 4.6% respectively, $p=0.86$, age-adjusted $p=0.69$).

Table 20 (p172) presents univariate and age-adjusted analyses. The mean age of men and women reporting 'internet information/support' was 25.9 years (standard deviation, SD 7.5) and 26.9 years (SD 8.8) respectively. Those not reporting this were older on average (men: 31.0 years, SD 8.0; women: 31.3 years, SD 9.7). The prevalence of reporting use of 'internet information/support' declined steeply with increasing age among both sexes (7.7% men, 7.8% women aged 16-24, to 1.8% men, 1.8% women aged 35-44, both $p<0.001$ for age-group difference).

A strong association was observed with education level. While 1.4% men and 2.0% women who left school aged 16 with GCSEs (General Certificates of Secondary Education) or equivalent qualifications, reported recent use of 'internet information/support', among those with or studying for further academic qualifications, this was 6.1% men and 5.9% women (both sexes: $p<0.001$), an association which remained after age-adjustment. Associations with socioeconomic status³⁹⁹ followed similar trends. Men in high-status occupations were more likely to report 'internet information/support', than those in lower-status occupations, before and after age-adjustment (managerial/professional men vs. men in semi-routine/routine occupations: aAOR 1.96, 95%CI: 1.27-2.93, $p<0.001$), while a similar finding among women reached borderline statistical significance after age-adjustment. Full-time students of both genders were also more likely than those in low-status occupations, to report 'internet information/support' even after taking account of their younger age (men aAOR: 1.95, 95%CI: 1.14-3.34; women aAOR: 1.93, 95%CI: 1.24-3.00).

Despite associations with these two individual measures of social status (education, socioeconomic status), there was no overall association between recent use of 'internet information/support' and area-level deprivation.¹⁸ However, use of 'internet information/support' was associated with Output Area Classification 2011 supergroup. Use was highest among 'cosmopolitans': residents of densely-populated urban areas characterised by relatively high proportions of single people, young adults, full-time students, and high ethnic integration³⁹⁸ (men: 12.5%, 95%CI: 9.0-17.2%; women 11.7%, 95%CI: 8.3-16.3%). There was little variation in use among other supergroups except, among women only, slightly lower use of 'internet information/support' in 'hard-pressed living' populations (residents of urban areas mostly in Northern England and Wales, characterised as having higher unemployment and lower proportions with higher-level qualifications than the national average³⁹⁸). Strong associations with OAC 2011 supergroup remained after age-adjustment (Table 20).

No overall association with ethnicity was observed among women after age-adjustment, but 'Asian/Asian British' men were more likely to report use of 'internet information/support' than White men (aAOR 2.11, 95%CI: 1.16-3.84, p=0.006). Notably, numbers in minority ethnic groups were relatively small (limiting power).

Having home internet access was reported by 93.5% of sexually-experienced 16-44-year-olds (95%CI: 92.9-94.0%). The minority who did not have home-internet were less likely to report use of 'internet information/support' than those who had (ORs: men: 0.30, 95%CI: 0.11-0.82, p=0.018; women 0.26, 95%CI: 0.11-0.58, p<0.001), with little change after adjusting for age.

Sexual behavioural factors

Use of 'internet information/support' was more commonly reported by women (but not men) reporting multiple sexual partners in the last year, and among men and women reporting new sexual partners in the last year, but these

associations disappeared after age-adjustment. Among women (but not men) use of 'internet information/support' was more commonly reported by those who reported multiple sexual partners in the previous year with whom they had not used condoms (aAOR 1.90, 95%CI: 1.11-3.26, p=0.03). Men reporting sex with another man in the previous five years were more likely to report use of 'internet information/support' (aAOR 2.44, 95%CI: 1.27-4.70, p=0.008), while no association with reporting same-sex sex in the previous five years was observed among women. Men and women reporting seeking sexual partners online within the previous year were more likely to report use of 'internet information/support', than those not reporting seeking partners in this way (men: aAOR 1.80, 95%CI: 1.16-2.79; women: aAOR: 3.00, 95%CI: 1.76-5.13).

Sexual healthcare use

No association was observed between reporting use of 'internet information/support' and reporting STI diagnosis/es in the past five years. Use of 'internet information/support' was more common among those reporting recent non-internet sources of sexual healthcare and advice/help, and having attended a GUM clinic in the last five years, but not after adjusting for age. No association was observed with having used STI services in the previous year (defined as reporting at least one of: GUM clinic attendance, chlamydia testing HIV testing) after adjusting for age.

Table 20: Variation in the prevalence and odds of reporting recent (last year) use of information/support websites for advice/help with one's sex-life ('internet information/support'), among sexually-experienced 16-44-year-olds

	Men				Women			
	Denominator (unweighted, weighted) ^a	Prevalence (95%CI)	OR (95%CI)	aAOR (95%CI)	Denominator (unweighted, weighted)	Prevalence (95%CI)	OR (95%CI)	aAOR (95%CI)
SOCIODEMOGRAPHICS								
Gender	3596, 3677	4.5% (3.9-5.3)	p=0.86	p=0.69	5274, 3682	4.6% (4.0-5.3)	p=0.86	p=0.69
Women			0.98 (0.79-1.21)	0.96 (0.77-1.19)			1	1
Men			1	1			1.02 (0.82-1.26)	1.04 (0.84-1.29)
Age			p<0.001	-			p<0.001	-
16-24	1361, 994	7.7% (6.3-9.4)	1	-	1713, 956	7.8% (6.4-9.4)	1	-
25-34	1451, 1299	4.9% (3.9-6.2)	0.62 (0.45-0.86)	-	2386, 1317	5.3% (4.3-6.5)	0.66 (0.49-0.89)	-
35-44	784, 1383	1.8% (1.1-3.0)	0.22 (0.13-0.39)	-	1175, 1409	1.8% (1.2-2.9)	0.22 (0.13-0.37)	-
Ethnic group			p=0.01	p=0.006			p=0.04	p=0.11
White	3134, 3118	4.0% (3.4-4.7)	1	1	4619, 3179	4.4% (3.8-5.1)	1	1
Asian/Asian British	190, 270	6.9% (4.0-11.6)	1.77 (0.98-3.21)	2.11 (1.16-3.84)	258, 220	3.8% (2.2-6.4)	0.86 (0.49-1.52)	0.96 (0.54-1.70)
Black/Black British	126, 140	7.8% (3.7-15.4)	2.01 (0.92-4.42)	2.11 (0.93-4.81)	174, 136	5.6% (3.0-10.2)	1.30 (0.67-2.52)	1.34 (0.70-2.59)
Mixed/Chinese/Other	108, 110	9.4% (5.1-16.9)	2.49 (1.26-4.93)	2.2 (1.13-4.26)	176, 117	11.1% (6.1-19.3)	2.71 (1.39-5.28)	2.32 (1.20-4.50)

Table 20, continued	Men				Women			
	Denominator (unweighted, weighted) ^a	Prevalence (95%CI)	OR (95%CI)	aAOR (95%CI)	Denominator (unweighted, weighted)	Prevalence (95%CI)	OR (95%CI)	aAOR (95%CI)
SOCIODEMOGRAPHICS, continued								
Education level^b			p<0.001	p<0.001			p<0.001	p<0.001
No academic qualifications	252, 275	0.8% (0.3-2.5)	0.60 (0.18-2.00)	0.65 (0.20-2.18)	372, 237	0.6% (0.2-1.9)	0.29 (0.08-1.04)	0.28 (0.08-0.98)
Academic qualifications typically gained at age 16	880, 912	1.4% (0.8-2.3)	1	1	1186, 863	2.0% (1.3-3.1)	1	1
Studying for/gained further academic qualifications	2354, 2419	6.1% (5.1-7.1)	4.57 (2.68-7.78)	3.79 (2.20-6.51)	3607, 2528	5.9% (5.1-6.8)	3.05 (1.88-4.97)	2.49 (1.52-4.06)
Socioeconomic status^c			p<0.001	p=0.001			p<0.001	p=0.06
Managerial/ professional	1060, 1262	4.5% (3.4-6.0)	1.46 (0.97-2.19)	1.93 (1.27-2.93)	1526, 1202	4.1% (3.2-5.3)	1.21 (0.79-1.85)	1.56 (1.02-2.40)
Intermediate	509, 554	3.0% (1.8-4.8)	0.94 (0.53-1.66)	1.16 (0.64-2.08)	1006, 719	3.9% (2.5-5.9)	1.14 (0.66-1.97)	1.32 (0.76-2.29)
Semi-routine/routine	1321, 1300	3.1% (2.4-4.1)	1	1	1582, 1028	3.4% (2.5-4.6)	1	1
No job	122, 99	1.6% (0.4-6.4)	0.48 (0.11-2.08)	0.33 (0.08-1.42)	418, 285	4.6% (2.9-7.3)	1.39 (0.78-2.46)	1.39 (0.79-2.46)
Full-time student	574, 452	11.1% (8.5-14.5)	3.85 (2.53-5.86)	1.95 (1.14-3.34)	717, 429	10.2% (7.9-13.1)	3.23 (2.14-4.89)	1.93 (1.24-3.00)
INTERNET ACCESS								
Access to internet at home			p=0.02	p=0.02			p<0.001	p<0.001
Yes	3327, 3442	4.7% (4.1-5.5)	1	1	4828, 3444	4.8% (4.2-5.6)	1	1
No	267, 232	1.5% (0.6-3.9)	0.30 (0.11-0.82)	0.31 (0.11-0.84)	443, 236	1.3% (0.6-2.8)	0.26 (0.11-0.58)	0.23 (0.10-0.52)

Table 20, continued	Men				Women			
	Denominator (unweighted, weighted) ^a	Prevalence (95%CI)	OR (95%CI)	aAOR (95%CI)	Denominator (unweighted, weighted)	Prevalence (95%CI)	OR (95%CI)	aAOR (95%CI)
AREA-LEVEL MEASURES								
Deprivation quintile^d			p=0.51	p=0.24			p=0.58	p=0.35
1, least deprived	642, 658	5.7% (4.2-7.7)	1	1	847, 632	5.5% (4.0-7.4)	1	1
2	653, 699	4.3% (3.1-6.0)	0.74 (0.46-1.20)	0.71 (0.44-1.14)	952, 699	4.4% (3.1-6.1)	0.79 (0.49-1.29)	0.78 (0.48-1.26)
3	690, 720	4.6% (3.3-6.5)	0.81 (0.50-1.30)	0.76 (0.47-1.23)	1031, 739	4.8% (3.5-6.7)	0.88 (0.55-1.41)	0.83 (0.51-1.35)
4	774, 823	4.3% (2.9-6.4)	0.75 (0.45-1.26)	0.69 (0.41-1.15)	1183, 821	4.8% (3.5-6.5)	0.87 (0.55-1.38)	0.82 (0.51-1.29)
5, most deprived	837, 776	3.8% (2.7-5.3)	0.66 (0.41-1.06)	0.58 (0.36-0.93)	1261, 792	3.7% (2.7-5.1)	0.68 (0.42-1.08)	0.61 (0.38-0.97)
Output area classification 2011			p<0.001	p<0.001			p<0.001	p<0.001
1: 'Rural residents'	276, 294	3.2% (1.8-5.6)	1	1	414, 313	4.0% (2.5-6.4)	1	1
2: 'Cosmopolitans'	302, 329	12.5% (9.0-17.2)	4.33 (2.17-8.63)	3.38 (1.68-6.77)	349, 266	11.7% (8.3-16.3)	3.20 (1.72-5.96)	2.51 (1.34-4.70)
3: 'Ethnicity central'	181, 225	5.4% (2.7-10.3)	1.71 (0.69-4.27)	1.58 (0.64-3.91)	307, 257	5.7% (3.5-9.0)	1.45 (0.72-2.91)	1.32 (0.65-2.68)
4: 'Multicultural metropolitans'	516, 595	3.7% (2.3-5.7)	1.15 (0.54-2.43)	1.04 (0.49-2.22)	772, 557	5.5% (3.9-7.7)	1.40 (0.76-2.57)	1.27 (0.69-2.36)
5: 'Urbanites'	665, 667	3.6% (2.4-5.3)	1.13 (0.55-2.30)	1.09 (0.53-2.24)	961, 667	4.8% (3.4-6.6)	1.20 (0.65-2.22)	1.14 (0.61-2.14)
6: 'Suburbanites'	587, 597	4.5% (3.2-6.3)	1.44 (0.72-2.85)	1.30 (0.65-2.59)	799, 608	4.1% (2.8-5.8)	1.02 (0.55-1.90)	1.02 (0.55-1.92)
7: 'Constrained city dwellers'	331, 271	4.1% (2.3-7.1)	1.28 (0.56-2.94)	1.06 (0.46-2.48)	488, 277	3.3% (2.0-5.4)	0.83 (0.41-1.69)	0.70 (0.35-1.42)
8: 'Hard-pressed living'	738, 698	2.8% (2.0-4.0)	0.87 (0.44-1.75)	0.76 (0.38-1.52)	1184, 736	2.0% (1.3-3.1)	0.50 (0.26-0.94)	0.45 (0.24-0.86)

Table 20, continued	Men				Women			
	Denominator (unweighted, weighted) ^a	Prevalence (95%CI)	OR (95%CI)	aAOR (95%CI)	Denominator (unweighted, weighted)	Prevalence (95%CI)	OR (95%CI)	aAOR (95%CI)
SEXUAL BEHAVIOUR, LAST YEAR								
Number of sexual partners			p=0.77	p=0.29			p=0.008	p=0.65
0	191, 174	4.6% (2.4-8.6)	1.06 (0.53-2.12)	0.95 (0.48-1.89)	284, 187	3.2% (1.7-6.0)	0.75 (0.38-1.48)	0.88 (0.45-1.73)
1	2320, 2612	4.4% (3.6-5.3)	1	1	3829, 2825	4.2% (3.6-5.0)	1	1
2+	1051, 857	5.0% (3.7-6.6)	1.14 (0.80-1.63)	0.72 (0.48-1.08)	1113, 631	6.9% (5.2-9.2)	1.69 (1.19-2.40)	1.18 (0.81-1.72)
New sexual partners			p<0.001	p=0.11			p<0.001	p=0.11
0	2129, 2503	3.3% (2.7-4.1)	1	1	3670, 2748	3.8% (3.2-4.6)	1	1
1+	1428, 1134	7.1% (5.7-8.9)	2.22 (1.61-3.07)	1.39 (0.93-2.09)	1553, 892	7.2% (5.7-8.9)	1.95 (1.43-2.65)	1.32 (0.94-1.85)
Number of sexual partners without a condom^e			p=0.12	p=0.30			p<0.001	p=0.03
0	862, 780	5.9% (4.4-7.8)	1	1	1007, 680	4.3% (3.1-5.8)	1	1
1	2139, 2412	4.1% (3.4-5.1)	0.69 (0.48-0.98)	0.96 (0.66-1.38)	3620, 2635	4.1% (3.5-4.9)	0.97 (0.67-1.40)	1.05 (0.73-1.50)
2+	523, 419	4.5% (3.1-6.7)	0.75 (0.46-1.25)	0.69 (0.42-1.13)	575, 317	10.0% (7.1-13.9)	2.51 (1.50-4.17)	1.90 (1.11-3.26)
Sought sexual partners online			p=0.004	p=0.009			p<0.001	p<0.001
No	3287, 3414	4.3% (3.6-5.0)	1	1	5079, 3559	4.4% (3.8-5.1)	1	1
Yes	306, 257	7.9% (5.4-11.6)	1.92 (1.24-3.00)	1.80 (1.16-2.79)	189, 116	11.8% (7.5-18.1)	2.93 (1.74-4.94)	3.00 (1.76-5.13)

Table 20, continued	Men				Women			
	Denominator (unweighted, weighted) ^a	Prevalence (95%CI)	OR (95%CI)	aAOR (95%CI)	Denominator (unweighted, weighted)	Prevalence (95%CI)	OR (95%CI)	aAOR (95%CI)
SEXUAL BEHAVIOUR, LAST 5 YEARS								
Number of sexual partners			p=0.04	p=0.96			p<0.001	p=0.18
0-1	1441, 1805	3.6% (2.8-4.7)	1	1	2649, 2116	3.8% (3.0-4.6)	1	1
2-4	1106, 1012	5.2% (4.0-6.7)	1.45 (0.99-2.13)	0.94 (0.63-1.41)	1630, 995	4.6% (3.6-5.8)	1.23 (0.88-1.71)	0.88 (0.63-1.23)
5+	1024, 837	5.8% (4.4-7.6)	1.64 (1.11-2.42)	0.95 (0.60-1.49)	958, 541	8.1% (6.1-10.7)	2.25 (1.53-3.29)	1.31 (0.85-2.01)
1+ same-sex partners			p=0.002	p=0.008			p=0.09	p=0.24
No	3459, 3561	4.3% (3.7-5.1)	1	1	4972, 3493	4.5% (3.9-5.2)	1	1
Yes	137, 116	10.9% (6.2-18.5)	2.71 (1.43-5.14)	2.44 (1.27-4.70)	302, 189	7.2% (4.3-11.9)	1.65 (0.93-2.93)	1.42 (0.80-2.52)
SEXUAL HEALTHCARE USE AND STI DIAGNOSIS/ES								
Non-internet sexual healthcare or advice/help, last year^f			p=0.004	p=0.42			p<0.001	p=0.11
Not reported	1205, 1453	3.1% (2.2-4.3)	1	1	1219, 1034	2.5% (1.7-3.8)	1	1
Yes	2391, 2223	5.5% (4.6-6.5)	1.8 (1.21-2.68)	1.19 (0.78-1.83)	4055, 2648	5.4% (4.7-6.3)	2.21 (1.41-3.45)	1.48 (0.91-2.41)
Attended GUM clinic, last 5 years			p=0.03	p=0.89			p<0.001	p=0.14
No	2670, 2902	4.1% (3.4-4.9)	1	1	3865, 2855	3.9% (3.3-4.6)	1	1
Yes	861, 712	5.9% (4.5-7.8)	1.47 (1.03-2.10)	1.03 (0.71-1.48)	1342, 779	7.4% (5.9-9.4)	1.98 (1.44-2.72)	1.31 (0.91-1.88)

Table 20, continued	Men				Women			
	Denominator (unweighted, weighted) ^a	Prevalence (95%CI)	OR (95%CI)	aAOR (95%CI)	Denominator (unweighted, weighted)	Prevalence (95%CI)	OR (95%CI)	aAOR (95%CI)
SEXUAL HEALTHCARE USE AND STI DIAGNOSIS/ES, continued								
STI service use, last year^g			p=0.27	p=0.08			p=0.02	p=0.61
Not reported	2723, 2974	4.3% (3.6-5.2)	1	1	3366, 2552	4.1% (3.4-4.9)	1	1
Yes	873, 703	5.3% (3.9-7.0)	1.22 (0.86-1.75)	0.72 (0.49-1.04)	1908, 1130	5.8% (4.7-7.2)	1.45 (1.06-1.98)	0.91 (0.63-1.31)
STI^h diagnosis, last 5 years			p=0.68	p=0.97			p=0.75	p=0.14
No	3300, 3408	4.5% (3.8-5.2)	1	1	4830, 3419	4.7% (4.0-5.4)	1	1
Yes	257, 225	5.0% (2.9-8.5)	1.13 (0.63-2.04)	0.99 (0.55-1.79)	398, 225	4.2% (2.4-7.3)	0.91 (0.50-1.64)	0.63 (0.35-1.16)

1=reference category. Throughout this table, 'sexual partners' refers to same-sex and opposite-sex partners.

^aDenominators for entire sample (sexually-experienced 16-44 year olds): Men: unweighted 3614, weighted 3697. Women: unweighted 5312, weighted 3703. Denominators vary due to item non-response.

^bDenominator restricted to those aged 17 and older. 'No academic qualifications': i.e. left school at 16 without passing any exams/gaining any qualifications (excludes qualifications gained at an older age); 'Academic qualifications typically gained at age 16': i.e. left school at 16 having passed some exams/gained some qualifications, e.g. English General Certificate of Secondary Education (GCSE) or equivalent; 'Studying for or attained further academic qualifications' i.e. left school at age 17 or older.

^cBased on National Statistics Socioeconomic Classification (NS-SEC) code. 'No job': no job of 10+ hours per week, in the last 10 years.

^dQuintile of adjusted Index of Multiple Deprivation (IMD) for Great Britain.

^eExcluding with women's same-sex partners.

^fDefined as: reporting GUM clinic attendance within the last year, or responses other than 'internet' at questions listed in Table 18, within the last year. Exceptions (non-internet responses which were ignored), were: (1) where participants had indicated friend, parent, relative, or partner as source of contraceptive supplies (free-text response); (2) where participants had selected 'family member/friend', 'self-help books/information leaflets', 'self-help groups' and 'have not sought any help' as sources of advice/help about their sex-life.

^gDefined as: reporting any of: GUM clinic attendance, chlamydia testing or HIV testing, within this last year.

^hNatsal definition of STIs excludes thrush.

4.3.3 Preference for internet sources of STI diagnosis/treatment, and condoms/contraception

Less than 2% of sexually-experienced participants aged 16-44 reported that the first place they would look for diagnosis/treatment if they suspected that they had an STI, would be an 'internet site offering treatment'. Among sexually-experienced 16-44-year-olds reporting use of any contraceptive method in the previous year, 5.5% men and 1.1% women indicated they would prefer to obtain supplies from an 'NHS or Department of Health website' (Table 21).

Table 21: Preference for internet sources of: STI diagnosis/treatment, and condoms/contraception, by gender

	Men		Women	
	Denominator (unweighted, weighted)	% (95%CI)	Denominator (unweighted, weighted)	% (95%CI)
Would first look on an internet site offering treatment, for diagnosis/treatment, if STI was suspected	3589, 3668	1.8% (1.3-2.5%)	5269, 3670	0.8% (0.6-1.1%)
Preferred source of contraceptive supplies would be NHS/Dept. of Health website	2793, 2743	5.5% (4.5-6.6%)	4116, 2781	1.1% (0.8-1.6%)

Table 19, p164 details question wording, response options and eligible participants.

4.4 Discussion

4.4.1 Main findings

Although internet access is nearly universal in Britain, these data from a national probability sample survey show that use of the internet for key sexual health reasons was uncommon in the British population in 2010-12. Specifically, the prevalence of reported use of internet STI services was very low, and reported use of the internet for condoms/contraceptive supplies was also uncommon, particularly amongst women. Reporting recent use of internet information and support websites for help/advice about one's sex-life was slightly higher, especially among younger people, and among those who reported sexual behaviours sometimes considered as markers of sexual risk, including men who have sex with men and people who sought sexual partners online. However, those using information/support websites for advice/help with their sex-lives may be from populations typically considered to have better access to sexual healthcare: the better-educated, residents of certain urban areas and, among men, those of higher socioeconomic status. Despite this potential social inequality, those who reported recent use of information/support websites were as likely to report previous STI diagnosis/es, as those who did not report this.

4.4.2 Findings in relation to other studies

To date, no other studies have estimated the prevalence of using the internet for sexual health reasons, or identified associated factors, using nationally-representative data. The association found in this study between use of information/support websites for advice/help with one's sex-life, and younger age, is unsurprising given young people's greater internet use,²¹⁰ smartphone ownership,²¹¹⁻²¹³ and greater need for sexual healthcare indicated by levels of reported STI diagnoses, GUM clinic use and STI prevalence.^{62,107} Research on the acceptability of using the internet to deliver conventional (sexual) health services reveals similar findings with respect to age^{295,299,301} and education.²⁸⁵ Differences in men and women's sexual behaviour^{400,401} and health-seeking behaviour,⁴⁰²⁻⁴⁰⁴ are well-documented, but this study revealed no statistically

significant difference by gender in the prevalence of reported use of information/support websites for advice/help with one's sex-life. However, there were some differences in associations observed among men and women, and more men than women reported that they would first look online for diagnosis/treatment if they suspected that they had an STI. In the English National Chlamydia Screening Programme (NCSP), more tests are performed among young women than among young men,¹²⁹ perhaps due to women's greater engagement with contraceptive and other health services where screening is offered. However, there is less discrepancy by gender for internet-ordered home-sampling compared to other NCSP testing venues (with the exception of military settings).¹²⁹ In this study, use of the internet for condoms/contraceptive supplies was reported by more men than women, perhaps reflecting gendered norms about who obtains condoms.⁴⁰⁵

Surveys of patients attending GUM clinics in England, conducted almost a decade before Natsal-3, found patients reporting internet sex-seeking were also more likely to report use of the internet for sexual health information,⁴⁰⁶ similar to the association observed in the current study between internet sex-seeking and use of information/support websites.

Echoing this study's finding, little difference was found by IMD quintile in the proportion of NCSP internet-ordered chlamydia home-sampling kits returned (2010).¹²⁹ However, no studies to date have used NCSP data to compare demographic or behavioural characteristics of those using internet-ordered kits with the wider population in the target age-range. Though internet-based sexual health services have been viewed as a promising way of reaching rural populations, this study found relatively low use of information/support websites in these areas.

4.4.3 Strengths and limitations

Use of Natsal-3 data has allowed these analyses to examine a wide range of sociodemographic, behavioural, and health service use variables, in a sample

representative of the resident British population, in relation to use of information/support websites for advice/help with one's sex-life. Despite survey data being self-reported, therefore subject to recall and social desirability biases, they are of high quality: use of CASI was demonstrated to facilitate reliable reporting of sensitive information,⁴⁰⁷ and cognitive testing of several survey modules maximised the likelihood of questions being interpreted as intended.⁴⁰⁸ Furthermore, the survey's response rate was similar to that achieved for other major social surveys undertaken in Britain at that time^{409,410}, and item non-response was typically very low.^{67,367} Importantly, in this rapidly evolving field, the study reported in this chapter focussed on reported behaviour in the year prior to the survey interview. Natsal-3 data are the most recent detailed quantitative data relevant to this topic, but are now several years old (collected 2010-2012). As noted in chapter 1 (section 1.7), since this time there have been increases in the proportion of people using the internet for health information in general, and a very rapid rise in smartphone ownership. Access via a personal device such as a smartphone may be more private than (e.g.) via a household's shared personal computer, perhaps facilitating internet use for sexual health information and sexual healthcare. It is also possible that the internet-based services available may have changed in nature, quantity and quality, which I further discuss in chapter 8.

The very low prevalence of most outcome measures examined meant that there was insufficient power to explore their associations with explanatory variables. The exception was reported use of the internet for advice/help with one's sex-life, but even this was reported by <5% of the study population. Due to the low prevalence of this outcome variable, rare behaviours could not be included as explanatory variables in this analysis (although extending the timeframe to within the previous five years, for some explanatory variables, increased prevalence and thus assisted with statistical power). The multivariable analysis was adjusted only for age, also in order to assist with statistical power. Due to small numbers in some sub-groups, some variables had to be treated crudely (e.g. ethnicity) to create categories to obtain sufficient sub-groups sizes, which limited explanatory potential. While Britain's major ethnic groups (Asian, Black,

White) were considered, differences could not be explored between Black Caribbean and Black African ethnic groups, for example. It was also necessary to have a sub-group labelled Mixed/Chinese/other, which is not particularly meaningful. Conducting an analysis among men and women combined would have increased the statistical power, but instead the data were stratified by gender to give a more meaningful analysis, in recognition of the differences between men and women's sexual behaviour and (sexual) health-seeking behaviour (explained in sections 4.2.5 and 4.4.2). This decision is supported by several differences between men and women, in the associations observed.

The Natsal-3 survey data serve numerous purposes, and the questions used (Table 18, Table 19) were not designed for this particular study. Of note, the main outcome measure of use of information/support websites for advice/help with one's sex-life, was based on responses to a question located in the survey module entitled 'Sexual Function'. It was assumed that the question was interpreted more broadly than about sexual function alone, as 'sexual function' was neither mentioned in the question, nor visible on the computer screen at the time, and 'sex-life' had been defined broadly, shortly before this question was asked (p161). It is impossible to know for sure how participants interpreted the survey questions. However, supporting this assumption, among sexually-active 16-44-year-olds who reported use of information/support websites at this question, over half agreed that they felt satisfied with their sex-life, over half disagreed that they felt distressed or worried about it, and more than two-thirds disagreed that they had avoided sex because of sexual difficulties (their own or a partner's) within the previous year (see Appendix 5). This suggests that many who reported use of internet help/advice with their sex-life were doing so for reasons other than sexual function problems.

In terms of applicability of this study's findings to sexual health as broadly-defined by the WHO³¹ (see p27 of this thesis), limitations in the available survey questions prevented construction of a meaningful composite measure of internet use for all sexual health issues. The main outcome measure used in this study may not have captured use of the internet for all types of sexual health

information/support, for example, support and counselling following non-volitional sex (it seems unlikely that participants would have considered this to be help/advice with their 'sex-life', although perhaps they would if non-volitional sex occurred in the context of a sexual relationship).

Despite this limitation, an advantage of this study is that it included use of the internet for a range of sexual health reasons, and also considered people's preference to use the internet for sexual healthcare (though without collecting data on which websites were used/preferred). However, the low proportions who reported a preference for using the internet for STI diagnosis/treatment, or a preference for accessing contraception from an NHS website, probably underestimate the proportions that might choose internet-based services if they were well-regulated and based in the NHS. This is because the relevant survey questions (Table 19, p164) each allowed a single response, and provided no description of the internet services, which might be difficult for participants to envisage or assumed to be costly, as such services were not available through the NHS. (Within the NCSP, internet-based home-sampling for chlamydia was available in 2010-12 when data were collected, but only for 16-24-year-olds and treatment was not available online.) The question also specified 'if an STI was suspected'. In this context, a consultation with a healthcare professional may seem most appropriate, while for a routine STI check-up, internet services might hold greater appeal. Searching for health-related information online has become more common in recent years (18% of adults in Great Britain reported doing this within the last 3 months in 2007, rising to 49% in 2015²¹⁴), and patients may look up symptoms and health information online before contacting a health professional. Given this trend, responses to the STI diagnosis/treatment question may underestimate the proportion who would use an internet-ordered testing and treatment service if they found a reputable one, during their online search.

Even a 'perfect' survey question, asked in a survey conducted very recently, cannot give a definitive answer as to who will use the online sexual health interventions and services of the future. However the main outcome measure

for this study, which addresses use of information/support websites (as distinct from lay advice/help sought online) for sexual health, broadly defined, reflects those who may take up online sexual health services and interventions, fitting with their existing sexual health-seeking behaviour.

4.4.4 Implications for policy and practice

Low levels of use of the internet for contraception and STI services may reflect the limited availability and quality of the available online services – particularly at the time the data were collected (2010-2012), and particularly in relation to STI testing and treatment.^{129,197,311} Of course, it may also reflect that many methods of contraception cannot feasibly or legally be provided online. Future qualitative and quantitative research could explore awareness, expectations and barriers to use of currently-available online sexual health services.

Greater proportions of people in Britain are estimated to have used information/support websites for advice/help with their sex-lives, particularly among young people. This suggests scope for expansion of provision, as this cohort ages, among younger cohorts who have also grown up using the internet, and as the range and quality of internet sexual healthcare increase (as is likely given existing trends. An example of improved quality is the legalisation and regulation of HIV self-testing in the UK, available online.⁴¹¹)

Findings suggest that if use of internet sexual healthcare followed patterns of internet use for information/support, health inequalities might increase, especially if expansion of online sexual healthcare was coupled with reduced provision of conventional sexual healthcare. ‘Digital divides’ by socioeconomic status have been widely documented,²⁰⁸ with e-health a specific area of concern.^{215,216} This study’s findings regarding education and socioeconomic status, may reflect that internet-use is lower among those with less education,²¹⁸ and lower incomes.²⁰⁹

Although home-internet access was high in the population of interest in Natsal-3, the survey did not ask about internet use more generally, including via a

personal device, which may have varied across social strata. Having a laptop, tablet or smartphone might allow greater access to the internet for sexual health, than a household's shared personal computer, if privacy from other household members is important.

Since the data were collected for Natsal-3, between 2010 and 2012, there have been further increases in smartphone ownership^{205,206} and internet access²⁰⁴ (further discussed in chapter 8), which may reduce differences in proportions using the internet for sexual health by socioeconomic status and/or education. However, if these differences relate to differences in healthcare-seeking behaviour, inequalities may be more persistent. Research should examine these associations further, and evaluations of new internet-based interventions and services should monitor and model impacts on both on STI transmission and on health inequalities. Interventions may also be required to promote e-health, should groups be identified which have good internet access, yet are underserved by online and conventional healthcare.

Chapter 5: Perceptions of remote self-testing within online care pathways for sexually transmitted infections: qualitative interview study

Aicken CRH, Fuller SS, Sutcliffe LJ, Estcourt CS, Gkatzidou V, Oakeshott P, Hone K, Sadiq ST, Sonnenberg P, Shahmanesh M. Young people's perceptions of smartphone-enabled self-testing and online care for sexually transmitted infections: qualitative interview study. *BMC Public Health*. 2016;16:974.

5.1 Introduction

5.1.1 Objective

The objective of this study was to explore perceptions and acceptability of a hypothetical remote self-testing device for STIs within an online care pathway to treatment and PN, among a group of potential users.

The study was part of the formative research in the development of both the self-testing device and the online care pathway. It was conducted at an early stage, when neither were ready for piloting, nor sufficiently well-defined to be simulated. It took place in parallel with other formative research, on the development of the user-interface¹ and the clinical content of the care pathway.²

5.1.2 Issues specific to this study

After designing this study, obtaining the necessary approvals and drafting the topic guide, I went on maternity leave. However, data from the study were needed urgently by the eSTI² Consortium to inform the development of an online care pathway for chlamydia (the resulting pilot version of this care pathway is described in chapter 6). In my absence, pilot interviews were conducted, some refinements to study design were made, and data collection was undertaken by a colleague. Colleagues conducted a rapid analysis of the interviews, which was not part of my thesis.

In this chapter I describe what I did, and what others did (Appendix 6 provides further details). I then present the results of a thematic analysis of the interview data which I undertook. My analysis was conducted independently of the (more

superficial) rapid analysis; I avoided reading or discussing the findings of the rapid analysis, until my own analysis was at an advanced stage. The impact of these unusual circumstances is considered in the Discussion (section 5.5).

5.2 Approach and conceptual framework

I used a mixed inductive-deductive approach: *a priori* evidence and ideas informed study design and the topic guide, and I allowed themes to emerge in the analysis.

To develop a conceptual framework, I used research evidence relative to the study's aim, and thought experiments.³⁵³ This framework was not intended to be exhaustive or proscriptive, fitting with the study's approach and the exploratory nature of the research.

As outlined in chapter 3, the proposed intervention could deliver public health benefit by reaching populations which underutilise existing STI services and by overcoming barriers to using such services. I conjectured that perceptions and experience of existing sexual health services, and perceptions and experience with the internet and smartphones (including for health), could influence the acceptability of the proposed intervention to potential users. For this I had in mind issues established in the research literature as affecting the acceptability of sexual healthcare (regarding existing services, chapter 1, p236; and internet-based STI testing services, chapter 2).

Because the proposed intervention is novel, I sought to explore interviewees' first impressions and assumptions about it, and also whether and how they thought they could, or would, use the intervention, and why (not).

The conceptual framework described above, and that of my doctoral research as a whole (chapter 3, p139) informed my choice of study population, the interview topic guide, and sampling strategy, as described and justified in Methods, overleaf. Demographic characteristics including gender and age influence STI prevalence, sexual behaviour, and sexual healthcare-seeking, and were used for sampling (also described and justified in Methods).

5.3 Methods

5.3.1 Study design and population

Individual in-depth interviews were conducted with young people, recruited from an Inner-London Further Education (FE) college in an area with high rates of STI diagnosis,³⁷³ and a socioeconomically-deprived and ethnically-diverse population. People from lower socioeconomic groups are, in general, over-represented among FE college students. At the college where the research took place, ethnic minority students, and particularly those of Black African and Black Caribbean ethnic origin, were over-represented, even relative to the diverse local population.⁴¹² Therefore, recruitment from this setting enabled us to reach a population at risk of STI, based on the local population's burden of infection, and the FE college student population's young age, ethnic composition and deprivation. Selection of the particular FE college was for convenience: prior to eSTI²'s commencement, the college had been used for STI research led by eSTI² Consortium colleagues at St. George's University of London. I could therefore make use of their existing relationship with college staff, and staff's support for sexual health research.

Eligible students were aged 16-24 years, and self-reported having had sex at least once.

5.3.2 Topic guide development

I drafted a topic guide, which consisted of: discussion of interviewees' experience with STI testing and sexual healthcare, an explanation of the proposed intervention by the interviewer, and then discussion of the various stages of self-testing and use of the online care pathway, using scenarios (p193) explored through open-ended questions. These scenarios were used primarily as tools to explore the perceptions and acceptability of the intervention (and not as a way of generating reliable evidence about how interviewees would actually behave under the circumstances described). Probes were included which related to issues known to influence acceptability of sexual healthcare (see chapters 1 and 2) and issues which could affect the use of new diagnostic and e-health technologies (e.g. usability, data security).

The topic guide was piloted by the interviewer. A number of changes were then made, which were discussed and agreed with me (see Appendix 6). Briefly, these concerned the need to make it easier to engage with the hypothetical intervention (leading to inclusion of an animation, which a colleague had developed for a separate study, shown in Box 3, p194), changes to terminology, shortening the topic guide, and starting the interview with a less sensitive topic. We agreed to start the interview by asking about smartphone ownership and internet use, which was straightforward and unthreatening for interviewees to discuss,⁴¹³ as well as providing relevant contextual data.

Provision of information specifically for disease surveillance purposes was not explicitly discussed because services primarily collect these data for clinical purposes.

5.3.3 Sampling and recruitment

A purposive sampling strategy³⁵⁰ was used, with gender and age-group as primary sampling criteria, and a target of 24-36 interviews (Table 22). The age-groups 16-19 and 20-24 were used because experience with sex, with sexual healthcare and with healthcare in general, are likely to increase with increasing age. Furthermore these categories are similar to those used in national STI surveillance data. Differences between men and women in sexual behaviour^{400,401} and healthcare-seeking behaviours^{62,402-404,414} are evidenced in the literature, and gender may therefore affect how any novel sexual healthcare intervention is perceived.

Table 22: Sample quotas for interviews with young people

		Gender		Total
		Female	Male	
Age-group	16-19 years	6-12	6-12	
	20-24 years	6-12	6-12	
Total				24-36

(My original intention to sample by experience of STI testing, instead of age-group, was abandoned, because of ethical issues in obtaining this sensitive information prior to consent.)

Following an email sent on behalf of the researchers to all students (Appendix 7b), and posters placed in the college, students were approached in college communal areas by the interviewer, or referred to him by staff. The interviewer explained to potential interviewees that the study would involve a face-to-face interview with him, lasting about an hour, to find out what they thought about a new way of testing for STIs. Further details of the study were provided orally and in information sheets (Appendix 7c).

5.3.4 Procedure

Interviews took place in private rooms at college sites. One male interviewer conducted and audio-recorded all interviews, after obtaining signed informed consent (Appendix 7d).

The topic guide, described here and in Box 2, was used flexibly, and some minor revisions were made as data collection progressed. The interviewer began by asking about interviewees' smartphone ownership, and use of the internet and smartphones, including for health. After exploring their experiences of STI testing, the interviewer asked interviewees what they understood by STI testing using their smartphones. He then provided a brief description of the proposed intervention, aided by an animation (Box 3, p194) which outlined stages a user would potentially go through: providing some registration information, operating the self-testing device with a sample of urine or vaginal swab, receiving their result on their smartphone, e.g. via bluetooth, and if positive, an online consultation, 'e-prescription', PN and sexual health advice. The interviewer explained that the test was still being developed, but that the animation showed what it might be like. The interviewer explained that obtaining treatment this way would be safe for most people (but he did not explain what would happen otherwise). Scenarios (Box 2) were used, with relevant probes, to explore acceptability and preferences relating to various

stages of the process, from self-testing, through to receipt of treatment for those testing positive, and PN.

Box 2: Summary of topic guide

Opening questions / 'ice-breaker'

- Smartphone ownership and use

Technology and healthcare experience

- Experience with smartphones and internet-use in relation to health
- Experience of STI testing and sexual healthcare use

First impressions & expectations of 'testing for STIs using your smartphone'

Description of the intervention

Interviewer describes proposed testing device and online care pathway, aided by an animation.

Scenarios used to explore acceptability and preferences

- USE OF ONLINE HEALTH PROMOTION ADVICE IF TESTED NEGATIVE
- USE OF REMOTE ONLINE CARE IF TESTED POSITIVE
- INPUTTING INFORMATION VIA SMARTPHONE/COMPUTER, ONLINE
 - Before using the test: registration information (contact details, sexual history)
 - If result was positive: medical information to check treatment is safe for you (e.g. allergies, symptoms)
- REMOTE CARE: OBTAINING TREATMENT VIA E-PRESCRIPTION
- REMOTE TESTING/CARE COMPARED TO CLINIC-BASED TESTING/CARE
- REMOTE CARE AS PART OF A 'VIRTUAL CLINIC' WITHIN THE NHS
 - Basis of intervention in the NHS
 - Views on a confidential but not anonymous service
 - Understanding of 'confidentiality'
 - Views on receiving a message reminder to collect/take treatment
- PARTNER NOTIFICATION (*interviewer explained likelihood of infection in sexual partners of those testing positive for an STI*)
 - Notifying a partner/s and providing a message/code with which partners could also obtain treatment in the same way, but without testing or waiting for a positive result
 - Being notified by a partner and receiving such a message/code

Views and impressions of using the service, at the end of the interview

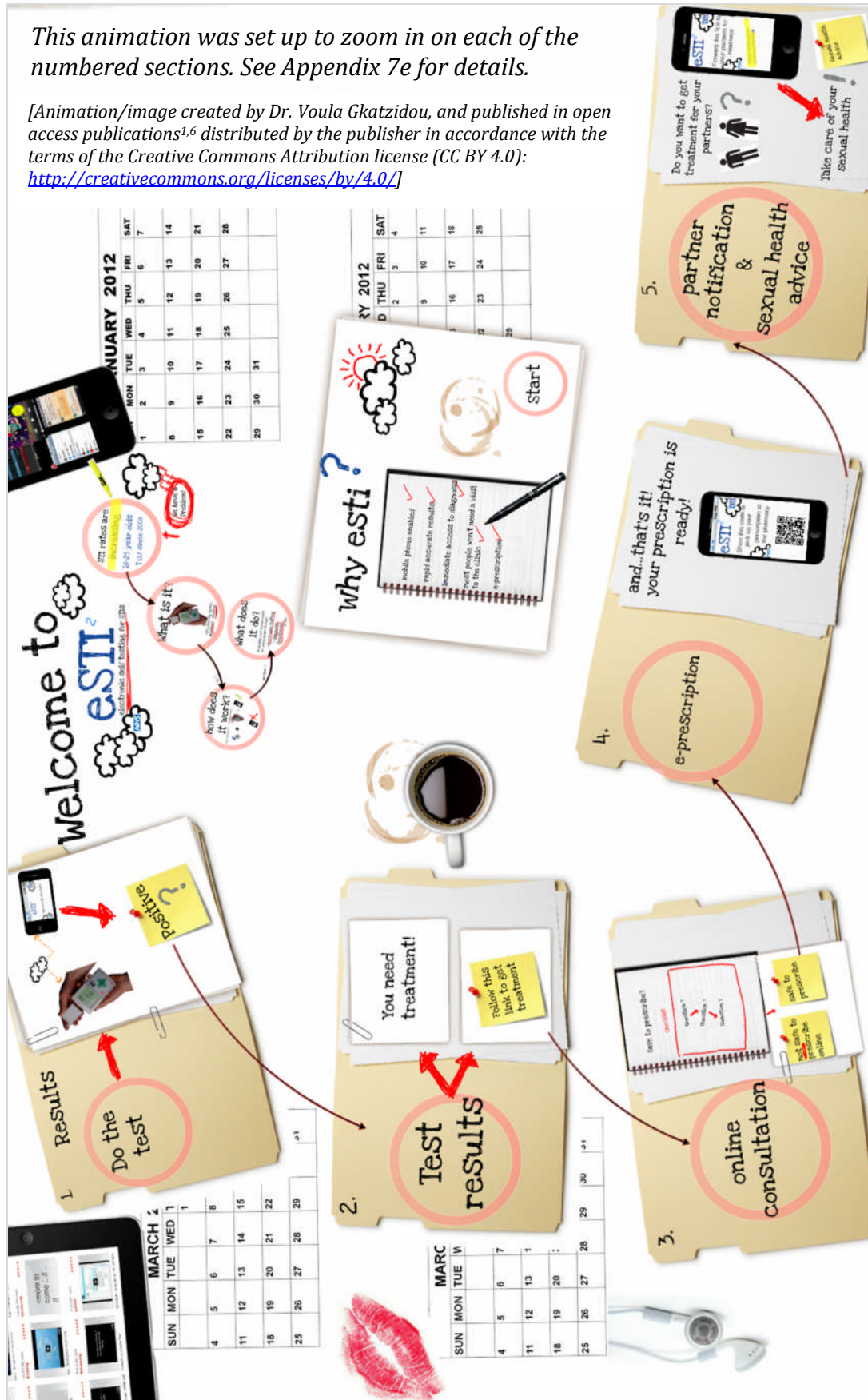
Reasons for taking part in the interview

Box 3: Screenshot of the animation

This animation was set up to zoom in on each of the numbered sections. See Appendix 7e for details.

[Animation/image created by Dr. Voula Gkatzidou, and published in open access publications^{1,6} distributed by the publisher in accordance with the terms of the Creative Commons Attribution license (CC BY 4.0):

<http://creativecommons.org/licenses/by/4.0/>]



Interviews focussed on exploring novel aspects of the proposed intervention, so aspects which are established as broadly acceptable, or have become common practice, were not explored (such as self-sampling,⁴¹⁵ and receipt of STI test results by text message, see chapter 2). Few details were provided about the test and online care pathway, for simplicity, and because of uncertainties at this stage in intervention development. Details unknown at the time of the interviews were not explored unless mentioned by interviewees (these included: the STI that the device would detect, described by the interviewer as chlamydia in the first instance ‘because it is an easier infection to treat’; specific clinical and disease surveillance information to be collected; cost; distribution; and whether the device would be for single or repeat use. These were being explored by colleagues, as explained in chapter 3, Table 15, p141).

The interviewer kept field-notes, recording circumstances of recruitment and impressions from interviews, using a template I had created (Appendix 7f). Interviews lasted 29-75 minutes (mean: 53mins). Each participant received £15 in recognition of their time and contribution to the study.

Ethical approval was provided by University College London Ethics Committee, ref: 3490/001.

5.3.5 Transcription, data management and familiarisation

Interviews were transcribed by a commercial transcription company, and checked by myself and the interviewer. For data familiarisation, I read transcripts repeatedly, alongside listening to recordings and reading the interviewer’s field-notes, and discussed with him his experiences of data collection.

5.3.6 Analysis

I conducted a thematic analysis following the process outlined by Braun and Clarke,³⁷⁴ using NVivo software and paper charts. I derived themes using a mixed inductive-deductive approach: identification of themes was influenced by emergent and recurring issues in the data, and by *a priori* issues relating to the

conceptual framework. Individuals' accounts of their views and experiences with existing STI testing services, and with smartphones and the internet, were used to contextualise their views on the novel service.

As analysis took place after data collection was complete, my initial findings could not be explored in subsequent interviews. However, once I had identified candidate themes, I refined them by applying them to each interviewees' data in turn, in an adapted process of constant comparison.⁴¹⁶ Saturation was achieved: no new themes were identified from later interviews, and themes fitted these interviews without further refinements to their definitions. Quotations were selected to represent themes, as described in chapter 3 (p155).

5.3.7 Quality assurance and reflexivity

The interviewer and I are both experienced in sexual health research with young people, and he is an experienced qualitative interviewer. At the time of data collection, he had submitted his own PhD thesis which predominantly used qualitative methods. I had limited experience of qualitative data analysis, so I undertook training, with the Social Research Association. Having recently lived, for several years, in the borough where the research took place, I was familiar with the local social and health service context.

For verification of my findings, the interviewer (Dr. Sebastian Fuller), our supervisor Dr. Maryam Shahmanesh (Senior Lecturer at UCL's Centre for Sexual Health and HIV Research), and Lorna Sutcliffe (Principal Researcher, Queen Mary University of London), who were familiar with the entire dataset having worked on the rapid analysis, provided feedback on my draft analysis. I take full responsibility for the interpretations I present, but acknowledge the contribution of discussions with colleagues at this stage, particularly the interviewer; our differing genders, backgrounds and experiences gave us a slightly different perspective on the data, resulting in a richer interpretation.

Through my immersion in the data I considered that the interviewer achieved a good rapport with interviewees of both sexes. However, the interviewer's age

(in his thirties), status as a university researcher and association with the development of advanced technology may have led to deference and social desirability bias in this group of young FE students (e.g. a reluctance to criticise the proposed intervention). Mindful of this, he sought to lessen the social distance between himself and interviewees by modifying the language he used and by explaining that he was not involved in the development of the testing technology, so would not be offended if they did not like or agree with some or all of the proposed format. Independently, the interviewer and I both noticed initial reluctance towards criticising the 'modern' and technologically complex intervention, in some interviews. This lessened as interviews progressed, and all interviewees expressed a mixture of positive and negative opinions about the novel intervention.

The interviewer reported that use of the animation helped interviewees understand the proposed intervention, compared to his experience in pilot interviews.

At the end of the interviews, interviewees were asked what motivated them to take part. My colleagues had suggested this, because of their concern that the £15 token of appreciation might unduly influence participation.

5.4 Results

5.4.1 Participants

Twenty-five interviews took place in Spring/Summer 2012 (Table 23). Interviewees were aged 16-23 years (mean: 19 years). The quota of 6-8 interviewees in each sex/age-group category was not filled for older females (n=2) prior to the end of the college's term.^{vi} However I and, independently, the three colleagues responsible for the rapid analysis (including the interviewer) considered saturation to have been reached within the sample achieved, i.e. no new findings emerged in later interviews. Due to the public and informal way in which recruitment often took place, the number approached who declined participation was not recorded, and the interviewer did not ask those who declined for their reasons for doing so. Two students scheduled an interview but did not participate.

Interviewees' accounts of their STI testing experience ranged from a single chlamydia screen, to repeated comprehensive testing in sexual health clinics. Use of STI testing in general practice and use of internet-ordered home-sampling for chlamydia were also reported. Two interviewees, both women, spontaneously mentioned that they had previously been treated for an STI (however this was not asked of other interviewees).

^{vi}A-level courses at the college are taken by younger students of both genders, but technical/vocational courses at the college are traditionally gendered (e.g. construction, electronics, beauty). The interviewer encountered more male students than female in the 20-24 age-group on the college campus which taught vocational courses. He therefore asked staff at both campuses to direct him to the locations where there were more 20-24 year old females. Unfortunately he only received this information one week before the end of the academic year, which limited his opportunities to recruit.

Table 23: Interviewees' characteristics

Characteristic	Number	
<i>Asked by the interviewer before the interview:</i>		
	Gender	Female Male
Age ^a	16-17	3 2
	18-19	4 6
	20-21	2 4
	22-23	0 4
Ethnicity ^b	Black/Black British, African	10
	Black/Black British, Caribbean	6
	Black British	5
	Mixed	3
	Muslim/Asian	1
Sexual orientation ^{b,c}	Straight	22
	Bisexual	2
	Gay	1
Has (a) current sexual partner(s)	Yes	15
	No	9
	'it's complicated'	1
<i>Reported during the interview:</i>		
STI testing experience	Yes	22
	No	3
Smartphone ownership	Yes, at time of interview	22
	Not currently, but has had (lost, in repair, broken)	3
	Never had a smartphone	0

^aFor sampling purposes, age-groups were 16-19 and 20-24 years, however no interviewees were aged 24 years.

^bSelf-defined. Self-defined ethnicity was grouped into categories by researchers.

^cAll three interviewees self-identifying as bisexual or gay were female.

5.4.2 Themes

The following themes were identified and are described below:

- Theme 1: Ease and convenience
- Theme 2: Speed
- Theme 3: Privacy
- Theme 4: Capabilities and limitations of technology
- Theme 5: Trustworthiness

Themes describe dimensions of how the intervention was perceived by interviewees. Organising themes like this enables me to represent, below, the

diversity of views interviewees expressed, as well as shared perceptions of the intervention.

Theme 1: Ease and convenience, and Theme 2: Speed

Themes 1 and 2 represent distinct concepts, but they were often discussed together by interviewees, so they are presented together here.

Interviewees described smartphone-enabled self-testing and online care pathways as making access to STI testing and treatment quicker, easier and more convenient than attending clinic or general practice. They associated self-testing with having greater control over when and where they could test – which they welcomed:

...you could be in the bath, be like using the toilet, and be like, let me just get this real quick and do this real quick. It's... convenient, very convenient. That's why I like it.
(V, 18-19-year-old man)

Long waits within sexual healthcare services were mentioned as a reason why some interviewees had opted to test 'online' – i.e. via the NCSP's internet-ordered postal home-sampling service (which this young woman calls a 'home test'):

I'll wait there [in clinic] for a little while but the waiting time's really long, could be sometimes four, five hours before you get seen. [Interviewer: Mm.] So I just normally end up walking out cos it's too long [...] then I normally just do a home test then.
(C, 18-19-year-old woman)

Universally interviewees sought easy access to testing, and if positive, rapid access to treatment. This young man's response was typical in prioritising speed and convenience of obtaining treatment. Asked whether he would follow a link to proceed to treatment following a positive self-test result, he agreed he would do so, in order 'to get it done and get it fixed and away as quickly as possible'.

I think you want treatment, you would follow the link, or if you feel comfortable you just go to the clinic quick and do what you need to do, but

I think follow the link because it is a lot quicker. More convenient. So I would follow the link.
(V, 18-19-year-old man)

Concerning waiting times for results, however, views on speed were more complex. Regarding the speed of operation of the proposed self-test, some expected a result within minutes, reasoning that new technology ought to provide this: *'everything is fast now'* (M, 18-19-year-old man). However, others reasoned that a rapid test might be less accurate: a tension between their desires for dependable, and yet rapid, results. Those who had used internet-based home-sampling described valuing avoiding clinic attendance and/or face-to-face consultations; they would rather their results arrived faster than from home-sampling services, but accepted waiting days or a week. This suggests that trade-offs exist between speed and privacy (theme 3), and between speed and perceived accuracy of the technology (theme 4). A further consideration was greater anxiety with longer waits for results:

...if I go and do my test I will be thinking I need to know like now or in one or two days, if not I will be starting to think, oh god maybe I've got something, innit?
(N, 22-23-year-old man)

Often, interviewees assumed that the testing device and online care pathway would be easy to use, though some expressed concerns about operating the device or completing lengthy online forms, emphasising the importance of ease of use.

Theme 3: Privacy

Interviewees discussed how they valued privacy in relation to their sexual healthcare. They used the word 'private' to refer to: concealment of sexual healthcare use and STI diagnosis; avoidance of face-to-face interactions in sexual healthcare; and confidentiality and data security. These sub-themes are discussed overleaf.

Concealing use of sexual healthcare and STI

Some male interviewees, in both age-groups, explained how they did not mind others discovering their use of sexual healthcare, for example:

I don't really care what people think of what I am doing, I just go and get myself sorted out and just leave.

(S, 18-19-year-old man, describing clinic attendance)

However many, including all of the female interviewees, spoke of wanting to conceal their sexual healthcare use from family and peers, as it suggested or revealed possible STI, risky sexual behaviour or that they were sexually-active. Sexual health clinic attendance was

...like announcing yourself, that "yeah, I'm [sexually] active." [...] ...and it's not just the fact that you're letting people know you're [sexually] active, it's the fact that you're letting people know that you're active and there's a possibility that you've got something.

(Y, 20-21-year-old man)

Thus, stigma related to sex and to STI was a barrier to using sexual health clinics (further discussed below). To avoid this, interviewees described how they might use clinic in '*discreet places far away from home*' (F, 16-17-year-old woman), use internet-based home-sampling, or attempt to enter sexual health clinics without being seen by people in the street:

...when you get outside you've kind of got to look around and make sure no one sees you and then quickly run in there.

(B, 18-19-year-old woman)

She described taking these precautions despite recognising, as interviewees typically did, that

...going to the clinic is the right thing, but you know, you don't really want people knowing what you're up to...

Young women expressed particular concern about the conclusions others might draw about their sexual activity. Interviewees of both genders selected female examples to illustrate the social consequences of being known to use sexual healthcare. This further indicated the possible greater stigma associated with sexual activity, for young women.

...even if she did, even if someone did go for the test, the first thing they will think is, "what would people say?" (D, 20-21-year-old woman)

...you can just say like, "I saw Jane yeah, at the clinic getting tested, it's possible she, I think she's probably got like chlamydia or something" and then nobody wants to go with Jane anymore, because like you don't want to catch anything... (Y, 20-21-year-old man)

If I hear a girl's gone to the clinic then she must obviously be a dirty girl, but that's sort of like, erm, that's the way I used to think sort of thing...

(W, 18-19-year-old man)

The local young people's contraception and sexual health clinic was mentioned. Conspicuous in its absence from interviewees' accounts was any mention of how attending such a service did not necessarily mean a person was testing for STIs.

Interviewees welcomed the perceived greater ability they would have to conceal their STI testing by using a self-test (although there were concerns about how concealable the test device itself would be). However, some concerns were expressed around the presence and visibility of electronic evidence of STI testing on the phone, for instance an app installed on the phone. Related to this point, there was great variation between interviewees in how privately they described keeping their phones: '*no one's really going to look at your phone*' (G, 18-19-year-old woman), versus '*youth nowadays, yeah, we always have each other's phones*' (Y, 20-21-year-old man).

Unsurprisingly, it was important for interviewees to be able to keep an STI diagnosis secret, if they tested positive. With the proposed intervention, they discussed how not only the results message, but an 'e-prescription' and other messages (e.g. text message reminders to collect treatment) could reveal their STI status, if seen by others. Similarly, preferences for treatment access (collection from community pharmacy using an 'e-prescription'; or received by post) reflected privacy concerns:

I don't like going to the [sexual health] clinic and coming out with prescriptions to be honest with you, but pharmacy, that's what they're for.

(G, 18-19-year-old woman, previous STI diagnosis)

Receiving treatment by post was perceived as more convenient, but slower than pharmacy, with implications for privacy dependent on living arrangements:

...post is alright too, but then again, because I don't live by myself, I live with my parents. Then, my mum sometimes likes to open my letters.

(I, 20-21-year-old woman)

Avoiding face-to-face contact

Some interviewees described how concerns about being recognised by staff had influenced their STI testing behaviour, and some of those with experience of sexual health clinics described embarrassment around giving a sexual history face-to-face. Regarding self-testing and providing information online:

I would rather that 'cause there's not no one in front of me like talking to me or looking at me...

(C, 18-19-year-old woman)

However, others expressed little concern for this aspect of privacy.

Confidentiality and data security

Concern about the confidentiality of the proposed service was rarely mentioned until prompted by the interviewer,^{vii} perhaps suggesting that the within the broad topic of privacy, the sub-themes discussed above (concealing sexual healthcare use and STI; avoiding face-to-face contact) were more important to interviewees. Alternatively, perhaps interviewees assumed such a service to be confidential, as did this young woman, who explained how she:

Automatic thought it would be like that. It should be anyways. [...] Just because, them things, certain things should be confidential anyways with that, so without saying, cos that's your personal life.

(A, 16-17-year-old woman)

^{vii}During the interviews, participants were asked their understanding of 'confidentiality'. Despite the interviewer's explanation during consent-taking, several could not define the term or misdefined it as confidence, e.g. self-confidence or confidence/trust in healthcare. Participants tended to use the broader term 'private' to describe how they wanted their information to be held, and services to be delivered. I use the standard definition of confidentiality, rather than how participants used the term.

Contrasting with the sub-themes discussed above, for which interviewees discussed strategies to protect their privacy (by their choice of services, or how they used them), interviewees did not discuss how to find out whether, or how to ensure that, a health service was confidential. This again suggests that confidentiality was assumed, or considered to be outside of individuals' control.

During the interview, the interviewer explained that with the proposed intervention, users would provide registration information prior to testing. The confidential but not anonymous nature of the service was accepted, with varying degrees of reluctance, on the basis that the NHS was trusted (see theme 5) and personal information was required to provide any necessary treatment, for one's own benefit. One of the more reluctant interviewees to accept this, explained:

*...you can't win them all. I think you just, I think you just have to succumb to that one and just like accept that you know what I need to make sure that I'm getting checked properly. I mean I've won the fact that I'm not talking to a human being, yeah? I'm talking to the device, yeah?
[...] ...because if you think about it yeah the NHS knows so much about you anyway [...] they have medical history on everyone.*

(Y, 20-21-year-old man)

There was variation in the extent to which interviewees trusted their smartphones and the internet, with regard to data security and confidentiality. Passwords and information to assure users that the app/website was secure, were discussed as making users more confident about this aspect of privacy (see also theme 5).

Theme 4: Capabilities and limitations of the proposed technology

Interviewees expressed some concerns about the prospect of self-testing and proceeding to treatment without professional, human assistance.

Accuracy of the novel, self-operated testing technology (also a sub-theme of Theme 5: trustworthiness)

As discussed (theme 2: speed), some interviewees expressed concern that a very rapid test could give an inaccurate result (while other interviewees perceived the self-test to be as accurate as clinic-based testing). Views on self-testing with novel technology, compared to 'experts' testing samples with established technology, were also diverse. For some interviewees, '*a result is a result*' (S, 18-19-year-old man), assumed to be accurate; they reasoned that clinics also tested urine, stored results on a computer, and with such an important purpose the testing device would have been checked prior to release. However, others questioned the accuracy of results from self-tests. As well as the speed of a rapid test, two further sources of doubt were identified: the novel technology and self-operation:

...this is still new. It has still little kinks to be found, little things to be found. Whereas the clinic is established, they are doing it there and then. But the longer it is out, the more confidence I would get in the technology.

(V, 18-19-year-old man)

...the clinic, doctors, they're more professional. That's exactly what [people] would think because that's what I would think as well but I would still put trust in my phone.

(X, 16-17-year-old man)

X then went on to contradict himself, suggesting some uncertainty: '*I'd rather get it off the doctor, cos your phone could come back inconclusive.*' Even some of those who said they would trust results from self-tests, described that they might test repeatedly or confirm self-test results by testing in clinic, to allay concerns about accuracy.

Interviewees often seemed not to have questioned the accuracy of clinic-based tests, until the interviewer asked them whether they would trust results from the new test. However, they explained that the accuracy of results was extremely important, for example:

...just don't let it go faulty [...] That's the most important thing in the whole wide world.

(F, 16-17-year-old woman)

Provision of personal and emotional support

There was a tension between interviewees' preferences for avoiding attending healthcare settings and avoiding face-to-face contact with healthcare professionals – for reasons of convenience, speed and privacy, themes 1-3 – and a desire, expressed by some, for contact with a healthcare professional if a positive result were received. Often this was related to anxieties which interviewees explained might not be addressed through an online service. This was the case for this man, who initially said he would attend clinic if he tested positive, because:

...I will be having thoughts running in my head, so I wouldn't even have time to go through the link [to access treatment] cos I think there would be tension and pressure on me, so, yeah. (P, 22-23-year-old man)

A telephone helpline was considered an acceptable way of providing this personal, human support.

If you have an infection it should give you information but it should also give you like phone numbers that you can call to talk to someone because at the end of the day I see it as, if it's something on your phone you don't really wanna read so much. But if you can talk to someone, not a computer, someone real, then you're most likely to listen.

(H, 18-19-year-old woman)

Protecting or compromising privacy

As discussed above (theme 3, privacy), the technology could enable users to conceal their sexual healthcare use and STI from those around them, but it could also reveal this information.

I wouldn't feel confident, that it's private and confidential. Say for instance you lend your friend your phone to call someone, they don't actually call the person and he's scrolling through your phone, he sees all the details that you've been doing and that, it just might expose your personal business.

(X, 16-17-year old man)

Interviewees suggested technological strategies for protecting privacy, for example, passwords, or:

If you said this information is not going anywhere else apart from onto the NHS database, more people will be like, 'oh okay'. And if you said it's not going to be stored on your phone, I think more people would feel more comfortable with it. (B, 18-19-year-old woman)

However, as discussed above regarding data security, some considered that breaches of privacy could not be completely prevented:

...there's no way of stopping that. That's just phones for you, that's smartphones for you. (L, 20-21 year old man)

Theme 5: Trustworthiness

Within the theme of trustworthiness, views were expressed about the accuracy of the proposed self-testing device. (The sub-theme 'accuracy of the proposed self-testing device', discussed in theme 4, also applied within theme 5).

Basis in the NHS

The perceived legitimacy of the proposed service was enhanced by its basis within the NHS:

That it's part of the NHS? It makes me feel safe, it makes me feel okay, because like NHS are there to help us innit, like they're there to help, to support us. (T, 20-21-year-old man)

If it wasn't a part of the NHS I'm more likely not to do it because it's what would it involve, what would it be a part of? Erm, it could just be a scam... [...]...making it a part of the NHS, I feel more comfortable.

(B, 18-19-year-old woman)

For others, however, a basis in the NHS made little difference provided the service was private and confidential.

5.4.3 Partner notification, the code for partners and epidemiological treatment

These topics were difficult for participants to engage with. For this reason, results are presented here in a separate section, and were omitted from the journal publication of this chapter. Interviewees (several of whom had not previously heard of PN) grasped the concept of PN rapidly, from the

interviewer's explanation, and agreed that it was important. However, asked whether they would forward the message to a partner, or use the link to access the online care pathway to treatment if sent it by a partner, some were apparently unable to give a response, or changed the views they expressed as they spoke. When understood, it was sometimes considered helpful, primarily because it helped the partner:

...it's giving obviously bad news, but it's giving you a way out sort of thing...
(W, 18-19-year-old man)

Varied views, and some concern, were expressed with the concept of epidemiological treatment (see glossary), which affected how the message for partners was perceived. This made the latter difficult to explore in the interview. Some expressed that 'treatment without testing' was appropriate, given the likelihood that sexual partners are both infected, however others considered this inappropriate or possibly harmful, as this interviewee suggested:

If you're only taking medication [without testing] it is either going to – you don't know if it is making what you have worse, or better. So it's better to get a test and then you get the treatment... (D, 20-21-year-old woman)

For these interviewees, the alternative was to test first, and only to take treatment if infected.

5.4.4 Interviewees' views on using the proposed intervention

All interviewees discussed that they and/or their peers would be more likely to test for STIs, and to do so more frequently, if self-testing were available, although the availability of sexual health clinical services and experts remained valued. Their enthusiasm for self-testing within online care pathways was captured in the following comment to the interviewer:

Just get it done quicker, just get it out there fast. Cos it sounds good, so it should be out there. (L, 20-21-year-old man)

5.4.5 Implications for intervention development

I derived the following recommendations from the interview data (Table 24).

