THE DEVIL'S IN THE DETAIL

Final report of the independent evaluation of the Summary Care Record and HealthSpace programmes

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Preface

This report builds on our interim evaluation of the Summary Care Record programme, published in 2008.[1-4] We used mainly qualitative methods to analyse the complex and conflict-ridden process of socio-technical change in the English National Health Service. Academics call this approach case study, which roughly translates as 'story-in-context'.

One version of the story holds that centrally-stored electronic summaries, accessible by patients and authorised staff, are linked with unassailable common goods like choice, empowerment, quality, safety, efficiency and personalised care – and that the 'tipping point' for their widespread adoption is imminent. Another version depicts policymakers as seduced by a vision of technological utopia, professional leaders as obsessed with standardisation, the public as largely disengaged, and the government as extending electronic surveillance into intimate parts of citizens' lives. Both versions can, to some extent, be backed up by 'evidence'. Readers who expect us to adjudicate on where the absolute truth lies will be disappointed. Our analysis is built on the assumption that facts are always contested and ambiguities impossible to expunge in the evaluation of large-scale IT programmes.

We considered this case study at two contrasting levels: the 'macro' story of national context and the 'micro' story of the actions and choices of individuals. At one end of the scale, we studied such things as Department of Health policy, the British Medical Association's conference debates and the waxing and waning of civil liberties protests. At the other end of the scale, we sat in clinics as patients consulted doctors or nurses – and in their living rooms as they accessed their electronic record remotely (or chose not to do so). Macro and micro were dynamically and reciprocally related, each shaping and constraining the other.

The SCR and HealthSpace programmes were large in scale and ambitious in scope. Their multiple stakeholders brought different values, priorities, ways of working and world views. All this makes for a long and complex report. Here are some suggestions for navigating it:

- For an overview of findings, see the Executive Summary in Chapter 1 (and for bottom-line recommendations, start at paragraph 1.50);
- For those unfamiliar with the UK context or our previous work, see Chapter 2;
- Those interested in the policy background and national-level efforts to implement the programmes will find these in Chapters 4 and 9:
- Managers embarking on local implementation of the SCR may find Chapter 5 helpful;
- Clinicians and patients who wonder how the SCR will affect their interactions and the handling of personal data should see the examples of front-line clinical care in Chapter 6;
- Those who expected us to state the key facts and give a clear direction of travel for the next stage should consider our analysis of 'wicked problems' in Chapter 8;
- Academics looking for theories and analytic insights will find them in Section 3.4 and Chapter 10 respectively;
- For citizens, professionals and journalists seeking to promote further debate, the points raised in the Discussion and Epilogue (Chapters 11 and 12) may provide a starting-point.

The SCR and HealthSpace programmes are still unfolding. The story so far is mainly about the delays and hurdles encountered in their implementation, peppered with examples of where the technologies were up and running and considered to add value – often in subtle, hard-to-articulate ways – by those using them. It is not yet possible to make final judgements on the extent to which the programmes have met their own objectives or the expectations placed on them by various stakeholders. But such judgements will at some stage be called for, and when that time comes, we hope this report will help to inform them.

Professor Trisha Greenhalgh OBE
7th May 2010

1. Executive summary and recommendations

Background (see Section 2)

1.1. This report summarises findings from Years 2 and 3 of a 3-year evaluation of the Summary Care Record (SCR) and HealthSpace programmes. It covers the period 1st May 2008 to 28th February 2010. It is intended for all stakeholders in these programmes, including the Department of Health (which funded the evaluation), NHS Connecting for Health (CFH), policymakers, the Information Commissioner, healthcare and ICT professionals, NHS staff, service users, citizens, academics and evaluation scholars. It should be read in conjunction with our Year 1 reports on the SCR programme (May 2008)[1] and data quality (May 2008).[2]

1.2. The SCR is an electronic summary of key health data, currently drawn from a patient's GP-held electronic record and accessible over a secure Internet connection by authorised healthcare staff. It is one of a suite of innovations being introduced as part of the National Programme for IT in the English National Health Service (NHS) and delivered via a central 'Spine'. Policy documents published in 2005-8 anticipated a number of benefits of the SCR, including:[5-8]

a. Better care (i.e. the SCR would improve clinical decision-making);
b. Safer care (i.e. the SCR would reduce risk of harm, especially medication errors);
c. More efficient care (e.g. the SCR would make consultations quicker);
d. More equitable care (i.e. the SCR would be particularly useful in patients unable to communicate or advocate for themselves);
e. Reduction in onward referral (e.g. the SCR would avoid unnecessary ambulance callouts, A&E attendances and hospital admissions);
f. Greater patient satisfaction (by allowing people to state care preferences, receive better care and access their record via HealthSpace).

1.3. HealthSpace is an internet-accessible personal organiser onto which people may enter health data (such as blood pressure) and plan health appointments. Through an advanced HealthSpace account, they can gain secure access to their SCR and email their GP using a function called Communicator. Policy documents published in 2005-8 anticipated five main benefits of HealthSpace:[5;9-11]

a. Personalisation of care (by supporting choice and increasing access options, HealthSpace would allow NHS care to be adapted to individual needs);
b. Patient empowerment (by entering their health data onto HealthSpace, and by accessing their SCR via an advanced HealthSpace account, patients would be better able to manage their illnesses, especially long term conditions);
c. Accountability, quality improvement and safety (patient input, supported by high-quality, accessible information, would drive up quality in the NHS – for example, by spotting data quality errors on their SCR);
d. Reduced NHS costs (e.g. more self-management would potentially reduce the cost of managing long-term conditions); and
e. Improved health literacy (the availability of HealthSpace would improve people's ability to understand and manage their illness).

1.4. We were asked to highlight that the SCR and HealthSpace are evolving technologies at an early stage of implementation. Versions evaluated were not the final, definitive ones envisaged by policymakers. As the main report makes clear, numerous environmental factors influenced delivery of the programmes over the timescale covered by the evaluation. This report should be read with this caveat in mind.

The evaluation (Section 3)

1.5. The full aims and terms of reference of the evaluation are set out in Section 3.1 of our main report. The research questions were:

a. At the 'micro' level, what is the usability, usage, functionality, and impact of the SCR and HealthSpace in participating localities, and what explains variation in their adoption and use?
b. At the 'macro' level, what is the social, political, technological and economic context into which these technologies are being introduced? How does this context shape and constrain micro level usability and usage – and how, conversely, does the experience at micro level impact on the macro context?
c. What aspects of implementation are seen by different participants and stakeholders as important? How (if at all) might these be expressed as generic, transferable implementation standards and strategies?
d. What can we learn from this project about how best to evaluate large-scale healthcare IT programmes more generally?

1.6. The evaluation consisted of a multi-level (national, regional and local) case study. We used a mixed-method approach which incorporated both quantitative and qualitative data. The empirical dataset for this phase of the evaluation consisted of:

a. A national quantitative dataset on SCR uploads, accesses and HealthSpace registrations provided by CFH, plus a dataset of 416,325 anonymised encounters in participating out-of-hours providers supplied by Adastra (software supplier);
b. In-depth qualitative (ethnographic) studies of 237 encounters between patients and doctors, nurses, pharmacists and call handlers in unscheduled care settings;
c. Interviews with approximately 100 individuals from CFH, NHS organisations, IT suppliers, professional bodies and patient organisations;
d. Ethnographic studies of 20 people living with long-term conditions (5 of whom had tried to use HealthSpace) and interviews with a further 15 patients and carers who had registered for HealthSpace and were using HealthSpace Communicator to email their GP;
e. Documentary evidence such as policies, business plans, minutes of meetings, internal reports, action plans, communications and media coverage;
f. Field notes from direct observation at over 100 meetings and events;
g. Verbal and written feedback from key stakeholders to earlier drafts of this report.

1.7. Collection and analysis of data was informed by academic perspectives outlined in Section 3.4 of our main report. In sum, we used Patten's utilisation-focused evaluation, supplemented by theories and methods from ethnomethodology, sociology, computer-supported cooperative work and empirical philosophy.[12;13]

1.8. When considering the extent to which benefits anticipated for the SCR and HealthSpace (paragraphs 1.2 and 1.3) had been realised, we took account of multiple data sources, including quantitative datasets (paragraph 1.6a); our direct observation of clinical encounters and the lived experience of chronic illness (paragraph 1.6b and 1.6d); interviews with front-line staff (paragraph 1.6c); 'risks and issues' documents prepared as background to board meetings (paragraph 1.6e); feedback (both orally and on structured reporting sheets) provided to CFH by local NHS managers and clinical leads (paragraph 1.6f); and activities undertaken locally and nationally to address perceived lack of emerging benefits (paragraph 1.6f).

Main findings: summary

1.9. When we began this phase of the evaluation in May 2008, four primary care trusts (PCTs) were actively involved in the SCR programme. About 150,000 SCRs had been created; 600,000 patients had been sent a letter informing them of the SCR programme, and 0.81% had formally opted out. About half these patients had also been informed of HealthSpace. About 200 patients had completed registration for an advanced HealthSpace account through which they could access their SCR.

1.10. As of 1st March 2010, 50 of 152 PCTs in England had begun to write to patients and 16 had begun to create SCRs. 8,853,358 people had been mailed about the SCR and 14,505 (0.65%) had opted out. 201 GP practices had 'gone live' (uploaded patient data to create SCRs). 1,243,911 SCRs existed and 14,266 had been accessed. 25 settings had achieved 'technical go-live' (i.e. had all technical links in place to use SCRs in clinical care). In settings using the Adastra interface (GP out-of-hours and walk-in centres), SCRs were being accessed in approximately 4% of all encounters and 22% of those in which a SCR was available. SCR accesses varied considerably depending on the setting, type of clinician, experience of clinician, nature of encounter and time of day. According to updates supplied by CFH, fewer than 30 SCRs per week appeared to be being accessed in secondary care settings across the country. Fourteen PCTs were participating in the HealthSpace programme but activity in most of these was described as at an early stage. Approximately 110,000 people had opened a basic HealthSpace account and 2219 had activated an advanced HealthSpace account.

1.11. Bearing in mind the caveat in paragraph 1.4, evidence that the SCR programme had so far achieved the benefits set out in paragraph 1.2 was limited. Specifically:

a. There was evidence of improved quality in some consultations, particularly those which involved medication decisions;
b. There was no direct evidence of safer care but findings were consistent with the conclusion that the SCR may reduce rare but important medication errors;
c. There was no consistent association between use of the SCR and consultation length;
d. There was evidence that the SCR was particularly useful in patients unable to communicate or advocate for themselves;
e. There was no evidence that use of the SCR was associated with reduction in onward referral;
f. Impact of the SCR on patient satisfaction was impossible to assess.

1.12. Bearing in mind the caveat in paragraph 1.4, in relation to HealthSpace:

a. There was no evidence to date of improved personalisation of care;
b. There was no evidence to date of increased patient empowerment or increased ability to manage long term conditions;
c. We did not find any patients who had used HealthSpace to input to the data quality process, so the anticipated benefits of improved accountability, quality improvement and safety as a result of such input were impossible to assess;
d. We had detected no reports of reduced NHS costs, though assessing such costs was beyond the scope of our evaluation;
e. There was no evidence to date of improved health literacy in patients as a result of using HealthSpace;
f. Few practices or patients had yet used Communicator.

Main findings: national level (Section 4, 5.5, 5.6 and 5.7)

1.13. The period May 2008 to February 2010 was characterised by a number of key developments at national level:

a. De facto responsibility for implementing the NPfIT shifted from CFH to the Strategic Health Authorities (SHAs), reflecting a statutory change in April 2007 that the NPfIT would become "locally owned and delivered". NHS organisations were encouraged to maximise creation of SCRs from GP-held records, promote use of these records in provider organisations and document locally-relevant benefits. Tools and resources were made available and National Implementation Managers appointed to support local business process development;
b. As a response to findings reported in our Year 1 evaluation, a change in the consent model was introduced such that clinicians were required to ask a patient's consent to access their SCR at the point of care. Largely as a result of this, support from professional bodies (especially the British Medical Association) for the SCR increased, though some concerns remained;
c. Some changes to contracts with IT suppliers were necessary to incorporate requirements that had not been fully anticipated at the outset of the programme. Some informants described these changes as costly;
d. CFH produced an internal report on the relatively low uptake and use of the SCR, particularly in secondary care settings. This report flagged a number of factors influencing use, including low numbers of SCRs created to date, complexity of implementation plans, perceptions about data quality and the practicalities of information governance measures;
e. Civil liberties groups continued to question the SCR programme;
f. The UK economy went into recession and public-sector services came to be characterised by growing uncertainty and a perception by NHS staff that financial controls were being tightened. The work of CFH became mainstreamed within the DoH in a new Health Informatics Directorate. Resources across the health economy for supporting NPfIT-related work diminished. Political parties began to prepare for a general election.

1.14. The perspective of commercial IT suppliers over this period can be summarised as follows:

a. British Telecommunications PLC (BT) produced and maintained the Spine under contract to the DoH and viewed the SCR programme as a component of a much larger contract. Some BT staff felt that the original specification had been set in board-level meetings where insufficient attention had been paid to the perspective of front-line users, though we were asked to note that this was a personal subjective view which did not represent the corporate view of BT;
b. The core business of GP system (GPSoC) suppliers was supporting local GP-held records. They perceived limited demand from their customers for the SCR but participated in the programme [i] to meet anticipated minimal specification requirements for continuing contracts to supply GP practices; [ii] to remain competitive in this niche market; and [iii] because positive relations with CFH were seen as important generally. Small size and competing commercial priorities limited the ability of some suppliers to deliver SCR functionality within the tight timeframes set out in business plans and respond to changes to specification;
c. In contrast, the main supplier of software to the GP out-of-hours service (Adastra) perceived high demand from their customers for a product that would enable them to view data from local GP records and saw the development of SCR functionality as a welcome part of their core business;
d. Small IT suppliers tended to have a close and responsive relationship with their customers and understood the 'workaday world' into which their products were

being introduced. Some supplier informants felt that CFH staff did not fully understand clinical work in primary and unscheduled care and that deadlines set for delivery of technical solutions were unrealistic and politically driven.

Main findings: NHS organisations (Sections 5.1 to 5.4)

1.15. During this period, participating SHAs and PCTs expected significant benefits from the SCR and sought to put measures in place to realise these. Strategic, technical and operational challenges which staff in these organisations reported during local implementation included:

a. NHS organisations struggled with multiple competing policy directives and a limited budget. The SCR and HealthSpace had a relatively low strategic priority, at least in the early days of these programmes;
b. Official accountabilities notwithstanding, there was a perceived lack of clarity on the division of responsibility between national and local parts of the programme and a feeling by some senior SHA staff that information held centrally by CFH (for example in relation to delays with software suppliers) was not being shared;
c. CFH's expectation that SHAs could control and monitor the performance of PCTs in 'deploying' the SCR was perceived to be unrealistic. Local managers were surprised at the immaturity of the technologies and business processes at the outset of the national roll-out and some felt underconfident to take this complex programme of work forward;
d. Delays in provision of technical solutions from GPSoC suppliers led to slippage in go-live dates for GP practices and a concomitant loss of local morale and motivation. Over 40% of all GP practices were using a system that was compliant in theory with SCR systems but which encountered significant 'bugs' (see Section 8.6) when go-lives were attempted, necessitating manual workarounds for what was intended to be an automated upload, though for some systems uploads were occurring more smoothly by the end of the evaluation period. A further 15% of GP practices (over 30% in some PCTs) were using systems that were unlikely ever to be compliant with the SCR;
e. The programmes were associated with unanticipated administrative workload, for example in relation to information governance measures to support secure access to the Spine (e.g. issuing smart cards for a highly mobile group of junior clinicians), investigate unauthorised accesses to the SCR (via a system of role based access controls, technical alerts and paper reports) and respond to patient queries;
f. Local Clinical Leads (12 sessional GPs and one nurse), overseen and supported by the National Clinical Directorate, attempted to engage their fellow clinicians and troubleshoot local issues, with differing success in different localities;
g. Implementation of the SCR programme occurred more rapidly in some localities than others. Where rapid progress occurred, it was associated with a positive socio-technical context for introducing the SCR: alignment of national and local policy goals; tension for change in out-of-hours services; top management buy-in; competent and enthusiastic middle management; strong local clinical engagement; absence of powerful opponents to the programme; close links with a key IT supplier and favourable technical capacity (e.g. high use of SCR-compliant GP systems).

Main findings: use and non-use of the SCR at the clinical front line (Sections 6 and 7)

1.16. In relation to use of SCRs by clinicians in unscheduled care settings, most of which were in a primary care setting:

a. We observed cases in which the SCR appeared to add value in the out-of-hours consultation, especially by informing medication decisions in patients who had been prescribed multiple medications and were unsure what these were. We also observed many cases in which a patient's SCR was not available but *might* have added value had it existed and had it contained the data needed for a key clinical decision;
b. We observed few cases in which the presence of the SCR unequivocally made care safer, or where care was unsafe in the absence of the SCR. This seemed to be because doctors, nurses and pharmacists tended to err on the side of caution. They took additional safety measures if key data were not available and they referred many patients on to the next step in the system 'just in case' whether SCR-held data were available to them or not;
c. When dealing with complex cases, health professionals sometimes found it stressful and challenging to make decisions in the absence of reliable data on medication and allergies. In such circumstances, the clinician expressed more confidence in their decision and described the consultation as "easier" when the SCR was available, even when the information on it did not change that decision;
d. Analysis of a large quantitative dataset of clinical encounters in out-of-hours settings showed that use of the SCR was significantly more common amongst experienced regular clinicians than occasional staff, in marker conditions where a drug or allergy history was likely to be important, and in cases where the patient had more than one diagnosis. SCRs were less likely to be accessed in the elderly (a finding which we could not explain) and in the early hours of the morning. However, most variation in SCR use remained unexplained even when these and other demographic and diagnostic variables were taken into account. There was no consistent association between use of the SCR and consultation length;
e. Qualitative data suggested that where the information held on the SCR was poorly matched with the scope of practice of the clinician (e.g. when a complex medication list was viewed by a nurse without senior-level prescribing training), the SCR appeared to reduce rather than increase clinician confidence and increase rather than reduce consultation length;
f. We encountered no examples of SCR use leading to a change in onward referral within the local health community, nor of a patient without a SCR whose onward referral decision was likely to have been different had a SCR been present;
g. We found it impossible to assess whether patients were more satisfied as a result of their SCR being present because satisfaction was a function of the consultation as a whole, not of the presence or absence of the SCR.

1.17. The above points resonated with findings from other data sources set out in paragraph 1.8. Thus, in contrast to expectations expressed by many stakeholders that the SCR would bring clear, easily defined and readily measurable benefits, we found that when benefits occurred, they were subtle, hard to articulate and difficult to isolate out from other aspects of the consultation. However, because it is rare for patients to encounter serious harm (e.g. from medication errors) in the primary care setting and the SCR was little used in any other setting, our findings do not exclude a significant positive impact of the SCR on patient safety.

1.18. Our findings indicated that like other medical records, SCRs sometimes contained incomplete or inaccurate data. Our study was not designed to quantify the prevalence of these. In particular, we observed cases in which:

a. The patient was taking medication which was not listed on the SCR (e.g. obtained from pharmacies, unscheduled care settings, the private sector, a relative's medication, a stockpiled supply of past drugs, or abroad);
b. The SCR listed 'current' medication which the patient was not taking;

c. The SCR indicated allergies or adverse reactions which the patient probably did not have;
d. The SCR failed to indicate allergies or adverse reactions which the patient probably did have.

1.19. Clinicians working in unscheduled care drew eclectically on multiple data sources – including the patient, electronic and paper records, and their own observations and measurements. When these data sources conflicted, they made a contextualised judgment about two things: (a) which source was most likely to be reliable and (b) the level of residual uncertainty in the case. We did not see any cases where incomplete or inaccurate data on the SCR led to harm or risk of harm to the patient – precisely because clinicians did *not* view the SCR as the sole source of reliable data.

1.20. When the SCR was not accessed in an unscheduled care consultation, reasons were sometimes multiple and complex, and included both social and technical factors. Examples of reasons for the SCR not being available or accessed included:

a. Information held on the SCR was not needed (most commonly because the patient had a minor illness and/or sought something other than a clinical decision e.g. reassurance, certification), so the clinician did not check if one was available;
b. Information held on the SCR was reliably provided by some other source (most commonly the patient or carer);
c. The patient did not have a SCR (most commonly because they were registered with a GP practice which was not participating or had yet to go live);
d. The patient's SCR was not available for technical reasons (e.g. temporary loss of the organisation's connection to the Spine, lack of access to a computer terminal);
e. The patient's SCR was not available for human reasons such as patient not identified on the Personal Demographic Service of the Spine (e.g. through mis-spelling of name); SCR use not compatible with organisational routines and micro-practices; staff member not trained, not issued with smart card, not authorised, not motivated, not encouraged or supported by seniors or overly concerned about information governance issues (e.g. fear of triggering an 'alert').

Main findings: mobile SCR (Section 7)

1.21. In a pilot study supported by an independent IT supplier in which district nurses were lent portable digital assistant (PDA) devices to access the SCRs of patients they visited on their rounds, initial technical and operational challenges were overcome for the duration of the pilot. Overall, the nurses found PDAs useful and many accessed SCRs regularly, though they would have liked more clinical information on the records. The PDAs were recalled by the supplier and subsequent negotiations centred on the cost of supplying the devices and who would meet these costs.

Wicked problems (Section 8)

1.22. A number of 'wicked' (pervasive, seemingly insoluble) problems became recurring agenda items in national and/or local meetings. These included:

a. Content and scope of the SCR. In particular, the task of defining a standard 'minimum dataset', 'enrichment dataset' and 'exclusion dataset' proved more difficult than originally anticipated;
b. Data quality. In particular, there was a tension between setting a high standard for a GP practice to be allowed to join the programme (hence SCRs would be more likely to be complete, accurate and trusted by clinicians) or lowering this

standard so as to increase the overall number of records, thus achieving critical mass and a higher 'hit rate';

c. The consent model. In particular, some front-line staff were reluctant to ask consent to view the SCR at the point of care because they saw this as unworkable, inappropriate or stressful;
d. Information governance. In particular, fears about possible security loopholes tended to generate expensive and time-consuming technical fixes and some staff perceived the system of alerts designed to pick up rare incidents of malicious access as cumbersome, bureaucratic and intrusive;
e. "Technical" problems. In reality, these often had social, political and legal elements as well; and
f. Children. In particular, questions of consent and information governance were raised by cases of 'at risk' children whose parents may seek to opt out on their behalf and the question of whether and how the SCR might be used to support child protection work;
g. Training. In particular, standardised, topic-based packages delivered predominantly via methods which did not involve active, on-the-job learning had limited potential to equip staff for the complex, situated and unpredictable challenges associated with delivering the programmes.

1.23. Wicked problems had a number of common characteristics:

a. They spanned the different 'worlds' of different stakeholder groups (paragraph 1.31), which brought different assumptions and values;
b. They involved a tension between different philosophical models of reality ('hard', rationalistic, factual versus 'soft', contextualised, interpretive);
c. They tended to include a claim on contested resources (i.e. not everyone agreed that money or time should be spent on them);
d. They were vulnerable to multiple external influences, some of which were not under the control of those charged with 'fixing' them;
e. They had complex interdependencies with other problems and issues in the programme; and
f. They produced unanticipated ramifications elsewhere in the system.

Main findings: HealthSpace (Section 9)

1.24. Fewer people registered for HealthSpace during the period of this evaluation than early strategy documents had predicted. Explanations for this included:

a. The SCR and HealthSpace programmes, originally linked at policy level, were later uncoupled both nationally and locally. Funding for HealthSpace moved from the NPfIT to the Darzi Next Stage Review stream, and many PCTs decided to address the SCR roll-out first and then (at a later date) invite patients to register for HealthSpace to view their SCR;
b. The initial version of HealthSpace was seen as 'clunky' and its functionality as limited;
c. A proposal for HealthSpace Extension with greatly increased functionality was initially rejected for funding and a scaled-down version based on a more recent survey of what potential users wanted only gained funding in January 2010; and
d. The registration process for HealthSpace was complex and a planned technical solution to allow online registration for advanced accounts had not yet become available.

1.25. In our study of the use and non-use of HealthSpace by patients, very few people who had registered for a HealthSpace account were willing to be interviewed. The main reason for declining appeared to be that they were not actively using the technology

and not interested in saying why this was. HealthSpace users interviewed found the current release of the technology of limited value; some had high hopes for future enhancements in functionality. One informant described the 'sleeping gym membership' phenomenon: registering for HealthSpace, accessing it once, then losing interest. Our study was not designed to quantify this phenomenon.

1.26. Ethnographic observation of a sample of people with diabetes and other long term conditions revealed insights about how HealthSpace may or may not help with the lived reality of chronic illness. In particular:

a. Some people appeared to lack the health literacy or IT literacy required to use a technology-based health organiser. Others were either not motivated to reflect on the progress of their condition or felt that this was a task for their doctor or nurse;
b. Some had no access to computers or saw them as serving other purposes in their lives (games, shopping, social networking);
c. Some were already using or exploring other ways of documenting and monitoring their condition e.g. paper (e.g. diabetes diary), bespoke software (Excel spreadsheet), or downloads for digital personal organisers (iPhone 'apps') and found these more fit for purpose than HealthSpace;
d. Many patients' needs were not primarily for codified data (e.g. blood glucose levels) but for practical knowledge of how to live with their condition and for emotional support. They tended to get this from other people (e.g. relatives, local diabetes support group, Facebook);
e. Some patients were constrained by poverty, an adverse physical environment (e.g. poor housing, overcrowding), major family stress, or serious disabilities related or unrelated to their condition (e.g. depression, stroke). Monitoring and managing their long term condition competed with these other problems for emotional and material resources and was rarely top of the priority list.

1.27. Attempts to introduce HealthSpace Communicator in three pilot practices produced examples of patients whose access to their GP, overall care and satisfaction appeared to be significantly enhanced by this technology, but such cases were rare. Even in these highly selected volunteer practices, and especially more widely, questions remain about the acceptability of Communicator to patients and staff and how its use could be aligned with the culture and routines of general practice.

1.28. Attempts in one locality to link an integrated record scheme for long term conditions (supported by an independent IT supplier and already in use between primary and secondary care) with patient access to records via HealthSpace met operational difficulties. Enthusiasm from patients, clinicians, the PCT and the supplier of 'middleware' was high and much work was undertaken by all parties. But challenges relating to information governance and complex commercial relationships had not been overcome by the time this report was submitted.

Analysis (Section 10)

1.29. The most striking overall characteristic of the SCR and HealthSpace programmes was their scale and complexity. They can be thought of as emerging from a heterogeneous socio-technical network with multiple interlocking sub-networks:

a. The design network: professional advisers, software developers (based variously in CFH, commercial IT companies and academic institutions), and a large and complex technical infrastructure;

b. The implementation network: civil servants, policymakers, national and local managers, clinical leads, suppliers, trainers and front-line NHS staff, as well as those who sought to 'resist' the implementation in different sectors;
c. The governance network: professional, legal and regulatory bodies; technical security features and the CFH staff who designed and built them; security testing contractors; business processes, tools, and systems that supported information governance activity; and individuals such as Caldicott Guardians and privacy officers;
d. The front-line user network: NHS clinicians, local administrators and call handlers, 'front end' software, terminals and smart card readers, patients using HealthSpace and the staff and systems who supported registration; and
e. The evaluation network: different groupings who deliberated in a highly contested space on what counted as 'success' in the programmes and how this should be measured, including policymakers and business managers who constructed the 'benefits realisation' case; teams and systems involved in in-house monitoring; official bodies such as the National Audit Office; the media and lobbyists who made claims and counter-claims about the justification and progress of the programmes; communications staff and systems within CFH; patients (whose healthcare experience was intended to improve); and our own team.

1.30. During this evaluation period, this complex socio-technical network was dynamic and unstable. At any time point, there was a particular alignment of people who were developing and implementing the technologies, using them (or not), training and supporting others to use them (or not), monitoring the performance and security of the system with a greater or lesser degree of success, and debating whether the programmes were 'on track', ethically justified and so on. Sometimes the technologies 'worked' in particular settings, and at other times they did not 'work' – either because particular technical components of the network failed (or had never been put in place), or because people in the network *chose* to behave in particular ways (e.g. because they felt ethically compelled to do so) or were *prevented* (socially or materially) from behaving as they would have wished to. In some parts of the programme, there appeared to be an overall trend towards stability of the network, but other parts are currently characterised by continuing instability.

1.31. The SCR and HealthSpace programmes spanned a number of different 'worlds' – political, clinical, technical, commercial, academic – with different institutional logics, as well as the personal world of the patient.

a. In the political world, the programmes were an exercise in modernising the NHS by delivering measurable benefits to patients and taxpayers;
b. In the clinical world, they were an initiative to improve the quality of care in an area (unscheduled care) where concerns had been raised about standards;
c. In the technical world, they were a software development project for 'use cases' characterised by unpredictability and a high degree of exceptionality;
d. In the commercial world, they represented (for some but not all ICT suppliers) relatively high-risk but potentially high-revenue business contracts;
e. In the academic world, they were complex case studies which demanded critical analysis through multiple disciplinary lenses including informatics, biomedicine, psychology, sociology and political science;
f. In the personal world, they were a potential encroachment (for good or ill) of the system into the lifeworld of the patient.

1.32. Differences in norms, values, priorities and ways of working between these six worlds, and imperfect attempts to bridge these differences, accounted for much of the instability in the socio-technical network – and this in turn explained many of the

challenges and frictions encountered as the complex collaborative tasks of design, implementation, governance, front-line use and evaluation were pursued.

1.33. The main organisations involved in the programmes each occupied one or more of these different institutional worlds. For example:

a. CFH's activity spanned political, technical and commercial worlds. Its activities were closely aligned with the prevailing government policy of the new public management, addressed via the development, justification and implementation of robust business models for public-sector spending. CFH's core business was the procurement and deployment of IT solutions on behalf of the NHS. At the time of this evaluation CFH's work on the SCR appeared to be well resourced and the implementation team could respond to problems by allocating staff and money to address them;
b. NHS provider organisations operated largely in the clinical world where 'business processes' and training for anything other than direct patient care tended to be given relatively low priority. Staff interviewed in these organisations perceived that there were severe and worsening constraints on resources and staff time;
c. IT suppliers operated in the commercial and technical worlds and were strongly customer-oriented;
d. Professional organisations occupied both the clinical world (in relation to professional standards and patient care) and the political world (in relation to clinicians' workload and liabilities).

1.34. A prominent finding in this study was the large amount of *work* involved in the SCR and HealthSpace programmes, the difficulty and complexity of this work, and its critical dependence on the qualities and capability of particular people. The numerous individuals involved in these programmes occupied disparate worlds, brought different values and spoke different 'languages'. Those who proved most pivotal held boundary roles between different organisations and sectors and managed to align – to some extent at least – the complex and competing institutional logics which characterised the programmes. They achieved this by engaging actively in what previous authors have called 'translation', which involves four stages:

a. Problem construction: defining a problem for which the SCR and/or HealthSpace offered a solution;
b. Selling the idea: getting others to accept this problem-solution link;
c. Enrolment: defining key roles and practices in the socio-technical network; and
d. Mobilisation: engaging others in fulfilling the roles, undertaking the practices and linking with others in the network.

1.35. A number of key boundary roles were apparent. For example:

a. National Clinical Directors tended to be well connected across all or most of the clinical, political, commercial and technical worlds. Their translation activities included influencing national policymaking groups within and beyond the NPfIT, negotiating with suppliers, engaging and mobilising professional bodies and attempting to secure funding streams to support new workstreams;
b. National Implementation Managers interfaced between CFH and managers in NHS organisations. They attempted to socialise the latter into the business processes and reporting structures required by CFH, and (equally importantly) conveyed the world of cash-limited, clinically-oriented NHS organisations to central CFH staff;
c. Local Clinical Leads' translation challenge was getting the SCR and HealthSpace on the agenda in local decision-making groups. Their efforts tended to be more

effective when their connections in the political world (e.g. PCT, Local Medical Committee) were strong.

