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How can we make self-sampling packs for sexually transmitted infections and bloodborne viruses more inclusive? A qualitative study with people with mild learning disabilities and low health literacy

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ABSTRACT

Objectives 1.5 million people in the UK have mild to moderate learning disabilities. STIs and bloodborne viruses (BBVs) are over-represented in people experiencing broader health inequalities, which include those with mild learning disabilities. Self-managed care, including self-sampling for STIs/BBVs, is increasingly commonplace, requiring agency and health literacy. To inform the development of a partner notification trial, we explored barriers and facilitators to correct use of an STI/BBV self-sampling pack among people with mild learning disabilities.

Methods Using purposive and convenience sampling we conducted four interviews and five gender-specific focus groups with 25 people (13 women, 12 men) with mild learning disabilities (July–August 2018) in Scotland. We balanced deductive and inductive thematic analyses of audio transcripts to explore issues associated with barriers and facilitators to correct use of the pack.

Results All participants found at least one element of the pack challenging or impossible, but welcomed the opportunity to undertake sexual health screening without attending a clinic and welcomed the inclusion of condoms. Reported barriers to correct use included perceived overly complex STI/BBV information and instructions, feeling overwhelmed and the manual dexterity required for blood sampling. Many women struggled interpreting anatomical diagrams depicting vulvovaginal self-swabbing. Facilitators included pre-existing STI/BBV knowledge, familiarity with self-management, good social support and knowing that the service afforded privacy.

Conclusion In the first study to explore the usability of self-sampling packs for STI/BBV in people with learning disabilities, participants found it challenging to use the pack. Limiting information to the minimum required to inform decision-making, 'easy read' formats, simple language, large font sizes and simpler diagrams could improve acceptability. However, some people will remain unable to engage with self-sampling at all. To avoid widening health inequalities, face-to-face options should continue to be provided for those unable or unwilling to engage with self-managed care.

INTRODUCTION

Healthcare systems worldwide are facing increasing demand.^{1 2} Recent shifts in healthcare policy and practice are focusing increasingly on self-managed and remote care as a way to address demand and in some cases increase access to care by using digital/online care pathways.^{3–5} The recent COVID-19 pandemic has accelerated the pace of change.⁶ Sexual healthcare is at the forefront of self-managed care, and services such as postal self-sampling for STIs/bloodborne virus (BBV) are commonplace^{7 8} and sometimes the recommended or sole option for asymptomatic people.⁷

Self-managed care demands agency and health literacy (the ability to seek health information, understand its relevance and enable people to act on that information and make decisions).^{9 10} Despite increasing use of self-managed care, the views and opinions of people with low health literacy are not known. This is important because some of those at greatest risk of STIs/BBV are from vulnerable groups who have low health literacy and already experience considerable health inequalities, particularly regarding access and uptake of healthcare.¹¹

People with learning disabilities often have low health literacy. This is because a learning disability is a lifelong condition that starts before adulthood and affects development; individuals will need assistance to understand information, learn new things and function independently.^{12–14} Within the UK there are 1.5 million people with mild to moderate learning disabilities,^{15 16} 26 000 of whom live in Scotland and are known to require support.¹⁷ However, there are almost three times as many people with learning disabilities, or who have been recorded as having additional support needs when at school, who do not identify as having learning disabilities in adulthood and importantly do not benefit from learning disability services.¹³

As part of intervention development, ahead of the LUSTRUM (Limiting Undetected Sexually Transmitted infections to Reduce Morbidity) partner notification randomised controlled trial of accelerated partner therapy (APT),⁷ we explored the perspectives of people with mild learning disabilities. We aimed to identify potentially modifiable elements of the partner STI/BBV self-sampling

packs with the broader aim of increasing access to this type of self-managed care for people with mild learning disabilities and people with low health literacy more broadly.

We aimed to address three research questions:

1. What challenges do people with mild learning disabilities encounter with self-managed care for STIs and BBV?
2. What are the views and opinions of people with mild learning disabilities on the self-sampling pack and its contents?
3. Which elements of the pack could be adjusted to improve uptake and facilitate correct usage?

METHODS

Participants

Participants were heterosexual people and men who have sex with men (MSM), with mild learning disabilities, aged 18–65 years and able to communicate in English.

We used existing relationships with community groups and organisations in Central Scotland and personal contacts to inform people with mild learning disabilities about the study. We sent formal letters/emails to our contacts and attended group meetings to discuss the study and answer any questions before recruitment.

Sampling and recruitment

We used purposive and convenience sampling, making efforts to recruit heterosexual people, MSM and people of non-cis genders.

Participant information sheets and consent forms were adjusted to address accessibility needs (online supplemental appendices 1 and 2). The lead researcher (AM) is a registered learning disability nurse. His expertise was used to develop all recruitment materials and other elements of the research processes which needed adapting.