Table 24: Development of STI self-testing within online care pathways: recommendations

Theme, sub-theme	Recommendations for development of testing device	Recommendations for development of the online care pathway
1: Ease and convenience	The device should be easy to use.	The amount of information users need to input should be kept to a minimum. ^a
2: Speed	The test should give results faster than conventional services, but not necessarily very rapidly. ^b	
3: Privacy		
Concealing use of sexual healthcare	The self-testing device needs to look inconspicuous (size, appearance).	The content and sender name of electronic messages (e.g. text messages, emails) should make no reference to STI testing or sexual healthcare use. An app downloaded to the phone may compromise privacy, so alternatives should be explored.
Concealing evidence of STI	The design of the device should enable users to keep all evidence of STI secret (e.g. results message).	The design of the care pathway should enable users to keep all evidence of STI secret (e.g. result, prescription, treatment). There was no consensus about whether treatment should be provided by post or collected from community pharmacy. The convenience and discretion of postal receipt of treatment was preferred by some, while others preferred the speed and privacy (from household members) of collecting treatment from a pharmacy. Privacy from household members was particularly important for young people living at home.
Avoiding face-to-face interactions		Within this intervention, a digital interface and minimal face-to-face contact with health service staff is preferred. ^c

<i>Table 24, continued</i> Theme, sub-theme	Recommendations for development of testing device	Recommendations for development of the online care pathway
<i>Confidentiality and data security</i>	It should be clear to users that the service is part of the NHS.	It should be clear to users that the service is part of the NHS. Confidentiality should be assured.
4: Capabilities and limitations of technology		
<i>Accuracy of the novel, self-operated testing technology</i>	Accuracy of results is very important. Accuracy is a concern with self-operation of novel testing technology (ways to increase confidence in the accuracy of the device, and minimise wasteful repeat-testing, need further exploration).	
<i>Provision of personal and emotional support</i>		Optional support from a health professional should be available. ^d Given the concern for privacy and convenience, this could be by telephone.
<i>Potential of technology to protect or compromise privacy</i>		Confidentiality should be assured. Passwords, assurances that the system is secure, and legitimacy (above) aid trust in data security.
5: Trustworthiness		
<i>Basis in the NHS and association with medical professionals</i>	It should be clear to users that the service is part of NHS sexual healthcare.	It should be clear to users that the service is part of NHS sexual healthcare and relevant measures to protect confidentiality apply.

^aThis needs to be balanced with clinical and disease surveillance requirements. ^bDiverse views were expressed, with some perceiving a very fast result to be less accurate. ^cWhere medically-appropriate for individuals, and with optional access to face-to-face clinical services. See also 'Provision of personal and emotional support'. ^dThe need for a helpline, from a clinical perspective, had already been established, but this research confirmed its importance to potential users and its role in providing emotional support.

5.5 Discussion

5.5.1 Main findings

A novel proposal for remote online self-testing and treatment for STIs was broadly acceptable to these ethnic-minority young people from a high-prevalence population. In deciding whether to use existing STI testing services, and considering self-testing, interviewees appeared to balance three main factors: speed, convenience and privacy. Remote self-testing was perceived to maintain privacy by reducing the risk of peers and family members discovering their use of sexual healthcare, through avoiding sexual health clinic attendance, and by avoiding potentially embarrassing face-to-face consultations. By reducing these privacy concerns, and facilitating access to testing, interviewees expressed that they might be more likely to test, or test more often, if remote self-testing were available.

New privacy concerns with this intervention concerned electronic evidence of sexual healthcare use or STI diagnosis visible on their phones, online data security, and postal provision of treatment. Interviewees described ways they could manage these risks, and how intervention design could assist with this, but some considered risks to online data security inevitable. Enthusiasm about the novel technology contrasted with some interviewees' doubts about the accuracy of a new, rapid, self-operated test, while the accuracy of conventional testing was not questioned.

Several interviewees' discomfort with sexual health consultations contrasted with their anticipated needs if they received a positive result or had particular concerns: to seek personalised support from healthcare professionals. The trustworthiness of remote self-testing and online care, including data security, was enhanced by its association with healthcare professionals and trusted NHS services.

5.5.2 Strengths and weaknesses of this study

As discussed (in chapters 1 and 3), formative research with potential users is important in the development of complex e-health interventions, and

particularly this one, which will be used remotely from healthcare professionals and health settings. As well as informing an understanding of perceptions and acceptability of the proposed intervention, specific recommendations for its development have been generated (Table 24). Several of these were supported (and none were contradicted) by related formative research.^{1,2}

As this study took place prior to the availability of the STI self-testing device and operational online care pathways, it relied on interviewees' ability to understand and engage with the hypothetical, novel intervention. To make it less abstract, a study population was chosen among whom the concept of STI testing was likely to be familiar, and the interviewer showed an animation to help describe the planned intervention. I decided against restricting recruitment to people with previous STI testing experience or STI diagnosis, as I sought to include those who test infrequently or not at all, who may experience more barriers to testing via existing services. Despite the hypothetical topic, the qualitative interviews generated rich, detailed accounts of perceptions of smartphone-enabled self-testing. Although only two interviewees disclosed having been treated for an STI, all engaged well with the concept of treatment via an 'e-prescription'. However many interviewees found provision of treatment to partners difficult to engage with, perhaps because this topic was far from their personal experience and particularly abstract. Most had no experience of STI, awareness of PN was poor, many were sceptical about the concept of taking treatment without having been diagnosed, and furthermore their views on the topic were dependent on the imagined partner(ship) and context of exposure. It was therefore difficult to discuss PN hypothetically, and still more so, to discuss a novel means of facilitating partners' access to treatment.

This study engaged effectively with a target audience. The demographic profile of our interviewees is intentionally close to that of those considered at elevated risk of STI, based on their age, ethnicity and recruitment from an urban, socioeconomically-deprived population;²⁸ thus a key target group for provision of STI services, for reasons of equity and public health need. It has been

somewhat more difficult to engage young men with STI screening,⁴¹⁷ and this study benefits from a strong sub-sample drawn from this group. However, men who have sex with men (MSM), another important risk group for STI, were not targeted for recruitment to the current study, because in this educational setting we did not wish to compromise the privacy of those not 'out' to their classmates. Recruitment of exclusively non-White interviewees (Table 23) was unintentional, largely reflecting the location and student population. (Some White students were approached, but declined participation, with reasons unknown.) The sampling quota for women aged 20-24, of 6-8 interviewees, was not filled (n=2), with implications for analysis and interpretation. My findings suggest a gender difference in the importance of concealing use of sexual healthcare, but this may also be influenced by female interviewees' young age profile, compared to males'. This was the only clear difference between men and women's expressed views in relation to the study topic (and there were no clear differences between age-groups), but had a stronger sample been achieved, I could have explored age-group and gender differences further.

An interviewer and interviewees' shared or different characteristics can influence qualitative interview data and analysis.³⁵¹ However data quality is not necessarily considered to be compromised by having a non-peer interviewer^{418,419} (e.g. a male interviewing females). In this study it is encouraging that although the same male interviewer, in his thirties, conducted all of the interviews on this sensitive topic, these young interviewees of both genders discussed their views and experience of sexual healthcare use freely, and the two who disclosed a previous STI (without prompting) were both female. We did not seek interviewees' comments on the transcripts, which could have increased data quality; it can be problematic to re-contact transient populations such as students in relation to research on a sensitive topic.⁵⁶ However both the interviewer and I checked the transcripts against the audio-recordings. There are potential advantages to multiple researchers/interviewers within one qualitative study,⁴²⁰ including being able to discuss findings with someone who knows the study and the data intimately,

which I did in order to enhance the analysis. (Further reflections on the unusual interview context are provided in section 5.5.5, p218).

Those interviewed, who chose to participate in a study about sexual health, may be particularly comfortable with STI testing and/or sexual healthcare. However some had little experience of testing, and some discussed their dislike of existing services, so it is unclear what effect this may have had on the data. Non-participants' privacy concerns may be greater than those discussed by interviewees, who chose to participate in an interview where they discussed sexual healthcare face-to-face. Interviewees' reflections on their reasons for participating (Appendix 7g) include diverse and credible motivations, suggesting that the £15 token of appreciation did not unduly influence participation.

Steps taken to reduce social desirability bias have been explained, but this study's premise that STIs are a problem, which can possibly be addressed through new services, was evident in information provided to interviewees. This may have prompted criticism of existing services, perhaps to justify not having tested as often as they felt they 'should' have done. However, interviewees' views on existing services reflected those identified in the literature,^{139,141,145-147} and all interviewees expressed both positive and negative views about aspects of the intervention, indicating critical engagement.

5.5.3 Discussion of study findings in comparison with other research

Until this study, no other research had explored the acceptability of remote STI self-testing linked with online care pathways. However, this proposed intervention does include some elements that have undergone limited evaluation in other studies. Qualitative research with US young women (conducted 2007-08) reported reservations about internet-use in relation to STI testing, including online privacy and data security concerns, and lack of personal support,³⁷¹ which feature far less in findings reported by similar qualitative research among Canadian young people.²⁹⁰ This study echoed similar findings concerning desire for support from healthcare professionals

following a positive diagnosis. Although privacy from peers and family was discussed as important by most interviewees (related to preferring to self-test instead of attending a sexual health clinic, preferring discreet messaging, and preferring not to receive treatment by post), online privacy/confidentiality and security provoked fewer concerns. This possibly reflect this study's interviewees' smartphone ownership (enabling more private internet access compared to, e.g., a shared home computer), their familiarity with 'the online', and the confidence in the NHS which they described. In the study by Bracebridge *et al.* (described in chapter 2, p114), 131 participants testing positive for chlamydia received treatment remotely, with 95.4% of them receiving it by post and the remainder, collecting treatment from a pharmacy. This contrasts with what my findings suggest, and unlike the current study, Bracebridge *et al.*'s study measured the behaviour of people who had actually been diagnosed with chlamydia. However, unlike users of the proposed self-test, these people had used a testing kit which they had received by post, therefore perhaps privacy from household members was not so important for these people or they had found ways to receive and open packages discreetly.

Similarly to the findings reported here, other internet-based STI testing services (internet-ordered home-sampling,^{371,372} downloadable laboratory requisition forms,^{290,292} see chapter 2), and self-testing for HIV,⁴²¹ have been perceived positively for their convenience and privacy. US clinic-attenders' views (discussed in focus-groups, 2008-09) on rapid home self-tests for STIs include concerns regarding accuracy and self-operation, and non-immediate access to treatment access.³⁷⁰ A US survey on the acceptability of home-sampling chlamydia and gonorrhoea among sexual minority youth found similar concerns about test accuracy with self-sampling⁴²² as I found with self-testing. Others have found that STI-related stigma was associated with girls' negative perceptions of disclosing sexual behaviour in a sexual healthcare context, but not boys',¹⁶⁵ similar to the gender difference I found.

Since my interviews took place, another eSTI² PhD student conducted a Discrete Choice Experiment (DCE) exploring attributes of the proposed intervention, and

found that young people had a particularly strong preference for accurate and rapid results.⁴²³ Research on unsupervised HIV self-testing has also revealed that users have concerns about the accuracy of self-tests and about the availability of counselling⁴²¹ and linkage to care in case of a positive result.⁴²⁴ These findings echo those of the current study, in which interviewees expressed concerns around accuracy of the novel, self-operated test, wanted support to be available, and valued linkage to treatment for those testing positive.

5.5.4 Meaning and implications

Findings suggest that remote self-testing and online care pathways, as described here, would be acceptable as a complement to existing STI services, provided that personal support from healthcare professionals is available to those testing remotely, and accuracy concerns are addressed. This research has informed intervention design, and has identified concerns that can be addressed, or need to be explored further. By reducing or removing barriers that participating young people associated with conventional STI testing, findings suggest that this complex intervention may enable earlier detection and treatment of STIs. This could benefit public health, through reduced STI transmission and reduced complications of infections. Remote STI testing may therefore be a useful adjunct to our repertoire of STI services, ideally integrated within online clinical pathways embedded within existing sexual healthcare provision.

In addition to findings from this (and other) formative research, intervention design must also take account what is technically possible, clinical safety, and public health concerns. In the development of the proposed intervention, it is important to recognise that young people may desire to keep secret not only any STI diagnosis/es, but their sexual healthcare use. Regarding 'evidence' of sexual healthcare use on users' smartphones, care needs to be taken regarding name of the sender and wording of text messages, while web-apps (which are not downloaded and installed to users' phones) are an alternative to 'native apps' (which are). NHS branding may confer trustworthiness. For speed and privacy from household members, collection of medication via 'e-prescription' from community pharmacies may be more suitable than postal treatment in this

young population, depending, of course, on the STI and the nature of the recommended treatment.

Innovations in sexual health clinics, such as ‘no-talk’ testing with registration and clinical information provided on paper or electronic forms (e.g. touch-screens),^{109,110,425} may already meet some of young people’s access and privacy needs. However, privacy from peers and family was a primary concern, and seeking sexual healthcare ‘in public’ threatened this. Co-location of GUM and contraceptive services has been suggested to reduce the stigma associated with using GUM services,¹⁴¹ but barriers remain for those who seek to conceal that they are sexually-active. My findings suggest that by removing the need to attend sexual health clinics (for many patients), our proposed intervention may further overcome barriers to sexual healthcare use, resulting in earlier detection of STI. Provided users are able to use the care pathway to access treatment promptly, public health benefits could result from decreased STI transmission and decreased complications of long-term infection.

Change to the proposed intervention since this study took place

Since these interviews, the proposed intervention has been envisaged slightly differently to how it was explained to interviewees. It is not certain that the device would communicate by the phone, but it might instead be ‘read’ by the users’ phone (using the phone’s camera and appropriate software). Unchanged details include: having a testing device which requires online registration before use, and receipt of results on users’ phones. It seems unlikely that this possible change would affect the overall acceptability of the intervention to users.

5.5.5 Reflections on researcher’s role and research conduct

Several issues that affect this study arose from my absence during piloting and data collection, and the conduct of interviews by another researcher. First, there was a risk that I would not achieve sufficient ‘immersion’ in the data than if I had done the interviews myself, potentially affecting the quality of my analysis. I addressed this through thorough familiarisation with the data (as described, p195). Second, I was not available to comment on the final topic guide, though I

agreed in principle to changes made by the interviewer in response to feasibility considerations and interview piloting. (These were: not to use STI testing experience as a sampling criterion, since this information could not ethically be obtained prior to consent to the study, and was difficult to dichotomise given generally high rates of previous testing among the students; use of the animation, see Methods). Third, I analysed the data after the end of data collection, which limited the extent to which I could explore my initial findings in greater depth in subsequent interviews. However, the topic guide changed little during data collection, reflecting the well-defined interview topic. Finally, the interviewer's and colleagues' familiarity with the data presented an opportunity for me to review my independently-generated findings with them (section 5.3.7). This process was less systematic but more comprehensive than second-coding a sub-sample of interviews.

On my return from maternity leave I decided not to conduct further interviews myself. This would have strengthened the sample, but were I only to interview White students and 20-24-year-old female students, it would be difficult to distinguish differences between demographic groups from the effects of having a different interviewer (and these effects are not well explored in qualitative research methodology⁴²⁶). Differences in interviewer style may have particular influence on the discussion of sensitive issues⁴²⁰ such as sexual health. The interviewer, my colleagues and I observed a high level of saturation in the existing dataset. The additional effort of interviewing additional students (perhaps including interviewees in well-sampled categories to allow between-interviewer comparisons), timing, needs of the wider project and logistical issues contributed to my decision not to conduct further interviews. Care pathway development had begun already, and there would be delays inherent in re-establishing relationships with the college and advertising the study to a new cohort of students. It seemed better use of my time and research resources to plan the next qualitative study (chapters 6-7) in which sampling limitations of the current study could be avoided, and the limitation of 'imaginability' of the intervention did not apply, since interviewees would have experience of online care.

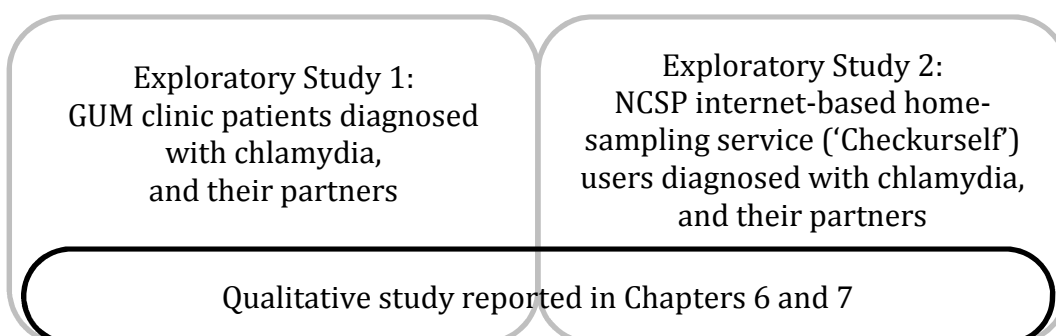
On reflection, I could have conducted the analysis more efficiently. I did not code the interview data by the stage of the care pathway being discussed. Lack of such an 'index' meant that I could not easily locate all the data excerpts about (for example) the self-test, or about PN. This made the analysis unnecessarily laborious (although I do not consider it to have affected the quality of the analysis). For these reasons, because of the larger dataset, and the need for a more transparent process to facilitate second-coding, I chose to use Framework³⁸⁶ for data management in the next qualitative study that I undertook (chapters 6-7). Limitations in the sample for this first qualitative study were also addressed in the second qualitative study.

Chapter 6: Qualitative interview study about use and appeal of the Online Chlamydia Pathway: Aims, Methods and Sample

6.1 Introduction

eSTI² Consortium colleagues developed the Online Chlamydia Pathway (OCP), the UK's first online clinical management pathway for any STI, or indeed any acute bacterial infection, within the NHS. To date, the OCP is experimental, and was piloted in Exploratory Studies, in which it was evaluated quantitatively to obtain preliminary evidence of acceptability, feasibility and safety.⁹ I conducted qualitative research to develop an understanding of the experience of using the OCP, and its appeal (chapters 6-7). My qualitative study was nested within the two Exploratory Studies^{viii} (Figure 14) which took place with people requiring chlamydia treatment, who opted to use the OCP to obtain this treatment.

Figure 14: One qualitative study nested within two Exploratory Studies



This chapter describes the aims, methods and sample of my qualitative interview study (results are presented and discussed in chapter 7), and relevant methods of the Exploratory Studies from which I recruited.

[To avoid confusion, in chapters 6 and 7 I refer to people who took part in the Exploratory Studies as 'participants', and those among them who took part in my qualitative study as 'interviewees'.]

^{viii} A third Exploratory Study also took place. Over the same period, this study piloted the OCP's results service among 1936 people who tested chlamydia-negative via the same NCSP internet-based home-sampling service (Checkurself). It is not discussed in my thesis because its participants did not use the Online Chlamydia Pathway and were not part of my research.

The OCP was designed to support patients from receipt of results, through to treatment and PN for those diagnosed with genital chlamydia, and to support patients' partners to access treatment.^{9,427} It did not include testing. A detailed description is provided later in this chapter. Briefly, after testing, users received a text message to inform them that their results were ready. They then logged in to receive their chlamydia results, and if positive, they could complete an online automated medical consultation (consisting of a series of fixed-response questions), to check the safety and appropriateness of standard antibiotic treatment. If clinically-appropriate, they could collect this treatment from a nominated pharmacy – potentially, without any face-to-face or telephone contact with health professionals, or attendance at healthcare settings, until this point. Access to face-to-face medical care was facilitated for people for whom remote management was inappropriate (e.g. those with certain symptoms indicating that they required examinations or further investigations), and for those allergic to the standard medication. A helpline was available throughout, for all OCP users.

6.1.1 Rationale for the Exploratory Studies

In the UK it is routine for sexual health services to communicate STI test results by text message (see chapter 2), automated telephone line^{428,429} or telephone call. However, whether patients would be willing and able, after accessing results online, to use an online clinical care pathway for chlamydia management, was unknown. The Exploratory Studies tested this by offering remote online care (the OCP) to people diagnosed with chlamydia following testing in conventional services, and their partners.

Chlamydia is the exemplar STI for this thesis (justified chapter 1, p62). Specifically for this study, chlamydia was an ideal candidate for 'proof-of-concept' of remote online treatment for STIs, since it is commonest among young people²⁸ whose smartphone ownership and internet use is high,^{208,214} and current clinical guidance recommends that most cases can be treated with one oral dose of a well-tolerated antibiotic, azithromycin.^{47,430} Young people

also tend to have few other medical conditions, and tend not to be taking other prescription medications.

Until the OCP, which has only been implemented in this research context, there has been no online access to STI treatment through the NHS. Outside the NHS, patients can purchase chlamydia treatment through online pharmacies, but this is problematic for reasons noted in chapters 1 and 2 (including: inappropriate treatments, lack of clinical follow-up or health promotion). In contrast, the OCP is compliant with UK regulatory, professional and prescribing guidance, and Public Health England's surveillance data requirements.⁹

6.1.2 Opportunity for qualitative exploration of Online Chlamydia Pathway use, in the context of remote, internet-enabled self-sampling

The two Exploratory Studies provided an opportunity to explore qualitatively the use and appeal of the OCP in groups with different experiences of testing (Table 25). The Exploratory Study among users of an NCSP internet-based home-sampling service ('Checkurself') was of particular relevance to informing an online care pathway for potential use with a future self-test. As noted in chapter 2, internet-based postal home-sampling services such as Checkurself are the closest currently-available service to self-testing for STIs within the NHS: users access testing online and self-sample remotely from health services, but post their sample back to a laboratory for testing. Therefore the population and/or context of testing may be similar to that of users of a future self-test, and views and experiences of the OCP may be potentially transferable to a self-testing context.

Table 25: Comparison of the process of STI testing among GUM patients and among Checkurself users

	GUM patients*	Checkurself users
Access to testing	Attend clinic	Online, request home-sampling kit, receive it by post
Provision of registration and other personal information	Paper or electronic form, in clinic, prior to face-to-face consultation and determination of what samples need to be taken	Eligibility for home-sampling checked online (locality, age); paper form provided with home-sampling kit
Clinical consultation?	Yes, face-to-face, with a healthcare professional	None
Physical examination?	For some patients, depending on symptoms disclosed	None
Biological samples	Blood sample taken by healthcare professional; vulvovaginal/anorectal/oropharyngeal swabs may be self-taken; urine self-taken	Self-taken urine sample
Infections typically tested for	Chlamydia, gonorrhoea, syphilis, HIV (additional infections, for some patients)	Chlamydia (in some localities, gonorrhoea too)
How does the patient/user submit samples to the lab?	N/A (dealt with by clinic staff)	By post, in prepaid envelope
Time to results	Approx. 7 days ⁴³¹	5-14 days ⁴³²

**Typical care for patients in study GUM clinics at the time of the study. As noted in chapter 1, some clinics offer a service without a consultation for some patients. Some also make self-sampling kits available, for patients to take away.*

6.2 Description of the Online Chlamydia Pathway

6.2.1 Overview

The Online Chlamydia Pathway (OCP, Figure 15) encompassed the multiple routes that patients could follow from receiving a text message allowing them to access their result online, to completion of clinical follow-up, after treatment.⁴³³ It included offline elements and managed routes to clinic/GP for some patients (described below and in Figure 15).

6.2.2 Role of the previous qualitative study in OCP design

Relevant recommendations from chapter 5's study⁶ (Table 24, p210) were applied by colleagues, alongside recommendations from other formative research,^{1,2,4,5} taking into account what was feasible, medically safe and appropriate. I was not directly involved in the OCP's design.

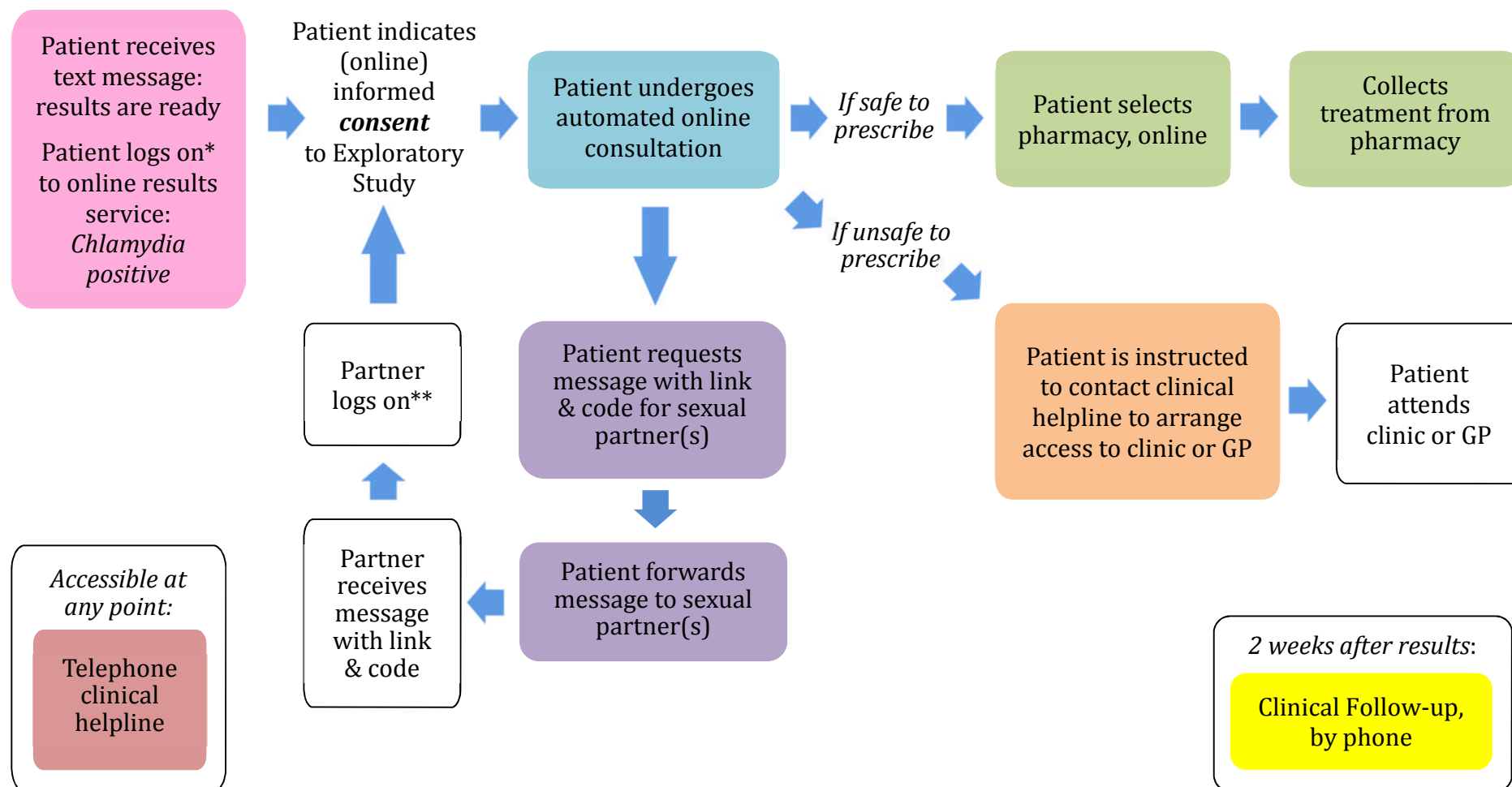
6.2.3 Description of the Online Chlamydia Pathway

Figure 15 shows the OCP. Patients received a text message informing them that their results were ready, and logged in using their date of birth and clinic number or mobile phone number. Those who received a positive chlamydia result (**pink box** in Figure 15; Figure 16a), were presented with basic information about chlamydia and its treatment, with links to further online information. They were offered the opportunity to proceed online (via the OCP), or seek treatment through conventional services (GUM, GP). Consent to Exploratory Study participation was sought, online, at this point, and was a condition of proceeding via the OCP (details on consent and eligibility to the Exploratory Studies are provided in section 6.6.2). At any point, participants could use conventional services instead of, or in addition to, the OCP.

(Those who received negative results were provided with health promotion information, online.)

Figure 15: The Online Chlamydia Pathway: simplified diagram

Adapted from ⁸. *Chlamydia-positive patients log on with a code provided at testing, or their mobile number and date of birth (depending on recruitment route) **Sexual partners proceed similarly to Chlamydia-positive patients after logging on.



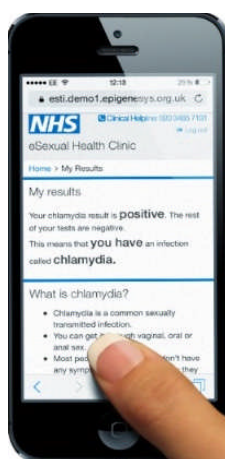
After indicating their consent to participate the Exploratory Studies, patients could proceed to the ‘online consultation’ (**blue box** in Figure 15; Figure 16b), an automated medical assessment which consisted of fixed-response (‘multiple choice’) questions about symptoms, allergies, medical conditions, demographics, and their sexual history: details about sexual partnership history and sexual behaviour. Questions were designed to:

- determine, using a clinical algorithm, whether it was safe for patients to receive standard treatment (azithromycin), remotely
- collect PN information
- conduct a risk assessment and identify other health needs.^{9,433}

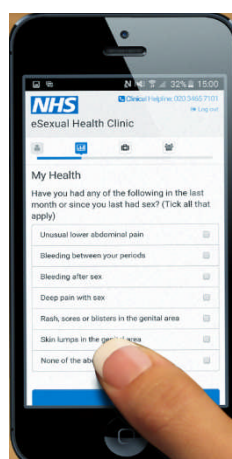
If patients’ responses indicated that it was safe to proceed online, they could then select, online, one of thirty community pharmacies, from where they would collect their treatment (**green boxes** in Figure 15; Figure 16c). This included some pharmacies which were open in the evenings and at weekends. In the Exploratory Studies, a special arrangement was in place for collection of treatment from community pharmacies participating in the research.

Figure 16: Screenshots of the OCP web-interface

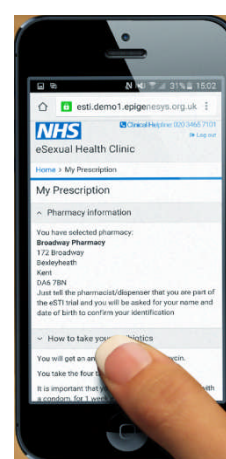
(a) online results service



(b) automated online consultation



(c) choosing a pharmacy



NB: the web-interface was optimised for smartphones and personal computers. [Unpublished image; reproduced with permission from Dr. Voula Gkatzidou.]

At any point, patients could telephone the Clinical Helpline (**red box** in Figure 15), staffed by a Research Health Adviser (RHA, see glossary), the number for

which was shown on the screen throughout. The role of the Clinical Helpline was to provide information and support regarding the diagnosis, treatment and PN, and assistance with online and offline aspects of the OCP, including facilitating access to face-to-face clinical services if desired or required.

If patients' responses to questions within the automated online consultation indicated that it was unsafe to proceed online, they could neither change their responses, nor choose a pharmacy. Instead they were instructed, online, to telephone the Clinical Helpline, to facilitate access to treatment and care through conventional services (**orange box** in Figure 15). In case they did not do so, the RHA staffing the helpline was simultaneously alerted to telephone them.

PN information was provided online, within the OCP: patients were advised to notify to their recent sexual partner(s). In addition to PN, should a partner wish to access treatment online, the index patient could request a text message or email to send their partner(s). This message contained a unique code which the partner could use to access the OCP (**purple boxes** in Figure 15) to obtain chlamydia treatment without a diagnosis (as recommended by clinical guidelines^{89,430}), and without testing. (Partners' testing is advised,⁸⁹ and could be included in future iterations of the OCP, but was not considered feasible in this exploratory research).

The RHA conducted Clinical Follow-up telephone calls (**yellow box**), to confirm that OCP users had been correctly treated, to collect patient-reported PN outcomes (whether partners had been informed of their exposure to chlamydia, treated, and related details), and to provide information and support as appropriate. (This follow-up is routine for chlamydia management.⁴⁷) Although Clinical Follow-up was largely by telephone call, text messages and email were used if the participant could not be reached this way. Participants were confirmed as having been correctly treated if they reported that they had taken treatment, had not vomited within two hours of taking azithromycin, and had had no sexual intercourse (including oral sex) within a week of treatment or with an untreated/inadequately treated partner (in line with chlamydia

management guidelines^{47,430}). The RHA followed up all participants, irrespective of how they used the OCP or how much of it they used. Clinical Follow-up could be completed, at the earliest, two weeks after results notification.

6.3 Scope of my qualitative interview study

The OCP's ongoing development needed to be informed by research with its users. Their views and experiences, as conveyed in in-depth interviews, were analysed to develop a detailed understanding of how they used the OCP, and the nature, and limits, to its appeal.

This qualitative study included the OCP's online and offline elements (rather than just the digital intervention or interface), and the wider context of care-seeking. As well as use of the 'e-prescription' from community pharmacy (remote treatment), I explored routes to clinic or GP for treatment, because for some users, this was necessary or desired, therefore it is an integral part of the OCP. Aspects outside the scope of my study are listed in Box 4.

Box 4: Aspects outside the scope of my qualitative study

• OCP design and delivery	}	Addressed by eSTI ² Consortium colleagues
• Safety and clinical care quality	}	
• Details of the digital interface	}	
• Analysis of the Exploratory Studies' quantitative findings	}	
• Costs and health economic aspects	}	
• Detailed integration of qualitative and quantitative findings	}	Planned
• Detailed exploration of partner notification		

6.4 Objectives of the qualitative study

(a) To describe how patients diagnosed with (or exposed to) chlamydia used an online care pathway to treatment and partner notification, based on views and experiences expressed in in-depth follow-up interviews.

Specifically, to:

- provide a rich description of OCP use, and contexts of use;
- identify barriers to, and facilitators of, prompt treatment;
- identify possible threats to the OCP's feasibility;
- describe the extent to which users' information and support needs were met through the OCP;
- generate suggestions for its ongoing refinement.

And secondarily, to:

- describe patients' experience of providing information online (which the OCP uses for clinical and surveillance purposes), and implications for the accuracy of these data;
- describe how the OCP supports or does not support partner notification and patients' partners' access to treatment.

(b) To develop a detailed understanding of the appeal of the OCP to its users, and the limits to this; and to offer interpretative explanations for the nature and limits to the OCP's appeal.

6.5 Approach and conceptual framework

6.5.1 Approach

I used an inductive approach, which was also informed by existing theory and evidence. Figure 17 outlines influences on the design and methods of the study, in addition to the research question.

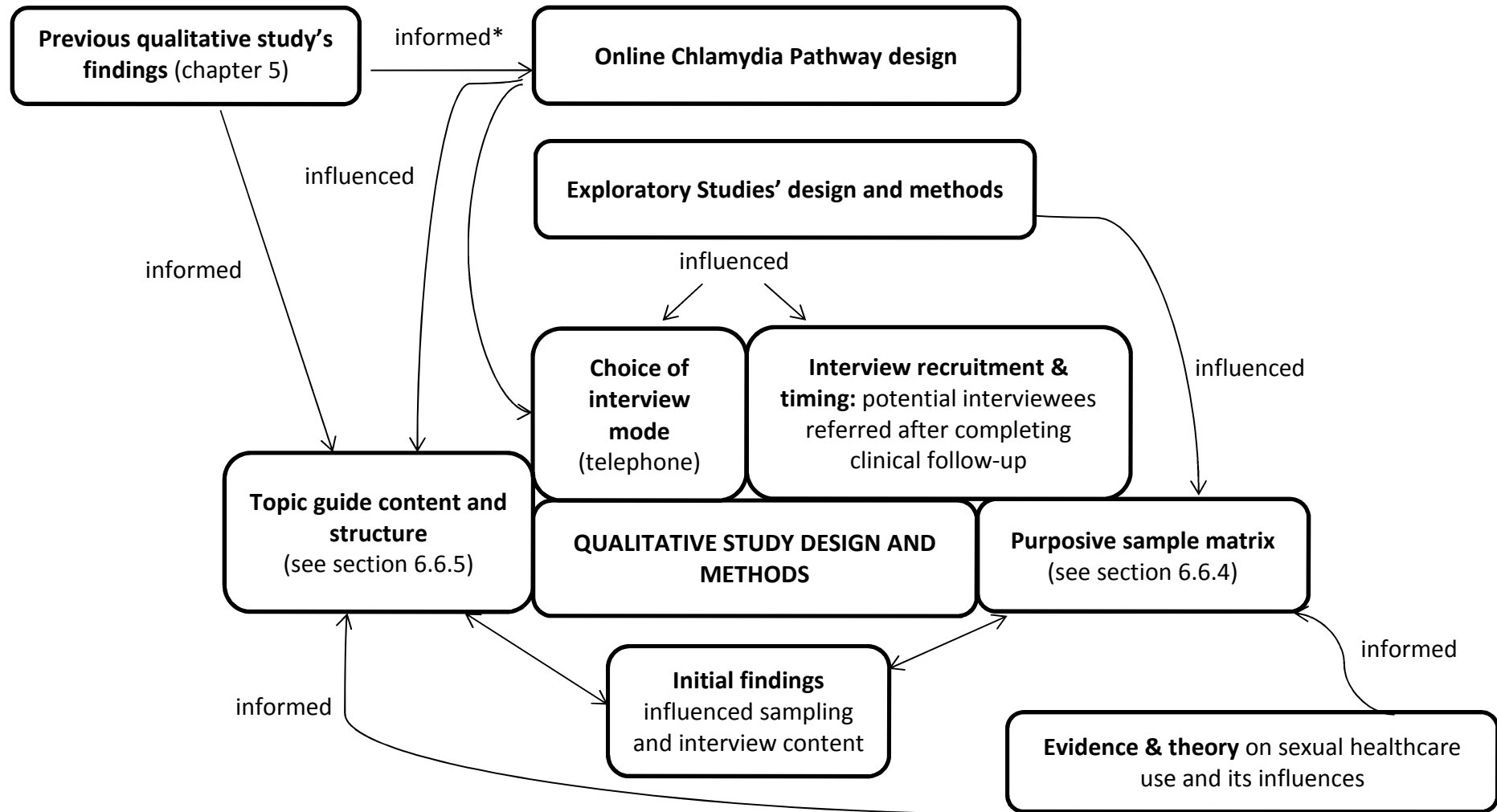
6.5.2 Relevant findings from the previous qualitative study

Acceptability and perceptions of hypothetical online care pathways for STI testing, diagnosis and treatment were explored the previous qualitative study (chapter 5⁶). In that study, interviewees were young people (aged 16-23) who mostly lacked experience of STI diagnosis and treatment. In the current study, the following findings were explored, this time based on interviewees' experience:

- The importance of **privacy** (in particular: the ability to conceal use of sexual healthcare and evidence of a positive result; avoiding face-to-face consultations), related to stigma surrounding STI, sexual activity, and use of sexual healthcare;
- Ambivalence regarding the potential for the internet and smartphone technology to protect or threaten privacy;
- A preference for **convenience**;
- An anticipated need for **support** from a health professional, following an STI diagnosis; this might conflict with preferences for convenience and privacy, thus provision of support by telephone might be acceptable.

Privacy, support and convenience were included in my topic guide. To avoid unduly influencing interviewees' accounts, these topics were explored after interviewees described their care, unless they spontaneously mentioned them. ICT issues, including usability of the digital interface and data security, were to be explored in another qualitative study (designed by Human Computer Interaction, HCI, colleagues in the eSTI² team) which did not take place, so I did not explore these issues in depth.

Figure 17: Influences on the design and methods of this qualitative study



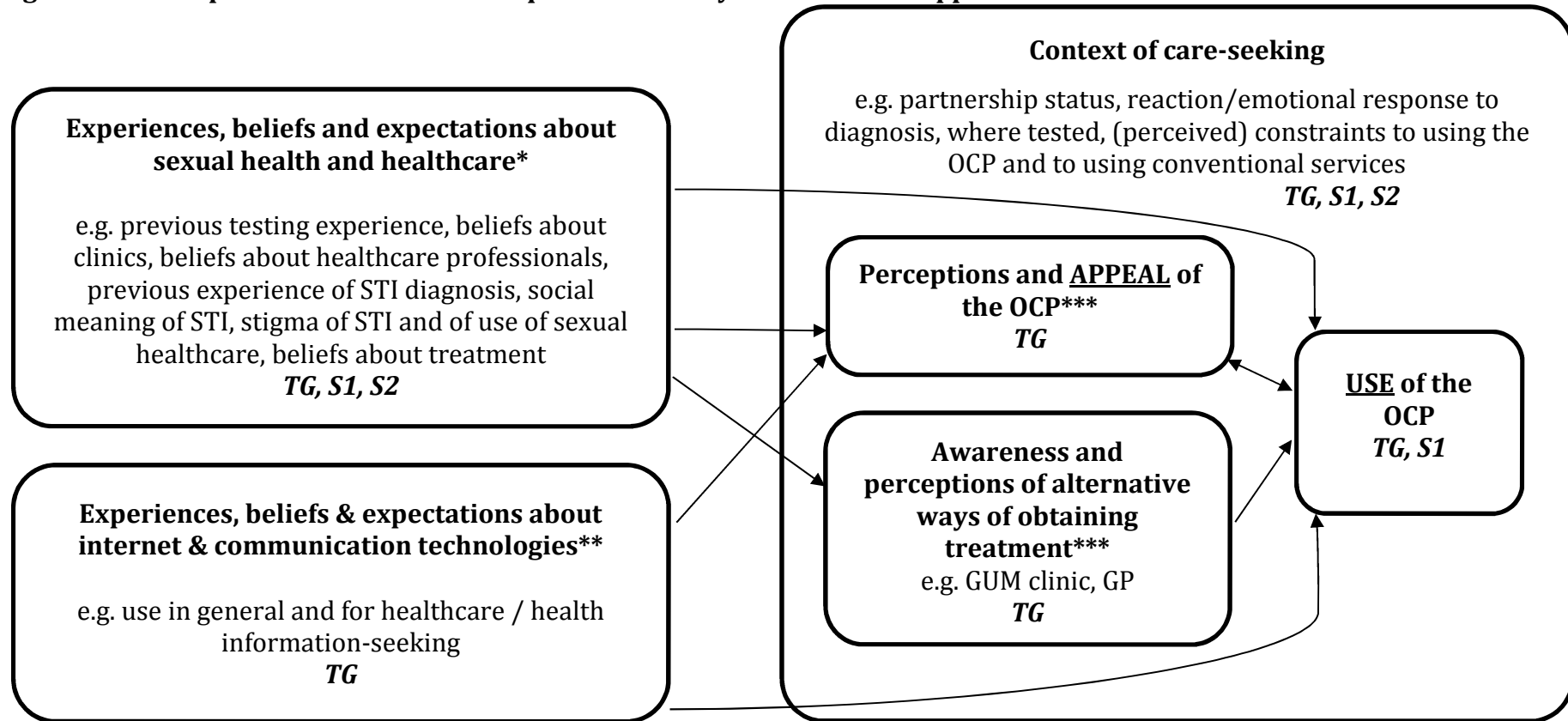
*Together with other formative research¹⁻⁵

6.5.3 Conceptual framework

I identified no single theory which was appropriate to describing or explaining the use, or the nature of the appeal, of the OCP – a novel e-health intervention which patients could use as a route to treatment, after a diagnosis of an acute, curable STI. I constructed the conceptual framework for this study using research evidence and theory (including the previous study), and thought experiments.³⁵³

The conceptual framework for this study (Figure 18) demonstrates what I had in mind when designing and conducting the study, but does not seek to provide an *a priori* explanation of use or appeal of the OCP. The figure also indicates which parts of the conceptual framework were incorporated in the topic guide and sampling strategy (detailed in Methods). The conceptual framework is intentionally simple, because I sought to be open to new and different factors and processes as data collection and analysis progressed.

Figure 18: Conceptual framework for the qualitative study about use and appeal of the OCP



Notes: The roles of gender and age were considered in all parts of the conceptual framework; other factors might operate similarly.

*Other (non-sexual) health and healthcare beliefs and experiences were discussed, if mentioned by interviewees.

**Depth of exploration of ICT experiences and beliefs was influenced by the planned HCI qualitative study.

***Discussions were informed by previous study's findings (chapter 5).

TG: included in topic guide; **S1, S2:** included as primary or secondary sampling criteria, in my purposive sample.

Evidence and theories informing the conceptual framework

The research literature on STI-related care-seeking and healthcare needs suggests diverse possible influences on the use of the OCP and its appeal.

Characteristics established as influencing the distribution of STIs and/or sexual healthcare needs, including gender and age, are of key interest in considering the OCP's use and appeal from a public health perspective, hence were used for sampling and/or explored during interviews. (Box 5 and Box 6, p244 and p245, present evidence for the role of these characteristics).

Perceptions of the OCP were conjectured to affect its use and appeal, and the previous study (chapter 5) had generated useful findings about what these perceptions might be. The Health Belief Model, HBM,^{434,435} a commonly-used health behaviour theory, incorporates 'perceived benefits and barriers' of a behaviour (in this case, OCP use) as influencing engagement with the behaviour. Understanding the benefits and barriers of seeking treatment 'online' would depend on beliefs about treatment (e.g. how important and urgent it is to get treated).

The OCP was offered as one possible route to treatment, alongside attending GUM or general practice (and interviewees may have been aware of other places where they could obtain treatment). I conjectured that awareness and perceptions of alternative services for obtaining treatment (including actual and perceived barriers to their use, see chapter 1, p236) could influence use of the OCP and its (relative) appeal. This conjecture is supported by the previous study's findings (chapter 5) and the wider literature (chapter 2) which suggest online services may overcome some barriers to using conventional services. Diffusion of Innovations theory, which seeks to explain how innovations spread through a population, also suggests that the *relative* advantage of an innovation, i.e. how the OCP compares with existing services, may influence its 'adoption'.³⁷⁷ (or in this study, its use and appeal). More broadly, individuals' experiences and expectations of health(care) and technology are could also be influential. Chapter 5 has described some of possible expectations and assumptions. In

diffusions theories, previous experiences can influence ‘familiarity’ with an innovation,⁴³⁶ even one they have not used before: its similarity to what people already know can affect their propensity to use it.

I also considered ‘actual behavioural control’ and ‘perceived behavioural control’ (from the Theory of Planned Behaviour, TPB,⁴³⁷ and related theories: Venkatesh’s Unified Theory of Acceptance and Use of Technology⁴³⁸ and Davis’ Technology Acceptance Model.⁴³⁹ Perceived behavioural control is considered synonymous with Bandura’s⁴⁴⁰ concept of ‘self-efficacy’,⁴⁴¹ which the HBM also includes). I termed these ‘constraints and perceived constraints’ in Figure 18, reflecting how there may be circumstances or features of the OCP, or indeed of conventional services, which make it difficult or impossible for individuals to use them (or lead them to perceive this to be the case).

Health behaviour theories (HBM, TPB) tend to assume rational decision-making.⁴⁴²⁻⁴⁴⁴ However emotional reactions and unconscious influences on health behaviour are also influential,^{445,446} and could affect how people feel about having chlamydia and about sexual healthcare, thus their behaviour and their needs for support (discussed in section 1.2, and in chapter 5’s findings).

Furthermore, the value of individualistic psychological theories of health behaviour is limited by their lack of explicit consideration of stigma and social context,⁴⁴⁷ including partnership context,⁴⁴⁴ which are relevant for a full understanding of healthcare-seeking and use of services for STIs. Such theories accommodate demographic, psychosocial and social structural factors as ‘modifying/external variables’, mediated through these theoretical models.^{435,437,442} These ‘variables’ feature prominently in the literature on sexual healthcare seeking, and so I chose to give them prominence in my conceptual framework (and choice of sampling criteria is further justified in the Methods of this chapter). In the analysis about appeal, in particular, I considered the social context and meaning for individuals, of having an STI, and of accessing and using healthcare services, with particular reference to theory on stigma (summarised in chapter 1, p48).

6.6 Methods

6.6.1 Sampling frame

The sampling frame for this study was people who had consented to participate in the Exploratory Studies, having received a positive chlamydia result or having been notified of chlamydia exposure as a sexual partner of another participant.

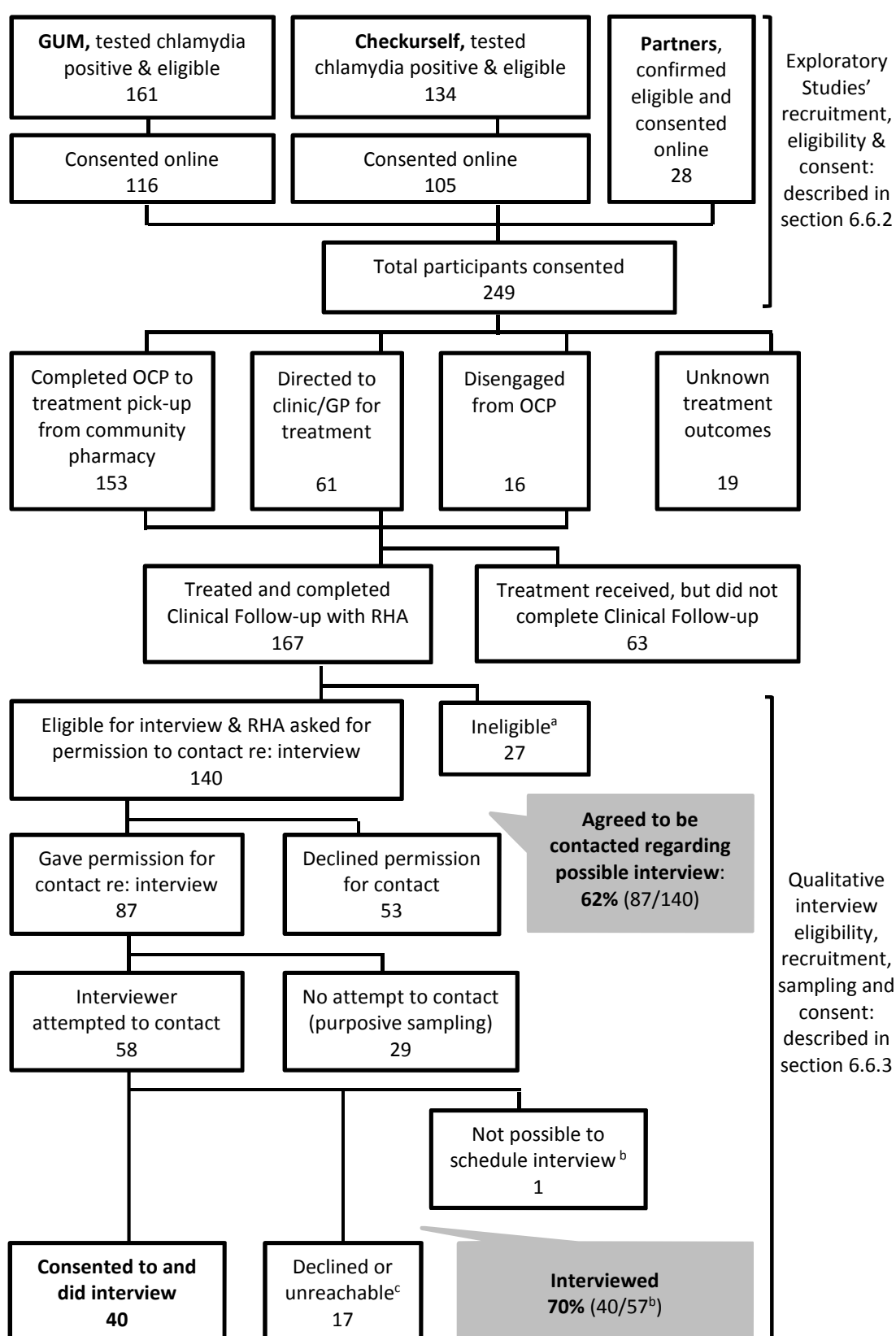
As described, the two Exploratory Studies took place among:

- GUM patients and their partners, and
- Checkurself patients and their partners.

All those within the sampling frame for my qualitative study had received treatment and had undergone Clinical Follow-up (described on p228) before recruitment took place.

For the purposes of sampling for my qualitative study, I considered there to be three recruitment routes to the two Exploratory Studies: GUM, Checkurself and Partner. Figure 19 shows the flow of participants through the Exploratory Studies, and qualitative interview recruitment. (Routes to testing, which did not constitute part of the OCP, are not shown, in order to focus on details relevant to the current study). Recruitment and eligibility for the Exploratory Studies, and (separately) my qualitative study, are described in sections 6.6.2 and 6.6.3 respectively.

Figure 19: Flow of participants through the studies



^aIncluding 4 who were not asked because interview recruitment had ceased; others were ineligible.

^b1 person agreed to an interview but was unavailable until after a 6-week trip abroad, so was excluded from the denominator. ^cIt was sometimes unclear whether potential interviewees had declined, or were unreachable by telephone. No distinction is made here.

6.6.2 Exploratory Studies' population, recruitment, eligibility and consent

Table 26 compares the populations from which the Exploratory Studies recruited.

Table 26: Exploratory Studies: recruitment routes

Recruitment route	GUM clinics	Checkurself	Partner
STI testing settings	3 London clinics serving diverse populations ^a	Various South London boroughs ^b	n/a
STI testing provision	Testing in clinic, for a range of STIs, as indicated by sexual history	Internet-based postal home-sampling, for genital chlamydia	n/a
Reason for requiring chlamydia treatment	Positive Chlamydia test result		Sexual contact of a chlamydia patient

^aAmbrose King Centre, Barts Sexual Health Centre, St. George's Courtyard Clinic – serving inner-city local and commuter populations, and suburban populations.

^bBexley, Bromley, Croydon, Greenwich, Lambeth & Southwark, Lewisham, Sutton & Merton, Wandsworth – inner-city and suburban areas; some areas provided dual testing for chlamydia and gonorrhoea.

GUM and NCSP recruitment sites for the Exploratory Studies were chosen by eSTI² colleagues, in order to test 'proof-of-concept' of the OCP with sufficient numbers of chlamydia-positive patients, in diverse populations. In order to ensure the Exploratory Studies' feasibility, and to enable oversight regarding clinical governance issues associated with the novel OCP, the GUM clinic sites chosen were those where the eSTI² Consortium's Principal Investigator (PI, Dr Tariq Sadiq), and the Exploratory Studies' PI (Prof Claudia Estcourt, one of my PhD supervisors) were based, and the NCSP sites were relatively close by.

Assessment of eligibility for the Exploratory Studies was informed by details that patients provided at testing (GUM clinic and Checkurself routes) or online (Partner route), and clinical details (Table 27).

Table 27: Eligibility criteria for the Exploratory Studies

<ul style="list-style-type: none"> • Tested positive for genital chlamydia, but did not simultaneously test positive for any other STI, or rectal or pharyngeal chlamydia^c • Logged on to access result within 7 days 	or	<ul style="list-style-type: none"> • Current/recent sexual partner of an Exploratory Study participant • Logged on to OCP
and		
<ul style="list-style-type: none"> • Not already treated for chlamydia • Aged 16 years or older • Able to read and understand written English • Provided a mobile telephone number 		

^cPatients testing positive for these infections require more complex clinical management, including a face-to-face consultation.

6.6.3 Qualitative interview eligibility and recruitment

As part of the OCP, all of those who consented to the Exploratory Studies were followed up at two weeks⁹ in Clinical Follow-up telephone calls conducted by RHAs. This included participants who had consented, but disengaged from the OCP.

Qualitative interview recruitment began once Clinical Follow-up was complete, and the RHA had administered a brief evaluation survey for the Exploratory Studies. The RHA checked participants' eligibility for a qualitative interview (Table 28). If eligible, she sought their permission to provide their first name and mobile phone number to me ('a researcher'). She explained that this was so I could contact them regarding a confidential research interview about what they thought of the way they got their treatment. She clarified that they were not, at this point, agreeing to an interview, and explained that I could provide more information about the interview study.

Table 28: Eligibility criteria for the qualitative follow-up interview study

In addition to eligibility criteria for the Exploratory Studies (Table 27):
<ul style="list-style-type: none"> • Completed Clinical Follow-up with Research Health Adviser (RHA) • Follow-up completed by telephone conversation (not text message*) • Adequate understanding of spoken English (as assessed by RHA)
*In rare cases, where participants did not respond to phone calls, treatment and PN outcomes were collected by text message or email. It was not considered feasible to discuss participation in the interview study in a text message conversation.

6.6.4 Purposive sampling and consent to the interviews

Through stratified purposive sampling³⁹¹ I sought diversity among my interviewees with respect to key characteristics by which their views and experiences of care might differ, in order to represent qualitatively the range and diversity of views and experiences on use and appeal of the OCP. My sample matrix (Table 29) was informed by:

- | | | |
|--|---|---|
| <ul style="list-style-type: none">• theory and evidence about possible influences on use and appeal of the OCP;• evidence about potential user groups;• evidence about public health need. | } | see conceptual framework (Figure 18, p235), Box 5 and Box 6, p244-245 |
|--|---|---|

Sampling criteria were also limited to data available prior to consent to the interview,⁴⁴⁸ i.e. that collected by the Exploratory Studies, and thus available to the RHAs. I did not have access to these data, so liaised with RHAs regarding sampling.

Table 29: Sample matrix, showing quotas

Characteristic	Gender	Male	Female	
Age (years)	16-24	6-12	6-12	
	≥25	6-12	6-12	
Recruitment route	GUM	6-12	6-12	
	Checkurself	6-12	6-12	
	Partner			
Use of care pathway	<i>Categories/strata not predetermined</i>			
Total (target sample size)				30-48

Empty cells indicate that no quotas were set in advance.

The target sample size, set for pragmatic reasons, was relatively large for a qualitative interview study,^{351,449} reflecting anticipated diversity in the experiences of OCP users, and therefore the number of interviews which might be required to achieve data saturation. Before the Exploratory Studies began, we did not know how participants would use the OCP, nor whether their partners would use it, so I did not pre-determine strata or quotas for OCP use, or quotas for partners.

Box 5: Justification for primary sampling criteria

Primary sampling criteria

Gender

- Differences by gender in healthcare-seeking behaviour and healthcare use, including for sexual health reasons.^{62,402-404,414}
- Differences in sexual behaviour^{400,401} and the 'sexual scripts' which shape these behaviours.^{450,451}
- Gendered social expectations and stereotypes regarding sexual behaviour⁴⁵² which may influence stigma surrounding sexual healthcare use;^{154,165} differences in the experience of chlamydia diagnosis.¹⁶⁶
- Differences in STI diagnosis rates²⁸ and prevalence, by gender.^{62,453}

Age

- Older interviewees may have greater experience of: sexual healthcare use (thus be able to make comparisons with their previous experience), sexual activity, STI, and healthcare use in general.
- Findings reported in chapter 5 suggest that concealing use of sexual healthcare may be particularly important for teenage young women.

Exploratory Studies' recruitment route (GUM, Checkurself, Partner)

- The recruitment route represents recent experience of sexual healthcare (see conceptual framework), and possibly preferences for remote internet-enabled vs. conventional healthcare:
 - Checkurself users had already selected and used 'remote' internet-enabled sexual healthcare;
 - GUM clinic participants had recent experience of clinic attendance and a face-to-face sexual health consultation.
- For those participating as partners, who will not have tested, initiation of online care and contexts of care-seeking will differ from those diagnosed with chlamydia.

With Checkurself participants expected to be aged 16-24 (they must declare this to use the service) and chlamydia-positive GUM patients slightly older on average, I expected overlap between age-group and recruitment route.

Use of the care pathway

- Sampling those who disengaged from the OCP, those directed to clinic, and those who collected their treatment via the 'remote' route, enabled exploration of the contexts and influences of these uses of the OCP.
- People who use different elements of the OCP (e.g. the helpline, message/code for partners) had experienced different parts of the intervention. It is important to understand whether non-users were aware of these elements.

Secondary sampling criteria, by which I sought diversity across the entire interview sample, are listed and justified in Box 6. Without additional effort, the

sample was diverse by all secondary sampling characteristics except sexual orientation. Throughout data collection I asked the RHAs to refer to me any potential interviewees reporting same-sex sexual partners.

Box 6: Justification for secondary sampling criteria

Secondary sampling criteria

Ethnicity

- Some differences by ethnicity in sexual behaviour^{454,455} and in sexual healthcare-seeking and use,^{453,454,456} within Britain.
- Ethnicity is a crude proxy for 'culture' by which sexual scripts vary.^{450,451}
- Differences in STI diagnosis rates²⁸ and prevalence⁴⁵³ between ethnic groups, such that ethnicity could be a marker of interviewees' own, or their peers', experience with STIs.

Testing setting (which GUM clinic or Checkurself area)

- The three GUM clinics and various Checkurself areas serve contrasting populations.

Partnership/relationship status

- Interviewees' partnership status could influence their reactions to their positive chlamydia result or exposure, what interviewees may want from their care, and PN.

Gender of recent partners; sexual orientation

- Use of the internet for sexual health is more common among MSM (chapter 4), who experience elevated rates of STI and HIV diagnosis,²⁸ and prevalence.^{62,414}
- Non-heterosexual people potentially faced with additional issues of stigma when using health services, which might contribute to the appeal of internet-based remote healthcare.

Previous STI diagnosis and treatment

- Previous experience of STI diagnosis and treatment may influence interviewees' perceptions of the OCP as a new way of receiving treatment.

My qualitative sampling strategy evolved during data collection and early analysis, as I further developed the theory underlying my sampling decisions.³⁵⁰ Throughout interview recruitment, I liaised with the Exploratory Studies' main RHA to refine sampling categories, presented and described the sample at Exploratory Studies data review meetings, and sought colleagues' advice on any un(der)represented categories. As the research proceeded it became clear that

problems in community pharmacy, experienced by a minority of the Exploratory Studies' participants, were recurring and affecting both the use and the appeal of the OCP. To understand these issues, I purposively sought to interview those who had experienced them.

Recruitment and consent to the interviews

With minimal delay, I made contact with potential interviewees by calling or texting their mobile phone. Text messages made no mention of chlamydia or sexual health (e.g. '...an interview about your recent healthcare...') in case they were read by someone else. I explained that I was making contact to discuss possibly interviewing them by telephone, that this interview would be confidential, would take about 30-45 minutes, and we could schedule it to suit them. I said I would email a £30 voucher straight afterwards, as a thank-you. I emphasised the value of the research, that it was voluntary, and that they could terminate the interview or skip a question they did not want to answer, without giving a reason (none did this). I sought to facilitate participation further by offering weekend days as well as week-days, and day-times and evenings.

The Exploratory Studies' patient information leaflets (PIL, Appendices 9a, b) had been provided to GUM patients at study clinics, and were included in Checkurself users' self-sampling kits. Similar information was provided online, where consent to Exploratory Study participation was sought. The PIL explained that some participants would be asked to participate in a voluntary telephone interview. By consenting to an Exploratory Study, all potential interviewees had indicated that they had read and understood the study information. However, at least two weeks had elapsed by the time I spoke to them, so I offered to read the PIL. I asked if they had questions, and answered these. If they agreed to be interviewed, I read them the consent form (Appendix 9c) and signed it myself after confirming their informed consent, as agreed with the ethics committee.

6.6.5 Development of the topic guide

Interviews used a topic guide, without pre-worded questions (summarised in Box 7, and provided in Appendix 9d). The topic guide included 'mapping'

questions,⁴⁵⁷ which asked participants to talk through what happened. I tailored the questions I asked and their sequence in response to what interviewees told me had happened, and I sought to find out timings (e.g. when interviewees had accessed results, completed the consultation, collected and taken treatment), to explore any delays.

There was no separate interview piloting phase. Before data collection, I practised my interview technique with two friends and a relative who had recently received healthcare involving multiple contacts with health services (although not for sexual health), using an adapted version of my topic guide. Two practice interviews were by telephone, one involved diagnosis and care for a stigmatised condition, and the three varied in their satisfaction with their healthcare. This practice enabled me to improve my questioning style and the flow of my topic guide. Once data collection began, I intended to exclude early interviews from the dataset if they were of poor quality, but this was not the case.

Box 7: Summary of topic guide

Opening questions/'ice-breaker': Internet use – in general, for health
First impressions of OCP

- Reason for choosing, expectations, awareness of other sources of treatment

Interviewee talks through what happened:

Probe for details, views, reasons for actions taken, how interviewees worked out what to do at each stage, and to check sequence of what happened & approximate timings.

- Testing experience (*not asked of those participating as partners*)
- Reaction to result (or message from partner)
- Care pathway use – what happened
- Experience of providing information online (online 'consultation')

[if applicable:] Being directed to clinic/GP

- Reaction, what happened (helpline use? Attendance, receiving treatment)

[if applicable:] Disengaging from the care pathway

- Reasons, what happened

Awareness and use of the telephone helpline

[if applicable:] E-prescription & picking up treatment from pharmacy

- Selecting a pharmacy
- Picking up treatment
- Taking treatment
- Acceptability of this process

What happened next? Talk through to Clinical Follow-up telephone call

[if applicable:] Partner notification

- People to tell about chlamydia diagnosis? Managed to do this? Experience. Suggestions for making this easier?
- Awareness, understanding, use of link and code for partners
- Reasons why/why not used; in principle acceptability

[for those participating as notified partners:] Getting treatment without testing

- Feelings/acceptability
- Use of other services

Topics to probe on unless already discussed:

Privacy

- More or less private via OCP compared to clinic/GP? Why?
- [*if privacy concerns mentioned*] What to keep private? Why?
- Comparison face-to-face vs. online sexual healthcare

Support, information, the helpline and use of other services

- Needs for info, support, help? At what stage? For what? What happened?
- Need for info/support now?
- Other health services used? What for/why/at what stage?
- Awareness, use, views of helpline (opening hrs?)

Speed – expectations & fit with what happened

Previous experience of STI testing/diagnosis

Final words & recommendations

- Expectations/needs met/unmet? Suggested improvements?
- How would you describe your experience? Recommend it? Why/why not?

Thoughts on eSTI² remote self-test

Reflections on interview; phone interview mode

Recorder off. Collect additional details (see Table 30), take email address. Thanks.

6.6.6 Data collection: in-depth interviews by telephone

I undertook 40 interviews, from August 2014 to March 2015, shortly after completion of each person's Clinical Follow-up (mean/median 5 days, IQR 1-7.5 days).^{ix} Interviews were digitally recorded from a landline to maximise audio quality. Recordings lasted a mean of 44 minutes (range 26-67mins), and the entire data collection phone call (including study explanation, informed consent and collection of quantitative data) took about an hour. I sent e-vouchers for an online retailer (value: £30) shortly after each interview. This amount did not appear to influence participation unduly, but it facilitated recruitment of a population who were typically busy and might otherwise consider it too difficult to schedule an interview.

After each interview I made notes about the process of recruitment, influences on interview conduct (e.g. distractions), ideas relevant to the analysis, issues to explore in future interviews, and improvements to my interview technique.

Recordings were transcribed by a commercial transcription company, which handles sensitive, confidential data, and with which I additionally arranged a Confidentiality Agreement. Audio-files were never linked to participants' names. I checked all transcripts by repeatedly listening to audio-recordings.

^{ix}All but one was interviewed within 10 days. The first potential interviewee referred to me was interviewed 21 days later because he went on holiday in between.

6.6.7 Data collection: quantitative, categorical data

Table 30 summarises the categorical data I obtained about each interviewee. I asked for demographic details after the interview (unless discussed in the interview), to avoid suggesting to interviewees that I considered these characteristics important, and because asking closed questions at the start could inhibit interviewees from providing the free-ranging responses that I sought in the interview.