1.36. Towards the end of the period we were evaluating, there was evidence of a more mature and responsive relationship between CFH staff and front-line implementation staff, born of a developing understanding of one another's 'worlds'. Relationships between CFH staff and GP system suppliers also appeared to have matured for similar reasons. We note these changes with cautious optimism.

1.37. Implementation of the technologies depended crucially on front-line NHS staff, who brought various beliefs, values, meaning-systems and motives to their organisational roles ('normative' influences). Their actions were shaped and constrained by such things as job descriptions, access privileges and the functionality and limitations of technologies ('causal' influences). Qualitative case studies of micro-level incidents and encounters (Section 10.5) showed that relatively small differences in normative and causal influences on individuals, along with the potentialities and constraints of the technologies, sometimes explained wide variations in actions and outcomes.

1.38. The SCR and HealthSpace technologies contained a number of inscribed assumptions about the nature of illness and the behaviour of patients and staff. For example, inscribed in the SCR was the assumption that GP practice staff would enter all key data in coded fields on the local record. The 'permission to view' screen inscribed powerful institutional messages about autonomy, trust, surveillance and performance management. Inscribed in the HealthSpace technology was the assumption that patients would be capable and motivated to monitor and manage their long term condition using biomarkers such as weight, blood pressure and blood test results. Mismatches between these inscribed assumptions and the reality of clinical work or living with illness explained much of the non-adoption, partial adoption and abandonment of these technologies at the level of the individual user.

Discussion (Section 11)

1.39. The question of how to measure success in these programmes was contested. We documented 28 different metrics used for the SCR programme (Table 11.1) and 14 for the HealthSpace programme (Table 11.2), each of which was given different significance by different stakeholder groups.[A]

1.40. At the outset, stakeholders from all 'worlds' appear to have shared a number of expectations of the material and technical properties of the SCR and HealthSpace technologies (e.g. many had imagined that the SCR would be near-universally accessible to staff and patients, that it would offer complete and accurate information and that it would 'work' with minimal maintenance effort). Given these unrealistic expectations, the first releases of the technologies were destined to disappoint: they were perceived as difficult to access, 'clunky' to use, offering considerably less functionality than expected and raising numerous ongoing operational challenges.

1.41. The PRINCE 2 model used in efforts to implement the programmes (the current government standard, in which explicit goals and milestones are systematically defined, pursued and signed off) appeared to be an efficient business tool for managing the parts of the programme that could be controlled, isolated into discrete work packages and 'managed' in the conventional sense of the word. But the sheer

[A] In response to an earlier draft of this report, CFH pointed out that "low uptake of HealthSpace was not explained in terms of the required change of culture for patients, the need for a new clinical context, and the need to target it on those most likely to benefit once advanced accounts are widely available." See paragraph 3.3.13 of our main report for an explanation of how footnotes such as this came to be added.

complexity of the socio-technical network, its embeddedness in wider institutional structures and the fact that many risks were outside CFH's control meant that this linear approach was a poor fit in many parts of the programme, particularly the 'wicked problems' listed in paragraph 1.22.

1.42. The huge scale of the programmes inevitably brought increased complexity as well as a tension between 'national coordination' and 'local ownership'. The tension between standardisation (which helps stabilise the socio-technical network) and contingency (which reflects and responds to local needs and priorities) can never be resolved; rather, it must be actively and creatively managed – and this gets harder as the network gets bigger. The Law of Medical Information appears to apply: *"the further information has to be able to circulate (i.e. the more diverse contexts it has to be usable in), the more work is required to disentangle the information from the context of its production. The question that then becomes pertinent is; who has to do this work, and who reaps the benefits?"*.[14]

1.43. The scale of the SCR programme, along with the struggles of the Information Commissioner to apply data protection legislation in a way that keeps pace with technological innovation, has created new ambiguities about who now 'owns' patients' medical records, who is responsible for assuring the quality and confidentiality of the data on those records and in what circumstances consent should be asked for sharing these data.

1.44. Risks identified in early strategy documents had included the possibility of delays in the delivery of compliant GP systems, difficulty introducing new business processes in NHS organisations, technical problems (e.g. interoperability), inadequate administrative capacity in the NHS, "professional resistance", high public opt-out rate and low use at the clinical front line. Measures to mitigate these risks had been couched largely in terms of providing a clear scope and specification for the technologies, adjusting deployment schedules to align with delivery dates from different suppliers (commencing with the most compliant), ensuring sound business processes and "communication about the benefits and importance of the SCR".

1.45. Some risks in the programmes were thus identified at the outset and successfully mitigated. But a number of mission-critical risks could not be mitigated and/or were not identified or fully explored. The standard DoH approach of assessing options and risks by a highly formalised process of assigning quantitative scores to subjective perceptions about complex issues may have lent a spurious objectivity to the risk assessment process and diverted attention from systematic *qualitative* methods such as deliberation or defending one's ideas in front of an audience.

1.46. The fortunes of the SCR and HealthSpace programmes appeared to turn partly on the philosophical question *"Where is the wisdom we have lost in knowledge?"*. Many though not all senior stakeholders in CFH, the professions and the IT industry viewed knowledge as stable and discrete data items which could be extracted from their context, placed on the SCR and transmitted to new people and contexts while retaining meaning. An alternative perspective holds that much knowledge is tied to particular people, organisations, experiences and practices and is difficult if not impossible to extract from its context or the people who know it.

1.47. The extent to which context matters depends on the type of data. As data fields in the SCR expand from 'hard' (objective, relatively uncontestable, relatively context-free e.g. medication) to 'soft' (subjective, contestable, context-bound e.g. some clinical diagnoses), the quality and trustworthiness of SCR-held data could be jeopardised. Furthermore, the context-bound nature of much knowledge underpins a radical and important suggestion: that very large, centrally stored record systems, though

expected to bring increased clarity, transparency and trust, may actually lead to confusion, paradox, and loss of trust.[15]

1.48. The programmes' strong emphasis on the structured reporting and collation of quantitative, 'factual' data meant that other forms of knowledge (such as personal experience; knowledge of a particular NHS organisation, locality or individual; and intuitive or emotional knowledge) were given limited emphasis. The culture of delivering training in discrete topic-based packages focusing on standard processes, procedures and responses sometimes but not always prepared staff adequately to cope with the complex and unpredictable challenges associated with implementing and using the SCR.

1.49. Most criticisms of the SCR and HealthSpace programmes to date have been presented as technical ('wrong underlying design'), operational ('poor programme management') or economic ('poor value for money') issues, and solutions have tended to be couched in terms of better design, better business processes or tighter financial management. Our findings suggest that at least some of the problems encountered in the SCR and HealthSpace programmes to date are essentially philosophical. If that is the case, the urgent question for public debate is not "Why have most of the benefits of these technologies not yet been realised?" but "To what extent were these programmes built on an inadequate conceptualisation of what knowledge is, a privileging of facts over values, a failure openly to debate what is reasonable and an unrealistic expectation that a defined input would produce a predictable output in a complex system?".

Recommendations

1.50. As an academic team whose task was to illuminate rather than judge the SCR and HealthSpace programmes, and whose brief specifically excluded financial audit or developing and applying performance metrics, it is beyond our remit to pass definitive comment on the success of the programmes. We recommend that those who make such judgements consider the points below.

1.51. Some important high-level decisions have already been signed off (and others are pending) by the DoH, HM Treasury, the boards of major IT companies, professional bodies, patient organisations and lobbying groups. Questions have been asked at this macro level about the goals of the programmes; their cost in relation to anticipated or established benefits; the extent to which they are 'on track' (and the extent to which fixed milestones are appropriate or helpful); whether the contractual relationship between suppliers and the state is optimal; whether the 'database state' has encroached too far on individual privacy and who now 'owns' the medical record of an NHS patient. We hope that public debate on these questions will continue and will take account of the points raised in paragraphs 1.39 to 1.49 above.

1.52. There is another macro question which has so far attracted much less public debate, which relates to the role of the individual in looking after their own health and in improving health services. The HealthSpace programme was built on the assumption that a significant proportion of patients will have the motivation and capacity to 'self manage' their long term condition using this technology; that this will reduce costs to the NHS; and that patients' access to their SCR via HealthSpace will contribute substantially to improving data quality. Notwithstanding our comment in paragraph 1.4 above, the findings of this study to date – that few people are currently interested in using HealthSpace to manage their illness or access their SCR – suggest that it may be time to revisit all these assumptions. Deliberation on the future of the HealthSpace programme should take account of the availability of low-cost technologies for supporting self-management and the rapid pace of change in the

market for such technologies. It should also reconsider the logic behind the policy-level link between 'empowerment' and a state-run online records service.

1.53. In relation to NHS organisations, this study has shown unequivocally that the SCR is not a plug-in technology and its implementation should not be left to the IT department. Like many other components of the NPfIT, the SCR requires fundamental changes to systems, protocols, budget allocation and existing hardware and software – and also to organisational culture and ways of working. Adjustments will be required to the roles of health professionals and support staff; the competences and attitudes they need to fulfil those roles effectively; what staff are performance-managed on and how; the way they relate to patients; the way they handle information; and the way they share information with others both within and across organisations. We recommend that organisations who are contemplating becoming part of the SCR programme ensure early and active involvement of staff at all levels in discussions on these issues.

1.54. The SCR and HealthSpace programmes raise questions for individual clinicians who seek to behave ethically and in accordance with the core values of their profession. Until recently, the goals of high-quality personal care, accurate record-keeping and patient confidentiality were straightforward, uncontested and commensurable. The introduction of national electronic shared records and the patient's acknowledged right to choose what data (if any) are entered on those records and who may view them means that the values and principles which have guided the health professions for centuries now come with inherent tensions and paradoxes. We are impressed that professional bodies appear to have recognised that good clinical practice in the technological age is a complex and situated achievement which is informed but not determined by lists of frequently asked questions, and that their role is more to keep debate open than to produce final answers. We hope they continue to take this stance.

1.55. The NHS and professional bodies should consider the implications of this study for training and support of front-line staff. Our empirical data highlight the lack of predictability or universal solutions at the level of the fine-grained detail of the patient encounter. We have shown that front-line staff must take account of the emergent detail of *particular* situations when considering such things as how the consent model should be operationalised, how and with whom patient data should be shared and whether data can be trusted. These findings raise questions about the extent to which standard operating procedures can or should substitute for reflection, situational judgement and real-time consultation with colleagues. To the extent that these latter skills and approaches are considered important, it must also be recognised that there is a limit to how far they can be standardised.

1.56. The SCR is a rapidly evolving technology. The version we evaluated was 'Release 1', which comprised three relatively hard data fields uploaded from a single source for which the guardian of the source data was readily identifiable, the consent model clear (implicit consent to upload; explicit consent to view) and the main use case relatively well-defined, though we still found variability in how staff operationalised these concepts in practice. The SCR has already begun to include an 'enriched' dataset which covers much broader and softer data fields and for which both content and consent to upload are differently interpreted by different staff in different settings. On the horizon is 'Release 2' – a plan for various staff in various NHS and non-NHS organisations to enter various types of data onto the SCR for viewing by various other staff in various other contexts, for which consent will be sought and applied in various ways. Healthcare organisations from Strategic Health Authorities to singlehanded GP practices should take note that the many uncertainties implicit in the previous sentence do not lend themselves to resolution by high-level committees,

no matter how exalted and/or inclusive their membership. There is much further debate to be had at local level with attention to the detail of what the proposed extensions to the technology mean for *our organisation*, *our staff, these patients, taking account of these particular priorities, constraints and contingencies*.

1.57. The SCR and HealthSpace have important implications for each of us as citizens. We must all make (or live with the consequences of not making) a number of personal decisions – whether to 'opt in' or 'opt out' of the SCR; whether to seek a discussion about how our own SCR should be 'enriched'; whether to modify these decisions as the technology evolves (see previous paragraph); whether to seek access to our SCR through HealthSpace and whether and how to challenge entries we do not consider accurate. The findings of this study suggest that for most people, engaging with these questions is a better option than not engaging with them.

1.58. Advocates of those who lack full understanding or capacity must attempt to achieve the difficult tasks set out in the previous paragraph on someone else's behalf, sometimes in tragic and emotionally-charged circumstances. The advent of nationally shared records suggests a new and/or extended role for public-sector and third-sector advocacy organisations in supporting such individuals and informing policy. This role appears to be one that must evolve with careful attention to what happens to real people in real situations.

1.59. Finally, all those who care about and/or seek to influence these programmes should note that dialogue (or lack of it) occurs in the context of multiple conflicting worlds (political, clinical, technical, commercial, academic and personal – and probably others as well). Strong feelings, misunderstandings, conflicting values and competing priorities are to be expected – and we offer no magic recipe for resolving them. But we do offer an observation from three years' involvement with these complex programmes: greatest progress appeared to be made when key stakeholders came together in uneasy dialogue, speaking each other's languages imperfectly and trying to understand where others were coming from (a state which has been termed 'accommodation'[16]), even when the hoped-for consensus never materialised. As the NHS reflects on an uncertain future, we believe that the fortunes of these programmes will continue to depend on (among other things) efforts to bridge the deep cultural and institutional divides which have so far characterised the NPfIT.

2. Introduction

2.1. Background

2.1.1. This report deliberately does not begin at the beginning, since it describes Years 2 and 3 of a 3-year evaluation. Our Year 1 evaluation reports describe the background and early months of the Summary Care Record (SCR) May 2007 to April 2008 which are available to download (http://www.haps.bham.ac.uk/publichealth/cfhep/)[1;2]. We take up the story on 1st May 2008 and cover the period to 28th February 2010.

2.1.2. When we began this phase of the evaluation, four PCTs were actively involved in the SCR programme. Just over 150,000 SCRs had been created and just over 600,000 patients had been sent a letter informing them of the SCR, of whom 0.81% had formally opted out of having one. Staff were not routinely accessing patients' SCRs in clinical consultations. Since then, uploads to create SCRs from GP records have continued and accessing of SCRs has risen in some NHS organisations.

2.1.3. "I'm a disillusioned champion", one clinician told us in November 2009. This person had been an enthusiast for the SCR in one of the early adopter sites and provided some optimistic quotes in earlier interviews. He had devoted much time and energy to implementation efforts described in Section 5 of this report. But the SCR was still a long way from being 'business as usual' in the NHS organisation where he worked.

2.1.4. This interviewee's comments may not be representative of everyone involved, but they broadly reflect three general trends that emerged as the SCR and HealthSpace programmes unfolded in participating localities from early 2008 to early 2010.[17] First, implementation took much longer than originally planned. Second, it was perceived by front-line clinicians, project managers and IT support staff as a more difficult and complex task than they had initially anticipated. And third, the elusive 'tipping point' (at which momentum for change becomes unstoppable[18]) for both programmes was perceived by many as continuing to recede into the future.[B]

2.1.5. One disillusioned champion does not make a summer, especially when he – along with policymakers, professional leaders and politicians up to and including the Prime Minister – may have had an unrealistic view of the time and workload needed to pull off an IT programme of epic proportions in a fragmented public-sector bureaucracy. To say that the programme is proving hard work and has slipped behind schedule is not to say that it has 'failed'. With that caveat in mind, this report addresses the *delays and challenges* faced by the SCR and HealthSpace programmes rather than offering a definitive picture of the adoption and use of the technologies.

2.2. Healthcare, health policy and IT policy in the UK

2.2.1. This section outlines the prevailing social, political, economic and institutional context within which the SCR and HealthSpace programmes were unfolding locally and nationally between 2008 and early 2010. It may be of particular interest to readers

[B] The very notion of a 'tipping point' for a programme as complex as the SCR or HealthSpace is probably flawed because the term was developed to describe the acceleration in uptake of simple innovations for which the adoption decision is individual and based on social influence. But this metaphor was widely used in relation to the SCR and HealthSpace at both national and local level.

unfamiliar with the government and healthcare system in the UK. For additional background detail, see our earlier publications.[1;3;4]

2.2.2. The UK National Health Service (NHS) was established in 1948 by a socialist government keen to offer healthcare that was universal and free at the point of delivery. It is highly cost-constrained and fiercely defended by politicians from all parties, though it is also widely considered to be Fordist (i.e. offering a very basic service, without choice or personalisation), bureaucratic and in need of modernisation.[19;20]

2.2.3. Disease patterns in the UK have shifted in recent years from a predominance of acute (short-term) to chronic (long-term) illness. Much chronic illness (such as asthma, diabetes, or high blood pressure) is incurable and needs systematic proactive care achieved through registration, recall and regular review of patients – tasks which are made considerably easier by computerised databases and structured templates.[21] The dramatic increase in life expectancy that has occurred over the past 20 years has meant that the absolute numbers of individuals with multiple chronic illnesses ('comorbidity') and those taking multiple medications ('polypharmacy') are rising, with the concomitant risk of drug interactions and allergies.[22] Managing patients with long term conditions, and particularly elderly people with multiple conditions, requires an up-to-date list of their medications (some of which have typically been prescribed elsewhere) and allergies.

2.2.4. The NHS has a relatively well-developed primary care sector, which at the time of this evaluation was undergoing rapid change.[20;23;24] From 1948 to 2004, every GP principal had a personal list of registered patients and was responsible for providing reactive care (i.e. dealing with illnesses as they presented) for individuals and families as well as proactive care (i.e. prevention and check-ups) 24 hours a day, 365 days a year. This system of comprehensive, longitudinal care from a personal family doctor has begun to give way to a much more diverse health economy. Since 2004 NHS patients no longer register with an individual GP but with a practice, and GPs need no longer provide 24-hour care.[25] An increasing proportion of patients with primary care problems are being seen in A&E departments.[26] Unscheduled care encounters also occur with NHS call centres, nurse-led walk-in centres, GP out-of-hours clinics, community (district) nursing services, hospital outreach services, private-sector providers working under contract to the NHS, polyclinics, Internet-based advice and support services, self-care and peer support programmes and the voluntary sector. The development of effective communication systems to link different providers has lagged behind the emergence of the various new service models, leading to a perception of fragmented care and duplication of effort.[25;27]

2.2.5. There is a growing tendency for long term conditions to be managed via 'shared' or 'integrated' care between primary and secondary care and for patients to be discharged 'sicker and quicker' from hospital to community-based care.[5] Integration of records between primary and secondary care, and also between different primary care providers (e.g. between district nurses and GP practices) is widely advocated as one way of improving the coordination and reducing the risk to patients when NHS care is distributed across multiple professionals and organisations. [5;28]

2.2.6. The most vulnerable members of society – notably the poor, those with communication barriers, refugees and asylum seekers, the very young, the very old, the very sick and those with a 'dual diagnosis' in mental health and drug addiction – tend to be seen disproportionately in unscheduled care settings by unfamiliar clinicians and in the absence of high-quality records.[25;29-31] Shared electronic records in the NHS are believed to have potential to reduce health inequalities as well as raising overall standards of care in unscheduled settings.[32;33]

2.2.7. The structure of the English NHS and the way funding flows into it and circulates within it is complex and beyond the scope of this report. Briefly, the NHS has a strong national branding but its constituent parts are geographically dispersed, heterogeneous in culture, and to some extent forced to compete with each other for resources in what is known as the 'internal market'.[34] As one senior informant in this study put it, *"we don't actually have 'a national health service', we have lots of different NHS organisations, and they don't sing from the same hymn sheet"* (senior executive of public-sector organisation set up to support NHS innovation, NC01).[C]

2.2.8. Following several scandals about the quality and safety of clinical care in the late 1990s and early 2000s, there is now a strong culture of accountability, surveillance, regulation and performance management ("the new public management") in the NHS and an expectation that all aspects of clinical work will be audited and these data made public.[35;36] This culture is embodied at organisational level in the growing regulatory infrastructure such as the National Institute for Health and Clinical Excellence, National Patient Safety Agency and National Service Frameworks, and also at individual level in the behaviour of (and expectations placed on) NHS staff.[37 D]

2.2.9. Since its election in 1997, the UK government has pursued policies aimed at 'modernising' public services (by which is meant, broadly, increasing efficiency, integration, accountability, transparency and orientation to the needs of the service user).[40;41] Government viewed the development of large-scale IT systems, along with the provision of information to support the exercising of choice by empowered citizens, as essential tools for achieving the policy goal of 'modernisation'.[42;43]

2.2.10. A landmark report by Derek Wanless, *Securing Our Future Health*, published in 2002, considered why health outcomes in the UK were lower than those in comparable countries and concluded that *"we have achieved less because we have spent very much less and not spent it well"* (page vii).[44] As well as various efficiency measures (e.g. deploying nurses rather than doctors and healthcare assistants rather than nurses in certain roles), Wanless recommended a substantial increase in investment in the NHS and in particular the development of state-of-the-art integrated IT systems to increase quality and efficiency.

2.2.11. A series of policy documents produced by the Department of Health between 1998 and 2008 sought to centralise control over the specification, procurement, resource management, performance management and delivery of information and IT, while at the same time seeking to put patients at the centre and 'personalise' care.[9;20;32;45-48 E] Early policy documents during this period talked about a remotely accessible medical record; later ones talked about a remotely accessible *summary* record.

2.2.12. The NPfIT, described in detail in the next section, emerged during a period of positive economic growth in which there was high investment in public services. In particular, the NHS enjoyed a growth in funding of 7% in real terms per year (around £6 billion) between 1999 and 2009.[49] This decade was a time in which state investment – and, according to critics, state interference – in public sector services rose sharply (for example, the proportion of gross domestic product accounted for by government spending rose from 37% to 53% between 2000 and 2009).[50]

[C] The near-universal tendency to refer to the NHS in the singular using the definite article may have contributed to the widespread under-estimation of the diversity of requirements and nature of constraints in different organisations, departments and settings and the need for extensive local tailoring of systems discussed in Chapter 5.

[D] This reflects a wider trend towards what critical academics have called 'the audit society' – in which a claim to transparency underpins efforts by managers to make visible, document and standardise professional practice.[38;39]

[E] The extent to which 'centralisation' and 'personalisation' were conflicting and even mutually exclusive goals is addressed in Section 11.3.

2.2.13. Spending of additional funds allocated to the NHS in 2003-8 (said to be non-recurrent and intended to achieve a modernised NHS which would operate more efficiently thereafter) has been criticised by the Public Accounts Committee and independent commentators.[51-53] Much spending is said to have gone on senior doctors' salaries, management consultants, high-cost drugs and technologies that would benefit relatively few people, training programmes of questionable quality or relevance and information systems that have yet to deliver benefits. Official estimates of NHS productivity over this period showed a fall instead of the expected rise.[54]

2.2.14. The UK entered a deep economic recession in January 2009, and the period 2011-17 is anticipated to be a long and bitter winter for public services in general and the NHS in particular.[49] A five-year plan published in December 2009 emphasised "delivering high quality healthcare in a tough financial environment".[55] In late January 2010 the Chief Executive of the NHS, Sir David Nicholson, told NHS staff that they must save £15-£20 billion by 2014 while also improving the quality of care.[56] But as the Economist commented in an editorial published (coincidentally) the same day: *"The revival of the state is creating a series of fierce debates that will shape policymaking over the coming decades. Governments are beginning to cut public spending in an attempt to deal with surging deficits. [….] But pruning will be still more difficult than it has ever been before. Getting the public sector to do 'more with less' is harder after two decades of public-sector reforms."* [50]

2.2.15. In summary, the publication of this evaluation occurs at a critical social and political conjuncture. At the time of writing, the UK 2010 general election is imminent. Future policy decisions in relation to both the SCR and HealthSpace rest not only on the findings presented in this report but also on assessments being undertaken by others of the current and potential impact of these programmes (paragraph 3.1.3), the overall resource made available to the public sector, the priority assigned to investment in IT systems relative to other competing demands on an increasingly constrained public purse.

2.3. The National Programme for IT

2.3.1. The NPfIT is an initiative by the English DoH which aims to provide comprehensive, secure electronic patient records (EPRs) in both primary and secondary care – and, eventually, to integrate these various systems within and beyond the healthcare sector (e.g. with social care). It is large in scale and ambitious in scope. Projected costs are around £12.4 billion for the ten years to 2014.[F] It formally began in 2002[32] but it expanded substantially after the 2005 general election, in which the development and integration of NHS IT systems was a prominent campaign promise by the Labour government.

2.3.2. NHS Connecting for Health (CFH) is the DoH's delivery arm for central components of the NPfIT. CFH's structure, culture and ways of working were summarised in Section 3.2 of our earlier report.[1] Briefly, it is a large, hierarchical organisation whose work is characterised by detailed planning, tight monitoring, extensive documentation, frequent reporting and controlled approach to release of information.

[F] This included £3.4 billion for *"[centrally allocated] local NHS expenditure"*; and £8.3 billion for *"[locally devolved] local expenditure"*.[57] We understand that the total budget allocation for the SCR programme is currently [financial data deleted at the request of CFH], though we have not had access to detailed financial costs.[58]

2.3.3. CFH's original Director General negotiated contracts with several large commercial IT suppliers (Local Services Providers, LSPs) in 2003-4. Each LSP was contracted to be the sole provider of the main hardware and software products for secondary care across a large region of England. He is said to have driven hard bargains with the LSPs ("transferring the risk") and some subsequently pulled out of their contracts, leaving the programme dependent on two major suppliers – British Telecommunications PLC (BT), which was deploying its subcontractor Cerner's main product Millenium in the south of England, and Computer Sciences Corporation (CSC) which was deploying iSoft's Lorenzo system in the north.

2.3.4. The LSPs invested heavily in development of new products for the NHS and were tied into contracts with CFH which included a steep financial penalty for non-delivery. Relationships between CFH and LSPs were perceived by many stakeholders as far from stable in the period 2008-10; technical solutions were sometimes delayed and there appeared to be anxiety in some quarters about financial risk and uncertainty of outcome. Whilst the LSPs potentially stood to gain profits from NHS contracts, it was believed by some that they had underestimated the technical, social and institutional challenges of developing a workable, networked EPR system for the NHS.

2.3.5. Whilst the negotiation of LSP contracts centrally is said to have saved an estimated £4 billion in economies of scale for the NHS,[57] it is also said to have come at a heavy price in intangibles – especially in terms of the goodwill that had previously characterised relationships between IT suppliers and the NHS (in which, for example, helpdesk support and call-outs were provided at nominal or no cost and given fast-track status). Whilst the LSP contracts did not impact directly on the much smaller SCR and HealthSpace programmes, they may have had an indirect impact on the general ethos of commercial relationships within the NPfIT.

2.3.6. The goal of providing standardised, interoperable information systems in the NPfIT is complicated by the fragmented nature of the NHS and the presence of multiple system providers. For example, whilst a patient's SCR is 'hosted' on the central Spine which is provided under contract by BT, it is created and updated by means of local software in GP practices. GPs are not NHS employees but private contractors, and different practices use different software for their local records. Providers of software to GP practices had negotiated strategically important subcontracts with the LSPs to provide the 'GP end' of the NPfIT (TPP SystmOne to CSC and InPS Vision to BT). The GP suppliers' contract with CFH to provide software for local GP records ('GPSoC') is described in Section 5.5.

2.3.7. Formal responsibility for delivering the NPfIT officially transferred from CFH to the Strategic Health Authorities (SHAs) under the NPfIT Local Ownership Programme on 1st April 2007. The then Chief Executive of the NHS, Sir Ian Carruthers, wrote to SHA Chief Executives in August 2006 informing them that they would become the Senior Responsible Officers for the NPfIT in their regions and were required to appoint a Chief Information Officer (CIO) to lead on this work and support PCTs to develop capacity in this area.

2.3.8. A review of information needs and provision in the NHS, *The Informatics Review*, published in 2008, based on a survey of 1000 front-line clinicians and managers as well as an online consultation with service users, acknowledged delays in the implementation of the NPfIT. These were attributed to the scale and complexity of the programme, lack of decisive leadership, fragmented governance and reporting arrangements, poor co-ordination, skills shortages, delays in development of technical solutions, and low public trust in large-scale public-sector IT systems.[48] The report identified a number of priorities including:

a. Improving leadership and accountability at both national and local level;
b. Improving co-ordination, and in particular greater use of 'strategic' (centrally chosen) rather than 'ad-hoc' (locally chosen) systems;
c. Developing and enforcing standards for clinical coding (e.g. the SNOMED system) and data quality more generally;
d. Developing the informatics workforce and training all staff;
e. Reassuring the public about security and confidentiality of systems;
f. Tightening up governance on procurement of systems;
g. Sharing information on potential interim solutions (i.e. locally funded systems that could be used while definitive NPfIT components are developed);
h. Developing and implementing approaches for using information systems to analyse and monitor clinical performance;
i. Developing information for patients and the public via NHS Choices (an online information portal), NHS Direct (telephone advice service for patients), HealthSpace (paragraph 3.4.8) and (eventually) an information portal on social care services, and ensuring that these are all integrated to provide consistent information and avoid duplication.

2.3.9. The problems of slippage, lack of return on implementation effort and general loss of momentum alluded to in Section 2.1 were perceived by some stakeholders to be occurring in relation to the NPfIT more widely. In March 2009, for example, the Public Accounts Committee reported that the NPfIT was four years behind schedule and identified three main reasons for this: the technically ambitious nature and huge scale of the programme; the need to restore flagging public confidence in relation to security and consent issues; and the fact that suppliers were having to do more to customise their products for individual NHS organisations than initially envisaged.[59]

2.3.10. In 2009 it was agreed that there would be a much closer relationship with the Department of Health Informatics Directorate and CFH, thereby ensuring that CFH's work was more closely aligned with other strategies and projects within the DoH.

2.3.11. In summary, the NPfIT is a large, ambitious and centrally driven programme which is closely linked to government and Department of Health policy. It involves complex contracting arrangements with multiple different commercial suppliers. The SCR and HealthSpace programmes, while large in absolute terms, are relatively small in relation to the wider NPfIT. The NPfIT has up to now been run by a semi-autonomous body but may shortly be more mainstreamed within the DoH and linked more explicitly to other policy streams.

2.4. The Summary Care Record and HealthSpace technologies

2.4.1. Software is, by nature, an evolving technology. The SCR and HealthSpace have already been through a number of releases, and more are planned. At any point in the evaluation, we were considering multiple versions of the technologies – the version currently in use and the various versions that are being scoped, developed and tested.[G] This section sets out the key material properties of these technologies and describes the main functionality of current releases and those in development.

2.4.2. The SCR is an electronic summary of key health data, currently drawn from a patient's GP-held electronic record and accessible over a secure Internet connection

[G] A key finding of this study was a mismatch between what the technologies could currently do and what people believed that they would at some stage be able to do. Design is, by nature "the science of the artificial" and hence some degree of mismatch between what is and what could be was to be expected. We discuss this further in Section 11.1.

by authorised healthcare staff. In its original form (i.e. almost all the 150,000 SCRs created in early adopter sites by mid 2008), it was limited to very basic ('level 1' or 'Release 1') information: medication, allergies and adverse reactions from the GP-held local detailed record (LDR). Some early adopter GPs participated in a further pilot in which they created 'enriched' SCRs on selected patients by adding additional material such as main diagnoses – either manually by dragging and dropping or via an automated upload of key data fields on targeted groups (e.g. diabetes). All level 1 information is added by the patient's GP practice.

2.4.3. Future plans for the SCR (see Section 4.1) include greatly expanded content added by people other than the patient's own GP. The exact nature of this 'level 2' content is the focus of continuing discussion. It is expected to comprise A&E reports, discharge summaries, outpatient letters, encounter data from out-of-hours providers and possibly pathology and/or radiology reports. In addition, it was originally hoped that patients accessing their SCR via HealthSpace would be able to add material (e.g. Word documents) to it. This is shown diagrammatically in Figure 2.1.