We recruited participants through gatekeepers (charitable/voluntary organisations) or directly, depending on the preference of the community group. Where recruitment was via gatekeepers we provided an information sheet which detailed the inclusion criteria and the participant information sheet to enable selective distribution. The inclusion criteria and ability to give informed consent were initially assessed by gatekeepers. Where we sought consent directly from potential participants, we assessed comprehension and understanding of the study information and ability to use this to make an informed decision. We also assessed ability to give informed consent before and throughout the interview/focus group.

Interviews and focus groups took place in community settings in Central Scotland between July and August 2018. Participants were required to dedicate approximately 1 hour to the study and had the option of a support person being present for part or all of the research activities. Participants were compensated with a £30 voucher.

All interviews were audio-recorded using digital devices and were transcribed in a Word document format for the purpose of analysis. Data collected were fully anonymised for reporting, presentation, archiving and/or publication purposes. All data were securely transported, transferred and stored in compliance with relevant data management guidelines.

In total, we conducted four interviews with one male and three female participants, and five focus groups that comprised three all-male groups with a total of 11 participants and two all-female groups with a total of 10 participants (table 1).

Procedure

The researchers (AM, GV and RL) conducted the interviews and focus groups using a semistructured topic guide (online

Table 1 Participant characteristics

	Gender	
	Female	Male
Age		
18–25	1	
26–35	5	5
36–45	4	5
46–55	2	2
56+	1	
Ethnicity		
White Scottish	12	12
Asian/Asian British	1	
Relationship status		
Single	3	7
Cohabiting (living with another person)	5	2
Married	1	2
Separated/divorced	1	
Widowed	1	
Other (in a relationship but not cohabiting)	3	1
Employment status		
Part-time employed	2	4
Unemployed	9	8
Retired	1	
College course	1	
Sexuality		
Heterosexual	9	9
Bisexual		1
Prefer not to say	4	2

supplemental appendix 3). Following introductions, the researcher(s) provided an explanation of the study. Researchers reminded participants that the interview/focus group would be audio-recorded and that they were free to leave at any point, and explained the processes for data handling and ensuring anonymity and confidentiality.

The researchers checked participants' understanding of the purpose of the interview or focus group, answered any questions and then sought informed written consent and completed demographic questions.

We began the interview/focus group by showing the participant(s) either the male and female self-sampling/APT packs and discussing how it should be used (figures 1 and 2). We explained that the packs would be provided to people diagnosed in clinics with chlamydia (described as the most common STI) to take to their sex partners. For this to happen, the sex partner would first need to have a telephone consultation with a qualified healthcare professional in clinic. We also explained that we had already conducted extensive pretrial work with diverse groups of people recruited from sexual health clinics and community settings to develop the pack's contents and instructions.

Self-sampling packs used in interviews and focus groups

The topic guides were used to elicit barriers and facilitators to using the pack before exploring the testing kit content and how they are used.

We asked participants to open the packs, look at the contents and tell us what they thought of the packs. We then asked participants to read the instructions in the pack, describe the contents of the pack and explain how they would use the contents.

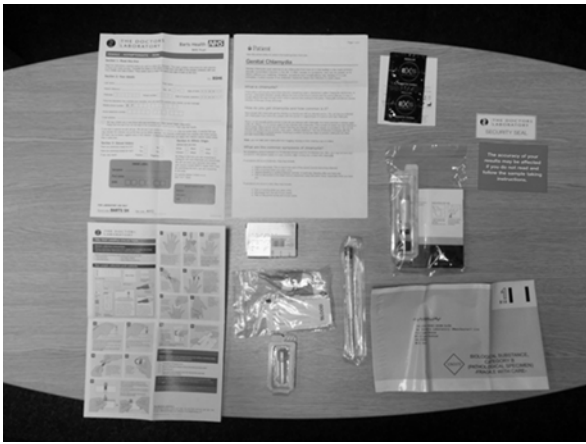


Figure 1 Visual aid pack (women). The pack contained information about chlamydia, instruction leaflet on how to use the pack, urine collection container (for men) or vulvovaginal swab (for women), blood sample collection kit, return envelope, security seal, red label (advising accuracy of tests depends on following sample taking instructions) and completing the laboratory form, and condoms.

Analysis

We combined focus group and individual interview data. We balanced deductive and inductive thematic analyses of audio transcripts¹⁸ to explore issues associated with the barriers and facilitators to correct use of the pack and its contents. Deductive analysis focused a priori on the barriers and facilitators to the correct use of the pack and its contents. In this way, the analysis balanced an inductive understanding of how participants understood the content of the self-sampling pack and its use. First, we conducted an initial sweep of the data enabling us to code in relation to the main elements of the pack, corresponding to the key research questions. Then we conducted a second round of more participant-led, inductive analysis. AM then coded these broad elements of the transcripts to generate participant-led themes. AM and MP reviewed and discussed the themes before defining and naming them. The data generated were stored and organised using NVivo V.11 software.