Table 30: Sources of categorical data about interviewees

Source	Data
Prior to the interview: <i>Indicated by Exploratory Study ID:</i> <i>From the Research Health Adviser:</i>	Recruitment route (GUM, Checkurself, Partner) Site (GUM clinic or Checkurself area) Linkage between sexual partners Gender
Reported during the in-depth interview	Previous STI testing Previous STI diagnosis OCP use: completeness, source of treatment, helpline use, request/use of code for partners Partnerships/relationships
Reported after the interview	Age Self-defined ethnicity Self-defined sexuality Partnership/relationship status

6.6.8 Data management and analyses

Thematic analyses

I conducted two thematic analyses^{351,374} using ‘Framework’:^{386,458} one analysis concerning use of the OCP and the other, its appeal. (Framework is a matrix-based method for data management, specifically data summary and display.⁴⁵⁸) Framework is compatible with thematic analysis⁴⁵⁸ and both are flexible, suited to a broad range of qualitative research approaches.^{351,459}

Data familiarisation

For data familiarisation, I repeatedly listened to the interview recordings and read through the transcripts, making notes as I did so. I mapped out, on one

sheet of paper for each interview, a summary of what had happened during their care, as an aide-memoire.

Coding

I generated descriptive codes for the data (Appendix 9e) based on: interviewees' characteristics, stages or aspects within the recent episode of care for chlamydia, and topics identified in the previous study as requiring further exploration. A code is a "descriptive or conceptual label that is assigned to excerpts of raw data in a process called 'coding' ".⁴⁵⁹ I developed the codes with reference to my conceptual framework, but I took care not to force this onto the data. My coding framework included different parts of the care pathway, so it could be used as an index, in order to facilitate the analysis of use of the OCP. It also included codes for views expressed on the OCP (aspects discussed positively, negatively or ambivalently) to aid the analysis of the OCP's appeal. In NVivo software, I began coding the transcripts, refining codes during this process.

A colleague with qualitative research experience read two of my interviews and provided comments on the coding frame. I revised it and we coded five interviews, iteratively comparing coding, and discussing differences. 80% agreement in coding has been suggested as a benchmark.⁴⁶⁰ We easily surpassed this at the outset. We were close to consensus with the last two of these interviews, and resolved differences through discussion. I coded the whole dataset with the refined coding frame.

Data summary and display: using Framework

I organised the coded data into matrices by case (interviewee) and code, labelling cases with individuals' characteristics and experiences (Table 30, p261). I summarised the data excerpts in each cell so that I could quickly read data about a particular code, or interviewee, and, using NVivo software, maintain linkage to the transcripts to avoid loss of context. (My coding frame also helped prevent loss of context, as data excerpts were coded to parts of the

care pathway. This was an improvement on the process I used in the previous study, see section 5.5.5).

Searching for themes

I began searching for themes while data collection was ongoing, reflecting that qualitative data analysis is often a non-linear process.^{351,353} At this stage, this involved noting down recurrent and emerging concepts related to my two objectives. I used the constant comparative technique,⁴¹⁶ continually checking and refining my ideas for themes as I gathered new data. I kept these quite 'loose' until I had coded all the interviews and completed the Framework matrices.

I worked through the completed Framework matrices and sought to identify provisional themes relevant to the study's aims (section 6.4). I did this through a process of abstraction and interpretation, as is conventional in thematic analysis^{351,374} and when Framework is used as described by its originators.^{386,458} I identified themes at the 'semantic' ('manifest') level⁴⁶¹, i.e. focussing on the 'explicit or surface meanings of the data' (what interviewees said).³⁷⁴ (Semantic/manifest themes contrast with latent themes, which 'go beyond the explicit content of the data' and concern the underlying conceptualisations and assumptions behind what interviewees actually said.³⁷⁴ Use of semantic thematic analysis fitted with my realist approach (chapter 3). In contrast, thematic analyses at the latent level are associated with constructionist research, with theme definition and description already involving significant amounts of interpretation and theorising.³⁷⁴)

Reviewing and defining themes

I searched for disconfirming evidence (evidence which did not fit or appeared to contradict the themes) in order to refine the themes. I used negative case analysis to strengthen the themes and the analysis as a whole 'by considering the instances and cases that do not fit' with the pattern observed in the rest of the data, in order to refine explanations.²¹ Primarily I did this by comparing the two accounts of people who disengaged from the OCP with the remainder of the

dataset, and by comparing those directed to clinic with those treated 'remotely'. I also searched for other accounts which challenged my analysis.

I summarised the provisional themes, named them (so as to capture the 'essence of [each] theme's focus'³⁵¹), and presented themes to the same colleague, who read several more transcripts, and provided feedback. After some refinements, we coded sections of the Framework matrices together, using these themes, again resolving differences of opinion through discussion. As I applied the agreed themes to the data and began drafting chapter 7, I identified sub-themes which helped to capture aspects of the agreed themes. I also compared groups of interviewees by their characteristics and experiences, to help explore how each theme applied to different groups, as well as under which conditions.

In thematic analysis conducted at the semantic level, there is progression from description, where themes are summarised and patterns in the data described, to interpretation, where researchers theorise the significance and meaning of these patterns, in relation to existing research and theory.⁴⁶² The interpretative stage of my analyses took place as I drafted the study's findings. In order to ensure my evolving analysis still 'rang true' to the data, I sought the second-coder's comments on a draft analysis.

Further analysis: treatment 'delays'

My maps of each interviewees' care enabled me to identify the points between results notification and treatment when delays occurred. By referring back to interviewees' accounts, I examined the contexts and possible reasons for these. I focussed on the interviewees who took more than 3 days to collect and take treatment, after receiving their message to say results were ready. Findings of this analysis are reported in section 7.2.4, p294.

6.6.9 Presentation of results

Results are presented in two sections of chapter 7, according to the study's twin objectives. Quotations were selected as described in chapter 3, p155. Selection of quotes was also influenced by my duty to protect interviewees' confidentiality from the partners, friends and siblings, who some interviewees mentioned were aware of certain details about their chlamydia episode, including the two couples who were interviewed. Anonymity in the research context is recognised as a continuum: from research participants being completely unidentifiable, to their identities being only partially concealed.⁴⁶³ Paired cases present a particular challenge to anonymity in reporting, since they share experiences.⁴⁶³ I took extra care when selecting quotes not to present too many details from any individual, which could make them identifiable to these close people. I omitted some of my observations about PN, where I had 'both sides of the story', because I could not report these without breaching confidentiality.

6.6.10 Quality assurance

Training courses on qualitative research design, in-depth interviewing, and writing up qualitative research (run by the Social Research Association, and NatCen Social Research) allowed me to develop my skills and knowledge. With senior colleagues and course facilitators (experienced qualitative researchers) I discussed: the study's theoretical basis, sample design, contingency planning in case of recruitment difficulties, appropriate and feasible objectives for my study, and practicalities and implications of conducting interviews by telephone. For the latter, I also sought guidance from the academic^{379,381-383,464-467} and grey literature.^{468,469} I circulated the study protocol to the eSTI² workstream 4 team researchers with qualitative research experience, and my supervisors. I take full responsibility for decisions I made.

I received constructive feedback on my interview technique and topic guide from Dr. Maryam Shahmanesh (Senior Lecturer at UCL's Centre for Sexual Health and HIV) and Lorna Sutcliffe (Principal Researcher at Queen Mary University of London), based on recordings and transcripts of early interviews.

Before and during data collection, I participated in two qualitative studies (unrelated to healthcare; one involved a telephone interview concerning a website I use), and used my experience as a research participant to reflect upon and improve my interview technique. My analysis benefited from second-coding and reviewing themes with Lorna Sutcliffe (as described in section 6.6.8), with Dr. Shahmanesh's supervision.

To develop further my qualitative research skills, I sought qualitative researchers with whom I could discuss my study. I joined qualitative research academic mailing lists, presented at UCL's Qualitative Health Research Symposium, and through this, met qualitative health researchers in other departments. I attended qualitative health research seminars and presented findings there, and presented to a multidisciplinary audience in my own department. Later, I delivered oral presentations of my findings at national sexual health and public health conferences (British Association for Sexual Health and HIV; Society for Social Medicine). In all of these fora I sought constructive feedback.

6.6.11 Ethical approval and research governance

Ethical approval for the eSTI² Chlamydia Online Care Pathway Pilot Study, which encompassed the Exploratory Studies and my qualitative interview study, was granted by Brighton & Sussex (NHS) Research Ethics Committee (ref: 13/LO/1111, IRAS project ID: 112513). I underwent a Disclosure and Barring Service check, and Barts Health NHS Trust (the responsible Trust for all participants in the Exploratory Studies) provided me with a Letter of Access for Research.

6.6.12 Reflections on study conduct and data collection

'Interviewer effects' (in which interviewees' perceptions of the interviewer result in effects on the data) may be reduced in telephone interviewing: my age (similar to the oldest interviewees), my White ethnicity and some other characteristics may not have been obvious.³⁸⁰ Even so, inevitably interview data are socially-constructed, and what interviewees told me may be consciously or

unconsciously influenced by, for example, my gender, my middle-class accent and my status as a researcher on a study about healthcare.

Concerns about social desirability could lead interviewees to, for example, avoid criticising the OCP, or to avoid disclosing behaviours they might perceive as 'wrong' or 'unhealthy'. To minimise this, I emphasised before the interview began that I am not a doctor or nurse, and did not design the 'online service'. I avoided introducing healthcare, epidemiological or clinical terminology. I explained to interviewees that I was interested in hearing their views and experiences, positive or negative, that I had no access to their medical records, and that interview data was not going to be linked to their records. It could inhibit frank discussion if I appeared to be checking up on interviewees, particularly since the Clinical Follow-up phone call had effectively emphasised 'correct' behaviour to potential interviewees (notifying all recent partners, taking treatment promptly, *etc.*). When I sought clarification about such details I phrased my questions in non-judgemental, non-confrontational way.

The need to obtain some specific details (e.g. on timings, whether or not the helpline was used) meant that I sometimes asked closed questions, and therefore needed to manage the impact of these on the interviews. I kept closed questions to a minimum. Telephone interviewing helped, because I could make brief notes about missing or unclear details without interrupting or distracting interviewees, and ask for this information during natural breaks in our conversations.

I had little direct involvement in the OCP's design and no involvement in its implementation, but my membership of the same research group potentially influences my perspective on the OCP. Aware of this, I deliberately sought not to become too familiar with the OCP, because my intention was to understand the OCP from interviewees' perspectives. Before interviews began (and perhaps related to my health services research experience), I recognised that I have a tendency to think of treatment- and care-seeking behaviour as linear, ending with treatment/PN. This could lead me to make assumptions about OCP use, to

neglect the wider context, and to work through an expected sequence of events rather than being open to diverse ways an interviewee may have navigated the OCP. I therefore began interviews with broad 'mapping questions'⁴⁵⁷. I used the OCP's novelty to my advantage, by explaining that I and other researchers did not know what it was like to use it.

From my perspective, it seemed no more difficult establish rapport in the interviews by phone than face-to-face (and interviewees reflected that they preferred phone interviews, in general, see Appendix 9g). A disadvantage of not being able to see their body language may have been outweighed by interviewees' perceptions of greater 'anonymity' when they could not be seen, and therefore greater openness in the interview. During short periods of silence in the interviews, I felt pressure to speak after what I felt was a shorter interval (even if just to say 'mhm', 'okay' and to indicate that I was still on the line) compared to when I have conducted interviews face-to-face. Once I recognised this, I used silences to my advantage, and interviewees, perhaps feeling the same pressure, tended to fill these silences.

I felt privileged that interviewees were able to share experiences with me that (as some explained) they had not shared with others, despite the potential embarrassment of this, which some acknowledged. It likely helped that by the time of the interview, they had received treatment (thus the episode of chlamydia was presumably resolved).

Being of a similar age to the oldest interviewees, and living with my partner and child, I felt I was in a different phase of life from many interviewees, many of whom were single, and only one of whom described having a child. There were some similarities between interviewees' descriptions of their lifestyles which I felt I could relate to, from my own and friends' experience in our twenties. However, I felt I had sufficient 'distance' from these experiences to avoid making assumptions. During data collection and analysis, I was working on my PhD research part-time. I found that use of Framework facilitated re-immersion in

the analytic process, and that having breaks from working on the study seemed to result in a more meaningful analysis, as others have observed.⁴⁷⁰

Further reflexive comments are presented in chapter 7's Discussion (section 7.4.2).

6.7 Sample description

6.7.1 Participation

62% of those eligible for a qualitative interview agreed for me to contact them. Sampling purposively, I telephoned and/or texted 58 of these. I interviewed 40, and one agreed to an interview but was unavailable for several weeks, giving a participation rate of 70% of those agreeing to be contacted and available within a reasonable timeframe. (See Figure 19, page 239; percentages in grey boxes.)

6.7.2 Sample size and characteristics

Characteristics of the 40 interviewees are shown in Table 31. They ranged in age from 18 to 35 years (median 25). As expected, interviewees who had tested via Checkurself tended to be slightly younger (median 22 years, range 18-32) than those who had tested in GUM (median 27 years, range 20-35; although two Checkurself interviewees were outside the NCSP's age range).

Primary sampling criteria

Pre-defined sampling quotas for age-group, gender, and GUM or Checkurself recruitment route were filled (chapter 6, Table 29, p243). I developed the sampling strata for OCP use as the study progressed, which are shown in the 'OCP use' section of Table 31.

Secondary sampling criteria

Without additional effort, diversity was achieved across the sample by most secondary sampling characteristics (Box 6, p245), with the exception of sexual orientation. (This reflects the sampling frame: only a small minority of the Exploratory Studies participants (4 men, 1 woman) reported having had same-sex partner(s) within the last six months. This largely results from the Exploratory Studies' eligibility criteria (Table 27, p241). Few MSM test positive for genital chlamydia without also testing positive for rectal or pharyngeal chlamydial infection⁴⁷¹ (which are swabbed for in GUM but not Checkurself) or co-infection with gonorrhoea.⁴⁷² Furthermore male GUM patients with symptoms of non-gonococcal urethritis (NGU), which is diagnosed based on symptoms and urethral smear microscopy and which is sometimes caused by *Chlamydia trachomatis*, are treated on the day they present to GUM, without waiting for results of definitive (organism-specific) diagnostic tests.^{203,473})

Table 31: Interviewees' characteristics

		Women	Men	Total	
Demographics					
Age, years	18-19	2	1	3	
	20-24	9	7	16	
	25-29	5	8	13	
	30-35	5	2	7	
	Age not disclosed (confirmed ≥16 years)	0	1	1	
Ethnicity ^a	Asian	1	2	3	
	Black	3	7	10	
	Mixed	3	1	4	
	White	14	9	23	
Relationship status ^b	Single	7	10	17	
	In relationship / has boyfriend/girlfriend	9	5	14	
	Split up with boyfriend, related to chlamydia	4	0	4	
	Casual partner(s) ^c	1	3	4	
	Not discussed	0	1	1	
Sexual orientation	Heterosexual, straight	19	19	38	
	Not discussed, but recent partners opposite sex ^d	2	0	2	
Experience of sexual healthcare					
Previous STI testing ^e	Yes	17	14	31	
	No	3	5	8	
	Not discussed	1	0	1	
Previous STI diagnosis	Yes ^f	8	5	13	
	Not had chlamydia before	1	1	2	
	No	12	13	25	
Recruitment route ^g	GUM	12	8	20	
	Checkurself	8	8	16	
	Partner	1	3	4	
Online Chlamydia Pathway use					
Route to treatment	Directed to clinic/GP for face-to-face assessment		6	1	7
	Disengaged from OCP and treated in clinic		2	1	3
	Completed to pharmacy treatment collection		13	17	30
	Of which	Problems with pharmacy treatment collection involving 2+ trips to pharmacy &/or helpline use	3	2	5
		No problems at pharmacy, or problems resolved during one visit and without helpline use	10	15	25
Helpline use	Yes – self-initiated		6	1	7
	Yes – when prompted to call (re: access to clinic)		3	1	4
	No		12	17	29
Requested message for partner(s)	Yes, requested and sent to 1+ partner		2	3	5
	Yes, requested but not sent		2	1	3
	No ^h		17	15	32
Totals		21	19	40	

^aSelf-defined by interviewees, and grouped into these categories by me. Most used census categories to describe their ethnicity. The sample included 13 who spoke English with a foreign accent (interviewer-assessed), distributed amongst the 4 ethnicity categories.

^bSelf-defined, and grouped into categories by me. 'Single' includes some who stated that they had recently split up with a partner, but this was unrelated to their chlamydia diagnosis.

^cIncluding: in-between/dating, it's complicated, still hanging on, not putting labels on it yet.

^dBoth were women in relationships with men, and only mentioned male sexual partners. It was an accidental omission not to ask them their sexual orientation.

^eBefore the current episode of care. Of those reporting that they had tested previously, two reported never having used face-to-face services for STI testing, but one of these had attended clinic following a previous chlamydia diagnosis.

^fWhere named, this was chlamydia, gonorrhoea, or both. One of the 13 with previous STI diagnosis had no prior experience of STI treatment. She had not received her result and learnt of her previous diagnosis at a subsequent clinic visit, by which time she tested negative.

^gDistributed among all three GUM clinics and 5 Checkyourself areas.

^hIncludes a small but unknown number to whom the message for partners was unavailable: the 4 participating via the Partner route, and some who were directed to clinic early on in the study. Part-way through the study, at during Clinical Follow-up phone calls, the RHA began offering participants the opportunity to log back on to request the message.

Chapter 7: Qualitative interview study about use and appeal of the Online Chlamydia Pathway: Results

Findings presented in Results section (a) of this chapter, corresponding to objective 3a, have been published:

Aicken CRH, Sutcliffe LJ, Gibbs J, Tickle LJ, Hone K, Harding-Esch E, Mercer CH, Sonnenberg P, Sadiq ST, Estcourt CS, Shahmanesh M. Using the eSexual Health Clinic to access chlamydia treatment and care via the internet: a qualitative interview study. *Sexually Transmitted Infections*. Published Online First: 7 October 2017. doi: 10.1136/sextrans-2017-053227

7.1 Introduction

This chapter presents the results of a qualitative study among users of the Online Chlamydia Pathway (OCP), the methods and sample for which were described in chapter 6.

7.1.1 Detailed objectives

3a: To describe how patients diagnosed with (or exposed to) chlamydia used an online care pathway to treatment and partner notification, based on views and experiences expressed in in-depth interviews.

Specifically, to:

- provide a rich, contextualised description of OCP use;
- identify barriers to, and facilitators of, prompt treatment;
- describe the extent to which users' information and support needs were met through the OCP;
- generate suggestions for its ongoing refinement.

And secondarily, to:

- describe users' experience of providing information online, and implications for the accuracy of these clinical and surveillance data;
- describe how the OCP supports or does not support partner notification and patients' partners' access to treatment.

3b: To develop a detailed understanding of the appeal of the OCP to its users, and the limits to this; and to offer interpretative explanations about the nature and limits of the OCP's appeal.

7.1.2 Summary: quantitative results from the Exploratory Studies

Colleagues' results are provided to contextualise my qualitative findings.

Box 8: Key quantitative findings from the eSTI² Exploratory Studies

Findings are from Estcourt et al.⁹, unless otherwise stated.

75% (221/295) of chlamydia-positive eligible patients consented to participation in the Exploratory Studies and use of the OCP.

Of these, at completion of Clinical Follow-up, 97% (112/116) of GUM patients and 89% (94/105) of Checkurself users were known to have been treated. 64% (74/116) of GUM patients and 57% (63/105) of Checkurself users proceeded online, selected a pharmacy and collected treatment from there ('remote' route). The remainder were treated upon attending clinic/GP.

21% of those treated via the 'remote' route, used the Helpline.

More women than men were directed to face-to-face clinical care (clinic/GP), largely because they disclosed symptoms requiring further investigation.

Those collecting treatment from community pharmacy did so rapidly: median 1 day (IQR: 0-1 days for GUM patients; 0-4 days for Checkurself users).

Problems at the pharmacy were reported by 32% (28/87) of those who collected treatment there, in a follow-up survey.⁴⁷⁴

Index-reported PN outcomes 'compared favourably' with those from routine PN in comparable studies:⁴⁷⁵

- 178 index patients reached at Clinical Follow-up (172/221 consented, 78%) reported 371 partners, 317 of whom were contactable (85%)
- Of contactable partners, 81% (256/317) were notified, and 38% reported to be treated (120/317).

Few partners used the OCP:

- 154 index patients reached the end stage of the OCP, and of these, 94 (61%) requested the message with link/code for partners. These 94 reported 280 partners.⁴⁷⁵ It is not known how many index patients forwarded the message, nor to how many partners.
- Only 28 partners accessed the OCP of which 19 received treatment from community pharmacy and 4 were known to be treated elsewhere.^{9,475}

Satisfaction with the OCP was high (in follow-up survey data)⁴⁷⁴

- 87% (of n=153) would recommend this 'online clinic' to friends (5% would not, 8% were unsure)
- 66% (of n=99) rated the online care they received as excellent and 20% as very good. None rated it as bad or very bad

7.1.3 Overview of presentation of results

I present findings of two complementary thematic analyses, addressing objectives 3a (use) and 3b (appeal), in separate Results sections.

Presentation of Results (a): Use of the OCP

Section 7.2, addressing objective 3a, presents a descriptive thematic analysis. This ‘mechanical argument’,³⁵⁰ describes and explains how people used the OCP, and draws practical implications for its refinement.

In section 7.2.1, I describe the themes which represent how people used the OCP. These themes applied differently at different stages of the pathway. Therefore I present findings (in sections 7.2.2-7.2.6) according to the OCP’s chronology, dividing it as shown in Figure 20. The divisions I made are necessarily artificial, and the ‘chunks’ are intentionally large, to minimise fragmentation of the narrative. Use of the Helpline and other services, and support- and information-seeking, occurred at various points, and to best describe their roles in care-seeking, they are mentioned where they were used.

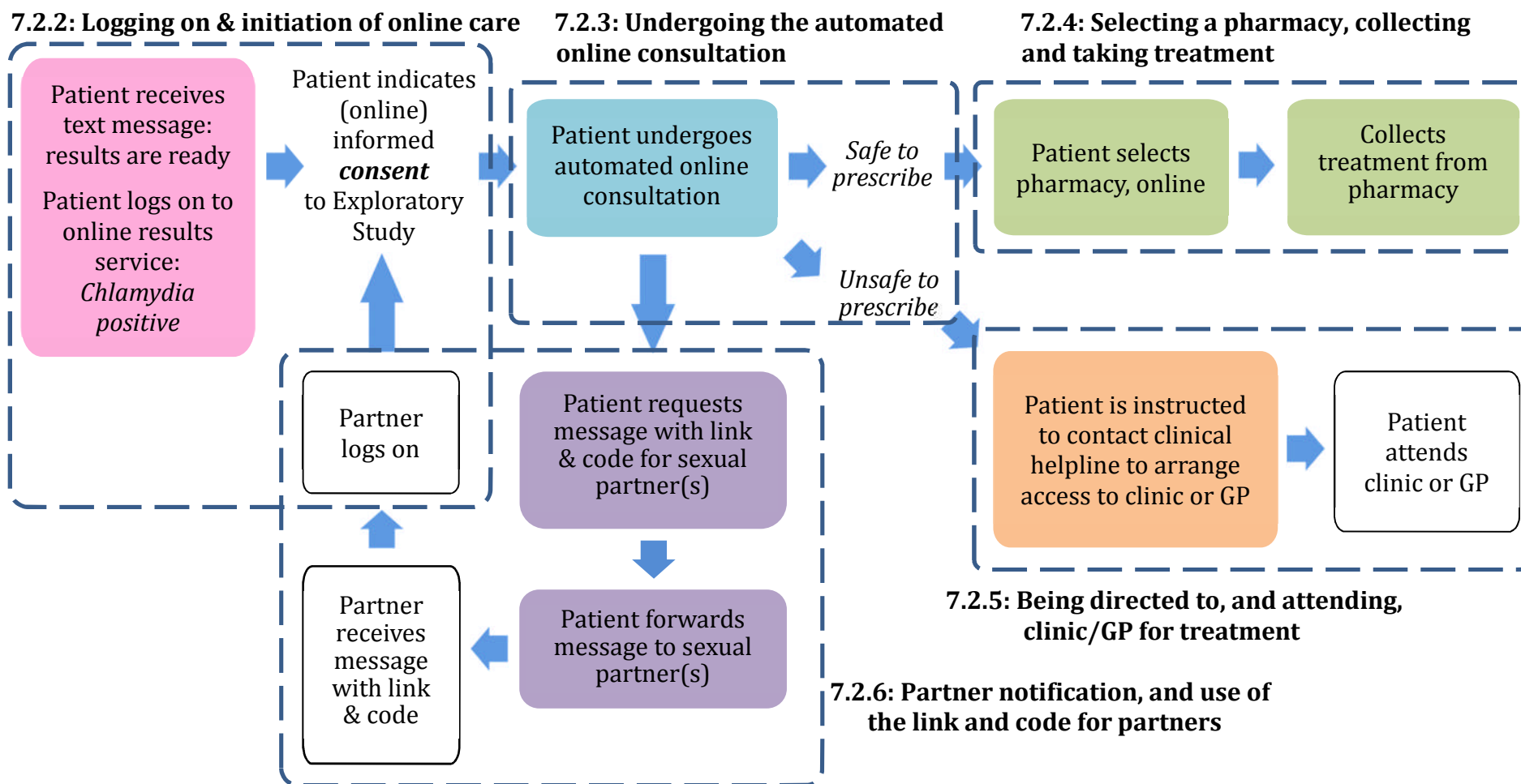
For each section 7.2.2-7.2.6, I present:

- **Description and diagram** of the relevant part of the care pathway.
- **Results:** Descriptive analysis of interviewees’ use of the OCP, referring to themes.
- **Implications:** Brief notes on whether use of the relevant part of the OCP was optimal from a public health perspective (outlined in chapter 3).

I provide sub-sample sizes (numbers of interviewees using various parts of the OCP), indicating, e.g., a need for cautious interpretation when few interviewees experienced a particular part of the OCP. (These numbers are not ‘results’, and provide no indication of the prevalence of experiences in the wider sample). In a few instances I present numbers when discussing negative cases (see glossary).

Figure 20: The Online Chlamydia Pathway: showing how it is divided for the purpose of presenting Results and Implications in this chapter

Bold text: section numbers within this chapter.



Pseudonyms and descriptors presented with quotes, in sections 7.2 and 7.3

With each quote, I provide interviewees' age, gender and fictional initials. The second initial indicates their route to participation in the Exploratory Studies:

- G: tested in GUM;
- C: tested via Checkurself;
- P: participated as a partner.

Presentation of Results (b): Appeal of the OCP, and limits to its appeal

Section 7.3 of the Results addresses objective 3b. This second thematic analysis is more interpretative than the previous one, discussing the significance of the OCP's appeal to its users, and relating this to theoretical constructs introduced earlier in this thesis. Findings are presented and interpreted theme by theme.

Additional descriptors presented with quotes, in Results (b), section 7.3

I additionally indicate how each interview quoted received treatment:

- “treated remotely”: collected treatment from community pharmacy’
- “directed to clinic/GP”: remote treatment was deemed medically inappropriate, based on information individuals had provided online, and the interviewee was directed to clinic/GP;
- “disengaged and treated in clinic”: interviewee abandoned the OCP and attended clinic for treatment.

7.2 Results (a): Use of the Online Chlamydia Pathway, and implications for its refinement

7.2.1 Themes describing use of the OCP

Four main themes and five sub-themes were identified.

Box 9: Themes and sub-themes describing use of the OCP

Short names for themes are emboldened.

1. **Acting with urgency**
2. **Protecting privacy**
 - a. **Concealing evidence** of STI, or sexual healthcare use
 - b. **Avoiding any risk of judgement** by healthcare professionals,
3. **Facing constraints and making choices**
 - a. **Experiencing constraints**
 - b. **Weighing up the options**, trying it out, **or going with the flow**
4. **Seeking peace of mind**
 - a. **Reacting to anxiety**

Theme 1: Acting with urgency

Interviewees described feeling a sense of urgency, which influenced their healthcare seeking behaviour. This varied from a compulsion to act immediately, to a more pragmatic approach, where interviewees balanced a desire to act quickly with convenience and other demands on their time (see **3a: experiencing constraints**).

Theme 2: Protecting privacy

Interviewees described using the OCP in ways which protected their privacy in relation to their chlamydia diagnosis and sexual healthcare. All sought some measure of privacy, discussing concern about whom they discussed their diagnosis with and how, and who might find out about it, but varied in how concerned they were about privacy. Two sub-themes capture how interviewees discussed using the OCP to protect their privacy.

Sub-theme **2a: concealing evidence** is about the concealment strategies that interviewees used to prevent those around them (e.g. colleagues, housemates, family, other healthcare-users) from finding out about their STI diagnosis or sexual healthcare use.

Sub-theme **2b: avoiding any risk of judgement by healthcare professionals** captures how some interviewees sought to avoid consulting healthcare professionals face-to-face about sexual health. Although interviewees discussed finding sexual healthcare staff to be generally non-judgemental, *'really nice'*, *'friendly'* and *'professional'*, fear of being judged by them could impact on their care-seeking behaviour. (This is interpreted in section 7.3). Interviewees gave examples of (perceived) judgemental behaviour which were second-hand (e.g. anecdotes from friends), or relatively subtle (e.g. being looked at in a particular way; an interviewee being told that her previous STI diagnosis *'might be due to the amount of partners'* she had had – DC, 24-year-old woman), which they explained impacted upon their own care-seeking.

In practice, this perceived judgement could be conveyed during face-to-face sexual healthcare interactions, and could be avoided by choosing online care. Specifically described as awkward or embarrassing were: discussion of a positive result; a healthcare professional's facial or verbal reaction to a patient's sexual history; and the moment during which a clinician waited for a response to a question about an interviewee's sexual behaviour. Interviewees understood that healthcare staff would have access to the sexual history information they provided online, but, as this man explained:

...they can do what they like with their face, they can say what they like to colleagues, as long as I don't see it, I don't mind. (TP, 25-year-old man)

Theme 3: Facing constraints and making choices

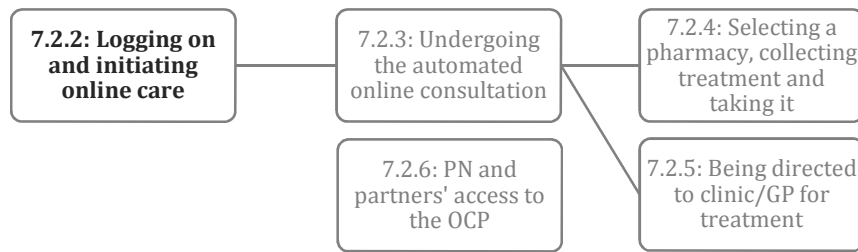
This theme is about decision-making in OCP use. Sub-theme **3a: experiencing constraints** encompasses issues which interviewees identified as preventing or hindering them from following certain courses of action. In particular, they discussed the difficulty of attending healthcare settings during their opening

hours, due to busy lifestyles (including: employment in jobs which involved working late; shifts which over-ran; education/training; and/or caring commitments). Feeling unable to disclose sexual healthcare needs in order to obtain time off (see **2: protecting privacy**) exacerbated these constraints. Constraints to OCP use included poor internet connectivity.

Sub-theme **3b: weighing up the options, trying it out, or going with the flow** captures the spectrum of approaches to initiating use of the OCP (section 7.2.2).

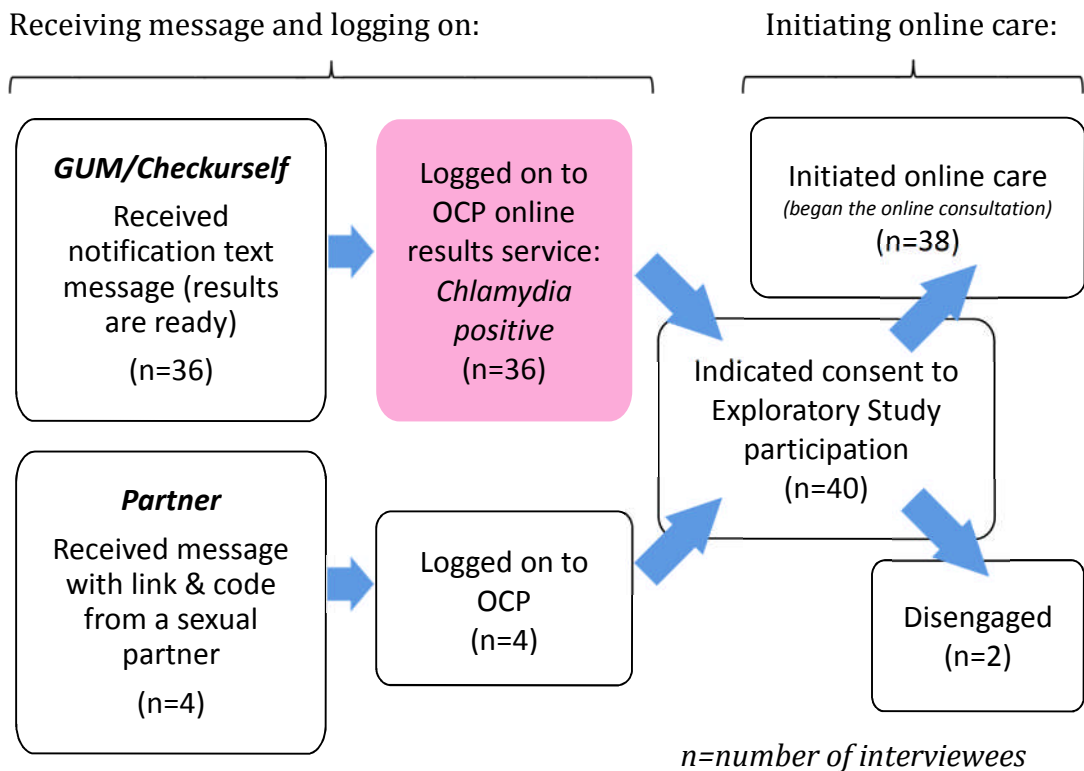
Theme 4: Seeking peace of mind

Seeking peace of mind captures the diverse ways in which interviewees described gaining relief or reassurance (including by seeking information and support), and for what. Some interviewees described how only receipt of treatment, or a subsequent negative test, would provide peace of mind. One aspect of this theme is **4a: reacting to anxiety**. Certain circumstances provoked anxiety (over and above interviewees' worries about chlamydia and/or healthcare use), which influenced interviewees' behaviour.



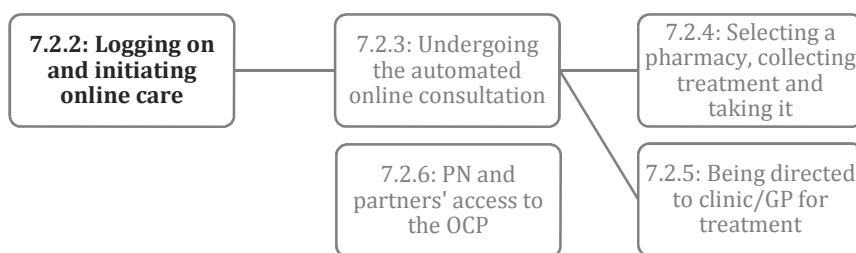
7.2.2 Logging on and initiating online care

Figure 21: Logging on and initiating online care



Description

Text messages containing a web-link to the online results service were sent on weekday mornings (when the OCP's Helpline was open, in case of queries). Patients accessed their chlamydia-positive results online with a code provided at testing, or with their mobile phone number and date of birth. With the result, brief information about chlamydia was provided, including that it is easy to treat with antibiotics, and web-links to further information. Options for obtaining treatment were presented: online, or attending a GUM clinic or general practice.



Partners logged on with a code which their sexual partner had sent them (described in sections 6.2 and 7.2.6). If eligible for the Exploratory Studies, they were provided with information online, as described above (and then their care pathway was identical to index patients’).

Results

Receiving the notification message and logging on

Logging on to obtain test results was described as easy and straightforward, and was valued for enabling greater privacy (**2a: concealing evidence**), compared to receiving results by text message,

‘cos you don’t know who’s gonna be like holding your phone at the time.

(VG, 26-year-old man)

However, interviewees with experience of STI testing, who were familiar with receiving results in a text message, sometimes assumed that the text message telling them to log on indicated a positive result:

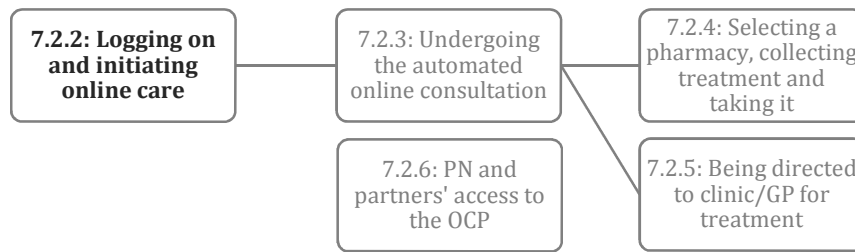
...every other time I’ve gone, it’s said you, it’s all negative. So when it had a number [with which to log on] I was like, oh fuck, that means there’s something, ‘scuse my French...

(WG, 29-year-old man)

This caused feelings of urgency and anxiety about logging on (**4a: reacting to anxiety**), particularly among GUM clinic users, who had tested for multiple STIs and HIV. For example, this woman described feeling ‘very apprehensive’ and checked her result immediately:

I wasn’t gonna wait. [Interviewer: Uh-huh, OK.] And I think it was a lot to do with the fact that it said “Your results are now ready to view online”. I’ve, I’ve never had anything before, so I was kind of – I just knew there was something, because usually it’d just be like, “All of your results are negative”.

(AG, 22-year-old woman)

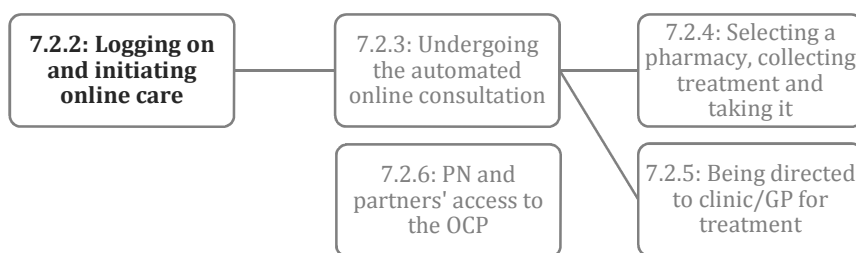


Typically, interviewees described accessing their result soon after receiving the ‘results are ready’ message (**1: acting with urgency**), irrespective of their location, or their assumptions about their results. Those who were at work or in public described accessing their result with sufficient privacy from those around them, usually using their smartphones (**2a: concealing evidence**). Working in a shared office, this man described how ‘*on my mobile I was, I was sure that nobody was looking*’. He explained:

...when I got the message I was like, yeah, I need to find out now [...] I just kind of looked around (laughs) and, and just, you know, pressed the link and, and got to the website and, and found out. (YC, 24-year-old man)

Exceptions, where interviewees described accessing their results later, related to privacy concerns (**2a: concealing evidence**) and **experiencing constraints (3a)** such as being particularly busy at work (*‘it’s not something I’d have wanted to open up on my desktop computer’*, *‘and I’m ridiculously busy as well, like frantic at the moment’* – VG, 26-year-old man). One interviewee described lacking mobile internet, and this was the only instance where an interviewee described accessing results the day after receiving the ‘results are ready’ message.

Two interviewees reported difficulties interpreting the results screen, but seemed unable to specify what was unclear. One described being very upset by her diagnosis, which indicated her boyfriend’s infidelity, while the other was unique among interviewees in expressing scepticism about the online, automated aspects of the OCP throughout her interview. Both valued having support from a person (**4: seeking peace of mind**), and received this in clinic (one disengaged from the OCP, and the other was directed to clinic).



There was no indication that those participating via the ‘partner’ route delayed logging on, but partners tended to describe less urgency than those logging on to access results (**1: acting with urgency**). They had this in common with the subset of ‘index patient’ interviewees who knew that they had been exposed to chlamydia when they tested (and so expected a positive result). This supports the interpretation that it was desire to find out results which provoked urgency about logging on.

Initiating online care

Captured by **3b: weighing up the options...going with the flow**, some interviewees described making considered decisions to proceed online:

I kind of curiously looked at it, saw what it was about and thought, actually, this is quite a good idea. (NC, 26-year-old man)

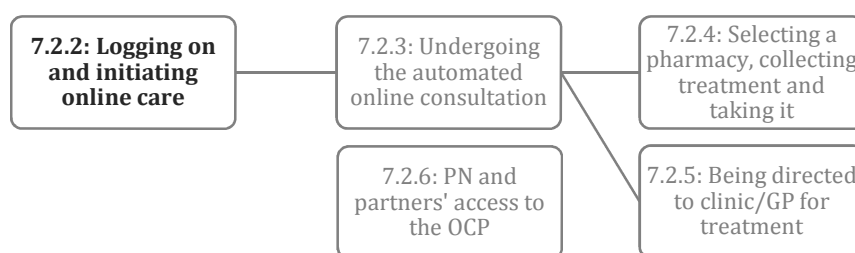
Others viewed the OCP as continuous with other ‘online’ aspects of their healthcare (e.g. Checkurself; online appointment booking systems), and proceeded online apparently without considering alternatives:

I then had to do an online, er test, online questionnaire thing... (UC, 21-year-old man)

Interviewees universally described wanting to act promptly, to ‘*get it sorted out as soon as I read those results*’^x (IG, 26-year-old woman; **1: acting with urgency**). Proceeding online was generally considered quicker than attending healthcare services:

...it then gives you the options, you know, go and see someone or go online. And I thought, well actually, you know, if I wanna get treated now... (NC, 26-year-old man)

^xReasons for valuing rapid treatment access are discussed in section 7.3.1.



Interviewees also described how difficulties attending clinic/GP (described in section 7.2.1, **3a: experiencing constraints**) led them to use OCP:

...because I couldn't go to the clinic to pick up the antibiotics for it, I chose the online option...

(MG, 27-year-old woman)

In addition, online information that chlamydia is common and easy to treat gave interviewees confidence to proceed online:

...I kind of know out of any STI, chlamydia's definitely probably the easiest to sort out. And especially when I was kind of looking into it [online].

(GG, 25-year-old woman)

...I quickly saw that what I had was a really common problem so, so it was fine. It was, well it was well-known, the treatments are well-known, so it was totally okay to just get the treatment online.

(TG, 26-year-old man who had not heard of chlamydia before)

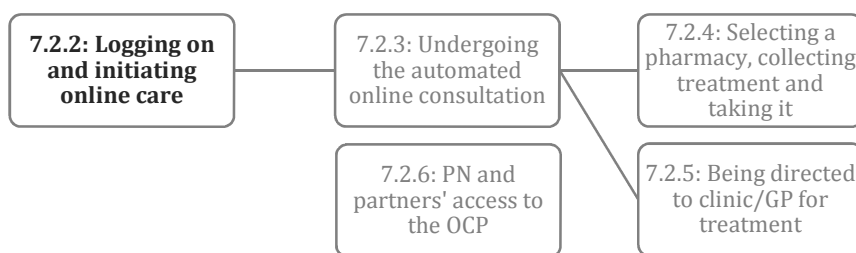
Those with limited experience of conventional sexual healthcare were particularly influenced by the online description of the OCP^{xi}:

...because it was all very well explained on the website, I knew what I was going for and what I would get. Otherwise I would have had to go to the doctor and see what he was saying and er, it would have been longer process, maybe more expensive. And an unknown process as well, whereas on the website I knew. I knew what was going to happen.

(YC, 24-year-old man)

Some of those who accessed their results in public moved to a more secluded location, or waited until later the same day, before continuing online. Despite

^{xi}Some interviewees expected to receive treatment by post. They discussed advantages and disadvantages of this, which were similar to those reported in chapter 5, and so are not repeated.



wanting to obtain treatment quickly, they sought privacy (**1: acting with urgency, 2a: concealing evidence**). They also discussed anticipating a need to concentrate and read online information (*'I knew I had to be focussed'* – YC, 24-year-old man), uncertainty about how long it would take, or wanting to use another device instead of their smartphone:

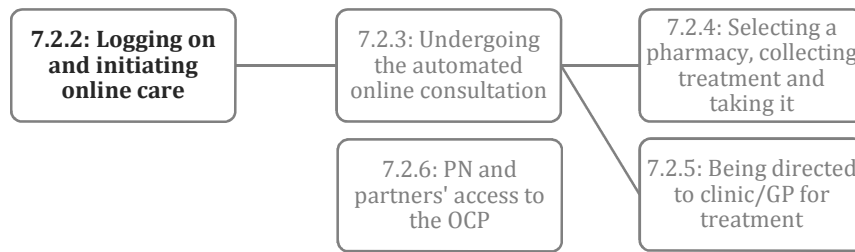
...I just waited a few hours for lunchtime, and I, I just tried to find some privacy and to go and check the information again on the laptop first, because, well I had more time, and you have a bigger screen so it's just easier to read. So I really read all the information which was included in the results and, yeah, after I, I answered the questions and ordered the medication online... (TG, 26-year-old man)

Although interviewees described reading helpful information online, they could not always recall whether they found this via the OCP, or their own web-searches.

Disengaging

Two women interviewees, who both tested in GUM, described disengaging after consenting to the Exploratory Studies. Both described being distressed by the relationship implications of their diagnosis (one because it indicated her boyfriend's infidelity, the other because she was worried about the impact on her new relationship). Both were students, and remarked on their flexibility to attend clinic on the day of their diagnoses (i.e. not **experiencing constraints, 3a**). Both went immediately to a clinic (**1: acting with urgency**) and were treated the same day. One described how she would have *'always gone to clinic'*, because she tended to worry about her health, and because of the professional, personal nature of the support she would get (**4: seeking reassurance**):

You get a lot of information [online] but sometimes you, you need to look at somebody's eyes and say, okay, I'm really sad about this, just tell me it's

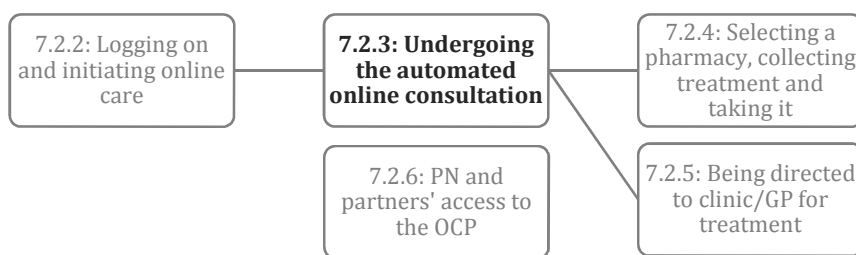


gonna be okay. Even though I know it's gonna be okay, but, just, you have a professional to tell me that... (FG, 34-year-old woman)

The other interviewee explained that she hoped to see the same empathic doctor, and had '*kind of expected it to take longer [online] than me physically going*' to clinic (CG, 24-year-old woman). She discussed how she might have chosen to proceed online, had she realised she might receive treatment the same day, to avoid the embarrassment of a consultation (**2: protecting privacy**).

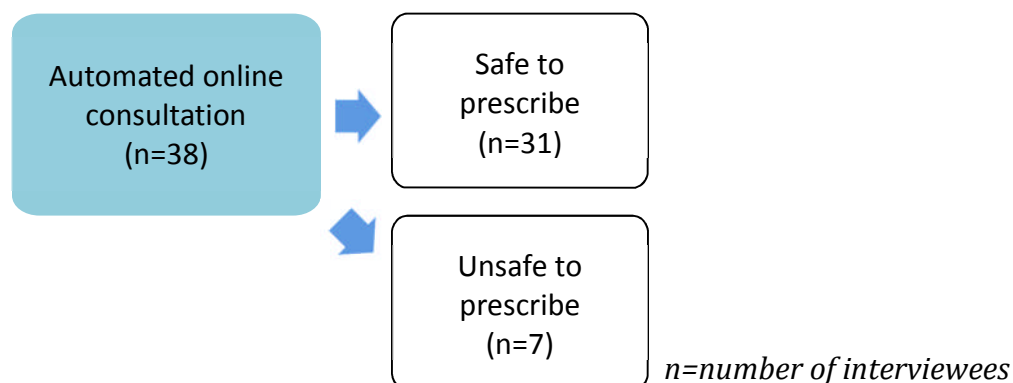
Implications

- The online results service enabled prompt, discreet access to results for OCP users. Interpretation of the chlamydia-positive results screen was generally unproblematic.
- Mobile internet connectivity needs to be considered should online sexual healthcare services be rolled out (e.g.) to rural areas, because users may seek to access results promptly, using their phones.
- Patients need to know in advance how their STI/HIV results will be communicated, to avoid alarm associated with assumed positive results, when they receive an unexpected 'results are ready' message and link.
- Online information that chlamydia is common and easily treatable, and a description of what the online service involves, may increase patients' confidence in using an online route to treatment, and provide reassurance.



7.2.3 Undergoing the online consultation

Figure 22: Undergoing the online consultation



Description

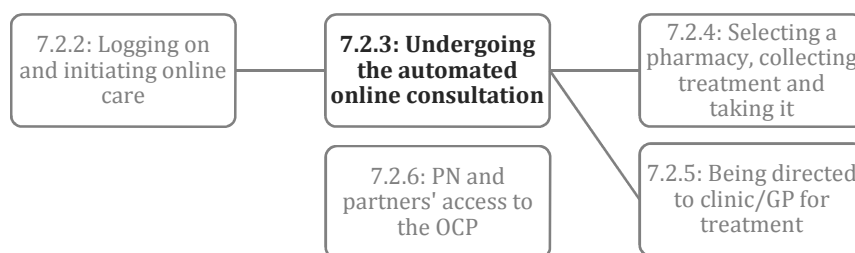
The online consultation was an automated questionnaire. Those reporting certain symptoms, or medical contraindications including allergies, were deemed clinically inappropriate for remote treatment with azithromycin. It was not possible for patients to navigate back to change their responses.

Results

Interviewees described completing the consultation in diverse locations. Those who described doing so at work described workplaces where they were not closely supervised, e.g. office-based white-collar/professional jobs.^{xii} Using their smartphones they completed the consultation discreetly, even in shared offices **(2a: concealing evidence)**:

I just sat in like, in a corner to make sure that nobody was checking what I was doing on my phone, but that's fine [...] because what I'm doing at work

^{xii}Also illustrative of this independence, two interviewees scheduled their interviews whilst they were at work. When I telephoned for the interview, they explained that they were using a separate office or meeting room, without telling their colleagues what they were using it for. I asked them whether this was OK, and they both said yes, expressing no concern for privacy or disciplinary issues, and preferring not to reschedule the interview.



is like, I'm the only one doing that, so they're not really checking what I'm doing at the moment... (BG, 27-year-old woman)

Interviewees used their smartphones to help conceal what they were doing.

This woman, who completed the consultation *'in the nail shop'*, explained:

...I just put my lighting down, on my phone so no one could see... (KP, 19-year-old woman)

The appearance of the web-interface helped in this respect:

...if you glance over someone's shoulder, you wouldn't know without reading in depth, what was going on. [...] ...it's quite a plain standard website, there's sort of nothing jazzy about it. Which is, which is good. (NC, 26-year-old man, treated remotely)

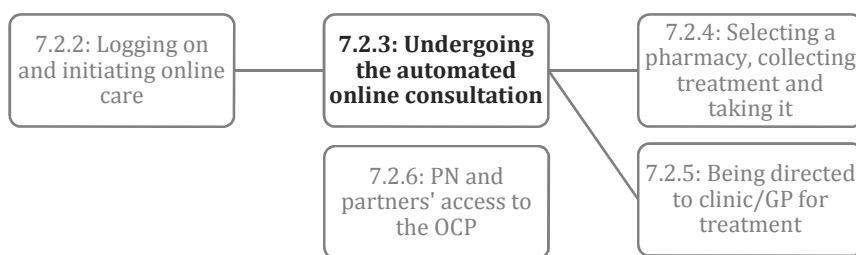
Interviewees described the consultation questions as easy to complete, and had no particular difficulties in selecting responses. Recall difficulties were sometimes mentioned (e.g. numbers of partners within a defined period), but:

...that will be the same, like face to face with a doctor, it's not about, like, internet. (KG, 30-year-old woman)

Navigating through the consultation was mostly unproblematic, although sometimes difficulties – attributed to interviewees' phones or the OCP web-app – led them to resume the consultation a few hours later, or on another device (**3a: experiencing constraints**). No evidence was found for misreporting symptoms.^{xiii}

For some, the *'faceless'* nature of the online consultation made it a *'more discreet'* and easier experience, with:

^{xiii} Among those who mentioned having symptoms, in the interviews, all n=6 of those directed to clinic described symptoms which should have triggered this, and all those who collected treatment from community pharmacy described symptoms which should not have triggered routing to clinic.



...no one there to give you their opinion straight away, or even kind of make a gesture that would suggest their opinion, it's just easier. You can be as honest as possible, I think. You can be more honest than if you go to a clinic. (OG, 27-year-old man)

The potential for the online consultation to facilitate accurate reporting applied particularly to sexual behaviour (partner numbers, condom use). Face-to-face, a fear of judgement could affect the reporting of sexual history details (**2b: avoiding any risk of judgement**):

...if the doctor would have been like, "Have you used a condom?" with kind of a different way of saying it... [Interviewer: Right.] ...rather than me just reading the text. Um, I, yeah I probably would have been, [in a clear voice:] "Yeah I used a condom..." [under his breath:] "...except that time, or that." I dunno. So that would have been awkward, but you feel er, kind of, you know, guilty? (YC, 24-year-old man)

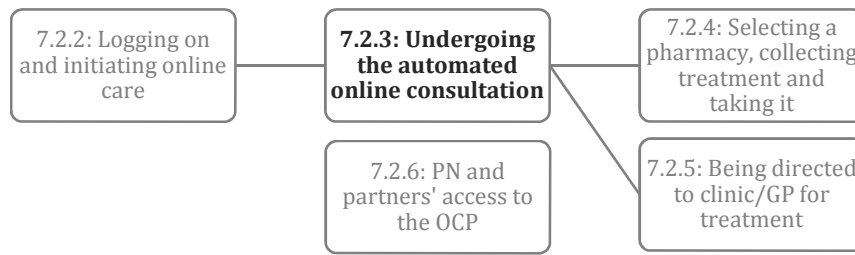
Contrasting a previous clinic visit with the online consultation, this woman explained:

...I sat there kind of thinking, trying to count up in my head and you could just feel the way she [the clinician] was looking at me, and because of the comments she'd made before, and I did make the number lower than I know it was. Obviously online you're thinking well this, you know it's just a form, I can be honest. (DC, 24-year-old woman;

see p269 for her report of the clinician's comment)

However, other interviewees expressed no such concerns, and described the online consultation as similarly private to a face-to-face consultation.

Two interviewees described completing the online consultation in another person's presence, in both cases their partner. One, living with his girlfriend ('my best friend, we're trying to build our lives together'), believed she was



infected before their relationship began (and described no negative feelings towards her). Her presence while he completed the online consultation:

...was fine, it was normal because we do everything together.

(PC, 22-year-old man)

The other said that his partner secretly completed her own online consultation, then told him about her chlamydia infection, and sent him the link/code to use the OCP. While he completed the online consultation ‘*she was reading everything*’, including his sexual history, which he found awkward:

...like, I’m not sure I want to be having this conversation...

(OP, 35-year-old man)

He explained that he tolerated this because it was ‘*an emergency*’, but could have answered the questions alone had he wanted to (**1: acting with urgency**). However it seemed he was not entirely in control of his privacy.

Receiving and seeking information online

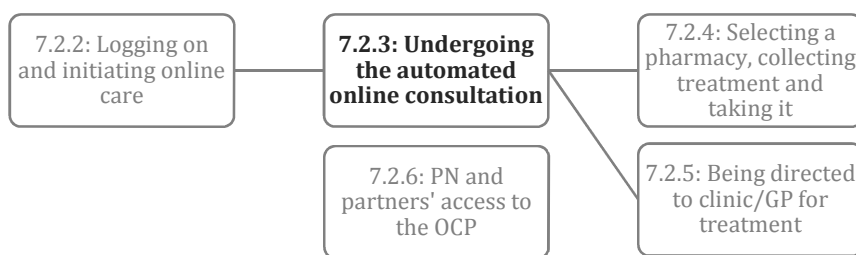
Those who completed the online consultation in private locations tended to describe finding all the information they needed online:

...it’s quite nice that it answers every question that could be coming through your head.

(LG, 20-year-old woman)

However, some completed the online consultation in public places where they were conscious of those around them (**2a: concealing evidence**), in a hurry (**1: acting with urgency**), and while anxious or panicking (**4a: reacting to anxiety**), which appeared to influence their use or recall of the OCP’s online information. For instance, this man described completing the consultation at his desk and reaching the pharmacy within an hour of receiving his result. He described feeling panic, and that:

I wanted to get it sorted straight away, straight away, sort it. And mobile’s quite discreet, you’re just on your mobile effectively no one really knows



what you're playing with, you could be on facebook or whatever, so I thought for all everyone around me knows I was just on facebook. But I wasn't. (laughs softly) (WG, 29-year-old man)

He commented that he had not found information about what chlamydia is, which 'would've been nice' to know. However:

Maybe it did say that but I was too busy frantically trying to (laughs) get to the antibiotic stage. (WG, as above)

Similarly, this interviewee described making an excuse to leave work immediately, and completing the consultation on the way home:

I was doing the thing on my phone, while I was on the bus [...] I had to get it sorted straight away... (RG, 35-year-old man)

After collecting treatment, he did a web-search to check that the pharmacist had given him the correct treatment, commenting that if the OCP website:

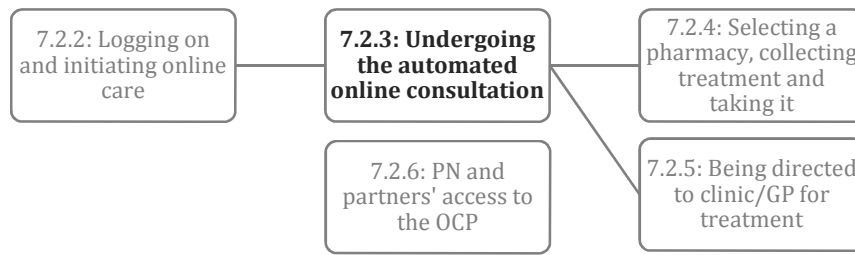
...had said something like "Get your treatment, it's going to be called this or this" it would have, yeah, I would've been happier... (RG, as above)

This information was displayed on the screen at the end of the consultation. A possible explanation for overlooking it, is that uptake of information may be 'all about timing':

...when you're pre-treatment, you just wanna get this done, you don't want to be asking any questions about it, you just want to get it resolved, you know, get rid of any infection. (OG, 27-year-old man)

Expanding upon this, OG explained how he appreciated the Clinical Follow-up phone call, but would not have been receptive to this contact earlier:

...say you've caught something right, you're probably embarrassed, upset, annoyed, angry, right? You just wanna get it sorted out. Once it's sorted out, you could probably speak more openly about it, cos then you're looking at it reflectively. (OG, as above)



Helpline awareness and use, and use of other services

When asked whether a helpline was needed, interviewees typically responded ‘definitely’, whether or not they had used it.

Normally, when you catch something or something's wrong with you, you probably panic and you'd not know what to do. But because I, it was so easy, I didn't have to call the service, I didn't have to make the call. But I think some people may not be able to do - or that, that channel still [...] should be available for some people that would need it.

(OG, 27-year-old man)

Interviewees explained that they would use the Helpline for information or technical assistance, if they needed it. Its role in providing emotional support was recognised (and valued) by women interviewees and several men.

However, other men would not use it for support:

...I mean generally guys don't do that... [...] ...it's difficult for me to ring up a random guy or girl, on a line, and be like [in a whining voice:] "oh, I need help" sort of thing, I don't really see myself as ever being that person. I'm not the person to ring up a helpline...

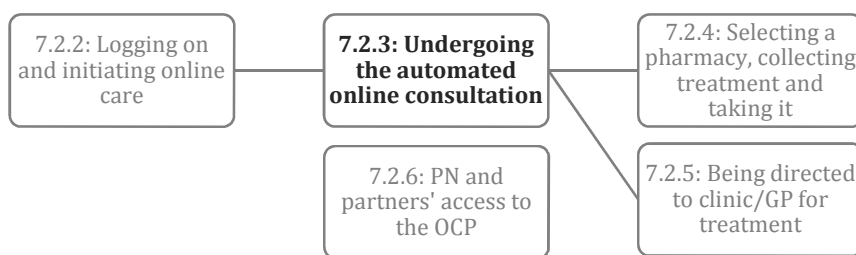
(WG, 29-year-old man)

Furthermore, some men had not realised that the Helpline could provide emotional support, although they valued it for other reasons:

...not everyone's gonna be so happy using technology on that level, some people might get a bit frustrated, might lose their PIN number like we were saying, you know, stuff like that. It just gives you that, that failsafe.

[Interviewer: Yeah. And anything else that, that it might be useful for, that helpline?] *Mm. In terms of that. Chasing results, I've already said that. Um (sighs) no, I... beats me (laughs).*

(OG, 27-year-old man)



Several interviewees who had not used the Helpline had apparently not realised that it existed. Typically, they stated that they did not look for it because they did not need it. However, some asked questions about chlamydia after obtaining treatment, at the Clinical Follow-up phone call or from their GP (either opportunistically or at a dedicated appointment), perhaps reflecting similar issues to those discussed on p282. Contextual reasons for not noticing the Helpline, related to **acting with urgency (1)** and **experiencing constraints (2a)** regarding technology use, were also discussed:

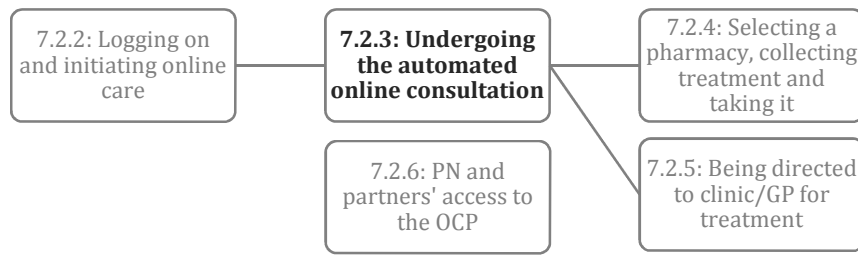
...maybe the reason I didn't notice it is because, A, I was filling it out in a hurry [...]. And, B, cos I, I have kind of, again this is my whole kind of like anti-technology, um, thing, I have a really old shoddy BlackBerry that just about holds up on internet, so it doesn't really kind of, display pages sometimes as it should. [Interviewer: Right, I see.] And if it does, I'm just thankful that it lets me to do what I want to do, I don't kind of like browse around the page that it's on. (SC, 24-year-old man)

Interviewees described feeling restricted about when and from where they could call the Helpline (related to **2: protecting privacy**), and some asked if it could be open in the evenings.

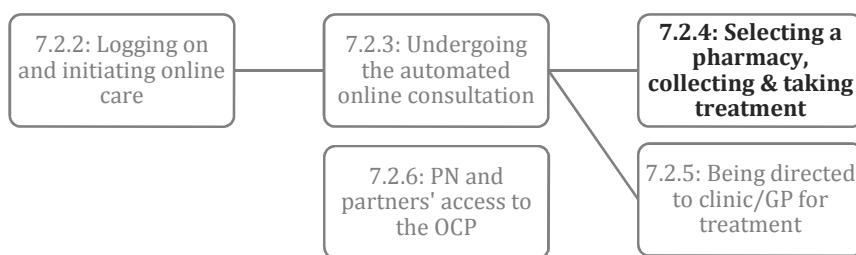
*It's not the sort of conversation you'd like to have at work and stuff. [...]
You just wouldn't want someone else to overhear it...* (HC, 22-year-old woman)

Implications

- The online consultation was straightforward to complete. Based on interviewees' accounts, sexual histories provided online may be more accurate than those provided face-to-face.

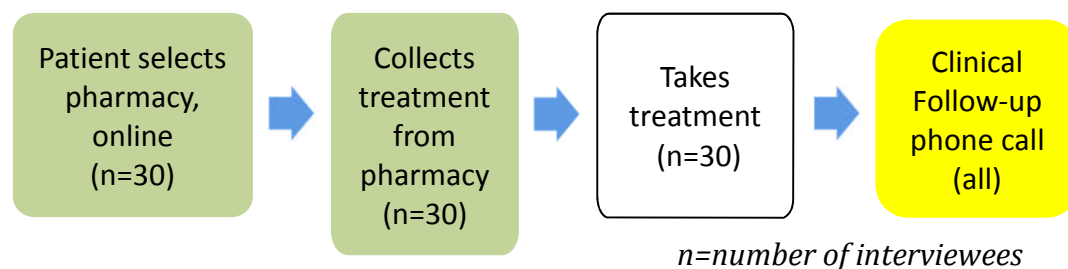


- Interviewees used various strategies to protect their privacy while completing the online consultation, and seemed able to do so adequately.
- Where noticed, information provided/found online was adequate and helpful. However awareness and uptake of the reliable information available via the OCP was sub-optimal, particularly for patients who accessed treatment rapidly. Ways to improve this should be explored further.
- The Helpline was valued by those who used it, and those who did not. Additional evening opening hours may be helpful.
- Those with older smartphones or in locations with poor internet connectivity may find it more difficult to use online healthcare.
- There is a risk of coercion or misuse, if patients complete online consultations in the presence of others, and feel they cannot answer honestly. Follow-up phone calls present an opportunity for health professionals to address this, provided they are aware of this possibility.



7.2.4 Selecting a pharmacy online, collecting and taking treatment

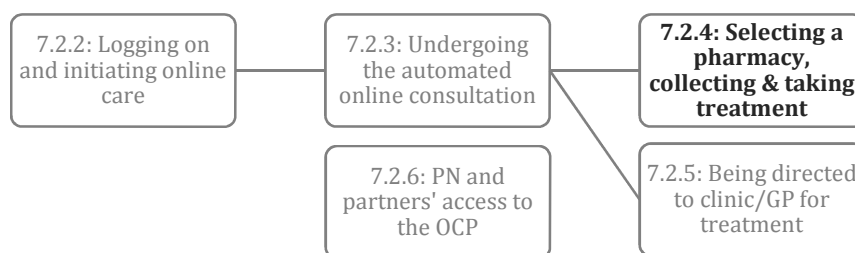
Figure 23: Selecting a pharmacy and picking up treatment



Description

Patients whose responses to the online consultation indicated that they were eligible for remote treatment with azithromycin, were provided with online instructions about how to take this medication (including that all of the pills should be taken at once, on an empty stomach). Patients could select a pharmacy from which to collect their treatment, from a list of those participating in the Exploratory Studies. They were texted their chosen pharmacy's address, and could not change the selected pharmacy. They were instructed to tell pharmacy staff their name and 'ESTI trial' to obtain treatment.

Pre-prepared treatment packs were available from participating pharmacies throughout the Exploratory Studies. When a patient selected a pharmacy, an automated email alerted the pharmacist that provision of treatment had been authorised for the individual concerned. Pharmacists had been instructed to provide a treatment pack after checking the person's name against the email. Other people could collect treatment on patients' behalf. Each pack included written information about how to take the medication, and pharmacists were told that it was not necessary to explain this to patients.