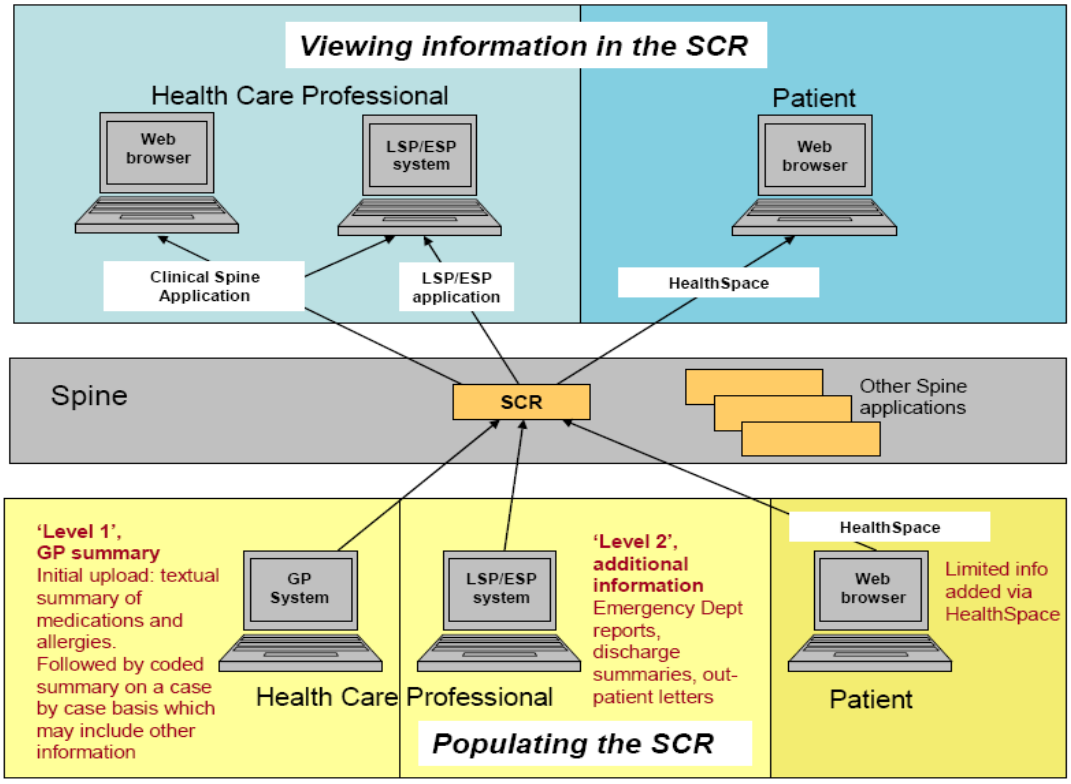

Figure 2.1: Simplified diagram of main components of the Summary Care Record as set out in Full Business Case by CFH (February 2008, page 7)[60 H]

2.4.4. The SCR was originally intended to be used in unscheduled care settings where little or no other information about the patient was available (for example when there was loss of consciousness, confusion or communication difficulties; or when the person was away from home and did not know what medication they were on). Designers and policymakers saw potential for extending the content of the SCR further – for example by creating the facility for staff in walk-in centres, out-of-hours centres, ambulance service and community services to add details of encounters or tests. However, this additional content was acknowledged by CFH to be speculative at the time this evaluation was being undertaken (see Section 4.1). The content and scope

[H] A later version of the Full Business Case for the SCR, dated September 2009, omits the HealthSpace component. See footnote to paragraph 4.1.3.

of the SCR are considered further in Section 8.2. See also a CFH document www.connectingforhealth.nhs.uk/systemsandservices/scr/documents/scrscopel.pdf.

2.4.5. The SCR is hosted on the Spine. As Figure 2.1 shows, health professionals may view it either directly through a web browser using the Clinical Spine Application (CSA) or (more recently) SCR application (SCRa) or indirectly via software that is integrated into other provider systems. For example, a nurse working in a walk-in clinic would generally use Adastra software to log her consultations. The Adastra software offers direct access to the SCR via a 'tab' which the nurse can click within the patient's Adastra record (see Figure 5.1, paragraph 5.6.7).

2.4.6. SCRs are created in batches by uploading level 1 information from a GP system onto the Spine. This upload is known as the 'go-live'. As Chapter 5 illustrates, it is both technically and operationally complex. Information on SCRs is updated regularly.

2.4.7. The SCR is protected by strict access controls in that nobody may access a patient's SCR unless they have what is called a 'legitimate relationship' with that patient. Access controls are explained further in Section 8.5.

2.4.8. HealthSpace (www.healthspace.nhs.uk) is a web-accessible service whereby NHS patients may store personal health data and link to the SCR and other distributed record services such as Choose and Book. It is an example of a personal health organiser – a rapidly emerging genre of technologies for supporting self-management of illness and risk factors.

2.4.9. The release we evaluated had limited functionality. It comprised a personal health organiser, calendar, address book, and access to SCR (via an 'advanced' account) for those whose GPs were participating in the programme at the time. In CFH's words: *"The [then] current service is limited by its lack of connectivity to wider NHS systems and lack of content and 'intelligence' in the product itself. Users must enter data themselves, but cannot share it more widely. Nor can they access information in other systems or carry out the kind of tasks that transactional online services commonly offer."* (specification for HealthSpace Extension, page 8).[61]

2.4.10. An advanced HealthSpace account allows the patient to view 'level 1' information (i.e. material uploaded from their GP-held record to the SCR). It does not allow viewing of 'level 2' material added from other sites.

2.4.11. Security and access for HealthSpace were complex. At the time this evaluation was being undertaken, a basic account could be created via an online registration and authentication process based on a user ID and password. Advanced accounts required completion of a complex registration process including personal attendance at a PCT front office or GP surgery (see paragraph 9.2.3).

2.4.12. Communicator is a secure messaging service within HealthSpace through which patients may send and receive email-type messages to a named member of staff (most usually their GP). It is described in Section 9.4.

2.4.13. HealthSpace may, in theory, interface with other medical record systems in use in the NHS – for example, in Section 9.5 we describe efforts to use the HealthSpace interface to allow patients with long term conditions access to a record that was already being shared between primary and secondary care.

2.5. Our Year 1 evaluation and stakeholders' responses

2.5.1. When our Year 1 evaluation reports appeared in 2008,[1;2] many people expressed surprise at their format and scope. We included quantitative data such as number of SCRs created to date but our analysis was mainly qualitative, focusing on contextual and human factors which helped explain the mixed fortunes of the programmes in four early adopter Primary Care Trusts (PCTs). As one senior stakeholder expressed it, *"We were expecting an audit and we got The Road to Wigan Pier"*.[I]

2.5.2. CFH broadly accepted our Year 1 report but disagreed on the detail of some points. We had observed that the governance of the programme was complex (it was then overseen by the high-level Care Records Programme Board which covered several other large programmes), and had suggested a senior leadership structure devoted solely to this programme. In response, CFH established a dedicated Summary Care Record Programme Board which met monthly from January 2009 (Section 4.1). CFH also placed a written response to our evaluation in the public domain,[63] and set up four working groups to address issues which we had flagged as "urgent".

2.5.3. We reported in 2008 that the consent model for the SCR was widely seen as overly complex and unworkable. The consent model at the time involved three advance options which patients and staff found confusing – 'store and share', 'store but don't share' and 'don't store'. It was based on an 'opt out' model (if a person did not take action following a mass mailing, a SCR would be created for them), and it did not require staff to ask consent to view the record at the point of care. The British Medical Association in particular had raised concerns that this model was unethical and possibly illegal, and a majority of their members' representatives had voted not to co-operate with it. We had recommended that CFH consider alternative models, notably that staff ask a patient's consent to view their record at the point of care.

2.5.4. In its response to our findings on the consent model, CFH said:

> *"Through the Evaluation there is a clear message that the existing consent model as it currently operates is considered by many to be complex and confusing. Consideration of the consent model cannot be wholly divorced from both scope and business change, but nevertheless this feedback is accepted. A refined consent model is proposed, simplifying the decisions for patients without removing the choices available, and providing the protection they and some of the healthcare professions desire over access to medical records. At this stage this is a proposed model, and greater consultation with key stakeholder groups is planned."*
>
> CFH official response to UCL Year 1 evaluation, July 2008, page 4[63]

The new consent model introduced by CFH is considered in Section 8.4.

2.5.5. We reported in 2008 on what our informants had perceived as a tendency to 'scope creep' in the SCR programme and recommended that CFH consider developing a tighter definition of what the SCR was to be used for. We contrasted the numerous different use scenarios being considered for the SCR (emergency care, medicines reconciliation, end of life care, ambulance service, community dental care, hospital outreach clinics) with the single and unambiguous use case ('emergency care') that had driven development of the Emergency Care Summary in Scotland.

2.5.6. In their response, CFH distinguished between scope of content and scope of use:

[I] *The Road to Wigan Pier* was a rich description by George Orwell of workers' experience down coal mines in the 1930s which might be described as a critical ethnography. Ethnographic case study and 'audit' in evaluation of IT programmes offer complementary perspectives; arguably, both are necessary to give a full picture.[62]

"There are two distinct but related aspects to the scope of the SCR; content and usage. Whilst both are well defined, a number of factors that may have led to confusion and the perception of scope creep have been identified. These relate mainly, although not exclusively, to how the SCR will be used rather than what information it will contain. The conclusion reached is that, whilst the content of the SCR should be unambiguously defined, local flexibility in usage should be allowed and indeed encouraged. However, to reduce the potential for confusion amongst patients and clinicians alike, it is recommended that communications be enhanced and strengthened."

CFH official response to UCL Year 1 evaluation, July 2008, page 3[63]

2.5.7. We agreed that flexibility to use the SCR adaptively was essential for its embedding into work practices and care pathways. But we remained concerned that promoting the SCR as (effectively) a 'container of information' that could be accessed remotely by staff in different contexts for different purposes before it had become established for a particular use case was a risky strategy. Whilst CFH saw the content of the SCR and its intended use scenarios as conceptually and operationally separable, we saw these as inextricably linked and co-evolving. These differences can be explained in terms of differing views of what knowledge *is*: knowledge as codifiable 'facts' that are unproblematically transferable between different contexts versus knowledge as tied to particular practices in particular contexts.[J]

2.5.8. We recommended in 2008 that the 'benefits realisation' work should be more balanced, e.g. by considering how the tension between benefits and 'disbenefits' played out in different situations. Our early fieldwork had revealed perceptions by clinicians and patients that they were being given a one-sided story, and we felt that a balanced message which included risks and trade-offs (e.g. risk of inaccurate information or malicious access, and an acknowledgement of civil liberties issues) was likely to increase rather than decrease the credibility of the programme.

2.5.9. CFH responded as follows:

"A considerable amount of work has been undertaken by the Programme, working with Early Adopters, to identify and better articulate the expected benefits of the SCR. To this end there is an ongoing programme of work, both within the SCR Programme and across the NPfIT to maintain the focus on benefits, and in particular those associated with improved patient care. Following consideration of observations made in the Evaluation, it is recognised that more attention should be given to so-called dis-benefits. This will not only provide a more balanced view but will also enable a more informed NHS, and in doing so it may be possible to reduce dis-benefits so they are more closely aligned with the realisation of benefits."

CFH official response to UCL Year 1 evaluation, July 2008, page 4[63]

2.5.10. The workstream set up by CFH to consider 'balancing benefits and disbenefits' sat awkwardly against the SCR strategy (Sections 2.2, 2.3 and 4.1), which was built on the assumption that the SCR (and shared records more generally) had inherent benefits and it was the purpose of the programme to 'realise' these:

"A number of recommendations are made in this [CFH] report, with the emphasis on implementing any proposed changes in a pragmatic way that should not detract from the benefits to patients and the NHS from the introduction of the SCR."

CFH official response to UCL Year 1 evaluation, July 2008, page 4[63]

[J] This issue (which philosophers of science would describe as a question of 'ontology') lies at the heart of the design strategy for the NPfIT and is considered further in Section 11.5.

2.5.11. It is worth noting that some (though by no means all) CFH staff found the notion of possible 'disbenefits' of the SCR difficult to conceptualise and conflated these with the risk assessment for the programme.

"There appears to be a key confusion here [in the minds of some CFH staff] about the difference between 'risks to the successful delivery of the programme' and 'risks associated with the programme being implemented successfully'."

Researcher's field notes from meeting with CFH to discuss response to Year 1 evaluation, 8th December 2008 (FN13)

Section 4.5 considers how CFH measured benefits. Our empirical findings on benefits and risks are set out in Sections 6.7 and Section 6.8 respectively.

2.5.12. Our 2008 report distinguished between 'project management' (designed for change initiatives with high levels of predictability and controllability) and 'programme management' (designed for initiatives which are unpredictable because of complexity, scale and the influence of multiple external variables) and invited CFH (and the politicians and policymakers who set its agenda) to consider shifting to a more flexible and adaptive approach to change which we predicted would be better suited to the complex, unpredictable and emergent nature of the programme.

2.5.13. In response, CFH said:

"The Early Adopter Programme was focused on 'proving' the concept and the technology, and identifying the requirement for business change. This is reflected in the planned approach for national implementation, with significant emphasis being placed on clinical ways of working and the changes that might be required in order to optimise the benefits realised locally. The work to provide guidance on business change as part of the SCR implementation is ongoing in preparation for supporting the national implementation of the SCR, and as such the Evaluation provides timely input into that work." (page 4)

"…there is a responsibility on the SCR Programme to deliver within the timeframes expected by the NHS. Not to do so would have the potential to delay or undermine expected benefits for patients…" (page 28)

CFH official response to UCL Year 1 evaluation, July 2008[63]

2.5.14. This response acknowledged the importance of the Year 1 evaluation in informing business change work occurring as the programme moved to national implementation. But it did not acknowledge the need to shift to a fundamentally different approach to change. Or, perhaps, the question of adopting a fundamentally different change model was put aside because this was not something which even the most senior people in the programme were able to do. As one person put it:

"This is the kind of world that we're in."

Senior CFH project manager at meeting between UCL and CFH to discuss response to Year 1 evaluation, 8th December 2008 (FN13/~02)

We revisit the change model in Sections 4.3 and 11.2. In Section 10.2 (Organisations and Their Worlds) we consider the 'world' to which this speaker was referring.

2.5.15. In addition to these priority areas for CFH, we suggested in our Year 1 report that stakeholders (including the public and politicians) might reflect on a number of generic issues, which we revisit in Chapter 11:

a. The policy debate. We felt that public debate on distributed electronic records had tended to be conducted by the minority of individuals with extreme views (positive or negative) and had been somewhat simplistic, polarised and tied to hypothetical situations. We hoped that the debate would become more nuanced and consider what is appropriate for whom under what circumstances;
b. Measuring success. Our Year 1 findings did not support the *a priori* use of any particular definitions or metrics of success. We felt that meaningful metrics must be developed organically alongside the operational characteristics of the technology-in-use, through a process of technological [re]design, consultation, negotiation, and policy deliberation – and that the fitness for purpose of such metrics must be continually questioned as the programme developed;
c. The 'national' versus 'local' tension. We questioned whether the scale and scope of the NPfIT was optimal or whether a collection of smaller systems with agreed interoperability standards may be more workable in the complex and heterogeneous environment of the NHS.

2.5.16. In general, the various other stakeholders in the SCR programme (see Section 2.5) received our Year 1 evaluation report positively.

a. Participating early adopter PCTs generally felt that their efforts had been acknowledged and perspective put across (perhaps mainly because they had had an opportunity to correct misinterpretations and inaccuracies in drafts);
b. Various professional bodies issued short statements saying they considered the evaluation to have covered the issues relevant to their members in a balanced way. The BMA, for example, felt that their concerns about the need for explicit informed consent had been captured, and agreed to a 'consent to view' model provided that this was subject to piloting and the public information programme was reviewed. They also accepted our argument that there was no simple metric for measuring the workload associated with the SCR programme;
c. Patient organisations felt the patient perspective had been captured. They agreed with our conclusion that different patients have different views and priorities at different times over the course of their illness, and that flexibility to accommodate the current needs and priorities of the patient was an important principle;
d. There was relatively little interest from the press, though some broadsheets interpreted our report as offering a negative assessment of government IT policy.

2.5.17. In summary, this document builds on a previous evaluation of the SCR, of which the main report was published in May 2008 and broadly accepted by all key stakeholders. This may have been due partly to the fact that the illuminative evaluation approach described in the next section is designed to identify perspectives of a range of stakeholders and explore how these multiple perspectives influence the unfolding of a programme. It explicitly draws back from suggesting what the 'right' perspective is. CFH put measures in place to take forward some key areas of work which we had flagged as "urgent", but two things appeared to be beyond their remit: they were not able to question the 'benefits realisation' strategy that underpinned national policy on the NPfIT, and they were not able to make fundamental changes to the change model for implementing the programmes.

2.5.18. An interim internal report on HealthSpace was submitted in September 2008 and a final version of that report, incorporating responses to peer reviewers' comments, in December 2008. It described largely negative attitudes to an early version of the technology in a sample of 21 patients. This report was not made public at the time because of stakeholders' concerns that preliminary findings on this small sample could be over-interpreted with adverse impact on the further roll-out of the programme. A summary of findings and issues for discussion were tabled at the Summary Care Record Implementation Board in September 2008.

3. The evaluation

3.1. Aim, scope and approach

3.1.1. This evaluation was commissioned via a competitive bidding process. Our remit was to assess implementation and impact of the SCR and HealthSpace; provide timely feedback to stakeholders; and contribute to the generation of an evaluative culture within CFH and the NPfIT. Our work is part of the Connecting for Health Evaluation Programme (CFHEP), led by Professor Lilford at the University of Birmingham, which was set up in response to a recommendation by a Ministerial Task Force and framed as a means by which 'transparency' in the NPfIT would be achieved.[33]

3.1.2. Our research questions were:

a. At the 'micro' level, what is the usability, usage, functionality, and impact of the SCR and HealthSpace in participating localities, and what explains variation in their adoption and use?
b. At the 'macro' level, what is the social, political, technological and economic context into which these technologies are being introduced? How does this context shape and constrain micro level usability and usage – and how, conversely, does the experience at micro level impact on the macro context?
c. What aspects of implementation are seen by different participants and stakeholders as important? How (if at all) might these be expressed as generic, transferable implementation standards and strategies?
d. What can we learn from this project about how best to evaluate large-scale healthcare IT programmes more generally?

3.1.3. This evaluation comprised (in total) a three-year project with 3.5 full-time equivalent academic staff. It was intended to supplement rather than replace other monitoring and audit work associated with the SCR, including:

a. Financial accounting by CFH and NHS organisations. Detailed reports on the NPfIT and NHS finances have been produced by the National Audit Office and Public Accounts Committee;[52;59]
b. Local project management and monitoring, including metrics to measure benefits and risks, by NHS organisations;
c. Statistics collected by IT suppliers about usage of their products;
d. Public education and information about the SCR and HealthSpace by CFH's Communications Department and local PCTs;
e. Monitoring enquires to information lines by providers of those services;
f. Technical testing by suppliers and CFH's technical department.

3.1.4. We drew on Michael Quinn Patton's utilisation-focused evaluation approach, defined as: *"the systematic collection of information about the characteristics, activities and outcomes of programs to make judgements about the program, improve program effectiveness, and/or inform decisions about future programming"* (page 33).[64] Further detail on this method is given in our earlier report, paragraphs 2.4.1 to 2.4.5.[1]

3.1.5. A key component of utilisation-focused evaluation is identification of stakeholders. The programme had numerous stakeholders who held different views about the purpose of the evaluation and what counted as 'rigorous' and 'valid' methods. Stakeholders included:

a. The Department of Health (who sponsored the evaluation), and CFH (who were responsible for delivering the NPfIT) expected the evaluation to provide feedback which would inform the national roll-out of programmes whose broad strategy and implementation plan had already been established, as well as providing wider lessons to inform the design of future programmes;
b. The Summary Care Record Advisory Group (SCRAG), an external body appointed by CFH to oversee the SCR programme, saw the independent evaluation as an important part of the governance of this initiative;
c. NHS organisations had mixed expectations of both the programmes and the evaluation. In general, participating SHAs, PCTs and provider organisations anticipated significant benefits from the technologies and hoped that our evaluation would contribute to capturing those benefits. As the work unfolded, some NHS staff welcomed our team as a means of feeding back complaints and concerns confidentially to CFH;
d. Professional bodies (e.g. British Medical Association, Royal College of Nursing) tended to view the SCR and HealthSpace as having potential advantages (improved quality and safety of care) and potential risks (breach of privacy). They sought to provide evidence-based guidance for their members, particularly in relation to consent and confidentiality. They also hoped the evaluation would identify practical issues such as workload, training needs and patients' concerns;
e. Patient organisations also saw advantages and risks in the programmes. In general they viewed the former as outweighing the latter. They were positive about the explicit 'empowerment' agenda in NHS IT policy and hoped that the evaluation would capture this benefit as well as confirming that security risks were minimal and providing a plain English summary of the issues for lay people;
f. Medico-legal bodies (e.g. Medical Protection Society and Medical Defence Union) saw the programmes as raising new medico-legal scenarios. The Information Commissioner's office (www.ico.gov.uk, *"the UK's independent authority set up to uphold information rights in the public interest, promoting openness by public bodies and data privacy for individuals"*) and the National Information Governance Board saw them as raising important questions about information governance in general and the application of the Data Protection Act in particular;
g. Academics and evaluation scholars in the UK and abroad viewed these programmes as a unique natural experiment in the introduction of a national stored and shared electronic record, the evaluation of which could potentially draw generalisable lessons for other large-scale IT programmes in healthcare;
h. The design and informatics communities saw these programmes as a significant test case for the feasibility of the overall design model (characterised by centralised development, detailed advanced specification and relatively limited scope for subsequent adjustments – an approach sometimes referred to as 'waterfall') and of CFH's approach to implementation (Section 4.3);
i. Civil liberties groups saw the programmes as representing infringement of privacy and a threat to clinician-patient trust. Such groups appeared to have mixed expectations of our evaluation. Some questioned our independence, refused to give interviews and expected us to endorse the programmes uncritically. Others strongly welcomed an independent evaluation by an academic team and anticipated that their ethical and social concerns would be fairly represented;
j. Front-line clinicians, to the extent that they knew about the SCR and HealthSpace at the time, expected clear guidance in relation to their own role;
k. The media and the public expected accurate facts about the programmes which they could draw upon to make judgements and hold informed debate.

3.1.6. Ethical approval was obtained from two Multi-centre Research Ethics Committees: Thames Valley in January 2007 (06/MRE12/81 and subsequent amendments) and North West 8 in September 2009 (09/H1013/36 and subsequent amendments), though some of the work described here was classed as 'audit' by NHS Research

Ethics Committees and hence outwith their remit. Ethical issues such as consent to participate, patient confidentiality and data protection are discussed in Section 3.2.

3.1.7. The Summary Care Record Independent Evaluation External Advisory Group (SCRIE EAG) met four times during the two years covered in this report and oversaw the management and governance of the evaluation. This group, whose membership is listed in the Acknowledgements, had a lay chair and representatives of clinicians, patients, professional bodies and academic peers. The terms of reference of the evaluation were formally agreed by the SCRIE EAG as set out in Boxes 3.1 and 3.2.

Box 3.1: Summary Care Record evaluation terms of reference

1. The SCR evaluation will take account of the general mission and terms of reference of the Connecting for Health Evaluation Programme.
2. The evaluation will follow the general principles of utilisation focused evaluation as set out in the original bid for CFH 002 [Year 1 phase of this evaluation] and approved by the SCRIE External Advisory Group.
3. The priority of the evaluation will be to explore the impact of the SCR and related technologies on NHS patients; the efforts of staff to use the SCR; and the challenges of integrating the SCR into the business-as-usual of patient care, taking account of the fact that this is an evolving technology. This emphasis reflects an amended version of the main SCR work package set out in the CFH 007 bid [Years 2 and 3 of this evaluation], which forms the basis of our contract with the DoH.
4. To the extent that there are delays in uptake of the SCR, it is within the remit of the evaluation team to explore the reasons for those delays.
5. The evaluation will be monitored as the SCR programme unfolds by the SCRIE External Advisory Group, who will advise on any changes to its focus and remit.

Box 3.2: HealthSpace evaluation terms of reference

1. The HealthSpace evaluation will take account of the general mission and terms of reference of the Connecting for Health Evaluation Programme.
2. The evaluation will follow the general principles of utilisation focused evaluation as set out in the original bid for CFH 002 and approved by the SCRIE External Advisory Group.
3. The priority of the evaluation will be to explore the impact of HealthSpace and related technologies on NHS patients; the efforts of staff to support the use of HealthSpace by patients; and the challenges of integrating HealthSpace into the business-as-usual of patient care, taking account of the fact that this is an evolving technology. This emphasis reflects the main HealthSpace work package set out in the CFH 007 bid, which forms the basis of our contract with the DoH.
4. The evaluation will take account of the point made by Connecting for Health that HealthSpace is policy and that even senior staff do not have the power to change or challenge this policy.
5. To the extent that there are delays in uptake of HealthSpace by NHS staff and patients, it is within the remit of the evaluation team to explore the reasons for those delays. For example, feedback should include comment on the processes by which the HealthSpace programme is being implemented at both national and local level.
6. The evaluation will be monitored as the HealthSpace programme unfolds by the SCRIE External Advisory Group, who will advise on any changes to its focus and remit.

3.1.8. Whilst we have commented previously that an 'evaluation culture' was at an early stage of development within CFH,[1] it was certainly the desire of many CFH staff, including senior executives, to work actively with our team and incorporate formative feedback into emerging work on the SCR and HealthSpace programmes.

3.2. Methods, data sources and ethical considerations

3.2.1. In line with the requirements of utilisation-focused evaluation (paragraph 3.1.4), we took a mixed-method approach i.e. we used a range of collection methods and data sources to capture as rich a picture of the programme as possible from as many angles as possible. Our field work involved several interrelated empirical studies:

a. A study of national level activity by CFH (Chapter 4 and Section 9.1);
b. A study of local efforts to implement the SCR by Strategic Health Authorities (SHAs, Section 5.1); Primary Care Trusts (PCTs, Sections 5.2 to 5.4), and efforts of these organisations to implement Health Space (Section 9.2);
c. A study of the perspectives and activity of IT suppliers (Sections 5.5 and 5.6);
d. A study of wider perspectives on the programmes, including those of professional bodies, civil liberties groups and patient organisations (Sections 5.7 and 5.8);
e. A study of the use and non-use of the SCR at the clinical front line (Chapter 6);
f. A study of the use and non-use of HealthSpace and HealthSpace Communicator by patients and carers (Sections 9.3 and 9.4);
g. Case studies of efforts to use the SCR and HealthSpace in locally adaptive ways including a pilot study of mobile Portable Digital Assistant (PDA) devices by district nurses (Chapter 7); and an initiative to offer patients with long term conditions access to locally shared records via HealthSpace (Section 9.5).

3.2.2. The data sources for the study are listed in Table 3.1. Whilst we had access to quantitative data (cumulative summary statistics on SCR creation and use from CFH and a large encounter dataset from Adastra), most data collected by our own team were qualitative, comprising interviews, field notes, communications such as email and free-text documents such as minutes of meetings. Interviews were a combination of narrative and semi-structured format. The individual was first asked to tell the story of the programme from their own perspective. In addition, an appropriate question list was constructed for the particular individual being interviewed and adapted flexibly as the interview unfolded so as to pursue themes raised by the interviewee (for this reason, we have not provided interview schedules or topic plans). Ethnographic data (for example, observations of meetings or clinical encounters) were collected using contemporaneous field notes, with the researcher writing down as much naturally occurring talk as possible. This kind of data raises particular issues around consent and confidentiality which we discuss below.

TABLE 3.1: SUMMARY OF DATA SOURCES

Research focus	Data source(s)
Background of NPfIT and government perspective on data sharing (Sections 2.3, 4.1 and 5.2)	Policy and related documents produced by government, DoH and CFH. Public domain material produced by Information Commissioner's Office; correspondence exchanged between ICO and CFH. Academic papers and commentaries.
Perspective and activity of CFH	20 interviews and approximately 100 informal meetings with senior executives, middle managers and members of committees and working groups. Field notes from observation

(Chapters 4 and 8; Sections 9.1 and 9.2)	at 60 boards, committees and conferences. Documentary sources including strategic outline cases and business cases for SCR and HealthSpace, memoranda of agreement, agendas and minutes of meetings, risks and issues documents, internal reports. CFH's comments on drafts of this report.
Perspective and activity of Strategic Health Authorities (SHAs, Section 5.1)	21 interviews and informal meetings with Chief Information Officers (CIOs) and SCR project managers. Field notes from observation at one CIO forum and 12 SHA Lead meetings. Documentary sources e.g. agendas and minutes of meetings, benefits realisation plans, updates submitted by SHAs to CFH.
Perspective and activity of Primary Care Trusts (PCTs, Sections 5.2 to 5.4)	12 interviews and approximately 30 informal meetings with PCT staff. Field notes from observation at 11 internal meetings such as project management groups. Documentary sources as above. PCTs' comments on a draft of this document.
Perspective of IT suppliers (Sections 5.5 and 5.6)	Field notes from 8 observational visits to supplier organisations. 15 interviews and 10 informal meetings with top and middle managers. Documentary sources comprising outline specifications and minutes of meetings. Suppliers' comments on a draft of this document.
Perspective of professional and medico-legal bodies (Section 5.7)	Publications, reports and commentaries from British Medical Association, Royal College of Nursing, Royal Pharmaceutical Society, Royal College of General Practitioners, Medical Defence Union, Medical Protection Society. Comments from these organisations on a draft of this document.
Perspective of citizens and the public (Section 5.8)	Publicly accessible information from patient organisations and lobbying groups. Interviews with 4 representatives from patient organisations. Field notes from attendance at two seminars held by patient organisations to discuss SCR and HealthSpace. Press articles. Comments from patient organisations on draft sections of this report.
Quantitative data on creation and use of SCRs (Section 6.2)	National statistics, updated weekly, produced by participating PCTs and collated centrally by CFH on number of SCRs created, number of settings where SCR was accessible by authorised staff, and number of people registered for HealthSpace. De-identified data supplied by Adastra on 416,325 encounters (representing 325,321 individual cases) both with and without SCR access in sites using Adastra software (GP out-of-hours and walk-in centres) from August 2008 to January 2010. Comments by CFH and Adastra on our interpretation of these data.
Use and non-use of the SCR at the clinical front line (Sections 6.3 to 6.8)	Semi-structured interviews with 67 front-line staff (listed in Table A1 in Appendix). Ethnographic field notes on 214 patients seen in clinical encounters in 13 unscheduled care settings, plus a further 23 cases dealt with by non-clinical call handlers (see Tables A2 to A6 in Appendix for demographic and clinical details on these). Comments by representatives of all organisations on a draft of the relevant section of this document. The unscheduled care organisations comprised: a. GP out-of-hours centres in Bolton, Bury and Medway, each of which offered [i] phone advice from GPs. [ii] face to face consultations by GPs ('base visits'). [iii] home visits by GPs. and [iv] telephone advice from call centre nurses. b. Walk-in centres in Bolton and Bury, where patients received treatment from nurses without a doctor on site; c. A&E departments in Bolton and Bury, where patients were triaged into three broad categories: [i] 'minor'. [ii] 'major'. and [iii] 'resuscitation'; d. Intermediate wards in Bolton and Bury hospitals, where patients were transferred from A&E before being admitted to a medical or surgical ward at the hospital. Hospital pharmacy work linked to these units was also studied; e. A community ward located in Bolton General Hospital; f. A diabetes outreach service in Bury, where an interdisciplinary team of a consultant diabetologist, diabetes specialist nurse and dietician saw patients referred by their GPs. This setting was not strictly 'unscheduled care' but had been chosen by the PCT as a possible site where the SCR might prove useful;

	g. A dental access centre in Bury, for patients with emergencies and not currently registered with a dentist or unable to get a timely appointment; and h. The North West Ambulance Service.
Bolton district nurse PDA pilot (Chapter 7)	Perspective of PDA supplier (see 'IT suppliers' above). Interviews with 2 nurse managers. 2 focus groups involving 4 district nurses, 2 nurse managers and one administrator who had participated in the pilot. Some nurses attended both focus groups, which were held several months apart. Documentary material including internal protocols and correspondence. Interviews with patients were sought but were not logistically possible. Comments by district nursing service and PDA supplier on draft section of this report.
Use and non-use of HealthSpace (Section 9.3)	Ethnographic studies of 20 people with diabetes (see paragraph 3.2.7 for details). Comments by two volunteers from this sample on draft section of this report.[K]
HealthSpace Communicator study (Section 9.4)	Practice profiles of the 3 participating GP practices (two in London and one in Bury). 6 interviews and 10 informal meetings or email exchanges with clinicians, managers and reception staff at the practices. Interviews with 15 patients and carers, mostly taking place in their homes and including observation of attempts to use Communicator. Field notes from observation at one regional and one national strategy meeting. Comments by CFH, clinicians and a volunteer from the patient sample on draft section of this report.[L]
Salford Integrated Record Pilot (Section 9.5)	9 interviews and 6 informal meetings with clinicians, managers, IT support staff and software suppliers. Field notes from observation at 2 internal project meetings and 3 patient forum meetings. Interviews with 6 patients involved in the scheme. Comments by clinical staff, PCT staff, patients and IT supplier on draft section.