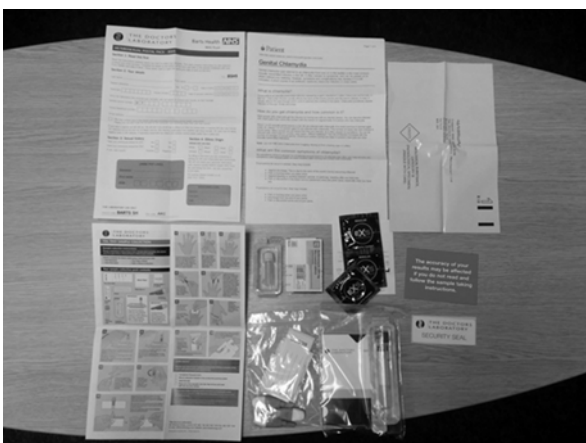


Figure 2 Visual aid pack (men). The pack contained information about chlamydia, instruction leaflet on how to use the pack, urine collection container (for men) or vulvovaginal swab (for women), blood sample collection kit, return envelope, security seal, red label (advising accuracy of tests depends on following sample taking instructions) and completing the laboratory form, and condoms.

RESULTS

Six key themes emerged. Table 2 shows representative verbatim quotations illustrating the underlying themes, relating to our three research questions.

We present a narrative discussion of each theme, drawing out barriers and facilitators to using the pack and its contents.

Accessing sexual healthcare

This theme identified some of the significant challenges that participants experience, particularly when accessing and trying to understand new and complex information.

Participants' knowledge of STIs was limited and this compounded the challenges of grasping new information. Although the participants all had a mild learning disability, this encompassed a range of cognitive abilities, specific difficulties and literacy skills. Written information was thought to be particularly challenging or inaccessible by all.

Support from others

Many participants explained that decisions about their health and well-being are often undertaken by others and restrictions put on risk-taking behaviours. Some participants continue to live with parents, highlighting this as a particular difficulty for sexual health when privacy was important.

Most participants received some support in their daily lives and often relied on guidance from others when navigating uncertain and unfamiliar areas. This was often with someone they trust and where privacy is respected, which was also the case when faced by a self-sampling pack.

Participants voiced a need for someone else to help navigate the pack, and due to the sensitivity or privacy around sexual health issues this was an additional consideration when asking for help. For some, the complexity of the pack and the knowledge and understanding required to undertake self-sampling meant that they would rather go to their general practitioner (GP) or sexual health service than try themselves.

Using the pack

Most participants described feeling overwhelmed to varying degrees when opening the pack and did not know where to start. This could prevent them from proceeding further.

Most participants found the details included in the chlamydia information sheets (the infection, health consequences, treatment and partner notification) (online supplemental appendix 4) to be too long and difficult to read. They could not relate the information to the actual sampling kits in the pack.

Despite the challenges voiced by most of the participants, the opportunity to use a self-sampling pack at home was welcomed by some due to convenience. Some also perceived self-sampling less embarrassing than attending a sexual health clinic or GP.

Accessibility of the pack

The inclusion of diagrams and pictures was seen as a welcome step towards an easier-to-read format by all participants. However, participants voiced problems interpreting the diagrams which illustrated the anatomical sites for self-sampling. This was a particular problem for women who had difficulties relating the diagrams to their own anatomy. Written information relating to each of the tests contained in the pack was felt to enhance the usability of the pack.

Participants suggested several improvements to aid clarity and remove ambiguity. These included adopting an 'easy read' format,¹⁹ avoiding columns of text, and simplifying how the