Results

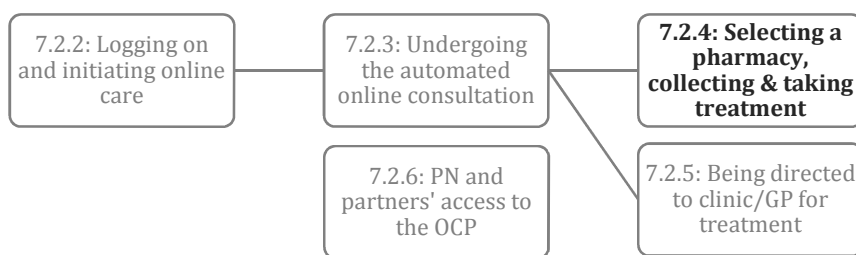
Selecting and going to the community pharmacy

Interviewees described choosing a pharmacy for its proximity to their home, work or place of study, or on a transport route between these locations, with a view to collecting their treatment promptly (**1: acting with urgency**) and with minimal disruption to their (often busy) routines (**3a: experiencing constraints**). For instance, this student picked up her treatment a few days after selecting

...[a] pharmacy on my way to work, that was like just so easy for me to just stop off and get it before I went to work... (KP, 19-year-old woman)

Nevertheless, visiting a pharmacy was sometimes described as difficult, necessitating leaving work early, or arriving late. However this was preferable to attending clinic: in a pharmacy *'it's not gonna be half the wait that I'd have to do if I go into the clinic'* (DG, 30-year-old woman). Given interviewees' busy schedules, the accuracy of pharmacy opening times provided online was important. For example, one interviewee described being late for work when her chosen pharmacy opened later than advertised; another described leaving work early to reach his pharmacy before it closed, only to find it was open later than advertised.

Although interviewees typically described checking their results and completing the online consultation promptly, there was greater variation in how promptly they attended the pharmacy. At one extreme, some interviewees described collecting treatment within a few hours of receiving their results. Others, despite completing the online consultation quickly, prioritised convenience, but still tended to describe collecting treatment within a few days. The few interviewees who described delays of longer than three days between receiving their result and attending the pharmacy, all described being away from home



(for work or on holiday; caring for a sick relative), i.e. constraints which would probably also impede their access to clinic or GP.

Variation in interviewees' understanding of when their treatment would be available influenced when they attended the pharmacy. While some correctly assumed that the treatment would be there all the time (as is normally the case when using a community pharmacy), others assumed that they had 'ordered' treatment online which was being dispatched to the pharmacy, in which case they attended the next day:

...I'd've preferred to have it sooner, but obviously it has to be posted to my selected GP, doesn't it? [Interviewer: To the pharmacist?] Yeah, my local pharmacist. (TP, 25-year-old man)

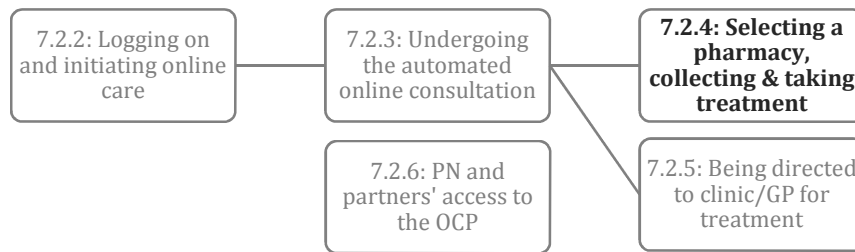
...I'd give it 24 hours, I wasn't sure how long it would take... [...] ...it didn't specify so... [Interviewer: Okay.] Common sense, I thought I'd give it a, give it a while... (DC, 24-year-old woman)

A possible source of this assumption is interviewees' experience of online shopping:

...there are other companies online, shopping companies that use that kind of service where you select somewhere local and pick it up so I think it's, it's catching on anyway in the internet. (QG, 22-year-old man)

Indeed, QG further stated, 'I never picked up a treatment online but then I haven't been to the doctors for years for anything...' suggesting that internet shopping may be a more familiar experience than healthcare use, for some.

Other uncertainties or misconceptions included whether to bring identification to the pharmacy. Some sent a partner (and one, his sister) to collect treatment for them, but others assumed that this would not be allowed.



In the pharmacy

Where pharmacy treatment collection worked as designed, interviewees described it as an easy, quick and private way to collect their treatment (**1: acting with urgency, 2: protecting privacy**; the appeal of the pharmacy process is further discussed in section 7.3). This man, who described the process as ‘seamless’, explained how pharmacy staff:

...seemed to know exactly what I was here for and I said I was part of an ESTI trial, grabbed some medicine, and I was out within about 5 minutes.

(QG, 22-year-old man)

As another interviewee described, pharmacy staff:

...knew what I was there for. Private – they told me to come over to like a sort of separate sort of room, and then they said “sit down” and they told me what to do, how, how to take the medicine, they gave me guidance, and that was it, and I was away.

(OG, 27-year-old man)

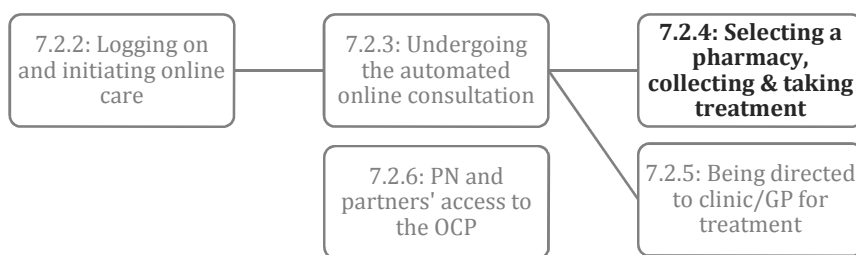
However in some interviewees’ accounts, privacy was threatened by the public nature of the pharmacy. They tended to find their own ways to minimise this (**2a: concealing evidence**):

I did wait until the pharmacy was literally dead and then I was just like “excuse me can I talk to you please”, like whispering, but it was fine.

(WG, 29-year-old man)

Privacy was sometimes further threatened when pharmacy staff lacked awareness of the study, and/or did not realise that the patient sought privacy.

...the guy was asking me like, “But which treatment do you need?” (laughs) I was like, “I’m not gonna tell you, I’m just going to show you on my phone because I don’t...” Er, it was, like I mean he was shouting in the pharmacy, like, “But what?” [Interviewer: Oh dear.] “What treatment, what for?” It



was like, "I can't tell you". Like he was like, "But tell me", so I just like, I had to show him on the phone, he was like, "Oh, okay, sorry".

(BG, 27-year-old woman)

Views about using the term 'ESTI' were mixed:

You know what STI means, but ESTI you don't... (OG, 29-year-old man)

...it's quite, like apparent what you're going in there for as well.

(VG, 26-year-old man)

Some interviewees described being told that the relevant staff member was not present, or that the treatment packs could not be located or had not yet arrived, which delayed their treatment access. Delays were exacerbated by interviewees' busy schedules, and by having no facility to change their chosen pharmacy (**1: acting with urgency, 3a: experiencing constraints**). For instance, this woman selected a pharmacy near her workplace, but when she arrived,

...there wasn't the normal people that work there, so they couldn't find the tablets that I was supposed to have, and because it was coming up to the bank holiday weekend, I ended up having to wait, for four days, so I could go back 'til the owners were back in the pharmacy, so I could get my prescription...

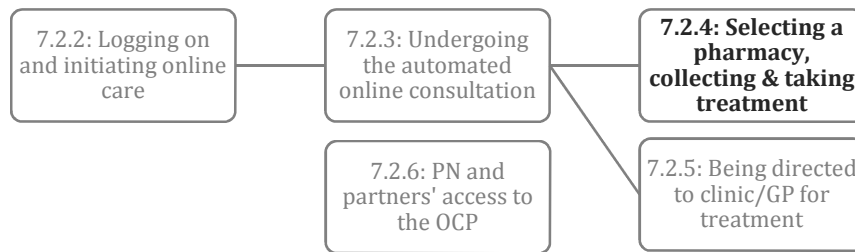
(IG, 26-year-old woman)

She explained 'if I was able to change, I could have collected my prescription from home over the weekend.' Similarly this woman left work early twice to reach the pharmacy in time, but both times was told to come back another day:

...I was like, I can't do that, I just, I already leave work earlier to make sure I can get my treatment, and like they won't allow me like to leave earlier every day...

(BG, 27-year-old woman)

Some such problems were resolved when interviewees (or staff) called the Helpline, which enabled them to receive treatment. Others did not call.



Information about taking treatment

Interview accounts revealed variation in whether or not pharmacists explained how to take the treatment, and variation in interviewees' views about having this interaction. Written information was generally well understood, but with some surprise about the one-off dosage. Some uncertainties about taking treatment, and side-effects, were resolved without calling the Helpline, either by searching online for information before or after taking treatment, or by visiting a GP after taking treatment.

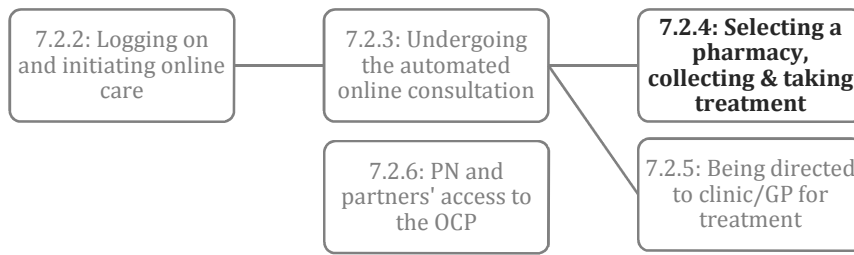
After treatment collection, health experiences and beliefs sometimes contributed to delays in taking treatment. For example, one interviewee took treatment about 4 days after initiating online care, explaining that she felt unwell last time she was treated for chlamydia, and so wanted to take treatment on her day off. Another, despite completing the online clinical consultation and collecting treatment promptly, described how he took it 1.5-2 weeks later. He explained that he had travelled to his family home for Christmas, that he never had an empty stomach during this holiday, and that he was not aware of any urgency, as he was not sexually-active during this period.

Clinical Follow-up phone call

At the follow-up phone call (which interviewees were not expecting), several interviewees asked the RHA for information, despite not necessarily having used the Helpline earlier (**4: seeking peace of mind**). Some discussed how they might have called the Helpline or used other services, without this contact:

...if I hadn't have got that [Follow-up] call I'd possibly would've used the telephone call [Helpline] just to make sure that it's gone and like any worries... [...] ...just any questions that you've got after the whole process.

(LG, 20-year-old woman)



...say like I was sick when I took the tablets, or something happened or anything like that [without the Follow-up call], I would have then had to have gone into the clinic or into my doctors, or something and go through the whole process again just to ask them...[...] ...was that meant to happen to me? (DG, 30-year-old woman)

The follow-up phone call therefore gave them:

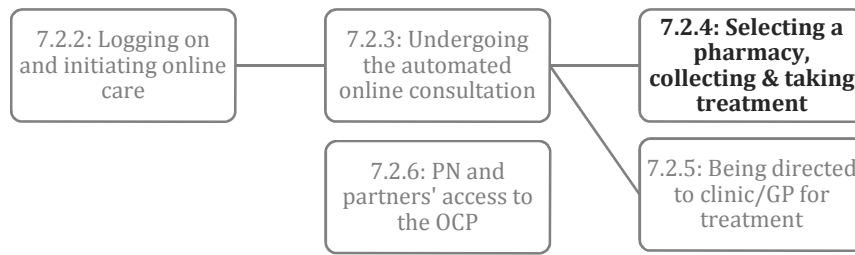
...a bit of closure. If I want closure, bit of direction, bit of how- bit of personal touch, "how, how did you find it?" [...] But yeah it was definitely needed, I don't think a text could solve that problem you need to, you need a person on the end. (OG, 27-year-old man)

However, some interviewees remained uneasy even after treatment (**4a: reacting to anxiety**), such that unexpected contact was worrying:

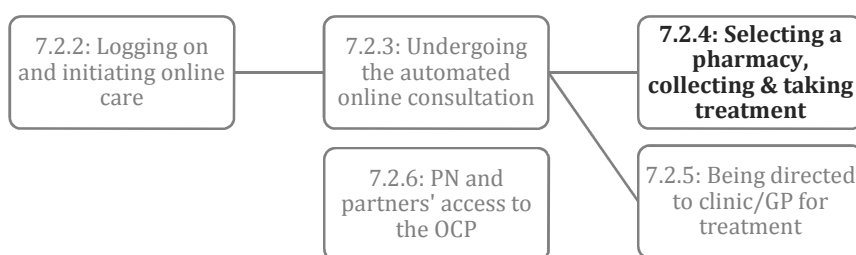
I missed the call, and all it said in the text message was "Please contact us". [Reading the text message:] ...it says "SMS from ESH Health Advisor, we have tried to call you on a private number, please call us to discuss your recent test results, thanks". And when I got that message, I was like "oh, why do they want me to call them back, is there something else I need to know?" [...] I was really nervous calling that number back, I thought they were gonna tell me I had something else... (AG, 22-year-old woman)

Implications

- The facility for selecting a pharmacy largely met users' needs.
- Community pharmacies are familiar, accessible and acceptable settings from which to collect treatment, but the OCP's process is unfamiliar. Clear information is needed (that, e.g. treatment can be collected immediately, by the patient or another person).



- The pharmacy process requires further refinement and evaluation, to identify what more can be done to support pharmacies to adhere to protocol, bearing in mind the importance of rapid treatment, and chlamydia patients' high requirements for prompt, discreet services.
- Increasing the geographic spread of participating pharmacies, ensuring advertised opening hours are accurate, and/or allowing patients to change their nominated pharmacy, may decrease time to treatment and increase satisfaction. (Current legislation has limited the scope for changing nominated pharmacies⁴³³).
- Discreetly-worded text messages to patients need to be phrased so as not to provoke additional anxiety, as patients may already be uneasy.



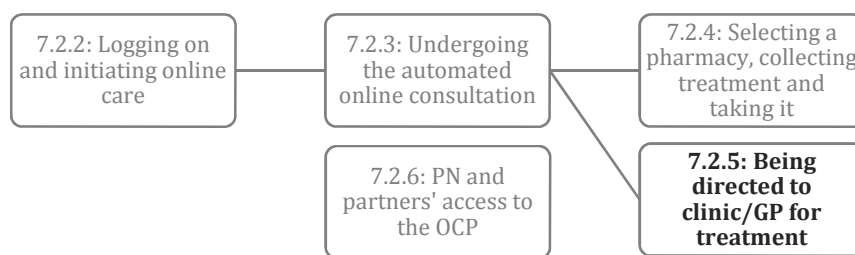
Barriers to prompt treatment among those treated remotely

Table 32 lists barriers to prompt treatment of patients using the remote route to treatment collection from community pharmacy (n=30), and suggests ways of overcoming these. It is based upon the accounts of those reporting a delay of more than three days between receiving the results notification message and taking treatment (n=8), but all barriers contributed to (shorter) delays in the wider dataset (n=30 interviewees). Although interviewees reported busy schedules and working late, these circumstances alone caused little delay, perhaps indicating the high priority given to prompt treatment.

Table 32: Barriers to accessing and taking treatment promptly among those treated 'remotely', and suggestions for overcoming them

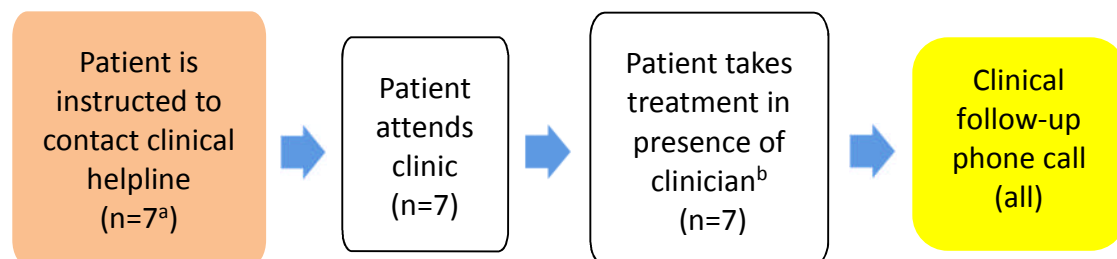
Barriers to accessing and taking treatment promptly	Possible ways of overcoming these barriers through OCP design
Characteristics of OCP design and implementation	
<ul style="list-style-type: none"> • Lack of explicit information that treatment was in stock all the time • Lack of awareness of the scheme among pharmacy staff* • Pharmacy staff aware but unable to give treatment* 	<ul style="list-style-type: none"> • Clear information for patients about when treatment is available • Involvement of more pharmacies, over a wider area • Facility to change the nominated pharmacy • Improved awareness of the scheme among pharmacy staff*
Barriers to patients' access to pharmacies	
<ul style="list-style-type: none"> • Being away from home for several days 	<ul style="list-style-type: none"> • Involvement of more pharmacies • Facility to change chosen pharmacy
Patients' health beliefs, and experiences	
<ul style="list-style-type: none"> • Seeking to avoid possible side-effects while at work • Lack of awareness of medical importance of prompt treatment 	<ul style="list-style-type: none"> • Reminder messages (if acceptable): <ul style="list-style-type: none"> - to collect treatment - to take treatment promptly • Displaying information on treatment/side effects, more prominently

(*See Discussion)



7.2.5 Being directed to clinic/GP for treatment

Figure 24: Being directed to clinic/GP for treatment



n=number of interviewees

^a6 disclosed symptoms, and 1, an allergy. ^bStandard practice in GUM clinics.

Description

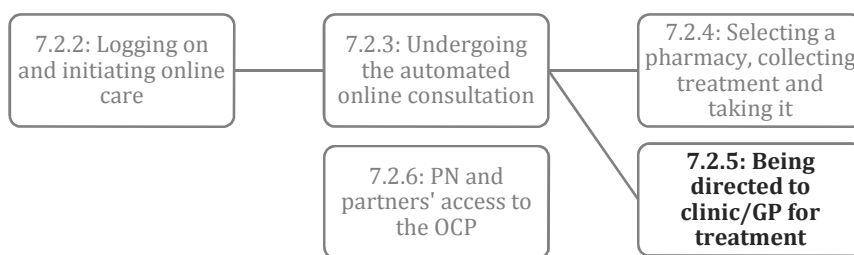
In the online consultation, patients were asked about symptoms, allergies and other contraindications to remote treatment with azithromycin. Disclosure of certain symptoms, allergies or contraindications would prevent them from being able to continue online. They were then informed to contact the Helpline, and could not navigate 'back' to change their responses. Via the Helpline, the RHA could book appointment at study clinics, and provide other clinics' details, to facilitate treatment access.

Results

The theme **4a: reacting to anxiety** was prominent at this stage. Symptomatic interviewees were concerned by being told that they could not continue online, and by the lack of online information about why this was.

I didn't understand why I couldn't have access, maybe I needed, I don't know, more, some more check-up that I didn't have like when I went to the sexual health centre. I should have just been treated straight away, so I don't know, don't understand [...] ...what can be worse, like if you have already got the problem.

(KG, 30-year-old woman)



This lack of information could lead to further worries, even for this interviewee, who understood that she had tested negative for non-chlamydial STIs:

Well you start thinking that there's more than just chlamydia behind it, that's it. [Interviewer: Okay, more as in...?] More as in more, yeah more disease probably or more, something more important behind it than just having chlamydia. (EG, 26-year-old woman)

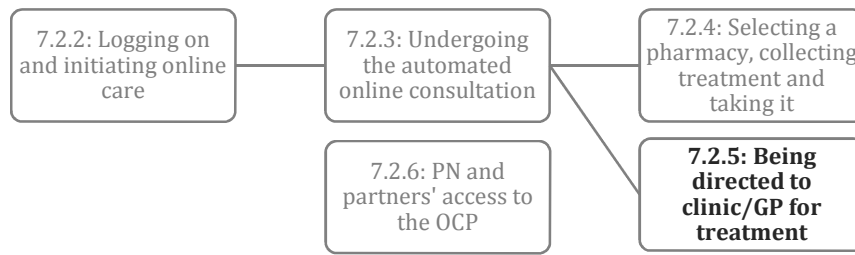
Anxiety could also be raised for Checkyourself patients, who had not been tested for a comprehensive range of STIs, and who believed that their symptoms could indicate a different STI (as is indeed the case). For this woman, who was 'anxious right up until the [clinic] appointment',

...the only thing that would have made me less anxious is that if I actually got tested for all other erm, sexual-related diseases[...] ...I was anxious about those other results. (KC, 21-year-old woman)

These anxieties were compounded for interviewees who had specifically sought to avoid clinic attendance.

Interviewees were typically in touch with the Helpline the same day (by calling it, or by being called), and some had already arranged a clinic visit by this time (**1: acting with urgency**). Symptomatic interviewees who were prevented from continuing online all reported attending clinic within a few days.

In contrast to the symptomatic women, the (one) male interviewee with symptoms expressed no anxiety, instead saying how 'annoying' it was to be prevented from continuing online. Nowhere in his interview did he express an understanding that his clinic visit may have been medically necessary. He appeared to stop himself from saying that he would under-report symptoms in order to avoid a clinic visit:



...it made me feel like I shouldn't have answered that question the way I did. I should have perhaps, er – not, yeah, no, no don't worry, sorry.

(UC, as above)

Other interviewees who were directed to clinic expressed that 'other people' might under-report symptoms, in the context of barriers to clinic attendance.

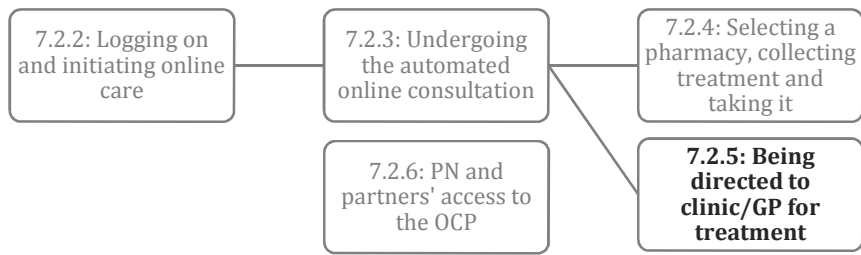
Symptomatic interviewees who received no further investigations in clinic questioned whether clinic attendance was necessary, and/or whether they should have been offered online care in the first place. This woman describes having had what she calls a 'smear test' when she tested in GUM and disclosed symptoms, but was not examined or tested when she returned to clinic:

...at my first appointment I mentioned already that I had bleeding between the periods, so obviously when I answer the question [online] I'm being honest, I'm saying again that I had bleeding between the periods. And then they tell me that I need to go back to the hospital. But in the end, that was not necessary because I mentioned it at the first time, so they could have just told me okay now you can, you need to get the treatment, and that's basically what they told me face to face, so I kind of yeah, wasting a bit of my time, going back there thinking that they might have to do more, more tests or something.

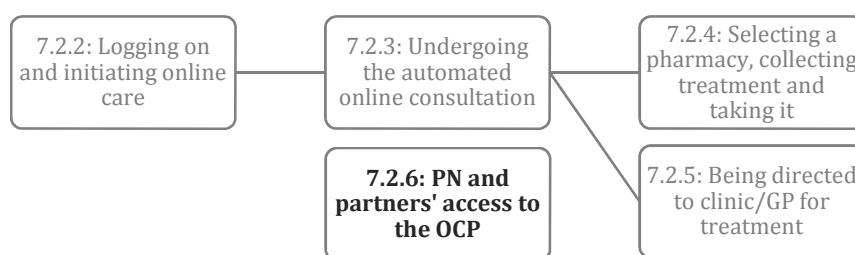
(EG, 26-year-old woman)

Implications

- Better expectation management is required, about what an online service can provide, e.g. information that remotely-delivered treatment may not be appropriate for everybody.
- Although patients were alarmed to be told that they needed to attend clinic, the Helpline provided reassurance within a short timeframe, and symptomatic interviewees attended quickly (within a few days).

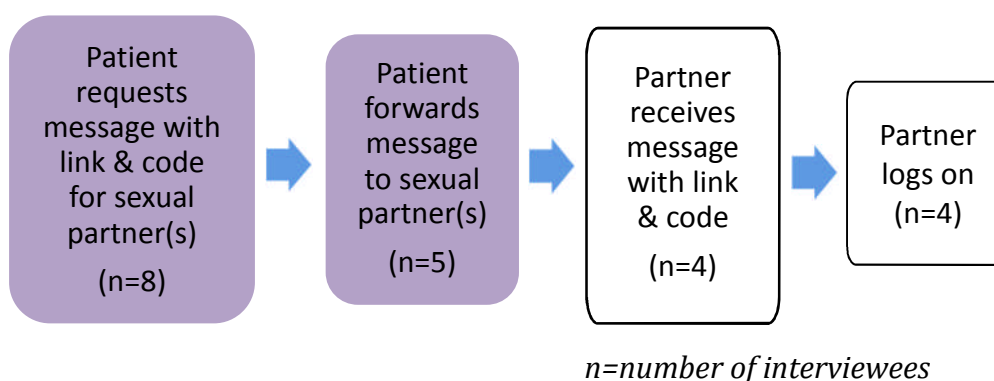


- Medical safety of prescribing is paramount, and it is important that future users do not under-report symptoms in order to avoid a clinic visit (with implications for morbidity and onward transmission of STI). Information provided online, via the Helpline, and in clinic, should be consistent, emphasising the importance of clinic attendance, and the possible precautionary nature of this.



7.2.6 Partner notification and partners' access to the OCP

Figure 25: Use of the message for partners' access to the OCP

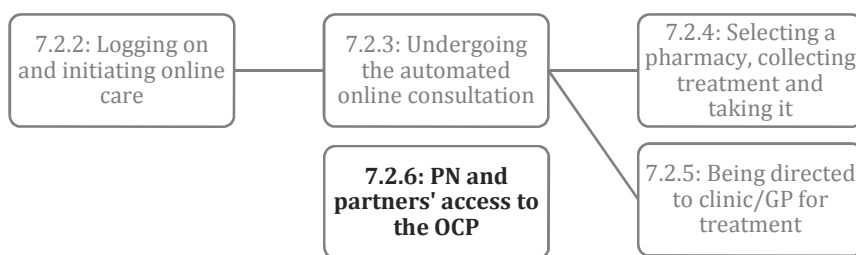


Description

Patients were encouraged to notify their partners in information provided online, and during the Clinical Follow-up telephone call (in which the RHA offered advice and assistance, and, as is standard clinic practice, recorded PN outcomes).

OCP users who had tested chlamydia-positive (n=36 interviewees) could request a message containing a web-link and code to forward to their partners. Using this link/code, partners could use the OCP too. (The message was intended to be sent after PN, and not intended as a means of notifying partners.) At Clinical Follow-up, the RHA again offered patients the opportunity to log in to request the link/code, if patients said their partners were not yet notified or treated.

With the link/code, partners of OCP users could log in, confirm their eligibility, and proceed online as per other participants. Thus, they could obtain treatment without testing (epidemiological treatment, see glossary).



Results

Almost all interviewees who discussed having recent, contactable sexual partners (who did not already know about their chlamydia exposure) described notifying them. However, few sent their partners the message containing the link/code. This section focuses on this message, as the unique and unexplored element of partner management via the OCP.

Awareness, understanding, requesting and sending the message to partners

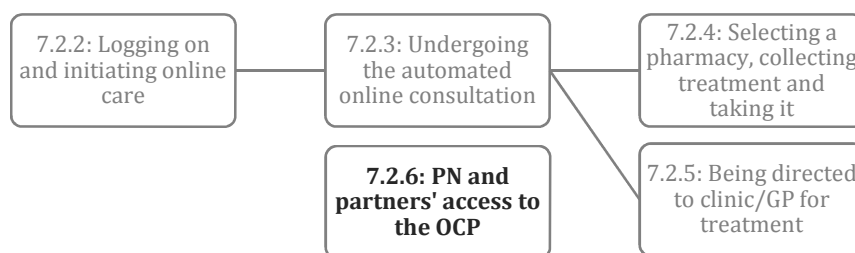
I asked interviewees whether they noticed that they could request a message for their recent sexual partners, and if so, how they understood it to work.

Interview accounts revealed recurrent misunderstandings and barriers. After exploring barriers to use, I explained how the message was intended to work. This was often challenging, but once interviewees understood it, some accepted it as a useful option to have.

High levels of awareness of the message for partners contrasted with recurrent misunderstanding of the function and nature of this message, including:

- that the OCP website would send the message directly to partners;
- that the message was intended as a means of PN: to be sent instead of notifying partners (e.g.) in person or by phone.

In these cases, reservations were as reported in the literature on IPN (see chapter 2), namely that communicating STI exposure anonymously or via text message was rude and was not the way they themselves would wish to be treated. A further misconception was that there was no need to request a link/code, because patients could simply forward the OCP's web-link (i.e. not understanding that partners required their own log-in code). However no interviewees described attempting this.



When the message was understood as researchers intended, and partners were contactable and not already notified, some interviewees still did not request the message because they believed partners could not (or should not) be treated without a diagnosis. They were unaware that epidemiological treatment is standard partner management for chlamydia. Some also reasoned that their partners ought to have a full STI screen, so might as well attend clinic for this and for treatment. Furthermore, some described having (had) partners outside the UK, as a reason for not requesting the message.

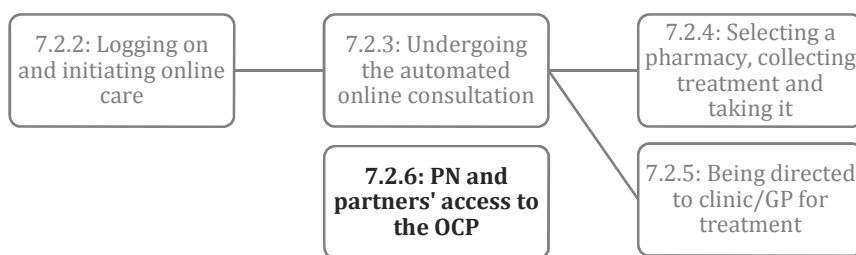
Others, with casual partners, considered it intrusive to suggest where a partner should seek treatment:

I'd rather leave it in their control. (WG, 29-year-old man)

...I suppose it's almost, some people could see it as though I'm trying to take control of the situation for them? It's... I think it's such a personal thing that... it could be seen as quite intrusive. [Interviewer: Right.] So, like I know that he has, has got that [chlamydia], but it's, it's down to him if he wants to go and ...get help with it, it's not... yeah it would be like me invading privacy really. (LG, 20-year-old woman, treated remotely)

This woman's views about notifying her two casual partners echoed this point, and exemplified interviewees' limited awareness of epidemiological treatment:

...they said they were going to sort it out themselves. So I kind of thought, okay, like let me not, like kind of, intrude on what they want to do. Like they kind of, at least they've got to go and get tested themselves at a different clinic or whatever. [...] But I think at the time I didn't really realise that [...] they could have the treatment, without having getting tested or whatever. [...] if I knew more [...] I probably would have just given it [the message] to them... (LC, 24-year-old woman, treated remotely)



It is unclear how much attention interviewees gave to reading about the partner code, given that PN for casual/former partners was sometimes described as a low priority. For instance, this woman expressed annoyance at her one night stand, and explained that when she was diagnosed, *'I was my own priority'*

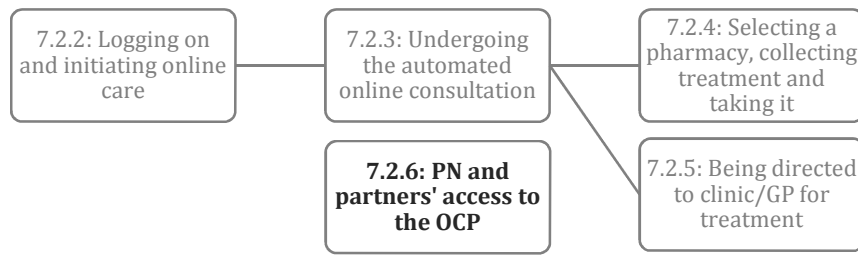
...they give you an option to forward a message [...] to anybody else that you might have slept with, I didn't even – that wasn't – it didn't even cross my mind, I didn't really care, you are on a back burner, whilst I deal with myself... (DG, 30-year-old woman)

Some interviewees described how they had only understood how the message and link/code worked, when the RHA explained it in the Clinical Follow-up phone call, by which time they had notified their partners (who were presumed treated).

Partners' use of the OCP

Only four interviewees had used the OCP as partners (reflecting low numbers of partners participating in the Exploratory Studies, Box 8, p264). None of them discussed problems logging on, and their experiences of using the OCP were remarkably similar to those of other interviewees, except that they expressed less urgency about logging on to the OCP. None mentioned using the Helpline or other services.

Some described how they would have preferred to test for chlamydia, in order to avoid taking medication unnecessarily, and/or to establish who had infected whom. Nevertheless, they described using the OCP without testing, because they sought treatment rapidly, and because of difficulties accessing clinic (**1: acting with urgency; 3a: experiencing constraints**).



Implications

- In-depth interview data (supported by patient-reported quantitative data, Box 8, p264) suggests that PN is being undertaken by OCP users.
- It is challenging to engage ‘index patients’ with novel partner management interventions, without a timely conversation with a healthcare professional. The message containing the link/code for partners was conceptually complex and difficult to understand when described online, suggesting that it requires high (health) literacy (however, it may be possible to improve its description e.g. through further cognitive testing).
- Acceptability of requesting and sending the link/code to partners may be increased by:
 - presenting it as an extra *option*, by which partners can be treated (to lessen concerns about ‘intruding’ in partners’ care-seeking);
 - explaining that it is standard clinical practice to provide chlamydia-exposed current/recent partners with treatment, without test results/diagnosis.

7.3 Results (b): Appeal of the Online Chlamydia Pathway

Through a second thematic analysis of the same interviews, I identified five themes (Box 10) which describe and explain the care pathway's appeal, and the limits to this. I discuss and interpret these with reference to relevant theory and evidence on: patients' experiences of having an STI, the significance of care- and treatment seeking, and barriers to using existing sexual healthcare. In section 7.3.6 I summarise how these themes interrelate.

Box 10: Themes and sub-themes describing the appeal of the OCP

Short names for themes are emboldened.

1. **Speed**: the option of a rapid route to treatment
2. **Ease and straightforwardness**: if it's easy to get treatment, it's easier to deal with having chlamydia
3. **Privacy**: sexual healthcare may be more private online
 - a. **Social privacy**: the ability to conceal sexual healthcare use and STI from those around you
 - b. **Facelessness**: avoiding awkward moments
4. **Flexibility and convenience**: healthcare that works around you
5. **Association with trusted services and professionals**

7.3.1 Speed: the option of a rapid route to treatment

The expectation of rapid treatment access was central to the OCP's appeal:

...privacy obviously was a benefit, I suppose, but, you know, it's getting the treatment the quickest, was probably my main reason for doing it.

(NC, 26-year-old man, treated remotely)

Rapid treatment was valued for health reasons, and also psychosocial reasons. While interviewees often were uncertain or vague about the medical effects of delayed chlamydia treatment, a prompt route to treatment signified a way of ridding themselves quickly of an infection which made them feel 'dirty' and 'not myself'. This suggests that (self-)disgust and stigma were underlying reasons for valuing rapid treatment access, as a way of removing the 'discrediting'¹⁶¹ STI. By

allowing users to ‘*deal with it straight away*’, the OCP could mitigate the emotional impact of having chlamydia,⁴⁹ as this student explained:

...it's sort of over and done with, you don't really have to deal with it that much. Whereas if you had to wait a few days to get your treatment, cos you've got to go back to the clinic which is far away or something, it's on your mind a lot more. [...] ...imagine you've got an essay to do and it's in the back of your mind constantly until you do it. It's just a constant worry.

(LG, 20-year-old woman, treated remotely)

Like LG, interviewees tended to discuss how the speed of the OCP compared favourably with attending conventional sexual health services (for which waiting times are a barrier to use¹⁴⁴).

The strength of negative feelings, among interviewees who experienced just a few days' delay in accessing treatment via the OCP,^{xiv} demonstrates how highly they valued rapid access to treatment. This woman's description of the impact of having to make a second visit to the pharmacy, was typical:

...I've never had anything like that [chlamydia] before and it was obviously quite a horrible feeling, so I was quite keen to get it sorted out obviously ASAP. And then when I found out that I couldn't [...] it just seemed like the longest wait ever, and I was quite frustrated at the time, quite upset about the whole thing...

(IG, 26-year-old woman, treated remotely)

Negative reactions to short delays also seemed to stem from a mismatch between interviewees' expectations about online services, and reality:

...when I saw I could have the treatment online, I was enthusiastic. I mean I did everything and it was impossible, so I felt like disappointed, I was like oh no, I really hoped like, I didn't have to wait, and I didn't have to book for another appointment and wait for another hour at the centre.

(KG, 30-year-old woman, directed to clinic)

Losing control (having done everything, it was impossible) seemed to contribute to feelings of disappointment, suggesting that users expected not

^{xiv} As reported in Box 8, p285, a minority of Exploratory Studies participants (32%, in a follow-up survey) reported any type of problem with pharmacy treatment collection, and treatment was collected rapidly despite these issues affecting some people (median 1 day after receiving results, IQRs 0-1 for GUM patients, 0-4 for Checkurself users).

only prompt access to treatment, but to have control over how they received their healthcare. Some interviewees exercised control over when they accessed and took treatment, valuing the ability to do this at their convenience (although still quite promptly). Taken together, this suggests that the *option* of rapid treatment access is paramount, rather than rapid treatment access in all circumstances (further discussed in section 7.3.4, **flexibility and convenience**).

The two interviewees who disengaged from the OCP after accessing their results serve as ‘negative cases’ against which the integrity of this theme can be checked. Their atypical behaviours and circumstances are described on p276. Like others, they valued rapid treatment access, but perceived that they could achieve this by attending clinic ‘*straight away*’. Both, distressed by their diagnosis, sought empathy through face-to-face contact with healthcare professionals, and considered the waiting time in clinic to be tolerable in these circumstances:

...it took almost two hours to see a doctor, which was a bit long, but, at the time [...] as I told you, all these things running through my head. And I didn't care about waiting... (CG, 24-year-old woman, disengaged)

7.3.2 Ease and straightforwardness: an easy route to treatment makes it easier to deal with having chlamydia

Interviewees typically described the OCP's process as straightforward and easy.

...so easy, how can anyone not be able to do it? (SC, 24-year-old man, treated remotely)

This ease was associated with the online nature of the service, which:

...probably will make life easier for a lot of younger generation, because obviously we're online these days, log on and get stuff done. People find that pretty easier. (ZP, man, treated remotely)

An easy, online route to treatment was described as making it easier to deal with a difficult situation, which some interviewees found difficult to talk about. As with the theme of **speed**, this speaks to the potential of the OCP to minimise (or at least, not to exacerbate) the disruptive impact of an STI diagnosis.

Exemplifying overlap between **ease and straightforwardness** and the themes of **privacy** and **flexibility and convenience**, the discreet and flexible service was perceived to make it ‘*much easier*’ for busy interviewees to receive healthcare, compared with attending clinic:

*....it's great to be able to just do the – kind of, at your own ease, not have to speak to someone if you don't want to, cos people can obviously be quite shy about the whole thing and it is slightly embarrassing, I suppose
[...] ...being able to do it online is a much easier process for a lot of people. I know I found it a lot easier, especially being at work that day.*

(IG, 26-year-old woman, treated remotely)

Interviewees universally valued having an easy route to treatment for themselves, but some expressed concern that this could lead others to take their sexual health less seriously:

...I think it's just getting, easy for people to get that treatment without maybe worrying there might be something more behind.

(EG, 26-year-old woman, directed to clinic)

7.3.3 Privacy: sexual healthcare may be more private online

Interviewees discussed how the OCP appealed to them through its potential to help them protect two types of privacy: social privacy and ‘facelessness’. All interviewees valued privacy in relation to their sexual healthcare, but to differing extents. Those who considered social privacy and/or ‘facelessness’ very important considered the OCP to be more private than attending clinic. In contrast, those who expressed that there was no need for embarrassment concerning sex or STIs, tended to discuss the OCP as similarly private to conventional sexual healthcare services.

Social privacy: concealing sexual healthcare use and STI from those around you

The term ‘social privacy’ (explained in the title above) is used by other eSTI² researchers.¹ Section 7.2 has explained how the design of the OCP’s web-interface enabled interviewees to maintain their social privacy, and that they

did not have to explain an absence from work (as they might if attending clinic). Interviewees compared the OCP's pharmacy treatment collection process favourably with the process of attending sexual health clinics:

...when you go clinic, you don't know who's in the clinic. You might see somebody who you don't wanna see, or someone who your mum knows, or anything so... Whereas if you go into the chemist and you just show them the message, then they know what you're talking about and they put your stuff in the bag and that's it. It's very discreet and private.

(JC, 32-year-old woman)

They valued that their reason for attending the pharmacy was not evident to other pharmacy users, particularly when they '*weren't treated any differently than you would if you were going to pick up, I don't know, some like flu tablets*':

...it's nicer because you could be going into that pharmacy for anything, nobody knows why you're going in there. Whereas if you've got to go back to the sexual health clinic, if a friend or someone that knows of you sees you going there, they automatically think "oh she may have something". And it's just, people can take it the wrong way.

(LG, 20-year-old woman, treated remotely)

In common with some other interviewees, LG describes perceiving a risk of being judged by other sexual health clinic attendees, even though:

...everybody in the waiting room is there for some sexual health reason, but it's still the judgement, because it's not something that's easily spoken about. [...] ...it's just the general thought of, around sexual health, like, and STIs.

(LG, as above)

Concern about social privacy related to interviewees' fear of being judged for their (assumed) sexual behaviour, and the nature of the STI or those infected (as '*disgusting*', '*dirty*'). By enabling concealment sexual healthcare use and STI, the OCP could help users to manage the stigma (including felt stigma¹⁶⁷) which concerns people seeking chlamydia treatment. OCP users could protect their social privacy through their own actions, whilst engaging with the OCP's online interface. However, whilst 'offline' (e.g. during pharmacy treatment collection),

they sometimes faced threats to their social privacy which were unexpected and outside their control.

There was a greater tendency for women interviewees, particularly younger women, to express concern about social privacy, and consequently to value the OCP for its potential to help them conceal their sexual healthcare use and STI. This may stem from gendered differences in norms surrounding sexual behaviour,⁵³ and therefore, the social implications of STI. Those who tested via Checkurself tended to express greater concern about social privacy than those who tested in GUM (evident in their expressed reasons for using Checkurself and the OCP, and their reactions to threats to social privacy). This suggests that experiences of clinic, preferences to receive services online, and perhaps interpersonal differences, are influential.

Those who expressed least concern about concealing their STI and sexual healthcare use tended to express views that 'normalised' chlamydia (i.e. they seemed to consider it to be quite ordinary, rather than unusual or especially stigmatising). For example, they remarked that it is relatively common, that they knew people who had had it, it is '*nothing to be ashamed of*', and that therefore they were not particularly worried about those around them finding out. Still, even those expressing little concern for social privacy spoke of how they would not wish certain people (e.g. parents, colleagues) to discover their diagnosis.

Facelessness: avoiding awkward moments

For some, the avoidance of face-to-face sexual healthcare consultations was important, and so getting treatment online appealed because of being '*kind of faceless*' (NC, 26-year-old, treated remotely). Describing how '*because you get rid of the human interaction*' it was more private online,

...you can feel a bit more confident just hiding behind a screen [of a smartphone/computer]. (GG, 25-year-old woman, treated remotely)

During sexual healthcare consultations:

...you feel like you've done something wrong. You've got something that you shouldn't have, and now you need someone's help, to get it... Because

without you telling them they are not going to give it to you, really. [...] And then you feel like, like.... I know they're not probably looking at you like that, but you know when you're told that you've got this disease or whatever, that they're just like "oh" you know. [...] ...they know you've done, you've had sex and, yeah. It's all a bit daunting.

(JC, 32-year-old woman, treated remotely)

JC's account acknowledges the subjective nature of her feelings of judgement. Sexual healthcare staff were, based on interviewees' previous experience, often described positively, and as non-judgemental. Interviewees who were treated in clinic universally described positive experiences. Nevertheless, the *possibility* of a staff member judging them was an important reason for some people to want to avoid clinic and instead use the OCP, or to feel trepidation about being directed to clinic. This, and the subjectivity discussed above, suggests that felt stigma¹⁶⁷ (internalised feelings of shame and embarrassment) plays a role in perceptions of being judged, and the ability to avoid this contributes to the appeal of online sexual healthcare.

Interviewees expressed little concern regarding face-to-face interactions with pharmacists, related to the limited nature of discussions with pharmacy staff (instead, it was social privacy which could be threatened in pharmacies). In general they discussed the 'faceless' telephone contact with the RHA as highly acceptable. This suggests that it is the desire to avoid exposure (rather than wanting to avoid contact with healthcare professionals), which explains the appeal of faceless sexual healthcare.

As with social privacy, the OCP's facelessness' tended to be appeal particularly to those who had tested via the 'faceless' Checkyourself (compared to GUM). It was discussed as less important by interviewees who sought human warmth.

7.3.4 Flexibility and convenience: healthcare that works around you

The OCP's provision of healthcare '*almost at my convenience*' (SC, 24-year-old man, treated remotely) was valued. In the context of employment and caring

responsibilities which made clinic attendance difficult, this woman explained why she liked the OCP:

...it's convenient. Like you don't have to go out of your way [...] everything's you. So it's when you click onto the link, when you can go, d'you know what I mean, to either the clinic or to a pharmacy, you pick your pharmacy, you go in when you can pick it up, and you take your treatment. So it works around you. Rather than you having to take time out to go and sort it out.

(DG, 30-year-old woman, treated remotely; emphasis as spoken)

A flexible, convenient route to treatment, which could fit around interviewees' everyday activities, was discussed as lessening the disruptive impact of seeking and receiving sexual healthcare:

...all I was interested in was getting the treatment and you know getting off to work to be honest. [...]...that's how this scheme does actually benefit you because you can just, it's not massively inflicting on your time and whatever, and you can just get on with what you're meant to be doing, pop in to get your treatment [...] it's just not made it such a massive deal for you...

(DC, 24-year-old woman, treated remotely)

Thus, promptly completing the online consultation but collecting treatment 'a couple of days later' was the choice of one woman, who 'didn't want it to disrupt [her] routine that much' (FC, 22-year-old woman, treated remotely).

Interviewees valued having options, which gave them some control over how they received their healthcare:

I think having as many options as possible, being completely kind of in control of how you get the treatment is really important, because I'm... you know, I made all the decisions myself, I chose what pharmacy to get them from, so having the option of, "Would you like a follow-up phone call and talk to someone? Would you like a follow-up text message?" um, you know. If you were super private then you could do a text message. If not, then I probably would have said, Yeah, phone call, let's talk to someone".

(FC, 22-year-old woman, treated remotely)

In contrast, being directed to clinic removed this sense of control. This young man would have preferred it if

...maybe they would have suggested to go to the clinic, rather than saying, you can't go any further, you have to go.

(UC, 21-year-old man, directed to clinic)

Being able to 'pop in' to a pharmacy was anticipated to be more convenient than attending clinic or general practice, but convenience was limited by the choice of pharmacies available, and the inability to change pharmacy if problems were experienced (as discussed in section 7.2.3).

The two interviewees who disengaged from the OCP, and attended clinic, again serve as 'negative cases', illustrating that the appeal of a flexible, convenient service is context-dependent. They were the only interviewees for whom the flexibility and convenience of the OCP did not appeal, and their circumstances have been described on p276. They did not require the OCP's flexibility because they were flexible themselves (and had other reasons for wanting to attend clinic):

...I had the time, at that time. You know, I was [studying] and I was at home all the time, and I just go, just... I was flexible to go there.

(FG, 34-year-old woman)

7.3.5 Association with established, trusted services and professionals

The OCP's association with existing, trusted NHS services conferred trustworthiness. This association was evident in the logos displayed on the web-interface, and in how users were offered the OCP:

Because I knew that I did order the kit and I knew that the kit was from the NHS. I, I just trusted everything that came with it, so I trusted the text, the link, and my results. I also trusted the treatment.

(KC, 21-year-old woman, directed to clinic for treatment)

Despite the appeal of the online route to treatment, access to a health professional remained highly valued. This is exemplified in how adamant interviewees were about the need for a helpline, and also how positively they

discussed the Clinical Follow-up telephone call (see sections 7.2.3-7.2.4). These, they discussed, could provide expert advice and reassurance to patients that they were following (or had followed) the correct process, and had treated their chlamydia correctly. This woman, who phoned the Helpline after receiving her result, explained:

...I probably knew what to do, but it's just because I was a bit overwhelmed about everything. I thought I need to speak to someone um, to clarify.

(JC, 32-year-old woman, treated remotely)

Concerning the Follow-up call:

...if no one called me, then I would've felt a bit like, well, is it done, what should I do? [...]...the follow-up phone call is definitely something that should stay.

(FC, 22-year-old woman, treated remotely)

For the most part, the Helpline was valued for convenience and speed of access, and its optional and 'faceless' nature, and so held similar appeal to the OCP as a whole. However, some interviewees expressed ambivalence about speaking to anyone. For example, MC, who was anxious about her symptoms and upset by her boyfriend's sexual infidelity, discussed her conversation with the RHA very positively, yet with ambivalence about her privacy:

...she did give me a lot of support. But at the same time this is something I just wanted to keep to myself and just have it sorted as soon as possible. I didn't really want to actually talk to anyone about it... [Interviewer: Okay.] It was something I wanted to keep to myself.

(MC, 19-year-old woman, treated remotely)

While it might be expected that distressed patients will seek human support and will not value an impersonal online service, interviewees' accounts suggested that this is not necessarily true. For illustration, I compare two women who both discussed feeling distressed about acquiring chlamydia after their boyfriends' infidelity. MC (above) preferred to proceed online without speaking to anyone, while CG's reaction (p276) was to proceed straight to clinic. CG hoped to speak to the same empathic doctor she had seen when she tested, while for MC, the prospect of explaining that she caught chlamydia as a result of

her boyfriend's '*cheating*' was too embarrassing and upsetting, and '*not something I want to talk about*'. However, in general, women tended to express a greater desire to speak with someone for empathy and support, than men. This gender differences may be related to chlamydia-diagnosed women's greater experience of blame, stigma, anxiety and worry,¹⁶⁶ perhaps due to differing gender norms surrounding sexual behaviour⁵³ and differences in the biological implications of chlamydial infection (described in chapter 1).

Having '*someone behind the machine*' (FC, 22-year-old woman), in the sense of human support and expertise, could enhance or detract from interviewees' experience of online care. This was most apparent when interviewees were directed to clinic for treatment. Although it was nice to have '*someone to kind of look after you and make sure that everything is fine*' (EG, 26-year-old woman), this implied a loss of the autonomy that they had expected from an online service.

These tensions, but also the adaptability of young and (otherwise) healthy people, are suggested by this man:

...people are obviously wary of new technologies, and are used to talking to a doctor. You feel reassured if you speak to a doctor and hear it from a person's mouth, than seeing it on a screen. But I think that will just take, maybe generational thing, it will take people a while to get used it. But for me doing everything online was... nothing really new. I never picked up a treatment online [before] but then I haven't been to the doctors for years for anything... (QG, 22-year-old man, treated remotely)

7.3.6 Overview of appeal and how themes interrelate

Sections 7.3.1-5 have described and interpreted the nature of the OCP's appeal and its limitations. Stepping back from this detail, what stands out from interviewees accounts is how positively they discussed their experiences with this novel intervention, particularly its online component and helpline.

The four themes of speed, ease, privacy, and flexibility/convenience all relate to the largely patient-led nature of using the OCP. The ease of using the pathway, and its flexibility and convenience, enabled interviewees to gain some control over how they received their sexual healthcare. In general, the OCP's design enabled them to protect their own privacy and to obtain treatment rapidly, which made it easier to deal with having an STI. Largely, they could balance the extent to which they chose to obtain treatment quickly and discreetly, with their other needs and activities, thus reducing the disruption posed by the STI and the need to seek treatment.

Conversely, when speed, convenience, privacy or ease were compromised, interviewees expressed frustration. As well as direct negative impacts on interviewees' experiences (detailed in sections 7.3.1-7.3.4), loss of control, in the context of raised expectations of a smooth, patient-led route to treatment, was apparent.

Underpinning the appeal of the novel OCP was its association with known, trusted services (the NHS, study clinics, and Checkyourself) and healthcare professionals. This gave OCP users confidence in using the novel online service, and they valued the opportunity to speak with health professionals without attending healthcare settings, for their expertise, for reassurance, and sometimes for human empathy. However, those directed to the clinic expressed mixed feelings about being prevented from continuing online. This revealed a tension between two aspects that interviewees valued: being in control of how they received their healthcare, and yet having this underpinned by established, trusted services and professionals.

7.4 Discussion

7.4.1 Main findings

Interviewees used the OCP to obtain their chlamydia treatment promptly, conveniently, discreetly and with ease, in the context of busy lifestyles which impeded access to clinic or general practice. Using the OCP was perceived to help reduce the emotional impact of having an STI, and interviewees valued the considerable control it gave them over when and where they completed the consultation, accessed information and support, and collected treatment. Online, they provided their sexual histories without the embarrassment or perceived risk of judgement which deterred some of them from attending conventional services (and perhaps more accurately). Using the OCP therefore enabled them to manage felt stigma, although the importance of this varied between individuals. Their confidence in this novel e-health intervention was enhanced and underpinned by its association with healthcare professionals and trusted NHS services.

Interviewees valued telephone contact with a Sexual Health Adviser, for the information, assistance, and tailored, human support which could be provided. However, other 'offline' parts of the pathway were sometimes problematic. The pharmacy treatment collection process could work well for patients, but could compromise the perceived advantages of an online route to treatment (privacy, ease, convenience, speed). Being directed to clinic could also preserve or compromise the appealing characteristics of the OCP, representing tensions inherent in a patient-led and yet medically-supervised care pathway, designed for clinical safety. Indeed, the frustration expressed regarding being directed to clinic, and regarding problems with pharmacy treatment collection, suggests that the prospect of receiving their healthcare 'online' may have raised interviewees' expectations of having control over their healthcare, to a medically-inappropriate extent.

Very few, minor issues with navigating the OCP were mentioned. However, uptake of online health information appeared to be influenced by interviewees' states of mind and contextual factors, such that some of them proceeded to

treatment without (apparently) reading the information provided online, or noticing the OCP's links to further information. Interviewees who described more private surroundings, and less urgency, found adequate, helpful information.

In general, interviewees discussed having notified their partners, but had poor awareness and understanding of the message to enable partners' access to the OCP. Once understood, this facility was considered potentially helpful, although barriers to its use remained.

7.4.2 Strengths and limitations

This is the first qualitative study among users of a novel, unique e-health intervention. It contributes a contextualised description of how people used an online care pathway for an acute, stigmatised condition, and also how this online pathway appealed to them (including limits to its appeal). E-health interventions may suffer from problems with usability⁴⁷⁶ and attrition,^{477,478} as people stop using them if they do not fit with their 'daily lives, habits or rituals'.⁴⁷⁹ By exploring the contexts and ways in which the intervention works well, or less well, I used realist qualitative research^{353,378} to generate suggestions for intervention refinement and ongoing evaluation. The qualitative research strategy allowed me to document otherwise unobservable behavioural and contextual details, to offer explanations for behaviours, and to draw out the deeper reasons underlying this e-health intervention's appeal. The study built upon relevant evidence and theory, including qualitative formative research (my own,⁶ chapter 5, and colleagues'¹), and is based on experiential accounts, which have greater authenticity than those generated in earlier studies.^{1,6}

The two thematic analyses make efficient use of the data, and are complementary: understanding the appeal of the OCP to its users was aided by understanding how they used it, and *vice versa*. However, by exploring how interviewees progressed through the OCP (to address objective 3a) I imposed some sort of structure upon interviewees' accounts, which may not have been present had I simply asked for their views on the OCP (to address objective 3b).

However, for this complex intervention, which is ‘received’ differently by different users, understanding their diverse experiences helped me to interpret their expressed views.

Quotas based on primary sampling criteria were filled, and the sample was diverse by secondary sampling criteria including ethnicity, experience of sexual healthcare and previous STI. The purposive sample was therefore strong, enabling use and appeal of the OCP to be explored from a range of perspectives by which I expected patients’ experiences to vary. Recruitment of patients who had self-sampled remotely via an online service (Checkyourself), and patients who had tested in clinic, enabled comparisons: the former may better represent users of a future self-test, while the latter had recent experience of face-to-face sexual healthcare and so might be better able to compare online and clinic-based sexual healthcare. However, I made comparisons tentatively, because these groups differ in other ways (e.g. their age-range, the STIs they tested for). Despite the sample’s strengths, the study is limited in its ability to explore disengagement from the pathway, and partners’ OCP use. The sample also lacks representation of MSM and women who have sex with women (WSW), despite attempts to recruit from these groups (which were rare in the Exploratory Studies, see p260, and Box 8, p264).

I did not purposively sample by interviewees’ education or socioeconomic status, nor systematically collect these data (although many interviewees mentioned professional, office-based employment, and/or university education). This could have been informative given the importance of ‘digital divides’ in e-health (chapter 1) and internet-use for sexual health (chapter 4), and associations between deprivation and STI prevalence.⁶² However, measuring socioeconomic status is not straightforward among the young age-group most affected by chlamydia (whose working life is beginning and whose education may be ongoing⁴⁸⁰), and the sampling frame was already complex.

The active sampling strategy, and participation of a large proportion of those approached, reduce the likelihood of over-representing the views of people who

may be more likely to volunteer to participate in research (e.g. opinionated people; those interested in technology or healthcare). However, those who did not participate may differ from interviewees, and I have scant information about reasons for non-participation. The sensitive nature of the topic and difficulty making time for an interview were mentioned by the few people I spoke to who declined an interview, despite my flexibility regarding interview scheduling and assurances of confidentiality. Those not interviewed may have been even busier, and more concerned about privacy, than interviewees were.

The data management method (Framework³⁸⁶), and thematic analysis,³⁷⁴ are both systematic, well-defined, and facilitate transparency. My familiarity with the dataset, creation of maps summarising interviewees' care, and linkage of Framework matrices to transcripts (in NVivo) helped ensure that the data excerpts were interpreted in context. Framework matrices facilitated second coding and constant comparison across this relatively large qualitative dataset, and thus definition of themes,⁴⁵⁹ and helped me to avoid giving undue 'weight' to particularly memorable interviews.

Second-coding strengthened my analysis by offering an additional perspective, and helping me reflect on my own perspective and influences on the research. The second-coder, a senior researcher who helped develop the OCP and Exploratory Studies, has a clinical background, while I do not. Our relationships to the intervention were complementary: she could quickly see what was 'supposed' to have happened to interviewees, while my perspective was intentionally naïve with respect to the inner workings of the OCP (see chapter 6, p256). Greater distance from intervention design and implementation than either of us had, could aid neutrality, but some knowledge of the OCP was necessary to comprehend interviewees' accounts. During the analysis I was aware of a possible temptation to discuss my research team's intervention positively. However, my research diary shows divergence between my expected and actual findings: I anticipated more criticism of the novel, online part of the OCP, and expected neither the difficulties with the pharmacy process, nor their

impact. Considering these issues has helped me to produce an account which I feel fairly reflects the data.

Fitting with my PhD research question and objectives, I interpreted interviewees' accounts through a health/healthcare 'lens': I believe in the importance of STI testing, treatment, and PN (as do my supervisors and colleagues). However, health implications are only part of the experience of having chlamydia,⁴⁸¹ and interviewees had priorities other than health(care). In my analyses about OCP use, I tended to view these priorities (and interviewees' views, beliefs, emotions, other activities, and contextual details) in terms of their potential to obstruct or facilitate prompt treatment, access to health information, and PN. In my analysis about the OCP's appeal, I referred to relevant theory and the wider literature on the experiences of having STIs including chlamydia (which largely focuses on women), to give explanatory depth to my analysis. It is encouraging that interviewees' experiences of chlamydia did not seem unusual when compared to this literature. Some accounts suggested milder psychosocial impacts than those discussed in the literature, perhaps reflecting how chlamydia has become more normalised (perhaps due to widespread screening), or that my study included men, who may experience fewer negative effects.¹⁶⁶

Retrospective accounts can be subject to distortion, post-event rationalisation, and recall issues,^{20,482} which may be minimised by conducting interviews soon after completion of care, as I did (mean/median: 5 days). Interviewees' recall seemed good, perhaps aided by probing and seeking clarification, which helps to generate detailed accounts,⁴⁸² and by allowing interviewees to describe their experiences in their own terms, which may increase the trustworthiness of the data.⁴⁸³ However, it has also been argued that the passage of time helps people to reflect upon and produce deeper descriptions of their experiences.⁴⁸³ Although interviewees seemed capable of reflecting, their feelings about having chlamydia and about their healthcare may still be developing.

Findings are credible when compared with the aggregate quantitative data about OCP use and acceptability (Box 8, p264; data are integrated in chapter 8, section 8.3). Interviewees discussed potentially socially-undesirable and sensitive behaviours and experiences (including: previous STI; having multiple, concurrent or casual sex partners; inconsistent condom-use; not notifying partners; lying to healthcare professionals). The 'faceless' telephone interview, my assurances of confidentiality, my separation from the clinical team, and non-judgemental interviewing, likely helped, and were appropriate to the topic (see p152). Telephone interviewing appeared effective from my perspective (chapter 6, p294) and acceptable to interviewees (Appendix 9f), but social desirability concerns may still have influenced interviewees' accounts.

Data security and e-health literacy were not explored in depth. These issues were to be explored in a colleague's qualitative HCI study, which was cancelled after my interviews began. I did not add them to my topic guide, because additional complex topics would be time-consuming to explore, which would reduce the depth of exploration of other interview topics.⁴⁵⁷ Although some interviewees mentioned data security, they discussed few, minor concerns. However, non-users, who may have greater concerns, were not interviewed

This qualitative study's conceptual framework and sampling strategy were suited to exploring individuals' use and appeal of a (largely) online route to treatment, fitting with the study's main objectives. However, PN and assisting partners' access to (online) healthcare are very different behaviours from using healthcare for oneself. These behaviours could better be explored through a dedicated study, using a different conceptual framework, and a sampling strategy which included partnership type.

Finally, my examination of barriers to prompt treatment among those treated remotely (p294) used a strict definition of 'delay': treatment more than three days after results notification (whereas the NCSP's recommendation is to treat within 30 days.¹³²) My choice was pragmatic, enabling eight interviews to contribute to this analysis, in a sample where most people were treated very

quickly.⁹ To enhance confidence in this small analysis, I checked that each barrier I identified also slowed progress to treatment in the wider sample of interviewees treated remotely. However, other barriers may exist.

7.4.3 Discussion of findings in the context of other research

Design research to develop the online interface,¹ and cognitive testing of the OCP's online text and consultation⁵ likely contributed to the ease with which interviewees used the online results service, completed the consultation, and selected a pharmacy. However, the current study has demonstrated how emotional reactions to a diagnosis may affect patients' ability to use the OCP optimally. This was not identified in formative research,^{1,6} underscoring the importance of research with people who have experienced a real diagnosis and intervention.

Findings from the analysis about the OCP's appeal provide greater depth and nuance to chapter 5's analysis about the acceptability and perceptions of STI self-testing within online care pathways.⁶ Mostly, they support this earlier study's findings (despite the studies' differences, Table 17, p154). The importance of optional access to a specialist sexual healthcare professional was confirmed. Women in the current study were concerned about social privacy, but expressed much less concern about others knowing that they were sexually-active, than chapter 5's women interviewees. Sexual healthcare use may be more normalised, and its signifying sexual activity less of a concern, in the current study's older age-group. Little concern about others seeing electronic 'evidence' of STI and sexual healthcare use suggests that the OCP's web-interface and message wording was effectively informed by formative research.^{1,5,6} In contrast to chapter 5's interviewees, interviewees in the current study expressed few concerns about data security, perhaps reflecting that the latter had self-selected to use e-healthcare, but also, changes in technology use between 2012 and 2014-15 (see section 1.7), and greater familiarity with doing a wider range of activities online. Age and socioeconomic differences may also contribute to differing norms surrounding technology use (e.g. chapter 5's

interviewees frequently discussed looking at each other's smartphones, which was rarely mentioned in the current study).

The potential for community pharmacies to deliver a quick, convenient sexual health service has been discussed elsewhere,^{484,485} but with similar challenges encountered, including suboptimal confidentiality at pharmacy counters⁴⁸⁴ and inconsistent availability of staff who have been trained to deliver new services.^{484,486}

One study on self-care health apps found that people who were asked to imagine having certain symptoms were alarmed by being told that they needed to see a healthcare professional, and might not take this advice seriously if they considered it to be given too readily, for a complaint that they perceived to be non-serious.⁴⁷⁶ Though similar to my findings about interviewees' experience of being directed to clinic (section 7.2.5), the current study's interviewees reported attending clinic promptly despite their doubt or alarm, and my findings have greater credibility, being based on e-healthcare use for a real condition.

New sexual health technologies have been claimed to enable greater control or autonomy,⁴⁸⁷ which interviewees in the current study valued. Sociological research about the medical encounter, based on interviews with Australian patients (not e-health), demonstrates how patients interacting with healthcare professionals may pursue 'passive patient' and 'consumer' strategies simultaneously, or vary them according to the context.⁴⁸⁸ Despite the absence of a conventional doctor-patient interaction, my findings echo this. For example, web-searches to check that the treatment provided was correct, and interviewees' reactions when they were prevented from continuing online, suggest a 'consumer' role, in which interviewees sought to be informed and in control of their healthcare. Examples of 'patient' roles include: trusting and following the OCP's instructions, and interviewees' appreciation of the Follow-up call, in which they were offered advice and reassured that they had, essentially, been 'good patients'.

Other studies have shown that sensitive behaviours may be under-reported face-to-face, compared to online⁴⁸⁹ or via CASI,⁴⁹⁰ as some interviewees suggested. I identified fear of judgement and embarrassment during face-to-face consultations as possible reasons for this, and showed how this fear may even be experienced by people who generally consider healthcare professionals to be non-judgemental. This supports Scambler and Hopkin's thesis that felt stigma has a significant impact on behaviour.¹⁶⁷ A review of CASI for clinic-based sexual history-taking (typically undertaken before testing/diagnosis) found it resulted in lower reporting of symptoms than being interviewed by a clinician,⁴⁹⁰ and while I found no evidence of this, it would be better explored in a larger, quantitative study.

Other findings about the OCP's appeal are echoed by evidence from other health areas. A systematic review of preferences in healthcare demonstrated that convenience is valued, independent of health outcomes,⁴⁹¹ and internet-based sexual healthcare in particular has been hypothesised to make sexual healthcare use more convenient³⁶⁶ (and see chapter 2). Associations with known, trusted services have been found to confer trustworthiness upon e-health services^{6,492,493} and potential users of sexual health websites prefer them to appear professional and authoritative.^{372,494} Stigma and embarrassment have repeatedly been identified as barriers to sexual health clinic attendance,¹⁴¹⁻¹⁴³ as has patients' employment,⁴⁹⁵ and this chapter's analyses have demonstrated how an online service can help some people to manage these barriers.