3.2.3. Cooperation with this independent evaluation was a condition of an organisation's involvement in the SCR programme. However, we did not assume consent to interview staff or observe activity on this basis. We approached the clinical director in each department or organisation to provide background information on the purpose of the evaluation and seek permission to study the use of the SCR in real clinical situations. Participation of individual staff and patients within each setting was voluntary. Because of large numbers of clinicians working in unscheduled care settings (the GP out-of-hours service in Bolton, for example, had between 125 and 150 GPs on its books, many of whom only worked one session a week) and the irregular nature of the sessions worked, we did not send written materials beforehand. Rather, we sought verbal consent from staff who were on duty on the day and assured them that they should not feel under any pressure to have us sit in.

3.2.4. Consent from patients was sought orally. They were alerted by NHS staff that a research project into the use of computers was being undertaken and detailed written information material approved by the Research Ethics Committee made available for distribution (though in practice, staff and patients rarely took up the offer of such information). For face to face consultations, in addition to written information supplied via the receptionist, the clinician generally said something like "I've got a colleague sitting in with me, is that OK?", and for phone consultations they said "I've got a colleague listening in, is that OK?". Where practically possible, we offered a verbal explanation of the purpose of our visit. In all cases we left the room if we considered that the patient was (or might become) uncomfortable with our presence.

3.2.5. Patients who were unconscious or unable to give consent were observed only by a medically qualified researcher who limited her observations to the use of information

[K] All service users interviewed for this section were offered the opportunity to comment but only two wished to do so.
[L] All service users interviewed for this section were invited at the time of interview to view a copy of the section but only one wished to do so.

sources by healthcare staff. Consent from relatives was obtained in all these cases except one unconscious unaccompanied person. In some situations the clinician consulting by phone did not ask the patient's consent, and in these cases only brief details of the case were recorded (e.g. age, gender, nature of complaint, whether the SCR was used or not). Where explicit verbal consent was given, we made detailed notes of the phone conversation. No identifying details on the patient were recorded. Where necessary the case was systematically fictionalised (for example one rare illness was changed to a different rare illness).

3.2.6. We audiotaped five of 67 staff interviews but found in pilot interviews that when interviewed on tape, staff seemed to give a perceived "correct" response from their organisation's perspective, whereas interviews held in a less formal atmosphere drew a greater variety of perspectives. We therefore stopped recording interviews.

3.2.7. Our study of use and non-use of HealthSpace took account of difficulties in recruiting participants to research on this technology (Section 9.3). We decided to approach people with diabetes and study their efforts to self-manage their condition either with or without HealthSpace.

a. We sought a sample of 20 individuals to give maximum variety in age, gender, ethnicity, health literacy, IT literacy, stage and severity of condition, and level of family support. We recruited from a range of settings including the local diabetes service, patient groups, community groups and ethnic organisations;
b. We undertook between one and three periods of detailed ethnographic observation on these individuals. We accompanied each one for periods of several hours as they went about their daily life, noting issues to do with their condition as these emerged (either raised spontaneously in conversation or encountered in actions and events);
c. We were interested in how participants managed their condition; what their information and communication needs were in relation to their long term condition; whether they identified these as such and how they addressed them;
d. In participants who used HealthSpace, we sought to understand how this technology fitted in with self-management. In non-users of HealthSpace (the majority of our sample), we sought to explore why they did not seek to use this technology for managing their condition and what, if anything, they used instead. We suggested to each participant that they might like to try using HealthSpace;
e. We noted any individuals (e.g. partner, other relatives, friends, peers, GP, specialist nurse) who helped the participant manage their condition and also noted the technologies (e.g. blood glucose meter, insulin pump, telephone, Internet) which they or their carers made use of. In some cases, a technology was used by a relative but not directly by the person with the condition;
f. We made brief contemporaneous notes and spent several hours immediately afterwards annotating these and adding our reflections. For each case, we constructed a map showing the index person plus the socio-technical network of people and technologies involved in managing the illness in its social context.

3.3. Data analysis

3.3.1. In building up the various national, regional, PCT and organisational-level studies of the SCR and HealthSpace in context, we followed the methodology of case study research. The challenge was to manage, collate and synthesise large amounts of qualitative data (e.g. field notes, documents, interviews, informal stories) and quantitative data (e.g. uptake and usage statistics). All data were processed (de-

identified, indexed, and coded) and stored manually or electronically. Electronic files were de-identified and stored on encrypted hard drives in accordance with UCL's data protection policy (available on request). [M]

3.3.2. Data analysis occurred in three overlapping stages:

a. Each data source was analysed separately using an appropriate technique (e.g. theory-driven thematic content analysis for qualitative data, appropriate statistical tests for quantitative data);
b. These first-order analyses were combined using narrative synthesis to produce a coherent, multi-level interpretation of the story in each site or setting; and
c. Insights from these cases were synthesised further in a cross-project analysis, drawing on a new over-arching theoretical framework (Section 3.4).

3.3.3. Data were analysed as soon as was practicable after we had collected them so as to feed emerging findings into the next phase of fieldwork. The synthesis phase involved presentations to participating organisations and incorporation of their feedback into our interpretations.

3.3.4. Analysis of documents such as strategy papers, business plans, contracts, memoranda of understanding, agendas and minutes of meetings and so on occurred at two levels. First, we considered their content in a conventional way (i.e. taking the texts 'at face value') by asking questions such as "What were the ideas and facts presented?"; "Were these reasonable, accurate and so on?". Second, we undertook a more in-depth analysis of texts, drawing on the principles of critical discourse analysis.[69] This approach considers the language, format and focus of the document with a view to exploring ideologies and power relations, using questions such as "Where did this text come from and why is it presented in this way, at this time, in this context to this audience?"; "What work does the text seek to do, and how?"; and "What is not being said here, and why?".[N]

3.3.5. In our qualitative analysis of patient encounters, we considered each encounter as an individual case study in a particular organisational context. For each case, we sought to gain an understanding of how the different actors involved (patient, clinician, call handler) interpreted their world and what aspects of the wider context influenced their decisions and actions in this case. As part of this micro-level analysis, we considered what technologies could and could not do in the particular conditions of use. This included, for example, an analysis of the decision models inscribed in software (inbuilt protocols, algorithms, pull-down menus and so on) and whether technologies were freestanding or interoperable with other technologies.

3.3.6. We also produced descriptive statistics on the 214 clinical encounters to gain an overview of our dataset. We used the Excel database to code the demographic, administrative, technical, clinical and quality/safety aspects of the cases as follows:

[M] For those interested in the academic small print, organisational case study researchers tend to fall into two broad schools: (a) those who follow the work of Robert Yin, whose philosophical position might be classified as social realist and who recommends a systematic sample of cases, the similarities and differences between which form the focus of analysis ("theoretical replication across multiple sites");[65] and (b) those who follow the work of Robert Stake, whose philosophical position might be classified as social constructivist and who recommends immersion in a single case, the reflexive and critical interpretation of which forms the focus of analysis ("the intrinsic study of the valued particular").[66] Comparison across cases is not a requirement in the constructivist school but may be used as an aid to interpretive analysis (as one might compare *King Lear* with *Macbeth*). An academic textbook explores these issues.[67] Our analytic approach does not align exclusively with either the realist or constructivist school but sees these perspectives as recursively related.[68]

[N] Academic readers from a social science background will be aware that discourse analysis is rising in popularity as a technique for exploring how macro-level issues impact on micro-level actions and outcomes in healthcare organisations and that the many philosophical approaches to discourse analysis defy a simple taxonomy.[70;71] The particular approach employed in this study will be set out in a forthcoming academic paper.

a. Demographic: age, gender, ethnicity, and whether the patient's SCR might have contained any information had it been available (i.e. whether they were known to have been prescribed medication or to have known allergies or adverse reactions);
b. Administrative: where seen, source of encounter (did the patient self-refer or were they referred from another care setting?), type and grade of health professional, source of drug or allergy information, site of onward referral if any;
c. Clinical: details on type and severity of illness including whether the patient's cognitive capacity was impaired;
d. Technical: whether a SCR existed on this patient (yes, no or unknown), whether it was accessed and why, and whether the SCR made any positive contribution to the encounter (or might have done if available);
e. Quality/safety: whether the SCR (if it was accessed) appeared to be associated with an improvement in quality, safety or efficiency of care, whether it appeared to reduced onward referral and/or hospital admission, and whether it appeared to increase the clinician's confidence in dealing with the case (yes, no, or possibly in each case). If the SCR was not available, whether it might have done so had it been present. For these assessments, two researchers coded the case independently and we attempted to calculate an inter-rater reliability score.[O]

3.3.7. Quantitative data supplied by CFH were aggregated and presented in graphical form (see for example Figure 6.1, paragraph 6.1.3), and not amenable to further analysis (e.g. there was no denominator). For the Adastra dataset on 416,325 unscheduled care encounters in primary care settings across three sites (Bolton, Bury and Medway), we asked the following questions:

a. What proportion of patients seen in unscheduled care have a SCR, and in what proportion of these is it accessed? What is the trend over time?
b. How does SCR access vary by site – and how does trend over time vary by site?
c. How does SCR access vary with patient characteristics (e.g. age, gender)?
d. How does SCR access vary by type of clinician and individual clinician?
e. How does SCR access vary by nature of complaint?
f. Is SCR use associated with reduced consultation length (e.g. is there any evidence that its use 'saves time')?

3.3.8. Quantitative analysis of data relating to these questions comprised simple descriptive statistics (e.g. percentages); χ^2-test for categorical variables; Pearson correlation coefficient for relationships over time; Mann-Whitney test for skewed continuous variables; and logistic regression to explore the contribution of different variables to an overall model of factors that influenced SCR use. Further details of the statistical analysis are available from the authors.

3.3.9. In analysing the ethnographic observation of people with long term conditions, we drew on the approach described by Atkinson and Hammersley, who emphasise the value of observing naturally occurring talk and action and interpreting these in context.[72] We placed greater significance on what people said and did, and how we observed them to react to events, in real-life situations than on what they *said* they believed or 'would do' in the context of a formal interview.

[O] Whilst this formal, quantitative assessment of clinical encounters in terms of particular SCR-related 'benefits' was part of our original methodology, the results set out in Chapter 6 show that in practice these judgements were difficult to make and impossible to interpret without bringing in a host of ifs and buts (i.e. without speculating on a number of unmeasurable variables which had possible but not certain influence on the case). See, for example, cases FN03/#20, FN07/#97 and FN03/#50 in paragraphs 6.7.6, 6.7.11 and 6.7.13, which raise more questions than they answer about whether the SCR produced 'benefits', and Sections 11.3 and 11.5 which consider why 'hard outcomes' so often eluded our own efforts and those of other stakeholders to capture them.

3.3.10. When analysing free text, ethnographic notes and other qualitative data, we used a traditional approach of immersion in the data through repeated reading, discussion amongst team members, developing provisional analytic categories and iteratively refining these categories by what is known as the constant comparative method (comparing our analysis to date with new data as these emerged).[73] We were particularly keen to use an open-ended analytic method because we sought to develop theory in parallel with collecting and analysing data. For this reason, we chose not to use computer software packages (such as NVIVO).[P]

3.3.11. Clinical cases depicted in the write-up of findings were anonymised using the 'critical fiction' technique in which the person's characteristics and the context of the consultation are systematically fictionalised and the presenting complaint modified in a way that retains the essential themes of the clinical case.[75] The minimum demographic details needed to understand the case were reported.

3.3.12. In drawing together disparate and conflicting findings into a coherent case study, we used narrative methodology (see Preface).[76] By placing findings in story form it is possible to make sense of complex interlocking events and depict the richness and interconnectedness of the different events, actions and perspectives. It is also possible, through narrative, to depict competing versions of events in that different people experience events differently and place more or less significance on them, thus opening up the findings to further debate and deliberation.[77] For example, comparing competing versions of the 'same' story by top management and front-line staff may reveal much about the culture and subculture of an organisation even when (indeed, precisely because) each version is acknowledged to be perspectival.[78]

3.3.13. Following standard practice in qualitative research, we included a phase of feeding back provisional findings to participants to check for errors and misinterpretations. In most cases, feedback consisted of correction of factual errors (e.g. dates) or addition of further relevant information. We presented our draft findings to mixed audiences (including patient representatives) in participating PCTs. Relevant sections of the draft report were submitted to NHS organisations, IT suppliers, professional bodies and other stakeholder groups to verify that we had captured their perspective. The full text of this report was read and approved by members of the SCRIE External Advisory Group (paragraph 3.1.7), which included representatives from CFH, professional bodies, patient groups and four senior academics from outside UCL. It was also read by three anonymous peer reviewers appointed by the Connecting for Health Evaluation Programme, whose comments fed into the final version. Where feedback questioned findings or interpretations which we felt were well supported by our data, we did not alter the text of this report but offered to include a footnote to indicate where and how others disagreed with the material presented.

3.4. Theoretical framework

3.4.1. We sought to extend existing theory and method in the analysis of large-scale IT programmes in healthcare. We noted the recent systematic review of the literature on electronic patient records, sponsored by the Connecting for Health Evaluation

[P] The advantages of computer-assisted analysis of qualitative data are increased speed and efficiency in the administrative aspects of data management such as filing, indexing, coding and conducting automated searches.[74] A disadvantage is the time needed to learn to use such packages, but we were already familiar with NVIVO so this was not a major factor in our decision. We decided against using a software package because of the well-described tendency for codes and categories to become fixed by the software, thus inhibiting exploratory analysis of data.[74]

Programme and undertaken by Car et al.[79] Our own team undertook an extensive systematic review of a somewhat broader literature than that covered by Car's team.[Q] This revealed some key philosophical schisms (essentially between positivist approaches which assume an unproblematic and measurable external reality and non-positivist approaches which question these assumptions) and different framings of the electronic record and its use (Table 3.2).[12]

TABLE 3.2: DIFFERENT FRAMINGS OF THE ELECTRONIC PATIENT RECORD AND ITS USE (summarised from a systematic literature review[12])

Focus	Alternative framings	Explanation
The EPR	'container' or 'itinerary'	Is the EPR best conceptualised as a passive container into which data are placed – or is it better to think of the EPR as an active player in the social practice of clinical care, shaping and constraining the nature of clinical work and offering opportunities for the [re]structuring of roles and relationships?
The user of the EPR	'information-processor' or 'member of socio-technical network'	Is the user of the EPR best conceptualised as an autonomous practitioner who processes information – or as part of a dynamic network of people and technologies through which information and communication flows in complex ways?
Organis-ational context	'the setting within which the EPR is implemented' or 'the EPR-in-use'	Is context best conceptualised as something that can be analytically separated from the EPR – or is it better to think of context as constituted as the EPR is used (and hence impossible to 'isolate out' as a discrete variable in the analysis)?
Clinical work and knowledge	'decision-making' or 'situated practice'	To what extent is it helpful and valid to view clinical work as a series of bounded decisions as opposed to a complex, continuous and context-bound social practice? To what extent is it helpful to view knowledge as separable from the context in which it is generated?
The process of change	'the logic of determinism' or 'the logic of opposition'	To what extent is it helpful and valid to view change as a politically neutral exercise in project management as opposed to an inherently conflict-ridden process shaped and constrained by institutional forces?
Implemen-tation success	'objectively defined' or 'socially negotiated'	To what extent should we consider the criteria for 'success' in EPR implementation to be self-evident and uncontested as opposed to differently defined by different stakeholders?
Complexity and scale	"the bigger the better" or "small is beautiful"	To what extent is the assumption that large-scale EPR systems will achieve better integration and economies of scale valid? Conversely, to what extent do large-scale 'integrated' IT systems merely increase complexity and cost while reducing the facility for local tailoring?

3.4.2. Our own theoretical stance is sited in an expanding interdisciplinary field of inquiry that draws on sociology, ethnomethodology, computer-supported cooperative work and empirical philosophy. Our analytic approach, which we have described in detail

[Q] Car et al's review focused mainly on health informatics and health services research – i.e. research done mainly by health professionals interested in IT and computer scientists working in health-related fields. Our own review focused mainly on research outside these fields, including information systems studies, ethnomethodology and empirical philosophy.

elsewhere, attempts to align and extend selected elements from the work of leading researchers from these disciplines including Bourdieu, Garfinkel, Suchman, Latour, Berg, Giddens, Orlikowski and Stones.[68] Briefly, we make the following assumptions:

a. It is more useful to think of the electronic record as an itinerary or map which *shapes and constrains* clinical and administrative work than as a passive 'container' for information about the patient;
b. It is useful to think of people and technologies as linked in complex, ever-changing socio-technical networks. This centres the analysis on 'the process of socio-technical change' rather than on 'implementing technologies';
c. In socio-technical systems (dynamic networks of people and technologies), both people and technologies 'act' (i.e. do things) but not in the same way. For example, people have feelings, motives and ideas whereas technologies do not;
d. Clinical work is complex and associated with a high degree of uncertainty and unpredictability. Even when based on standardised guidelines and protocols, clinical actions are tied to the particularities and contingencies of local situations.

3.4.3. We consider socio-technical systems at three levels: 'micro' (that is, the individual people and technologies involved, and the moment-to-moment unfolding of action in any specific situation); 'meso' (that is, the organisations and other social groupings in which individuals operate and interact); and 'macro' (that is, the wider social context in which individuals act and make choices) (Figure 3.1).[13]

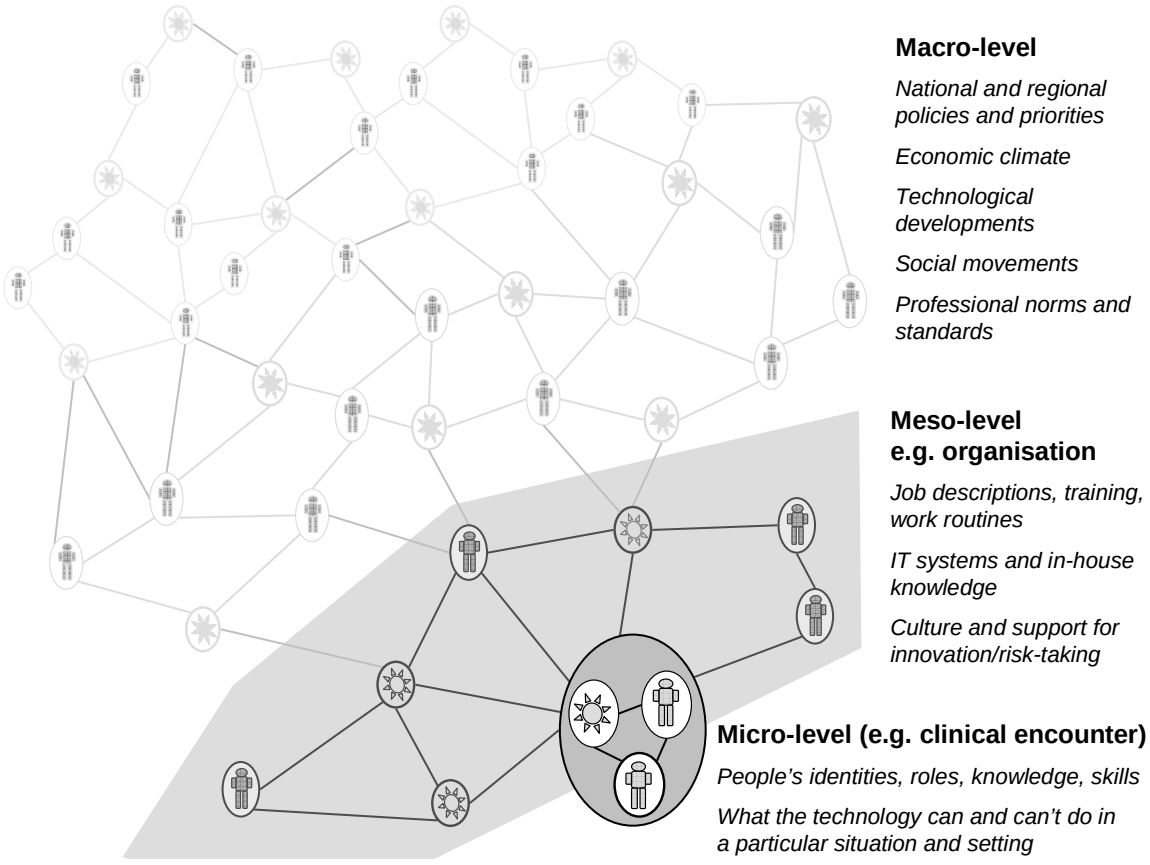

Figure 3.1: Diagrammatic representation of the socio-technical network associated with a complex technology, showing multiple levels of analysis ©

3.4.4. We thus analyse at three levels:

a. At macro level, we analyse national and regional policies and priorities, the economic climate, legal constraints, technological developments, and social movements (e.g. civil liberties). These external social structures both *create possibilities* and *limit what is possible* for individuals in particular situations;[R]
b. At meso level, we analyse the strategies, routines, protocols and unwritten rules and norms which make up life in organisations. The meso level includes 'hard' elements such as job descriptions, human resource practices (e.g. what individuals in an organisation are performance managed on), IT systems, care pathways, skill sets and resource allocation – as well as 'soft' elements such as organisational culture and level of support for innovation and risk-taking;[82]
c. At micro level, we analyse the knowledge (explicit/formal and tacit/embodied) which humans possess; the meanings they assign to technologies and to their own and others' behaviour; and how these are affected by wider social structures (e.g. how individuals' knowledge and behaviour is affected by their internalised knowledge of what Bourdieu called the 'field'[83] and Stones calls the 'strategic terrain',[81] including what we think other people know, how we expect them to behave and how trust plays out in different circumstances). We also consider what is 'inscribed' in technologies (e.g. as decision models or security protocols) and in what technologies can and cannot do in particular conditions of use.

3.4.5. Thus, we build up a picture of the process of change as shaped and constrained both by what individuals and technologies do at the front line ('micro') and also by the norms, expectations, symbolic meanings and economic and technological capacity prevailing in wider society ('macro') – and mediated via such things as organisational mission statements, terms of reference, standards, routines and ways of working. Individual action (whether using or not using particular technologies) has both intended and unintended consequences which feed back into the system, changing it in ways that are impossible fully to predict in advance.

3.4.6. The analysis of the dynamic links between macro, meso and micro levels of society, focusing in particular on how both individual agents and technologies act (or fail to act) in particular local situations, allows us to study both the *adoption and use* of new technologies and the *non-adoption and non-use* of these technologies. Furthermore, this theoretical position allows adoption and non-adoption to be studied *symmetrically* (i.e. using the same concepts, theories and empirical methods for researching both phenomena), thus – potentially at least – redressing a well-described pro-innovation bias in the research literature on adoption of innovations.[82 S]

3.4.7. In applying this analytic framework, we sought to build up a rich picture of the use and non-use of the technologies in different settings, explaining the micro behaviour of clinicians and patients in terms of over-arching meso (organisational) and macro (external social) structures which created possibilities for action and limited what was possible in a particular situation. Returning to field sites at a later date allowed us to consider both *what* had changed and *how* (at macro, meso and micro level).

[R] Academic readers will recognise the close links between this position and structuration theory, originally proposed by Anthony Giddens and more recently extended by Robert Stones.[80;81] Our analytic approach, which extends contemporary versions of structuration theory using selected elements of actor-network theory, was developed in collaboration with Prof Stones, though responsibility for any misinterpretation of his work lies with the lead author of this report.[68]

[S] A recurring problem in large-scale IT programmes is 'slippage', and the NPfIT was no exception. In late 2009, all the research teams in the Connecting for Health Evaluation Programme were offered the option of bidding for additional funding to extend their evaluation period. We chose not to do this because we saw an inherent pro-innovation bias in 'waiting until the programme gets underway and then evaluating it'. In a previous systematic review, we identified several hundred studies on adoption of innovations and only one on non-adoption.[82] We believe that the 'symmetrical' approach described in this report represents a significant methodological advance for studying complex innovations that are characterised by delayed adoption, partial adoption or adoption followed by abandonment.

4. Implementing the SCR programme: Connecting for Health

4.1. Strategy 2007-2010

4.1.1. In any evaluation, it is important to assess progress against the original vision and business plan. When strategy documents and business cases were supplied to us by CFH, they had sometimes had material deemed "commercial in confidence" removed or bespoke extracts prepared for us. Hence, this section should be read with the caveat that our dataset may have been incomplete. It was beyond our remit to pass judgement on the budget allocation or financial management of the programme (see terms of reference paragraph 3.1.7). In view of this, we have restricted the material presented in this section to what we feel is background for the findings and interpretations presented in later sections.

4.1.2. Funding requests for the programmes in the NPfIT (in common with almost all major spending decisions in the NHS) are prepared by senior CFH staff and considered first by the Department of Health Capital Investment Board (CIB), then by government ministers responsible for NHS spending and finally by Her Majesty's Treasury. The procedure for gaining approval is complex and requires an initial Strategic Outline Case, then (generally) an Outline Business Case and then a Full Business Case. The last two of these are required to follow a "five-case approach to NHS IM&T business cases" by setting out:

a. 'The Strategic Case' to explain why the investment is needed and in particular to set out the anticipated benefits of the programme – both 'cash releasing' (saving money that can be allocated elsewhere in the system) and 'non cash releasing' (improving quality, safety or the patient experience);
b. 'The Economic Case' to identify a preferred business option;
c. 'The Financial Case' to demonstrate how the scheme will be made affordable;
d. 'The Commercial Case' to set out procurement requirements; and
e. 'The Management Case' to demonstrate that the scheme is achievable and can be successfully delivered in accordance with accepted best practice.

4.1.3. In relation to the SCR programme, CFH staff supplied us with two documents:

a. A 45-page Strategic Outline Case, version 1.0, dated 20th October 2007; and
b. A 143-page Full Business Case, draft 0.5, dated 26th February 2008.[60 T]

4.1.4. The Strategic Outline Case referred to four policy and policy-related documents: the *Comprehensive Spending Review* (1998) and subsequent Public Sector Agreements (PSAs)*; Our Health, Our Care, Our Say* (2005)*, Direction of Travel for Urgent Care* (2006), and *Our NHS, Our Future* (2007).[5-7;85]

4.1.5. The 1998 *Comprehensive Spending Review* was a landmark document published by HM Treasury soon after the Labour government first came to power, which set out the vision for modernising public services (see Section 2.2) and announced that all government departments would be required to set explicit targets for Public Sector Agreements and demonstrate how they were delivering against these. The two

[T] According to this document, the SCR programme went direct from a Strategic Outline Case to the Full Business Case without an Outline Business Case. After the draft version of this evaluation report was submitted to CFH in March 2010, we were supplied with a later version of the Full Business Case, dated 25th September 2009.[84] Some aspects of the material presented in this section were dropped from the latest version of the business case. In particular, as noted in Chapter 9, HealthSpace was uncoupled from this business case. Hence, this section mainly represents an account of the original strategy and business case which informed the work we were evaluating between May 2008 and February 2010.

specific PSAs from the 2004 *Spending Review* which the SCR programme was considered likely to deliver against were *"improve health outcomes for people with long-term conditions"* and *"improve the patient experience"* (page 15).[86]

4.1.6. *Our Health, Our Care, Our Say* emphasised the need to improve access to services in health and community care, reduce inequality of access, promote self-care and provide personalised care closer to home.

4.1.7. *Direction of Travel for Urgent Care* highlighted a difference in quality between 'in hours' and out-of-hours NHS services and sought to bring the latter up to the standard of the former (*"People using services and [their] carers should expect 24/7 consistent and rigorous assessment of the urgency of their care need and an appropriate and prompt response to that need"* – page 16[6]). It also sought to resolve the current ambiguity and lack of clarity in the definition and scope of unscheduled and out-of-hours care (page 11), and align health and social aspects of care (*"Urgent care will only be truly effective when it is able to respond in an integrated way to urgent health and social care needs"* – page 12[6]).

4.1.8. *Our NHS, Our Future* was an interim report by Lord Darzi which summarised a consultation with 3000 NHS staff and service users, and made recommendations for an across-the-board improvement in the quality of services.[7] The final version of this report, entitled *High Quality Health for All: NHS Next Stage Review* (usually referred to simply as the *Next Stage Review* or the *Darzi Review*) placed particular emphasis on developing local clinical leadership, placing the patient at the centre of care, resourcing change efforts, creating an infrastructure to support implementation, providing state-of-the-art technology and developing protocols and systems to ensure that hoped-for benefits were fully realised in all parts of the programme.[20]

4.1.9. The original Full Business Case (February 2008) considered five options for implementing the SCR:

Option 1. 'Do minimum' – i.e. wait until Local Services Providers have fully integrated their Care Records Service solutions; *"leave the market to innovate"* in relation to patient access to their own records; and support early adopter sites as they implement the SCR at their own pace.
Option 2. Introduce level 1 information content (see paragraph 2.4.3) over 3 years.
Option 3. Introduce level 1 and 2 information content over 3 years.
Option 4. Introduce level 1 and 2 information content over 5 years.
Option 5. Introduce level 1 and 2 information content over 7 years.

4.1.10. These different options played out differently in terms of estimated costs. The last four all required a strictly timetabled approach to project management with clear and largely non-negotiable milestones. Option 4 was selected as the preferred one on the basis of cost and of how long the implementation would realistically take. (*"Overall will incur extra expenditure over option 1, but will deliver benefits more quickly and will keep the momentum of the SCR programme going"* – page 87[60]).

4.1.11. Option 1 ('do minimum') was rejected mainly because of *"the greater risk of NHS users being 'turned off' the SCR due to the delay to the start of deployment"* (page 59) and because, CFH felt, this option *"would do nothing to realise policy drivers, investment objectives and benefits for several years"* (page 87).[60]

4.1.12. The original Full Business Case recognised the future potential for adding additional content and use cases for the SCR, including remote access via mobile devices, but did not seek funding to implement these further changes.

"This business case does not include expansion of the information held on the SCR beyond 'level 2' – for example information concerning care plans, ambulance reports and patient encounters with Out-of-Hours services, mental health, NHS Direct and health and social care settings. This is because not enough is known at present regarding aspects such as the specific information content, information governance issues, costs, technical implications and relative priorities of the various possible extra information components."

Full Business Case for SCR (February 2008), page 44[60]

4.1.13. The option of introducing the SCR for only some NHS service users (e.g. those with long term conditions) was considered but rejected in favour of rolling out for all NHS patients. CFH commented that this whole-population option

"….[w]ill be a challenge for both suppliers and the NHS, but delivers well against policy drivers and investment objectives"

Full Business Case for SCR (February 2008), page 85[60]

4.1.14. The option of allowing only health professionals to access the SCR was considered but rejected in favour of also allowing service users to access their own SCR via HealthSpace. This was because

"….[a]lthough the most expensive and challenging option, [this] will maximise benefits and realisation of investment objectives"

Full Business Case for SCR (February 2008), page 86[60]

4.1.15. The possibility of making the SCR available in all or most NHS care settings (e.g. GP surgeries, outpatient clinics) as well as unscheduled care was rejected on the basis of much greater cost for minimum or no incremental benefit.

4.1.16. Two options were considered for patients to access their own SCRs: HealthSpace and "other means" (a generic category which embraced everything from paper printouts to a new freestanding computer application). HealthSpace was considered the preferred option, because

"the existing HealthSpace application […] is already developed and undergoing early adopter evaluation, and hence is a low risk, low cost mechanism for patients accessing their own SCR records"

Full Business Case for SCR (February 2008), page 85[60]

Strategy for the HealthSpace programme is considered in Section 9.1.