Table 2 Extracts illustrating themes within participants' accounts

Emergent themes	Illustrative quotations
Research question 1: what challenges do people with mild learning disabilities encounter with self-managed care for STIs and BBV?	
Accessing sexual healthcare	"If you've got learning difficulties, you need the help. You can't just read that..." [leaflet] (GF1) "Well, you've explained it [self-sampling pack] to me so it's easy when somebody's explaining to me." (DF1) "...but if you don't have a comprehension about why you'd be getting this [self-sampling pack], so that would freak you out." (GF3)
Support from others	"...if you live at home, with no support, and you don't want your mum to know that you're sexually active, how do you go about it?" (GF3) "I wouldn't ask somebody that I couldn't trust because I would like to keep that private." (DF1) "I'd get my support worker to help me." (EM2) "I'd rather go to the doctor's, 'cause then you'd know what's getting done, right then." (GF4)
Research question 2: what are the views and opinions of people with mild learning disabilities on the self-sampling pack and its contents?	
Using the pack	"...it's not giving you, like, instructions, like it's not a clear indication there of how to use it." (DF2) "Well, to be honest with you, it can be a bit daunting." (DM4) "Are these for likes of to find out if you've got sexual diseases as well...as well as doing it the other way? Because I've not heard of doing it this way." (DF1)
Accessibility of the pack	"...the steps, the diagram is okay, but the writing should be a [little] bit bigger." (DM4) "...because it [stages on leaflet] goes across, and down, is that confusing, would it be easier if it had everything in a row?" (GF3)
Research question 3: which elements of the pack could be adjusted to improve uptake and facilitate correct usage in this group?	
Contents of the pack	"Yeah, but it's not explaining it more, see if it's done the right way or the wrong way... so it's not clear... I think that would be a lot tricky for some people to get caught out on." (GM5) "But what, why, what STI is it for? [self-sampling pack]" (GF8) "But it's like, they've gave you a blood sample bottle, but they've given you nothing to take it with." (GM3) "Definitely include them [condoms] because people might not want to get infected again." (DF3)
Using the contents of the pack	"I'm not going to say what I think... I just call it my back passage... See, you wouldn't know if that's the back to the front... [anatomical diagram]." (DF1) "Because I think you could do the swab, and you might have taken it wrongly. Or you could have taken it incorrectly, and it would have given an improper reading." (GF3) "These [blood sample kit] look like what, if you're a diabetic, you have to go and get your sugars done, and that's what I was meaning." (GF1) "I'm diabetic, so I know I'm used to needles." (GM3)

Due to the small sample size, participant characteristics are limited to gender to prevent deductive disclosure (F, female; M, male; G/D/E code relates to locality). BBV, bloodborne virus.

key health messages are presented within the pack to create a more user-friendly feel. Specific suggestions included making it easier to identify items mentioned in the guidance notes with the pack components by numbering them and cross-referencing. For some, an accompanying online 'YouTube' video would be welcomed. (Videos were available as part of the wider trials; however, participants taking part in this study were not made aware of them.²⁰)

Contents of the pack

The number of test components in the pack created some anxiety and participants had difficulty understanding their purpose. The perceived lack of a clear process and sequence for undertaking the different activities needed to successfully self-sample was problematic. Interpreting anatomical diagrams depicting sampling sites and diagrams showing what to do with the samples were thought to be particularly challenging.

Condoms contained in the pack were familiar to most participants and were seen as a positive step in preventing future STIs.

Using the contents of the pack

Overall participants found the process daunting and at times confusing. They voiced fears about efficacy, most stating that they would need support to undertake the tests. Obtaining samples was felt to be particularly difficult; most participants felt unclear about what was required, how to take the samples and what to do with them subsequently.

Many women did not seem to have sufficient understanding of their own anatomy and experienced difficulties in interpreting the anatomical diagrams. This led to a lack of confidence in their ability to follow the instructions provided to take a vulvovaginal

swab. They also voiced concerns about appropriate technique and the potential for issues with reliability of the test by doing it incorrectly.

The motor skills and manual dexterity required for taking blood samples gave cause for concern and were felt to be a significant barrier to successful self-sampling. However, where participants had previous experience of similar procedures, such as diabetic monitoring, the familiarity gave more confidence.

DISCUSSION

All participants in this study found at least one element of the pack challenging or impossible. Some felt able to manage some of the tasks alone or with help from someone trusted, but others expressed bewilderment and a lack of ability to engage with the pack. However, many welcomed the opportunity to undertake sexual health screening without attending a sexual health clinic, and the inclusion of condoms in the pack was regarded as a positive STI prevention message.

Blood sampling and interpretation of female self-swabbing instructions appeared particularly difficult. Reduced manual dexterity, low knowledge of genital anatomy and overly complex instructions and diagrams contributed to the problems described. Adjustments to the pack structure and contents might increase accessibility, including limiting text to only the minimum required for completing self-samples, 'easy read' formats, simple language, large font sizes and simpler diagrams of anatomy and how to take samples.

To our knowledge, this is the first study to explore barriers and facilitators to use of an STI/BBV self-sampling pack in people with learning disabilities. As sexual ill health disproportionately affects those with limited agency, low literacy and low health

literacy, these findings increase our understanding of the challenges of self-managed care in this vulnerable group and suggest how problems might be overcome.

There are several limitations. Our sample was restricted to people from one area of Scotland and is unlikely to represent the full range of learning disabilities people experience. Most self-managed sexual healthcare requires initial digital engagement, such as ordering a pack online, whereas our study focused 'downstream' on the pack itself. In reality, it is likely that some people would not have managed to take even the first step of ordering online and therefore effectively excluded from self-managed care pathways altogether. We had already extensively optimised the packs by simplifying their components in the context of pretrial development work for a partner notification randomised controlled trial.⁷ Self-sampling packs in contemporary use may not have been developed with this focus on usability. As such, our findings may somewhat overestimate acceptability and feasibility of this type of care for people with mild learning disabilities.