7.4.4 Meaning and implications

This study has generated practical suggestions to inform the refinement and ongoing evaluation of remote, internet-enabled care pathways for the management of genital chlamydia. Interviewees' desire for prompt treatment, the OCP's potential to facilitate this, and suggestions which may further speed it up, together support the OCP's potential to deliver public health benefit by reducing onward transmission and morbidity through prompt treatment.

However, the medical appropriateness and feasibility of my suggestions for OCP refinement, and their acceptability to OCP users, need to be considered.

Some of the themes from the two thematic analyses are comparable, which reflects how progress along this care pathway was predominantly patient-led: patients used it in ways which took advantage of the characteristics that they valued. Patients eligible for remote treatment, for whom speed, privacy, ease and convenience was preserved throughout the pharmacy process, expressed the greatest satisfaction with the OCP. In general, OCP users had a degree of control over how they used the care pathway, yet progress was supervised, which met their desires for a service which looked after them, but gave them some choice and flexibility over how and when they accessed care. Interfaces between online and offline parts of the OCP are 'weak links' in the pathway, requiring improvement. The appealing characteristics of the OCP (section 7.3) should be preserved, as far as is feasible and appropriate, throughout online and 'offline' parts of the pathway, which may enhance the OCP's acceptability and effectiveness. Offering options within online healthcare interventions may increase their acceptability, and may give users some of the autonomy which appeals to them. For example, having the flexibility to change the chosen pharmacy may reduce dissatisfaction, and speed up time to treatment.

For symptomatic patients directed to clinic, some anxiety about medical complications is reasonable and perhaps inevitable: concern about potentially serious complications is indeed why they are being sent to clinic. Modifications to this part of the care pathway should not necessarily seek to prevent such anxieties, which appear to cause patients to attend clinic promptly. However, better expectation management could mean that when (some) patients are told that their medical situation is not serious after all, they do not interpret this as the online pathway 'not working'. Under-reporting of symptoms, if users of online pathways learn which symptoms 'trigger' routing to clinic and do not believe clinic attendance is important in these circumstances, is a risk which requires further exploration.

Further efforts and more time for pharmacy staff to become familiar the OCP's process may reduce the problems observed in the pharmacy process. However, training, support and remuneration were provided, and participating pharmacies had all agreed that they could give out treatment packs at any time during their advertised opening hours (as a condition of participation). Similar issues reported in other studies (p323) suggest that occasional problems may be intractable. Providing treatment to Exploratory Studies participants was a relatively rare event, even among the Studies' most-used pharmacies, and rare tasks may inevitably be difficult to perform consistently well. More generally, UK pharmacists are increasingly called upon to perform a range of additional primary healthcare roles, but the evidence supporting this is mixed.^{484,486,496-498} The Exploratory Studies' community pharmacies often delivered a quick, discreet service, but it is worrisome that this was not always sufficiently confidential.

This study demonstrates how being unable to change one's chosen pharmacy is problematic for chlamydia patients, who are typically young and otherwise healthy people, busy working and/or studying, and who desire and require treatment at short notice. Currently, GP patients using the NHS e-prescribing service can collect their medication from a single chosen community pharmacy, but e-prescribing legislation means that medicines prescribed by GUM clinics (within which the OCP was embedded) cannot be dispensed in community pharmacies.⁴³³ The method designed for the Exploratory Studies⁴³³ enabled pre-prepared treatment packs to be given to named patients, who could collect treatment from one chosen pharmacy. If updated, e-prescribing regulations could better support electronic prescribing for future e-(sexual) health users.

Care pathways in general have been criticised for being overly linear, and for neglecting the needs and experiences of individual patients,⁴⁹⁹ yet *online* care pathways can enable patients to use healthcare in diverse ways. The OCP's design broadly followed the chronology of a face-to-face consultation^{433xv} (a

^{xv} A difference was that a sexual history was taken, online, after the diagnosis was communicated; in clinic, sexual history-taking normally happens before testing.

diagnosis was communicated, information was offered, and the appropriateness of treatment was checked, prior to prescribing). Facilitating access to health information throughout, including post-treatment, may help online pathways to meet the needs of individuals who wish to obtain treatment very quickly but have questions afterwards, and those who want plentiful, detailed information at diagnosis. Prompts to engage with online information may make up for the loss of the 'teachable moment' which occurs with (self-)testing in healthcare settings.⁹⁶ Online care pathways could be personalised further, e.g. by tailoring health information or targeting online interventions to patients' sexual history.

Some patients' use of the OCP in the presence of others risks loss of confidentiality and unintentional disclosure, and indicates a possibility of coercive use (although no instances of this were discussed). Health Advisers conducting Clinical Follow-up calls need to be aware of this, for safeguarding, and because it may affect the accuracy of sexual history details provided online.

The OCP was embedded within specialist clinical services, and enabled telephone access to expert Sexual Health Advisers via the Helpline (used by a large minority of Exploratory Studies participants, Box 8, p264) and Clinical Follow-up call. As well as being important for clinical safety,^{5,9} these aspects were highly valued, confirming that optional emotional and psychosocial support remains important^{50,52} in an e-health context.

Barriers identified in the current study, regarding use of the message for partners, confirm and extend chapter 5's tentative findings. Opportunities to facilitate partners' swift access to treatment will be missed, if patients do not understand how this facility works until Clinical Follow-up. Improvements to the online explanation of the message, and presenting it as a means of offering partners an extra option for receiving treatment, may help. However it may remain conceptually difficult to understand, especially for patients who prioritise their own treatment.

This study took place among eligible people who chose to access online routes to treatment. Findings are not necessarily transferable to all chlamydia patients. The Exploratory Studies' eligibility criteria (which were in place to protect clinical care quality and to test proof-of-concept of the OCP) will have removed some, but not all, medically-complex patients, and patients aged under 16. Their experiences of chlamydia, their needs, and their abilities to navigate the novel OCP, may be different. However, it is encouraging that despite lacking prior knowledge or awareness of the OCP, interviewees were generally able to use it effectively (and a large proportion of those offered it, did so⁹). If deployed in future, uptake of the OCP may be influenced by familiarity with other e-health technologies, and communication with others who have used it,³⁷⁷ which may further increase its uptake and how effectively it is used (but with some risks, discussed in section 7.2.5).

Regarding the transferability of my findings to online care pathways for other STIs (discussed further in section 8.4.5), some interviewees' uptake of the novel online service appeared to be influenced by their perceptions of chlamydia as common and easy to treat. Other STIs may be perceived differently. However it is encouraging that some interviewees (from outside the UK) who described not having heard of chlamydia until their diagnosis, read the online information provided with their chlamydia-positive result.

7.4.5 Unanswered questions and future research

This study could not explain why some people did not use the OCP (non-users did not consent to the Exploratory Studies, and so could not be interviewed; the two interviewees who disengaged from the OCP may differ from those who did not consent). It is important to explore perceptions of e-health interventions among people who have not accepted them, because there logistical or perceptual barriers may be addressable. Research among non-users is necessary for a fuller understanding of the limits to the OCP's appeal.

Neither this study, nor the Exploratory Studies, examined pharmacy staff's experiences of implementing the OCP. Such research, and detailed interrogation

of the Exploratory Studies' quantitative data, may identify tractable barriers to implementation. Research with RHAs could also be helpful, although the lead RHA worked within the Exploratory Studies' team, and so implementation issues that she identified were often resolved quickly (e.g. adjusting Helpline opening hours).

Exploration of PN and the message for partners was a secondary objective in this study (the latter was a highly experimental component of the OCP). PN is complex and merits its own detailed study, perhaps within an RCT of the OCP.

Given that use of the internet for sexual health is relatively high among MSM (chapter 4), who experience elevated STI/HIV risk, their particular needs should be considered in the development of appropriate STI treatment pathways. Education and/or individual socioeconomic status need to be included in qualitative and quantitative components of a future evaluation. The mechanisms by which these factors, and e-health literacy, affect use of e-health interventions warrants further study (e-health literacy is discussed in chapter 8).

A future evaluation of the OCP needs to consider the evolving context of healthcare, in order to distinguish between changes to the appeal of online healthcare, and the appeal of the next iteration of the OCP.

Chapter 8: Discussion

8.1 Introduction

My doctoral research has informed the development of a highly innovative and complex e-health intervention. I have made recommendations to maximise this intervention's potential public health benefit, based on empirical evidence and relevant theory. My findings have also contributed to the intervention's ongoing evaluation, and can now inform an RCT of the Online Chlamydia Pathway (OCP), so that its effectiveness as a public health intervention can be ascertained. An accurate diagnostic self-test is not yet available, but once it is developed, my findings can inform its implementation within online care pathways. In this thesis, I used chlamydia as an exemplar STI, as justified in chapter 1.

The current chapter summarises the key findings that arise directly from my doctoral research (in section 8.2), and relates these to the thesis' conceptual framework, which is based on an epidemiological understanding of how the intervention may deliver public health benefit (section 3.4.1, p139). Then, I integrate my qualitative findings together with quantitative results from the OCP Exploratory Studies (section 8.3). I discuss the relative importance and limitations of my findings, and strengths and weaknesses of my research strategy as a whole (section 8.4; strengths and weaknesses of each study have been discussed in chapters 4-7). I then discuss my findings in relation to the concept of e-health literacy (section 8.5). I describe the status of the self-test and online care pathways at the completion of my doctoral research in section 8.6.1. In the remainder of section 8.6, I summarise other relevant contextual changes which have occurred during my doctoral research, and which influence the implications of my findings. In so doing, I set the contribution of my work on 'e-sexual health' in the context of the drive to promote e-health within the NHS, financial constraints on NHS services, diagnostic advances, and persistent 'digital divides' in e-health. I discuss the meaning and implications of my research findings in this wider context (section 8.7). Finally, I discuss future directions for this intervention including how it may best fit within the wider sexual healthcare delivery system (section 8.8).

8.2 The potential for STI self-testing within online care pathways, to benefit public health: summary of key findings

I structure this section according to my thesis' conceptual framework, which I presented in chapter 3, section 3.4 (where I also described the scope of my doctoral research). There, I justified why I focussed primarily on testing and treatment, and secondarily on PN and disease surveillance. This decision was based on public health importance as well as on what could be explored during intervention development.

8.2.1 Testing: potential to increase detection of undiagnosed STIs

An internet-enabled remote self-test could potentially increase detection of undiagnosed STIs if it provided an accessible and acceptable testing service, which overcame barriers to using conventional services, particularly for those at high STI risk and those who do not use existing testing services.

The literature on barriers to accessing sexual health services, including difficulties attending clinic and some people's aversion to face-to-face consultations in sexual health (chapter 1), suggested that a remote, online service may reduce barriers to testing, in the context of high internet and smartphone use in the age-groups most affected by STIs. Through my scoping literature review (chapter 2) I identified internet-based home self-sampling as the most similar currently-available service to the proposed internet-based self-test. I found some evidence to support its potential to expand access to testing and to reach under-served groups, although generalisability from contexts without universal access to healthcare, to the UK's publicly-provided and open-access sexual health service context, is limited.

I generated the first nationally-representative estimates of the prevalence of internet-use for sexual health reasons, among sexually-experienced 16-44-year-olds, in chapter 4's analysis of British probability survey data. I used this as indicative evidence about the population to whom the proposed intervention may appeal. Prevalence of reporting use of internet-based STI-testing and treatment was very low, but this may reflect the very limited nature of the

online services which were available in 2010-12. Reported use of information/support websites for advice/help with one's sex-life was an outcome with sufficient prevalence to explore associations with demographic and behavioural indicators of sexual health need. Strong evidence that sexually-experienced young people were more likely to report this outcome than older adults is promising, because young people are a risk group for STIs. They may continue to use the internet for sexual health, thus normalising this behaviour as they age. Associations with greater education among both sexes, and with higher socioeconomic status among men, are less encouraging, as these groups are among those conventionally considered to be well-served by existing healthcare services. Furthermore there was no association observed with previous STI testing, or with previous STI diagnosis, and so there was limited evidence of internet-based sexual health services' potential to reach underserved populations.

In the first qualitative study in my doctoral research (chapter 5), I explored the acceptability of a hypothetical STI self-test within online care pathways. I chose a group among whom increased testing might deliver particular public health benefit: sexually-active young people from an ethnically-diverse, high STI prevalence population. Considerable enthusiasm was expressed for the intervention, which interviewees specifically discussed as helping to overcome barriers that they associated with existing STI testing services. I used the study to generate practical recommendations (Table 24, section 5.4.5) to increase further its acceptability to this high risk group; thus, opportunities were taken to incorporate potential users' views early in intervention design. Issues were identified and described which require further exploration as the device is developed and implemented (beyond the scope of my research). These include the need to explore how to prevent wasteful repeat testing, and to increase users' confidence in the results of the novel self-test.

8.2.2 Treatment: potential to provide rapid effective treatment and care

At the outset of this doctoral research, online care pathways for receiving treatment and care following remote receipt of a STI diagnosis, were novel

(confirmed by chapter 2's scoping review). Indeed, such care pathways were, and remain, novel for any health condition. Where STI treatment was provided online, it was purchasable through commercial online pharmacies/sellers (sometimes requiring some sort of individualised online consultation or communication), and the available evidence indicated that it was not always provided safely, nor with concern for prevention of STI transmission (section 2.3.5).

The first qualitative study (chapter 5) showed that an online care pathway may be an acceptable way to deliver STI treatment and care, and helped to develop an understanding of the nature of its acceptability to potential users. Support surrounding a positive test result was identified as important, and concerns were expressed about privacy surrounding receipt of treatment by post. However, most interviewees had not experienced an STI diagnosis, which limited the potential of this study to inform the post-diagnosis part of the pathway (a limitation which I addressed through the second qualitative study).

These findings, and others' formative research with potential users, informed the development of the first online care pathway for the remote clinical management of an acute infection within the NHS, the Online Chlamydia Pathway (OCP). I used the opportunity provided by pilot Exploratory Studies of the OCP to explore how this pathway was experienced among people requiring chlamydia treatment who had opted for this online route to treatment (second qualitative study, chapters 6 and 7).

My thematic analyses in chapter 7 constituted: a contextualised description of how people used the OCP, leading to suggestions for its refinement; and a more interpretative analysis of the nature of the appeal of the intervention and its limitations. Interviewees used the OCP in order to obtain treatment rapidly, and valued how the OCP gave them the ability to do so, conveniently. I identified further possible ways to expedite further this rapid treatment access, which may lead to public health and acceptability benefits. An online route to chlamydia treatment is broadly acceptable among its users, with the availability

of a Helpline staffed by Sexual Health Advisers being valued by its users and non-users alike. Attention to the convenience, privacy, flexibility and speed of 'offline' parts of the pathway require further attention to reduce (short) delays to treatment, and to increase acceptability.

8.2.3 Partner notification, partners' treatment access, and disease surveillance

The potential for the online care pathway to maintain or improve PN, and online information provision (which would serve clinical and disease surveillance purposes), were explored as secondary objectives in my qualitative studies. I also examined a means of enabling partners to access an online pathway for treatment.

Partner notification and partners' access to online care

As discussed, the hypothetical nature of chapter 5's study and the inexperienced study population (most had no previous STI diagnosis) made PN abstract, hindering its meaningful exploration. The concept of providing a link and code for patients to forward, to enable partners to access the OCP for an online consultation and treatment, was also abstract for them. Beliefs about the appropriateness of treatment without testing, affected some participants' views on enabling partners' access to the OCP (an option for partners to request a test will be included, in future). Limitations were overcome in the second qualitative study (chapters 6-7) by interviewing an experienced population. However, discussion of uptake and use of the link and code for partners was hindered by poor awareness of this facility and recurrent misunderstandings of how it worked. My descriptions of the nature of these misunderstandings may inform improvements to how it is explained, or when it is offered. The data that I gained suggested that this facility was considered useful, but forwarding the message could be viewed as an intrusion on casual (ex-)partners' healthcare-seeking. In the spirit of e-health users' desire for flexibility and control over their healthcare, it could be described to index patients as a way to give their partners an additional option for receiving their chlamydia treatment.

Disease surveillance

In chapter 7's analysis, completion of the online consultation 'facelessly' was suggested to lead to more accurate provision of sexual history details. Fuller disclosure of sexual history could improve the quality of surveillance data for future STI surveillance systems (the forthcoming GUMCADv3 will include data on sexual behaviour and PN outcomes⁵⁰⁰), and could facilitate PN. A basis in NHS services, assurance of confidentiality, passwords, and not storing information on users' phones, reduced concerns about data security.

Safeguarding and influences on the accuracy of data used for surveillance and PN

A risk which became apparent in the second qualitative study, but which was not fully explored because it was so unusual, was the presence of others (e.g. a partner) when someone is providing information online. This could in theory lead to under-reporting of sexual behaviour, which services need to be aware of (as discussed in chapter 7). My studies found no evidence of safeguarding problems or coercion, but the potential presence of others while self-testing or completing an online consultation indicates that this is a possibility. Health Advisers delivering the OCP's Clinical Follow-up need to be aware of this.

8.3 Integration: views and experiences of STI self-testing and online care pathways

The value of mixed methods (qualitative and quantitative) research is recognised, in the development and evaluation of complex interventions,^{357,358,501} and specifically, e-health interventions³⁶¹ and the implementation of new diagnostic technologies.³⁶³ Compared to presenting findings separately, new knowledge and insights can be generated by integrating qualitative and quantitative components of a study,^{502,503} and by synthesising qualitative studies.^{504,505}

In Table 33, I map comparable themes from the thesis' three qualitative analyses, and position these together with quantitative evidence from the OCP Exploratory Studies, using methods described in Appendix 10. I present a synthesis of the findings in the text which follows (and not in the table, due to space constraints), in which I take account of the studies' different methodologies, aims, study populations, and interventions, which are summarised in the table's column headings.

Table 33: Views and experiences of STI self-testing and online care pathways: integration and synthesis

	Chapter 5, qualitative study 1, thesis obj. 2	Box 8: colleagues' quantitative findings	Chapter 7, qualitative study 2, thesis objective 3a	Chapter 7, qualitative study 2, thesis objective 3b
Intervention	Hypothetical STI self-test within online pathways	The Online Chlamydia Pathway (OCP)		
Study topic	Perceptions and conceptual acceptability	Feasibility, acceptability	Use	Appeal
Population	Young people in a high STI prevalence area	People diagnosed with or exposed to chlamydia, who opted to use the OCP, in Exploratory Studies		
Acceptability	<i>Broadly acceptable;* discussed positively in relation to barriers to using existing services</i>	<i>High uptake among those eligible (75%). 86% of users surveyed rated care as excellent/very good</i>		<i>Discussed positively;* interfaces with offline part of OCP are sometimes problematic</i>
Themes	Speed <i>Fast results and treatment are preferred, but very fast results may not be trusted</i>	<i>Median 1 day to treatment collection, among those collecting treatment from community pharmacy</i>	Acting with urgency <i>Users may feel compelled to act fast on receipt of positive results. Some overlook the availability of health information in a rush to obtain treatment</i>	Speed: the option of a rapid route to treatment <i>Preference for rapid treatment is context-dependent, balanced with other needs/activities</i>
	Privacy -concealing use of SH & evidence of STI <i>Both are important, related to the stigma of STI, and of any/risky sexual activity, especially for young women</i> -avoiding face-to-face interactions in SH <i>Self-testing/online care was valued for enabling avoidance of potentially embarrassing interactions</i> -confidentiality and data security <i>Data insecurity may be inevitable, with ICT</i>		Protecting privacy -concealing evidence of STI, or SH use <i>OCP users managed to protect their privacy from those around them when using online parts of the pathway, but some were unable to maintain this during pharmacy treatment collection</i> -avoiding any risk of judgement <i>Some used the OCP to avoid any risk of potentially judgemental face-to-face interactions with HCPs in SH, despite generally positive perceptions of these HCPs</i>	Privacy: SH may be more private online -social privacy <i>was important (to varying extents) to all OCP users. Threats to privacy at interfaces with offline parts of the pathway were perceived negatively</i> -facelessness, avoiding awkward moments <i>For some, a 'faceless' service was extremely important, while for others this aspect held no particular appeal</i>

	<p><u>Capabilities & limitations of technology</u></p> <p>-potential to protect or compromise privacy <i>Users should be able to conceal SH seeking & STI</i></p> <p>-provision of personal and emotional support <i>If STI-positive, support from a HCP was considered vital</i></p> <p>-accuracy (see below)</p>			<p><i>The OCP was trusted (see below) and its confidentiality and security were apparently assumed</i></p>
	<p><u>Trustworthiness</u></p> <p>-accuracy of novel, self-operated testing technology <i>Some questioned the self-test's accuracy, discussing repeat-testing to check results</i></p> <p>-NHS basis & association with HCPs <i>enhanced the perceived trustworthiness of the intervention</i></p>	<p><i>21% of those treated by the remote route (pharmacy treatment collection) used the Helpline, staffed by a Sexual Health Adviser. This suggests that provision of support by telephone is important⁹</i></p>	<p><u>Seeking peace of mind</u></p> <p><i>The prospect of a fast, easy, private route to treatment was reassuring. Discussions with the SHA via the Helpline or during Clinical Follow-up, and the OCP's online information and resources, were further sources of reassurance/support</i></p>	<p><u>Association with trusted services & professionals</u></p> <p><i>Users valued the option of receiving expert support (e.g. via the helpline, or linkage to clinical services)</i></p> <p><i>Association with known and trusted NHS services (clinics, Checkurself) underpinned the perceived trustworthiness of the OCP</i></p>
	<p><u>Ease and convenience</u></p> <p><i>Self-testing with online care was perceived as easier and more convenient than attending SH settings, which (interviewees discussed) may lead to increased testing</i></p>	<p><i>Feasibility of using the OCP was demonstrated in Exploratory Studies, in which 97% users who had tested in GUM, and 89% who had done so via Checkurself, were reported as having received treatment</i></p>	<p><u>Facing constraints & making choices</u></p> <p>-weighing up the options... or going with the flow <i>Some read about the OCP before using it; others 'clicked through'</i></p> <p>-experiencing constraints <i>to using the OCP included being away from home, problems with pharmacy treatment collection, and being directed to clinic in the context of barriers to attendance</i></p>	<p><u>Ease and straightforwardness: if it's easy to get treatment, it's easier to deal with having chlamydia</u></p> <p><u>Flexibility and convenience: healthcare which works around you</u> <i>OCP was valued for enabling treatment access with minimal disruption to daily activities. Considerable disappointment where this expectation was not met</i></p>

Abbreviations specific to this table: HCPs, healthcare professionals; obj., objective; SH, sexual healthcare. Other abbreviations are defined in the glossary.

*Reasons for acceptability/appeal are discussed in the cells below.

Acceptability

Online self-testing and care for STIs is broadly acceptable. High uptake of the OCP and its popularity amongst its users are encouraging, but reasons for non-use require exploration, and may include its unacceptability or inaccessibility to some groups.

Speed

Finding out results rapidly minimised anxiety, although issues with trust in very rapid results from self-testing need further exploration. After receiving their chlamydia diagnosis, users of the OCP sought, and often received, treatment very quickly. Rapid treatment access was valued because of its perceived health benefits, but also because it enabled chlamydia-positive individuals to rid themselves of a stigmatising infection and helped them to resolve an uncomfortable or distressing situation. OCP users had high expectations for a quick online service, and expressed low tolerance for delays or hindrances which were outside of their control. However, the speed with which they chose to seek treatment was context-dependent. Users of e-healthcare for chlamydia may choose to balance their desire to obtain treatment rapidly, with their other activities and needs, in order to minimise the disruption to their lives posed by the STI and the need to seek healthcare for it.

Privacy

The ability to conceal evidence of having an STI, and use of sexual healthcare, was an important feature of STI self-testing and online care pathways for some people, especially for young women. The ability to engage with sexual healthcare 'facelessly' was also important, for some. 'Faceless' sexual healthcare enabled users to avoid embarrassment and the fear of being judged. As has been discussed, privacy needs relate to the stigmatised nature of STIs, sexual healthcare use as a stigma cue for socially-undesirable (or any) sexual activity, and felt stigma.

With appropriate design features in the web-interface,^{1,6} users of the OCP were largely able to protect their privacy, however this could be compromised at

treatment collection in the pharmacy, or if they were directed to clinic. High expectations of privacy, among some users of e-health interventions for sexual health, should be considered in the design and implementation of online and 'offline' elements of these interventions.

Data security and confidentiality were of greater concern among people considering a hypothetical online care pathway, than they were among people who opted to use the OCP. This may reflect changing norms over time. Alternatively, such concerns may be present among people opting not to use e-healthcare, and this requires further exploration.

Trust, reassurance and support

A basis in trusted NHS services, and an association with healthcare professionals, contributed to the perceived trustworthiness of the novel self-test and online care pathways. These features also enabled users to access specialist support and reassurance, if required. Although the web-interface was feasible to use unaided in most cases, access to expert health professionals remained highly valued, and was essential for some users. A telephone helpline was an appropriate way to provide reassurance and support, information, and technical assistance, in the current context. Information provided online was also highly-valued. However, engagement with online health information during use of the OCP was incomplete, related to some users' emotional reactions and the context of treatment-seeking.

Ease, convenience and flexibility

The prospect of a quick, easy, convenient route to STI treatment is in itself reassuring. (Re)attending a sexual health clinic represented a potential disruption to normal activities (e.g. work, study), and a potential threat to privacy, which could exacerbate negative feelings about having an STI.

An online care pathway for chlamydia, an easy-to-treat STI, was feasible and easy for sexual health patients to use in most cases, with no or minimal assistance from healthcare professionals.

8.4 Strengths and limitations

Strengths and limitations of my research strategy need to be understood in terms of the formative nature of this research, and the eSTI² team's activities, which have impacted upon and complemented my research (see chapter 3).

8.4.1 Iterative qualitative formative research

When developing conceptual frameworks for my qualitative studies, I drew on research evidence, relevant theory, and thought experiments. This strategy reflected my realist perspective,³⁵³ and the recommendation that a multidisciplinary approach should be taken in the development of e-health,⁴⁷⁹ consonant with the multidisciplinary nature of public health and health services research. My qualitative studies' conceptual frameworks were applied loosely, informing study design, rather than representing fixed preconceived ideas. I used the qualitative studies to develop, iteratively, an understanding of the use and appeal of the OCP. This helped me to develop a detailed and nuanced understanding of the online pathway. Once a prototype self-test is ready, there will be opportunities to develop further chapter 5's findings about its acceptability.

In chapter 3, I described the importance of qualitative formative research in the development of complex interventions, and particularly e-health interventions. By engaging with potential users from a very early stage in intervention development, I have elucidated issues which affect feasibility, acceptability and potential public health impact. The successful demonstration of proof-of-concept of the OCP⁹ suggests that, together, my own (chapter 5) and colleagues' formative research has helped to avoid major problems which can result from insufficient or late engagement with end-users. Detailed accounts of OCP use, in the second qualitative study (chapter 7), further informed intervention refinement in advance of an RCT.

8.4.2 MSM: an important but unrepresented group in this doctoral research

The views and experiences of MSM are unrepresented in this doctoral research, and their needs and preferences may differ from the predominantly heterosexual populations of my qualitative studies. MSM are an obvious group for future formative research regarding STI self-testing delivered using e-health, based on their burden of STI,⁵⁸ high engagement with internet and app technologies for dating and sex-seeking,⁵⁰⁶ and some evidence of greater acceptability of online sexual health interventions among this group (see chapters 2 and 4). However, MSM also tend to engage well with sexual health clinical services (among 16-44-year-olds, an estimated 45% (95%CI 35.0-55.5) of men who reported having had sex with a man within the last 5 years, reported having attended clinic during this period, compared to 19.6% men overall (95%CI 18.2–21.2)).⁶² That said, risk of STI/HIV is much greater among MSM than in the general population, and it is concerning that many MSM had not recently engaged with sexual health clinics. Some MSM's use of the internet for sexual health reasons may be influenced by concerns about discussing their same-sex sexual behaviour, and about being judged as having engaged in risky behaviour.⁵⁰⁷ Furthermore, services tailored to the needs of this group may not be present in all areas (e.g. rural areas, small towns), and in such circumstances online healthcare may be more attractive to them.

However, issues in the medical management of MSM's sexual health (explained in chapter 6, section 6.7.2, p260) mean that clinic-based care may currently be more appropriate than remote care. In person, a larger range of prevention and harm reduction interventions, including HIV pre-exposure prophylaxis, can be offered, perhaps with some online elements of care acting as a 'hook' to encourage engagement with clinic-based services. Care pathways for MSM may therefore need to be different in content and nature, as well as tailored to this group's preferences and needs.

8.4.3 Research embedded within a wider research programme to develop a complex intervention

The opportunity for this doctoral research was presented by the eSTI² Research Consortium, which followed the Medical Research Council's established and rigorous framework for developing and evaluating complex public health interventions.³⁵⁷ E-health is a rapidly evolving field, which poses a challenge to the development and evaluation of e-health interventions. This was addressed by rapid communication and implementation of recommendations that I (and others) derived from our research, within our research team. Formative research involves iterative developmental and evaluative work, hence it is appropriate for researchers developing, implementing and evaluating an intervention to work closely together (with greater independence advised at later stages in evaluation³⁵⁸).

Throughout my research, I could consult academic and clinical colleagues from the multi-disciplinary eSTI² team. The many benefits of this included ensuring that I was aware of the relevant practical and medical issues in healthcare delivery, and receiving constructive feedback on my research plans and data collection materials. My closeness to the team developing the OCP potentially posed a threat to my neutrality with respect to the conduct and interpretation of my qualitative research, which I recognised and took steps to address (discussed in chapters 6 and 7).

8.4.4 Data sources and study design

My doctoral research's three studies adhered to good practice in research conduct, appropriate to their distinct quantitative and qualitative methodologies, in order to elicit self-reported data on sensitive topics.

Appropriate to the realist approach of this thesis (chapter 3), Natsal-3 data and my qualitative interview data have been treated as reliable approximations of interviewees' behaviours, thoughts and feelings, but with a critical eye to the potential effects of the way these data were generated. The validity of Natsal data has been extensively discussed.^{367,407,508} In my qualitative analyses, reflexivity and the involvement of colleagues (chapters 5-7) have helped me to

engage critically with my own assumptions and initial interpretations, enhancing the dependability of my findings, while maintaining a public health focus.

For this thesis' second qualitative study, it is encouraging that quantitative behavioural and attitudinal data from the Exploratory Studies supported my qualitative findings (e.g. about the acceptability of the OCP and the speed with which it was used). In section 8.3, integrating the separate studies' findings increased their credibility and enhanced their interpretation.

8.4.5 Relevance of my research to a future remote self-test within online care pathways

To maximise the relevance of my two qualitative studies' findings to a future self-test within online care pathways, I took steps to make the intervention as 'real' as possible for interviewees. The steps taken were different in the two studies, appropriate to the different stages of intervention development. In the first qualitative study (chapter 5) the animation served as a visual aid, helping interviewees to engage with the complex, hypothetical intervention, which was not yet sufficiently well-defined to simulate or pilot. The qualitative research design provided space for the interviewees to request clarification about details of the intervention, and for the interviewer to detect and address misunderstandings. Credibility and dependability of the second qualitative study's findings (chapters 6-7) was greatly enhanced by being based on interviewees' experiences. The OCP exemplifies remote online chlamydia care, but without a self-test. Recruitment of users of internet-based home-sampling served to 'simulate' internet-based self-testing, maximising the transferability of findings to the self-testing context.

Once a self-test is ready, it will need to be evaluated within an online care pathway (and some further development will be required, e.g. the pre-testing risk-assessment part of the online pathway, informed by research on some internet-enabled self-sampling programmes⁵⁰⁹). Meanwhile, the OCP may be

deployed as an adjunct to existing testing via GUM clinics or home-sampling, and chapter 7's findings are directly applicable to these contexts.

My doctoral research, using chlamydia as an exemplar infection, will also be informative for self-testing and care pathways of other STIs.^{xvi} Chlamydia is likely to be well-known relative to other STIs, as a result of the National Chlamydia Screening Programme and relatively high rates of diagnosis. It is unclear what effect patients' perceptions of different STIs would have on their experience of remote testing and online care, and thus the transferability of my findings. Other STIs may be perceived as more serious, or as more stigmatising, and patients' information needs may be greater. Based on the conceptual understanding which this thesis has developed, a more severe or worrying diagnosis could lead patients to seek face-to-face support in clinic, or alternatively could lead them to be keener to receive care 'facelessly' online. Yet since all STIs are stigmatised and can have long-term health impacts, many relevant issues may be common to all these infections. The partnership and social context of infection and diagnosis may have greater influence on patients' healthcare behaviours and preferences than which STI is diagnosed. However, as discussed in chapter 1, currently, non-chlamydial bacterial STIs are not considered to be treatable remotely. If these STIs are diagnosed remotely, issues surrounding transitions from the online/remote context, to engagement with face-to-face clinical care, may be particularly relevant.

8.4.6 Transferability to other UK settings

Natsal-3 data, analysed for chapter 4's study, are broadly representative of the British resident population, which includes England, Wales and Scotland but not Northern Ireland. Limited comparable survey evidence about young people's first sexual experiences in Northern Ireland suggested that these were similar to their British counterparts.⁵¹⁰ Sexual healthcare provision through dedicated, confidential sexual health clinics is common to all four countries of the UK.

^{xvi} Currently, the eSTI² team believe other STIs to be inappropriate for remote management, for reasons described in section 1.6.5. However, the recommended treatment for other STIs may change at some point, or an online pathway providing STI test results could direct everyone who tested positive for non-chlamydial STIs to clinic-based care.

However, Northern Ireland is socially conservative in relation to sexuality (e.g. regarding access to termination of pregnancy, and public attitudes to homosexuality).^{511,512} Should this conservatism translate into barriers to using sexual health clinics, self-testing and discreet online access to sexual healthcare could be particularly appealing.

Both of my thesis' qualitative studies took place among London residents, and yet, as I set out to do (in section 1.1), I have discussed thesis findings in relation to England's health service and policy context. The qualitative research concept of 'transferability' is relevant here, i.e. the extent to which findings are applicable to a different (wider) context. (Transferability is similar to the concept of external validity⁵¹³ or generalisability⁵¹⁴ as applied in quantitative research, though there is debate about this⁵¹⁵). The study population for chapter 5's formative research was not chosen to be typical. It was chosen because the intervention might serve to benefit this high STI prevalence, young population (reasons are discussed on p236). Findings may be transferable to other urban populations in England, although research with people of a broader range of ethnicities may be beneficial, given evidence of unmet need for sexual healthcare and barriers to its use, among ethnic groups whose STI risk is not especially high.^{64,516,517} Findings may be more limited in their transferability to remote rural populations. For these populations, geographical distance is a barrier to use of sexual health clinics which is not faced by London populations, and difficulties in accessing conventional services may mean that self-testing and e-health services hold greater relative appeal, than among urban populations.

The Exploratory Studies from which I recruited for the second qualitative study also took place in London, and the reasons for my colleagues' choice of recruitment sites are stated in chapter 6 (p240). London's population is culturally and ethnically diverse, as were my interviewees, which enabled qualitative representation of a wide range of perspectives. The Exploratory Studies' recruitment from services based in diverse localities within Greater London likely means my findings would be broadly transferable to other English

cities' populations. With respect to rural populations, the limitation discussed above applies. Geographical constraints to using conventional clinical services may also 'push' people for whom e-health services are unsuitable, to use e-healthcare. This may include people with limited digital skills (discussed overleaf in section 8.5), and people with complex health and psychosocial needs which are best addressed in person, who in other areas might attend sexual health clinics. This could mean that rural and other underserved populations might include people who would use the OCP differently from Exploratory Studies participants and my interviewees (e.g. experiencing difficulties in using it; greater use of the helpline). Reasons for, and limitations of, its appeal to them may also differ.

The intervention discussed in this thesis has initially been developed for an English health service context (health being a devolved matter in the UK). Regarding the wider UK populations of Scotland, Wales and Northern Ireland, one difference is the absence of nationally-organised chlamydia screening programmes.^{63,518,519} Therefore there may be lower awareness of chlamydia as an easy to treat infection, and perhaps greater stigma (although comparative studies have not been found). If this is the case, users might experience greater concern for privacy, and greater needs for health information and support. However, it is encouraging that in my second qualitative study, interviewees from outside the UK, some of whom had not previously heard of chlamydia, discussed the OCP positively and were able to use it, perhaps suggesting differences might not be so great.

8.5 Discussion of thesis findings in relation to e-health literacy

Technology ownership/access, and internet access (see section 1.7) are necessary for patients to engage with online e-healthcare. However, my research has not considered in detail the skills which individuals require^{xvii} in order to use an online care pathway most effectively. Here I present a literature review on e-health literacy in relation to engagement with e-healthcare, and discuss how my findings relate to it. (The search strategy is described in Appendix 12).

8.5.1 What is e-health literacy and how is it measured?

E-health literacy was defined by Norman and Skinner as ‘the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem’.⁵²⁰ It requires skills beyond health literacy⁵²¹ and digital literacy (see glossary), as well as literacy in the sense of reading and comprehension of the written word.

A self-reported e-health literacy scale (eHEALS) was developed over a decade ago¹⁴ and has since been used widely.⁵²¹ In early research the eHEALS measure correlated closely with internet use.⁵²¹ More recently, some research has suggested that eHEALS scores may poorly predict engagement with e-health,⁵²²⁻⁵²⁴ thus its external validity has been questioned.^{522,525} It has also been suggested by some (but not others⁵²⁶) that eHEALS may be measuring two constructs (one to do with knowledge about e-health resources – finding and using them – and the other to do with the ability to evaluate them).⁵²⁷ The eHEALS measure has been criticised for relying on self-report, as people may over-estimate their skills,⁵²² and especially their ability to evaluate online information.^{525,528}

Changes in technology and internet use (principally the rise of social media and mobile devices such as smartphones) mean that e-health literacy requires a

^{xvii} I presume that when using online e-healthcare for sexual health reasons, users should not need to ask friends, partners or others around them for help. However, some assistance might be available remotely, by the e-health service itself.

changing set of skills.⁵²¹ Relevant to the current intervention, these include how well and how comfortably a person can navigate through and provide information on a mobile device, their skills in appraising the quality and credibility of the intervention and the other online sources of information that they may use, and assessment online safety/security.^{13,521,529}

8.5.2 Social patterning of e-health literacy

I discuss the social patterning of e-health literacy based on research which mostly uses eHEALS (despite its limitations). I focus on general patterns, recognising that although diverse study populations have been surveyed, there is a lack of recent data representative of England's (or the UK's) general population.

Younger and more educated adults are generally found to have greater e-health literacy,⁵³⁰⁻⁵³⁴ (although not in all studies⁵²⁸), as are women^{535,536} (but not in all populations⁵³³). However, younger people may have greater trouble appraising the information that they find.⁵³⁰ Technology use (e.g. more time spent online,⁵³⁶ use of more devices⁵³² and greater internet and smartphone access⁵³⁴) is unsurprisingly positively associated with e-health literacy. A systematic review of e-health literacy in underserved populations in the US identified an absence of evidence on the e-health literacy skills of rural populations,⁵³⁷ despite the common assumption that e-health serves to benefit them. A Canadian study of older adult ethnic minority immigrants found that they had low e-health literacy, and that there were cultural and linguistic barriers to these marginalized groups' engagement with e-health.⁵³³

Surveys in various countries have demonstrated associations between greater eHEALS scores (i.e. higher e-health literacy) and reporting healthy lifestyles (e.g. physical exercise, healthy diets^{531,538}). One US study's headline finding was that among HIV-positive women, e-health literacy was associated with HIV transmission risk behaviour (defined as condomless sex or drug use within the past 30 days), but the sample size was small and the finding would not normally be considered statistically significant ($p=0.11$).⁵³⁹

8.5.3 Implications for my findings

Although digital divides in access to the internet are closing, as access has become almost universal, the skills required to use online e-healthcare effectively are unequally distributed across the population. Disparities in e-health literacy could mean that e-healthcare may be most suitable for those who are already well-served by conventional services. This presents a mechanism by which the proposed intervention could contribute to health inequalities.

An online pathway for an acute STI, used remotely from healthcare settings and with no or minimal supervision, requires a relatively high skill level. People with low e-health literacy may be less likely to engage with it, and if they do so, they may use it less effectively, e.g. benefitting less from online health information, due to difficulties with navigation or comprehension. Indeed, a US study among young MSM found that users of an online HIV and sexual health information intervention who had higher e-health literacy may benefit more than those with lower e-health literacy.⁵⁴⁰ This led the authors to suggest that e-health literacy training could be provided alongside e-health interventions, or tailoring to e-health literacy level could take place.⁵⁴⁰ However, people using e-healthcare for treatable STIs and other acute conditions would perhaps be unlikely to engage in training prior to use. Given the urgency with which chapter 7's chlamydia-diagnosed interviewees sought treatment, they may also be unwilling to answer additional questions to allow intervention tailoring.

Problems with online information provision could differentially affect those with low e-health literacy. The text of the OCP was pretested with a sample of clinic attenders, and was designed not to require users to spell the names of medications that they might be taking,⁴³³ yet the health information provided in linked websites may require more than basic literacy skills.⁵⁴¹ Evidence from a systematic review suggests that mobile apps, used on touch-screen devices and with visual and audio, may be an appropriate way of enabling people with low health literacy to receive and provide information.⁵⁴¹ There is also potential for minority groups to be underserved by e-health interventions which do not take

into account linguistic and cultural considerations,⁵³³ and translation into other languages could begin to address this. However, there may always be people for whom use of an online care pathway will be very difficult (for instance those with particular disabilities), for whom accessible face-to-face alternatives are needed.

Low e-health literacy and lack of internet access are not the only factors limiting engagement in e-healthcare. A US study among low-income women found that eHEALS score only weakly predicted use or potential adoption of digital health-management, suggesting that other motivating factors are influential⁵²⁴ (or perhaps that the eHEALS measure needs revision.^{522,527}) Chapter 7's findings suggest a role for emotional and contextual factors in influencing uptake of the OCP's online information. Although I did not specifically examine e-health literacy and digital skills in this study (as explained on p232), my findings do not suggest that those who overlooked online information lacked e-health literacy skills. Future research with non-users of the OCP could consider low e-health literacy as a potential barrier to uptake.

8.6 Contextual changes

My doctoral research (data collection 2010-2015, see Appendix 2) has taken place in a changing context, which shapes the implications of my findings (next section, 8.7).

8.6.1 eSTI²'s Workstream 4: research advances and future plans

The OCP was developed, piloted, and demonstrated to be safe, acceptable and feasible, using chlamydia results from existing testing services,⁹ and is being refined ahead of a planned RCT. This trial will include process evaluation and cost-effectiveness analysis. Despite progress with the diagnostic technology,^{193,542} an accurate diagnostic self-testing device for multiple STIs is not yet available.

Related to the eSTI² Consortium's work, colleagues are now working on an online care pathway to be used with home self-testing for HIV. This aims to link users with reactive tests (see glossary) into clinical care for confirmatory testing and, if necessary, ongoing management. At the time of thesis completion, there are no plans to develop online care pathways for the treatment and clinical management of other STIs, but colleagues' 'eClinical Care Pathway Framework' (which supported development of the OCP) provides a process by which online care pathways could be developed for other conditions.⁵

8.6.2 Increasing internet and smartphone use, but persistent 'digital divides' in e-health

Further increases in internet access have occurred since 2010 (see chapter 1); smartphone ownership is now nearly universal among the young age-group²⁰⁷ most affected by chlamydia, and has increased among older age-groups. Smartphones are, since 2015, the main device by which people access the internet.²¹⁹ Use of the internet for healthcare has also increased: in 2016, just over half of adults in Britain reported searching for health information online, and 15% used the internet to make appointments with healthcare professionals.⁵⁴³ Digital divides by household income, education, and long-term

ill-health or disability^{xviii} remain, but are narrowing. For instance, in 2013, adults with no formal educational qualifications were considerably less likely to use the internet, than those with basic or higher-level qualifications (40% vs. 84-95%), but this represents an increase from 31% among those without qualifications since 2011, and smaller increase among the more educated.⁵⁴⁴ However, because disparities in internet access mirror the social patterning of many health harms and risks, there is concern that digital health interventions could widen health inequalities.⁵⁴⁵ This may be less important for bacterial STIs, which are associated with greater deprivation but also younger age (see chapter 1).

Inequalities in engagement with e-healthcare may also stem from inequalities in the skills required to use them. I have discussed e-health literacy, but other knowledge and skills may also be relevant. Research from other (non-STI) health areas^{492,546-549} suggests that inequalities in the uptake and use of e-health technologies and online healthcare are associated with differences in education and health literacy (see glossary), and also lower income and ethnic minority status.⁵⁵⁰ There is also some evidence of worse health outcomes or lower adoption of protective behaviours among patients with poorer health literacy, across various health conditions (including HIV⁵⁵¹ and other infectious diseases⁵⁵²) although the pattern is not consistent. Limitations to meaningful access to e-health suggest that the 'inverse care law' may apply, by which those in greatest need of healthcare have the poorest access to it.^{553,554}

E-healthcare, and research literature about its use, has largely focussed on self-management of long-term conditions where patients already have face-to-face contact with clinicians, and have potentially had greater opportunity to become health literate in relation to their condition, than have patients who are newly diagnosed with an acute, curable STI, remote from healthcare services.

^{xviii} Internet access/use is not always measured by these demographics in recent representative population surveys (e.g. ONS Internet Access Survey; Ofcom Communications Market Report), therefore the example in the following sentence is a few years old.

8.6.3 Advances in diagnostics and their regulation

As explained, an accurate diagnostic test for STIs, suitable for home self-testing, remains unavailable.

Since the start of this doctoral research, a NAAT platform has been developed which tests for chlamydia and gonorrhoea (Cepheid Xpert CT/NG, GeneXpert). It is a large, costly machine which ‘batch-tests’ multiple samples, and so is inappropriate for remote self-testing or for settings where few tests take place. However, it can be used in laboratories, or as a near-patient test in sexual health clinics. It generates results within two hours, which is faster than previous methods of chlamydia testing, and approaches the 30 minute definition of a rapid test.¹⁷³ Rapid tests may reduce loss to follow-up and thus may be suited for marginalised populations;³⁶³ such tests reduce the duration of infectivity, enabling communication of results and provision of treatment within a single clinic visit. In practice, however, results may be communicated later that day, when patients have left the clinic. For example, a busy London NHS GUM service, Dean Street Express, uses this technology for asymptomatic patients, together with rapid-testing for HIV (which gives reactive or negative test results on the spot), and a somewhat slower test for syphilis. It communicates STI test results by text message within 2-6 hours,⁴²⁵ and treatment is provided at a return visit to clinic. This service has not yet been formally evaluated, but by deploying this rapid-testing technology in a population with high rates of partner change, opportunities for onward transmission may be reduced,⁵⁵⁵ particularly if treatment is also provided rapidly. Findings from my qualitative research suggest that such a service could appeal because of its speed and avoidance of a face-to-face sexual health consultations, but that the need to attend clinic could be perceived as inconvenient, and is a barrier for those who wish to conceal their sexual healthcare use. Rapid-testing within a clinic context increases the options available to patients, but remote self-testing within online care pathways has additional benefits.

The recent availability of HIV self-testing may have increased the public’s awareness of diagnostic self-testing technology. HIV self-testing was legalised in

the UK in 2014, and an HIV self-test (BioSure), using a sample of blood, was licensed in 2015.⁴¹¹ Available for purchase online and face-to-face, it represents an advance on previously-available rapid tests for HIV (Oraquick) which were less accurate and not approved for home use in the UK. The test provides negative or 'reactive' results, with the latter requiring confirmatory testing. Ethical concerns with HIV self-testing are arguably greater than with self-testing for chlamydia or other STIs: users' emotional reactions to reactive results may be more extreme, and the consequences of loss to follow-up are more severe. Research studies from around the world have considered the use of such tests in supervised and unsupervised home-testing contexts (i.e. with and without a health-worker present), with some evidence of increased testing among populations who had not previously tested.⁵⁵⁶ Unsupervised self-testing is most relevant to the current context (with provisos similar to those discussed in section 8.4.5). A recent systematic review concluded that the convenience and privacy of HIV home self-testing may be particularly appealing.⁵⁵⁷ However errors in test use and interpretation of results are risks where testing is unsupervised²³⁹ and these errors may be more likely among those with lower education.⁵⁵⁷ Similar issues have been identified among MSM in the UK, in research which additionally identified a risk of increasing health inequalities.⁵⁵⁸ This is a huge and important area of research, within which a recurring issue is linkage to care in the case of reactive results,^{557,559} highlighting the importance of deploying such tests within care pathways. Loss of surveillance data can also be addressed by requiring users to register a test online (or by some other means) before use.

The Medicines and Healthcare products Regulatory Agency (MHRA), which regulates medicines and medical products in the UK, estimates that online purchasing of such items is growing, but with fake or unlicensed items accounting for more than half of those purchased online, and low consumer awareness of this issue.¹⁹⁹ In 2016 it launched a campaign, specifically targeting young adults, drawing their attention to the problem of unlicensed/fake STI testing kits and medications.¹⁹⁹

8.6.4 Changes and innovations in sexual healthcare for STIs, including e-health with remote self-sampling or rapid-testing

With the exception of the OCP, no examples of automated online clinical care pathways to STI treatment and management have been found, by my eSTI² team colleagues, or through an updated literature search (March 2017, Appendix 11. In this literature search, for which I used similar search terms to chapter 2's scoping review, I identified 941 documents and reviewed their titles and abstracts).

A diversification of models of service provision in sexual healthcare for STIs has been evident during my doctoral research. For testing, publicly-funded and within the NHS, this includes the use of 'pick-up packs' from some clinics, for home self-sampling for STIs (as well as self-sampling within clinic premises, discussed in chapter 1). It also includes internet-based home-sampling for a wider range of infections, including HIV, and for a wider age-range than the NCSP is targeting (available in some areas, e.g. Checkyourself Plus and SH:24, which include chlamydia, gonorrhoea, syphilis and HIV). SH:24 is underpinned by a theoretical model which was refined with the input of stakeholders, including only 4 service users.³⁶⁶ It was then developed using a 'design-based approach' in which it was made available and refined on a 6-8-week rolling basis, with ongoing collection of feedback from users (which has reportedly been very positive).⁵⁶⁰ It was evaluated in an RCT,^{561,562} but before this trial's completion, it was commissioned to expand its services to additional localities.⁵⁶³ The published evidence consists of analysis of usage metrics and mixed-methods evidence on its acceptability. However, in e-health (and in general), such evidence is not sufficient to establish individual or population health benefit.⁵⁶⁴ Implementation of internet-ordered home-sampling services has been prompted by financial pressures,⁵⁶⁵ but apparent value for money is also insufficient evidence of health benefit,⁵⁶⁴ if benefits and risks are not rigorously assessed. The lack of robust evidence for these types of provision is concerning, as is the observation that RCTs of unsupervised self-sampling have failed to consider potential harms.¹⁴⁹ Harms could result from missed opportunities to identify other health needs and to test for other infections, as

well as loss to follow-up¹⁴⁹ and loss of surveillance data. A recent publication⁵⁶¹ and the SH:24 website⁵⁶⁶ state that chlamydia treatment can be provided by post after a text message consultation,⁵⁶⁰ but the details of this consultation, whether it meets regulatory requirements and clinical guidance, and whether it is based on robust prior evidence of effectiveness and safety, are unclear. Mechanisms to cap costs of testing through such a service are being employed by SH:24, involving limiting the number of self-testing packs which can be requested in any one day, per postcode area.⁵⁶⁷ Wasteful repeat self-sampling (analogous to wasteful repeat self-testing, discussed in chapter 5 and section 8.2.1) evidently needs to be minimised in the context of limited resources, but this means of limiting self-sampling is unevaluated and bears no relation to individuals' need for testing, risking missing opportunities to identify infections.

A similar postal home-sampling service has been piloted in California, US (and is coincidentally named 'eSTI') enabling testing for chlamydia, gonorrhoea and trichomoniasis, for women only.³⁶⁵ Remote treatment is provided by means of a prescription faxed to a pharmacy (no details were provided about how the safety and appropriateness of remote treatment was checked).³⁶⁵ In a small feasibility pilot, only 8 patients tested positive (for chlamydia and trichomoniasis), with 6 of these managed remotely.³⁶⁵ That the only reported barrier to pharmacy treatment collection was lack of health insurance and inability to pay for treatment, reflects the different health service context (in which free STI treatment is only available at public health STI clinics) but also the very small number of women among whom remote management was piloted. Economic modelling has been undertaken,⁵⁶⁸ and study authors tentatively concluded, from pilot data, that it is more cost-effective than clinic-based care (within the local healthcare context). However, they note that a comparative trial is necessary to determine effectiveness and cost-effectiveness, relative to clinic-based testing and treatment.⁵⁶⁸

The London Sexual Health Services Transformation Project (an initiative of London Councils), planned that all publicly-funded sexual health clinical services in London would be accessible online by April 2017, with patients

being directed to services or offered self-sampling.⁵⁶⁹ Online triage would be used to direct people to the 'most appropriate' service^{565,569} but the basis of this, and whether clinic visits would be available to all, is not entirely clear. This 'model of high-volume testing'⁵⁷⁰ could lead to more STIs being detected if it is used in sufficient volume by those at sufficiently high risk of infection. To deliver public health benefit, it needs a way to ensure prompt, effective treatment of those testing positive, and an effective means of supporting PN. It also needs to ensure that those with other health needs are not missed. It remains to be seen how and by whom the online interface and the self-sampling service will be used. However, such a model of service delivery may enable GUM clinics to focus on delivering services to high-risk patients⁵⁶⁵ (see section 8.8). A similar model was run by Amsterdam's STI clinic, where young low-risk patients (defined based on online risk-assessment) were screened for chlamydia only. Of almost two-thousand asymptomatic heterosexual young people identified as low-risk, 80% were sent a home self-sampling kit, and the remainder booked clinic appointments with (18%) or without (2%) sexual health counselling.⁵⁷¹ However, due to limited clinic capacity, about a third of those requesting an appointment were not provided with one, and may subsequently have chosen to receive a kit; therefore the actual preference for clinic attendance may be higher than uptake of home-sampling suggests.⁵⁷¹

Private (commercial) services continue to provide paid-for STI testing and treatment services. Because they do not contribute to surveillance data, no figures are available about levels of use, nor the proportion of these services provided online. There is also a dearth of published research on the nature, individual health benefit and safety of commercial online STI services. Recently some such services were criticised by the British Association for Sexual Health and HIV for providing treatment 'in the absence of test results, examination and testing for co-existing STIs' and were specifically criticised for the possible effect this would have on the development of antimicrobial resistance.¹⁹⁸ In contrast to publicly-funded health services, which have a duty to protect individual and public health, commercial sexual health services have no responsibility to reach those at greatest need of STI testing and care. Indeed

commercial services may benefit through greater demand, if reinfection takes place, and if NHS sexual health services become less accessible. Problems with these services which were discussed in chapter 2 may still apply (including poor linkage with GUM clinics in case of complications, and inconsistent or absent PN and health promotion advice).

8.6.5 Health service policy, finance and readiness to support e-health

E-healthcare within the NHS is not yet sufficiently well supported, but health policy documents continue to promote e-health and innovation. NHS England's 2014 Five Year Forward View discusses continued financial pressures on the NHS, but also promotes innovation in technology and in models of healthcare provision,⁵⁷² both within services (e.g. for medical records, communication between staff) and at the interface with patients in the delivery of healthcare (as this thesis has considered). However, ambitions to innovate contrast with the track-record of large-scale ICT infrastructure projects, which have continually been delayed. For example, the National Information Bureau's 2014 report states an aim for electronic health records to be available across the NHS by 2020,⁵⁷³ echoing earlier, unfulfilled plans to do so by 2004⁵⁷⁴ (within and prior to the Connecting for Health project, which overspent and was eventually abandoned⁵⁷⁵). One possible explanation is health 'system inertia', which refers to how the complexity of large-scale health systems, and competing demands on, them can hinder changes⁵⁷⁶ such as the successful implementation of e-health at scale.⁵⁷⁷ Organisational change and discontinuities within the NHS, and budget constraints, have hindered e-health implementation in recent years⁵⁴⁹ and in the past.^{578,579}

The regulatory and legislative environment is also not fully supportive of innovative e-health projects such as eSTI²'s (although some progress is being made). For example, the NHS's electronic prescribing (e-prescribing) system within primary care is geared towards the management of stable, long-term conditions, and the regulatory framework for this and for e-prescribing in secondary care (including GUM clinics) is different.⁴³³ Prescribing from GUM clinics to community pharmacy (i.e. from secondary to primary care) is further

hindered by the need for NHS numbers, which GUM clinics do not use (due to their enhanced confidentiality, see section 1.4.1).⁴³³ The special arrangement which was in place within the OCP's Exploratory Studies, for treatment collection from one nominated pharmacy which could not be changed,⁹ is clearly not ideal, and is at odds with patients' expectations and needs for flexibility (as discussed in chapter 7). Furthermore it appeared difficult for pharmacies to implement, despite training and reimbursement, and therefore may not be scalable in its current form.

Forthcoming NHS accreditation of health apps has been recently announced.^{572,573} This is encouraging in general, and for sexual health in particular, given the poor quality and potentially harmful advice provided by STI apps which are currently available.⁵⁸⁰

E-health within the NHS continues to be promoted as promising the greatest benefits for the most vulnerable patients,⁵⁸¹ but the evidence base for this remains unclear, and is questionable given digital divides discussed in sections 8.5 and 8.6.2. In general, recent health policy documents lack meaningful consideration of health inequalities. As the 2014 House of Commons Health Committee report notes: there is a 'growing mismatch' between the commitment to prevention of ill-health voiced in the Five Year Forward View,⁵⁷² and spending on public health including prevention, which has reduced,⁵⁸² which will be continue to be cut year-on-year until 2020,^{583,584} and which will no longer be 'ring-fenced' from 2018/19.⁵⁸⁵ The Health Committee report explains that this is a false economy, set to increase future health and social care costs, and health inequalities.⁵⁸⁵

The Health Committee report notes that sexual health is among the three areas of concern highlighted by PHE, and singles out this health area to exemplify the fragmentation that results from lack of clarity over commissioning, and the division of commissioning responsibilities between different bodies.⁵⁸⁵ This is

also discussed in a recent King's Fund^{xix} report.⁵⁶⁵ In addition, there has been further tendering and decommissioning of established GUM clinic services over the course of my doctoral research, including clinic closures and reduced opening times in some areas, despite rising demand for sexual healthcare.⁵⁶⁵ These pressures, and other financial pressures, threaten the ability of GUM clinics to deliver an accessible service.^{185,565} Health Adviser posts have been cut (resulting in reduced support with PN), and reductions in services have reportedly been most severe in the 'upstream' areas of prevention, sexual health promotion, and services targeting high risk groups.⁵⁶⁵ The public health importance of such activities, and of the accessibility of sexual healthcare, has been explained in chapter 1. However, the King's Fund's research found that some commissioners do not seem to understand the potential individual and public health impacts of their decisions, in relation to STIs.⁵⁶⁵

8.6.6 Summary and implications of contextual changes

New models of service delivery, technological advances and funding cuts, are together resulting in a rapid pace of change in this health area. Services are being delivered in ways which are encouraged by policy but which are untested and under-evaluated. Remote self-sampling risks harms, some of which may be addressed by delivery within care pathways such as the OCP. However, the assumed lower costs of delivering these interventions, compared to clinic-based care, needs to be examined in relation to public health outcomes through economic evaluation. Furthermore, services' capacity to support novel e-healthcare interventions must be taken into account.

^{xix} The King's Fund is an independent charity 'working in England to achieve the vision that the best possible health and care is available to all'.

8.7 Meaning and implications

8.7.1 Summary of meaning and implications for refinement and evaluation of the OCP

Users' high requirements for a convenient, rapid service, and to be in control, making choices about how they receive their healthcare, need to be considered in future iterations of this intervention. Essentially, they may be 'impatient patients'. Their desire to act promptly should be supported in intervention design, and also in delivery, particularly where this desire aligns with clinical and public health goals of prompt treatment (which reduces the duration of infection). During receipt of this e-health intervention, data security and confidentiality need to be preserved, but also privacy from those around users/patients, including people who may see their smartphone, or see them obtaining treatment. This relates to the stigmatised nature of STIs, and how use of sexual healthcare may be perceived as a 'stigma cue', indicating STI, or risky or socially-sanctioned sexual activity. The aversion some feel towards discussing their sexual health face-to-face, also related to stigma and fear of judgement, does not necessarily imply a lack of willingness to have these discussions by telephone, nor a lack of respect for medical professionals and established sexual health services. Indeed, the basis of this novel online service within existing trusted and specialist services, seems optimal both from users' perspectives and from the perspectives of clinical safety and public health. As has been discussed, some tensions may inevitably remain between desire for control over one's healthcare, and for that healthcare to be in the hands of a professional service.

The OCP is likely to be evaluated in an RCT. Evaluation design is beyond the scope of this thesis, but my findings can inform the logic model by which it is conceptualised to deliver public health benefit, which in turn informs appropriate process evaluation measures.⁵⁸⁶ Economic evaluation is necessary, and my findings about how people use the OCP (section 7.2) can inform comprehensive health economic modelling.

The demographic and other characteristics of users of an innovation tends to change over time,³⁷⁷ as does the social meaning health technologies hold for their users,⁴⁸⁷ and thus how they may be used. This affects the individual and public health benefit, meaning that process evaluation (already recommended to be integral within evaluations^{358,378}) is particularly important.

People with chlamydia who are presented with the opportunity to use the OCP and choose not to do so, are an obvious group for future qualitative research, as we have scant information about why these people did not proceed online. Their reasons may be addressable (as discussed in chapter 7).

Chapter 4's findings indicate a need to consider impacts on health inequalities, which is also justified by the research literature on e-health and on similar STI interventions (see sections 8.6.2 and 8.6.4), the current health service context (section 8.6.5), and evidence on e-health literacy (section 8.5). Measuring socioeconomic status, education attainment, and health or e-health literacy at the point of testing, for example, could be used to test hypotheses that those with greater education, higher socioeconomic status, or greater (e-)health literacy may be more likely to opt for online care, better able to adhere to it, find it more acceptable, or use it more effectively. Mixed-methods research could help identify mechanisms for any associations found (for example, those with greater education or higher socioeconomic status may be better placed to consult friends or family who are healthcare professionals).

Process evaluation needs to address how the OCP could be implemented outside of a research context. This includes how to embed the intervention within the NHS and its institutions,³⁶⁰ as the organisational context may help or hinder successful implementation.⁵⁸⁷ Implementation research will need to take a broad and holistic perspective⁴⁷⁹ compared to my doctoral research (e.g. including funding issues, infrastructure). Stakeholders including policy-makers and commissioners will need to be engaged before this intervention is deployed, within the changing landscape of sexual health commissioning, funding and regulation. No research was carried out in the Exploratory Studies with

pharmacy staff involved in intervention delivery (see chapter 7); this, and research with clinic managers and staff, may help us understand how best to embed this intervention into clinic and pharmacy practice.

With health being a devolved matter in the UK, implementation research would be particularly useful if the intervention is deployed outside of England, where there may be different guidelines and practices within different parts of the health service, and different surveillance systems which would need to interface with an online care pathway. Also, anecdotally, London sexual health services are generally quicker to adopt innovations than those elsewhere in England. Now that formative and early evaluative research has demonstrated the potential of this intervention in a London context where it is well-supported, facilitators and barriers to implementation require fuller exploration elsewhere.

8.7.2 Summary of meaning and implications for a future remote self-test, deployed within online care pathways

Chapter 5's findings, and evidence from HIV self-testing (section 8.6.3), suggest that once available, an STI self-test would be used. Multiple issues discussed in section 8.6 point to the value of embedding the device within an online care pathway linked to NHS clinical services. Furthermore, this seems acceptable to potential users and enhances the credibility of the intervention.

Once a self-testing device is ready, further formative research will be needed to address users' trust in results, and wasteful repeat use (identified by chapter 5's study), as well as distribution, costs and other issues beyond this thesis' scope (Table 15, p141). There also is a need for evaluation of the self-test within online pathways, including health economic evaluation, and assessment of potential harms as well as benefits. Issues relevant to the OCP's evaluation (discussed in section 8.6.2) also apply to the evaluation of the pathways which include a diagnostic device.

8.7.3 Summary of meaning and implications for e-health research

My research, together with the Exploratory Studies' findings, has demonstrated that it is possible for some people who received online a new diagnosis of an acute and stigmatised condition, to use an unfamiliar e-healthcare intervention successfully. Much research on the delivery of healthcare online has focused on chronic conditions (e.g. diabetes) where users of e-healthcare have had more time to become sufficiently knowledgeable about their condition, have longer to practice and become familiar with using a new e-healthcare intervention, and receive face-to-face support before initiating use. Set in contrast to this, the challenge to OCP users was considerable. Therefore findings are very encouraging (although there is no assumption that everyone, under all circumstances, will be able or willing to use the novel intervention).

My research suggested that some OCP users' emotional states, feelings of urgency, and use of the intervention in a public context, could reduce individuals' engagement with online health information. This could limit the potential of online e-healthcare services for acute infections to promote healthy behaviour and prevent re-infection. The design of e-health interventions for STI treatment (and, e.g., HIV/STI testing, access to emergency contraception, post-exposure prophylaxis for HIV, as well as other 'acute' health needs) needs to consider ways to promote better engagement with health promotion information. This may include prompts to engage with information after treatment (or testing), as well as beforehand. Users may also be anxious that any communication from the service could indicate bad news, for instance another positive result, and so messages must be very clear. Situational and emotional contexts of use need to be considered in the design of e-healthcare for acute, stigmatised and worrying health problems.

My findings suggest that trust in e-health services is enhanced by their association with trusted NHS services, a finding which is likely to apply to other health areas. Embedding such e-health services within clinical services thus enhances acceptability, as well as safety, and provides other benefits. Patients using online e-health services may expect a high level of control over the

healthcare they receive. Appreciation of this, and of the need to manage these expectations, may aid the design of future e-healthcare interventions. E-healthcare services delivered largely online may always require an interface with 'the offline', for instance where patients collect medication. In their design, it is vital that smooth transitions are facilitated, which preserve, where possible, the characteristics of an online service which users value.

Privacy concerns for this e-health intervention varied in nature and intensity between different people. All patients should be able to conceal their use of sexual healthcare from those around them, should they wish to do so. The impact of fear of judgement on people's desire to avoid face-to-face interactions in sexual health is considerable. Qualitative findings indicate how chlamydia remains stigmatised, despite public awareness of this relatively common STI.

8.8 Future directions

NHS sexual health services are at a crossroads, where, as a result of financial pressures, access to STI testing may already be decreasing (although we lack reporting systems to monitor this) and services are under increasing pressure. Decreased access could lead to later diagnoses and increased morbidity, perhaps differentially affecting the most vulnerable. Decreased access could also result in an increase in prevalence which could, in turn, lead to a vicious circle⁸⁵ of onward transmission and more new infections.

Diagnostic advances mean that a self-test for STIs is on the horizon, whether delivered commercially, or (as proposed by eSTI²) publicly and within an online care pathway. It is therefore too late to ask whether STI self-testing should be available – it probably will be; or whether it will be used – again, it probably will be.