4.1.17. The original Full Business Case for the SCR appears to have used relatively optimistic estimates of the future uptake and use of the SCR. For example, it stated:

"based on experience to date within the early adopter community, approximately 10% of GP practices may refuse to take part in SCR creation, not reach the required data quality standards or would have GP systems whose suppliers cannot or will not undertake the work needed to integrate them with Spine"

Full Business Case for SCR (February 2008), page 46[60] [U]

4.1.18. The governance structure for the national roll-out of the SCR programme comprised:

a. The National Programme Board, which oversaw the whole NPfIT;

[U] Our May 2008 report on the early adopter programme reported that fewer than half the practices in Bolton and Bury, and none in South Birmingham and Dorset, had uploaded data to start creating SCRs.[1] These interim figures did not represent final participation levels but neither did they support a projected level of 90% participation. Furthermore, early adopter sites had been selected on the basis of various attributes likely to increase the chances of successful deployment locally.[4]

b. The NHS Care Records Programme Board, which oversaw the SCR programme plus other elements of the Care Records Service;
c. The SCR Programme Board, the main governance body for the SCR, which oversaw the implementation of this programme;
d. The National Clinical Reference Panel (NCRP), a sub panel of the Care Records Service Programme Board, whose remit was to oversee the clinical content of the SCR (in communication with the over-arching Clinical Content Governance Board), set priority areas for further development of SCR content, and oversee patient and clinical matters; and
e. The Summary Care Record Advisory Group (SCRAG), recommended as part of the Ministerial Taskforce Report on the SCR[33] and the official non-executive group charged with ensuring that its recommendations were taken forward.

4.1.19. The SCR programme was subject to stringent information governance procedures to ensure technical security and protection of confidentiality. From October 2007 the National Information Governance Board for Health and Social Care (NIGB) was established with a remit to address ethical issues, interpret law and policies, and advise on information governance matters at national level. The NIGB had a lay chair (Harry Cayton) and reported directly to the Secretary of State for Health. At operational level, information governance was considered an integral part of development and implementation activity by all CFH departments. A technical team took responsibility for implementing and testing security standards across the NPfIT. Information governance is considered in Section 8.5.

4.1.20. At the time we submitted this report (March 2010), the revised Full Business Case for the SCR had been approved by the DoH Capital Investment Board but we understand it was still awaiting approval by HM Treasury (see paragraph 4.1.2).

4.2. What Connecting for Health expected of the SCR

4.2.1. Strategy documents and the original business case for the SCR considered that this technology would help to meet a number of the key priorities set out in the Darzi review:

a. Equity of access, outcomes and treatment quality:

"The SCR will provide information that is often not readily available within urgent care settings which will help ensure that outcomes and treatment quality are improved. It will be particularly valuable for people who are otherwise disadvantaged through language or other personal communication barriers, to ensure equity of access."

Strategic Outline Case for SCR, page 3[86]

b. Improved clinical effectiveness:

"[The SCR] will reduce incidents of patients being inconvenienced through treatment not being provided at the point of care due to lack of information. […] [The SCR] is a prime example of a new technology innovation that can be used to directly improve patient outcomes"

Full Business Case for SCR (February 2008), page 36[60]

c. Improved clinical safety, especially in relation to hospital-acquired infections:

"the increased ability to treat urgent care patients and the knock-on effect of less call on secondary care services that emanates from the SCR results in a reduced

incidence of hospital-borne Health Care Associated Infections across the population"

Full Business Case for SCR (February 2008), page 36[60]

d. Local accountability:

"[the SCR] is a prime example of a highly clinically-focused part of the NHS CFH portfolio whose main aim is to improve clinical care and is locally driven through implementation plans reflecting identified local benefits"

Full Business Case for SCR (February 2008), page 36[60]

e. Patient empowerment (by accessing their SCR via HealthSpace, people would be better informed about their illnesses) and choice (a distributed record would mean the person could seek care from several possible sites and settings):

"The SCR provides the public with not only a choice but also a greater insight and access to their medical history and control of their own health".

Quote attributed to NHS Next Stage Review Primary and Community Care Strategy – cited in CFH's response to that document, page 19[87 V]

f. Improved patient satisfaction

"Improved patient satisfaction as a consequence of their ability to state their preferences (e.g. for end-of-life care), better and more timely clinical interventions, more 'joined up' healthcare delivery and (via HealthSpace advanced accounts) greater patient involvement in their healthcare."

Full Business Case for SCR (February 2008), page 10[60]

4.2.2. The various benefits anticipated for the SCR were based largely on focus groups of front-line clinicians who were asked to estimate how much time or other resource might be saved in different situations (either releasing cash or allowing some other beneficial activity to be undertaken). Anticipated benefits were differently quantified in different early documents, reflecting the uncertainty around the estimates:

a. One set of data supplied to us by CFH anticipated that SCR use would render unnecessary one in 25 home visits, one in 200 ambulance call-outs to urgent care centres, one in 100 referrals from out-of-hours centres to A&E, and one in 100 emergency admissions of patients presenting to A&E;
b. The Full Business Case for the SCR (February 2008, page 116) anticipated that use of the SCR would make GP out-of-hours telephone calls, base visits and home visits 15% shorter, A&E and walk-in centre encounters 33% shorter, attendances at acute medical, surgical and elderly assessment units 50% shorter, and mental health crisis intervention encounters 60% shorter;[60]
c. Impact on medication safety in hospitals was anticipated to be substantial on the basis of an assumption (borne out by independent data[88]) that around 10% of hospital patients currently experience an adverse reaction to a medication;
d. There was no specific estimate of safety benefit in primary care settings. Serious adverse drug reactions are much less common in the primary care setting, though since over 600 million prescriptions are issued annually, most of which occur in primary care, even benefits that occur very rarely may be significant.[88]

4.2.3. Considering the different possible framings of the electronic patient record (Table 3.2, paragraph 3.4.1), the majority of CFH staff, whether clinically qualified or not, appeared to share a particular perspective on the SCR and its use:

[V] We were unable to find the original source for the text quoted here. CFH have confirmed that the quote was incorrectly attributed to the Darzi review in their response. It is possible that the text was in a draft version of that document issued for consultation and subsequently altered in the final version.

a. They framed the SCR as (essentially) a technology-based container for information about the patient (*"the SCR is just a big bucket in which to put information in, just a bucket to put the encounters in"* – CFH staff member, SHA Programme Leads Forum, December 09);
b. They framed users of the SCR as people making clinical decisions;
c. They framed 'context' as separate and separable from the SCR rather than as constituted in particular ways through the use (or non-use) of the SCR;
d. They tended to describe the process of implementing the SCR as "deployment" and saw it largely as an exercise in project management, though they recognised that it was a highly complex and difficult project that required engagement of multiple stakeholders;
e. They framed success of the programme in terms of specific, measurable benefits that could and should be predefined, though they recognised that different benefits were likely to be realised in different contexts;
f. They considered it as given that a national IT system for the NHS with widespread integration between its components was a desirable goal.

4.2.4. They tended to speak of the SCR in somewhat idealised terms. We noted four tendencies in particular amongst CFH staff and others involved in the programme:[W]

a. A tendency to couch a wide range of issues relating to quality, safety and efficiency in the NHS in terms of lack of information and the solution in terms of more and/or better information:

   "What are your issues that the SCR can fix"? – CFH staff member inviting contributions from SHA Programme Leads, January 2009

b. A tendency to assume that electronically-held, distributed information would generally be characterised by completeness and accuracy:

   "Traditionally we've spent a lot of time arguing about whether the data's right, we want to have a single source of data that we all believe is the truth…so we can use the information to make better decisions […] ultimately to give people better care, better outcomes through better use of information"."

   Tim Straughan, Chief Executive, NHS Information Centre for Health and Social Care, Keynote lecture, CFH/ASSIST Annual Conference, 4th June 2009

c. A tendency to assume that integration of records across the NHS would eventually reduce duplication and inconsistency; and

d. A tendency to assume that patients would be interested in accessing their records and self-managing their long-term condition, and that this would impact on health outcomes and health service use (e.g. more self-management would mean fewer appointments).

4.3. Operationalising the national roll-out

4.3.1. The period covered by this evaluation represented a shift from a small-scale early adopter phase to a much larger national rollout over a relatively short timescale.

[W] Even though these tendencies seem intuitively reasonable, there was already some empirical research evidence suggesting that they were based on questionable assumptions.[89;90] Our own findings (Chapter 6) raised further questions in this regard. We are not suggesting that these tendencies reflected official policy on the SCR, merely that many though not all staff working on the programme took a hopeful perspective on the benefits it would bring.

"The [SCR implementation] team had been operating in a handholding early adopter phase, and we had to move quickly to a situation where we were involving 10 SHAs, 152 PCTs and 8500 GP practices and there's no way you can hand hold those kind of numbers. The foundations were laid, the knowledge was there in a small number of people and organisations, and the challenge then became, 'how do we move from person-to-person transaction to putting processes and guidance in place that can support those larger numbers?'"

Senior CFH executive, SCR programme (FX11)

The NHS Operating Framework

4.3.2. The way SHAs take on new nationally-set tasks and targets is for these to be placed in an annual work plan published by the Department of Health, known as the NHS Operating Framework.

a. The 2008-9 Operating Framework mentioned the SCR and HealthSpace only as an *"expected"* development.

b. The 2009-10 Operating Framework (published in December 2008) stated:

"The introduction of the Summary Care Record (SCR) will improve patient care, in particular for those with a long-term condition or requiring urgent care. SHAs will agree the timeline for implementing the SCR with PCTs as commissioners" (paragraph 51);[91]

c. The 2010-11 Operating Framework (published in December 2009) made a single reference to the SCR:

"Innovative use of new and emerging technology and systems, alongside implementation of national capabilities, including the summary care record (SCR) service and electronic prescription services (EPS), can support the development of new models of care. Recent pilots have demonstrated innovative use of such technologies; these will now be extended in partnership with local health communities to include the accelerated evaluation and roll-out of assisted care pilots, extraction of learning from the National Pandemic Flu Service and exploration of mobile working for community nurses." (paragraph 3.74)[92]

4.3.3. In late 2008, the Department of Health published an Informatics Planning document which built on the 2009-10 Operating Framework and set out the responsibilities of NHS organisations in broad terms as follows:

"Individual NHS organisations working collaboratively within local health communities [LHCs] should plan for the roll-out of the SCR across LHCs with a focus on urgent care setting will have commenced during 2008/09, once compliant software is available. SHAs will agree the timeline for implementing the SCR with PCTs as commissioners, and full roll-out of the SCR will be demonstrated in LHC plans. Roll-out will be based on a two year window for the full deployment of SCR from the date on which all GP systems in the PCT are compliant. PCTs will manage compliancy of GP systems in accordance with their primary care informatics strategy and to bring forward the benefits offered by SCR."

NHS Informatics Planning Document 2009-10, page 13[93]

4.3.4. More specifically, responsibilities of NHS organisations for implementing the SCR programme were described thus:[93]

a. All NHS providers (including GP practices and the provider function of PCTs) were required to achieve operational readiness for deployment, staff training, clinician engagement and data quality accreditation; ensure that GP practices

had systems which supported the SCR; and implement a public information programme to inform patients of the implications of the SCR and (implicitly) their options for opting out;

b. PCT commissioners were required to lead the development of LHC (local health community) informatics plans including effective preparation and planning for SCR implementation and systematic benefit realisation;
c. SHAs were required to agree and co-ordinate consistent public information programme messages and ensure authority-wide achievement of SCR implementation.

4.3.5. The Informatics Planning document for 2010-11, published in December 2009, reads as follows:

"PCTs, as commissioners, should agree a timeline with their SHA for the creation of SCRs at all SCR-compliant GP practices in the financial year 2010/11. Subject to the business case being approved, PCTs should agree an implementation plan for the care settings that will realise the benefits of access to SCRs, including timeframe and approach to undertaking a Public Information Programme."

NHS Informatics Planning Document 2009-10 (page 11)[94]

Organising from the centre

4.3.6. Official accountabilities notwithstanding, transfer of responsibility for the NPfIT from CFH to the SHAs took time (see quote paragraph 4.3.1) and was not fully operational by early 2010. Key posts in some SHAs were unfilled; the division of labour between the SHAs and CFH was still being clarified; and SHA chief executives were reflecting on the SCR's priority against other strategic 'must-dos'. CFH was keen to maintain a national branding for the SCR programme and avoid local health communities having to 'reinvent the wheel'. De facto, setting strategy and pursuing targets for delivering the SCR programme remained largely a nationally-driven exercise throughout the period of this evaluation and the metaphor of "hand-holding" was frequently used by senior managers to describe their relationship with local health communities.

4.3.7. The SCR Programme Board at CFH met monthly and considered both strategic issues relating to future extensions or modifications to the programme and operational issues relating to the implementation of the current programme. Towards the end of 2008, the SHA Programme Leads Forum was established which merged with the Early Adopter Implementation Board for the SCR. This forum met monthly and saw its role as addressing the operational front line including such issues as project management, stakeholder engagement, the public information programme and information governance. In addition, a Chief Information Officers (CIOs) Forum, attended by the SHA CIOs, met monthly and considered the implementation of all aspects of the NPfIT. This latter group saw its role largely in terms of making strategic-level decisions and signing off agreements.

4.3.8. The original management structure of the SCR programme as set out in the Full Business Case (February 2008, page 16) is reproduced in Figure 4.1 (in which 'local NHS' represents the various out-of-hours and other unscheduled care providers).[60] It involved six main workstreams: [technical] design, operational readiness, business change, communications, deployment, and planning and reporting.

4.3.9. CFH appointed a number of clinically qualified Directors and National Clinical Leads. These individuals, whose role was to engage their fellow clinicians and lead implementation efforts nationally, had a track record of success and seniority within their profession, a high level of credibility amongst their peers and subordinates (i.e.

they were both 'peer' and 'expert' opinion leaders[82]), and connection to a range of different organisations, professional bodies and professional networks. For example:

a. The National Clinical Director for the SCR and HealthSpace, Dr Gillian Braunold, was a part-time partner in an inner-city GP practice as well as an active member of the British Medical Association. Prior to taking on her CFH role, she had been chair of her Local Medical Committee as well as a regional BMA representative and deputy chair of the Joint GP IT Committee of the General Practitioners Committee and Royal College of General Practitioners (JGPITC) and member of the BMA's Working Party on NHS IT. She was also well connected in the Department of Health;
b. One of the National Clinical Leads for GPs, Dr Manpreet Pujara, was a part-time GP as well as the Chair of the National User Group for the GP system supplier EMIS. He represented EMIS users at the JGPITC, as well as CFH's GP Pan User Group and the GP Systems of Choice User Group;
c. The Medical Director at CFH, Dr Simon Eccles, began his clinical career in various hospital specialties and still works as a consultant in emergency medicine. He took an early interest in medical politics and was instrumental in negotiating changes to junior doctors' contracts. He later joined a number of committees at the BMA and had in the past held a non-executive role in a commercial IT company;
d. The National Patient Lead at CFH, Marlene Winfield, had a long history of working in the voluntary sector, especially in relation to patient activism and medical injury claims. Before joining CFH she had been Head of Policy Research and Strategy at the National Consumer Council and chaired the Litigant Information Subcommittee of the Civil Justice Council.

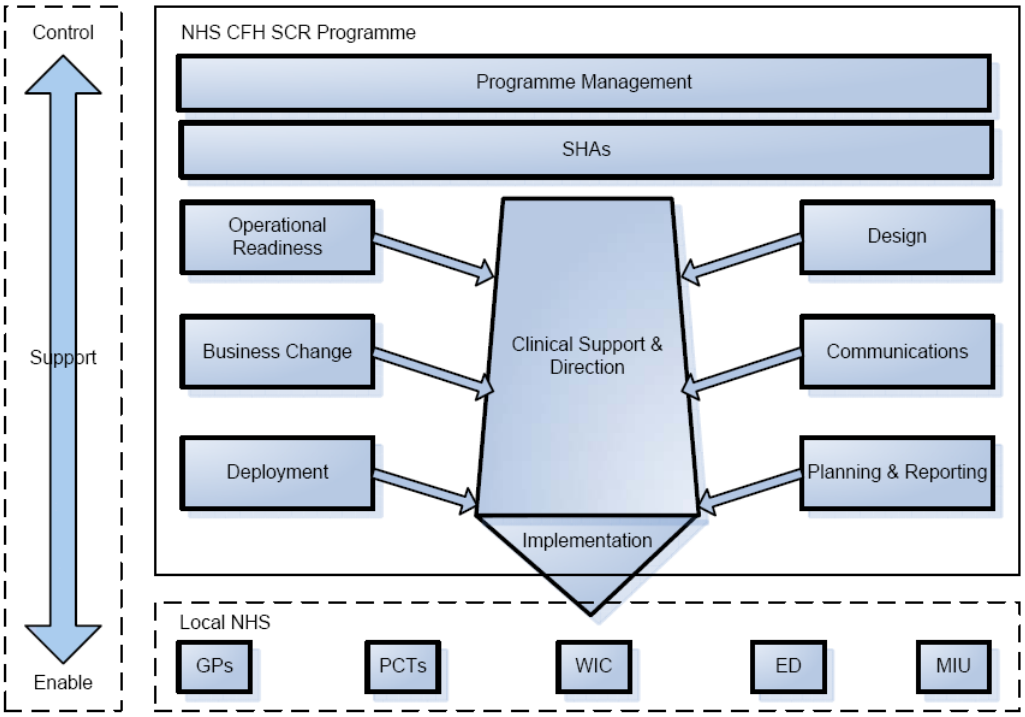

Figure 4.1: Original structure for operational management of SCR programme (reproduced from February 2008 version of Full Business Case, page 13[60])

Making local links

4.3.10. To manage the link between national and local implementation, CFH appointed a team of five Implementation Managers (later renamed National Implementation Managers or NIMs). Each was assigned to two SHAs for which they would be the single point of access into CFH. Their brief was to support SCR implementation in at least one PCT per SHA. As the programme expanded, further NIMs were appointed.

4.3.11. A group of local Clinical Leads (mostly GPs working one or two sessions per week) recruited from participating PCTs, to work under the guidance of the National Clinical Lead. The role of the local Clinical Leads was envisaged as being an "ambassador" and public face for the SCR, securing support from key stakeholders (especially the Local Medical Committee), managing clinical expectations, supporting change, facilitating the sharing of good practice, reporting progress back to CFH, and escalating problems to them that needed to be addressed nationally.[95] The perspective of Clinical Leads is considered in Section 5.2.

4.3.12. Whereas in the early adopter phase, CFH had worked directly with participating PCTs to run small-scale 'engagement' meetings with stakeholders such as GP practices and Local Medical Committees, the scale and pace of the national roll-out largely precluded this option. Local Clinical Leads were encouraged to undertake engagement work with their fellow clinicians. In addition, CFH organised some large regional engagement events (notably a well-attended 'LMC event' held in London in December 2009) with presentations from both CFH staff and local champions.

4.3.13. CFH set up an online resource archive and national information portal (eSpace) through which staff in participating NHS organisations could download tools and resources including guidance documents, templates, a Readiness Assessment Tool (comprising a checklist against which PCTs could self-assess as 'red', 'amber' or 'green') and various resources on information governance and engagement. There was also a facility to post questions and comments onto a secure bulletin board, though in practice this was little used (for example on 1st March 2010, the latest 'news' item was dated 2nd October 2009 and despite there being 577 members, almost all messages had been posted by CFH staff). The site contained a great deal of material (reflecting the many dimensions of the programme) and even CFH staff found it difficult to navigate (*"I struggle to use it and I work here"* – CFH staff member giving presentation at Clinical Directorate, December 2009).

4.3.14. CFH placed great value on maintaining a master overview of progress and emphasised the 'reporting back' role of the SHA Programme Leads. Initially, senior project managers sought weekly reports summarising the current state of play (collating PCTs' responses to the Readiness Assessment Tool on a SHA-level Progress Status Report, including key milestones achieved last month, key milestones planned this month, key lessons learned, key risks and issues, key benefits demonstrated), which central CFH staff would in turn collate to update their national Plan on a Page (POAP). This approach was subsequently relaxed somewhat, partly because NHS managers felt that the reporting interval was too tight and partly because not all staff bought into this formalised reporting regimen.

4.3.15. Much work was done within CFH by what was known as the business readiness team. Staff produced a set of business process maps covering a wide range of eventualities that might occur at the front line (e.g. responding to a patient's request to see their GP summary record, dealing with a parent who sought to opt out on behalf of their child, managing a legitimate relationship alert, and so on). An example of part of one such map is given in Figure 4.2.

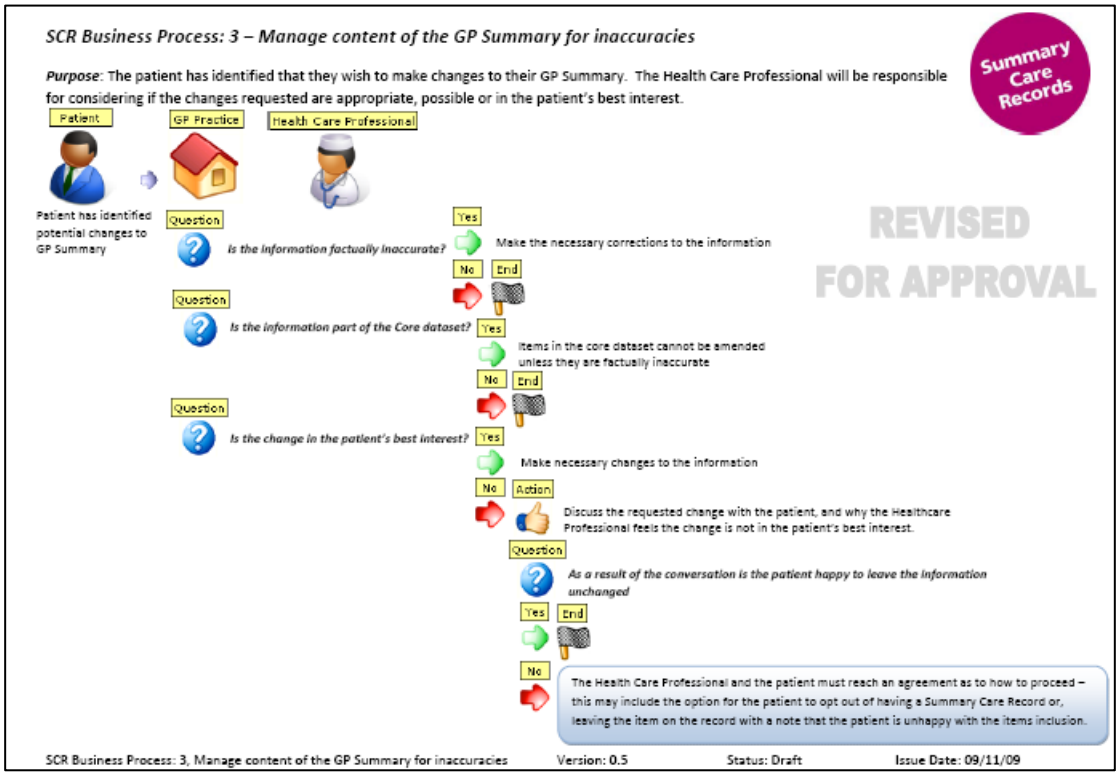

Figure 4.2: Example of a business process map produced by CFH

Communications

4.3.16. The Communications department of CFH produced a number of resources, both to support project management and to communicate the benefits of the SCR to stakeholders locally and nationally. These included:

a. 'Concept training' resources (Powerpoint presentations and leaflets introducing the SCR to staff);
b. Posters, leaflets and DVDs aimed at service users;
c. Template press releases and patient letters to use in public information programmes;
d. Organisational 'case studies' (stories of how the SCR was being used, valued and producing benefits in NHS organisations); and
e. Individual 'case studies' (stories of real patients who had allegedly benefited from having a SCR, reproduced with consent, see example paragraph 7.3.9).

4.3.17. The release of information from CFH, especially its Communications department, was strictly controlled. Materials went through a rigorous approval process and required a standardised branding and multiple sign-offs before release – an approach which sometimes led to delays in releasing materials.

"National Implementation Presentation v1.0 – Approved
Document Status: This is a controlled document.
This document version is only valid at the time it is retrieved from the controlled file store, after which a new approved version will replace it. On receipt of a new issue, please destroy all previous issues (unless a specified earlier issue is base-lined for use throughout the programme)."

From introductory slide of CFH's SCR concept training resource, version 1.0

Testing

4.3.18. A major component of the SCR implementation was CFH's Common Assurance Process (testing). This comprised a highly structured and sequential approach which involved CFH, NHS organisations and suppliers. It included:

a. Deployment user acceptance testing – a test in a non-live environment to ensure that the system is working as planned;
b. Ready for operations testing – the phase in which the service management processes around live running of the software were validated prior to a go-live. Examples are validation of management reporting, helpdesk scripts, processes and tools, operational support processes (a support manual), capacity planning and backup and recovery processes;
c. Integration – 'end-to-end' testing of the live system, including interfaces between the services and the services supplied by the integrated service providers;
d. Integration witness testing – undertaken by CFH compliance team who attended on-site to witness the functionality of the system. Test scripts were agreed in advance and a series of documents provided;
e. Penetration testing – a security test to identify vulnerabilities in systems open to attack. This step was a central element in the Common Assurance Process. It was usually undertaken by accredited penetration testing specialist organisations under subcontract. A report and risk assessment was produced and submitted to CFH for review.

The public information programme

4.3.19. Given the pressures on the SCR programme to deliver benefits as quickly as possible and what many perceived as a legal requirement to gain consent before creating SCRs, it was seen as high priority to run a public information programme (or PIP) to inform patients about the SCR and offer them an opportunity to opt out. In the early adopter phase, these mailshots were run at PCT level and usually targeted specifically at patients whose GP practices were intending to go live imminently.[1] It was considered key to success to undertake local engagement work with general practices and other NHS staff before commencing the information programme. We have written a separate academic paper on this early communication work.[96]

4.3.20. The initial plan for the national roll-out was to follow a similar incremental, PCT by PCT, model. But feedback from the SHAs (Section 5.1) made it clear that few had any plans to run a PIP imminently and a significant barrier was claimed to be the cost of the mailshot. Furthermore, the national roll-out was unfolding at the same time as the build-up to a general election, and the main opposition party had already published a review of the NPfIT which challenged the principle of large-scale, centrally run databases.[97] A change of government was seen as a significant risk to the SCR programme, and various internal incentives and targets were created within CFH to make substantial progress by the end of 2009 (for example 'one million SCRs created by date X').

4.3.21. Given the perceived urgency to create as many SCRs as possible in as short a time as possible, the SCR Programme Board decided to run the public information programme on a region by region basis (an approach which became known as the 'regional PIP') via a national mailing house, and to send letters to all patients, even those whose GP practices were not actively participating in the programme. Because of this rapid increase in scale of the programme, the policy of engaging GP practices by a personal visit was replaced by an 'information pack' containing click-through Powerpoint presentations and a DVD.

4.3.22. To encourage early participation, a funding incentive from the DoH was offered to SHAs who sent letters by March 2010. Because of the large numbers involved (20 million patients would be written to in four months), each SHA was required to book a 'slot' in the mailhouse queue. An initial plan to send one letter per household rather than one per individual was vetoed by the Information Commissioner.

4.3.23. As this report was submitted in early March 2010, the regional PIP was underway and large numbers of people were receiving letters informing them that their SCR would soon be created. The British Medical Association had just issued a statement expressing its concern that the SCR roll-out appeared to be happening too hastily and in a way that was unlikely to lead to full informed consent.[98] Different Local Medical Committees were 'customising' the patient information letter in different ways depending on their level of support for the SCR programme, and interest from the press and civil liberties groups was high.

4.3.24. In sum, over the course of late 2009 and early 2010, the PIP shifted from a locally run initiative closely tailored to what was happening in the person's own GP practice (and hence, what was happening in relation to the person's own record) to what some SHA Programme Leads described as a rush for slots in which several million patients would receive a letter that was not necessarily linked to specific plans by their own GP practice to create records.

4.4. What Connecting for Health expected of NHS organisations

4.4.1. Local implementation of the SCR programme was viewed by CFH as dependent on a number of factors (listed below in the order set out in CFH's guidance document):[95]

a. Project management and governance controls;
b. Local ownership and clinical sponsorship;
c. Support from patients and patient organisations;
d. A full-time project manager;
e. Stakeholder buy-in (particularly, lack of powerful opponents);
f. Good stakeholder communication;
g. A public-facing information programme;
h. Training of front-line staff;
i. A benefits realisation strategy – i.e. identification of what benefits the SCR would deliver locally and a plan to manage and evaluate against these benefits; and
j. Early involvement of organisations where the SCR is intended to be used.

4.4.2. CFH expected that PCT project managers would help produce a Project Initiation Document; work towards a state of 'readiness' for joining the programme by addressing clinical engagement, data quality, staff training and the public information programme; liaise with suppliers and support the go-live phase in GP practices; manage the introduction of the SCR into selected NHS organisations locally; and undertake 'benefits realisation' work in liaison with a Benefits Lead at their local SHA.

4.4.3. CFH viewed benefits realisation work as comprising a number of linked tasks:[X]

[X] The emphasis on defining, charting and "proving" benefits reflects the wider emphasis in the civil service on Public Sector Agreements oriented to specific deliverables closely tied to funding allocation (see Section 4.1). In short, if benefits were not demonstrated, the programme risked losing its funding. However, as we note in Section 11.1, 'benefits' is a term that is open to interpretation and as such, projects came under pressure to define and measure them.

- *"Review the benefits described in the PID [Project Initiation Document] and produce the detailed benefit statements;*
- *Set up and populate a benefits database;*
- *Identify actions needed to achieve the benefits and allocate local responsibilities at appropriate senior levels;*
- *Define the appropriate 'metrics' for each benefit, and perform and record the results of applying the metrics pre- and post-business go-live;*
- *Identify and document any new benefits and also any non-benefits;*
- *Prove/disprove identified benefits and produce reports for local project board."*

Readiness Assessment Guidance for SHAs and PCTs, page 14[95]

4.4.4. All NHS organisations are required to have a Caldicott Guardian – a named individual who must ensure that systems are in place to protect confidentiality and comply with data protection law. The National Information Governance Board proposed that PCTs should also appoint a privacy officer – a more junior role for day to day management of information governance issues. The key information governance task at PCT level was seen as auditing the alerts that were generated automatically when a SCR was accessed without an apparent legitimate relationship, reconciling these with other data sources (e.g. admissions lists) and escalating anomalies (see Section 8.5).

4.4.5. CFH envisaged that PCTs would set up a 'front office' function (to deal with patient enquiries and correspondence, for example relating to opt-outs) and a 'back office' function (for work that was not directly patient-facing). Staffing requirements for SCR implementation as originally envisaged are set out in Figure 4.3.[60]

Figure 4.3: Deployment and support staffing roles envisaged for SCR programme (reproduced from February 2008 Full Business Case for SCR, page 50)[Y]

4.4.6. Prior to uploads, a number of activities had to be completed at the practice. In-house computers had to be audited and if necessary upgraded; demographic details of local patient records had to be synchronised with records on the PDS; and RBAC codes for all staff need to be changed.

[Y] The notation in this table includes the symbols # ('level 2 only roles' – i.e. only needed once the SCR functionality is extended to include write access from NHS organisations other than GP surgeries) and $ ('operational only roles'). 'SRO' = Senior Responsible Officer. 'Project Manager for Local Support' was later renamed 'National Implementation Manager'.

4.5. Measuring benefits and charting progress

4.5.1. As described above (Section 2.2 and 4.4), the SCR programme was strongly oriented to achieving deliverables on public-sector investment ('realising the benefits'). All SHAs were required to produce a detailed planning document (typically, an Excel spreadsheet) setting out a series of locally-relevant benefits from the SCR and how they would measure them, and to report on these periodically. Extracts from an example of such a document are shown in Table 5.1, paragraph 5.1.18.