Evidence suggests that uptake of online postal self-sampling is greater in people from more affluent areas,²¹ which may be viewed as a proxy for health literacy level. It is perhaps unsurprising that people with mild learning disabilities perceived considerable barriers. Evaluations of existing online self-sampling services report sample return rates of 54%–72.5% and blood samples are the least likely to be returned.^{22–23} Blood sampling was felt to be particularly challenging for our participants, partly due to difficulties with manual dexterity often coexisting with learning disabilities. Participants with prior experience of diabetic monitoring perceived fewer barriers, which suggests that opportunities to learn how to collect blood samples might encourage engagement.

A previous qualitative study of young people's perceptions of smartphone-enabled self-testing and online care for STIs suggested that some participants were concerned about the accuracy of self-testing.²¹ Similar views were expressed in this study, but concerns related to the participants' perceived ability to take appropriate samples rather than the accuracy of the test itself.

Although the development of the packs was informed by extensive qualitative research with the intention of creating a simple-to-use pack and to fit the financial constraints of the trial, it was not accessible to most of our participants. This suggests that people with even mild learning disabilities and people with low literacy will need highly tailored self-sampling packs to enable engagement with this type of self-managed care.

'Easy read' formats,¹⁹ specific layouts, reduction and simplification of information to the minimum, avoiding ambiguity and having a step-by-step guide, with a clear start and end point for sequencing of tests, and ensuring kit components are clearly matched to the accompanying instructions could facilitate pack use. An accompanying video clip could be helpful, but this would need to accurately reflect the exact pack the person is using to avoid further confusion.

Even if adjusted packs are provided, there will be considerable challenges in identifying who would benefit from them, as many people with mild learning disabilities and people with poor health literacy are not known to sexual health services. People from these groups may be more likely to take inadequate samples or sample incorrectly, which may lead to false negative results due to poor technique rather than true absence of infection.

As sexual healthcare becomes increasingly self-managed, we risk excluding vulnerable individuals because they are unable or unwilling to engage with processes which require sophisticated levels of health and digital literacy.¹³ Education and training for

healthcare professionals to assist identification of those individuals is likely to help, but an 'online first' approach²⁴ may exclude people with mild learning disabilities from engaging with care at all. Easily accessible alternatives (face-to-face options) are essential to avoid widening health inequalities further.

Although we focused on self-sampling packs for STIs and BBV, our findings will have broad generalisability to other areas of healthcare. These findings may also be of use with people from a broad range of ethnicities, people who speak English as a second language or who do not speak English.

Sexual health services have been at the forefront of self-managed care, but little attention has been given to the needs of those who are not health and digitally literate. Future work needs to quantify and characterise people with sexual health needs and risks who choose not to or are unable to engage with self-managed care. To avoid amplifying health inequalities further, we must develop ways of identifying people who may need additional support in a timely and sensitive way and develop accessible alternative models of care.

Key messages

- ▶ People with mild learning disabilities found the existing self-sampling pack overly complex; many would not use it and did not feel able to engage with self-managed care at all.
- ▶ Minimum 'need to know' information, very simple diagrams and 'easy read' formats specific to the needs of people with mild learning disabilities could improve acceptability.
- ▶ Adoption of self-sampling and other elements of self-managed care without provision of alternative care models could widen health inequalities.
- ▶ Face-to-face options need to be provided, but identifying those with limited health literacy will be challenging.

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Appendix 1: “Testing a sexual health treatment pack”

Participant Information Sheet

Study 5

Group discussions with participants from the public

We would like to invite you to take part in a research study on improving a sexual health service. We would like to hear what you think about a sexual health treatment pack. Before you decide it is important you understand what taking part in the study will involve. Please read the following information carefully and discuss it with others if you wish.

Who we are

We are researchers working at Glasgow Caledonian University and University College London. We are currently working on a study called LUSTRUM, which aims to improve sexual health services in the UK. The study is funded by the National Institute for Health Research (NIHR).

Why are we doing this study?

Sexual health is very important, and is part of the wider public health. In recent years, there has been an increase in infections which can be passed on during sex (sexually transmitted infections or STIs). It is very important that people who have a sexually



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transmitted infection (STI) get treated, so that they get better and the infection does not spread to their sex partners. This is why we would like to find out what people think about a new sexual health treatment pack. This treatment pack is for the sex partners of people who have an STI.



This is what the sexual health treatment pack contains. We will show you the treatment pack on the day of the group discussion.

Why have we invited you to take part?

We want many different people to be involved in our study. We invite people who are 18-65 years old and who are able to decide for themselves if they want to take part in the study.