Rather than asking whether such an intervention can deliver public health benefit, the question is how to maximise the opportunities for it to do so, which my research has begun to address. My research has conceptualised remote self-testing for STIs within online care pathways to be delivered as a complement to existing sexual health services: as one way of delivering sexual healthcare. However, as I have demonstrated in sections 8.6.4 and 8.6.5, such services are changing. A health systems perspective is called for, one that recognises the current barriers to implementing e-healthcare within the NHS, that any new sexual health service may impact on use of other sexual health services, and which considers how all types of sexual health services together meet the needs of the population, through an appropriate combination of online, clinic-based and other services. This includes timely access to testing for those most at risk of STI, timely treatment and PN support for those testing positive, and identification and addressing of other health needs. Those at greatest risk must be reached by this combination of services, and all services need to contribute to the disease surveillance systems that inform public health action.

A comprehensive sexual health service for STIs includes provision of health promotion (which can be targeted and tailored to individuals based on their characteristics and the behaviours they disclose), and sign-posting to a range of other health and social services (e.g. contraception, drug and alcohol misuse, or domestic violence services), some of which currently need to be, or can better be, delivered in person. However, the evidence base for interactive digital sexual health promotion interventions is growing.^{588,589} Now that proof of concept for the OCP has been demonstrated,⁹ the further development of online STI care pathways can utilise the interactive potential of an electronic pathway to allow further personalisation to meet individuals' needs, and perhaps online provision of some of these elements of care. However, the need to link some patients, in a timely manner, to services which are currently delivered face-to-face, further emphasises the importance of embedding this online pathway within NHS clinical care.

The greatest benefit to public health may be achieved if self-testing within online care is delivered with no or minimal reduction to existing clinic-based services. One way the proposed intervention may benefit public health is by providing rapid access to testing and treatment for patients whose medical and other needs are relatively straightforward. Thus, it could be used to expand access and increase case-finding, and to provide rapid online routes to treatment for suitable patients. Clinic-based services could then focus their efforts on engaging with those who remain hard to reach, on providing of telephone support to users of remote services who require this, on the management of medically complex cases and those who require additional support (e.g. those who are distressed, and those with lower health literacy, and those aged under 16), and on more intensive efforts to reach and treat partners of those who test positive for STIs. This may mitigate the risk of novel services being less accessible to some of those in greatest need, which is important for reasons of health equity, and because those in STI risk groups contribute substantially to the persistence of STIs within a population (explained in chapter 1). The changing case-mix of patients seen face-to-face in clinic would

probably require more of healthcare professionals' time per patient seen, and a different mixture of clinical and communication skills.

The pace of change in this healthcare area necessitates two things: increases in the capacity of the health system to support and integrate e-health,^{577,590} and an evidence-based approach. The former has been discussed in sections 8.6.5-6. For the latter, novel services need to be developed and implemented within an evaluative framework, as eSTI² has employed. More intelligent use of surveillance data has been suggested as a way of maximising the public health benefit of publicly-provided sexual health services,⁵⁷⁰ but threats to this include delivery of services outside the NHS (and so outside surveillance systems) and the lower completeness of STI surveillance data from non-specialist sexual health services.⁵⁹¹ Remote self-testing within online care pathways could potentially provide more detailed data, available at shorter intervals or in real time, compared to that provided by traditional services (e.g. location of test use, and sexual network data ascertainable by linking information on partners, if acceptable). This could enable rapid responses to changing patterns of STI diagnosis, informing (e.g.) health promotion and testing targeted to a particular locality or group. 'Big data' has been suggested to complement conventional surveillance data to enhance public health research, although this requires mechanisms to ensure data security and ethical use, and novel transdisciplinary skills and approaches to analysis, in order to be effectively used for health benefit.⁵⁹²

8.9 Conclusion

This thesis has presented detailed research on the first online care pathway for any newly-diagnosed infection within the NHS, which was designed in accordance with relevant regulations and clinical guidelines. By informing the development and ongoing evaluation of remote self-testing for STIs within online care pathways, my findings can help to maximise this intervention's public health benefit. Such potential benefit would be attained by reduced durations of infection, through acceptable and accessible provision of testing, rapid and acceptable routes to treatment, and support for PN. As it may not be acceptable, accessible and appropriate for everyone, it is best deployed as a complement to the existing range of sexual health services, and embedded within specialist NHS sexual health clinical services.

Future evaluations of the OCP, and of remote self-testing within online care pathways, require integral process evaluation and health economic evaluation. Such evaluations need to consider individual and public health benefits, but also potential harms, such as the risk of widening health inequalities, which my research has helped to identify. A health systems perspective to evaluation is needed, in order to ensure that the increasingly diverse landscape of sexual health services can deliver access to sexual healthcare according to need, to maximise the overall public health gain.

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Appendices

Appendix 1: eSTI², its workstreams and diagnostic evaluation pipeline

eSTI² Research consortium (www.eSTI2.org.uk) was led from St. George's University of London, by Dr Tariq Sadiq. Other member institutions included UCL, Queen Mary University of London, Brunel University, University of Warwick and Public Health England. It also involved commercial partners.

Funding details are provided in the main body of this thesis (Acknowledgements).

eSTI²'s four workstreams were:

Workstream 1: Translational Microbiology

Workstream 2: Micro-engineering

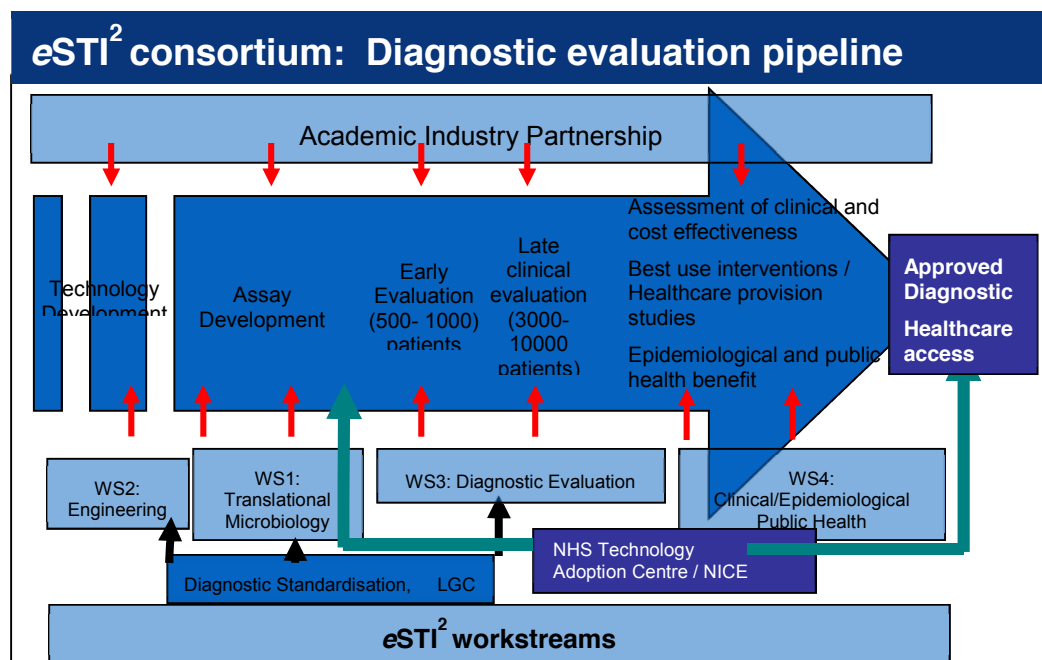
Workstream 3: Diagnostic and clinical evaluation

Workstream 4: Clinical, public health and economic impacts – developing and testing an eSTI² clinical pathway

My PhD was linked to Workstream 4.

Figure A1: eSTI² diagnostic evaluation pipeline

Showing the input of the four Workstreams (WS1-4) to the development of the diagnostic self-test and associated care pathways, as planned at the beginning of the grant. [Credit: eSTI² colleagues]



Appendix 2: Doctoral research timelines

Table A1 shows selected doctoral research activities related to my three studies, in relation to relevant eSTI² and Natsal-3 research activities.

Table A1: Interface between my research activities and eSTI² and Natsal-3 activities relevant to my research

Date	Doctoral research activities	Main relevant eSTI ² WS4 activities	Natsal-3 data collection and availability
October 2010	Start of doctoral research		Data collection
January 2011		Grant start: February	
April			
July	Protocol, approvals for qual. study 1		
October			
January 2012	Maternity leave		
April		Interviews for qual. study 1	
July		Colleagues' rapid analysis of interviews	
October			
January 2013	Qual. study 1 analysis begins		
April	Protocol for qual. study 2		
July		Ethical approval for Online Chlamydia Pathway Exploratory Study*	
October			Data available**
January 2014	Natsal-3 analysis		
April			
July	Qual. study 2 data collection and initial analysis	Online Chlamydia Pathway Exploratory Study data collection	
October			
January 2015			
April	Qual. study 2 in-depth analysis		
July			
October			
January 2016 onwards	Writing up		
Key:	<div> <div></div> Natsal-3 survey analysis Chapter 4 <div></div> Qual. study 1: Qualitative interviews with young people: perceptions of hypothetical self-test/online care Chapter 5 <div></div> Qual. study 2: Qualitative interviews with people testing positive for chlamydia who chose online care: views and experiences Chapters 6,7 </div>		

*Ethical approval for the pilot study included approval for the nested qualitative study: my second qualitative study.

**An extract of the cleaned dataset was available, on application, to members of Natsal-3 study team institutions, including UCL.

Appendix 3: History of Genitourinary Medicine (GUM) clinics

The UK has a long history of efforts to control STIs (formerly termed ‘venereal disease’, VD). The first voluntary VD clinic was the London Lock Hospital, established in 1746.^{a1,a2} There was a need for a dedicated hospital: other hospitals could, and did, refuse to admit VD patients on moral grounds.^{a2} The London Lock Hospital offered treatment (although this was ineffective), and housed and rehabilitated ‘penitent’ women,^{a1} who were often poor and starving,^{a3} implying a moral as well as medical function. Lock Hospitals had existed for several hundred years previously, for leprosy and later syphilis, and the name ‘lock’ may refer to isolation and containment (or the word for the bandages lepers used to cover their sores)^{a2} suggesting a public health purpose: controlling the spread of disease.

Parliamentary concerns about the health of men in the military – thus, the defence of the British Empire – contributed to the Contagious Diseases Acts (of 1864, 1866 and 1869), which targeted sex-workers in certain army and naval districts, but not the men themselves.^{a4} Under these Acts, those suspected of engaging in sex-work could be arrested, subjected to medical examinations, and confined until they were declared free of VD, or had served their sentence.^{a5} Examinations were invasive and unsafe, diagnoses were uncertain, and in any case, syphilis was still incurable.^{a5} Following pressure from a growing women’s movement and other campaigners, these Acts were repealed in 1886.^{a4} There remained virtually no provision for VD treatment for civilians, and little policy interest in this,^{a6} although policies as late as 1909 recommended the detention of those with VD.^{a7}

The situation changed following the discovery of Salvarsan (arsphenamine), the first antimicrobial identified for any infection. This effective treatment for syphilis was introduced in 1911,^{a8} but many of those infected remained untreated because treatment facilities were inadequate; treatment was not covered by National Insurance provision, so had to be paid for.^{a7} The Royal Commission on Venereal Diseases was established to research this, and in its 1916 report it recognised these inadequacies, and also the public health and economic impact of VD, the ‘moral

stigma’ of these diseases, and the fact that treatment was often ‘unduly delayed’.^{a9} It recommended the establishment of open access, confidential, publicly-funded VD treatment centres.^{a7,a9,a10} These facilities significantly predate the 1948 founding of the UK’s National Health Service (NHS). Britain did not make ‘VD’ notifiableⁱ or criminalise its transmission (as other countries did),^{a11} but the emphasis was on making services accessible.

The role of services in tracing the sexual contacts of STI cases (‘contact tracing’, now termed partner notification, PN) also pre-dates the NHS. Although contact tracing had a public health role in limiting the spread of infection, archival research from Scotland suggests that because it did not fall within the statutory remit of the newly-established VD clinics of the late 1910s, its legal basis was questionable and contact tracing activities were carried out somewhat covertly in the interwar years.^{a12} With the increase in STIs (gonorrhoea, syphilis) that occurred during the Second World War there was pressure to control STIs, resulting in the Defence of the Realm Act (1942) which empowered Medical Officers of Health to require the sexual contacts reported by more than one infected person to present for treatment and remain under their supervision until no longer infectious.^{a12} Legal provision protected women from malicious accusations^{a12} but the discourse surrounding ‘VD’ remained sexist.

The last century has seen huge changes in social norms and laws with respect to sexual freedom and gender equality, widespread recognition of the importance and legitimacy of STI prevention and education, advances in the diagnosis and treatment of STIs, and in the last three decades a relatively newly-identified infection – HIV. Naturally, these changes have affected the activities of the clinics we have today. However, GUM clinics currently remain accessible without referral, with no prescription charges for STI treatment (as is usually the case for NHS-prescribed medicines in England), and the service is confidential: patients do not

ⁱ A notifiable disease is one which healthcare professionals have a statutory duty to report cases (and suspected cases) of, to the relevant authorities. This is not the same as contributing data to surveillance programmes: STIs are still not notifiable in England.

have to reveal their identity, and medical records are kept separately from other NHS records. These features reflect that STIs remain stigmatised, and that barriers to service use could reduce the individual and public health benefit that clinics could deliver.

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Appendix 4: Scoping literature review: Index of included studies

Table A2: Index of studies included in chapter 2's scoping literature review (each document's full reference is provided in the thesis' bibliography)

Notes/key: Additional author names and/or first words of title are provided in some cases, to distinguish between documents with the same first author, publication year and document type. *, § pairs of documents reporting the same data; ‡ article with erratum. *Document type:* 'article', journal article; 'abstract', conference abstract. *Search source:* DB, found via database search; CON, found via conference abstract search and not already found via database search.

Publication details			Topic (section of chapter 2)					Search source
Author(s)	Year	Document type	Appointment booking, triage, reminders (section 2.3.2)	Internet-based access to testing (section 2.3.3)	Results notification (section 2.3.4)	Consultations and treatment (section 2.3.5)	Partner notification (section 2.3.6)	
Ahmed <i>et al.</i>	2013	article		X				DB
Andersen <i>et al.</i>	2001	article		X				DB
Apoola <i>et al.</i>	2006	article					X	DB
Bernstein <i>et al.</i>	2013	abstract					X	CON
Bilardi <i>et al.</i> ('Let...')	2010	article					X	DB
Bilardi <i>et al.</i> ('Experiences ...')	2010	article					X	DB
Bracebridge <i>et al.</i>	2012	article			X	X		DB
Brook, Farmer, Murphy <i>et al.</i> *	2013	abstract	X					CON
Brook, Farmer, McSorley <i>et al.</i> *	2013	abstract	X					CON
Brown <i>et al.</i>	2009	article			X			DB
Brugha <i>et al.</i>	2011	article			X			DB
Buhrer-Skinner <i>et al.</i>	2009	article			X			DB
Chai <i>et al.</i>	2010	article		X				DB
Challenor & Deegan	2009	article			X			DB
Cohen <i>et al.</i>	2008	article	X					DB
Cook <i>et al.</i>	2010	abstract			X			DB
Dhar <i>et al.</i>	2006	article			X			DB
Ehlman <i>et al.</i>	2010	article					X	DB

Table A2, continued			Topic					Search source
Author(s)	Year	Document type	Appointment booking, triage, reminders	Internet-based access to testing	Results notification	Consultations and treatment	Partner notification	
Gaydos, Rizzo-Price <i>et al.</i>	2006	article		X				DB
Gaydos <i>et al.</i> ‡	2006	article		X				DB
Gaydos <i>et al.</i> ‡	2006	erratum		X				DB
Gaydos <i>et al.</i> ('Can e-technology...')	2009	article		X	X			DB
Gaydos <i>et al.</i> ('Males will submit...')	2009	article		X				DB
Gaydos, Barnes <i>et al.</i>	2011	article		X				DB
Gaydos <i>et al.</i> ('Risk...')	2011	abstract		X				DB
Gaydos <i>et al.</i> ('Characteristics...')	2011	abstract		X				DB
Gaydos, Hsieh <i>et al.</i>	2011	article		X				DB
Götz <i>et al.</i>	2013	abstract					X	CON
Graseck <i>et al.</i>	2012	article		X				DB
Greacen <i>et al.</i>	2012	article		X				DB
Greenland <i>et al.</i>	2011	article		X	X			DB
Hightow-Weidman <i>et al.</i>	2012	abstract					X	CON
Hopkins <i>et al.</i>	2010	article					X	DB
Hottes <i>et al.</i>	2011	abstract		X				DB
Hottes <i>et al.</i> ("Internet based...")	2012	article		X				DB
Hottes <i>et al.</i> ("Impact of a...")	2012	abstract		X				CON
Huang <i>et al.</i>	2011	article		X				DB
Jackson	2012	abstract					X	CON
Jenkins <i>et al.</i>	2011	article		X				DB
Jenkins <i>et al.</i>	2012	article		X				DB
Jones <i>et al.</i>	2010	article	X					DB
Kerani <i>et al.</i> ("A randomized...")	2011	article					X	DB
Kerani <i>et al.</i> ("Acceptability...")	2011	abstract					X	DB

Table A2, continued			Topic					Search source
Author(s)	Year	Document type	Appointment booking, triage, reminders	Internet-based access to testing	Results notification	Consultations and treatment	Partner notification	
Kerani <i>et al.</i>	2013	article					X	DB
Klausner <i>et al.</i>	2004	article		X				DB
Klausner <i>et al.</i>	2000	article					X	DB
Koekenbier <i>et al.</i>	2008	article		X	X			DB
Koekenbier, Dokkum <i>et al.</i>	2011	abstract		X				DB
Koekenbier, Kalma <i>et al.</i>	2011	abstract		X				DB
Koekenbier <i>et al.</i>	2013	abstract			X			CON
Kwan <i>et al.</i>	2012	article		X				DB
Ladd <i>et al.</i>	2012	abstract					X	CON
Ladd <i>et al.</i>	2011	abstract		X				DB
Lawton & Andrady	2011	abstract	X		X			CON
Levine <i>et al.</i>	2005	article		X				DB
Levine <i>et al.</i>	2008	article					X	DB
Lim <i>et al.</i>	2008	article			X			DB
Ling <i>et al.</i>	2010	article			X			DB
Malbon <i>et al.</i>	2012	abstract			X			DB
Mendez & Mather	2012	letter					X	DB
Menon-Johansson <i>et al.</i>	2006	article			X			DB
Menon-Johansson <i>et al.</i>	2010	article	X		X			DB
Mettey <i>et al.</i>	2012	abstract					X	CON
Mimiaga <i>et al.</i>	2009	article					X	DB
Mimiaga, Fair <i>et al.</i>	2008	article					X	DB
Mimiaga, Tetu <i>et al.</i>	2008	article					X	DB
Miners <i>et al.</i>	2012	article			X			DB
Muessig <i>et al.</i>	2013	article	-	-	-	-	-	DB

<i>Table A2, continued</i>			Topic					Search source
Author(s)	Year	Document type	Appointment booking, triage, reminders	Internet-based access to testing	Results notification	Consultations and treatment	Partner notification	
Muvva <i>et al.</i>	2012	abstract		X				CON
Nair <i>et al.</i>	2008	letter	X					DB
Novak & Karlsson	2006	article		X				DB
Novak & Novak	2012	article		X				DB
Novak & Novak	2013	article		X				DB
Op de Coul <i>et al.</i>	2012	article		X				DB
Owens <i>et al.</i>	2010	article		X				DB
Pant Pai <i>et al.</i>	2013	article		X				DB
Plant <i>et al.</i>	2012	article					X	DB
Platteau <i>et al.</i>	2012	article			X			DB
Price <i>et al.</i>	2009	letter	X					DB
Reed <i>et al.</i>	2013	abstract			X			CON
Rietmeijer <i>et al.</i>	2011	article					X	DB
Ross <i>et al.</i>	2000	article	X		X			DB
Ross <i>et al.</i>	2007	article	X					DB
Rotblatt <i>et al.</i>	2012	abstract		X				CON
Rushing & Stephens	2012	article		X				DB
Ryan <i>et al.</i>	2006	article		X				DB
Saadatmand <i>et al.</i>	2012	article			X			DB
Scott <i>et al.</i>	2010	abstract					X	DB
Shoveller <i>et al.</i>	2012	article		X				DB
Simons <i>et al.</i>	2012	abstract		X				CON
Simons <i>et al.</i>	2013	abstract		X				CON
Spielberg <i>et al.</i>	2013	abstract			X			CON
Swarbrick <i>et al.</i>	2010	article	X					DB

<i>Table A2, continued</i>			Topic					Search source
Author(s)	Year	Document type	Appointment booking, triage, reminders	Internet-based access to testing	Results notification	Consultations and treatment	Partner notification	
Tripathi <i>et al.</i> §	2012	article			X			DB
Tripathi <i>et al.</i> §	2012	abstract			X			CON
van Bergen <i>et al.</i>	2010	article		X	X		X	DB
van den Broek <i>et al.</i>	2010	article		X				DB
van den Broek <i>et al.</i>	2012	article		X				DB
Vest <i>et al.</i>	2007	article					X	DB
Vivancos <i>et al.</i>	2007	article				X		DB
Wohlfeiler <i>et al.</i>	2012	abstract					X	CON
Woodhall <i>et al.</i>	2012	article		X				DB
Woodhall <i>et al.</i>	2011	abstract		X				CON
Dept. of Health ('10 high impact...')	2012	grey lit.	X		X			DB
Totals:			12	46	27	2	26	104 (84 DB, 20 CON)

Appendix 5: Reporting of sexual difficulties among sexually-active 16-44-year-olds reporting internet-use for information/support with their sex-life, in Natsal-3

Data in the table below demonstrate the large proportion reporting recent use of information/support websites for advice/help with their sex life who reported: sexual satisfaction, absence of distress, having not avoided sex due to sexual difficulties. This suggests that many who reported use of internet information/support were doing so for reasons other than sexual function problems.

Table A3: Reporting sexual satisfaction, sexual distress/worry, and avoidance of sex due to sexual difficulties, among those reporting internet-use for information/support with their sex-life, within the past year

		Men	Women
		Percentage (95%CI)	Percentage (95%CI)
<i>Denominator (unweighted, weighted)</i>		<i>205, 166</i>	<i>249, 170</i>
Satisfied with sex life	Agree or strongly agree*	60.6% (52.8-67.9)	56.5% (49.2-63.5)
	Neither agree nor disagreed	16.1% (11.3-22.3)	15.5% (10.8-21.8)
	Disagree or strongly disagree**	23.3% (17.4-30.5)	27.9% (21.9-34.9)
Distressed/ worried about sex life	Agree or strongly agree**	24.0% (17.9-31.2)	24.4% (18.6-31.3)
	Neither agree nor disagreed	14.9% (10.3-21.2)	19.0% (13.6-25.9)
	Disagree or strongly disagree*	61.1% (53.3-68.4)	56.6% (49.1-63.8)
Avoided sex in past year due to sexual difficulties (own/ partners')	Agree or strongly agree**	17.3% (12.0-24.3)	23.8% (18.2-30.6)
	Neither agree nor disagreed	13.9% (9.4-20.1)	7.9% (5.3-11.3)
	Disagree or strongly disagree*	68.8% (61.1-75.6)	68.2% (61.3-74.4)
Summary measure <i>(based on responses to the above survey questions)</i>	Satisfied with sex life, <u>and</u> not distressed worried about sex life, <u>and</u> did not avoid sex due to sexual difficulties <i>(all * responses, above)</i>	48.8% (37.1-52.8)	37.5% (30.5-45.1)
	Not satisfied with sex life, <u>or</u> distressed/worried about sex life, <u>or</u> avoided sex due to sexual difficulties <i>(any ** responses)</i>	38.0% (30.8-45.7)	41.0% (34.1-48.2)
	Equivocal <i>(all other combinations of responses)</i>	17.2% (12.4-23.4)	21.5% (16.1-28.1)

Appendix 6: Division of research tasks in the study reported in chapter 5

Table A4: Division of research tasks for the study reported in chapter 5

Research task	Researcher(s) involved
Protocol for the study and study materials (Participant Information Leaflet, consent form, topic guide, fieldnotes pro-forma, email for college to circulate to students)	Catherine Aicken (CA), with input from supervisors
UCL ethics application, Data Protection registration and UCL risk assessment	CA
Initial contact with the study site	CA
Liaising with the study site to arrange access, room availability, <i>etc.</i>	Sebastian Fuller (SF)
Piloting	SF
Amendments to the topic guide and sampling frame (see below*)	SF, Maryam Shahmanesh (MS)
Creating the animation	Voula Gkatzidou, with input from SF
Recruitment, informed consent, interviewing	SF
Transcription of the interviews	Commercial transcription co.
Checking and correcting interview transcripts	SF, CA
Design and conduct of in-depth thematic analysis, and interpretation	CA, with supervision from MS and discussion with SF & Lorna Sutcliffe (LS)
<i>Rapid analysis of the same interview data (not part of PhD)</i>	<i>SF, MS, LS and others</i>

*During my maternity leave SF piloted the topic guide and refined it, with supervision from MS. The topic guide was shortened in discussion with other study team members.

I was consulted and agreed to the following changes:

Topic guide:

- avoiding use of term 'surveillance' (regarding data used for public health purposes) – considered misleading because info is collected primarily for clinical purposes, with surveillance a secondary use; 'surveillance' could sound unnecessarily intrusive
- reducing the detailed questions on acceptability of providing data – for brevity, and because detailed questions could result in a focus on acceptability of data provision, instead of acceptability of providing routine data *by mobile phone/internet*. The questions used focussed on acceptability of providing different types of data (personal, sexual history, clinical data) by mobile phone/internet.
- the term 'remote' (e.g. remote testing) was removed as it could be unclear – and replaced with eClinic, eTest and so on, which was explained.

Sampling frame:

- In the purposive sample, age groups were used for stratification, rather than STI testing experience, for ethical and feasibility reasons, given recruitment in public college settings.

As is the nature of qualitative research, the topic guide evolved during the process of conducting the interviews and I was not involved in making these changes.

Appendix 7: First qualitative study (chapter 5): Study materials and interviewees' reflections

7a Information Sheet for Colleges

eSTI² Qualitative Research with Young People Information Sheet for Colleges

Introduction

Sexually transmitted infections (STIs) are a major public health issue in the UK. With STI rates sustained or rising, particularly among young people in the 16-24 year age group (Health Protection Agency, 2008), there is a need to increase testing among the general population, particularly those at increased risk of STI. Currently in the UK, almost all testing for sexually transmitted infections (STIs) takes place in healthcare settings, for the most part in Genito-urinary Medicine (GUM) clinics – or, in the case of the National Chlamydia Screening Programme, community screening sites. One possible solution to increase STI testing in young people is to offer testing away from health services (*remotely*) – in the community and perhaps in the patient's home. This is a key theme of the eSTI² research consortium.

eSTI² consortium

The eSTI² consortium is developing an STI diagnostic device, which could be activated through a mobile phone such that the user could test for STIs and receive their result rapidly via their phone, while infectious disease surveillance could also be undertaken. Users who test positive for an infection could access treatment and management away from traditional healthcare settings, i.e. remotely, for instance with an electronic prescription which could be redeemed at a pharmacy, or receiving treatment by post. Additionally, it would be possible to provide relevant health promotion advice, either generic or tailored, online or by phone, and to facilitate partner notification, so that the patient's whole care pathway could take place remotely from health settings.

Focus of qualitative research

The aim and objective of this study is to explore young people's views of remote STI testing, management and initiation of partner notification, preferences and acceptability of this among young people. Research questions are thus focused on what young people like and dislike about the idea of remote testing, management of sexually transmitted infections and the remote initiation of partner notification of STIs.

What is asked of participants?

In the interview, the researcher will ask participants about their opinions on different aspects of the new way of testing described above. He will also ask some brief information about participants, including whether they have used sexual health services in the past. Interviews will be done in private at the college, and what participants tell the researcher will be kept confidential (private). These interviews will be recorded.

Research participant rights

The interview is not compulsory in any way, even after the participant has agreed to take part. Interviews can be stopped at any time, or if there is a question the participant doesn't want to answer, it can be skipped. Choosing not to take part, stopping the interview or missing a question will not affect the standard of healthcare or education the participant receives in any way.

Once interviews are completed all recordings will be kept on password-protected computers, and any participant identifying information (e.g., names, location of

eSTI2 Qualitative Research with Young People Information Sheet for Colleges

interview, etc.) will be removed from resulting transcriptions. These measures ensure that participants' personal information and opinions remain confidential, as per the UK Data Protection Act research regulations. This information will be clearly provided to all participants prior to all interviews.

What are we asking of London-based Colleges?

Approximately 25 young people in London-based colleges, aged 16 to 24, who are sexually active (have had sex at least once before), will be needed to take part in this research. We want to get a balance of men and women, and people who have and have not used sexual health services before. In order to ensure that this research is conducted in the best way possible, particularly for those young people who are potential participants, we are asking for your help in approaching students to take part in the research. Key areas of assistance are:

- **Recruitment:** for example, identifying particular students or classes that may be interested in the study, and/or allowing access to college classrooms for short introductory speeches to introduce the study and/or posting A4 flyers promoting the research throughout the college.
- **Interview space:** provision of a safe, private space where individual interviews can take place within the college.

Further questions?

Please contact:

- Sebastian S Fuller, UCL Division of Population Health Sciences, eSTI2 Qualitative Researcher: 075 3400 4759; Sebastian.fuller@ucl.ac.uk
- Claudia Estcourt, Reader in Sexual Health & HIV Centre for Immunology & Infectious Disease, Blizard Institute, Barts & The London School of Medicine & Dentistry: 020 7882 2316; c.s.estcourt@qmul.ac.uk

Thank you for your interest in the eSTI2 qualitative study, we look forward to working with you!



7b Text of email sent to FE college students

Dear student,

Would you like to help with health research?

University researchers would like to interview 16-24 year olds, to find out what you think about a new test for sexually transmitted infections (STIs). We are interested in your opinions – we will not be doing any tests for STIs. Because the research is about sexual health, we would like to interview people who have some sexual experience (have had sex at least once before).

The interview would take place at college, and what you say would be confidential to the university research team. All data will be collected and stored in accordance with the Data Protection Act 1998. You would be offered a £15 voucher to say thank you for taking part. For more information see: *[participant information sheet, provided as weblink/attachment.]*

If you are interested, please email *[researcher's email address.]* He can tell you more about the study before you agree to take part.

Thank you for your time.

Information Sheet for Research Participants

You will be given a copy of this information sheet.

Title of Project: **Acceptability and preferences concerning remote self-testing for sexually transmitted infections (STIs), the initiation of partner notification remotely, and associated STI surveillance, to young people**

This study has been approved by the UCL Research Ethics Committee (Project ID Number): 3490/001

Researcher	Catherine Aicken / Sebastian Fuller
Work Address	University College London - Centre for Sexual Health and HIV Research, Mortimer Market Centre, off Capper Street, London WC1E 6JB
Contact Details	<i>[email address; phone number]</i>

We would like to invite you to participate in this research project. It involves an interview with a researcher.

What is the study about?

We want to find out what people think about a new way of testing for sexually transmitted infections (infections that can be passed from person to person through sex, such as Chlamydia).

The new test would test a small amount of urine (pee), and could be made to work using a mobile phone (a smartphone). This means that the person doing the test might not need to go to a clinic or to see a doctor or nurse. They could receive the test result on their phone. If the test was positive, then they could even be sent a prescription for medicine on their phone.

We are interested in your opinions to guide us with the development of the test. The interview will not involve any STI tests or taking any samples.

What do the researchers want to find out?

We don't know whether the new way of testing for sexually transmitted infections (without seeing a doctor or nurse) is acceptable to young people. It might be better for some people, compared to going to a clinic or a GP, and not so good for others. There might be some things about it which you would like, and other things which would put you off.

What you tell us will help healthcare researchers understand how they should design the new way of testing, to meet young people's needs and preferences. Your participation will help design health services for the future.

How can I help?

The study involves one interview, which will take about one hour. The researcher can arrange a time that suits you. To thank you for taking part, the researcher will offer you a voucher for £15 at the end of the interview.

The researcher will ask you to sign a 'consent form' to say that you would like to take part in the interview. In the interview, he/she will ask you your opinions about different aspects of the new way of testing. He/she will also ask some brief information about you, including whether you have used sexual health services in the past. Interviews will be done in private at the college, and what you tell the researcher will be kept confidential (private). If you agree, the interview will be recorded.

Who is taking part in this research?

We are asking people aged 16 to 24, who are sexually active (have had sex at least once before) to take part in this research. We also want to get a balance of men and women, and people who have and have not used sexual health services before.

If you have not had sex, please do not take part in the research. You do not need to tell anybody why you are not taking part.

Do I have to take part?

No. It is completely up to you whether you take part or not.

If you want to stop the interview, or if there is a question you don't want to answer, you can say. You do not have to say why. Choosing not to take part, stopping the interview or missing a question will not affect the standard of healthcare or education you receive in any way.

What happens to my information?

All information, including what you tell us in the interview, is kept confidential (private) within the research team. No one outside the research team will have access to information which could be used to identify you. The researchers will remove any information which could identify you (like your name) so that the data we keep is anonymous. Once this has been done, it will not be possible to withdraw your data.

When we write our study report, we will not mention any names or other identifying information.

Can I find out the results of the study?

Yes. If you would like to be sent a copy of the study report, please contact the researcher using the email or phone number above.

Can I keep this information sheet?

Yes, this information sheet is for you to keep.

All data will be collected and stored in accordance with the Data Protection Act 1998.

7d Informed Consent form for research participants

Informed Consent Form for Research Participants

Please complete this form after you have read the Information Sheet.

Title of Project: **Acceptability and preferences concerning remote self-testing for sexually transmitted infections (STIs), the initiation of partner notification remotely, and associated STI surveillance, to young people**

This study has been approved by the UCL Research Ethics Committee (Project ID Number): 3490/001

Thank you for your interest in taking part in this research. Before you agree to take part, the person organising the research must explain the project to you.

If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

Participant's Statement

- I have read the notes written above and the Information Sheet, and I understand what the study involves.
- I agree that my interview will be audio-recorded and I consent to the use of this material by the research team, as part of the study.
- I am assured that the confidentiality of my personal data will be upheld through the removal of personal identifiers (information which could be used to identify me).
- I understand that if I decide that I no longer wish to take part in this project, I can notify the researchers and withdraw immediately, before the data are anonymised. I understand that once my data have been anonymised, it will not be possible to withdraw the data.
- I consent to the processing of my personal information for the purposes of this research study.
- I understand that such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.
- I understand that the information I have submitted will be published as a report, and that I can contact the researchers to get a copy. Confidentiality and anonymity will be maintained and it will not be possible to identify me from any publications.
- I agree that the research project named above has been explained to me to my satisfaction and I agree to take part in this study.

Signed:

Date:

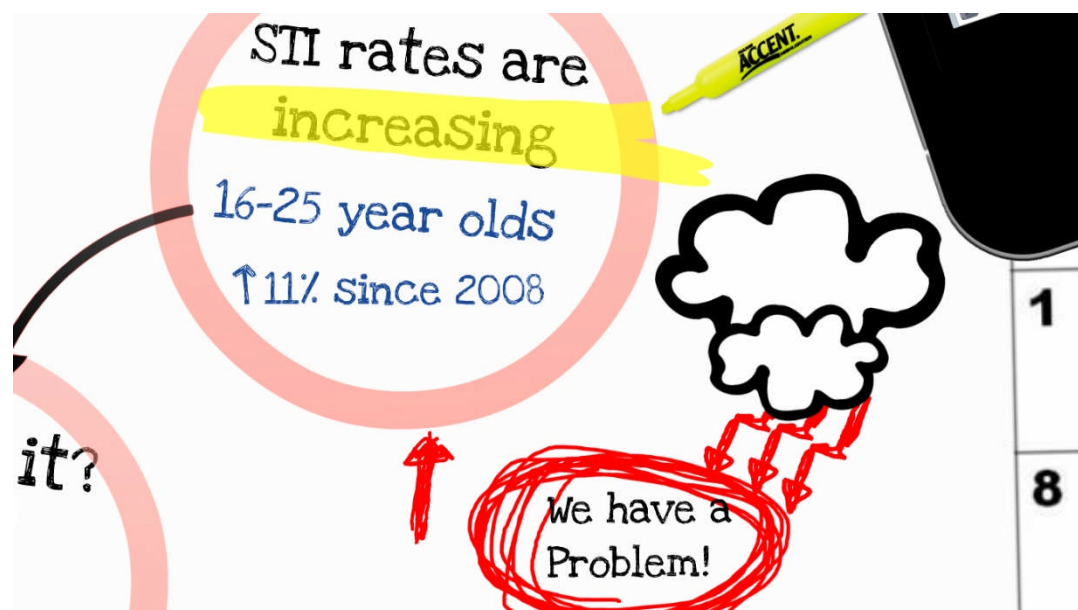
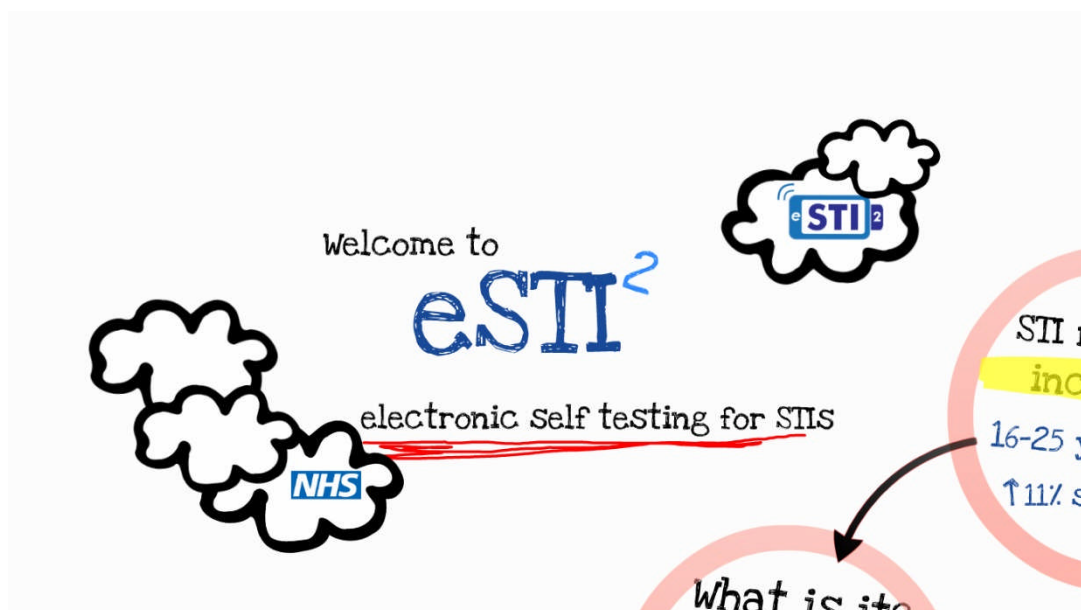
7e Screenshots from the animation

This animation was created by Voula Gkatzidou, with input from Sebastian Fuller, using 'prezi', a web-based programme for creating presentations.

First, an overview of the whole animation was shown (see main text, Chapter 5, section 5.3.4).

The animation zoomed in on different parts of the picture below in turn (presented below; the components of the picture did not move).

Figure A2: Screenshots from the animation shown in the first qualitative study



what is it?



STI e-testing device
anywhere - anytime

how does
it work?

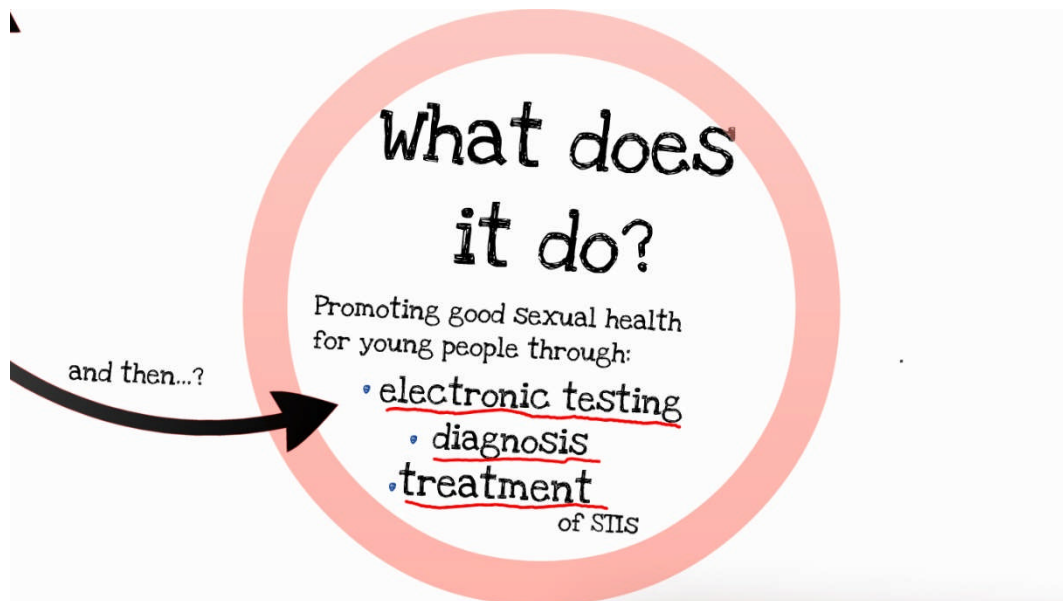
urine collection kit



testing device

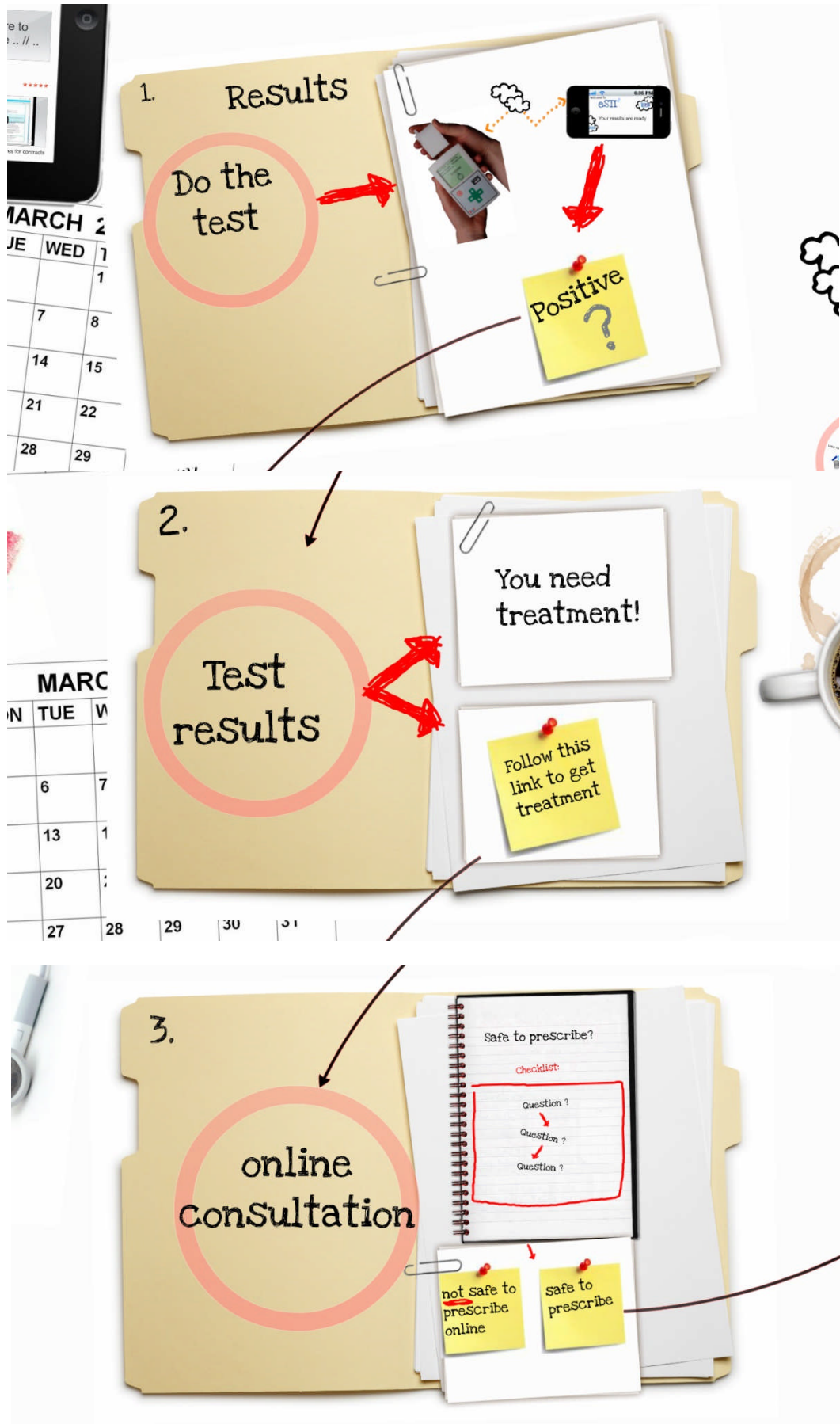


So...?



The screen-shot below was excluded because showing it might influence discussion of the self-test's desirable characteristics (speed, accuracy):







The image of the whole animation (from which these screenshots are taken) is published in open access journal articles (listed below), and was distributed by the journals' publisher in accordance with the terms of the Creative Commons Attribution license (CC BY 4.0):

<http://creativecommons.org/licenses/by/4.0/>

Gkatzidou V, Hone K, Sutcliffe L, Gibbs J, Sadiq ST, Szczepura A, Sonnenberg P, Estcourt C. User interface design for mobile-based sexual health interventions for young people: Design recommendations from a qualitative study on an online Chlamydia clinical care pathway. *BMC Medical Informatics and Decision Making*. 2015;15:72.

Aicken CR, Fuller SS, Sutcliffe LJ, Estcourt CS, Gkatzidou V, Oakeshott P, Hone K, Sadiq ST, Sonnenberg P, Shahmanesh M. Young people's perceptions of smartphone-enabled self-testing and online care for sexually transmitted infections: qualitative interview study. *BMC Public Health*. 2016;16:974.

7f Fieldnotes pro-forma

I prepared this document for the interviewer, to record detailed contextual data which would assist with my analysis. It was one of the steps taken to 'make up for' my absence during data collection, and the fact that I did not conduct the interviews myself.

Participant number:
Location:

Gender:
Date:

First thing: did the recording work? Has it been backed up?
If no... please make extensive notes of whatever you can remember below!

Data quality and completeness:

Any questions/topics which required lots of probing? Why do you think this was? (e.g. cognitively difficult to answer / comprehension was a problem / sensitive topic / recall difficult)

Any questions/topics where the respondent didn't answer, or didn't give a straightforward answer? Why do you think this was?

Was there any point where it seemed like the respondent might not be telling the (whole) truth, or was being evasive? Why do you think this was?

Any questions/topics you felt unable to cover, or which were missed for any reason? Please note what happened.

Any circumstances that adversely affected data collection (e.g. interruptions)?

Did the participant mention anything of note before or after the recording?

Did you feel you established a good rapport with the participant? (Please note if this changed during the course of the interview, if so in relation to which topic/s)

Body language:

Mainly open or closed? If you noticed, when did this change – on which topics was it open and which closed?

Eye contact – lots or little? If you noticed, when did this change – on what topics was it good and not so good?

Any other observations?

Are any amendments needed to the interview guide or conduct of the interview? (Anything which doesn't work, where the order doesn't flow, **or** where you want to clarify what the intention is behind the question, *etc...*)

(For completion when you get a quiet moment – maybe after each week, or every few interviews – as often as you like. There's no need to listen back over the interviews or read the transcripts to do this – it's just your impressions and thoughts)

Themes that seem to be emerging from the interviews at this stage:

Features of eSTI² care pathways that seem to be viewed consistently positively or negatively, so far (or mainly positively or negatively):

(Mainly) positive things (& why/how):

(Mainly) negative things (& why/how):

Do any differences seem to be emerging between the different groups in the purposive sampling frame?

7g Interviewees' reflections on their motivations for participation

At the end of the interviews, the interviewer asked interviewees their reasons for taking part in the interview (with minimal probing)

Just one person (his quote is asterisked*, below) mentioned no other reason for taking part than the token of appreciation (£15). His interview was close to average length and he engaged well with the topic, providing thoughtful answers.

Below is a selection of quotes to illustrate the reasons interviewees gave for participating. I have not conducted a thorough thematic analysis because the topic was not thoroughly explored in the interviews.

The interview as a novel experience

I just wanted to like try something new

The topic: interest in sexual health (and wanting to help) and/or curiosity about the novel technology

I wanted to know how it works. [Interviewer: Mm.] And I won't lie, I did like want the £15. [Interviewer: Yeah.] But I wanted to know how it works!

...because I'm a young person myself. I don't have the time to keep going to the clinic but if these things are quite easy to just pick up [...] it's going to be helpful to me... and also I just wanted to see what's really coming in new [technology] [...] I was interested in the test itself and what it's going to look like, I can't wait to see what it's going to look like....

...it was the topic firstly, because I love seeing new things like new phones, new inventions, I was going to do it but you said £15, that drew me more. But the idea of the new device drew me more.

...then there's a long queue [in the clinic] and some people get tired of waiting and just go, because my friends do that, they can't wait for long, so they just end up going. [Interviewer: Mm.] But yeah, that's why I wanted to try and have a discussion and see what it's about...

I really wanted to know about the e-thingy.

Reasons related to their own experiences and situations

...you told me what it [the interview] was properly about... [Interviewer: Mm.] ...with the STIs um, you don't have to go to clinic, and, obviously being gay... [Interviewer: Mhm.] ...I don't really want to go to a clinic to let everybody, it is obvious that I'm gay but I don't really want to go to a clinic, I don't like clinics...

Do you know what it is, forget the money at the moment, yeah, I suffer from herpes and I have always wanted them to do more with the NHS. I have always wanted the

health clinics to do more for us because there's loads of kids out there that don't go to clinic... [...] I just want to see a change to the sexual health part of the NHS... [...] We don't have more options.

...you said that you'd be, um, talking to me about sexual health. Like in the past I wouldn't care about my sexual health but now I'm growing up and getting wiser, I'm caring more about my health and my sexual life... [...] That's one reason I did this interview.

Advice from others

[Another interviewee told me] it was good, it was so fantastic [...] he really enjoyed the interview... [...] ...scared, but when my friend said oh that was amazing, that was good, I said, "oh I will try it today" (laughter)

...they was just like this is a good, a good thing, you might see if you can do it as well...

The token of appreciation

**The truth, or what should I say? [Interviewer: The truth, absolutely!] Fifteen pounds. [...] It's true, because it's an hour interview.*

...I wanted to find out more about it and then you said £15, and then I got really excited (both laugh)

Doing the interview fitted in with other activities

[In addition to other reasons:] Plus I was going to come college today as well to do revision.

Wanting to offer opinions and have a voice

...well I'm the kind of, the person that likes to, um I don't know, I like to influence people [...] ...and I like to know more too, about stuff.

...do you know what else drew me in as well? You came and approached me, which we don't really get as young kids, because it's either our attitude stinks, we're too loud, or it's something about our appearance, why people don't really approach us. So for you to approach me and ask me if I wanted to do it I felt that there's someone out there that actually does care about what we think, that our opinions do matter. [...] I wasn't really worried about the money, even though I know I would get it, but it was more I wanted to just put my little bit in, yeah, I wanted to put my little bit in.

Appendix 8: Comparison of this thesis' two qualitative studies

The first qualitative study is described in Chapter 5, and the second in Chapters 6-7.




Table A5: Differences and similarities between the two qualitative studies

	First qualitative study	Second qualitative study
<i>Dates of data collection</i>	2012	2014-2015
<i>Lead for key research tasks</i>		
Study design	Myself	Myself
Data collection: interviewer	Colleague	Myself
Analysis	Myself	Myself
<i>Infection</i>	STIs – Chlamydia as exemplar	Chlamydia only
<i>Nature of interview accounts</i>	Hypothetical	Experiential
<i>Interview mode</i>	Face-to-face	Telephone
<i>Study sample</i>		
Sample size	25	40
Age (years)	16-23	18-35
Ethnicity	All non-White	Diverse
Social/educational background	FE college students	Diverse
Experience of STI testing	Discussed in interviews and reported by 22/25	39/40 reported ever having tested (1 partner had not); and 31/39 had tested prior to current episode of care
Experience of STI diagnosis or PN for STI	Spontaneously disclosed by 2/25	All (condition of participation)
<i>Aspects of remote self-testing and online care pathways explored in the interviews</i>		
Using the self-testing device	Yes	(Yes)*
Provision of registration information	Yes (before testing)	Yes (after receipt of results)
Receipt of results notification message	No	Yes
Receipt of results	Yes	Yes
Online automated clinical consultation	Yes	Yes
Receipt of 'e-prescription'	Yes	Yes
Collection of treatment	Yes	Yes
Receipt of treatment by post	Yes	No
Routes to clinical care and attendance at clinic	No	Yes
Partner notification	Yes	Yes
Providing link/code for partners	Yes	Yes
<i>Role of findings within eSTI² Consortium</i>	Contributed to development and design of self-test and online care pathways	Qualitative component of Exploratory Studies about the OCP; findings informed development & evaluation of OCP
<i>Analysis</i>	Thematic analysis	Thematic analysis using Framework for data management

*Explored hypothetically, with minimal probing, at the end of the interview.

Appendix 9: Second qualitative study (chapters 6-7): Study materials and interviewees' reflections

9a Patient Information Leaflet: GUM



eSTI² chlamydia clinical care pathway study

Electronic Self-Testing Instruments for Sexually Transmitted Infections (eSTI²)

Doctors and researchers from our sexual health service are leading some exciting new research to see whether getting treatment for chlamydia, one of the commonest STIs, is easier and quicker for patients online than coming back into clinic. If you are being tested for Chlamydia today you may be able to take part in this study. Please read this leaflet to find out what it means for you.

What is this study about?

eSTI² chlamydia clinical care pathway study is part of the eSTI² consortium, which is a major programme of research led by St George's University of London & St George's Healthcare NHS Trust. The programme aims to create new STI tests which can be used in a person's own home using mobile phone technologies, linked up to internet-based NHS sexual health care.

In this part of the research, we hope to find out if online treatment is acceptable to patients and whether it can lead to more people getting the correct treatment faster. This is a completely new way of treating people with chlamydia within the NHS and so we are developing and running it as part of a research study.

What is chlamydia?

Chlamydia is a common infection passed from person to person through having sex. Chlamydia can be completely cured with antibiotic tablets. If chlamydia is not properly treated it can lead to serious health problems such as infertility and ectopic (tubal) pregnancy. Most people who have chlamydia do not have any symptoms.

What do I have to do?

Once your results are ready (usually in about seven days), we will send you a text message with a secure link so that you can log onto our eSexual Health clinic and get your results. As long as you keep this to yourself, no one else will see or be able to access your results.

What happens if I agree to be part of the study?

If your tests show that you have chlamydia, you will be offered online treatment. We need to check that the antibiotic treatment is right for you so first we will ask you a few questions about your health in a short online medical consultation. If it is safe to do so, and you want to get treatment this way, we will arrange to have your treatment ready for you at a local pharmacy. You can pick it up from there without needing to come back into clinic and the treatment is free of charge. There's also a way for your sex partners to access free treatment online too. Because this is a research study, we will ask you to give your consent to take part online. This research has been approved by XXXXXXXXXX Research Ethics

What if I'd rather come back to clinic? There is no problem if you prefer to come back to clinic to get your treatment. You do not have to give a reason and this will not affect your medical care in any way.

What if I want to speak to someone from the clinic?

If you have any concerns about your results or if you would like to speak to a clinic sexual health adviser you can call our dedicated Clinical Helpline based at St Bartholomew's Hospital, you will see the number as you log in for your results. They will be able to give you advice and help arrange treatment in a way that suits you.

Will my data be kept confidential? All information which is collected about you during the course of the research will be kept strictly confidential, and any information about you which leaves the e-sexual health clinic will not include any personal details.

Is there anything else I may need to do?

If you have chlamydia, about two weeks after getting your results, the clinic sexual health adviser will call you to make sure everything has gone ok with your treatment. This is no different from what happens normally. The health adviser will ask you a few questions about your views of online treatment so that we can understand what people like and don't like about the system. At that stage the health adviser may ask you if you would like to take part in a more in depth 20-45 minute telephone discussion about the study with one of the researchers. If you agree, the health adviser will set up a time for the researcher to call you and explain more about this part of the research. We will reimburse you £30 for your time.

Who is funding this study? This study is funded by the Medical Research Council as part of a Consortium Grant under Phase II of the UKCRC Translational Infection Research Initiative.

Who is leading the research? Dr Claudia Estcourt from Barts Health NHS Trust and Dr Tariq Sadiq from St George's Healthcare NHS Trust are leading the research.

When will the research finish? The eSTI² Clinical Care Pathway Pilot Study should be completed by end of 2016. Non-identifiable data will be kept to evaluate the online NHS clinic. Your medical records will still exist as part of NHS records. A report of the research findings will be available on the eSTI² website and on the NHS e-sexual health clinic.

Still have questions? If you are still unsure about anything or have any questions about this research study, or the wider eSTI² project, please contact the eSTI² Study Research Co-ordinator: Christine Chow on XXXXX XXX XXXX. Alternatively, you can speak to a Health Advisor via the study telephone hotline on XXX XXXX XXX.

If you have any concerns about your treatment or make a complaint, please contact the eSTI² Study Research Co-ordinator in the first instance. If you want to speak to someone outside of the research team, or if you remain unhappy and wish to complain formally, please contact the Patient Advice and Liaison Service (PALS). Email PALS@bartsandthelondon.nhs.uk. Phone: 020 359 42040 / 42050.

20130611_eSTI2_GUM_InformationSheet_BH_FINAL_v2

This is the leaflet for Barts Health patients. The leaflet for St George's patients was identical apart from the logo (top right, first page).

9b Patient Information Leaflet: NCSP internet (Checkurself) patients



NCSP Patient Information Leaflet eSTI² chlamydia clinical care pathway study

Electronic Self-Testing Instruments for Sexually Transmitted Infections (eSTI²)

Checkurself, as part of the National Chlamydia Screening Programme (NCSP), is taking part in some exciting new research to see whether getting treatment for chlamydia, one of the commonest STIs, is easier and quicker for patients online than going to see a GP, pharmacist or sexual health clinic. As you are being tested for Chlamydia, you may be able to take part in this study. Please read this leaflet to find out what it means for you.

What is this study about?

eSTI² chlamydia clinical care pathway study is part of the eSTI² consortium, which is a major programme of research led by St George's University of London & St George's Healthcare NHS Trust. In partnership with Checkurself, as part of the NCSP, the eSTI² consortium aims to create new STI tests which can be used in a person's own home using mobile phone technologies, linked up to internet-based NHS sexual health care.

In this part of the research, we hope to find out if online treatment is acceptable to patients and whether it can lead to more people getting the correct treatment faster. This is a completely new way of treating people with chlamydia within the NHS and so we are developing and running it as part of a research study.

What is chlamydia?

Chlamydia is a common infection passed from person to person through having sex. Chlamydia can be completely cured with antibiotic tablets. If chlamydia is not properly treated it can lead to serious health problems such as infertility and ectopic (tubal) pregnancy. Most people who have chlamydia do not have any symptoms.

What do I have to do?

Once your results are ready (usually in about seven days), we will send you a text message with a secure link so that you can log onto our eSexual Health clinic and get your results. As long as you keep this to yourself, no one else will see or be able to access your results.

What happens if I agree to be part of the study?

If your tests show that you have chlamydia, you will be offered online treatment. We need to check that the antibiotic treatment is right for you so first we will ask you a few questions about your health in a short online medical consultation. If it is safe to do so, and you want to get treatment this way, we will arrange to have your treatment ready for you to collect at a local pharmacy and

the treatment is free of charge. There's also a way for your sex partners to access free treatment online too. Because this is a research study, we will ask you to give your consent to take part online. This research has been approved by XXXXXXXXXX Research Ethics

What if I'd rather see my GP or go to the chlamydia screening office?

There is no problem if you prefer to do this. You do not have to give a reason and this will not affect your medical care in any way.

Will my data be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential, and any information about you which leaves the eSexual Health clinic will not include any personal details.

Is there anything else I may need to do?

If you have chlamydia, about two weeks after getting your results, the clinic sexual health adviser will call you to make sure everything has gone ok with your treatment. This is no different from what happens normally. The health adviser will ask you a few questions about your views of online treatment so that we can understand what people like and don't like about the system. At that stage the health adviser may ask you if you would like to take part in a more in depth 20-45 minute telephone discussion about the study with one of the researchers. If you agree, the health adviser will set up a time for the researcher to call you and explain more about this part of the research. We will reimburse £30 you for your time.

Who is funding this study? This study is funded by the Medical Research Council as part of a Consortium Grant under Phase II of the UKCRC Translational Infection Research Initiative.

Who is leading the research? Dr Claudia Estcourt from Barts Health NHS Trust and Dr Tariq Sadiq from St George's Healthcare NHS Trust are leading the research.

When will the research finish? The eSTI² Clinical Care Pathway Pilot Study should be completed by end of 2016. Non-identifiable data will be kept to evaluate the online NHS clinic. Your medical records will still exist as part of NHS records. A report of the research findings will be available on the eSTI² website and on the online NHS clinic.

What if I still have questions? If you are still unsure about anything or have any questions about this research study, or the wider eSTI² project, please contact the eSTI² Study Research Co-ordinator: Christine Chow on XXXXX XXX XXXX. Alternatively, you can speak to a Health Advisor via the study telephone hotline on XXX XXXX XXX.

If you have any concerns about your treatment or to make a complaint, please contact the eSTI² Study Research Co-ordinator in the first instance. If you want to speak to someone outside of the research team, or if you remain unhappy and wish to complain formally, please contact the Patient Advice and Liaison Service (PALS). Email PALS@bartsandthelondon.nhs.uk. Phone: 020 359 42040 / 42050.

20130611_eSTI2_NCSP_InformationSheet_FINAL_v2

9c Informed consent form for telephone interview

To be completed by researcher, by phone, before start of telephone interview.

Patient identification number for this research study: _____

Research ethics study number: Brighton & Sussex (NHS) Research Ethics Committee
ref: 13/LO/1111; IRAS project ID: 112513.

Name of study: eSTI² Chlamydia Clinical Care Pathway Pilot Study Interview sub-study:

Views and experiences of people diagnosed with chlamydia, who have chosen remote online clinical care pathways for management and partner notification: Qualitative interview study

Name of researcher and university: Ms. Catherine Aicken, UCL

Please tick each section

1.	I confirm that I have read or have had read to me, and understand, the information sheet dated for the above study. I have had the opportunity to consider the information, ask questions, and have had these answered satisfactorily.	
2.	I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without my medical care or legal rights being affected.	
3.	I understand that this interview will be audio-recorded. I understand that neither my name nor any other identifying information will be associated with the audio-recording or transcripts of the interview.	
4.	I understand that direct quotes from what I say may be used in published research reports or articles, but that my name and other information that could identify me will be removed.	
5.	I agree to take part in the above research study (interview).	

Person taking consent

Name: CATHERINE AICKEN

Signature: _____

Position and university: PhD student, UCL

Date: ____/____/____

9d Topic guide

Headings in the topic guide are in bold. Objectives are described in square brackets. Not all topics will apply to all participants.

INTRODUCTION AND INFORMED CONSENT

Explain purpose of the follow-up interviews:

“Using the internet to get chlamydia treatment is very new in the NHS. Finding out you think about it, and what it’s like using it, is really important in making sure these new services meet people’s needs.”

Explain what the interview involves:

“The interview is voluntary, confidential and lasts roughly half-an-hour. I can email you a £30 voucher straight afterwards, as a thank-you for your time and help with the study. The interview isn’t a survey – it’s more like a conversation.”

Explain who I am:

“I’m a researcher at a university (UCL).”

“Do you have any questions?”

Researcher goes through consent form by telephone, confirming informed consent to interview, and that it will be recorded.

Read through Patient Information Leaflet if they have not read it.

Thank interviewee for their help with the study, and for agreeing to this extra interview.

Confirm interviewee is comfortable, isn’t likely to be disturbed or overheard, and that their mobile phone is charged.

CLARIFY INTERVIEWER’S ROLE: “As I’m researcher, not a healthcare worker, I don’t have access to your medical notes or information you’ve already provided. This is to protect your confidentiality. Please bear with me if I ask you something you’ve already told someone else. I *am* interested in what happened during your care, so I can find out what it’s like to use this new system – but I’m *not* checking up on you.”

“I also didn’t design the online system – so please hope you can feel free to tell me what you think about it, whether it was good or bad.”

“If I ask you a question that you don’t want to answer, please tell me, and we’ll move on to the next topic.”

INTERNET USE [*objective: start interview with non-threatening, easy-to-answer questions.*

Build rapport and gain a little understanding of respondent’s life (e.g. working, studying, ...)]

Can you tell me a bit about your use of the internet?

- How often do you use it? What device do you use?
- What do you use it for? (social, work/study, online dating...) How do you find it?
- Ever used for healthcare? What’s that like?

FIRST IMPRESSIONS (of eSTI² care pathway) AND TALK-THROUGH

[Objectives: begin 'mapping out' participants' experiences and views; I use this broad, general question topic to encourage the participant to talk, opening up the atmosphere of the qualitative interview, in which the participant does most of the talking]

First impressions (of eSTI² care pathway)

If I can take you back to when you first got your chlamydia result...

When you saw that you might be able to get your treatment online without going to a clinic or doctor, what did you think about it?

Appeal (reasons for opting for online care)

Expectations

- What would it be like?
- Any expectations of what it would involve? details
- feelings about own ability to use it

Awareness and expectations of alternatives to online care

- expectations of *routine* care in GUM/NCSP (i.e. what would happen if you *didn't* choose online care)
- any other places you could have gone?

Talk-through what happened

I'm really interested in the process from when you first got the message about your result, onwards. Please can you talk me through what happened - as if you're describing it to someone who doesn't know anything about it

- ***Let participant talk.*** Interviewer to probe on the below topics, if they come up.

[NCSP/GUM study arms:] TESTING EXPERIENCE (for current episode)

[Objective: establish context of care-seeking & online care pathway use]

- choice of testing service (GUM/NCSP)
- reasons for choice (incl lay referral?)
- comparison with *any previous STI testing experience (previous STI mentioned?)*
- reasons for testing
- views and experience of providing information at this stage (before result)
- (understanding of) what tested for?

REACTIONS TO RESULT (OR MESSAGE FROM PARTNER) AND SUBSEQUENT PRIORITIES

[Objectives: explore contextual factors, healthcare beliefs, health beliefs: establish respondents' (reported) needs/goals for seeking care; explore context of care-seeking; relative importance of getting treatment promptly vs. addressing other needs; motivation to seek care online]

Reactions to message – *how long ago?*

- when accessed (straight away/later), reasons
- how accessed (device, location, in private?), reasons
- ease of using PIN details

Reactions to result itself

(or news that have been exposed to CT)

- Feelings/thoughts
- Belief/trust, reasons
- Next step(s), immediate priorities

Meaning of result

(or news that have been exposed to CT)

- urgency/importance of treatment (& understanding of consequences of not treating the infection)

CARE PATHWAY USE/BEHAVIOUR:

[Objectives: explore reported behaviour and experiences of care-seeking and reasons/feelings attributed to these; explore views as they relate to specific stages in the care-seeking of patients who chose online care.]