4.5.2. Much activity within CFH was oriented towards collating the benefits of the SCR as these were demonstrated at the clinical front line and disseminating these nationally. A series of case reports was produced by the Communications department, mostly as A5 leaflets, describing real patients who had been helped by the presence of a SCR.[Z] 'Benefits' case studies were produced for different professional groups (GPs, district nurses, pharmacists etc), each featuring a local champion and a clinical story.

4.5.3. There have been multiple targets set by multiple bodies for how much progress should be made in the SCR programme by what date. At policy level, the idea of electronic summary records, accessible by authorised staff throughout the NHS, was first mooted in *The NHS Plan* in 2000.[99] In 2002, it was anticipated that summary records would be accessible from unscheduled care settings by the end of 2005 and viewable by patients by the end of 2007.[32] By 2005, the target for reaching the goal of an electronic summary on every NHS patient who had not opted out had shifted to 2010[47] and by 2009 to 2014-15.[59]

4.5.4. Operational targets have slipped in parallel with these high-level targets, though front-line project managers have tended to offer an upbeat message of the likely pace of progress and the challenges associated with achieving it.

CFH presenter: "In quarter 1, by end June 09 target is 486,000 records created.... By March 2010, target is 13 million records created. 69 PCTs should have written to patients by end March 2010, 14 PCTs should be completed."

Question from SHA representative: "What does 'completed' mean?"

CFH presenter: "It means that within that PCT at least 60% of patients have a SCR and at least 3 care settings within that local community have access. This target shouldn't be that difficult to achieve".

Field notes from SHA Programme Leads Forum, January 2009

4.5.5. CFH produced weekly monitoring statistics giving the cumulative number of people mailed in the public information programme; the number of SCRs created and the number of SCRs accessed (see example Figure 6.1, paragraph 6.1.3). These progress statistics were emailed to senior managers and clinical leads in CFH, SHAs and PCTs, and formed a rolling agenda item at meetings. Thus, attention was drawn to quantitative data which addressed questions of the general format 'How many…?' and 'How quickly…?'. The collection, distribution and consideration of qualitative data which addressed questions of the general format 'Why…?' or 'Why not…?' appeared to be less systematic and viewed as less important.

[Z] These are available for download on http://www.connectingforhealth.nhs.uk/systemsandservices/scr/staff/aboutscr/comms/case.

4.6. Managing risks

4.6.1. The February 2008 version of the Full Business Case for the SCR included a lengthy section on risks and corresponding measures to mitigate these. These are listed in full in Table 11.3, paragraph 11.4.2.

4.6.2. The SCR Programme Board considered a rolling 'Red Risks and Issues' document at every meeting. Key risks and issues regularly discussed by the SCR Programme Board included:

a. Delays in approval of the business case;
b. Delays in provision of technical solutions by GPSoC suppliers;
c. Capacity problems e.g. insufficient supplier capacity to support SCR uploads from GP practices at the pace expected; insufficient staffing and resource in PCTs and SHAs to implement the programme and support ongoing SCR use;
d. Difficulties and delays in aligning systems and processes to ensure seamless use of the SCR in front-line clinical care in all provider organisations;
e. Reluctance of front-line staff to accept or use the SCR;
f. Difficulties and delays in modifications to contracts with suppliers e.g. for new functionality;
g. Issues relating to third party decisions e.g. withdrawal of funding for data quality work by GP practices (paragraph 8.3.2);
h. Negative media coverage;
i. Change of government.

4.6.3. Each major risk was discussed and an action plan produced which was then revisited at the next meeting. However, many risks were out of CFH's control and hence actions agreed at the Programme Board had limited potential to mitigate these risks. Indeed, the 'Red Risks and Issues' document was typically dealt with quickly in Programme Board meetings since many items were deferred as 'awaiting action from supplier', 'awaiting Treasury decision' and so on.

4.6.4. In mid 2009 CFH produced a draft internal report which explored reasons for the low usage of the SCR in many unscheduled care settings, particularly those in secondary care. This was based partly on interim feedback provided by our own team but mainly on material collected directly by CFH. This report identified a number of reasons why many staff at the clinical front line were not accessing the SCR:

a. Limited numbers of SCRs had been created (leading to what NHS staff referred to as a 'low hit rate');
b. Complexity of implementation plans – for example, ensuring that uploads, training and communications occur in a logical order in each locality:
c. Limited information currently available on the SCR (very few SCRs yet contained the 'enriched' dataset described in paragraph 2.4.2);
d. A perception by front-line staff that the data on the SCR was of variable quality – a finding attributed partly to lack of ongoing resource to support data quality work in primary care;
e. Confusion and fear amongst front-line staff about information governance issues:
f. The considerable 'business change' challenges with the SCR in many front-line settings. In particular, efforts to embed the use of the SCR as business as usual had met with multiple hurdles including cultural resistance, entrenched ways of working, difficulties ensuring that all staff were trained and the training maintained, and limited understanding of operational challenges;

g. Issues with the technology itself and the infrastructure needed to view it. This was seen as due partly to system performance (implicitly, that performance was sometimes slow and/or unreliable), partly to the current design of the SCR viewer (too many screens, too many requests for passwords), and partly to limitations in local ICT infrastructure (e.g. lack of computers, terminals, printers);
h. A continuing tension between national and local ownership;
i. The lack of technical integration in secondary care settings. It was recognised that the introduction of the integrated Adastra solution (in which the SCR appeared as a tab within the in-house system) had greatly increased SCR accesses in primary care settings. The need for a separate 'SCR viewer' in settings that did not use Adastra was considered to be compounded by the presence of 'competing' products such as TPP and SystmOne;
j. Limited understanding amongst front-line staff of how to use the SCR and of its potential benefits; and
k. Poor communication between PCTs, GP practices and hospitals, which meant that different parts of a local health community were not always aware of what was going elsewhere. In particular, hospitals in some early adopter sites were not made aware that SCR uploads had now reached the levels needed for a good 'hit rate'.

4.6.5. These findings have recently begun to be addressed at strategic level by a number of new initiatives, including renewed efforts to accelerate the enrichment of records for patients with long term conditions; renewed efforts to engage front-line staff (with *"a greater emphasis on usage and benefits"* – SCR Programme Board agenda paper 5.3, November 2009); support for a series of 'exemplar sites' for the SCR in different care settings; updated implementation guidance and a review of the 'end to end' information governance model with a focus on its appropriateness in different clinical environments. At the time of writing, all these work streams were in the process of being established. We revisit the issue of risk management in Section 11.4.

5. Implementing the SCR programme: Other stakeholders

5.1. Strategic Health Authorities

5.1.1. SHAs' strategic involvement in the SCR programme occurred via the Chief Information Officers (CIOs, see paragraph 2.3.7) whose Forum met monthly and covered all aspects of the NPfIT as set out in the NHS Operating Framework (paragraph 4.3.2 ff). This Forum was formal in ethos and kept fairly strictly to a predefined agenda. Its members had signed off the original Full Business Case (which included commitments for resourcing and operationalising the SCR roll-out) in late 2008. CIOs were keen to cooperate in efforts to realise benefits from the SCR and welcomed business support tools provided by CFH. Table 5.1, paragraph 5.1.18, shows an example of a provisional benefits document produced by a local team using guidance from CFH.

5.1.2. CIOs appeared to view the SCR as a relatively straightforward and uncontroversial element of the NPfIT, partly because the larger hospital systems were taking their attention and were associated with more controversy and partly because the benefits of the SCR were considered to be clear.

5.1.3. Early documents produced by SHAs and PCTs under CFH's guidance sometimes assumed that the benefits of the SCR were self-evident and far-reaching.

> *"The decrease in GP OoH [out-of-hours] calls converting to home or GP surgery visits and reduced time spent handing calls in OoH centres will combine to increase GP OoH capacity. Secondary care capacity will be increased due to the decrease in emergency admissions, decreased emergency process bed days and decreased emergency length of stay discussed above in the secondary care category. Together these two benefits will combine to increase provider productivity, aided by the reduced time taken triaging patients in A&E."*
>
> From introduction to 'realising the benefits' spreadsheet
> by participating PCT (source code withheld)

5.1.4. The operational aspects of the SCR programme were addressed by Programme Leads appointed by the SHAs and usually referred to as 'SHA Leads'. CFH set up a monthly Programme Leads Forum as a focus for information sharing, reporting, troubleshooting and (where necessary) escalating problems to national level. The original membership included the ten SHA Leads along with eight CFH staff: the National Clinical Director, Senior Implementation Manager, National Programme Manager (Chair), and the five National Implementation Managers.

5.1.5. The SHA Leads Forum consisted of formal presentations from CFH, brief structured reports ("your three headline issues") from each SHA and open discussion. SHA Leads shared ideas and experiences informally in the coffee and lunch breaks. Despite a mismatch in culture and perspectives between CFH and NHS staff, the atmosphere in these meetings was generally cordial, supportive and pragmatic. Outside formal presentations, time was spent airing and attempting to address the numerous operational challenges being encountered at the implementation coal face, many of which were recurring agenda items unresolved from the previous meeting. It was clear that most of these problems had no easy answers (*"God, this is difficult"* – newly appointed SHA Lead in Programme Leads Forum, FF12, date withheld)

5.1.6. The SHA Programme Leads came from diverse backgrounds and differed considerably in terms of the posts they held within their SHA, their technical

understanding, and how they perceived their role. Some saw themselves as leading and managing the SCR programme for their SHA and overseeing the work of participating PCTs in their area. Others saw themselves as little more than 'conduits', relaying information gained at the forums back to their respective SHAs and PCTs.

5.1.7. Many SHA Leads felt that some CFH staff did not understand the nature of the relationship between the SHAs and their PCTs. These Leads considered that CFH staff assumed that this relationship was simple, hierarchical and managerial – i.e. that SHAs could issue instructions and PCTs would then deliver.

"We mean controlling, selling the agenda, identifying the PCTs, making sure their plans are up to speed, monitoring, assuring, being in charge when they go live […], there's only six of us, there's too many PCTs for us to realistically be able to do that, we're not going to be able to support it like we're doing for the Fast Followers." [AA]

CFH staff member in SHA Programme Leads Forum in response to a question on the role of the SHA in the SCR programme, January 2009 (FF06)

5.1.8. In contrast, SHA Leads viewed the SHA-PCT relationship in more complex terms. PCTs are accountable to *both* their SHA *and* their local population, hence negotiation was often needed over when a national 'must-do' policy should take precedence over a pressing local issue and/or how national policy may or may not be customised by 'street level bureaucrats'.[BB] PCTs might 'play the game' by claiming delays beyond their control or by feeding information selectively back to the SHAs. In practice, the way SHAs got PCTs to deliver on policy priorities was more about dialogue and diplomacy than about directives and sanctions. [102]

"It's not my job to insist, but it's useful for them [PCTs] to know the principles".

"we can't mandate or insist."

SHA Chief Information Officers, CIO Forum, July 2009 (FJ26)

5.1.9. CFH staff made frequent reference to the Business Case which the SHA CIO forum had signed off in 2008. SHA Leads considered that this Business Case bore little relation to the reality on the ground. Particular perceived discrepancies included:

a. The high time input needed for the SCR role.

SHA Lead: "Do you see the SHAs having the resources to be able to absorb the transfer of knowledge from CFH and the structure to be able to take it out to the PCTs? I can't, I can count 0.5 of a day per week for this."

CFH staff member: "This is how we see it working in the SHA, ¾ of a person to work solely on SCR. That's what CIO's have signed off in the Business Case."

SHA Lead: "Just by signing off a Business Case doesn't necessarily mean anything, there might have been some arm twisting to sign the Business Case."

SHA Programme Leads Forum, January 2009 (FF06)

b. The perceived lack of a dedicated budget for SCR-related activity.

"Our assumption with the NLOP model was that funding and resources would follow. It hasn't happened."

SHA Lead in Programme Leads Forum, January 2009 (FF06)

[AA] For a brief period in late 2008, a handful of PCTs who signed up to the programme immediately after the early adopters were referred to as 'fast followers'. This terminology was abandoned shortly afterwards.

[BB] Exworthy showed in a paper entitled *'How great expectations in Westminster may be dashed locally'* that national policy is necessarily changed as it undergoes local adaptation and implementation.[100] Similarly, Checkland has shown that GP practices customise policy documents in a way that makes sense locally but which involves a far less linear implementation chain than those at the centre typically assume.[101]

5.1.10. SHA Leads were surprised at the SCR programme's early stage of development given that the technology was being rolled out nationally. Almost all had assumed that technical detail and process aspects of the programme had been finalised in the early adopter phase and that they would be attending the Forum to be *"told what to do"*. Once they joined the Forum, they realised that the programme actually involved technologies and business processes that were in a very early stage of development and some described these as having been put together *"on the fly"*.

5.1.11. Despite much talk about local ownership, control of the Forum remained partly in the hands of CFH, who provided administrative support and set the agenda (though they did consult the Leads on this). CFH senior staff decided that National Implementation Managers would not attend the Forum, much to the dismay of the SHA Leads who found the NIMs' practical knowledge and past experience more useful than the formal and somewhat idealised Powerpoint presentations of CFH senior staff. They would have liked more informal discussion amongst those working at the coal face.

5.1.12. Overall, the SHA Leads were positive about the Forum. They found the face to face meetings worthwhile; they felt they had a voice in them and that their collective voice had more influence on CFH than any one of them would have had individually. Furthermore, some Leads became more positive about the meetings as time went on – because, they felt, CFH staff had listened to feedback, became more aware of the reality on the ground and increasingly took this into account when offering solutions.

"I quite like it, I find it useful listening to other Trusts, the other SHA's all find slightly different problems, or when we come across the same problems we can gang up."
SHA Programme Lead, July 2009 (FF20)

5.1.13. Some Leads had negative comments. Most remained frustrated at what they saw as CFH's limited awareness of the front-line reality of the NHS. Some complained about *"poor communication"*, especially a perception that the information portal was difficult to navigate, contained documents that were out of date and did not provide the key current documents needed for their role. Some felt meetings could be held less frequently, and that an internal restructuring in CFH had led to key senior staff on the Forum being replaced, taking a good deal of experiential knowledge with them (*"they have the knowledge and now they're gone"* – SHA Lead, June 2009, FF17).

5.1.14. There was relatively little lateral communication between SHA Leads except when they met at the Forum. Leads suggested to us that they would like more sharing of locally-produced documents (especially from early adopters) which they could then adapt for local use, but this seemed to occur only in a limited way. This was perhaps partly influenced by CFH's strong emphasis on a systematic, controlled approach to the release of information (paragraph 4.3.17). We revisit this point in Section 11.5.

5.1.15. The two most talked-about issues raised in open discussion in the SHA Leads Forum was the repeated delays in availability of technological solutions, a theme we cover in Section 8.6, and persisting deployment challenges with solutions that had received Full Rollout Approval (FRA). The term 'Full Rollout Approval' was considered by Leads to be an ambiguous term, implying (for some) that all further deployments were seen as likely to progress uneventfully. Suppliers, however, felt that complex software products can rarely if ever be given the 'all clear' to roll out in multiple different local environments without continuing technical support. Other barriers to local implementation as perceived by the SHA Leads are listed in Box 5.1.

Box 5.1: Summary of barriers to local implementation of the SCR as perceived by SHA Programme Leads

Delays in availability of technical solutions

Technical problems deploying solutions that had received 'Full Rollout Approval'

Lack of readiness of toolkit / business processes

Fragmentation of accountability and confusion of responsibilities between CFH, SHAs and PCTs

Lack of agreed data quality standard or resource for achieving this

Lack of integration of IT issues into general change management vision locally

Competing priorities on resources within both SHAs and PCTs

Lack of clarity on what the actual costs of the programme would be and what is to be paid for nationally versus locally (e.g. no specific resource available in PCTs for public information programme, GP training by suppliers or the integrated Adastra solution)

Delays in getting national agreements in place e.g. mailhouse contracts

On-going uncertainty about SCR and HealthSpace Business Case approval

Lack of clear, well-documented benefits hence limited local enthusiasm

Delayed or conflicting information coming from CFH to SHAs

Lack of exchange of locally-produced documents between SHAs and PCTs

Lack of learning from one another and from early adopter PCTs

Cost of training and (for some) lack of dedicated budget for this (some saw 'mandatory' supplier training as unnecessary and overpriced)

Potential overlap, confusion and competition for resources between SCR and local detailed record (e.g. TPP, Lorenzo)

5.1.16. SHA Leads were ambivalent about the regional public information programme that was scheduled for January to April 2010. On the one hand, they were keen to sign up for this because funding was being provided centrally. On the other hand, they were concerned that writing to patients before essential groundwork to engage both professionals and the public had been completed, before key technical solutions for their locality had Full Roll-out Approval, and before clarity had been achieved on precisely what data would be uploaded in 'enriched' and 'level 2' SCRs (see Section 2.4) might be a hostage to fortune.

5.1.17. Another concern about the mass mailout linked to the public information programme was the problem of 'returned letters'. In areas of high population turnover (e.g. some parts of London or anywhere with a university), up to 25% of letters might be returned as 'not known at this address'. Patients to whom these letters had been addressed were likely (though not certain) to be 'ghosts' – i.e. their medical record was held by a GP who was not providing active services to them (e.g. because they had moved away without telling the GP). PCTs generally sought to remove 'ghosts' from GP lists when these were discovered in mailshots (a policy which, from a PCT's perspective, could generate cost savings). But such an approach could lead to substantial loss of income to GPs and hence negativity towards the programme at a time when clinical buy-in was needed.

5.1.18. In summary, our interviews and observations suggested a dissonance between the 'top management' view of local implementation as articulated by CFH and the CIOs (essentially, a straightforward if ambitious effort to realise the SCR's intrinsic benefits) and the 'coal face' view as articulated by the SHA Programme Leads (an under-resourced and operationally complex initiative with ambiguous lines of responsibility which was seriously hampered by influences beyond their control).

TABLE 5.1: EXTRACT FROM A 'BENEFITS' TABLE PRODUCED BY A PCT							
Ref	Facility offered by SCR	Relevant care settings	Effect	Outcome	Beneficiary	Benefit type	Inv Obj
1	SCR holds key patient information that is not always readily available via other sources	Urgent care settings outside of hospitals	Improves the incidence, speed & appropriateness of patient assessment and treatment	Improved incidence, speed and appropriateness of patient assessment and treatment in urgent care settings outside of hospitals results in fewer OOH home visits	OOH services	£NCR ('non cash releasing')	Efficiency and effectiveness
2	SCR holds key patient information (see 'important assumptions' above for specifics) that is not always readily available via other sources	Urgent care settings outside of hospitals	Improves the incidence, speed & appropriateness of patient assessment and treatment	Improved incidence, speed and appropriateness of patient assessment and treatment in urgent care settings outside of hospitals results in fewer ambulance call outs from urgent care settings and so improved prioritisation of calls and increased capacity within the ambulance services	Ambulance service	£NCR	Efficiency and effectiveness
3	SCR holds key patient information (see 'important assumptions' above for specifics) that is not always readily available via other sources	OOH services and NHS Direct	Improves the incidence, speed & appropriateness of patient assessment and treatment	Improved incidence, speed and appropriateness of patient assessment and treatment in OOH services and NHS Direct results in them referring fewer patients to Emergency Depts, Minor Injury Units and Walk In Centres so increasing the capacity of these services and reducing the number of Emergency Dept 4 hour breaches	Hospital Emergency Departments	£NCR	Efficiency and effectiveness
4	SCR holds key patient information (see 'important assumptions' above for specifics) that is not always readily available via other sources	Urgent care settings outside of hospitals	Improves the incidence, speed & appropriateness of patient assessment and treatment	Improved incidence, speed and appropriateness of patient assessment and treatment in urgent care settings outside of hospitals results in fewer hospital emergency admissions, and so increased capacity of elective care leading to quicker elective treatment for patients and so better performance against the 18 week target	Hospital elective care	£NCR	Efficiency and effectiveness
5	SCR holds key patient information (see 'important assumptions' above for specifics) that is not always readily available via other sources	All urgent care settings	Improves the incidence, speed and appropriateness of patient assessment and treatment	Improves patient outcomes by reducing adverse drug reactions, repeat tests and procedures, IRMER risk and deterioration in health caused by delays in getting the right treatment in urgent care settings, including outside of England for patients with advanced HealthSpace accounts as patient can give clinicians access to their SCR via HealthSpace. For example, research suggests that for every 1m prescriptions, 18 people die as result of adverse drug reaction (ADR) and at any one time the equivalent of up to 7 hospitals (of 800 beds each) in England are occupied by patients with ADRs. If better information reduces this by only 0.1% then 1 life every 8 weeks could be saved (around 1 life per 50 million scripts).	Patient	Q ('quality')	Patient care

6	SCR holds key patient information (see 'important assumptions' above for specifics) that is not always readily available via other sources	All urgent care settings	Reduces the number of unnecessary prescriptions, tests and procedures	Reduces the number, and so cost, of unnecessary prescriptions, tests and procedures	Mainly Emergency Dept & MIUs	Q	Efficiency and effectiveness
7	SCR holds key patient information (see 'important assumptions' above for specifics) that is not always readily available via other sources	All urgent care settings	Improves the incidence, speed and appropriateness of patient assessment and treatment	Reduces delays in receiving treatment at the time and also the inconvenience of being referred on to the GP and hospital due to assessment and/or treatment not being possible at the time	Patient	Q	Patient experience
8	SCR holds key patient information (see 'important assumptions' above for specifics) that is not always readily available via other sources	All urgent care settings	Patients are not asked the same basic questions so frequently	Patients have their expectations fulfilled that their clinical information is shared to enable joined-up care delivery	Patient	Q	Patient experience
9	SCR holds key patient information (see 'important assumptions' above for specifics) that is not always readily available via other sources	All urgent care settings	Reduces administration and paperwork involved in establishing and recording key patient information	Reduced administration and paperwork involved in establishing and recording key patient information during an urgent care patient encounter frees up time within urgent care settings that can be put to better use	All urgent care settings	£NCR	Efficiency and effectiveness
11	When GPs are treating temporary residents and new patients (prior to record from previous GP arriving) during normal GP consultations, SCR holds key patient information (see 'important assumptions' above for specifics) that is not always readily available via other sources	Primary care	Improves the incidence, speed and appropriateness of patient assessment and treatment	Information on SCR available to GPs when treating temporary residents and new patients during normal GP consultations improves patient outcomes by reducing adverse drug reactions, repeat tests and procedures, the IRMER risk and deterioration in health caused by delays in getting the right treatment	Patient	Q	Patient care
12	When GPs are treating temporary residents and new patients (prior to record from previous GP arriving) during normal GP consultations, SCR holds key patient information (see 'important assumptions' above for specifics) that is not always readily available via other sources	Primary care	Improves the incidence, speed and appropriateness of patient assessment and treatment	Information on SCR available to GPs when treating temporary residents (including holidaymakers and students) and new patients during normal GP consultations reduces delays in patients receiving treatment and also the incidence of not being treated at all	Patient	Q	Patient experience
13	As a consequence of 'point to point messaging' functionality available via 'level 2' SCR, GP systems automatically and quickly receive details of discharge summaries, Emergency Dept reports and outpatient letters from the SCR	Primary care	GPs, primary care teams and community care teams have more timely and legible prompts to act following receipt of information such as discharge summaries, Emergency Dept reports and outpatient letters	Primary care teams follow up a patient's discharge from hospital more quickly, thus improving patient outcomes	Patient	Q	Patient care

14	As a consequence of 'point to point messaging' functionality available via 'level 2' SCR, GP systems automatically and quickly receive details of discharge summaries, Emergency Dept reports and outpatient letters from the SCR	Primary care	Reduces the administrative effort required in GP practices in entering information such as discharge summaries, Emergency Dept reports and outpatient letters into their systems	Reduced administrative effort in GP practices entering hospital discharge information into their systems frees up time that can be put to better use	GP practices	£NCR	Efficiency and effectiveness
15	Patients with advanced HealthSpace accounts can use HealthSpace to access and check information to their SCR from any internet-enabled PC regardless of location	All	Patients are empowered to gain more control over, and understanding of, their own health	By using HealthSpace to access their own SCR, patients with advanced HealthSpace accounts can take more responsibility for their own health and care, and can deliver a more mature clinician-patient relationship	Patient	Q	Patient experience
16	Patients with advanced HealthSpace accounts can use HealthSpace to access and check information to their SCR from any internet-enabled PC regardless of location	All	Patients with advanced HealthSpace accounts can point out data quality errors	By using HealthSpace to access their own SCR, patients with advanced HealthSpace accounts can point out data quality errors which leads to a reduced risk of clinical errors caused by health care professionals referring to inaccurate information	Patient	Q	Patient care
17	GP system data is quality assured via the IM&T DES process that is part of SCR deployment	Primary care	The quality of data within GP systems is improved	Improved quality of GP system data reduces clinical risk to patients resulting from poor data quality and so improves patient outcomes	Patient	Q	Patient care
18	SCR may, via e.g. Emergency Dept letters or IP letters, hold details of current or past Health Care Associated Infections such as MRSA	All urgent care settings	Health professionals can more readily identify such patients in urgent care scenarios and so can immediately place them in isolation, although the information will not be flagged up as an alert	Reduces the incidence of Health Care Associated Infections across the population	Patient	Q	Patient care
19	Patients with advanced HealthSpace accounts can use HealthSpace to record their specific needs regarding aspects such as spiritual needs and end of life care preferences	All	Patients' own choices can be reflected in the care they receive	Patients with advanced HealthSpace accounts have improved satisfaction and confidence in the service delivered to them	Patient	Q	Patient experience
20	SCR may hold copies of Emergency Dept reports, IP discharge summaries and OP reports	All	Allows health care professionals to identify unusual patterns of healthcare events (e.g. many Emergency Dept visits) and see information that would sometimes be withheld during patient encounters	The ability of health care professionals to identify unusual patterns of healthcare events improves the protection of children and vulnerable adults	Patient	Q	Patient care
21	SCR may contain violent patient indicators	All	Alerts staff to the risk associated with dealing with a violent patient	The ability to readily see a violent patient indicator improves the protection of staff	NHS staff	Q	Efficiency and effectiveness

5.2. The Clinical Directorate

5.2.1. The Clinical Directorate for the SCR evolved out of the early adopter GP Clinical Leads Group and was constituted in 2009 to coincide with what was then referred to as the 'fast followers' phase of the SCR implementation. It met face to face six-weekly and had a six-weekly conference call. Its purpose was to provide additional resource to CFH's SCR core clinical engagement team as the programme moved to a national rollout phase. It originally comprised six PCT Clinical Leads (four early adopters and two fast followers) and six members of CFH (the National Clinical Director for SCR and HealthSpace, three SCR Clinical Advisors, a Clinical Safety Officer and the National Clinical Lead for Medicines Management). As more PCTs became involved in the programme, their Clinical Leads joined the group.

5.2.2. PCT Clinical Leads were initially all GPs; a nurse joined in late 2009. All had a strong interest in IT and considered that IT solutions had great potential for improving patient care. They differed in the time allotted to their role, the amount of knowledge they had about the non-technical aspects of the programme and the amount of influence they had in their local health community. In contrast with Clinical Leads in early adopter PCTs (who were typically members of their PCT Professional Executive Committee, SCR Programme Boards and/or Local Medical Committees[4]), those appointed after the early adopter phase were recruited at various CFH engagement events and some lacked experience or connections in local health politics (*"they [PCT Clinical Leads] can't go into their LMC events cold….they'd get slaughtered"* – CFH staff member, SHA Leads Forum, July 2009).

5.2.3. The task list for PCT Clinical Leads was extensive, and centred on engaging their clinical colleagues locally (*"capture their hearts and minds"*); encouraging them to 'enrich' SCRs and use HealthSpace Communicator; obtaining stories of benefits (preferably from named local clinicians) for CFH communication materials; and promoting usage of the SCR by 'chasing up' colleagues in particular settings. These tasks tended to outstrip the time available and sometimes required an additional budget to which the Clinical Leads did not have access. One pointed out that he only had six hours a month to dedicate to SCR-related work but the role was so open-ended it could have taken far more.

5.2.4. CFH staff provided advice and tools for clinical engagement, such as techniques for *"reducing resistance"*. PCT Clinical Leads were encouraged to invite their Local Medical Committee to be represented on SCR project boards and hold engagement events modelled on the well-received national engagement events reported in our Year 1 evaluation.[1] Whereas the national engagement events had been led by experienced CFH National Clinical Leads who had considerable seniority and credibility, and who answered questions without briefing notes, PCT Clinical Leads were given a standard presentation and a list of 'frequently asked questions'.[CC]

5.2.5. The Clinical Directorate meetings consisted of PCT Clinical Leads reporting back on local progress and issues, plus presentations from CFH staff (updates on the national rollout, updates on suppliers), and discussions about CFH policies and documents, much of which overlapped with material covered in the SHA Forum. Similar requests for greater clarity and guidance came up in both meetings, especially about enrichment of records, data quality requirements, consent, audits and alerts. There appeared to be little direct information exchange between Clinical Leads and their corresponding SHA Lead; rather, each tended to look to their own national forum.

[CC] This example illustrates the difficulty of maintaining intervention fidelity when an apparently successful programme or component of a programme is transferred to a new setting.[103]

5.2.6. The Clinical Directorate was also a forum for CFH to find out the extent to which their processes and procedures were being followed at the front line and if not, explore why. For example, it was at Clinical Directorate meetings that CFH discovered model-reality gaps in relation to the opt-out process (verbal opt-outs were apparently being accepted in some practices and no central record being kept of who had opted out); newly registering patients (some but not all practices which had uploaded SCRs were issuing a 'new patient pack' to introduce new patients to the SCR and explain their options for opting out); and third-party opt-outs (some but not all practices were keeping a record of parents who had sought to opt their children out and routinely looked at the child's record in such cases).

5.2.7. The Clinical Directorate was also a forum at which various non-clinical CFH staff and consultants gave presentations and asked for "clinical feedback". For example, the Communications department sought the Clinical Leads' input on posters, and business managers asked them to check and approve business process maps. When new functionality for the SCR or HealthSpace was designed, the Clinical Leads were shown screen shots in a click-through Powerpoint presentation to confirm that the new design was considered clinically appropriate and acceptable.

5.2.8. The PCT Clinical Leads tended to view themselves not only as ambassadors for the SCR but as advisors on the IT aspects. As one described it, *"I see our role as teacher to novices"* (FL03). Other PCT staff affirmed that the Clinical Leads were often a good source of advice and information on the 'IT' aspects of the programme (for example, they could explain the different upgrades to software).

5.2.9. Attendance at the Clinical Leads meetings was erratic, perhaps because the Leads had limited time. In interviews, they expressed frustration about what they perceived to be *"reinventing the wheel"*, lessons learned (especially from early adopter sites) not being shared, and the lack of any on-going process for capturing lessons learned. Their perception was that as each new PCT came on board, they faced similar issues (e.g. clinical engagement, public information programme) but there was perceived to be insufficient guidance on how to go about this. As one early adopter Clinical Lead put it, *"the same mistakes are being made two years on"* (FL06).

5.2.10. These criticisms are at first glance surprising, since much was done by CFH to create logs of lessons learnt and develop and distribute tools such as business process maps and FAQs. The problem probably stems from the focus within the programme on capturing formal, codified knowledge (hence, CFH's focus on reporting and documentation and the expectation of both SHA Programme Leads and Clinical Leads for "national guidance") at the expense of more informal knowledge-sharing and CFH's reluctance to distribute material that had not been through an official approvals and branding process – a theme we pick up in Section 11.5.

5.2.11. There was also a tension in the Clinical Directorate between supporting 'local ownership' and providing a strong national steer complete with a set of standardised documents. This became especially acute when local variation (for example in managing opt-outs) was picked up and commented on by the press – to which CFH tended to respond by producing standardised forms and 'exemplar' letters and encouraged PCTs to follow these closely. This was also partly due to the expectation from the Information Commissioner's Office that guidance provided nationally would be passed consistently to local NHS organisations.

5.2.12. As the national rollout gathers pace, CFH are considering expanding the Clinical Directorate (e.g. by inviting SHA and secondary care Clinical Leads). However, since the group is already large it may be split into two (north and south). CFH also plan to widen engagement within the clinical community through their web portal eSpace.