Do you have to take part?

You do not have to take part in the study if you don't want to. If you decide to take part, we will call you to arrange the day and time to talk with us whenever it is best for you.



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What will happen if you decide to take part in the study?

If you agree to take part, we will ask you to take part in a group discussion with other people and the researchers. We will show you the treatment pack and then we will ask you questions to find out what you think about it, and if you think it is easy or difficult to use and why you think that. We will not ask you anything personal.



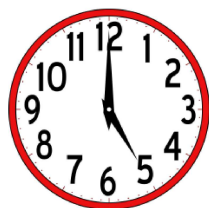
There is no right or wrong answer to these questions. We just want to know what you think. We will also give you a questionnaire with some questions about your age, ethnic background, employment, education level, sexuality, and relationships.

Before we start the group discussion we will ask you to sign a consent form, which means you agree to take part in the study. You can bring a member of staff, a relative or a friend to the group discussion if you wish.



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How long will the group discussion last?



The group discussion will last approximately 1 hour, and this is a one-off discussion, so we will not ask you to come back.



We will record the group discussion to help us remember everything you say.

How will we keep the recording safe and make sure you are not identified from it?

**CONFIDENTIAL
FOLDER**

Your personal details will be kept private. We will not share with other people personal things you say to us, unless it has to do with keeping you safe. In this case, we will tell someone who can help you like your support worker, or your doctor.

What are the possible advantages of taking part?

Taking part in this study will not help you personally. As a way to thank you for your time and sharing your thoughts with us, we will give you a £30 voucher after the group discussion. You can use



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the voucher in most high street shops (e.g. Boots, Argos, Iceland etc).

What are the possible disadvantages of taking part?

We do not expect any disadvantages but during the group discussion we will check if you feel comfortable and happy to answer questions. You can decide to leave the group discussion at any time without giving us a reason.

What will happen to the results of the study?

The results of the study will be shared with healthcare services, academics, professionals and practitioners, community based organisations and service users. We will use the things you and others say to write reports and academic papers, and make presentations about the study. We may use the exact words that you say but we will not use your name. Instead we will use numbers or made up names

What if you want more information?

We will share updates of the research and its progress through the project website (www.lustrum.org.uk) and through the project twitter account '@LUSTRUM_5'



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If you want more information about the study you can contact:

In Glasgow:

Dr Maria Pothoulaki
Glasgow Caledonian University
(email: Maria.Pothoulaki@gcu.ac.uk)
(tel.0141-3313701)

Professor Paul Flowers
Glasgow Caledonian University
(email: P.Flowers@gcu.ac.uk)
(tel.0141- 3318617)

Mr Alan Middleton
Glasgow Caledonian University
(email: Alan.Middleton@gcu.ac.uk)
(tel. 0141-3313811)

Thank you for taking the time to consider taking part in this study

**LUSTRUM**

Limiting Undetected Sexually Transmitted Infections to RedUce Morbidity

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Appendix 11: "Testing a sexual health treatment pack"**Study 5****Group discussion - Consent Form**

Researchers: Dr Maria Pothoulaki, Mr Alan Middleton, Professor Paul Flowers (Glasgow Caledonian University)

Please tick the boxes below if you agree



I have read and understood the information sheet about the study (dated 1 September 2017, version 1).

I have had the opportunity to ask questions

My age is between 18 and 65 years of age

I understand that if I want I can leave the group discussion at any point



LUSTRUM

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I agree to the group discussion being audio-recorded

I agree for researchers to use my direct words (quotations) in publications, reports and/or presentations, without revealing my name.

I understand that my personal details will not be shared outside the research team

I understand that the only reason for sharing my details is if I am in danger and need help to keep me safe

I understand the information about the study and I can decide to take part

I agree to take part in the study

Please write
your name

Date

Please sign
above here

Researcher's
name

Date

Researcher's
signature





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Infections to RedUce Morbidity

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Appendix 3: “Maximising intervention reach to wider populations: Testing the APT intervention pack”

INTERVIEW SCHEDULE

Study 5

I. Introduction

- *Introduction of the facilitator/researcher and participant*
- *Explain information about the study, the purpose of the interview and the type of questions that will be asked*
- *Explain that the participant is free to leave at any point*
- *Explain the use of the audio-recorder and how data will be handled*
- *Explain what type of information/data will be shared and with whom (anonymity and confidentiality)*
- *Check understanding of information, ask if participant has any questions and take informed written consent*
- *Ask Demographic questions*
(Audio-recorder on)

II. Presentation of the Accelerated Partner Therapy (APT) intervention pack

- *Presentation of visual aid (APT Pack) and a brief background summary of how it will be used*

III. Assessing the strengths and weaknesses of the APT pack

- *Ask participant to open the pack, have a look at the contents of the pack and voice their thoughts*
- *Ask participants to read carefully the instructions in the pack*
- *How do you think about the pack?*
- *What are the contents in this pack?*
- *How are the contents used?*

**LUSTRUM**Limiting Undetected Sexually Transmitted
Infections to RedUce Morbidity

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Example of questions to be asked for each of the items in the APT pack

- Why is the Genital chlamydia information placed in the pack?
- What is good about it?
- What is bad about it?
- How could it be better?