- how worked out what to do
- any delay? Why?
- Any change of location / device? Why?

How it feels to do an 'e-Consultation'

- What is it like? – vs. if you'd gone to GP / sexual health clinic
- Advantages and disadvantages
- Anything missing, from that experience? (probe: reassurance, information, trust)
- Anything extra?

Information provision

- experience of answering questions
- amount of questions, time taken
- complexity of questions / wording / ease of finding the right response
- perceived relevance, importance of: providing information, accuracy
- anything seem unclear or strange?
- Went straight through vs. stopped at any point? (details, reasons; any change of device?)
- Confidence in own ability to do online consultation – and any change from outset?

IF ANY CONCERNS: probe why?

- due to the type of information/topic, or means of providing it (web-app/device/internet)

[IF APPLICABLE:] Being routed to clinic

Reactions to being told need to attend clinic

- feelings – in context of initial reasons for choosing online care (e.g. speed/ convenience/ privacy)
- perceptions of why (including importance, urgency)

Subsequent care-seeking

- Whether actually went
- Use of any other services – which, why?
- Reasons

[IF APPLICABLE:] What happened around clinic visit

Experience of finding the clinic, getting there, attending

- seamlessness of process (e.g. staff knowledge of 'online care'/fast-tracking)

Face to face consultation

- comparison with online consultation
- adv/disadv
- anything extra/missing

Getting treatment

- obtaining treatment
- understanding how to take treatment
- treatment taken/not taken? reasons
- anything else you were told to do? Or not do?

[IF APPLICABLE:] Dropping off the care pathway

Establish at what point in care pathway participant stopped using it

Reasons/cause

- suggested changes to care pathway

Use of any other services

- which?
- What happened?
- needs met/unmet

Knowledge of telephone clinical helpline

- reasons for use/non-use

[IF APPLICABLE:] E-prescription and treatment

If mentioned: Confidence in /Trustworthiness of prescribing process (getting right treatment for you)

- reasons;
- suggested improvements?

Selecting a pharmacy

- clear what to do?
- Feelings about attending a pharmacy

Attending the pharmacy – **how soon after results?**

- when/any delays? Reasons
- clear what to do?
- experience of picking up treatment

Taking treatment

- understanding how to take treatment
- whether taken or not taken – and why/why not?
- anything else you were told to do? Or not do?

'In-principle' acceptability of 'e-prescription'

What happened next?

- Talk through up to RHA final f'up
- *(gauge whether NCSP participants – comprehensive testing sought?)*

[IF APPLICABLE:] Partner notification

Screen where you can request a message for people you've had sex with

- recall
- expectations of what would happen if you requested the PN message
- expectations of what partners would do if they were sent the message
- benefits/disadvantages to this message
- effect (or anticipated effect) of message on discussions with partners (e.g. made it easier, more difficult)

Use of PN message for partners

- reasons why / why not
- what done – when sent, to all partners? Some? Reasons

If thought the website was going to send a text straight to partners:

My understanding is that it should send you a message with a code that you can give to people, so they can get their treatment online the same way you did. You're not the first person who's understood that the website sends a message to partners, so it's obviously not clear!

If you'd known you would get the code yourself, to give to people when you wanted to, so they could use this online system, what would you have done? Why/why not?

Facilitating PN *It can be difficult to tell people you've had sex with that they might have chlamydia*

- Could anything have made it easier, for you? Anyone unable to tell? Reasons

[FOR THOSE PARTICIPATING AS PARTNERS]

Feelings about getting treatment without testing

Use of any other services

- reasons (including testing for other infections; repeat CT testing)
- support

PRIVACY

[Objectives: explore meaning and importance of privacy / not being seen during a consultation / not being seen attending sexual health setting – building on findings from previous interview study]

More or less private to get care the way you did, compared to [alternative]? Why?

Any point where anyone found out you'd had chlamydia, and you hadn't wanted them to know? Any point where you thought this might happen?

IF privacy concerns are mentioned by interviewee – probe

- what wanted to keep private (e.g. use of sexual health services; own reaction to being asked sexual history question face-to-face)
- perceived consequences of others (who?) finding out; reasons for thinking this
- Importance of privacy in choice to get care online

Re: services with no face-to-face contact vs. services delivered in person (if mentioned)

- What is it about *[what participant said: e.g. answering questions about sex, attending a service]* in person that makes it *[e.g. uncomfortable, reassuring, embarrassing]*?

SUPPORT, THE CLINICAL HELPLINE AND USE OF OTHER SERVICES

[Objectives: establish needs for support and their nature; whether this impacts upon care-seeking (drop-out, use of additional services); use, awareness and experience of helpline]

Through whole process: need for information, support, help?

- Needs met/unmet – details (for what, why?)
- Any other services/websites/people consulted/looked at/asked - since getting result
- Importance of these

Unmet needs (if any) at point of interview – feel you still need to speak to anyone now?

Use any other health services now?

- Any further needs unmet? (e.g. where wanted to speak to someone but couldn't/didn't)
- Whether/how unmet needs could have been met online / away from health services?
- Direct question: further testing?

Knowledge and views of telephone clinical helpline

- Use/non-use; attempts to use (got through?)
- expectations: who might speak to; views of what helpline could offer
- Experiences (if any): who spoke to, what about, what stage, whether helpful
- Perceived importance of helpline
- Opening hours/accessibility (if can only be open some times, when should this be?)

EASE/CONVENIENCE/SPEED (also 'seamlessness')

[Objectives: explore these overlapping themes which emerged from the previous study]

?revisit any mention of these unless addressed already

Fit between expectations and what actually happened

- Any suggested changes (not already mentioned)

*******Let participant know that we are nearing the end of the interview*******

FINAL WORDS AND RECOMMENDATIONS *[Objectives: now that details have been discussed, explore overall views/experiences once more; set scene for closure of the interview]*

Revisit initial care-seeking goals/expectations

- Extent these were met through online care pathway?... through other services? ... still unmet?

How would you describe it – few words

Recommendations (e.g. if a friend had chlamydia and could get care online, what would you advise?)

- Recommend it? reasons

Suggested improvements

Brief: Thoughts about eSTI² remote self-test:

I.e.: if you'd been able to do it all online / away from medical settings

HOW WAS THE INTERVIEW?

I'm interviewing people on the phone at the moment.

What if I'd been able to interview you in person?

(if asked location: at clinic, your home, a university office in central London, other convenient place)

Thoughts what it'd have been like talking face-to-face, likelihood of taking part

- Probe mentions of difference giving info face-to-face – from earlier in the interview

RECORDER OFF

Demographics/details	If GUM: clinic you tested at
Age (note down gender)	If NCSP: borough of residence
Self-defined: ethnic group	sexuality "relationship status"

*** THANK YOU FOR HELPING WITH THIS RESEARCH ***

*** ARRANGE SENDING VOUCHER - GET EMAIL ADDRESS AND CHECK IT ***

9e Coding framework

Interviewee characteristics (categorical data):

Gender; Age (years); Ethnicity*; Relationship status*.

Participation route to Exploratory Study*; Care pathway use*; Pharmacy problems*; Helpline use*; PN code request/use*; Treatment 'delayed' (taken >3days after results notification).

**Categories as in sample characteristics table, chapter 6.*

- 1 Background of participants
 - 1.1 Current study or employment
 - 1.2 Sexual relationships and partnerships
 - 1.3 Activities, routines, travel
 - 1.4 Living arrangements and location
 - 1.5 Other – including friends, social life, where from
- 2 Current episode of care – up to initiation of OCP
 - 2.1 Context and reasons for testing
 - 2.2 Choosing which service to use
 - 2.3 Experience of accessing and attending GUM
 - 2.4 Experience of ordering and returning Checkurself kit
 - 2.5 Other (including trying to use any other services, e.g. GP)
- 3 Receiving chlamydia result (or notification of exposure**) and initiation
 - 3.1 Receiving results notification (or partner code**) and logging on
 - 3.2 Reaction and priorities after finding out result (or PN**)
 - 3.3 Expectations and prior awareness of online care
 - 3.4 Expectations, awareness and views on alternatives to online care
 - 3.5 Other
- 4 Current episode of care – after results (or notification of exposure**)
 - 4.1 Online consultation
 - 4.2 Pharmacy – choosing, visiting, collecting treatment
 - 4.3 Disengagement from online care and what happened next
 - 4.4 Treatment – taking it, being given it
 - 4.5 Seeking and/or receiving information and support
 - 4.6 Helpline awareness, views and use
 - 4.7 Partner notification (with or without using partner code)
 - 4.8 Clinical follow-up call
 - 4.9 Other (including using other services, telling other people)
- 5 Likes and dislikes about the OCP
 - 5.1 What appeals about the OCP, what they liked
 - 5.2 What's off-putting about the OCP, what they didn't like
 - 5.3 Ambivalent views, mixed feelings
 - 5.4 Suggested improvements
 - 5.5 Other

- 6 Privacy
- 7 (Sexual) health and healthcare experiences, beliefs and expectations
 - 7.1 Previous STI diagnosis/es
 - 7.2 Previous STI testing including which services
 - 7.3 STI, chlamydia (including transmission, symptoms)
 - 7.4 Healthcare services, NHS
 - 7.5 Healthcare workers
 - 7.6 Sources of health information (including online)
 - 7.7 Treatment
 - 7.8 PN
 - 7.9 Other
- 8 ICT and internet experience, expectations, beliefs

Additional codes:

- 9 Views expressed about eSTI² remote self-testing
- 10 Views expressed about telephone interview mode

****Brackets indicate the experience of people using the OCP as partners of other Exploratory Studies participants, for whom the same codes were used in order to facilitate comparison with people who had been diagnosed with chlamydia.**

9f Interviewees' reflections on the telephone interview mode

Towards the end of the interview, I asked interviewees how the interview went, and then asked their thoughts on interview mode (with minimal probing). I did not phrase the question the same way for each person, and sometimes before I could open this topic, interviewees spontaneously commented on it. Because of these inconsistencies, I present no quantitative breakdown of their responses.

Most interviewees discussed how they preferred a telephone interview, some explaining that they would still have taken part in the research if it had been a face-to-face interview, and others stating that they would be unlikely to participate in a face-to-face interview, or definitely would not do so. Just two expressed a preference for a face-to-face interview.

Below is a summary of the issues they mentioned, with illustrative quotes. This is not a thorough qualitative analysis; the topic was not thoroughly explored. The views expressed may have been influenced by the rapport we had developed by this point (the end of the interview) and what we had spoken about, and of course, that they had agreed to and were still taking part in a telephone interview.

On the phone you can be more honest

I think perhaps on the phone you can be more honest [Interviewer: Uh-huh?] Cos you, you're less able to see what the other person's body language and reaction us, to what you're saying, so you can be completely honest with your opinions.

...I wouldn't like you to come and see me. [...] I personally would be sincere but I do feel, some people might have a problem saying this type of thing if you are right in front of them

Face-to-face is a bit awkward

Oh it'd be a bit awkward... [...] Because I'd feel like I'm getting told off (laughing) [...] [Whereas by phone it has not felt this way, because:] I can't see your face, I can't see your eyes, you're not looking at me.

I feel freer just, do you know what I mean, not having to kind of see somebody and their reactions and whatever.

Face-to-face is more secretive, more confidential

...on the phone, you've told me it's confidential, it even feels more confidential because – you just can't see my face.

...over the phone it's still a bit more confidential if you get what I mean. Like nobody will see you going for it... [...] You can never put a face to a name then.

Phone interviews are convenient, compared to face-to-face interviews

...just the easiness of phone calls and you can do it whenever, wherever, and it doesn't require having to take the time up to get somewhere and meet you and whatever. Doing it on the phone is quite convenient, isn't it?

Ah, that would probably be tricky in terms of scheduling as you've seen even on the phone is er, is tough so, and in person it would have been probably a bit tougher.

I haven't had sort of, had to stop my day and rearrange things to have this conversation with you. Whereas meeting in person, you would have to rearrange things a little bit more.

Comfort and self-presentation

If offered a face-to-face interview: ...I'd have to sort of you know go somewhere else, whereas I can just sit here with like a cup of coffee...

Either would be OK, but if it was a face-to-face interview: As long as I felt comfortable with you, um (pause) I don't have, you know, I feel absolutely, I'd feel fine. Especially if I'm doing it in my own home or something

On the phone: ...this way, I'm sat in my pyjamas. [Interviewer: So am I actually.] (both laugh) There you go, neither of us have had to even put a bit of make up on this morning to have this conversation. (both laugh)

Being in a private place – mixed views on the merits of interview modes

...I suppose if you were having a face to face interview, you know you are guaranteed to be in a private place somewhere. But [...] because you text me saying like, exactly what time I was having the phone call, So I knew I could get to somewhere at that time that was like, private enough for me.

It's more convenient if the interviewer visits the interviewee, but: ...it's harder for people to find somewhere [...] where two people can meet [...] whereas if you're having a conversation on the phone, it's a little bit more discreet.

Audibility

[Face to face] Maybe better because I can travel, well I can hear you properly (laughs) [Interviewer: Is it, sorry is it still a bad line?] Yeah a little bit

...it would have been clear maybe the conversation because of the noise on this phone or something... [...] English is not my first language (laughs)

Agreeing to a face-to-face interview signifies an obligation to take part

...before, when I spoke to you on the phone, I said, "Yeah call me this time", I sort of, I don't know, seventy percent sure that I'd do this, I'd actually go through with the whole process... [...] say for example, I'd finished with my [work] now, and I had something else I had to do, then I wouldn't feel bad, then going, "Oh actually it's not a good time" [Interviewer: OK.] But if I'd actually, we've made an appointment, you were coming round my house, then, it's a bit – you feel more obliged. So if that was the only option when you first said it, I might've well said no.

Appendix 10: Integration methods

Integration '*involves the generation of a tangible relationship among methods, data and/or perspectives, retaining the integrity of each, through a set of actions clearly specified by the research team, and that allows them to 'know more' about their research topic*' (Moran-Ellis *et al.*, p51^{b1}). Qualitative findings from this thesis were integrated with my colleagues' key quantitative findings from the Exploratory Studies (Box 8). Integration therefore took place at the level of perspectives and interpretation of findings, after the datasets had been analysed separately.

First, comparable themes from each of the three qualitative analyses were identified. The themes were summarised, and placed alongside each other in a matrix, to facilitate comparison (as has been done by others, including Flowers *et al.*, 2017^{b2}). Quantitative results were added to the matrix where they provided relevant insights into the themes. This process can itself be considered thematic, as it uses the themes from the qualitative studies to organise the findings.^{b3}

Then, following the realist approach of this thesis, the findings from quantitative and qualitative studies were considered for their potential to provide unique and complementary findings on similar topics, through their different methodologies. The different study populations, different interventions, the study populations' differing relationships to the intervention, and the different aims and objectives of the analyses, were taken into account in the interpretation. I paid particular attention to these differences when considering convergent and divergent findings (e.g. differences in the apparent importance of data security, between my two qualitative studies), in order to offer the most meaningful interpretation.

Note on similarities between themes

Similarities between the themes generated in the qualitative studies reflects that participants discussed similar issues in relation to online care pathways for STIs. Similarities also reflect that the qualitative studies were not conducted independently, but iteratively, with the second qualitative study building on the findings of the first (as well as iteratively informing the development of the OCP). In practical terms, this meant that the design of the second qualitative study, and content of the topic guide, were influenced by findings from the first qualitative study which I identified as warranting further investigation. My own developing ideas also inevitably influenced conduct of the interviews for the second qualitative study, and my analyses.

As noted in Chapter 7, the largely patient-led nature of the OCP explains similarities between themes identified in the second qualitative study's two analyses (about use, and about appeal of the OCP). Patients were able to use the intervention in ways which took advantage of the features that they liked about it.

Note on the Exploratory Studies' approach to mixed-methods and integration

The eSTI² team's design of the Exploratory Studies did not include methods for the integration of quantitative and qualitative data. I recognise concerns expressed about mixed-methods studies which present quantitative and qualitative data separately^{b4} as the Exploratory Studies' first two published papers have done.^{b5,b6} Together with other eSTI² researchers, I am working on detailed integration of the quantitative and qualitative data to inform refinement of the OCP (eSexual Health Clinic).^{b7} This detailed integration has not been included in the thesis, because it is ongoing and collaborative, and concerns parts of the OCP (e.g. its online results service^{b8}).

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Appendix 11: Updated literature search for the thesis

A literature search was conducted on 15th March 2017, in PubMed, and restricted to documents with a publication date of 2013 onwards. This led to 941 documents being identified.

(ehealth[MeSH Terms] OR ehealth[Other Term] OR ehealth[Title/Abstract] OR e-health[Other Term] OR e-health[Title/Abstract] OR mhealth[Other Term] OR m-health[Title/Abstract] OR internet[Other Term] OR internet[Title/Abstract] OR online[Other Term] OR online[Title/Abstract] OR app[Other Term] OR app[Title/Abstract] OR apps[Other Term] OR apps[Title/Abstract])
AND
(sexually transmitted disease[MeSH term] OR sexually transmitted infection*[Other term] OR sexually transmitted infection*[Title/Abstract] OR sexually transmitted disease*[Other term] OR sexually transmitted disease*[Title/Abstract] OR chlamydia[MeSH Terms] OR chlamydia infection*[MeSH Terms] OR chlamydia[Other Term] OR chlamydia[Title/Abstract] OR genitourinary medicine[Other Term] OR genitourinary medicine[Title/Abstract] OR genito-urinary medicine[Other Term] OR genito-urinary medicine[Title/Abstract])

The MeSH term 'ehealth' is synonymous with the MeSH term telemedicine (indeed when searched on the PubMed website, e-health appears as "telemedicine" in the search details box). The terms i-health, ihealth (sometimes used to refer to internet-based e-health) were not used because the search engine did not recognise these words, and displayed a message indicating that they were not used.

I reviewed the titles and abstracts of the 941 papers. Reflecting this thesis' focus, I sought research on automated online care pathways for STI treatment and care, and found none except for the OCP.

(Inclusion criteria for this literature search, conducted at the end of my doctoral research, contrast with the broader inclusion criteria I used in chapter 2's scoping

review. At this earlier stage, I knew from colleagues' research that no such online care pathways yet existed. Therefore, I had sought evidence about a broad range of uses of communications technology in STI service delivery, which I could draw upon to inform my research and eSTI²'s).

Appendix 12: e-health literacy literature search

A literature search was conducted on 1st August 2017, using OvidSP search engine to search Embase 1974 to 2017 July 31 and Ovid MEDLINE® Daily Update July 31, 2017, using the multi-field search. The search strategy (conducted across ‘all fields’) was as follows:

e-health litera* OR ehealth litera* OR digital literacy OR digitally literate

After automated de-duplication, 184 records were identified.

In order to include research which might have been published outside of academic health and medical journals, I repeated the above search using Endnote (reference management software) to search Web of Science, across ‘Title/Abstract/Keywords’. This led to the identification of 3928 records, narrowed down to 1102 (in addition to the 184) by restricting to records containing the term ‘health’ in ‘any field’.

After automated and manual deduplication, this gave a total of 1112 unique records, a large proportion of which were very recent. The 1112 records were reduced to those most relevant to the social patterning of e-health literacy, and to adults’ engagement with e-healthcare, with a developed country focus.^{c1} Conference abstracts, editorials, books, and documents published in languages other than English were excluded.

Documents published before 2015 were excluded unless they were cited multiple times as key references in recent included studies. This was done for feasibility, given the number of records, and to enable a recent focus on a topic affected by social media, smartphones and other internet-enabled digital devices, and apps – as well as rapid changes in how widespread these technologies are, what they are used for, and the intensity of their use. (These technologies have been used for some years, but a delay between research and publication was assumed).

Bibliography for this appendix

- c1. United Nations. Country classification. *World Economic Situation and Prospects 2014*. Country classification.
http://www.un.org/en/development/desa/policy/wesp/wesp_current/2014wesp_country_classification.pdf

Appendix 13: Further publications and research dissemination linked to this doctoral research

A list of publications, conference presentations and posters presenting parts of my thesis has been provided in the main body of this dissertation. In addition, the following are linked to my doctoral research with the eSTI² Consortium.

Rapid analysis of data collected for chapter 5's study:

Conference presentation by co-author

Fuller SS, **Aicken C**, Sutcliffe LJ, Estcourt CS, Gkatzidou V, Hone K, Sonnenberg P, Oakeshott P, Sadiq ST, Shahmanesh M.
What are young people's perceptions of using electronic self-tests for STIs linked to mobile technology for diagnosis and care (eSTI2)?
Oral presentation by co-author at *ISSTD conference*, Vienna, Austria, July 2013.
Abstract published in *Sexually Transmitted Infections* 2013. 89;Suppl1:A69-70.

Research dissemination related to the Exploratory Studies (described in chapter 6)

Peer-reviewed journal articles

Links to full texts are provided.

Quantitative results from the Exploratory Studies of the Online Chlamydia Pathway/eSexual Health Clinic:

Estcourt CS, Gibbs J, Sutcliffe LJ, Gkatzidou V, Tickle L, Hone K, **Aicken C**, Lowndes CM, Harding-Esch EM, Eaton S, Oakeshott P, Szczepura A, Ashcroft R, Copas A, Nettleship A, Sadiq ST, Sonnenberg P. The eSexual Health Clinic system for sexually transmitted infection management, prevention and control: exploratory studies demonstrating safety, feasibility and public health utility. *Lancet Public Health*. 2017;2:182-190.

[http://dx.doi.org/10.1016/S2468-2667\(17\)30034-8](http://dx.doi.org/10.1016/S2468-2667(17)30034-8)

Mixed-methods evaluation of the OCP/eSexual Health Clinic's results service (using data from my qualitative study, chapter 7)

Gibbs J, **Aicken CRH**, Sutcliffe LJ, Gkatzidou V, Tickle L, Hone K, Sadiq ST, Sonnenberg P, Estcourt CS. Mixed-methods evaluation of a novel online sexually transmitted infection results service. *Sexually Transmitted Infections*. Published Online First: 11 January 2018.

<http://dx.doi.org/10.1136/sextrans-2017-053318>

Conference presentations and posters

Gibbs J, Sonnenberg P, Tickle L, Sutcliffe L, Gkatzidou V, Hone K, **Aicken C**, Sadiq ST, Estcourt C. P209 Outcomes of partner notification (PN) for sex partners of people with chlamydia, managed via the Online Chlamydia Pathway. Poster at *BASHH conference*, Oxford, 10-12 July 2016.

Abstract published in *Sexually Transmitted Infections*. 2016;92(Suppl1):A89.

Estcourt CS, Gibbs J, Sutcliffe LJ, Gkatzidou V, Tickle L, Hone K, **Aicken C**, Lowndes C, Harding-Esch E, Eaton S, Oakeshott P, Szczepura A, Ashcroft R, Hogan G, Nettleship A, Pinson D, Sadiq ST, Sonnenberg P. Is an automated online clinical care pathway for people with genital Chlamydia (Chlamydia-OCCP) within an eSexual Health Clinic feasible and acceptable? Proof of concept study. Oral presentation by co-author at *ISSTD conference*, Brisbane, September 2015.

Abstract published in: *Sexually Transmitted Infections* 2015;91(Suppl2):A55.

Gibbs J, Sutcliffe L, **Aicken C**, Tickle L, Wu S, Shimmin H, Ashcroft RE, Sadiq ST, Sonnenberg P, Estcourt C. A novel ePrescribing System linking an online eSexual Health Clinic & Community Pharmacies. Oral presentation by co-author, at *e-Prescribing and Medication Management Symposium*, School of Pharmacy, UCL. 25th November 2015.

User-centred design research carried out in parallel with the study reported in chapter 5:

Conference poster

Voula G [*sic: should be Gkatzidou V*], Balachandran W, Lowndes C, Howell-Jones R, **Aicken CR**, Mercer CH, Sutcliffe L, Sonnenberg P, Jackson M, Estcourt CS, Sadiq ST, Hone K. *A user centred approach to the design of point-of-care and self-test mobile phone diagnostics for sexually transmitted infections (STIs)*. Poster at the 4th Joint BASHH-ASTDA meeting, Brighton UK, 27-29th June 2012.

Abstract published in: *Sexually Transmitted Infections* 2012;88(Suppl1):A47.

Appendix 14: Published peer-reviewed journal articles presenting studies from this thesis

Links to full texts are provided.

Aicken CRH, Estcourt CS, Johnson AM, Sonnenberg P, Wellings K, Mercer CH. Use of the internet for sexual health among sexually experienced persons aged 16 to 44 years: evidence from a nationally representative survey of the British population.

Journal of Medical Internet Research. 2016;18(1):e14.

<http://dx.doi.org/10.2196/jmir.4373>

<http://www.jmir.org/2016/1/e14/>

thesis objective 1, chapter 4

Aicken CRH, Fuller SS, Sutcliffe LJ, Estcourt CS, Gkatzidou V, Oakeshott P, Hone K, Sadiq ST, Sonnenberg P, Shahmanesh M.

Young people's perceptions of smartphone-enabled self-testing and online care for sexually transmitted infections: qualitative interview study.

BMC Public Health. 2016;16:974.

<http://dx.doi.org/10.1186/s12889-016-3648-y>

<https://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-016-3648-y>

thesis objective 2, chapter 5

Aicken CRH, Sutcliffe LJ, Gibbs J, Tickle LJ, Hone K, Harding-Esch E, Mercer CH, Sonnenberg P, Sadiq ST, Estcourt CS, Shahmanesh M.

Using the eSexual Health Clinic to access chlamydia treatment and care via the internet: a qualitative interview study.

Sexually Transmitted Infections. Published Online First, 7th October 2017.

<http://dx.doi.org/10.1136/sextrans-2017-053227>

<http://sti.bmj.com/content/early/2017/10/07/sextrans-2017-053227>

thesis objective 3a, chapters 6 and 7

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Original Paper

Use of the Internet for Sexual Health Among Sexually Experienced Persons Aged 16 to 44 Years: Evidence from a Nationally Representative Survey of the British Population

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Abstract

Background: Those who go online regarding their sexual health are potential users of new Internet-based sexual health interventions. Understanding the size and characteristics of this population is important in informing intervention design and delivery.

Objective: We aimed to estimate the prevalence in Britain of recent use of the Internet for key sexual health reasons (for chlamydia testing, human immunodeficiency virus [HIV] testing, sexually transmitted infection [STI] treatment, condoms/contraceptives, and help/advice with one's sex life) and to identify associated sociodemographic and behavioral factors.

Methods: Complex survey analysis of data from 8926 sexually experienced persons aged 16-44 years in a 2010-2012 probability survey of Britain's resident population. Prevalence of recent (past year) use of Internet sources for key sexual health reasons was estimated. Factors associated with use of information/support websites were identified using logistic regression to calculate age-adjusted odds ratios (AORs).

Results: Recent Internet use for chlamydia/HIV testing or STI treatment (combined) was very low (men: 0.31%; women: 0.16%), whereas 2.35% of men and 0.51% of women reported obtaining condoms/contraceptives online. Additionally, 4.49% of men and 4.57% of women reported recent use of information/support websites for advice/help with their sex lives. Prevalence declined with age (men 16-24 years: 7.7%; 35-44 years: 1.84%, $P<.001$; women 16-24 years: 7.8%; 35-44 years: 1.84%, $P<.001$). Use of information/support websites was strongly associated with men's higher socioeconomic status (managerial/professional vs semiroutine/routine: AOR 1.93, 95% CI 1.27-2.93, $P<.001$). Despite no overall association with area-level deprivation, those in densely populated urban areas were more likely to report use of information/support websites than those living in rural areas (men: AOR 3.38, 95% CI 1.68-6.77, $P<.001$; women: AOR 2.51, 95% CI 1.34-4.70, $P<.001$). No statistically significant association was observed with number of sex partners reported after age adjustment, but use was more common among men reporting same-sex partners (last 5 years: AOR 2.44, 95% CI 1.27-4.70), women reporting sex with multiple partners without condoms (last year: AOR 1.90, 95% CI 1.11-3.26), and, among both sexes, reporting seeking sex online (last year, men: AOR 1.80, 95% CI 1.16-2.79;

women: AOR 3.00, 95% CI 1.76-5.13). No association was observed with reporting STI diagnosis/es (last 5 years) or (after age adjustment) recent use of any STI service or non-Internet sexual health seeking.

Conclusions: A minority in Britain used the Internet for the sexual health reasons examined. Use of information/support websites was reported by those at greater STI risk, including younger people, indicating that demand for online STI services, and Internet-based sexual health interventions in general, may increase over time in this and subsequent cohorts. However, the impact on health inequalities needs addressing during design and evaluation of online sexual health interventions so that they maximize public health benefit.

(*J Med Internet Res* 2016;18(1):e14) doi:[10.2196/jmir.4373](https://doi.org/10.2196/jmir.4373)

KEYWORDS

sexual health; sexually transmitted diseases; contraception; health care-seeking behavior; Internet; eHealth; surveys; information-seeking behavior

Introduction

Sexual health is increasingly recognized as encompassing physical, mental, and emotional well-being in relation to sexuality and sexual relationships, and freedom from coercion [1]. In Britain, and globally, there has been an expansion in online sexual health services [2-5]. As well as providing information, these services take advantage of the interactive potential of the Internet, such as for sexual health promotion [6], to aid contraceptive choices [7], or for individual counseling via Web chat [8,9]. Condoms and contraceptives are purchasable online from Internet vendors and pharmacies. Regarding sexually transmitted infections (STIs), England's National Chlamydia Screening Programme (NCSP) provides free, Internet-ordered home-sampling kits to those aged 16-24 years in many localities [5]. Privately provided Internet-ordered STI and human immunodeficiency virus (HIV) testing and STI treatment services are increasingly available, although they have been poorly regulated and of variable quality [3,5]. Recently, the British government legalized HIV home tests, which have been available for purchase online since 2015 [10].

Internet access is now nearly universal among people of reproductive age in the United Kingdom (98% aged 16-34 years, 93% aged 35-44 years in 2013) and more than one-third regularly uses the Internet to find information on health-related issues [11]. Although new Internet-based sexual health services continue to be developed [12-15], the number and characteristics of people who use currently available online sexual health services in Britain are unknown. To inform the design and delivery of new online sexual health interventions and services, we need to understand the demographic and behavioral characteristics of existing users. This will help inform whether Internet-based services could reach populations that underutilize conventional sexual health services relative to their need for sexual health care. This may include people at elevated risk of STI, such as young people (aged 16-24 years), people of black ethnic origins, men who have sex with men (MSM) [16], those who report multiple sexual partners, those living in deprived areas [17], and sexually active people who report no recent sexual health care use. This evidence is necessary for estimating the likely impact of online services which are currently being developed, and for informing the targeting of these services to maximize public health benefit. This study aims to fill this evidence gap by providing evidence of the British population's

use of existing Internet-based sexual health services and the population who report using them. We conjectured that those reporting use of the Internet for these reasons might represent a population likely to take up online sexual health services that are currently being developed. Our study's focus was on the year before the survey interview to provide a contemporary picture in a rapidly changing field.

Specific objectives were (1) to estimate the prevalence of reporting recent (in the previous year) use of the Internet as a source of chlamydia testing, HIV testing, STI treatment, condoms/contraceptive supplies, and help/advice with one's sex life from information/support websites among sexually experienced men and women; (2) to describe the population reporting this; and (3) to estimate the proportions reporting a preference for online sexual health care.

Methods

Natsal-3 Survey Design and Administration

Britain's third National Survey of Sexual Attitudes and Lifestyles (Natsal-3 [18,19]) is a probability sample survey conducted between 2010 and 2012 among the British resident population aged 16 to 74 years (N=15,162). Natsal-3 asked detailed demographic and behavioral questions and a number of questions about sources used for various types of sexual health care and advice/help with one's sex life (including the Internet). Detailed methods have been reported elsewhere; briefly, Natsal-3 used a multistage, clustered, and stratified probability sample design with a boost sample of those aged 16 to 34 years [18,19]. An interviewer visited each selected household and randomly selected one person in the eligible age range to participate, with oral informed consent. Participants completed the survey using a mixture of computer-assisted personal interview (CAPI) conducted face-to-face and computer-assisted self-interview (CASI) for the more sensitive questions [18,19]. Natsal-3 achieved an overall response rate of 57.7% and a cooperation rate (of eligible addresses contacted) of 65.8% [18,19].

The full survey is available online [20]. Variables used in this study were based on self-reported responses to closed-ended survey questions, except Index of Multiple Deprivation (IMD) quintile [21] and Output Area Classification (OAC) 2011 supergroup (OAC 2011 categorizes census output areas into 8 supergroups based on population characteristics) [22,23]. These

were added to the dataset according to participants' postcodes. National Statistics Socio-Economic Classification (NS-SEC) was derived from responses to standard questions [24].

Population of Interest: Sexually Experienced Persons Aged 16 to 44 Years

Several survey questions relevant to these analyses were not asked to participants aged 45 years and older. Therefore, the denominator for this study was limited to those aged 16 to 44 years, the age group in which most STI diagnoses occur [16], and which approximates women's reproductive age. We further limited the denominator to sexually experienced people, defined as those who reported ever having had any opposite- or same-sex sexual partners, because they are most likely to require sexual health services.

Outcome Variables

Outcome variables for this study included reported use of Internet services for key sexual health reasons (Table 1) and reporting the Internet as a preferred source of contraception, or for STI treatment/diagnosis if an STI was suspected (Table 2). The wording of these survey questions is described in Tables 1 and 2. Of specific relevance to the question about help/advice with one's sex life (first question in Table 1), shortly before this question, participants were presented with the following broad definition of *sex life*: "An individual's sex life includes their sexual thoughts, sexual feelings, sexual activity and sexual relationships."

For timeframe, the question on sources of contraceptive supplies referred to the past year. Questions on HIV testing, chlamydia testing, and STI treatment referred to the last occurrence. For comparability, only participants who indicated that this last occurrence was in the previous year (determined from responses to other survey questions) were included as reporting these behaviors.

Explanatory Variables

We had the following categories of explanatory variables: participants' sociodemographics, Internet access, area-level measures, sexual behavior (in the past year and past 5 years), sexual health care use, and STI diagnosis. Variables for sexual behavior and service use were selected to match the timeframe of the primary outcome variable (the year before the survey interview). Some variables corresponding to the 5 years before the interview were included (having had same-sex partners, number of sexual partners, sexual health clinic attendance, and STI diagnosis) to reflect greater variability in certain behaviors in the population over this longer period [25].

Statistical Methods

Data were analyzed using the complex survey functions of Stata 12 to take account of clustering, stratification, and weighting of the Natsal-3 sample. Weights were applied to adjust for unequal probabilities of selection for participation in the survey. All analyses were conducted separately by sex. Participants with missing data for a given variable were excluded from analyses using this variable because item nonresponse in

Natsal-3 was low (typically less than 0.5% in the CAPI and 1%-3% in the CASI) [18].

Logistic regression was used to obtain crude odds ratios to compare estimates of the odds of reporting use of information/support websites for advice/help with one's sex life, by each explanatory variable. Multivariable logistic regression was used, adjusting only for age, as a potential confounder of associations with NS-SEC code, which contained a "full-time student" category; OAC 2011, which was based on population characteristics including age; recent STI diagnosis; and sexual behavior variables because young people report greater numbers of recent and new sexual partners than older adults [25].

The observed low prevalences of other outcome variables meant that it was not possible to explore their associated factors. Statistical significance was considered as $P < .05$ for all analyses.

Ethical Approval

The Natsal-3 study was approved by the Oxfordshire Research Ethics Committee A (Ref: 10/H0604/27).

Results

Prevalence of Reported Recent Use of the Internet for Selected Sexual Health Reasons

Among sexually experienced persons aged 16 to 44 years, Internet use for chlamydia testing, HIV testing, or STI treatment (combined) in the previous year was reported by 0.31% (12/3702) men and 0.16% (6/3716) women (Figure 1). (Note: numerators and denominators are weighted and rounded to the nearest integer so may be subject to rounding errors.) Mostly this was chlamydia testing. No one in the sample reported Internet treatment for STIs other than chlamydia. Also, no one aged 35 to 44 years reported using the Internet for chlamydia testing, HIV testing, or STI treatment. Use of Internet sources of contraception/condoms in the past year was a little more common, especially among men (men: 2.35%, 87/3702; women: 0.51%, 19/3716). (Participants were not asked which method they obtained online, but it is likely that this was mostly condoms: 114 of 122 men and women reporting obtaining contraceptive supplies online in the past year reported use of male [$n=113$] and/or female [$n=2$] condoms in this period.) Use of information and support websites for advice/help with one's sex life in the past year was more common still, reported by 4.49% (166/3702) men and 4.57% (170/3716) women. Overall, use of the Internet for any of these sexual health reasons in the past year was reported by 6.85% men (95% CI 6.02-7.78) and 5.15% women (95% CI 4.50-5.89). In contrast, 60.2% men (95% CI 58.2-62.1) and 71.7% women (95% CI 70.2-73.2) reported use of non-Internet sources of sexual health care or advice/help with their sex lives, in the past year. (We defined this as GUM clinic attendance; use of non-Internet sources of chlamydia/HIV testing, STI treatment, or condoms/contraceptive supplies; or non-Internet sources of advice/help with one's sex life, excluding self-help and friends/family, in the past year.)

Table 1. Details of the Natsal-3 survey questions used as outcome variables in these analyses of sexually experienced persons aged 16 to 44 years (unweighted N=8926, weighted N=7400).

Question wording	Timeframe; number of responses permitted	Response options	Respondents eligible for each survey question	Number eligible for each question, unweighted (weighted)
Have you sought help or advice regarding your sex life from any of the following sources in the last year?	During previous year; multiple responses	Information and support sites on the Internet; ^a family member/friend; self-help books/information leaflets; self-help groups; helpline; GP/family doctor; sexual health/GUM/STI clinic; psychiatrist or psychologist; relationship counsellor; other type of clinic or doctor; have not sought any help	Entire sample of the current study	8926 (7400)
Have you got contraception from any of these sources in the last year?	During previous year; multiple responses	Internet website; ^a a doctor or nurse at your GP's surgery; sexual health clinic (GUM clinic); family planning clinic / contraceptive clinic / reproductive health clinic; NHS antenatal clinic / midwife; private doctor or clinic; youth advisory clinic (eg, Brook clinic); pharmacy/chemist; supplies from school/college/university services; over the counter at a petrol station/supermarket/other shop; vending machine; mail order; hospital accident and emergency (A&E) department; any other type of place (please say where); I have not got contraception in the last year	Those reporting use of any contraceptive method ^b in the last year	7182 (5862)
When you were last tested for chlamydia, where were you offered the test?	Last occurrence; single response	Internet; ^a GP surgery; sexual health clinic (GUM clinic); NHS family planning clinic / contraceptive clinic / reproductive health clinic; antenatal clinic/midwife; private non-NHS clinics or doctor; youth advisory clinic (eg, Brook Clinic); School/college/university; termination of pregnancy (abortion) clinic; hospital accident and emergency (A&E) department; pharmacy/chemist; other non-health care place (eg, youth club, festival, bar); somewhere else	Those reporting chlamydia testing in the last year	2387 (1545)
Where were you tested? (the last HIV test if more than one)	Last occurrence; single response	Internet site offering postal kit; ^a GP surgery; sexual health clinic (GUM clinic); NHS family planning clinic / contraceptive clinic / reproductive health clinic; antenatal clinic / midwife; private non-NHS clinic or doctor; youth advisory clinic (eg, Brook clinic); termination of pregnancy (abortion) clinic; hospital accident and emergency (A&E) department; somewhere else	Those reporting HIV testing in the last year	802 (562)
Where were you last treated for [STI ^c]?	Last occurrence; single response	Internet site offering treatment; ^a GP surgery; sexual health clinic (GUM clinic); NHS family planning clinic / contraceptive clinic / reproductive health clinic; antenatal clinic / midwife; private non-NHS clinic or doctor; pharmacy/chemist; youth advisory clinic (eg, Brook clinic); termination of pregnancy (abortion) clinic; hospital accident and emergency (A&E) department; somewhere else	Those reporting having been told by a doctor / health professional that they had an STI in the last year	178 (117)

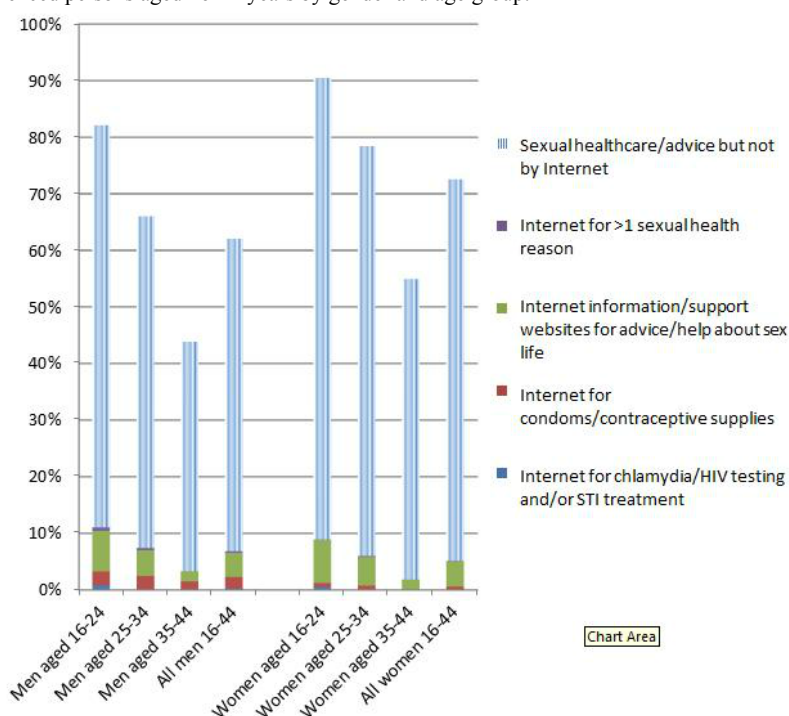
^a Internet response options.^b Including condoms.^c Separate questions were asked about the following infections: chlamydia; gonorrhea; genital warts; syphilis; *Trichomonas vaginalis*; genital herpes; nonspecific urethritis (NSU) or nongonococcal urethritis (NGU).

Table 2. Natsal-3 survey questions about preferred sources of sexual health care.

Question wording ^a	Response options	Respondents eligible for each survey question	Number eligible for each question, un-weighted (weighted)
If you thought that you might have an infection that is transmitted by sex, where would you <i>first</i> go to seek diagnosis and/or treatment?	Internet site offering treatment; ^b GP surgery; sexual health clinic (GUM clinic); NHS Family planning clinic/contraceptive clinic/reproductive health clinic; NHS antenatal clinic/midwife; private non-NHS clinic or doctor; pharmacy/chemist; youth advisory clinic (eg, Brook clinic); hospital accident and emergency (A&E) department; somewhere else	Those reporting any lifetime sexual partners	8858 (7338)
If all of these different types of service were available in your area and easy to get to, which one would you prefer to get contraception from?	NHS or Department of Health website; ^b a doctor or Nurse at your GP's surgery; sexual health clinic (GUM clinic); family planning clinic / contraceptive clinic / reproductive health clinic; youth advisory clinic (eg, Brook clinic); pharmacy/chemist; none of these; not needed	Those reporting use of any method in the last year	6909 (5524)

^a Use of italics reflects emphasis given in the survey. One response could be selected at each question.

^b Internet response options.

Figure 1. Percentage reporting seeking sexual health care and advice/help with one's sex life in the previous year, and specifically using the Internet to do so, among sexually experienced persons aged 16-44 years by gender and age group.

Associations with Reporting Use of Information and Support Websites for Advice/Help with One's Sex Life

Sociodemographic Factors

Mean age of men and women reporting use of Internet information/support websites for advice/help with their sex life (based on the first question described in Table 1 and hereon referred to as "Internet information/support" for brevity) was

25.9 years (SD 7.5) and 26.9 years (SD 8.8), respectively, in this sample aged 16 to 44 years. Those not reporting this were on average older (men: 31.0 years, SD 8.0; women: 31.3 years, SD 9.7). The prevalence of reporting use of Internet information/support declined steeply with increasing age among both sexes (7.7% men, 7.8% women aged 16-24 years to 1.84% men, 1.84% women aged 35-44, both $P < .001$). Tables 3 and 4 present univariate and age-adjusted analyses among men and women, respectively.

Table 3. Variation in the prevalence and odds of reporting recent (past year) use of information/support websites for advice/help with one's sex life (Internet information/support) among sexually experienced men aged 16 to 44 years.^a

Variable	N, unweighted (weighted)	Prevalence (95% CI)	OR (95% CI)	P	AOR (95% CI)	P
Sociodemographics						
Age (years)				<.001		—
16-24	1361 (994)	7.7% (6.3-9.4)	1		—	
25-34	1451 (1299)	4.93% (3.90-6.23)	0.62 (0.45-0.86)		—	
35-44	784 (1383)	1.84% (1.12-3.02)	0.22 (0.13-0.39)		—	
Ethnic group				.007		.004
White	3134 (3118)	4.01% (3.39-4.75)	1		1	
Asian/Asian British	190 (270)	6.9% (4.0-11.6)	1.77 (0.98-3.21)		2.11 (1.16-3.84)	
Black/black British	126 (140)	7.8% (3.7-15.4)	2.01 (0.92-4.42)		2.11 (0.93-4.81)	
Mixed/Chinese/other	108 (110)	9.4% (5.1-16.8)	2.49 (1.26-4.93)		2.2 (1.13-4.26)	
Education level^b				<.001		<.001
No academic qualifications	252 (275)	0.8% (0.3-2.5)	0.60 (0.18-2.00)		0.65 (0.20-2.18)	
Academic qualifications typically gained at age 16	880 (912)	1.4% (0.8-2.3)	1		1	
Studying for/attained further academic qualifications	2354 (2419)	6.05% (5.13-7.13)	4.57 (2.68-7.78)		3.79 (2.20-6.51)	
Socioeconomic status^c				<.001		.001
Managerial/professional	1060 (1262)	4.53% (3.42-5.98)	1.46 (0.97-2.19)		1.93 (1.27-2.93)	
Intermediate	509 (554)	3.0% (1.8-4.8)	0.94 (0.53-1.66)		1.16 (0.64-2.08)	
Semiroutine/routine	1321 (1300)	3.15% (2.40-4.11)	1		1	
No job	122 (99)	1.6% (0.4-6.4)	0.48 (0.11-2.08)		0.33 (0.08-1.42)	
Full-time student	574 (452)	11.1% (8.5-14.5)	3.85 (2.53-5.86)		1.95 (1.14-3.34)	
Internet access						
Access to Internet at home				.02		.02
Yes	3327 (3442)	4.73% (4.06-5.51)	1		1	
No	267 (232)	1.5% (0.6-3.9)	0.30 (0.11-0.82)		0.31 (0.11-0.84)	
Area-level measures						
Deprivation^d				.51		.24
1 (least deprived)	642 (658)	5.7% (4.2-7.7)	1		1	
2	653 (699)	4.3% (3.1-6.0)	0.74 (0.46-1.20)		0.71 (0.44-1.14)	
3	690 (720)	4.6% (3.3-6.5)	0.81 (0.50-1.30)		0.76 (0.47-1.23)	
4	774 (823)	4.3% (2.9-6.4)	0.75 (0.45-1.26)		0.69 (0.41-1.15)	
5 (most deprived)	837 (776)	3.8% (2.7-5.3)	0.66 (0.41-1.06)		0.58 (0.36-0.93)	
Output Area Classification 2011				<.001		<.001
1: "Rural residents"	276 (294)	3.2% (1.8-5.6)	1		1	
2: "Cosmopolitans"	302 (329)	12.5% (9.0-17.2)	4.33 (2.17-8.63)		3.38 (1.68-6.77)	
3: "Ethnicity central"	181 (225)	5.4% (2.7-10.3)	1.71 (0.69-4.27)		1.58 (0.64-3.91)	
4: "Multicultural metropolitans"	516 (595)	3.7% (2.3-5.7)	1.15 (0.54-2.43)		1.04 (0.49-2.22)	
5: "Urbanites"	665 (667)	3.6% (2.4-5.3)	1.13 (0.55-2.30)		1.09 (0.53-2.24)	
6: "Suburbanites"	587 (597)	4.5% (3.2-6.3)	1.44 (0.72-2.85)		1.30 (0.65-2.59)	

Variable	N, unweighted (weighted)	Prevalence (95% CI)	OR (95% CI)	<i>P</i>	AOR (95% CI)	<i>P</i>
7: "Constrained city dwellers"	331 (271)	4.1% (2.3-7.1)	1.28 (0.56-2.94)		1.06 (0.46-2.48)	
8: "Hard-pressed living"	738 (698)	2.8% (2.0-4.0)	0.87 (0.44-1.75)		0.76 (0.38-1.52)	
Sexual behavior, last year						
Number of sexual partners				.77		.29
0	191 (174)	4.6% (2.4-8.6)	1.06 (0.53-2.12)		0.95 (0.48-1.89)	
1	2320 (2612)	4.37% (3.63-5.26)	1		1	
2+	1051 (857)	5.0% (3.7-6.6)	1.14 (0.80-1.63)		0.72 (0.48-1.08)	
≥1 new sexual partners				<.001		.11
No	2129 (2503)	3.34% (2.71-4.12)	1		1	
Yes	1428 (1134)	7.14% (5.74-8.85)	2.22 (1.61-3.07)		1.39 (0.93-2.09)	
Number of sexual partners with- out a condom				.12		.30
0	862 (780)	5.9% (4.4-7.8)	1		1	
1	2139 (2412)	4.15% (3.40-5.05)	0.69 (0.48-0.98)		0.96 (0.66-1.38)	
≥2	523 (419)	4.5% (3.1-6.7)	0.75 (0.46-1.25)		0.69 (0.42-1.13)	
Seeking sexual partners online				.004		.009
No	3287 (3414)	4.28% (3.64-5.03)	1		1	
Yes	306 (257)	7.9% (5.4-11.6)	1.92 (1.24-3.00)		1.80 (1.16-2.79)	
Sexual behavior, last 5 years						
Number of sexual partners				.04		.96
0-1	1441 (1805)	3.63% (2.82-4.66)	1		1	
2-4	1106 (1012)	5.17% (3.98-6.70)	1.45 (0.99-2.13)		0.94 (0.63-1.41)	
≥5	1024 (837)	5.8% (4.4-7.6)	1.64 (1.11-2.42)		0.95 (0.60-1.49)	
≥1 same-sex partners				.002		.008
No	3459 (3561)	4.32% (3.68-5.06)	1		1	
Yes	137 (116)	10.9% (6.2-18.5)	2.71 (1.43-5.14)		2.44 (1.27-4.70)	
Sexual health care use and STI						
Non-Internet sexual health care or advice/help, last year^e				.004		.42
Yes	2391 (2223)	5.46% (4.57-6.51)	1		1	
Not reported	1205 (1453)	3.10% (2.24-4.28)	0.55 (0.37-0.82)		0.84 (0.55-1.29)	
Attended STI clinic, last 5 years				.03		.89
Yes	861 (712)	5.9% (4.5-7.8)	1		1	
No	2670 (2902)	4.11% (3.41-4.95)	0.68 (0.48-0.97)		0.97 (0.67-1.41)	
STI service use, last year^f				.27		.08
Yes	873 (703)	5.3% (3.9-7.0)	1		1	
Not reported	2723 (2974)	4.35% (3.64-5.19)	0.82 (0.57-1.17)		1.40 (0.96-2.02)	
STI^g diagnosis, last 5 years				.68		.97
No	3300 (3408)	4.47% (3.81-5.24)	1		1	

Variable	N, unweighted (weighted)	Prevalence (95% CI)	OR (95% CI)	<i>P</i>	AOR (95% CI)	<i>P</i>
Yes	257 (225)	5.0% (2.9-8.5)	1.13 (0.63-2.04)		0.99 (0.55-1.79)	

^a Unweighted N=3614, weighted N=3697. Denominators vary due to item nonresponse.

^b Denominator restricted to those aged 17 and older. No academic qualifications: left school at age 16 without passing any exams/gaining any qualifications (excludes qualifications gained at an older age); academic qualifications typically gained at age 16: left school at 16 having passed some exams/gained some qualifications (eg, English General Certificate of Secondary Education [GCSE] or equivalent); studying for or attained further academic qualifications: left school at age 17 or older.

^c Based on National Statistics Socioeconomic Classification (NS-SEC) code. No job: no job of ≥ 10 hours per week in the last 10 years.

^d Quintile of adjusted Index of Multiple Deprivation for Great Britain.

^e Defined as reporting STI clinic attendance within the last year or responses other than "Internet" for questions listed in Table 1 within the last year. Exceptions (non-Internet responses which were ignored) were (1) where participants had indicated friend, parent/relative, or partner as sources of contraceptive supplies (free-text response) and (2) where participants had selected "family member/friend," "self-help books/information leaflets," "self-help groups," and "have not sought any help" as sources of advice/help about their sex life.

^f Defined as reporting any of: STI clinic attendance, chlamydia testing, or HIV testing within this last year.

^g Natsal definition of STIs excludes thrush.

A strong association was observed with education level; 1.4% of men and 2.0% of women who left school aged 16 years with General Certificates of Secondary Education (GCSEs), or equivalent qualifications, reported recent use of Internet information/support compared to 6.05% of men and 5.87% of women with, or studying for, further academic qualifications (both sexes: $P<.001$), an association which remained after age adjustment. Associations with socioeconomic status [24] followed similar trends. Men in high-status occupations were more likely to report Internet information/support than those in lower-status occupations, before and after age adjustment (managerial/professional men vs men in semiroutine/routine occupations: age-adjusted OR [AOR] 1.93, 95% CI 1.27-2.93, $P<.001$), whereas a similar finding among women reached borderline statistical significance after age adjustment. Full-time students of both genders were also more likely than those in lower-status occupations to report Internet information/support even after taking account of their younger age (men: AOR 1.95, 95% CI 1.14-3.34; women: AOR 1.93, 95% CI 1.24-3.00).

Despite associations with these individual measures of social status (education, socioeconomic status), no overall association was observed between recent use of Internet information/support and area-level deprivation [21]. Use of Internet information/support was associated with OAC 2011 supergroup.

Use was high among "cosmopolitans" (residents of densely populated urban areas characterized by relatively high proportions of single people, young adults, full-time students, and high ethnic integration) [23] (men: 12.5%, 95% CI 9.0-17.2; women 11.7%, 95% CI 8.3-16.3). There was little variation between other supergroups except, among women only, slightly lower use of Internet information/support in "hard-pressed living" areas (mostly urban areas in Northern England and Wales with higher unemployment and lower proportions with higher-level qualifications than the national average) [23]. Strong associations with OAC 2011 supergroup remained after age adjustment (see Tables 3 and 4).

No overall association with ethnicity was observed among women after age adjustment, but Asian/Asian British men were more likely to report use of Internet information/support than white men (AOR 2.11, 95% CI 1.16-3.84, $P=.004$). Notably, numbers in minority ethnic groups were relatively small.

Having home Internet access was reported by 93.5% (95% CI 92.9-94.0) of sexually experienced persons aged 16 to 44 years. The minority who did not have home Internet were less likely to report use of Internet information/support than those who had (men: OR 0.30, 95% CI 0.11-0.82, $P=.02$; women: OR 0.26, 95% CI 0.11-0.58, $P<.001$) with little change after adjusting for age.

Table 4. Variation in the prevalence and odds of reporting recent (past year) use of Internet information/support among sexually experienced women aged 16 to 44 years.^a

Variable	N, unweighted (weighted)	Prevalence (95% CI)	OR (95% CI)	P	AOR (95% CI)	P
Sociodemographics						
Age (years)				<.001		—
16-24	1713 (956)	7.8% (6.4-9.4)	1		—	
25-34	2386 (1317)	5.28% (4.32-6.45)	0.66 (0.49-0.89)		—	
35-44	1175 (1409)	1.84% (1.16-2.90)	0.22 (0.13-0.37)		—	
Ethnic group				.02		.07
White	4619 (3179)	4.39% (3.76-5.10)	1		1	
Asian/Asian British	258 (220)	3.8% (2.2-6.4)	0.86 (0.49-1.52)		0.96 (0.54-1.70)	
Black/black British	174 (136)	5.6% (3.0-10.2)	1.30 (0.67-2.52)		1.34 (0.70-2.59)	
Mixed/Chinese/other	176 (117)	11.1% (6.1-19.3)	2.71 (1.39-5.28)		2.32 (1.20-4.50)	
Education level^b				<.001		<.001
No academic qualifications	372 (237)	0.6% (0.2-1.9)	0.29 (0.08-1.04)		0.28 (0.08-0.98)	
Academic qualifications typically gained at age 16	1186 (863)	2.0% (1.3-3.1)	1		1	
Studying for/attained further academic qualifications	3607 (2528)	5.87% (5.07-6.79)	3.05 (1.88-4.97)		2.49 (1.52-4.06)	
Socioeconomic status^c				<.001		.06
Managerial/professional	1526 (1202)	4.08% (3.16-5.26)	1.21 (0.79-1.85)		1.56 (1.02-2.40)	
Intermediate	1006 (719)	3.9% (2.5-5.9)	1.14 (0.66-1.97)		1.32 (0.76-2.29)	
Semiroutine/routine	1582 (1028)	3.39% (2.50-4.60)	1		1	
No job	418 (285)	4.6% (2.9-7.3)	1.39 (0.78-2.46)		1.39 (0.79-2.46)	
Full-time student	717 (429)	10.2% (7.9-13.1)	3.23 (2.14-4.89)		1.93 (1.24-3.00)	
Internet access						
Access to Internet from home				.001		<.001
Yes	4828 (3444)	4.84% (4.21-5.56)	1		1	
No	443 (236)	1.3% (0.6-2.8)	0.26 (0.11-0.58)		0.23 (0.10-0.52)	
Area-level measures						
Deprivation^d				.58		.35
1 (least deprived)	847 (632)	5.5% (4.0-7.4)	1		1	
2	952 (699)	4.4% (3.1-6.1)	0.79 (0.49-1.29)		0.78 (0.48-1.26)	
3	1031 (739)	4.8% (3.5-6.7)	0.88 (0.55-1.41)		0.83 (0.51-1.35)	
4	1183 (821)	4.8% (3.5-6.5)	0.87 (0.55-1.38)		0.82 (0.51-1.29)	
5 (most deprived)	1261 (792)	3.7% (2.7-5.1)	0.68 (0.42-1.08)		0.61 (0.38-0.97)	
Output Area Classification 2011				<.001		<.001
1: "Rural residents"	414 (313)	4.0% (2.5-6.4)	1		1	
2: "Cosmopolitans"	349 (266)	11.7% (8.3-16.3)	3.20 (1.72-5.96)		2.51 (1.34-4.70)	
3: "Ethnicity central"	307 (257)	5.7% (3.5-9.0)	1.45 (0.72-2.91)		1.32 (0.65-2.68)	
4: "Multicultural metropolitans"	772 (557)	5.5% (3.9-7.7)	1.40 (0.76-2.57)		1.27 (0.69-2.36)	
5: "Urbanites"	961 (667)	4.8% (3.4-6.6)	1.20 (0.65-2.22)		1.14 (0.61-2.14)	
6: "Suburbanites"	799 (608)	4.1% (2.8-5.8)	1.02 (0.55-1.90)		1.02 (0.55-1.92)	
7: "Constrained city dwellers"	488 (277)	3.3% (2.0-5.4)	0.83 (0.41-1.69)		0.70 (0.35-1.42)	

Variable	N, unweighted (weighted)	Prevalence (95% CI)	OR (95% CI)	P	AOR (95% CI)	P
8: "Hard-pressed living"	1184 (736)	2.0% (1.3-3.1)	0.50 (0.26-0.94)		0.45 (0.24-0.86)	
Sexual behavior, last year						
Number of sexual partners				.008		.65
0	284 (187)	3.2% (1.7-6.0)	0.75 (0.38-1.48)		0.88 (0.45-1.73)	
1	3829 (2825)	4.22% (3.58-4.96)	1		1	
≥2	1113 (631)	6.9% (5.2-9.2)	1.69 (1.19-2.40)		1.18 (0.81-1.72)	
≥1 new sexual partners				<.001		.11
No	3670 (2748)	3.82% (3.19-4.56)	1		1	
Yes	1553 (892)	7.2% (5.7-8.9)	1.95 (1.43-2.65)		1.32 (0.94-1.85)	
Number of partners without a condom				<.001		.03
0	1007 (680)	4.3% (3.1-5.8)	1		1	
1	3620 (2635)	4.12% (3.47-4.89)	0.97 (0.67-1.40)		1.05 (0.73-1.50)	
≥2	575 (317)	10.0% (7.1-13.9)	2.51 (1.50-4.17)		1.90 (1.11-3.26)	
Seeking sexual partners online				<.001		<.001
No	5079 (3559)	4.38% (3.78-5.06)	1		1	
Yes	189 (116)	11.8% (7.5-18.1)	2.93 (1.74-4.94)		3.00 (1.76-5.13)	
Sexual behavior, last 5 years						
Number of sexual partners				<.001		.18
0-1	2649 (2116)	3.77% (3.05-4.65)	1		1	
2-4	1630 (995)	4.6% (3.6-5.8)	1.23 (0.88-1.71)		0.88 (0.63-1.23)	
≥5	958 (541)	8.1% (6.1-10.7)	2.25 (1.53-3.29)		1.31 (0.85-2.01)	
≥1 same-sex partners				.09		.24
No	4972 (3493)	4.47% (3.87-5.16)	1		1	
Yes	302 (189)	7.2% (4.3-11.9)	1.65 (0.93-2.93)		1.42 (0.80-2.52)	
Sexual health care use and STI						
Non-Internet sexual health care or advice/help, last year^e				<.001		.11
Yes	4055 (2648)	5.42% (4.66-6.30)	1		1	
Not reported	1219 (1034)	2.53% (1.70-3.75)	0.45 (0.29-0.71)		0.68 (0.42-1.10)	
Attended STI clinic, last 5 years				<.001		.14
Yes	1342 (779)	7.4% (5.9-9.4)	1		1	
No	3865 (2855)	3.90% (3.27-4.63)	0.51 (0.37-0.69)		0.76 (0.53-1.09)	
STI service use, last year^f				.02		.61
Yes	1908 (1130)	5.80% (4.65-7.22)	1		1	
Not reported	3366 (2552)	4.08% (3.39-4.90)	0.69 (0.51-0.94)		1.10 (0.77-1.58)	
STI^g diagnosis, last 5 years				.75		.14
No	4830 (3419)	4.65% (4.03-5.36)	1		1	

Variable	N, unweighted (weighted)	Prevalence (95% CI)	OR (95% CI)	P	AOR (95% CI)	P
Yes	398 (225)	4.2% (2.4-7.3)	0.91 (0.50-1.64)		0.63 (0.35-1.16)	

^a Unweighted N=5312, weighted N=3703. Denominators vary due to item nonresponse.

^b Denominator restricted to those aged 17 and older. No academic qualifications: left school at age 16 without passing any exams/gaining any qualifications (excludes qualifications gained at an older age); academic qualifications typically gained at age 16: left school at 16 having passed some exams/gained some qualifications (eg, English General Certificate of Secondary Education [GCSE] or equivalent); studying for or attained further academic qualifications: left school at age 17 or older.

^c Based on National Statistics Socioeconomic Classification (NS-SEC) code. No job: no job of ≥ 10 hours per week in the last 10 years.

^d Quintile of adjusted Index of Multiple Deprivation for Great Britain.

^e Defined as reporting STI clinic attendance within the last year or responses other than "Internet" for questions listed in Table 1 within the last year. Exceptions (non-Internet responses which were ignored) were (1) where participants had indicated friend, parent/relative, or partner as sources of contraceptive supplies (free-text response) and (2) where participants had selected "family member/friend," "self-help books/information leaflets," "self-help groups," and "have not sought any help" as sources of advice/help about their sex life.

^f Defined as reporting any of: STI clinic attendance, chlamydia testing, or HIV testing within this last year.

^g Natsal definition of STIs excludes thrush.

Sexual Behavioral Factors

Use of Internet information/support was more commonly reported by women (but not men) reporting multiple sexual partners in the last year and among both men and women reporting new sexual partners in the last year, but these associations disappeared after age adjustment. Among women (but not men), use of Internet information/support was more commonly reported by those who reported multiple sexual partners in the previous year with whom they had not used condoms (AOR 1.90, 95% CI 1.11-3.26, $P=.03$). Men reporting sex with another man in the previous 5 years were more likely to report use of Internet information/support (AOR 2.44, 95% CI 1.27-4.70, $P=.008$), whereas no association with same-sex sex in the previous 5 years was observed among women. Men and women reporting seeking sexual partners online within the previous year were more likely to report use of Internet information/support than those not reporting seeking partners in this way (men: AOR 1.80, 95% CI 1.16-2.79; women: AOR 3.00, 95% CI 1.76-5.13).

Sexual Health Care Use

No association was observed between reporting use of Internet information/support and reporting STI diagnosis or diagnoses in the past 5 years. Use of Internet information/support was more common among those reporting recent non-Internet sources of sexual health care and advice/help, and having attended an STI clinic in the last 5 years, but not after adjusting for age. No association was observed with having used STI services in the previous year.

Preference for Internet Sources of Diagnosis/Treatment of Sexually Transmitted Infections and Condoms/Contraception

Less than 2% of sexually experienced participants aged 16 to 44 years reported that the first place they would look for diagnosis/treatment if they suspected that they had an STI would be an Internet site offering treatment. Among sexually experienced persons aged 16 to 44 years reporting use of any contraceptive method in the previous year, 5.45% men and 1.14% women indicated they would prefer to obtain supplies from an NHS or Department of Health website (Table 5).

Table 5. Preference for Internet sources of diagnosis/treatment of sexually transmitted infections and condoms/contraception.

Header	Men		Women	
	N, unweighted (weighted)	% (95% CI)	N, unweighted (weighted)	% (95% CI)
Would first look on an Internet site offering treatment for diagnosis/treatment if STI suspected ^a	3589 (3668)	1.77% (1.27-2.46)	5269 (3670)	0.81% (0.57-1.14)
Preferred source of contraceptive supplies would be NHS/Dept of Health website ^a	2793 (2743)	5.45% (4.52-6.56)	4116 (2781)	1.14% (0.82-1.58)

^a Question wording, response options, and eligible respondents are detailed in Table 2.

Discussion

Principal Findings

Although Internet access is nearly universal in Britain, data from a recent national probability sample survey show that use of the Internet for key sexual health reasons is rare in the British

population. Specifically, prevalence of reported use of Internet STI services is very low and reported use of the Internet for condoms/contraceptive supplies is also uncommon, particularly among women. Reporting recent use of Internet information and support websites for help/advice about one's sex life was slightly higher, especially among younger people and among

those who reported higher sexual risk behavior, including MSM and people who sought sexual partners online. However, those using information/support websites for advice/help with their sex lives may be from populations typically considered to have better access to sexual health care: the better-educated, residents of certain urban areas, and (among men) those of higher socioeconomic status. Despite this potential social inequality, those who reported recent use of information/support websites were as likely to report at least one previous STI diagnosis as those who did not report this.