5.3. The first two PCTs to join the SCR programme

Bolton

5.3.1. Bolton was the first early adopter site for the SCR, whose experience was described in detail in our Year 1 report.[1] Briefly, Bolton was chosen because of its track record in ICT investment, local enthusiasm, medium size, a single A&E department, two-thirds of practices using the SCR-compliant INPS GP system, relatively good data quality, proximity to Leeds and stable population. Bolton worked hard to implement the SCR but decided to run only a minimal HealthSpace campaign because the technology was still in the early stages of development.

5.3.2. At the end of Year 1 of our evaluation, the entire PCT population had been mailed (237,759 patients). 14 of 57 practices were data accredited, 10 had uploaded records (59,641 patients) and 22% of Bolton's population had a SCR. 13 practices were using a SCR-incompatible system, and the remainder were not ready to participate in the project or objected to it. Public opt-out rate was 0.97%. The GP out-of-hours service, walk-in centre and A&E Department had all achieved technical go-live but there was no routine SCR usage. Two practices had started 'enriching' selected patient records. Only 66 patients had activated an advanced HealthSpace account.

5.3.3. The following key developments shaped the project over the next two years:

a. The early adopter phase ended in March 2009. Initially the PCT negotiated a continued direct link with CFH because of ongoing issues with uploads;
b. The change in consent model was implemented in mid 2009 once the switch-over had been made to the latest version of the SCR application (2008B) which allowed the recording of consent to view;
c. A memorandum of understanding was developed for use between the PCT and new practices, outlining each party's responsibilities in relation to SCR creation;
d. When the IM&T DES (paragraph 8.3.2) ended in March 09, components 1 and 2 of this (including Paperlite – paragraph 8.3.3) were maintained as the data quality requirements for joining the SCR programme. Additional requirements are under discussion at SHA level;
e. The *Darzi Review*[27] became a key driver for local innovation, and its emphasis on patient safety was seen to link with implementation and usage of the SCR locally.

5.3.4. The SCR gradually lost its 'special status' as an early adopter project within Bolton and became more mainstreamed alongside other work. Early in 2009, project team meetings were moved to monthly before being discontinued. Board meetings continued on a more or less monthly basis. When the full-time project manager moved to the SHA in March 09, the project entered a very quiet phase, which coincided with delays in readiness of technical solutions for uploading more records. When a new project manager appointment was made in July 09, the project was re-started. The new project manager has other responsibilities alongside the SCR.

5.3.5. Ten further practices went live in late 2009 or early 2010, making a total of 25 out of 57 practices, covering 51% of the registered population (132,500 patients). 32 practices are still not participating in the programme. Reasons include being on a non-compliant system (6 practices), not yet having met data quality requirements, opposition to the project or other priorities. Nine practices are currently involved in enriching selected records, including adding end-of-life information on patients who require community based terminal care.[DD]

[DD] The 'end of life' initiative whereby SCRs are 'enriched' with information including the patient's choice for place of death and information about relatives and carers has been widely publicised by CFH as a locally driven extension of the original

5.3.6. The process of creating SCRs was experienced as time-consuming and labour-intensive for PCT staff and GP practices (*"additional costs came up out of the woodwork"* – Senior Manager, FF10), and informants considered it far removed from the initial expectation that all practices would be participating in the project and records would be uploaded fairly swiftly. Reasons for this mismatch include delays in technical solutions, problems during uploads, or practices taking time to reach the required data quality accreditation or postponing participation due to other priorities or lack of resources.

5.3.7. The PCT continued informing patients of the SCR through leaflets and posters, and patients were written to again to let them know about the change in consent model and the option of 'enriched' records. There was ongoing work informing new patients.

5.3.8. In terms of SCR usage in unscheduled care, by 1st March 2010:

a. The GP out-of-hours service had been using the integrated Adastra solution since spring 2008 (see Section 6.4). This service was the biggest SCR user and 'enriched' records in particular were seen as extremely useful. The walk-in centre was live with the integrated Adastra solution, and there were some accesses;
b. SCR accesses in the A&E department were virtually nil (see Section 6.5) and there were no accesses by the ambulance service (Section 6.6);
c. Pharmacists were able to view records in the hospital pharmacy and intermediate wards including the Bolton Community Unit. However, accesses were low (see Section 6.5 and 6.6);[EE]
d. District nurses attached to participating practices were given access to the SCR via mobile devices for a pilot study (Section 7), and the nurses of a community-based intermediate care unit had recently become able to view records.

5.3.9. Thus, whilst 9 sites were officially 'live' for SCR viewing, only two were regularly accessing SCRs. There are plans to enable further sites and some have been provisionally identified. However, as deployment of Lorenzo Regional Care to many of these is planned, which has an integrated SCR viewer, and access through SCRa is perceived by many front-line staff to be too time-consuming for routine use, most were on hold at the time of writing.

5.3.10. Attempts were made to increase uptake of advance HealthSpace accounts, including enabling registrations in Bolton's public libraries and a small number of GP practices, but neither generated much patient interest and the former was deemed inappropriate by the Information Commissioner because non-PCT staff would be processing applications. Currently the processes to open an account at the public health library are still in place, but HealthSpace is "not being pushed" until further functionality has been developed. The introduction of Communicator (see Section 9.4) at selected practices is currently being considered.

5.3.11. The project has received much less coverage in the local news than during our first year of evaluation, partly because the addition of consent to view has made it less controversial, but also perhaps because its novelty has worn off. Local press articles are generally supportive of the scheme. Despite considerable local efforts to inform the public, staff report that many appear unaware of the SCR programme but say

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vision for the SCR. Stories about patients who had a 'good death' supported by the SCR are in circulation. We considered studying this end-of-life work, particularly since it linked with another policy 'must-do' from the DoH.[104] However, we decided that because of what we perceived as pressure to find 'good news stories', our own interest in the end-of-life project could potentially have ethical implications for patients or carers, so we chose not to study this part of the programme.

[EE] We were asked to add here that pharmacists were actively consulted on their needs in relation to the SCR and contributed to a revision of requirements in relation to the 'date last issued' problem (paragraph 6.5.19).

that very few people object to their SCR being accessed when asked at the point of care.

5.3.12. The Local Medical Committee welcomed the introduction of the permission to view consent model (Section 8.4) but has expressed concerns about assuming implied consent for enriching records. For this reason, some practices are asking patients for their explicit consent to enrich their SCR.

5.3.13. In summary, the SCR programme in Bolton has been expanding slowly but steadily. Local resistance to the project has decreased significantly, partly because of the change in the consent model, but some practices remain opposed. The work has taken more time and consumed more resources than expected.

Bury

5.3.14. Bury was the second of six early adopter sites. It was chosen because of medium size, all practices using the same GP system (INPS), relatively good data quality, and local enthusiasm for the project. At the end of Year 1 of our evaluation, 118,750 patients of 24 practices had been mailed; all these practices were data accredited and 93,547 records uploaded (48% of the PCT population). The remaining practices were not willing to participate in the project for various reasons, at least for the time being. Public opt-out rate was low (0.66%). A small number of viewing sites had gone live (GP out-of-hours and A&E), but there was no routine usage of SCRs. Patients had been informed about HealthSpace in parallel with the SCR, but uptake was low.

5.3.15. The following key developments shaped the project over the next two years:

a. As in Bolton, responsibilities for the project transferred from CFH to North West SHA. This was marked locally with the initiation of a new project ('phase II');
b. The change in consent model was implemented locally once the technical changes had been made to the SCR application. Bury piloted this and ran both applications in parallel to ensure a smooth transition;
c. After the end of the IM&T DES in March 2009, component 1 (including Paperlite) remained as a data quality requirement for the SCR;
d. Bury also became an early adopter for Lorenzo Regional Care, and the system was implemented in the hospital late in 2009 as well as in various community services. There has been some redirection of resources from SCR to Lorenzo, which is perceived as having impacted negatively on progress of the former;
e. Two new Darzi Centres ('polyclinics') opened in 2009. The central Bury site now houses the out-of-hours service, the walk-in centre, the dental access centre and a new private out-of-hours GP service (Rock Healthcare) alongside GP practices and a pharmacy;
f. Local team and board meetings reduced in frequency and regularity and project management became mainstreamed within general PCT IT work;
g. The PCT took over responsibility for uploading records from CFH and the GP supplier by sharing a resource across three PCTs in the North East NPfIT sector;
h. Bury's Chief Executive continued his strong support of the project until his retirement in October 2009. Since then, there has been less hands-on involvement at executive level but this is not perceived to have had detrimental effects since the new CEO is not opposed to the project;
i. The PCT continued informing patients of the SCR through leaflets and posters, and patients were written to again to let them know about the change in consent model and the option of 'enriched' records. There was also ongoing work involved in informing new patients. An informal memorandum of understanding was put in place between the PCT and new practices.

5.3.16. By 1st March 2010, 25 of 33 practices had joined the programme and about 72% of the PCT's population have a SCR. The public opt-out rate remains low. Of 8 remaining practices, one is due to join the programme shortly and seven have not yet committed to participating in the project. 12 practices are involved in 'enriching' SCRs.

5.3.17. Like Bolton, Bury found creation of SCRs labour-intensive and time-consuming for similar reasons – including technical problems during upload (gradually reduced through technical adjustments to the GP system), local IT infrastructure issues, practices' other priorities and conditions that needed to be in place prior to upload, such as data quality and SCR roles on smart cards. Practices were also concerned about losing patients as a result of returned mail.

5.3.18. The PCT has committed to an ongoing process of informing patients, especially children, which includes a locally filmed, joint Bury/Bolton DVD that is included in lesson plans in schools and used by school nurses. Despite this, awareness continues to be low but there are generally no objections when the SCR is explained. Some of these ongoing communication costs were not anticipated.

5.3.19. During Years 2 and 3 of our evaluation, several more care settings went live with the SCR. In total, 11 sites are able to access SCRs but many have very low usage (see Sections 6.5 and 6.6). The A&E Department is waiting for impending release of an integrated version of the Ascribe system but as this version enables the addition of discharge summaries to the SCR, there are issues to be resolved around consent and responsibilities. Hospital pharmacists were previously the biggest SCR users, but usage has decreased because of 'date last issued' (paragraph 6.5.19). The Dental Access Centre, a service for unregistered patients and emergencies, has very low SCR usage and most SCR accesses are for demographic information.

5.3.20. Pennine Care, a mental health trust, initially made some accesses but stopped when the consent model changed. SCRs would need to be viewed prior to visiting patients, but there are concerns and practical challenges around doing this, as phone contact is not necessarily with the patient. The tier 2 diabetes service, a 'one stop shop' with a specialist consultant, nurse and a dietician, which GPs refer selected patients to for initial advice as well as reviews, also has very few accesses. More recently, Rock Healthcare and a community support team for children with learning disabilities (Cambeck Close) have gone live with the SCR, and there are plans to connect other services such as the palliative care team, hospice, district nursing evening service and the rapid response team.

5.3.21. Bury included HealthSpace information in letters to patients from the start, but uptake of advanced accounts has remained low. As new functionality is planned (including online registration), local promotion for this phase was given 'moderate' status, including adding leaflets to patient letters. Two practices were involved in piloting Communicator, but recruitment has proved difficult and only a small number of patients are currently participating (Section 9.4).

5.3.22. There was little opposition in Bury from the start, and this has remained the case. The Local Medical Committee has been kept up to date with developments, which has been helped by one of the project board members also being a LMC member. Overall, the project is considered to be steady progress, and three quarters of Bury's population now have a SCR. Low usage in many 'technically live' sites is frustrating for the local team who have worked hard to get the project to the current stage.

5.4. Other PCTs

South Birmingham

5.4.1. South Birmingham was officially an early adopter PCT but because the predominant GP software system was EMIS, most go-lives were delayed because a technical solution was awaited (see Section 5.5), and activity was considerably less than planned from mid 2008 to mid 2009. In the interim, the PCT confined its SCR work to a handful of non-EMIS practices as well as continuing to support practices to achieve data quality accreditation. The PCT made the decision to continue to apply the standards of the IM&T DES regardless of whether these were to be dropped as a national requirement. Communication materials were rewritten to reflect the change in the consent model to permission to view.

5.4.2. In summer 2009, the solution for EMIS LV was delivered and a 'First of Type' upload conducted. However, the PCT decided to wait until Full Rollout Approval (see Section 5.5) was obtained before resuming their public information programme. Full Rollout Approval was given in October 2009, but further technical issues delayed the anticipated uploads again. By February 2010, with most of the outstanding technical issues finally resolved, the pace of the project in South Birmingham quickened, and by 1st March 2010, SCRs had been created on 21% of the local population.

5.4.3. SCR viewing had not yet begun in Birmingham by the time this report was submitted. Negotiations to deploy SCRs in GP out-of-hours centres was ongoing. The SCR was not seen as high on the list of priorities by the local out-of-hours provider (Badger). One barrier is that this provider covers three PCTs, one of which had indicated that they were not planning to go ahead with the SCR. In addition, a H1N1 flu outbreak occurred as this decision was being contemplated (thus diverting attention and resources), and the provider moved to a new site. PCT staff expressed hope that a forthcoming renegotiation of contract with Badger may provide the opportunity to create incentives for supporting SCR use.

5.4.4. 50 staff have been trained in accessing SCRs. A DAU (Day Assessment Unit) and Birmingham Dental Hospital have achieved technical go-live. Other proposed access sites include walk-in centres, local hospitals, diabetes services and Birmingham Children's Hospital. Although this last setting is not within the PCT's area, children from local practices are sent to the hospital. The plan is to support go-lives in these additional sites once 60% of the population have a SCR.

5.4.5. Access for their mobile workforce was considered an important feature in South Birmingham's original plans for deployment of the SCR, and PCT was earmarked to be a pilot site for the mobile BT solution (Section 7). However, because of delays with the EMIS solution, the pilot was transferred to Bolton. In preparation for the SCR, the PCT purchased 23 toughbook mobile PCs which were scheduled to be rolled out to the district nurses and the rapid response team. We were told that information governance issues had delayed their active use, though informants expected these to be resolved shortly.

Dorset

5.4.6. Dorset was another early adopter whose start was delayed. As we reported back in 2008, local enthusiasm for the SCR at the start of the project was high because Dorset had been a pilot site for a previous electronic record project (ERDIP).[1] However, there was much frustration due to delays in delivering compliant GP systems and other ongoing technical issues (see Section 8.6).

5.4.7. Like South Birmingham, Dorset experienced delays to their plans while waiting for the EMIS LV solution as well as continuing issues with other GP systems, (iSoft & InPS). The length of time between the public information programme and creation of SCRs extended to several months (and up to two years in some sites). The PCT decided to write to these patients again advising them of the delay.

5.4.8. Dorset's project manager retired during this time, and his successor, appointed in 2009, is also the SCR project manager for neighbouring Poole and Bournmouth .The current focus is on completing the public information programme and achieving go-live for creating SCRs in as many practices as possible by the end of March 2010. As of end February, Dorset had written to 70% of its population and created SCRs on 36%. Of 60 GP practices (77% EMIS, 15% InPS, and 8% iSoft.), only four have declined to become involved with the SCR programme.

5.4.9. Dorset's plan for supporting SCR viewing is to begin with MIUs (Minor Injuries Units) once surrounding GP practices have created SCRs on 70% of the population. SCR work has highlighted non-use of smartcards by some MIU nursing staff and efforts are being made to ensure that smartcard use becomes business as usual. There is one technically live SCR viewing site reported in Dorset (Shaftesbury MIU), but at the time this report was submitted there had been no accesses of the SCR. Along with the remaining six MIUs, Dorset's plans include introducing the SCR to their main hospital A&E department in Dorchester, a polyclinic and South West Ambulance Service, once 50% of the population has SCRs.

5.4.10. Staff in Dorset identified the following key issues affecting the rollout locally:

a. Whilst some technical issues (such as the speed with which a GP system runs) were not specifically SCR related, they nevertheless required unforeseen upgrades to either software or hardware. The problem typically only comes to light when the SCR is introduced and systems have to be fixed (at further unbudgeted cost) before the upload can be completed;
b. The costs for GP systems training were perceived to be higher than anticipated, as were costs for the integrated Adastra solution[FF] and the training required for GP practice staff. Because Dorset was an early adopter, there were no accurate cost estimates available to them when they signed up;
c. GP suppliers were not perceived to have responded in a timely way to technical problems (but see supplier perspective in next section);
d. CFH were perceived as providing only limited support after a First of Type upload and to have given Full Rollout Approval (see Section 5.5) before systems had been adequately tested in the full range of environments;
e. Problems identified and lessons learned in First of Type deployments in other PCTs were allegedly not fully communicated to them;
f. They were unhappy with a change in National Implementation Managers – those assigned to support the SHA and PCTs were allegedly unfamiliar with the SCR;
g. A financial incentive from CFH to GPs of £2.50 per patient to approve registration for HealthSpace advanced accounts has been withdrawn. In the absence of this incentive, this initiative has lost momentum locally.

Medway

5.4.11. In contrast with the two previous examples (both early adopter PCTs who encountered numerous frustrating delays), Medway joined the SCR programme as

[FF] Adastra asked us to point out that an agreement has recently been signed with CFH in which the integrated Adastra interface will be funded centrally.

one of the first sites in the main national rollout and made rapid progress. Medway is a relatively deprived part of north Kent with a population of 270,000. There is high unemployment and a higher than average proportion of children and young adults. Priority clinical areas identified in the PCT's 2008/9 strategic plan included improving management of long-term conditions and improving standards in urgent and emergency care. Whilst there were funding pressures, the PCT's budget rose by 12% in real terms (broadly, because there was investment in improving health services in deprived areas) so it had some scope to invest in new projects.

5.4.12. We were told that the SCR programme in Medway had positive backing from the PCT Chief Executive; the IM&T Department in the PCT was innovative, enthusiastic and highly competent; the out-of-hours service was well-run and liked to innovate with technology; and the out-of-hours centre had strong leadership from its Medical Director. The SHA project manager and PCT manager for the SCR had extensive NHS experience and took a critical and proactive approach to local implementation.

5.4.13. 92% of GP practices in Medway used SCR-compliant software (the other 8% were using EMIS PCS), and 72% were using iSoft or InPS. There was very little resistance to the SCR from local clinicians – perhaps partly because improving out-of-hours care was an agreed priority and the SCR was perceived as aligning closely with that goal. Medway out-of-hours centre is unusual in that 80% of the clinicians working there are local GPs. Hence, when GPs were approached about an initiative to provide shared records in the out-of-hours centre, many immediately saw potential benefits and backed the project.

5.4.14. The public information programme began in March 2009. The PCT experienced some problems with "technical" delays and training (see Sections 8.6 and 8.8) but these were largely overcome. The first SCRs were created in early June 2009 and by the end of February 2010, 19 out of 80 practices had gone live with 112,000 records created (40% of the registered population).

5.4.15. One unscheduled care provider organisation – the out-of-hours GP clinic, which operates on two sites – has gone live with SCR viewing and was visited by our team as part of the fieldwork described in Chapter 6. Medway out-of-hours centre had close links with Adastra, who provide out-of-hours system software including an integrated SCR viewer (see Section 5.6). Adastra is a local company and the Medical Director works sessions in the out-of-hours clinic. It is probably no coincidence that a senior clinician in the out-of-hours centre told us *"The SCR is no problem here"*.

5.4.16. Apart from technical and operational issues with go-lives, the main problem experienced by Medway was smart cards. Most staff in the out-of-hours clinic did not routinely use smart cards until the SCR was introduced, and getting people to carry and use these required substantial cultural change.

5.4.17. In summary, whilst Medway encountered numerous challenges, a number of factors combined to create a positive socio-technical context for introducing the SCR: alignment of national and local policy goals; tension for change in out-of-hours services; top management buy-in; competent and enthusiastic middle management; strong local clinical engagement; absence of powerful opponents to the programme; close links with a key IT supplier and favourable existing technical capacity (e.g. high use of SCR-compliant GP systems). It is perhaps worth noting that this combination of factors aligns closely with our tentative predictions in 2008 of necessary preconditions made on the basis of our analysis of early adopter PCTs.[4]

5.5. GP system suppliers

The GPSoC suppliers

5.5.1. Under the GPSoC ('GP systems of choice') agreement, NHS GP practices may choose between the system provided by their LSP (see Section 2.3) or an accredited alternative from an independent supplier. The key pricing principles of GPSoC include an all-inclusive core software licence charge per practice; a fixed price for the duration of the GPSoC Framework; and some ongoing system development included in the core software licence charge.

5.5.2. Five GP systems are currently accredited to GPSoC level 2 or above (the minimum required for PCTs to provide funding): EMIS, INPS, iSoft, TPP and Microtest.[GG] The two LSPs, BT and CSC, offer INPS' Vision3 and TPP's SystmOne respectively.[HH] Each needed to develop additional functionality to create and maintain SCRs. Practices could not go live until their chosen supplier was ready with the key technology.

5.5.3. Egton Medical Information Systems (EMIS) was founded in the 1980s by two GPs. It is the largest GP system supplier with a market share of 50-60%. EMIS has three primary care products: LV, which is a text-based system (DOS) (43% of the total GP system market), PCS (14%), which is Windows-based, and EMIS Web, which is web-based and can be used across health communities to share data. At the time this report was submitted, EMIS Web had not been fully released but we understand that it is intended eventually to replace LV and PCS. Currently it is run in parallel to either LV or PCS. EMIS has no plans to develop a SCR interface for its PCS version.

5.5.4. In-Practice Systems (INPS) was started in 1984, also by a GP. It is now owned by CEGEDIM, a French company. It is the second largest GP system provider in the UK. INPS has a single GP system, Vision 3. BT, the LSP for London, offers Vision 3 as part of its contract.

5.5.5. TPP entered the UK market in 1999. Its product, SystmOne, is an integrated shared solution and includes GP, child health and community. TPP is part of the CSC Alliance and SystmOne is the system offered by CSC, the LSP for the North Midlands and East.

5.5.6. iSoft is a large international Australian owned company founded in 1994. The company currently offers two primary care products, Premiere and Synergy, the latter of which is SCR-compliant. It is developing Lorenzo Primary Care, a shared product intended to address a recent loss in UK primary care market share. iSoft are also represented in the UK with Lorenzo Regional Care.

5.5.7. Overall, relationships between the different GPSoC suppliers appeared to be collegial rather than commercial. In particular, INPS and EMIS had what their staff described as a "friendly competitiveness". In particular, there are personal ties between the GP founders and other long-serving staff. TPP (now part of CSC) is a relative newcomer to the market.

[GG] A sixth supplier, Healthy Software, is due to become compliant shortly. Two other suppliers, Seetec and Waveform Solutions, are no longer part of GPSoC. Seetec withdrew from the UK primary care system market in November 2008, and Waveform's GPSoC contract was terminated by CFH in 2009. Various smaller, suppliers were either not selected or chose not to participate in GPSoC, effectively ending their role in the UK GP system market and leaving it to a few major players.

[HH] See http://www.connectingforhealth.nhs.uk/systemsandservices/gpsupport/gpsoc/systems/suppliers for a list of suppliers and their systems.

5.5.8. As of 1st March 2010, four of the five GPSoC suppliers were participating in the SCR programme, i.e. had developed functionality for their systems to upload a GP summary to the Spine and flag opted-out records; a fifth was working towards this. Suppliers were developing further functionality (e.g. changes to the consent model). More generally, all suppliers had developed or were moving towards shared and web-based systems in order to build in the potential for access by third parties.

5.5.9. Different suppliers use different coding systems. EMIS, INPS and iSoft use Read 2; TPP uses Read 3. The SCR is based on a different coding system, SNOMED CT. Suppliers felt that the software for the GP2GP system was easier to develop than that for the SCR because the data were going from one GP system into another, and all used some form of Read codes. However, the electronic prescription service (EPS) is seen as technically even more challenging than the SCR because there is considered to be no tolerance for error. (*"A prescription is a prescription, it's got to be right"* – GPSoC supplier, FS13).

5.5.10. Suppliers considered that whilst the technical challenges of the SCR programme were moderate, the political challenges were high. The perceived political sensitivity of the programme meant that targets and deadlines had, they felt, sometimes been political rather than based on readiness, user demand or clinical need, and that this had impacted negatively on clarity of requirements and quality of the end product.

5.5.11. The GPSoC suppliers we interviewed pointed out that the key relationship they have is with GP practices and PCTs, not with CFH. They were keen to develop user-friendly functionality because problems with the software would risk their customer relations and consume resources in terms of support time. Some felt that issues of client relationships were sacrificed to the political pressures of the programme.

> *"[...] we have to support them [users] at the end of the day, so if we create a problem we have to address it." "I think usability is something that CFH hadn't always considered before. You may technically meet the requirement, but how're you gonna use it, because it takes me 20 minutes to do it."*
>
> GPSoC supplier (FS03)

GPSoC suppliers' involvement in the SCR programme

5.5.12. The GPSoC suppliers were clear that they did not develop the SCR functionality for the benefit of their customers. Indeed, they pointed out that many of their customers were not interested in the SCR because there was no direct benefit for them.

> *"There's other CFH projects like GP2GP and EPS2 which do have value for the GP, but GP summaries, as far as I can see, is something that they don't want."*
>
> GPSoC supplier (FS02)

5.5.13. The GPSoC suppliers participated in the SCR programme for three main reasons:

a. SCR compatibility was seen as a requirement for staying accredited under GPSoC (*"It [SCR] is something we have to have on our system to be accredited as a GP supplier, so we've got to deal with it."* – GPSoC supplier, FS01);
b. All the suppliers sought to provide the same (or better) functionality as their competitors (*"It's important because it's part of what we've got to achieve to be a player in the market, so any of the national requirements therefore do have a priority. We can't sell to PCTs and practices if our system doesn't tick certain boxes."* – GPSoC supplier, FS01);
c. The value of the contract with CFH ("*It's a huge amount of work and it does take up a huge amount of our time, and a lot of our end users would rather we did*

different things, but I think the commercial relationship with CFH is quite a good one" – GPSoC supplier, FS02).

5.5.14. INPS was the first supplier to develop SCR functionality. INPS had a good relationship with CFH and agreed to take the project on, but some staff felt that the disadvantages of being the first supplier in such a complex and politically sensitive project outweighed the advantages.

5.5.15. GPSoC suppliers expressed a general concern that CFH IT projects tended to follow each other in quick succession without any breaks in between for either suppliers or NHS organisations to consolidate the changes or draw breath. The perception was that there was little lateral collaboration or coordination between different CFH teams, with the result that one CFH team would typically be unaware of concurrent demands being made on suppliers and practices by other teams within CFH.

5.5.16. CFH had no direct control over supplier delivery dates, but was very dependent on them to achieve its targets. However, GPSoC contracts with CFH were important for suppliers, which made the relationship complex. Some alluded to a history of poor relationships when initial contracts were being negotiated (Section 2.3) and there was a sense that all sides now wished to build more productive relationships and avoid delays. Despite this, we were told that at least two of the suppliers involved in the SCR programme *"threatened to walk out"* during early negotiations. Only after renegotiations (particularly about the testing process) were these situations resolved.

5.5.17. Generally, relationships with CFH were seen by suppliers to have improved considerably since the early days of the NPfIT, and many interviewees said they now had a good working relationship with individual CFH staff, though CFH as an organisation was often perceived as "faceless" and "bureaucratic".

"*Once we got together and started having face-to-face meetings, rather than just e-mailing or conference calling, that really improved the relationship*."

GPSoC supplier (FS14)

5.5.18. Some supplier informants felt that the SCR programme had initially been characterised by lack of coordination and frequent changes of staff:

"Working with them on EPS release 2, it's a lot more organised and the communication channels are really well established, and I think there is a central person managing the whole project. [...] They [SCR team] have had quite a lot of transitions throughout the team from the beginning, so it's been quite fluid throughout the process."

GPSoC supplier (FS14)

Specifying and developing the SCR

5.5.19. The requirements for the SCR went through several iterations until they were workable. [II]

[II] The over-arching model for IT development in the NPfIT was 'waterfall' (characterised by detailed advance specification, formal quality and governance arrangements, strong process control and rigorous practices) as opposed to 'agile' (in which requirements and solutions are co-developed via rapid prototyping, fast iteration, and a flexible and emergent approach to quality and governance).[105] The relative strengths and weaknesses of the 'waterfall' versus 'agile' approach are hotly debated in the computer science community. Some commentators view 'agile' approaches as appropriate for small-scale projects where the development context is highly creative and requirements typically change rapidly but ill-suited to large-scale, public-sector programmes where a high degree of consistency and standardisation is required and requirements can and should be pre-specified. We reflect on this tension in Section 11.2.

"*They re-issued them three times. [...] it's actually more difficult [than starting from scratch] because you are trying to edit existing code sometimes rather than if you'd known upfront what you wanted, you probably would have written it a different way in some instances."*

INPS informant (source code withheld)

5.5.20. Some informants felt that CFH had issued requirements 'top down' rather than engaged in a dialogue with the suppliers. As a result, problems that could have been identified at the outset had not been fully solved at design stage.

"*We had some involvement but not an awful lot. Successful projects in IT are often born through collaboration and asking what's the best way of doing things and coming together to a shared approach. But this was more 'this is how we think how it's got to be done'."*

GPSoC supplier (FS13)

5.5.21. INPS found being the first supplier on the SCR project immensely resource-intensive and felt that it hindered them from developing improvements to the software which their customers were actually asking for. This, they felt, put them at a competitive disadvantage compared to suppliers who implemented later and were given a more refined specification.

5.5.22. All suppliers felt that CFH's approach to evolving requirements had improved as the overall relationship improved.

"They're much more open now to changes in the way of working. When they first came in, it was very much them demanding 'you shall do this and this is how you should do it', whereas we've now managed to build up a relationship with them to say 'well, actually that's not the best approach' and we work through that and come up with different ways of approaching problems."

GPSoC supplier (FS01)

5.5.23. In recent months, CFH have begun to arrange regular 'requirements workshops' with the GPSoC suppliers to help them interpret user requirements in context.

"*Because all systems are built differently, they'll all interpret the requirements differently, because they interpret them in the framework of how their system works. Don't think you can ever write requirements that cater for every system. Have to accept that suppliers will interpret them in different ways."*

CFH staff member, SCR programme (FX14)

5.5.24. Many GPSoC supplier informants in our sample felt that they were sometimes asked to make changes to their software to achieve a change in functionality that would make more sense if it was done centrally on the Spine. It was felt that CFH did not like to approach BT about changes to the Spine, because this would involve expensive changes to contracts and BT, as a larger company, was more of a "heavyweight".

5.5.25. SCR functionality was a major technical challenge, especially for INPS who were the first to attempt it. It was easier in some systems than others, and the investment needed also depended on the extent to which the functionality was built into the system, rather than as a 'quick add-on'. They felt that this issue explained much of the mismatch of expectations around delivery dates.

Testing

5.5.26. Testing (paragraph 4.3.18) was a major piece of work in all CFH projects and accounted for many of the delays in delivery dates, mostly because of CFH's Common Assurance Process.

"For many historical reasons, and also from the way it's been designed, the testing process is incredibly elongated".

GPSoC supplier (FS13)

5.5.27. Some suppliers and PCT IT managers perceived that CFH staff had a somewhat 'tick-box' view of the testing process – believing, for example, that once a product had passed the Common Assurance Process, had a successful First of Type (FoT) upload in a small number of practices and attained Full Rollout Approval (FRA), it was then 'bug free' and transferable to all new contexts. In reality, much further testing often needed to be done (e.g. performance on different platforms)

"[…] you never have 100% perfect software, it's just not possible. That's something they don't seem to understand. It's never finished."

GPSoC supplier (FS03)

5.5.28. CFH's Common Assurance Process was considered by some suppliers as very inflexible. These informants felt that as a result, software is sometimes released that has known 'bugs', because fixing them prior to release would require a lengthy re-run of the testing process. The inflexible testing (and to a lesser extent, the inflexible requirements specification) process was seen as stifling supplier agility and their ability to respond to their customers' needs quickly (hence their competitiveness).