(Ask the above questions for each of the APT pack items: condoms, instruction leaflet on how to use the pack, medication, urine collection container, blood collection pack, envelope, security seal, red label, laboratory form.)

- If you were to use the pack, what would you find most difficult?
- If you were to use the pack, what would you find most easy?
- What/who would help in using the pack?
- What would you recommend to the people who make the pack?

IV. Conclusion

Check if the participant has any questions or comments.

Thank you for participating in our study!



View this article online at: patient.info/sexual-health/sexually-transmitted-infections-leaflet/chlamydia

Chlamydia

Around 3 to 7 in 100 sexually active young people in the UK are infected with chlamydia. It is most common in those aged under 25.

What is chlamydia?

Chlamydia is a [sexually transmitted infection \(STI\)](#) caused by a germ (bacterium) called *Chlamydia trachomatis*. In women, chlamydial infection usually affects the neck of the womb (cervix) and the womb (uterus). In men, it usually affects the pipe through which urine is passed (the urethra) in the penis. Chlamydia also sometimes causes infection of the eye, throat and lungs.

How do you get chlamydia and how common is it?

59%

of people would be worried about contracting chlamydia from a casual sexual encounter.

Source: Patient Sexual Health Survey (<https://patient.info/sexual-health-at-christmas>)

Most people with chlamydia get the infection by having sex with an infected person. You can become infected with chlamydia if you come into contact with the semen or vaginal fluids of a person who has chlamydia.

In 2015 in England, there were 200,288 new cases of chlamydia. Around 3 to 7 in 100 sexually active young people in the UK are infected with chlamydia. It is most common in those aged under 25. Many of those infected have no symptoms - 7 in 10 infected women and 5 in 10 infected men. They would not be aware they have the infection. You can be infected with chlamydia for months, even years, without realising it. The risk of infection increases with the number of changes of sexual partner. Wearing a condom during sex helps to protect you from chlamydia and other STIs.

Note: you **cannot** catch chlamydia from hugging, kissing or from sharing cups or cutlery.

What are the common symptoms of chlamydia?

Symptoms in women

No symptoms occur in around 7 in 10 infected women. Also, you may not have any symptoms until several weeks (or even months) after coming into contact with chlamydia.

If symptoms do occur in women, they may include:

- Vaginal discharge. This is due to the neck of the womb (cervix) becoming inflamed.
- Pain or burning when you pass urine.
- Vaginal bleeding or spotting between periods. In particular, bleeding after you have sex.
- Pain or discomfort in the lower tummy (abdomen) area (the pelvic area), especially when you have sex.

Symptoms in men

No symptoms occur in 5 in 10 infected men.

If symptoms do occur in men, they may include:

- Pain or burning when you pass urine.
- Discharge from the end of your penis.
- Pain or discomfort at the end of your penis.

Do I need any tests?

Tests for females

The best test is a vaginal swab. A swab is a small ball of cotton wool on the end of a stick which is used to obtain mucus and cells to send to the laboratory for testing. It is inserted about 5 cm into your vagina and turned (rotated) gently for a few seconds. This test can be done by a health professional but it is also possible for you to do the test yourself. This is usually an option you are given if invited to have screening tests for chlamydia.

This is the most accurate test. There are two other possible tests. One is a swab taken from the neck of the womb (cervix) by a nurse or doctor. The other is a urine test. When testing urine for chlamydia you should provide a urine sample after not having passed urine for at least an hour. You catch the first part of the urine stream in the container.

Tests for males

For men the usual test is a urine test, collected in the same way as for women above. The other option is for a health professional to take a swab from the pipe through which urine is passed (the urethra) in the penis.

Other tests

If you have had anal or oral sex then you may have a back passage (rectal) or throat swab taken.

If infection with chlamydia is confirmed, you will be advised to have [tests for other STIs](#).

Note: the **cervical screening (cervical smear) test** does **not** test for chlamydia.

What is the treatment for chlamydia?

It is important that treatment for chlamydia should be started without delay. In some people where chlamydia is strongly suspected, this may even mean starting treatment before test results are available. Prompt treatment reduces the risk of complications in the future.

A short course of an [antibiotic medicine](#) usually clears chlamydial infection. You should tell your doctor if you are (or may be) pregnant or are breast-feeding. This may affect the choice of antibiotic. You should not have sex until you and your sexual partner have finished treatment (or for seven days after treatment with a single-dose antibiotic).