Findings in Relation to Other Studies

We know of no other studies that have estimated the prevalence of use of the Internet for sexual health reasons or identified associated factors in a nationally representative sample. The association we found between use of information/support websites for advice/help with one's sex life, and younger age, is unsurprising given young people's greater Internet use [26], smartphone ownership [27-29], and greater need for sexual health care indicated by levels of reported STI diagnoses and STI clinic use [16,17]. Research on the acceptability of using the Internet to deliver conventional sexual health services reveals similar findings with respect to age [30-32] and education [33].

Differences in men's and women's sexual behaviors [34,35] and health-seeking behaviors [36-38] are well-documented, but our study revealed little difference by sex in the prevalence of reported use of information/support websites for advice/help with one's sex life (although there were some differences in associations observed among men and women, and more men than women reported that they would first look online for diagnosis/treatment if they suspected that they had an STI). In the English chlamydia screening program, the NCSP, more tests are performed among young women than among young men [5], perhaps due to women's greater engagement with contraceptive and other health services where screening is offered. Women also account for a greater proportion of tests in the NCSP's Internet-ordered home-sampling services, but with less discrepancy by gender compared to other NCSP testing venues (with the exception of military settings) [5]. In our study, use of the Internet for condoms/contraceptive supplies was reported by more men than women, perhaps reflecting gendered norms about who obtains condoms [39].

Surveys of patients attending genitourinary medicine (GUM) clinics in England, conducted almost a decade before Natsal-3, found patients reporting Internet sex seeking were also more likely to report use of the Internet for sexual health information [40], similar to the association we observed between Internet sex seeking and use of information/support websites.

Echoing our study's finding, little difference was found by IMD quintile in the proportion of NCSP Internet-ordered chlamydia home-sampling kits returned (2010) [5]. However, we found no studies using NCSP data to compare demographic or behavioral characteristics of those using Internet-ordered kits with the wider population in the target age range. Although Internet-based sexual health services have been viewed as a promising way of reaching rural populations, we found relatively low use of information/support websites in these areas.

Strengths and Limitations

Use of Natsal-3 data has allowed our analyses to examine a wide range of sociodemographic, behavioral, and health service use variables, in a sample representative of the resident British population, in relation to use of information/support websites for advice/help with one's sex life. Despite survey data being self-reported and, therefore, subject to recall and social desirability biases, they are of high quality; use of CASI was demonstrated to facilitate reliable reporting of sensitive information [41] and cognitive testing of several survey modules maximized the likelihood of questions being interpreted as intended [42]. Furthermore, the survey's response rate was similar to that achieved for other major social surveys undertaken in Britain at that time [43,44] and item nonresponse was typically very low [18,19]. Importantly, in this rapidly evolving field, we focused on reported behavior in the year before the survey interview and Natsal-3 data are relatively recent (collected 2010-2012). However, there may have been changes in norms regarding Internet use for sexual health since data collection.

The very low prevalence of most outcome variables examined meant that their associations could not be explored. The exception was reported use of the Internet for advice/help with one's sex life, but even this was reported by less than 5% of the study population; therefore, rare behaviors could not be included as explanatory variables in the analysis. We adjusted only for age in the multivariable analysis. Due to small numbers in some subgroups, we had to treat some variables crudely (eg, ethnicity), creating categories large enough to obtain sufficient subgroup sizes. This limits explanatory potential; for example, we cannot explore differences between black Caribbean and black African ethnicities. The subgroup mixed/Chinese/other is not particularly meaningful, although creation of this category gave sufficient subgroup sizes to explore associations with Britain's major ethnic groups (Asian, black, white).

Natsal-3 survey questions (Tables 1 and 2) serve various purposes and were not designed for our particular study. We cannot be sure about how questions were interpreted. Our main outcome variable (use of information/support websites for advice/help with one's sex life) was based on responses to a question located in the survey module entitled "Sexual Function." However, we assumed that the question was interpreted more broadly than about sexual function alone because "sexual function" was neither mentioned in the question nor visible on the computer screen at the time, and sex life was defined broadly (see Methods). Supporting our assumption, we found that among sexually active persons aged 16 to 44 years who reported use of information/support websites at this question, more than half agreed that they felt satisfied with their sex life, more than half disagreed that they felt distressed or worried about it, and more than two-thirds disagreed that they had avoided sex because of sexual difficulties (their own or a partner's; data not shown). This suggests that many who reported use of Internet help/advice with their sex life were doing so for reasons other than sexual function problems, although we cannot be sure. In terms of applicability of our findings to sexual health broadly defined [1], our variable may not have captured use of the Internet in relation to all aspects of sexual health, such as

support and counseling following nonvolitional sex. It seems unlikely that participants would have considered this type of service use to be help/advice with their sex life, although perhaps they would if nonvolitional sex occurred in the context of a sexual relationship.

An advantage of our study is that we were able to consider those who had used the Internet for a range of sexual health reasons and also those who would prefer to use it for sexual health care, although we lack data on which particular websites were used/preferred. However, the low proportions who reported a preference for using the Internet for STI diagnosis/treatment, or a preference for accessing contraception from an NHS website, probably underestimate the proportions that might choose Internet-based services if they were well-regulated and based in the NHS. This is because relevant survey questions (Table 2) each allowed a single response and provided no description of the Internet services, which might be difficult for respondents to envisage or assumed to be costly because such services are not currently available through the NHS. The question also specified “if an STI was suspected”: in this context, a consultation with a health care professional may seem most appropriate, whereas for a routine STI check-up, Internet services might hold greater appeal. Given how common it has become to look up symptoms and health information online before contacting a health professional, we believe that responses to the STI diagnosis/treatment question might poorly reflect the proportion that would use an Internet-ordered test if they found a reputable service offering this during their online search.

We acknowledge that even an ideal survey question cannot give us a definitive answer about who will use online sexual health interventions and services in the future. However, we feel our main outcome variable, which addresses use of information/support websites (as distinct from lay advice/help sought online) for sexual health broadly defined, reflects those who may take up online sexual health services and interventions, fitting with their existing sexual health-seeking behavior.

Implications for Policy and Practice

Low levels of use of the Internet for contraception and STI services may reflect the limited availability and quality of currently available online services—particularly at the time the data were collected (2010-12) and in relation to STI testing and

treatment [3,5,45]. Also, many methods of contraception cannot feasibly or legally be provided online. Qualitative and quantitative research could explore awareness, expectations, and barriers to use of currently available online sexual health services.

Greater proportions reported use of information/support websites for advice/help with their sex lives, particularly among young people. This suggests scope for expansion of provision in the future, in this cohort and subsequent cohorts who have also grown up with the Internet, and as the range and quality of Internet sexual health care increase (as is likely given existing trends). An example of improved quality is the legalization and regulation of HIV home testing in the United Kingdom, available online [10]. However, our study suggests that if use of Internet sexual health care followed patterns of online help/advice seeking, health inequalities might increase, especially if expansion of online sexual health care was coupled with reduced provision of conventional sexual health care. “Digital divides” by socioeconomic status have been widely documented [11], with eHealth a specific area of concern [46,47]. This study’s findings regarding education and socioeconomic status may reflect that Internet use is lower among those with less education and lower incomes [48]. Although home Internet access was high in the population of interest in Natsal-3, the survey did not ask about Internet use more generally, including via a personal device, which may vary across social strata. Having a smartphone or laptop/tablet might allow greater access to the Internet for sexual health than a household’s shared personal computer if privacy from other household members is important. Since the data were collected for Natsal-3 between 2010 and 2012, there have been further increases in smartphone ownership [49,50] and Internet access [51], which may reduce differences in proportions using the Internet for sexual health by socioeconomic status and/or education. However, if these differences relate to differences in health care-seeking behavior, inequalities may be more persistent. Research should examine these associations further and evaluations of new Internet-based interventions and services should monitor and model impacts on both on STI transmission and on health inequalities. Interventions may also be required to promote eHealth should groups be identified that have good Internet access, yet are underserved by online and conventional health care.

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Conflicts of Interest

None declared.

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Abbreviations

AOR: age-adjusted odds ratio
CAPI: computer-assisted personal interview
CASI: computer-assisted self-interview
GCSE: General Certificate of Secondary Education
GUM: genitourinary medicine
HIV: human immunodeficiency virus
IMD: Index of Multiple Deprivation
MSM: men who have sex with men
NHS: National Health Service
NS-SEC: National Statistics Socio-Economic Classification
OAC: Output Area Classification
STI: sexually transmitted infection

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RESEARCH ARTICLE

Open Access



Young people's perceptions of smartphone-enabled self-testing and online care for sexually transmitted infections: qualitative interview study

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Abstract

Background: Control of sexually transmitted infections (STI) is a global public health priority. Despite the UK's free, confidential sexual health clinical services, those at greatest risk of STIs, including young people, report barriers to use. These include: embarrassment regarding face-to-face consultations; the time-commitment needed to attend clinic; privacy concerns (e.g. being seen attending clinic); and issues related to confidentiality.

A smartphone-enabled STI self-testing device, linked with online clinical care pathways for treatment, partner notification, and disease surveillance, is being developed by the eSTI² consortium. It is intended to benefit public health, and could do so by increasing testing among populations which underutilise existing services and/or by enabling rapid provision of effective treatment. We explored its acceptability among potential users.

Methods: In-depth interviews were conducted in 2012 with 25 sexually-experienced 16–24 year olds, recruited from Further Education colleges in an urban, high STI prevalence area. Thematic analysis was undertaken.

Results: Nine females and 16 males participated. 21 self-defined as Black; three, mixed ethnicity; and one, Muslim/Asian. 22 reported experience of STI testing, two reported previous STI diagnoses, and all had owned smartphones. Participants expressed enthusiasm about the proposed service, and suggested that they and their peers would use it and test more often if it were available. Utilizing sexual healthcare was perceived to be easier and faster with STI self-testing and online clinical care, which facilitated concealment of STI testing from peers/family, and avoided embarrassing face-to-face consultations. Despite these perceived advantages to privacy, new privacy concerns arose regarding communications technology: principally the risk inherent in having evidence of STI testing or diagnosis visible or retrievable on their phone. Some concerns arose regarding the proposed self-test's accuracy, related to self-operation and the technology's novelty. Several expressed anxiety around the possibility of being diagnosed and treated without any contact with healthcare professionals.

Conclusions: Remote STI self-testing and online care appealed to these young people. It addressed barriers they associated with conventional STI services, thus may benefit public health through earlier detection and treatment. Our findings underpin development of online care pathways, as part of ongoing research to create this complex e-health intervention.

Keywords: Acceptability of healthcare, Clinical pathways, eHealth, Internet, Mobile health, Sexually transmitted infections

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Background

Sexually transmitted infections (STI) are a major public health issue in England, and young people are particularly affected [1, 2]. STI services seek to identify, diagnose and treat people with these often asymptomatic infections, in order to prevent transmission and minimise medical complications associated with repeat and long-term infection.

Young people's high STI rates persist despite good provision of confidential, free sexual healthcare in the UK (including London, where our study took place), through a range of specialist and community services, and the National Chlamydia Screening Programme (NCSP) for England's sexually-active under-25s [1, 2]. Specialist genito-urinary medicine (GUM) clinics provide free testing and treatment for a comprehensive range of STIs and HIV. Sexual health clinics specifically for young people (e.g. Brook) provide free contraceptive and sexual health services, with STI service provision varying between clinics. STI testing is often available through contraceptive clinics and general practice, also without charge. Within the NCSP, free screening for chlamydia is delivered through various channels, including community and healthcare settings, and via internet-ordered postal home-sampling kits (a service which was widely-available in the years leading up to our study [3]). Self-taken samples of urine (for males) or vulvo-vaginal swabs (for females) are sent to a laboratory for testing with the result communicated some days after, typically by telephone or text message (SMS).

Over the last decade there have been considerable efforts to widen access to sexual health services by extended and weekend opening hours within specialist services, delivered from National Health Service (NHS) genitourinary medicine (GUM)/sexual health clinics. These are open-access (can be used without referral), offer comprehensive STI testing and account for the majority of reported STI diagnoses [2]. However, STI clinic attendance is viewed by some as stigmatising [4], which negatively impacts upon expectations and experiences of attending clinic [5]. General practitioners (GPs) have been encouraged to take on greater roles in sexual health but have been perceived to offer variable quality, less confidential services [4, 6]. Across all settings, young people report fear of judgment by staff, and embarrassment, which can deter sexual healthcare-seeking, with particular concerns regarding face-to-face consultations [6]. Young people also report embarrassment [7] and stigma [8] associated with accepting offers of chlamydia screening even though this does not require a consultation. Receiving chlamydia home-sampling kits by post avoids face-to-face offers of screening, but can compromise privacy [4].

Currently, reliable rapid point of care tests for many STIs are unavailable, but could deliver benefits in terms of reduced complications, from faster provision of treatment in clinics [9, 10], and reduced transmission, since sexual risk behaviour may continue while patients are awaiting diagnosis and treatment [11, 12]. Such benefits may also be derived from a rapid self-test, provided that users who test positive are promptly and effectively treated. The *Electronic Self-testing Instruments for Sexually Transmitted Infections* (eSTI²) consortium is developing an accurate, rapid smartphone-enabled diagnostic self-test for multiple STIs, linked to online clinical management pathways which would be designed to provide safe, appropriate treatment and care. This complex intervention makes use of young adults' relatively high use of internet [13] and smartphone technologies [14]. It is envisaged that users would register (providing information for public health surveillance), do the test, receive their diagnosis and, if positive, provide medical information to enable safe prescribing of appropriate antibiotic treatment, all online via their smartphone. If appropriate, antibiotic treatment could be posted to them, or an electronic authorisation ("e-prescription") could allow collection from a pharmacy. For many users, this whole process could take place 'remotely', without seeing or speaking to healthcare professionals, or attending clinical settings.

Smartphone-enabled STI self-testing, linked to online clinical management pathways, is a unique and complex intervention. Although some examples of online STI care exist [3, 15–21] these only represent parts of the remote online care pathway we propose, with limited information on acceptability. Qualitative research on the acceptability of home self-testing [22] and internet use in relation to STI testing [23–26] suggests that potential users have reservations around safety, test reliability, online privacy and confidentiality. Much of this research [22–25] was conducted in the US and Canada (i.e. differing health service contexts), and findings may not be transferable to our proposed intervention. Therefore, formative research was needed to inform the development of our proposed complex e-health intervention [27–29], which is intended as an adjunct to existing services (rather than a replacement) and which may reach populations which under-use existing services.

In this study, we explored perceptions and acceptability of remote STI self-testing and associated online care pathways to treatment (a hypothetical intervention), among young people from an Inner-London locality with high rates of STIs [30] and large populations of Black Caribbean and African ethnic origin. As our study population reflects public health need for STI services, and young urban populations may also be 'early adopters' of new technologies, we considered them potential users of our novel intervention.

This study took place early in the development of the self-test and the online care pathways, and was part of a programme of formative research which informed this complex intervention's development. Other formative research considered user-interface design [31] and clinical care quality and safety [32], which together with this study led to a recent proof-of-concept study of an online care pathway for chlamydia, with mixed-methods evaluation. Survey research has provided indicative evidence about the user population [33], and development of the self-testing device [34] is ongoing.

Methods

Study design and population

Individual in-depth interviews were conducted with young people, recruited from an Inner-London Further Education (FE) college. In the UK, FE colleges provide post-compulsory education for those aged 16 and older, often vocational, and are distinct from Higher Education institutions – universities – which provide degree-level academic qualifications. People from lower socio-economic groups are over-represented among FE college students. Eligible students were aged 16–24 years, and self-reported having had sex at least once.

Sampling and recruitment

A purposive sampling strategy [35] was used, with gender and age-group as primary sampling criteria, and a target of 24–36 interviews. We used the age-groups 16–19 and 20–24 because experience with sex, and with sexual healthcare and healthcare in general, are likely to increase with increasing age. Furthermore these categories are similar to those used in national STI surveillance data. Following an email sent on behalf of the researchers to all students, and posters placed in the college, students were approached in college communal areas by the interviewer, or referred to him by staff. The interviewer explained to potential participants that the study would involve a face-to-face interview with him, which would last about an hour, to find out what they thought about a new way of testing for STIs. Further details of the study were provided orally and in information sheets.

Procedure

Interviews took place in private rooms at college sites. One male interviewer (SF) conducted and audio-recorded all interviews. The topic guide, described briefly here, had been piloted, and was used flexibly and revised iteratively between interviews. The interviewer began by asking about participants' experience with smartphone technology, internet-use in relation to health, and STI testing. First impressions of 'testing for STIs using your smartphone' were explored. Then, participants

were provided with a brief description of the proposed testing device and associated online care pathway, aided by an animation (Additional file 1) which outlined stages a user would potentially go through (operating the self-testing device with a sample of urine or vaginal swab, receiving their result, and if positive, an online consultation, 'e-prescription,' partner notification and sexual health advice). The interviewer explained that the test was still being developed, but that the animation showed what it might be like. Few details were provided about the test and online care pathway, for simplicity, and because of uncertainties at this stage in intervention development. The interviewer explained that obtaining treatment this way would be safe for most people (but not what would happen otherwise). Scenarios were used to explore acceptability and preferences of various stages, from self-testing, through to receipt of treatment for those testing positive (Additional file 2). Participants were asked for their understanding of 'confidentiality'. Interviews explored acceptability of providing personal details, sexual history, and medical information to verify treatment safety, using their smartphone. Participants were asked if they would use the service described and why (not). The interviewer, mindful of his somewhat older age, status as a university researcher, association with novel technology, and the implications of these for social desirability bias in the views participants might express, sought to lessen the social distance between himself and participants by mirroring participants' language use, and emphasised that he was not developing the intervention and so would not be offended if they did not like or agree with some or all of the proposed format. The interviewer kept field-notes, recording circumstances of recruitment and impressions from interviews. Interviews lasted 29–75 min (mean: 53mins). Each participant received £15 in recognition of their time and contribution to the study.

Interviews focused on exploring novel aspects of the proposed intervention; aspects that are established as broadly acceptable or have become common practice (e.g. self-sampling [36], receipt of STI test results by text-message) were not explored. Details unknown at the time of the interviews were also not explored unless mentioned by interviewees (including: which infections the device would detect – described by the interviewer as chlamydia in the first instance 'because it is an easier infection to treat', specific clinical and disease surveillance information to be collected, cost, distribution, and whether the device would be for single or repeat use). These are being explored in ongoing research.

Analysis

A thematic analysis [37] was conducted by CA, using NVivo software and paper charts. For data familiarisation, transcripts were read repeatedly, alongside listening to recordings and reading field-notes. A mixed inductive-

deductive approach was used: identification of themes was influenced by emergent and recurring issues in the data, and by *a priori* issues relating to study aims. Individuals' accounts of their views and experiences with existing STI testing services, and with smartphones and the internet, were used to contextualise their views on the novel service. Analysis took place after data collection was complete, meaning that initial findings could not be explored in subsequent interviews.

SF and MS, who were familiar with the entire dataset, provided detailed feedback on CA's draft analysis, for verification of findings. Participants' comments were not sought on either the transcripts or study findings. This was impractical because of the end of the college's academic year and study timelines. We also had concerns for participants' privacy if we contacted them about the study, given the eligibility criteria and sensitive content of the interviews.

Results

Participants

Twenty-five interviews took place in Spring/Summer 2012 (Table 1). Interviewees were aged 16–23 years (mean:

19 years). The quota of 6–8 participants in each sex/age-group category was not filled for older females ($n = 2$ participants) prior to the end of the college's term.¹ However CA and (independently) MS, SF, LJS considered saturation to have been reached within the total sample achieved (i.e. no new findings emerged in later interviews). Due to the way recruitment took place, the number approached who declined participation (and their reasons) were not recorded. Two students scheduled an interview but did not participate.

Participants' accounts of their STI testing experience ranged from a single chlamydia screen, to repeated comprehensive testing in sexual health clinics. Use of STI testing in general practice and use of internet-ordered home-sampling for chlamydia were also reported. Two participants, both women, spontaneously mentioned that they had previously been diagnosed with an STI (however this question was not asked of all participants).

Perceptions of self-testing with online care pathways, in relation to barriers to use of existing sexual healthcare

Barriers to use of existing sexual healthcare discussed by participants were consistent with those identified in the

Table 1 Participants' characteristics

Characteristic		Number	
Asked by the interviewer before the interview:			
	Gender	Female	Male
Age ^a	16–17	3	2
	18–19	4	6
	20–21	2	4
	22–23	0	4
Ethnicity ^b	Black/Black British, African	10	
	Black/Black British, Caribbean	6	
	Black British	5	
	Mixed	3	
	Muslim/Asian	1	
Self-defined sexual orientation ^{b, c}	Straight	22	
	Bisexual	2	
	Gay	1	
Current sexual partner/s	Yes	15	
	No	9	
	‘it’s complicated’	1	
Reported during the interview:			
STI testing experience	Yes	22	
	No	3	
Smartphone ownership	Yes, at time of interview	22	
	Not currently, but has had (lost, in repair, broken)	3	
	Never had a smartphone	0	

^aFor sampling purposes, age-groups were 16–19 and 20–24 years, however no participants were aged 24 years

^bSelf-defined by participants. Ethnicity categories were grouped by researchers

^cAll three respondents self-identifying as bisexual or gay were female

literature (see Introduction). We focus on perceptions of how the proposed intervention might address barriers to testing using existing services.

Making access to STI testing quicker, easier and more convenient

Participants described smartphone-enabled self-testing and online care pathways as making access to STI testing and treatment easier and more convenient than existing services. They associated self-testing with having greater control over when and where they could test – which they welcomed.

...you could be in the bath, be like using the toilet, and be like, let me just get this real quick and do this real quick. It's... convenient, very convenient. That's why I like it (V, young man, 18–19 years old)

Often, participants assumed that the testing device and online care pathway would be easy to use, though some expressed concerns about operating the device or completing lengthy online forms, emphasising the importance of ease of use.

'Faceless' sexual healthcare

Some participants described how concerns about being recognised by staff influenced their STI testing behaviour, and some of those with experience of sexual health clinics described embarrassment around giving a sexual history face-to-face. Self-testing and providing information 'facelessly' online was advantageous for these participants.

I would rather that 'cause there's not no one in front of me like talking to me or looking at me... (C, young woman, 18–19 years old)

Concealing use of sexual healthcare

Some male participants, in both age-groups, explained how they did not mind others discovering their use of sexual healthcare. However many, including all of the female participants, spoke of wanting to conceal their sexual healthcare use from family and peers as it suggested or revealed possible STI, risky sexual behaviour or that they were sexually-active. This was described as a barrier to using sexual health clinics: participants described how they might seek '*discreet places far away from home*' (F, young woman, 16–17 years old), use internet-based home-sampling, or '*when you get outside you've kind of got to look around and make sure no one sees you and then quickly run in there*' (B, young woman, 18–19 years old). Young women expressed particular concern about the conclusions others might draw about their sexual activity.

Participants welcomed the perceived greater ability they would have to conceal their STI testing by using a self-test, although there were concerns about the test device itself being concealable. There was also anxiety around the presence and visibility of electronic evidence of STI testing on the phone, for instance an app installed on the phone. Related to this point, there was great variation in how privately people described keeping their phones: '*no one's really going to look at your phone*' (G, young woman, 18–19 years old), versus '*youth nowadays, yeah, we always have each other's phones*' (Y, young man, 20–21 years old).

Further perceptions about remote self-testing with online care

In this section we describe perceptions about remote self-testing with online care pathways, which informed an understanding of the proposed intervention's acceptability, and its development.

Speed of testing

Participants expressed varied views about the speed of test-operation (in contrast with their universal interest in rapid access to testing and - if positive - treatment). Some expected a result within minutes, reasoning that new technology ought to provide this; '*everything is fast now*' (M, young man, 18–19 years old). Others reasoned that a rapid test might be less accurate: a tension between their desire for dependable, yet rapid, results. Those who had used internet-based home-sampling, who described valuing avoiding clinic attendance and/or face-to-face consultations, would rather their results arrived faster than from home-sampling services but accepted waiting days or a week. This suggests that trade-offs exist between speed and privacy, and between speed and perceived accuracy.

Self-testing with new technology versus professionals testing using established technology

For some participants '*a result is a result*' (S, young man, 18–19 years old), assumed to be accurate; they reasoned that clinics also tested urine, stored results on a computer, and with such an important purpose, the testing device would have been checked prior to release. Others questioned the accuracy of results from self-tests. Two main sources of doubt were identified: the novel technology and self-operation. Concerning the technology:

...this is still new. It has still little kinks to be found, little things to be found. Whereas the clinic is established, they are doing it there and then. But the longer it is out, the more confidence I would get in the technology. (V, young man, 18–19 years old)

Participants often seemed not to have questioned the accuracy of clinic-based tests, until the interviewer asked whether they would trust the new test. Self-operated technology was an issue for this young person:

...the clinic, doctors, they're more professional. That's exactly what [people] would think because that's what I would think as well but I would still put trust in my phone. (X, young man, 16–17 years old)

He went on to say *'I'd rather get it off the doctor, cos your phone could come back inconclusive.'* Even some of those who said they would trust results from self-tests, described repeat-testing or confirming results in clinic as ways to allay concerns about accuracy. Participants explained that the accuracy of results was extremely important:

...just don't let it go faulty [...] That's the most important thing in the whole wide world (F, young woman, 16–17 years old).

Personal support from healthcare professionals

There was a tension between participants' preferences for avoiding clinical contact when accessing testing, and a desire, expressed by some, for contact with a healthcare professional if a positive result were received. Often this was related to anxieties which participants explained might not be addressed through an online service:

...I will be having thoughts running in my head, so I wouldn't even have time to go through the link [to access treatment] 'cause I think there would be tension and pressure on me, so, yeah. (P, young man, 22–23 years old)

A telephone helpline was considered an acceptable way of providing this human support.

If you have an infection it should give you information but it should also give you like phone numbers that you can call to talk to someone because at the end of the day I see it as, if it's something on your phone you don't really wanna read so much. But if you can talk to someone, not a computer, someone real, then you're most likely to listen. (H, young woman, 18–19 years old)

Legitimacy and credibility

A basis in the NHS and association with medical professionals enhanced the perceived legitimacy of the proposed service

That it's part of the NHS? It makes me feel safe, it makes me feel okay, because like NHS are there to help

us innit, like they're there to help, to support us. (T, young man, 20–21 years old)

For some, however, a basis in the NHS made little difference provided the service was private and confidential.²

Confidentiality, data security and trust

Participants were told that with the proposed intervention, users would provide registration information prior to testing. The confidential but not anonymous nature of the service was accepted with varying degrees of reluctance, on the basis that the NHS was trusted and personal information was required to provide any necessary treatment, for one's own benefit. Participants' views revealed assumptions that data provided to an NHS service were shared across the NHS, *'the NHS knows so much about you anyway...'* (Y, young man, 20–21 years old).

There was variation in the extent to which participants trusted their smartphones and the internet, with regard to confidentiality. Passwords, assurance that the app/website was secure, and the legitimacy of the service aided trust in data security.

Concealing evidence of an STI

Unsurprisingly, participants described the importance of keeping an STI diagnosis secret. However with the proposed intervention, they discussed how not only the results message, but an 'e-prescription' and other messages (e.g. text message reminders to collect treatment) could reveal their STI status, if seen by others. Similarly, preferences for treatment access (collection from community pharmacy using an 'e-prescription'; or received by post) reflected privacy concerns.

I don't like going to the [sexual health] clinic and coming out with prescriptions to be honest with you, but pharmacy, that's what they're for. (G, young woman, 18–19 years old, previous STI diagnosis)

Receiving treatment by post was perceived as more convenient, but slower than pharmacy, with implications for privacy dependent on living arrangements:

...post is alright too, but then again, because I don't live by myself, I live with my parents. Then, my mum sometimes likes to open my letters (I, young woman, 20–21 years old)

Final word

Overall there was enthusiasm for this innovation: *'Just get it done quicker, just get it out there fast. Cos it sounds good, so it should be out there'* (L, young man, 20–21 years old).

Implications for development of the proposed intervention

Table 2 presents tentative design recommendations, and recommendations for further work to develop the proposed intervention. For ease of reference to the analysis, the same headings are used as above.

Discussion

Main findings

A novel proposal for remote online self-testing and treatment for STIs was broadly acceptable to these ethnic-minority young people from a high-prevalence population. In deciding whether to use existing STI testing services, and considering self-testing, participants appeared to balance three main factors: speed, convenience and privacy. Remote self-testing was perceived to maintain privacy by reducing the risk of peers and family members discovering their use of sexual healthcare, through avoiding sexual health clinic attendance, and by avoiding potentially embarrassing face-to-face consultations. By reducing these privacy concerns, and facilitating access to testing, participants expressed that they might be more likely to test, or test more often, if remote self-testing were available.

New privacy concerns with this novel intervention concerned electronic evidence of sexual healthcare use or STI diagnosis visible on their phone, online data security, and postal provision of treatment. Participants described ways they could manage these risks, and how intervention design could assist with this, but some considered risks to online data security inevitable. Enthusiasm about the novel technology contrasted with some participants' doubts about the accuracy of a novel, rapid, self-operated test, while accuracy of conventional testing was not questioned. Several participants' discomfort with sexual health consultations contrasted with their anticipated needs if they received a positive result or had particular concerns: to seek personalised support from healthcare professionals. Credibility of remote self-testing and online care, including data security, was enhanced by its association with healthcare professionals and trusted NHS services.

Strengths and weaknesses of this study

Formative research is particularly important in the development of complex interventions [27], especially in e-health [28]. During development, qualitative research can contribute to an intervention's success by informing

Table 2 Recommendations for the development of STI self-testing within online care pathways

Theme	Recommendations for development
Making access to STI testing quicker, easier and more convenient	The amount of information users need to input should be kept to a minimum. ^a The device should be easy to use.
'Faceless' sexual healthcare	Face-to-face contact with health service staff should be minimised. ^b
Concealing use of sexual healthcare	The self-testing device needs to look inconspicuous (size, appearance). The content and sender name of electronic communications (text messages, emails) should make no reference to STI testing or use of sexual healthcare. An app downloaded to the phone may compromise privacy, so alternatives should be explored.
Speed of testing	The test should give results faster than conventional services, but not necessarily very rapidly. ^c
Self-testing with new technology vs. professionals testing using established technology	Accuracy of results is very important. Accuracy is a concern with self-operation of novel testing technology (ways to increase confidence in the accuracy of the device, and minimise wasteful repeat-testing, need further exploration).
Personal support from healthcare professionals	Optional support from a health professional should be available. ^d Given the concern for privacy and convenience, this could be by telephone.
Legitimacy and credibility	Confidentiality should be assured. It should be clear to users that the service is part of the NHS.
Confidentiality, data security and trust	It should be clear to users that the service is part of the NHS. Passwords, assurances that the system is secure, and legitimacy (above) aid trust in data security.
Concealing evidence of an STI	The design of the device and care pathways should enable users to keep all evidence of STI secret (including: results message, prescription, treatment) Convenience/discretion of postal receipt of treatment was preferred by some, while others preferred the speed and privacy (from household members) of collecting treatment from community pharmacy.

^aThis needs to be balanced with clinical and disease surveillance requirements

^bWhere medically-appropriate for individuals, and preferred. See also 'Personal support from healthcare professionals'

^cDiverse views were expressed, with some perceiving a very fast result to be less accurate

^dThe need for a helpline from a clinical perspective had already been established, but this research confirmed its importance to potential users and its role in providing emotional support

an understanding of user-behaviour [29], particularly relevant for our intervention, which will be used remotely with minimal supervision. As well as informing an understanding of perceptions and acceptability of the proposed novel intervention, we made specific recommendations for its development (Table 2). Several of these were supported (and none were contradicted) by related formative research [31, 32]. However, as this study took place prior to the availability of the STI self-testing device and operational online care pathways, we relied on participants' ability to understand and engage with the hypothetical, novel intervention. To make it less abstract we chose a study population among whom STI testing was likely to be familiar, and the interviewer showed an animation to help describe the planned intervention. We decided against restricting recruitment to people with previous STI testing experience or STI diagnosis, as we sought to include those who test infrequently or not at all, who may experience more barriers to testing via existing services. Despite the hypothetical topic, interviews gained rich, detailed accounts of perceptions of smartphone-enabled self-testing, and although only two had been treated for an STI, participants also engaged well with the concept of treatment via an 'e-prescription'. However many interviewees found provision of treatment to partners difficult to engage with, perhaps because this topic was far from their personal experience and particularly abstract (requiring them to imagine a partner and a context in which STI transmission could have occurred, as well as imagining having been diagnosed with an STI following use of the novel self-test). For reasons of data quality we have not presented findings on this topic.

Engagement with target audiences is recognised as an important challenge to e-sexual health interventions [38], which may be aided by incorporating potential users' views throughout development. The demographic profile of our participants is close to that of those considered at elevated risk of STI, based on their age, ethnicity and recruitment from an urban, deprived population [2]; thus a key target group for provision of STI services, for reasons of equity and public health need. However, men who have sex with men (MSM), another important risk group for STI, were not targeted for recruitment to the current study because in this educational setting, we did not wish to compromise the privacy of those not 'out' to their classmates. Recruitment of exclusively non-White participants (Table 1) was unintentional, largely reflecting the location and student population. (Some White students were approached, but declined participation, with reasons unknown.) The sampling quota for women aged 20–24 (6–8 participants) was not filled ($n = 2$), with implications for analysis and interpretation. Our findings suggest a gender difference in the importance of concealing use of sexual healthcare,

but this may also be influenced by female participants' young age profile, compared to male participants. This was the only clear difference between men and women's expressed views in relation to the study topic (and there were no clear differences between age-groups), but had we achieved a stronger sample we might have been able to explore age-group and gender differences further.

In qualitative research, it is recognised that the interviewer and participants' shared or different characteristics influence the data (as discussed in [39]). Data quality is not necessarily considered to be compromised by having a non-peer interviewer [40, 41] (e.g. a male interviewing females). In this study it is encouraging that although the same male interviewer conducted all of the interviews on this sensitive topic, interviewees of both genders discussed their views and experience of sexual healthcare use freely, and the two interviewees who disclosed their previous STI diagnoses (without prompting) were both female. We did not seek participants' comments on the transcripts, which could have increased data quality, however all transcripts were checked against the audio-recordings. Those interviewed, who chose to participate in a study about sexual health, may be particularly comfortable with STI testing and/or sexual healthcare. However some had little experience of testing, and some discussed their dislike of existing services, so it is unclear what effect this may have had on the data. Non-participants' privacy concerns may be greater than those discussed by participants, who chose to participate in an interview where they discussed sexual healthcare face-to-face.

As explained, we took steps to reduce social desirability bias, but our study's premise that STIs are a problem, which can possibly be addressed through new services, was evident in information provided to participants. This may have prompted criticism of existing services. However, participants' views on existing services reflected those identified in the literature [4–8], and all participants expressed both positive and negative views about aspects of the novel intervention, indicating critical engagement.

Comparison of our findings with the published literature

We know of no other research exploring the acceptability of remote self-testing linked with online care for STIs, as our proposed intervention is unique. However, our intervention does include some elements that have undergone limited evaluation in other studies. Qualitative research with US young women (conducted 2007–08) reported reservations about internet-use in relation to STI testing, including online privacy and data security concerns, and lack of personal support [23], which feature far less in findings reported in similar qualitative

research among Canadian young people [25]. Our study echoed similar findings concerning desire for support from healthcare professionals following a positive diagnosis. Although privacy from peers and family was discussed as important by most participants (related to preferring to self-test instead of attending a sexual health clinic, and preferring discreet messaging) online privacy/confidentiality and security provoked fewer concerns. This possibly reflects our sample's smartphone ownership, and the confidence in the NHS which they described.

Similarly to our findings, other online sexual health services (internet-ordered home-sampling [23]; downloadable laboratory forms for STI testing without face-to-face consultations [24, 25]) have been perceived positively for their convenience and privacy. US clinic-attenders' views (focus-groups, 2008–09) on rapid home self-tests for STIs include concerns regarding accuracy and self-operation, and non-immediate treatment access [22]. A US survey on the acceptability of home-sampling among sexual minority youth found similar concerns about test accuracy and home self-sampling [42]. Our participants also expressed concerns around accuracy and self-operation, with linkage to treatment perceived positively.

Meaning and implications of our study

Our findings suggest that remote self-testing and online care pathways, as described here, would be acceptable as a complement to existing STI services, provided that personal support from healthcare professionals is available to those testing remotely, and accuracy concerns are addressed.

In addition to findings from this (and other) formative research, intervention design must also take account what is technically possible, clinical safety, and public health concerns (see Further Research, below). In the development of the proposed intervention, we need to consider that young people may desire to keep secret not only any STI diagnosis/es, but their sexual healthcare use. Regarding 'evidence' of sexual healthcare use on users' smartphones, care needs to be taken regarding name of the sender and wording of text messages, while web-apps (which are not downloaded or installed to users' phones) are an alternative to native apps, and NHS branding may confer trustworthiness. For speed and privacy from household members, collection of medication via 'e-prescription' from community pharmacies may be more suitable than postal treatment in this young population, depending, of course, on the STI and the nature of the recommended treatment.

Innovations in sexual health clinics, e.g. 'no-talk' testing with registration/clinical information provided on paper or electronic forms (e.g. touch-screens) [43–45], may already meet some of young people's access and privacy needs. However our findings suggest that by

removing the need to attend sexual health clinics (for many patients), our intervention may overcome further barriers to sexual healthcare use, resulting in earlier detection of STI. Provided users are able to use the care pathway to access treatment promptly, public health benefits would result from decreased STI transmission and decreased complications of long-term infection.

Unanswered questions and future research

Findings from our study, together with other formative research [31, 32], have informed intervention design. In terms of its accessibility, potential users' health literacy and use of appropriate terminology are being considered in its development. Building on this programme of research, online care pathways for chlamydia treatment [32] were recently piloted for feasibility, acceptability and preliminary evidence of effectiveness, and qualitative research was conducted with people who used these online pathways, informed by the findings we present here. Development of the rapid testing device is ongoing.

Future research must continue to explore the acceptability and feasibility of remote self-testing for STIs and online clinical care pathways, among young people and other potential user-groups (such as MSM, other age-groups and ethnicities), and identify barriers and facilitators to implementation, including costs to users and to the health service. Further research could also explore how acceptability varies between different STIs and when testing for multiple infections. A recent exploratory pilot study about the feasibility, acceptability and safety of an online clinical care pathway for chlamydia was conducted, using mixed-methods (articles in preparation). Sampling limitations of the study reported in this article were addressed in this recent research, which will give us greater scope to explore the role of gender and other factors.

Conclusions

Our research has informed intervention design, and identified concerns that can be addressed, or need to be explored further. By reducing or removing barriers that participating young people associated with conventional STI testing, our findings suggest that this complex intervention may enable earlier detection and treatment of STIs, thus delivering public health benefit through reduced transmission and reduced complications of infections. Remote STI testing may be a useful adjunct to our repertoire of STI services, ideally integrated within online clinical pathways embedded within existing sexual healthcare provision.

Endnotes

¹While A-level courses at the college are taken by younger students of both genders, technical/vocational courses at the college are traditionally gendered (e.g.

construction, electronics, beauty). The interviewer encountered more male students than female in the 20–24 age-group on the college campus which taught vocational courses. He therefore asked staff at both campuses to direct him to the locations where there were more 20–24 year old females. Unfortunately he only received this information one week before the end of the academic year, which limited his opportunities to recruit. The high level saturation within the sample achieved, and requirements for the interviews to inform the next phase of our research, led to our decision not to recruit further participants when the college re-opened.

²During the interviews, participants were asked their understanding of ‘confidentiality’. Despite the interviewer’s explanation during consent-taking, several could not define the term, and several misdefined it as confidence, referring to self-confidence or confidence/trust in healthcare. Participants tended to use the broader term ‘private’ to describe how they wanted their information to be held, and services to be. We use the standard definition of confidentiality, rather than how participants used the term.

Additional files

Additional file 1: The animation, showing the proposed testing device and online care pathway. (PNG 1579 kb)

Additional file 2: Summary of scenarios discussed in the interviews. (DOCX 20 kb)

Abbreviations

eSTI²: Electronic Self-Testing Instruments for Sexually Transmitted Infection Control, the Research Consortium developing the remote self-test and online care pathways, and which carried out this study; GUM: Genito-urinary medicine; NCSP: England’s National Chlamydia Screening Programme; NHS: The United Kingdom’s National Health Service; STI: Sexually transmitted infection; UK: United Kingdom (of Great Britain and Northern Ireland); US: United States (of America)

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Availability of data and material

The data that support the findings of this study are available from the corresponding author [CA] upon reasonable request. No individually identifiable data will be shared. The data are not publicly available because interview transcripts contain information that could compromise research participant privacy and consent.

Authors’ contributions

CA designed this study, with input from all authors, and obtained the necessary approvals. SF conducted the pilot and all of the interviews. VG designed the animation, with SF’s input. MS supervised SF and CA. CA conducted the analysis, and SF, LJS and MS, who were familiar with the entire dataset, verified her findings. CA wrote the first draft and led the writing of this paper. PS, CSE, KH, PO and STS, applicants on the eSTI² Grant, wrote the overall proposal and obtained funding. All authors contributed to the drafting of the manuscript.

Competing interests

The authors declare that they have no competing interests.

Consent for publication

Not applicable.

Ethics approval and consent to participate

Ethical approval was provided by University College London Ethics Committee, ref: 3490/001. Each participant provided signed informed consent prior to their interview.

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ORIGINAL ARTICLE

Using the eSexual Health Clinic to access chlamydia treatment and care via the internet: a qualitative interview study

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ABSTRACT

Objective We developed the eSexual Health Clinic (eSHC), an innovative, complex clinical and public health intervention, embedded within a specialist sexual health service. Patients with genital chlamydia access their results online and are offered medical management via an automated online clinical consultation, leading to antibiotic collection from community pharmacy. A telephone helpline, staffed by Sexual Health Advisers, is available to support patients and direct them to conventional services if appropriate. We sought to understand how patients used this ehealth intervention.

Methods Within exploratory studies of the eSHC (2014–2015), we conducted in-depth interviews with a purposive sample of 36 patients diagnosed with chlamydia, who had chosen to use the eSHC (age 18–35, 20 female, 16 male). Thematic analysis was conducted.

Results Participants described choosing to use this ehealth intervention to obtain treatment rapidly, conveniently and privately, within busy lifestyles that hindered clinic access. They described completing the online consultation promptly, discreetly and with ease. The information provided online was considered comprehensive, reassuring and helpful, but some overlooked it in their haste to obtain treatment. Participants generally described being able to collect treatment from pharmacies discreetly and promptly, but for some, poor awareness of the eSHC by pharmacy staff undermined their ability to do this. Those unsuitable for remote management, who were directed to clinic, described frustration and concern about health implications and clinic attendance. However, the helpline was a highly valued source of information, assistance and support.

Conclusion The eSHC is a promising adjunct to traditional care. Its users have high expectations for convenience, speed and privacy, which may be compromised when transitioning from online to face-to-face elements of the eSHC. Managing expectations and improving implementation of the pharmacy process, could improve their experiences. Positive views on the helpline provide further support for embedding this ehealth intervention within a specialist clinical service.

INTRODUCTION

STI rates remain high in England, despite existing STI control measures.^{1,2} Prompt effective treatment of diagnosed STIs is vital to reduce harms associated

with long-term infection and onward transmission. However, timely access to genitourinary medicine (GUM) clinics is threatened by increasing financial pressures.^{3,4} ehealth may increase access and convenience, at a potentially reduced cost.^{5–7} Globally, the push for internet-based healthcare, combined with the realisation that traditional models of face-to-face physician-led care are unsustainable, has never been stronger, but underpinning research on acceptability and effectiveness is lacking.

Sexual health is a promising arena for ehealth. In the UK, young people, a risk-group for STI,¹ have near-universal internet access⁸ and report greater internet-use for help/advice with their sex-lives than older age-groups.⁹ Online services may enhance privacy in this sensitive and stigmatised area.¹⁰ However, development and evaluation of ehealth services, as complex interventions, requires an understanding of the mechanisms and contexts in which they work,¹¹ including a contextualised understanding of users' behaviour.¹²

Through detailed formative research,^{10 13 14} we developed an online clinical pathway for STI management, using genital chlamydia as an exemplar. This pathway was deployed within an eSexual Health Clinic (eSHC, [figure 1](#)),¹⁵ a web-application, which people logged into to access their STI test results. Via the eSHC web-application, people testing positive for chlamydia were provided with information and were offered the opportunity to follow an automated online clinical consultation, consisting of tailored questions on presence of symptoms, medical history, drugs and allergies, sexual history and a risk assessment for blood borne viruses.¹⁶ If safe and appropriate, this led to collection of treatment from a chosen community pharmacy. A helpline, staffed by a specialist Sexual Health Adviser (SHA), was available throughout and facilitated access to clinic/general practice (GP) for those for whom 'remote' management (away from clinical services and medical professionals) was inappropriate. All users were followed up by telephone by an SHA, to check treatment was taken correctly, ascertain partner notification (PN) outcomes and provide support if needed.

The eSHC is unique within the National Health Service (NHS), in enabling users to receive a new medical diagnosis online and (if safe, appropriate

eSexual Health Clinic System

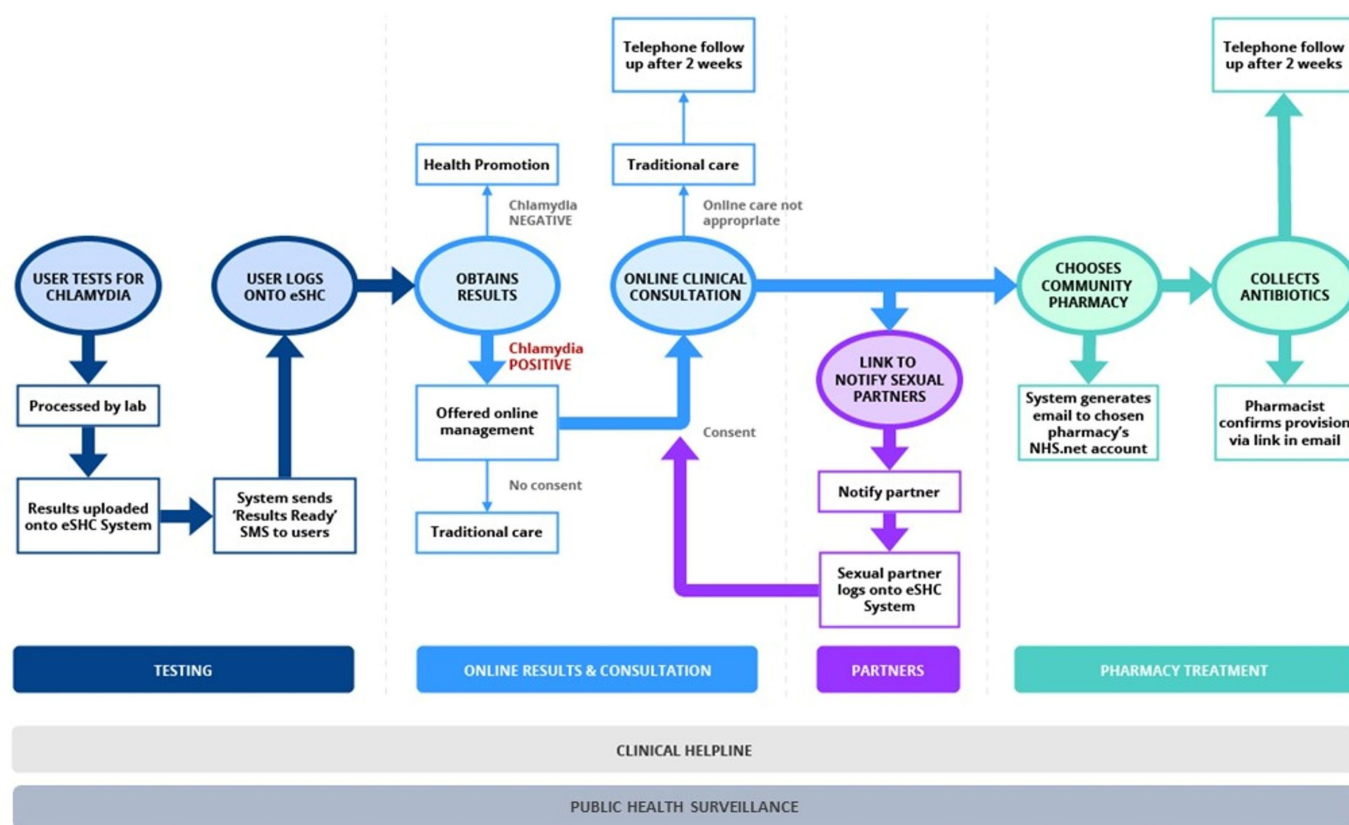


Figure 1 The eSHC. This figure was published in *The Lancet Public Health*, 2017;2(4):182–90, Estcourt *et al*, 'The eSexual Health Clinic system for management, prevention and control of sexually transmitted infections: exploratory studies in people testing for *Chlamydia trachomatis*.' Elsevier 2017. Notes: Only those testing chlamydia positive were included in the current study. Those testing negative were not interviewed and we do not report data on the small number of people who participated as notified sexual partners of chlamydia-positive study participants. Health information was available on results screen and via links to reputable websites. Patients who reported, in the online consultation, symptoms indicative of potentially complex infection or allergies, an underlying medical condition or that they were on medication which meant that they needed an alternative antibiotic, were alerted to telephone the helpline to facilitate access to traditional care. The Sexual Health Adviser staffing the helpline was simultaneously alerted to telephone the patient, in case they did not make contact. All those consenting to participation in the Exploratory Studies were followed up (top of figure). eSHC, eSexual Health Clinic; SMS, short messaging system (text message).

and desired) proceed to treatment, 'remote' from medical settings and with minimal supervision. The few existing NHS online STI services enable access to testing,^{17 18} but treatment of those testing positive requires individualised assessment by a clinician,¹⁶ in healthcare settings or by telephone.

We piloted the eSHC in exploratory studies.¹⁵ Within these, we conducted qualitative research among people who had tested positive for chlamydia (the focus of this article) to understand the experience of using this internet-based intervention, in order to inform its refinement and future evaluation.

METHODS

Setting and population

This qualitative study took place among participants of the exploratory studies who had tested positive for genital chlamydia. These studies' methods are detailed elsewhere.¹⁵ Briefly, people who had tested in two GUM services or via South London internet-based postal home-sampling ('Checkurself', within the National Chlamydia Screening Programme, NCSP) received their chlamydia-positive result online and were offered the opportunity to use the eSHC (figure 1). Those coinfecting with another STI or extragenital

chlamydia, aged under 16, unable to read English or not providing a mobile phone number, were ineligible and managed as per standard care.

Interview recruitment and sampling

During the eSHC's follow-up phone-call, SHAs asked patients with adequate spoken English for permission to pass their first name and mobile number to a researcher, to discuss a possible telephone interview.

Sampling was purposive,¹⁹ with quotas of 6–12 women and men in age-group (16–24, ≥25 years) and testing service (clinic or 'Checkurself') categories (total: eight categories). Additional sampling categories, developed during data collection, captured diversity in eSHC use (which was unknown a priori).

Data collection

One female interviewer (CA) conducted in-depth interviews by telephone, with oral informed consent. She introduced herself as a non-clinical researcher, interested in understanding what it is like to use the eSHC. Interviews took place on average 5

Table 1 Sample characteristics, reported behaviours and experiences

Gender*		Women	Men	Total
Demographics				
Age (years)*	18–24	10	8	18
	25–35	10	8	18
Ethnicity†	Asian	1	2	3
	Black	2	5	7
	Mixed	3	1	4
	White	14	8	22
Relationship status†	Single	7	9	16
	In relationship	8	3	11
	Split up with partner, related to chlamydia diagnosis	4	0	4
	Casual partner/s	1	3	4
	Not discussed	0	1	1
Sexual orientation†	Heterosexual, straight	18	16	34
	Not discussed (but recent partners opposite sex)	2	0	2
Experience of sexual healthcare				
Previous STI testing†	Yes	16	12	28
	No	3	4	7
	Not discussed	1	0	1
Previous STI diagnosis†	Yes	7	5	12
	Not had chlamydia before	1	0	1
	No	12	11	25
Testing (this episode)*	In a sexual health (GUM) clinic	12	8	20
	Via internet-based postal home-sampling (NCSP Checkurself)	8	8	16
eSexual Health Clinic use				
Route to treatment*	Directed to clinic/GP	6	1	7
	Disengaged from eSHC and treated in clinic	2	1	3
	Completed to pharmacy treatment collection	12	14	26
	of which: Problems with treatment collection: 2+ trips to pharmacy and/or helpline use	3	1	4
	No problems at pharmacy or problems resolved during one visit without helpline	9	13	22
Helpline use	Yes, self-initiated	6	0	6
	Yes, when prompted, re: being directed to clinic	3	1	4
	No	11	15	26
Total		20	16	36

*Primary sampling characteristics.

†Secondary sampling characteristics, by which we sought diversity across the entire sample.

GUM, genitourinary medicine; NCSP, National Chlamydia Screening Programme.

days after completion of eSHC follow-up, using a topic guide informed by previous research^{10 13} (see online supplementary file 1). Participants were offered a £30 e-voucher as reimbursement. Data collection ceased when sampling quotas were full and no new findings were emerging.

Data management and analysis

Transcripts of audio-recordings (average: 44 min) were checked to ensure accuracy and anonymity.

We conducted a thematic analysis,²⁰ using Framework²¹ for data management, in which data are organised into matrices by participant and descriptive code. Codes were based on elements of the eSHC (figure 1) and topics identified in previous research.¹⁰ Two researchers double-coded a selection of transcripts and agreed with the codes (CA and LS, in discussion with MS). CA coded transcripts in NVivo and then identified four emergent themes describing how participants used the eSHC from these ordered data. Themes were refined in discussion with LS and MS and applied to the data in a second phase of coding.

Ethical approval was granted by Brighton & Sussex (NHS) Research Ethics Committee (ref:13/LO/1111).

RESULTS

Sixty-two per cent (87/140) of the eligible patients agreed to be contacted, of which the interviewer attempted to contact 58 and interviewed 40 (69%ⁱ, including four partners of chlamydia-positive eSHC users, data not reported). Table 1 describes this study's 36 participants.

Themes describing use of the eSexual Health Clinic

1: Do something, fast!

Participants assumed that the eSHC would facilitate rapid treatment, which influenced their choice to proceed online following their chlamydia diagnosis. As this participant explained:

ⁱRelated to telephone recruitment, where phone calls sometimes were unanswered, reasons for non-participation were often unknown.

Health services research

[the website] gives you the options, you know, go and see someone or go online. And I thought, well actually, y'know, if I wanna get treated now... (26-year-old man, tested via Checkurself)

This urge to act quickly following receipt of their chlamydia diagnosis led to some participants to proceed immediately online using their smartphones. They described how this enabled rapid completion of the online consultation, while maintaining privacy (discussed below, theme 2), even in public locations:

I wanted to get it sorted straight away[...] And mobile's quite discreet[...] I thought for all everyone around me knows I was just on facebook. (29-year-old man, tested in clinic, completed online consultation at his desk in a shared office)

For others, feelings of urgency were balanced with privacy concerns and technology constraints (themes 2 and 3). Thus, some completed the online consultation later the same day they received their results and changed location and/or device.

[During my lunch-break] I just tried to find some privacy and to go and check the information again on the laptop first, because, well I had more time, and you have a bigger screen so it's just easier to read. So I really read all the information which was included in the results and, yeah, after, I answered the questions and ordered the medication online. (26-year-old man, tested in clinic)

Participants typically described the information provided online as helpful and comprehensive. However, some of those who felt panic and rushed through the consultation on their smartphones while in public, considered the information inadequate and mentioned missing details which were actually present. As this man, who described lacking information about what chlamydia is, explained:

Maybe it did say that but I was too busy frantically trying to [laughs] get to the antibiotic stage. (29-year-old man, tested in clinic)

In contrast, using the eSHC's web-interface at relaxed pace, in greater privacy (theme 2) appeared to result in greater uptake or recall of the information provided.

Participants described the process of completing the online clinical consultation and selecting (online) a pharmacy from which to collect treatment, as quick and easy. Treatment collection from pharmacies generally worked well, preserving participants' desire for prompt treatment access and comparing favourably with their experiences of clinic. Describing the process as 'seamless', this man explained that pharmacy staff:

...seemed to know exactly what I was here for and I said I was part of an eSTI trial, grabbed some medicine, and I was out within about five minutes. (22-year-old, tested in clinic)

However, in some cases, pharmacy staff were apparently unaware of the study or could not locate treatment packs, such that participants needed to return to the pharmacy on another occasion. This led to a short delay for participants (a few days), but had a significant impact on their experience, in the context of having an STI requiring treatment:

... it just seemed like the longest wait ever and I was quite frustrated at the time, quite upset. (26-year-old woman, tested in clinic)

Participants generally described taking treatment the day they collected it (and with a good understanding of information received in treatment-packs and online.)

2: Protecting privacy

All participants described acting to conceal their STI and treatment-seeking from those around them, but to varying extents.

Some, particularly Checkurself users, sought to avoid the embarrassment and exposure that they associated with sexual health clinic attendance. For them, the eSHC was:

...definitely a much more, sort of less embarrassing way to go about it, without, y'know, having to worry about seeing anyone you know [in clinic]. (20-year-old woman, tested via Checkurself)

When completing the online consultation, some protected their privacy by using their smartphone, while others changed location (as discussed, theme 1). Participants described providing information via the online consultation with ease and some considered it a more private way of providing sexual history details, with:

...no one there to give you their opinions straight away, or even kind of make a gesture that would suggest their opinion. You can be as honest as possible, I think. You can be more honest than if you go to a clinic. (27-year-old man, tested in clinic)

While some participants mentioned concerns about online data security, they appeared to accept this as an inevitable part of the online experience:

...on the internet, it's just that fear of maybe someone else is going to get the information. [Interviewer: Was that a concern for you?] No, no, er- no, actually cos I do a lot of things on the internet, so I actually trust the internet. A lot. (22-year-old man, tested via Checkurself)

However, privacy was sometimes threatened during transitions from online, to offline, public space. For instance, when the pharmacy treatment collection process worked as intended, participants could maintain discretion about their reason for attending the pharmacy, but when pharmacy staff were unaware of the study, participants' attempts to explain their needs in this public setting were perceived to compromise privacy:

...three or four people sat about a metre behind me[...] I don't think [staff] clicked that it was something I didn't really want to be shouting about. [They said:] 'No I don't get- I don't know what you're on about!' Erm, just shhh... (24-year-old woman, tested via Checkurself)

3: Choices and non-choices

Positive perceptions of the eSHC as a fast, private way to obtain treatment influenced participants' choice to use it (themes 1 and 2). In addition, they described how this choice was influenced or constrained by difficulties (re)attending conventional services, in the context of busy lifestyles.

[To attend clinic] I have to either book an appointment, which is also not gonna be easy cos of my working hours, or get there really, really early[...] when I saw it, an online option to do it, I thought this is much— probably gonna be much easier. (27-year-old man, tested in clinic)

Certain constraints also influenced how participants used the intervention. For instance, although all described completing the online consultation the day they received their results (theme 1), some delayed collecting treatment because they were away from home (a constraint which also hindered their access to conventional services via which they could obtain treatment, such as sexual health clinics or general practice).

Problems that some participants experienced with pharmacy treatment collection were exacerbated when participants faced difficulties reattending:

...they were asking me to come back another day and I was like, I can't do that[...] I already leave work earlier to make sure I can

get my treatment, and like they won't allow me like to leave earlier every day... (27-year-old woman, tested in clinic)

4: Seeking peace of mind

Following diagnosis, the prospect of a quick, discreet and convenient route to treatment via the eSHC (as discussed, themes 1–3) was reassuring, as was the eSHC's basis in NHS services, which conferred trustworthiness:

...I knew that the [home sampling]-kit was from the NHS. I, I just trusted everything that came with it, so I trusted the text, the link, and my results. I also trusted the treatment. (21-year-old woman, tested via Checkursel)

To resolve concerns about their chlamydia infection, its treatment and implications, participants sought information online, some used the helpline and two described contacting other services (eg, GP). In the interviews, participants typically discussed how it is 'definitely' necessary to have a helpline available. However, while they were using the eSHC, some had not noticed that a helpline was provided when they were using the eSHC (despite the number being displayed on each page of the eSHC web-application; they commented that they probably had not noticed or looked for it, because they had not needed it themselves). Helpline users described using it for information, technical assistance and/or support:

I probably knew what to do, but it's just because I was a bit overwhelmed about everything. I thought I need to speak to someone... (32-year-old woman, tested via Checkursel)

Those who sought support described the helpline particularly positively:

...it's always nice to have someone to kind of look after you and make sure that everything is fine. (26-year-old woman, tested in clinic)

Similarly, participants appreciated the 'closure' and 'personal touch' (29-year-old man, tested in clinic) of the follow-up phone-call:

...if no one called me, then I would've felt a bit like, 'well, is it done, what should I do?' (22-year-old woman, tested via Checkursel)

Alternative experiences

We used alternative experiences described by participants to refine themes and to illustrate further how they interrelate.²²

Being directed to clinic for treatment

As an integral part of the eSHC, patients whose online consultation responses indicated that 'remote' provision of Azithromycin was inappropriate were instructed to call the helpline and could not continue online. By telephone, the SHA emphasised the importance of attending clinic, offered to book an appointment and provided information.

Those who had disclosed symptoms online described annoyance and anxiety about their health and about attending clinic—which, by choosing the eSHC, many had sought to avoid (see themes 1–3). For instance, this woman felt 'really upset', because she 'thought it would be a bit embarrassing to go to the clinic':

... also because it said [online], 'because you said that you've got one of the symptoms you need to come,' so I was like, I hope it doesn't mean it's going to be more complicated... (22-year-old, tested via Checkursel)

Helpline contact, informing participants of the precautionary nature of this visit, was reassuring (theme 4). However, some remained unconvinced that clinic attendance had been necessary.

Abandoning the eSHC

Two participants received their diagnosis online, but abandoned the eSHC and attended clinic. Both described being particularly upset about the impact of their diagnosis on relationships (and one, on her health). Contrasting with the busy schedules discussed by others, both described having the flexibility to attend clinic the day they received their results (themes 1, 3) and sought reassurance through human contact (theme 4).

I felt more relieved, like, talking to someone[...], even though I knew, you know, I had all the information[...], I was looking for a bit of comfort. (34-year-old woman, tested in clinic)

DISCUSSION

This is the first qualitative study describing the experience of using a novel online sexual health intervention, which enabled some users to proceed from receipt of results to treatment collection without seeing or speaking to a clinician.¹⁵ Generally, the eSHC enabled patients to receive chlamydia treatment promptly and discreetly, within busy lifestyles. They provided sensitive information online easily and without embarrassment, yet valued the helpline's availability. Greatest satisfaction was expressed by those who obtained treatment from community pharmacies without problems, for whom the perceived benefits of online care were preserved 'offline'. However, these benefits were sometimes compromised when transitioning from online, to offline/public spaces: among the minority¹⁵ directed to clinic for treatment or at pharmacy treatment collection.

The eSHC provides an alternative management option for patients with uncomplicated chlamydia and was embedded within a specialist service, providing safeguards, specialist health professional support and follow-up, and facilitated clinic access. Positive views about the eSHC helpline (staffed by sexual health clinic SHAs) support the eSHC's basis in specialist services. Patients' expectations of a rapid, discreet and convenient service must be borne in mind during refinement of 'offline' parts of the eSHC. Clarification that not everyone will be medically appropriate for online management may better manage expectations.

Awareness and uptake of online health information appeared to be influenced by context. Where users were calm and their surroundings private, they found the information comprehensive and reassuring. Our study highlights the impact of some users' feelings of anxiety and urgency of treatment-seeking, on uptake of online health information following diagnosis of an acute, stigmatised condition. The potential loss of 'teachable moments'²³ that this precipitates may apply to future internet-based sexual health services, eg, for emergency hormonal contraception, or HIV self-testing. Despite evidence of effectiveness of some internet-based sexual health promotion interventions,²⁴ these have not yet been studied within online care pathways. Further research is needed to explore ways to improve uptake of online health promotion, for those testing positive or negative, including consideration of ehealth literacy.

Despite participants being recently diagnosed with an STI, thus potentially difficult to research, we achieved a strong, diverse sample, qualitatively representing those who had tested in clinic and via internet-based home-sampling and those with/without experience of STI treatment, whose perspectives may differ. However, men who have sex with men (MSM) were

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unrepresented; very few participated in the exploratory studies (people with coinfection and extragenital chlamydia, both more common among MSM, were excluded).

All participants chose the eSHC, so our findings do not extend to everyone with chlamydia (or other STIs). Those with lower health literacy or digital literacy may be unable or unwilling to use ehealth.²⁵ Patients were offered the eSHC after using established NHS testing services, which enhanced their confidence in using it.

Interviewing shortly after completion of care helped minimise recall issues. Telephone interviewing was appropriate to the sensitive topic and participants' choice of 'remote' health-care, but those who declined participation may have had higher requirements for privacy and convenience.

There is a dearth of similar studies. As e-prescribing is typically physician-mediated, studies of patients' experience of this have limited relevance to the eSHC, while research on commercial online pharmacies' vendors' treatment provision focuses on quality and legality.^{26–28} Our findings extend and complement our previous research, which explored the acceptability of a hypothetical STI self-test and online care, in a younger population.¹⁰ Some differences (eg, lower concerns about online data security) may reflect the current study population's older age-range and experience of internet-based healthcare.

This study informs the eSHC's refinement for future evaluation. Mixed-methods analysis of the eSHC's support for PN is underway. Future qualitative research must explore the views of non-users of the eSHC and MSM. Mindful of concerns that ehealth could widen health inequalities,^{29–30} evaluation must include assessment of the educational and socioeconomic status of users and non-users.

Key messages

- The eSexual Health Clinic is unique in supporting patients from online receipt of a new chlamydia diagnosis, to treatment, remotely and with minimal supervision.
- Building on formative research, we used qualitative interviews to generate a contextualised description of patients' experience of using this novel ehealth intervention.
- Patients described obtaining treatment rapidly and discreetly online compared with attending a clinic, but valued optional access to specialist sexual healthcare professionals by telephone, for reassurance, assistance and information.
- Refinement to 'offline' parts of this ehealth intervention, to preserve privacy, convenience and speed of treatment, may further increase its acceptability.

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Contributors CRHA led the design of this qualitative study as part of her PhD research, conducted the interviews, led the analysis and wrote the first draft of the manuscript. LT, as the exploratory studies' lead Research Health Adviser, enabled recruitment. LJS second-coded a selection of the interviews and, together with MS, informed definition of themes and interpretation. JG and LT provided detailed insights on the analysis and interpretation. CHM, MS and CSE provided guidance on all stages of the study as CRHA's PhD supervisors and PS, STS, JG, LJS, LT, KH

and EMH-E contributed to study design and interpretation of findings. CSE and PS led, and LJS managed, the exploratory studies from which interview participants were recruited. STS was the Principal Investigator of the eSTI2 Consortium, within which this programme of research took place. All authors contributed to drafting the manuscript and approved the final version.

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Using the eSexual Health Clinic to access chlamydia treatment and care via the internet: a qualitative interview study

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