The most commonly used antibiotics are:

- [Doxycycline](#) one tablet twice a day for seven days; **or**
- [Azithromycin](#) one tablet only - single dose.

Other options are used if these are not suitable for you. Your doctor will advise.

Does my partner need to be treated?

Yes. Also, any other sexual partners within the previous six months should also be tested for infection.

If your sexual partner is infected and not treated then chlamydia can be passed back to you again after you are treated.

There may be certain occasions when you may not want to contact partners from previous relationships. In these cases staff at the clinic can contact previous partners for you without disclosing your details. This is because it is important that anyone who is at risk of infection with chlamydia be both identified and treated.

Why should I have treatment if I have no symptoms?

If you are infected with chlamydia, it is essential that you take treatment even if you do not have any symptoms of chlamydial infection. Reasons for this include:

- The infection may spread and cause serious complications (see below). This can be months or years after you are first infected.
- You can still pass on the infection to your sexual partner(s) even if you do not have symptoms.

Do I need to be tested again after treatment?

You do not usually need to have a test to check the treatment worked if you have taken an antibiotic medicine correctly. However, it is advisable to have another test for chlamydia in the following situations:

- If you think you have had sex with a person with chlamydia.

- If your symptoms do not improve after treatment.
- If you had unprotected sex before you finished the treatment.
- If you did not complete the course of treatment.
- If you are pregnant. (If you are pregnant and have been treated for chlamydia, you should have another test three weeks later.)

Also in England, the national screening programme advises that if you are aged under 25 and have had a positive test for chlamydia, you should have a repeat test three months later. This is to check the infection has cleared completely and that you have not got it back again.

What are the possible complications of chlamydia?

- If left untreated, the infection may seriously affect the womb (uterus) and Fallopian tubes - [this is called pelvic inflammatory disease \(PID\)](#). 10-40 women in 100 with chlamydia develop PID. This may develop suddenly and cause a high temperature (fever) and pain. It can also develop slowly over months or years without causing symptoms (also known as silent PID). However, over time, scarring or damage to the Fallopian tubes may occur and can cause:
 - Persistent (chronic) pelvic pain.
 - [Difficulty becoming pregnant \(infertility\)](#).
 - An increased risk of [ectopic pregnancy](#) if you become pregnant. In this condition, the pregnancy develops in a Fallopian tube and can cause serious life-threatening problems.
- The risk of developing some complications of pregnancy, such as [miscarriage](#), [premature birth](#) and stillbirth, is increased in pregnant women with untreated chlamydia.
- If you have untreated chlamydia during childbirth, your baby may develop a chlamydial infection of their eye or lung during the birth.
- Possibly reduced fertility in men.
- [Reactive arthritis](#) is a rare complication which can occur both in men and in women. In this condition, you get painful swollen joints. It may also appear as combined symptoms of inflammation of the eye and of the pipe through which urine is passed (urethra). It may be due to the immune system 'over-reacting' to chlamydial infection in some cases.

The risk of complications is much reduced if chlamydial infection is treated early.

Who can be screened for chlamydia?

In England there is a National Chlamydia Screening Programme. This offers chlamydial screening for sexually active women and men aged under 25 years. In this age group, screening is undertaken yearly or each time these women and men have a new sexual partner. The aims of this programme are to detect chlamydia early so it can be treated promptly. This should reduce the risk of transmission and also reduce the risk of developing complications. You can find information about screening at your GP surgery or local pharmacy. It is also available through family planning clinics, genitourinary medicine (GUM) clinics or online.

In countries where there is not a screening programme, testing is still offered regularly to sexually active young people. You can request testing regularly if you are in this category. You can do this through your GP or by attending a GUM clinic. It may be available in other ways (for example, online) depending on the area in which you live.

Certain other groups of people are also recommended to undergo screening for chlamydia. For example:

- If you have a partner with chlamydia.
- If you have another STI.
- If you are a semen or egg donor.
- If you are having an abortion (termination of pregnancy).
- If you have had two or more sexual partners in the past year.

Men will be asked to give a urine sample and women can either give a urine sample or take a swab. A swab is a small ball of cotton wool on the end of a stick, used to take a sample of mucus and cells for laboratory testing. Women can take the swab themselves from the lower vagina.

Further reading & references

- [Sexually transmitted infections \(STIs\): surveillance, data, screening and management](#); Public Health England, 2016
- [Sexually Transmitted Infections in Primary Care](#); Royal College of General Practitioners and British Association for Sexual Health and HIV (Apr 2013)
- [National guideline for the management of chancroid](#); British Association of Sexual Health and HIV (2014)
- [Towards elimination of HIV transmission, AIDS and HIV-related deaths in the UK](#); Public Health England (November 2017)

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