"Sometimes we can't fix problems that we find because CFH say 'no, this is the release, this is finished, this is what we've tested, and this is exactly what we want you to ship, not something that you found issues and fixed [subsequently]."

GPSoC supplier (FS02)

5.5.29. The suppliers perceived a need for close alignment and liaison between a dedicated CFH testing team who were familiar with the SCR technology and the supplier's implementation team when the product reached the testing stage. Initially it was perceived that CFH staff did not understand the need for a close and evolving relationship during testing (working instead on a simpler checklist of 'technology ready' or 'technology not ready'), so the early stages of the programme (they felt) met with avoidable delays.

Deployment

5.5.30. Full Rollout Approval (FRA) was generally given by CFH after successful uploads have been achieved in a FoT (plus, sometimes, one or two additional practices) and these systems had been in use for 45 days and been technically and clinically approved by the practice, the PCT and CFH. Following FRA, the software was then deployed to a further site to test the business process for deployment.

5.5.31. Some stakeholders initially assumed that data would be uploaded to create SCRs 'at the push of a button', but many uploads, even after FRA had been given, were far from this straightforward. It was reported to us that uploads sometimes failed completely, disabled other national applications, slowed down the system or created duplicate records. Small problems could have a large impact, sometimes rendering the upload impossible or freezing local terminals. There were major differences

between systems in terms of number of records uploaded per hour and when and how uploads occurred (e.g. unsupervised during the night, start and stop during the day). In some systems uploads are occurring routinely with few operational problems.

5.5.32. Because of these and other "technical" issues (see Section 8.6), deployment required significant supplier resource. The relatively small size of the GPSoC suppliers has meant that as the SCR programme enters a phase of rapid expansion following the regional public information programme (paragraph 4.3.21), supplier capacity to support local deployments could become a significant rate limiting step.

Training

5.5.33. Another rate limiting step in the national roll-out is likely to be training. One supplier pointed out that the IT-literacy of practice staff is variable but many require a great deal of support to learn even 'simple' new functionality. GPs with a keen interest in technology often represented their colleagues on user groups or committees. The risk was that their views were taken as representative of GPs or practice staff. In reality, IT professionals may have a better understanding of the needs of the 'average' user than a 'techy' GP who claims to represent their colleagues.

5.5.34. PCTs were expected to order training (for their own staff and on behalf of practices) directly from the suppliers. Whilst delivering this training generated revenue for suppliers, it was also very resource-intensive. Suppliers had a limited number of freelance or permanently employed trainers, hence many did not anticipate being able to meet the demand which a large expansion of the programme would generate.

"I think there's a lack of understanding that we've got to divert trainers from other things to deliver this."

GPSoC supplier (FS01)

5.5.35. Some PCTs were perceived as unwilling to book supplier training directly, preferring to use a train-the-trainers model to reduce costs (and perhaps increase training capacity in anticipation of a rise in demand). Whilst suppliers offered this option and understood the rationale behind it, they were concerned about quality control. Poor training, they felt, could create work for their technical support teams at a later date:

"There might be a false economy that they're not paying for the training upfront… we bear the cost, and everyone else possibly."

GPSoC supplier (FS03)

5.5.36. Suppliers have introduced a policy of not accepting requests to support go-lives in practices until training has been booked. One PCT's guidance notes read:

"[Supplier X] will not respond to Schedule A submissions until training dates have been agreed for the sites or Train the Trainer sessions and an accepted quote and purchase order have been returned by the PCT."

Summary Care Record Go-Live Preparation PCT Guidance (name of PCT withheld)

5.5.37. As the SCR programme enters an expansion phase, practices are being sent a 'self study' pack (developed by CFH but distributed by PCTs, with whom responsibility for training lies) rather than having face-to-face concept training (Section 8.8). There is concern amongst suppliers that this will not be sufficient (indeed, that it may not be read at all), and that the concept training will be picked up (unremunerated) by the supplier when they go to do the system training:

"[...] it's just a Powerpoint and a user guide, and this worries me, [...] makes me wonder how informed the practices are actually gonna be. [...] I think the concept

training really goes a long way to getting practices to buy into the SCR project and really see the benefits. And people in a practice are really busy, and they haven't got time to sit and read a 38 page document."

GPSoC supplier (FS14)

5.5.38. Whilst most suppliers felt they had reaped limited returns to date on their investment in the SCR programme, they were now heavily involved in training NHS staff in the use of the SCR. Some expressed concern that they would be negatively impacted if the programme were now curtailed or withdrawn because they would not be able to generate revenue through training.

5.6. Other IT suppliers

BT

5.6.1. BT is one of the largest providers of communications solutions and services in the country. It is delivering three contracts on the NPfIT; the Spine, the N3 broadband network and is the LSP for London and more recently also for a limited number of Trusts in the South of England. BT's contract with NHS CFH exceeds £1.5 bn.

5.6.2. Some clinical and technical staff within BT felt that the issue of the underlying computational architecture of the NPfIT had not been fully understood by senior executives who had negotiated the original contract, though this was not the official view of BT. In particular, staff questioned the apparent assumption that clinical procedures and processes can be 'standardised'. Some BT staff also considered that front-line clinical staff had had insufficient input to the specification, though again this was their personal subjective view.

5.6.3. As is standard practice with most supplier contracts, contractual changes were made via change control notes (CCNs). Such changes tended to be costly, hence decisions by CFH to issue CCNs tended to be made cautiously. As a consequence, modifications to requirements were perceived by some staff as difficult to achieve.

"*You do the elaboration on them [requirements] and you run into this rigidity problem. The technical people will come back and say anything's that not in the paragraph will need a change in the contract*."

Senior BT staff member, SCR workstream (FS06)

Adastra

5.6.4. Adastra is the leading provider of software to GP out of hours services in the UK, with over 90% of the market share. The Adastra system is also used in a wide variety of unscheduled care settings such as walk-in centres, polyclinics and primary care front-ends in A&E. From its origins as a private company in 1994, Adastra has grown to become part of the Advanced Computer Software Group, a public company with a leading position in the delivery of integrated care. Adastra retains close ties with its many customers in out-of-hours, including the local out of hours service (Medway) where Adastra's Medical Director still practices as a GP. Medway joined the national rollout of the SCR soon after the early adopter phase. The centre is a test site for Adastra upgrades and works closely with the company to give feedback and shape new releases (Section 5.5).

5.6.5. Adastra staff felt they had a very good working understanding of how out-of-hours care worked, and some felt that this understanding was not always shared by CFH.

"Initially it was a bit of a challenge to communicate the mechanics of out-of-hours services to CFH but we got there in the end"

Adastra senior staff member (FS04/~03)

5.6.6. In contrast to the GPSoC suppliers (Section 5.5), Adastra saw SCR functionality as something their customers wanted and which they were keen to provide. In this setting the SCR is in line with the company's priorities to enhance their system according to customer demand:

"Ever since we started in out-of-hours, we've been asked 'why can't we see the GP record?'" "The things that are high on our agenda are what our customers want."

Senior staff members, Adastra (FS04/~01 and 02)

5.6.7. Adastra invested heavily in creating an integrated interface so the SCR could be viewed from within the application rather than via a separate window (Figure 5.1).

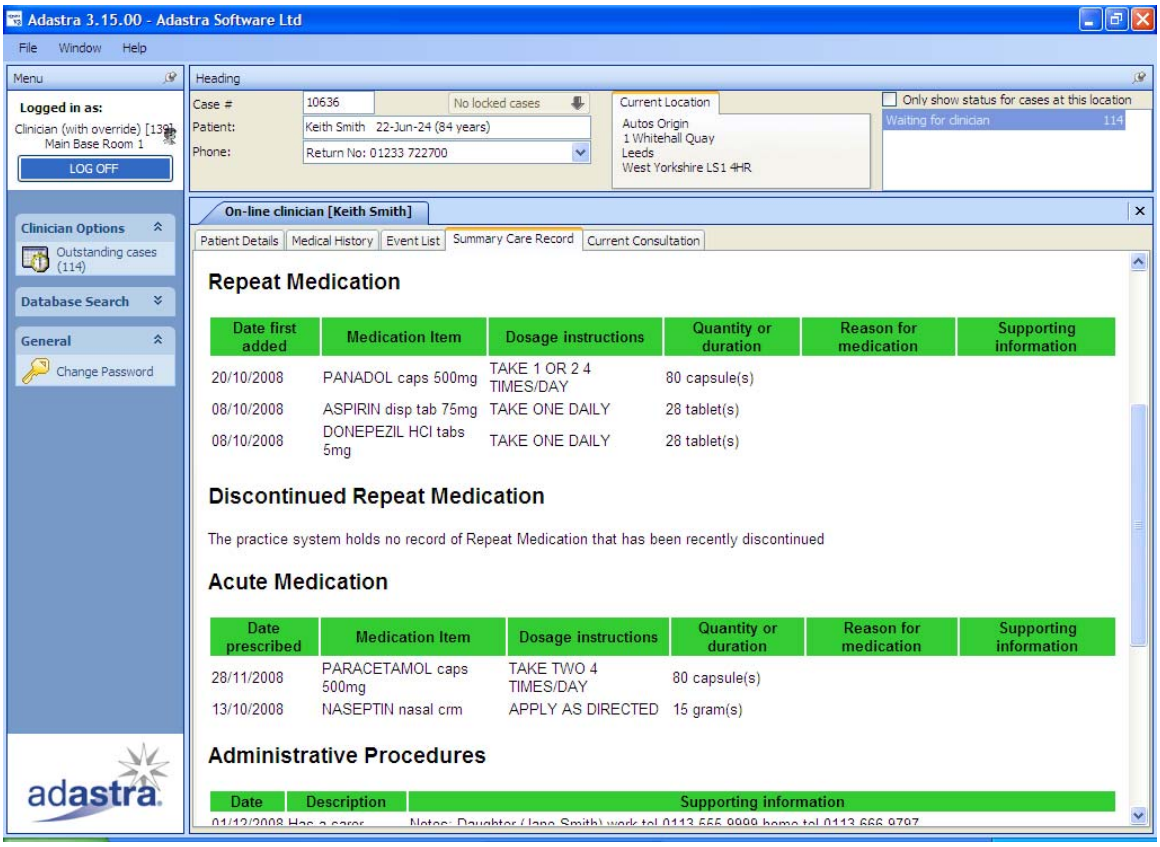


Figure 5.1: The integrated Adastra interface (screen shot from training database, kindly supplied by Adastra)

5.6.8. Like the GPSoC suppliers, Adastra viewed training revenue as an incentive to become involved with the SCR programme, though this was seen as relatively low importance compared to meeting customer needs.

5.6.9. Adastra also provides a number of PCTs with a web-based register for end-of-life care. This provides a secure repository for care preferences that can be accessed by care professionals without complex technical integrations with other healthcare systems. Whilst some informants viewed this as a rival product to the SCR, Adastra staff considered it as an interim solution pending the widespread roll-out of the SCR which would record end-of-life care preferences along with other Release 2 data.

5.7. Professional bodies

5.7.1. Professional organisations such as the British Medical Association, Medical Protection Society, Royal College of General Practitioners, Royal College of Nursing and Royal Pharmaceutical Society all sought to protect and advise their members about the implications of shared electronic records for issues such as security, confidentiality, safety and workload.

5.7.2. Such organisations tended to support technological innovation and saw state-of-the-art IT systems as an integral part of modern clinical practice. But they were also aware that heavy-handed information governance procedures placed staff at risk of being accused of "unauthorised access" when they were just doing their job; that the material reality of many systems was far from state-of-the-art; and that IT systems that were poorly designed had an opportunity cost in terms of direct patient care.

"People [nurses] do want to be seen to be being good people, they have endorsed new technology, they're using it at home, they want to be using the best technology in the work situation but they don't want to have a huge great collar round their neck. So there's a sense that IT is the future direction, most people don't want to be seen to be laggards, they want to be seen as part of the modernisation movement, they want to do their bit, professionalism is partly about working with the latest IT, but at an operational level it's currently costly, clunky and plagued with uncertainties."

Senior staff member, Royal College of Nursing (FS11)

5.7.3. At the time of this evaluation, many professional organisations were issuing cautious interim guidance and emphasising that the rules of good professional practice (e.g. record keeping, confidentiality, clinical governance) applied equally whether records were paper, locally held or nationally shared. But it was recognised that these principles were likely to play out differently at the operational level, and many organisations prepared 'what-if' scenarios in the form of frequently asked questions.[JJ] As a recent commentary put it, *"…information flows in an era of abundant data are changing the relationship between technology and the role of the state once again. Many of today's rules look increasingly archaic. Privacy laws were not designed for networks. Rules for document retention presume paper records."*[106]

5.7.4. Professional organisations thus broadly supported the 'modernising' promise of the SCR whilst also being cautious of its implications in relation to their members' professional duty of confidentiality and their legal liabilities in relation to data protection and clinical negligence. Their members often included protagonists for both 'sides'. It was usually but not always the case that the 'pro-SCR' lobby tended to sit on a specialist IT committee or working group and the 'anti-SCR' lobby tended to play more generalist roles or sit on an ethics or professional standards committee. For example, members of the subcommittee of the Royal College of General Practitioners who worked with CFH to produce guidance for data quality work on SCRs expressed positive attitudes to shared records, but members of the same organisation's ethics committee contacted our team to express their concerns.

5.7.5. The British Medical Association delegated much of its decision-making power on IT issues to a dedicated NHS IT Working Party chaired by Dame Deirdre Hine. In addition, the Joint GP IT Committee of the General Practitioners Committee and the Royal College of General Practitioners (JGPITC) was vocal on IT developments. In 2007-8, this committee was chaired by Dr Paul Cundy, an individual with deep personal misgivings about shared patient records who was often an isolated but

[JJ] See for example this list of FAQs, produced jointly by CFH and the Medical Protection Society; http://www.connectingforhealth.nhs.uk/systemsandservices/scr/staff/faqs/mpsfaqs

powerful voice in the meetings. Dr Cundy's views resonated strongly with those of some delegates at the BMA's Annual Representative Meetings, where some speakers on the SCR were opposed to its introduction on ethical grounds (amongst other reasons). Some members of the NHS IT Working Party felt that both Dr Cundy and some ARM delegates were (to some extent at least) minority single-issue campaigners who did not really represent the rank and file of BMA members (despite the fact that several motions opposing the SCR were passed by a clear margin at the 2008 meeting). Dr Cundy was faithfully representing the views of many of the GPs within the BMA whereas the Working Party had the views of the full range of membership to consider. When a new chair of the JGPITC was appointed in late 2008 (which, coincidentally, was also the time when the new consent model was introduced, which had been agreed with Dame Deirdre Hine and Dr Paul Cundy), many outsiders perceived a 'sea change' in the BMA's perspective on the SCR.

5.7.6. Whilst the BMA's overall stance towards the SCR appeared to become more positive as the programme unfolded, the rapid expansion of the public information programme was viewed negatively (see Section 4.3).[98]

5.7.7. Some specialist bodies within the medical profession felt the overall balance between benefits and risks was adverse.

"There's a remarkable lack of concern about the SCR from the Royal Colleges, other than the Royal College of Psychiatrists. The other Royal Colleges seem to me quite pro. […] The main emphasis from the other Royal Colleges is: 'What can this do for us, how will it benefit clinicians?', without asking 'What are the dangers for patients?'"

GP with special interest in mental health in focus group at specialist Mental Health Trust, September 2008 (FM04/~01)

5.8. Patients and citizens

5.8.1. The perspective of patient organisations broadly mirrored that of professional organisations. Many were enthusiastic about the SCR and HealthSpace because these technologies appeared to represent greater patient involvement and a more modern and efficient NHS. A survey done as part of our Year 1 report showed that most patients, whether they had stigmatising medical conditions or not, viewed the tradeoff between risk and benefit of the SCR in positive terms – but that most had not considered the issue in depth and were not interested in HealthSpace.[3]

5.8.2. Some service users who considered themselves 'politically active' in their patient organisation were cynical of the rhetoric of 'empowerment' in the SCR and HealthSpace programmes. They viewed empowerment as to do with confrontation and direct action, not about forming partnerships with professionals or placing their trust in information governance procedures overseen by the state – a stance that was not generally understood by NHS or CFH staff, as the following exchange illustrates:

GP enthusiast for SCR is giving a Powerpoint presentation to a group of service users and carers.

Questioner from floor: "Can a patient delete their record if they find it's inaccurate?"

GP presenter: "Ooh, don't give me a heart attack, we wouldn't want that. There would have to be lots of clinical governance and due diligence around making corrections. We do want patients to contribute to their record, but not to delete them."

Field notes from 'study day' on the SCR organised by national patient organisation for a long term condition (FM05)

5.8.3. Healthcare IT policy post-2004 unfolded in a context of fierce debate about the role of IT in public life. On the one hand, electronic surveillance was viewed as an essential tool in preserving national security. But as the capacity to store and share data within and across public sector organisations increased, and as stories of security breaches and data loss appeared periodically in the media, so public concern grew about the ethical, social and legal implications of such practices.[KK]

5.8.4. Our Year 1 report described opposition from civil liberties groups and the Information Commissioner to uploading personal medical data to a centrally held SCR database without the explicit consent of the data subjects.[1] The Big Opt-Out Campaign (www.thebigoptout.org), which included senior doctors and prominent academics, made efforts to inform the public and encourage people actively to opt out. Civil liberties campaigners used Freedom of Information Act requests to investigate how PCTs were handling opt-out requests and expose inconsistencies between them to illustrate the argument that there was no consistent national policy on this issue.

5.8.5. The 2008 Thomas Walport Data Sharing Review, written jointly by the Information Commissioner and the Director of the Wellcome Trust, raised concerns about standards for safeguarding personal data in public and private organisations and made a series of recommendations aimed at transforming the attitudes, practices and organisational culture of those who collect, manage and share such data.[108]

5.8.6. In March 2009, the Joseph Rowntree Reform Trust published *Database State*, which argued that government surveillance was becoming an accepted fact of life in the UK and that a quarter of large-scale public sector databases in the UK breached data protection law.[109] Perceived dangers included serious breaches of privacy, identity fraud, specific unforeseen harms of particular databases and failure of large-scale IT systems to deliver on their implicit promise of providing complete, accurate and trustworthy information. It argued that such databases would tend to exacerbate rather than reduce socio-economic inequalities, since certain potentially vulnerable groups (e.g. young black men, single parents, children) would be more likely to feature on state databases and/or less able to opt out than the average citizen.

5.8.7. *Database State* expressed three concerns. First, SCR-held data might be viewable by administrators and civil servants even when the patient had 'opted out'. Second, there was a perceived lack of clarity about what data fields would be held on the SCR. In particular, the report expressed concern that its then-current restriction to medication, allergies and adverse reactions could be extended to a full electronic record available nationally. Third, the risk-benefit ratio of the SCR appeared to the authors less favourable than that of *"a proper, purpose-designed emergency medical record"* (page 13). All these issues are considered further in Chapter 8.

5.8.8. The first point relates to what happens to a person's data should they opt out *after* their SCR has been created. An individual who opts out before the go-live in their GP practice will have a 'blank' record created, marked by a 'flag' (93C3, meaning "no data may leave the practice"). But someone who opts out after the go-live will not, according to *Database State*, be able to request that clinical data already uploaded to their SCR be permanently deleted; the SCR will merely be flagged 'do not access'.[LL]

[KK] For example, the 2009 Coroners and Justice Bill, Section 8, clauses 151-154, put before Parliament in January 2009, initially proposed to legalise the sharing of data for security purposes between government departments, the NHS and private sector organisations with heavy penalties for those who failed to comply. After strong protests from civil liberties campaigners and doctors' professional bodies, NHS records were excluded from the Bill in March 2009.[107]

[LL] This issue has symbolic significance in civil liberties circles. It recurred in CFH board meetings partly because some members were genuinely concerned about it and partly because of the perceived risk to the reputation of the programme if reservations of civil liberties campaigners were not addressed. See Section 8.5 for further discussion on deleting SCRs.

6. Use and non-use of the SCR at the clinical front line

6.1. Overview of quantitative data

6.1.1. Data sources for our study of use and non-use of the SCR in clinical care are listed in Table 3.1, paragraph 3.2.2. CFH supplied cumulative statistics on SCR creation and accesses, and Adastra supplied de-identified raw data on 416,325 out-of-hours primary care encounters in Bolton, Bury and Medway from August 08 to January 10. We also had a qualitative dataset collected by our own team, including interviews with 67 staff and ethnographic observation of 237 encounters (see next section). This section considers the quantitative datasets.

6.1.2. Mixed-method research uses both quantitative and qualitative data to answer different types of question about a multifaceted problem. Questions of the format 'How many…?' and 'How quickly…?' are readily answered with numbers, though the accuracy and representativeness of those numbers may be challenged. Questions which begin 'Why…?' and 'How…?' require detailed analysis of a smaller sample of cases. It is an important research principle that quantitative data should not be used to answer 'why' or 'how' questions any more than qualitative data should be used to answer 'how many' questions. Therein lies the potential strength of mixed-method research – and the potential for misinterpretation if these principles are ignored.

6.1.3. Data supplied by CFH (Figure 6.1) show that uptake and use of the SCR was greater in primary care settings than in secondary care. Accesses of the SCR from the integrated Adastra viewer (reflecting activity in GP out-of-hours and walk-in centres) rose steadily (though in a non-linear way) since early 2009. Direct accesses via the SCR application (reflecting activity in A&E departments and other secondary care settings) were low and showed no upward trend.

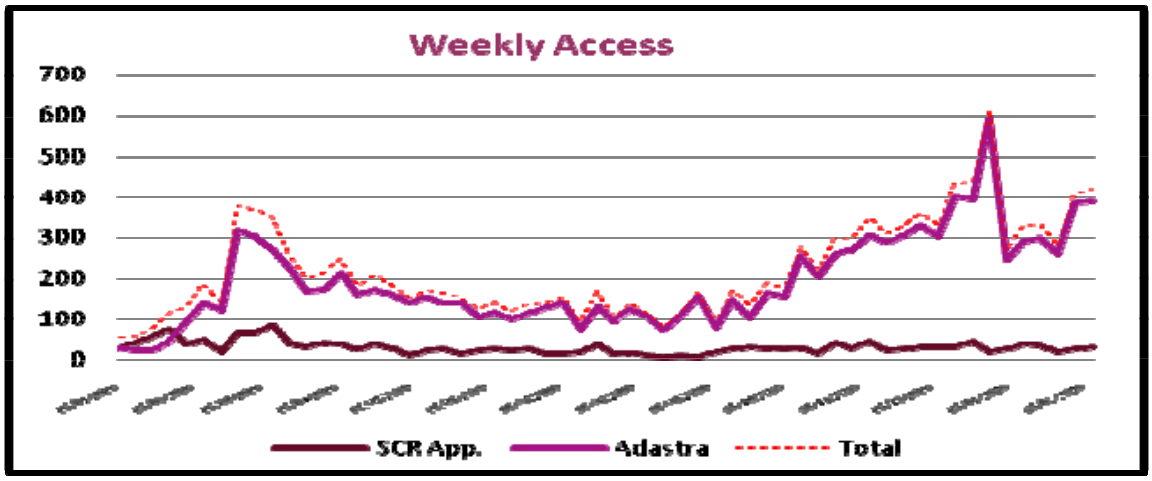


Figure 6.1: Weekly access rates for SCR Jan 09 – Feb 2010, data supplied by CFH[MM]

6.1.4. Table 6.1 reports research questions and statistical analysis for the Adastra dataset.

[MM] The data in this graph lack a denominator – i.e. the graph gives absolute numbers of SCR accesses in England but not the total number of patients seen in unscheduled care. Using indirect (and somewhat old) data from other sources, we calculate that approximately 400,000 patients are seen in England and Wales A&E departments per week; 200,000 in GP out-of-hours centres and 1000 in walk-in centres.[110-112] The last figure is probably an underestimate. As described later in this section, SCR access in participating sites is now around 4% of all encounters and 22% of encounters in which a SCR is available.

Table 6.1: Factors influencing whether a SCR was accessed in an unscheduled primary care consultation		
Research question	Finding	Interpretation
What proportion of cases involved a SCR access?	Overall, a SCR was accessed in 4.3% of encounters (21.6% of patients with a SCR) in Bolton, 4.6% (20.3% of patients with a SCR) in Bury and 2.1% (19.6% of patients with a SCR) in Medway.	These overall rates masked considerable variation by date, clinician, type of illness and other variables (see below). The SCR is not necessarily clinically needed in a consultation so 100% access is not the 'gold standard'.
Was SCR access increasing in these sites over time?	SCR accesses increased significantly ($r = 0.075$, $p < 0.0001$) but in a non-linear way over time and with very different patterns seen in different sites. • In Bolton, SCR accesses showed a slight *decrease* over time (logistic regression $\chi^2(1) = 28.5$, $p < 0.0001$, odds ratio per quarter 0.92 (95% CI: 0.90, 0.95). This result masks a complicated pattern of rising, declining and then rising use. • In Bury, SCR accesses increased significantly over time (logistic regression $\chi^2(1) = 278.1$, $p < 0.0001$, odds ratio per quarter 1.24; 95% CI: 1.21, 1.27). • In Medway, SCR accesses increased significantly and rapidly over time (logistic regression $\chi^2(1) = 741.8$, $p < 0.0001$, odds ratio per quarter 6.62; 95% CI: 5.67, 7.73).	The three sites illustrate limited adoption followed by partial abandonment (Bolton); limited adoption with slow incremental growth (Bury); and rapid adoption after a late start (Medway). The fall in access rates in Bolton may have been partly due to a premises move in which some staff temporarily lost access privileges. All sites showed a 'dip' in accesses during periods (e.g. Christmas) when the proportion of locums and inexperienced staff was higher. Medway was unusual in that very few locums and temporary staff were used.
How did SCR access vary with date and time seen?	SCR access varied significantly by • Day of the week, being highest on Wednesdays (3.5%) and lowest on Thursdays (2.2%); χ^2-test; $\chi^2(6) = 171$, $p < 0.001$. • Hour of the day, being highest in late morning (3.3%) and lowest in the early hours of the morning (1.5%); $\chi^2(23) = 244$, $p < 0.001$.	This finding may be due to a confounding variable, e.g. proportion of locums and inexperienced staff working on different days and at different times.
How did SCR access vary with age and gender of patient?	SCR was slightly more likely to be accessed in women patients than men (2.8% vs 2.6%; $\chi^2(1) = 20.0$, $p < 0.001$), and more likely to be accessed in younger patients than older ones (Mann-Whitney test, $z = 7.7$, $p < 0.0001$).	The 'significant' gender difference may not be clinically significant since the dataset was very large. Variation by age was accounted for by low accesses in the over 80s, a surprising finding which was not readily explained.
How far do all the above variables explain variation in SCR access?	A multivariate logistic regression model incorporating site, age, gender, date, day, and time variables (details available from authors) was highly significant (χ^2 test; $\chi^2(17) = 2658$, $p < 0.0001$) and all variables were statistically independent of each other. However, the pseudo-R^2 value was only 3.6%.	The model explained only a tiny proportion of variation. Most variation in SCR access is not due to the age or gender of the patient or where or when they are seen.

How does SCR access vary with clinician variables (identity, experience)	Variation in SCR use by clinician was highly significant (e.g. in Bury, $\chi^2(103) = 3591$, $p < 0.0001$, pseudo-R^2 = 15%). Nurses were no more or less likely to access SCRs than doctors ($\chi^2(1) = 2.3$, $p = 0.13$). Clinicians who saw more cases were more likely to access SCRs. e.g. in Bury, the 10 clinicians who saw most cases were collectively involved in 20.4% of all consultations. They used the SCR in 5.3% of encounters compared with 2.2% for all other clinicians ($\chi^2(1) = 470.9$, p < 0.0001, pseudo-R^2 = 2%, odds ratio 2.43, 95% CI 2.25-2.62).	The most significant single factor provided in the dataset predicting SCR access was which clinician was seeing the patient, which accounted for 15% of the total variance. Relatively low *overall* use of the SCR was partly explained by the fact that some clinicians (typically, regular, experienced staff) accessed SCRs frequently while others (typically locums and short term staff) did not access them at all.
How does SCR access vary with the nature of the complaint?	We considered urinary tract infection (Read code K15.. [cystitis] or K190. [urinary tract infection, site not specified]) as a marker for a common illness in which knowledge of recently prescribed medication was likely to be relevant. These cases were more likely than the average encounter to involve SCR access (χ^2 test; 5.5% versus 3.9% overall; $\chi^2(1) = 45.1$; odds ratio 1.42; 95% CI: 1.29, 1.58). Using 'dressing of skin' (7G2E) as a marker for an encounter where allergy data were likely to be relevant (since many people are allergic to sticking plaster), we obtained similar results (5.6% versus 3.9% overall; $\chi^2(1) = 20.3$; odds ratio 1.44; 95% CI: 1.24, 1.68). Encounters in which more than one Read code was assigned were significantly more likely than the average encounter to involve SCR access (5.4% versus 3.9% overall; $\chi^2(1) = 78.7$; odds ratio 1.43; 95% CI: 1.33, 1.55).	Analysis by nature of complaint was limited by marked inconsistency between sites, and between clinicians within sites, in the use of codes on the Adastra system. With that caveat, there is some evidence that the SCR was more likely to be accessed when information on current or recent drugs and allergies was needed, and when the patient had complex needs. However, variation by diagnostic code was les marked than variation between clinicians.
What impact does SCR access have on length of consultation?	When the SCR was accessed by doctors, consultations were significantly longer overall (Mann-Whitney test; z = -5.2, p < 0.0001) but differences varied considerably between sites, being significantly *longer* in Bolton ($z = -13.7$, $p = <$ 0.0001), significantly *shorter* in Bury ($z = 2.7$, $p = 0.006$) and no different in Medway ($z = 0.5$, $p = 0.60$). When the SCR was accessed by nurses, consultation length was significantly longer overall (median duration 3 minutes longer, z = -7.5, p < 0.0001), though differences were not consistent between sites (Bolton significantly longer by 5 minutes, $z = -7.7$, $p = <$ 0.0001; Bury significantly longer by 2.5 minutes, $z = -4.8$, $p = 0.0001$; Medway no significant difference, $z = 0.1$, $p = 0.9$).	There was no consistent effect of the SCR on consultation length for either doctors or nurses. The differences demonstrated are likely to be attributable to confounding variables – for example that the SCR was more likely to be accessed for non-trivial illness.

Note: The proportion of the local population who had a SCR increased from 33% to 50% in Bolton and 65% to 77% in Bury in the 18-month period covered by the dataset. Data from Medway (which joined in August 09) were only analysed for the last six months, in which SCR availability increased from 0 to 33%.

6.1.1. The findings in Table 6.1 can be summarised as follows:

a. There was wide variation in rates of SCR access between different clinical settings and different clinicians. Some doctors and nurses accessed SCRs a lot and some did not access them at all. Regular staff were significantly more likely to access SCRs than occasional staff and locums;
b. SCRs were significantly less likely to be accessed at certain times and on certain days, perhaps reflecting when less experienced clinicians were on duty;
c. SCRs were significantly less likely to be accessed in the over 80s for reasons which are unclear;
d. Clinical coding of reason for encounter varied between sites and clinicians, making analysis by such codes unreliable. There was some limited evidence that SCRs were more likely to be accessed in conditions for which a drug or allergy history was relevant, and in patients with more than one diagnosis;
e. There was no consistent association between SCR use and consultation length for doctors or nurses. Longer overall consultation length when a SCR was accessed might have been due to confounding variables (e.g. experience of the clinician, complexity of the case).[NN]

6.2. Overview of qualitative data

6.2.1. The main focus of our work in unscheduled care was qualitative. In our 67 interviews and 237 directly observed encounters, staff described and showed us *how* they used the SCR in their day to day work – or *why* they could not or would not use it. Upstream of that, they showed us *what their day to day work consisted of*. This is important. At an early stage in this fieldwork, we were told a story of how a senior manager from CFH had shadowed a nurse for a day and was described as *"shell shocked"* (FN25/~01). Stories about software designers or IT trainers allegedly not understanding the nature of clinical work or failing to take account of the material, financial and cultural constraints of the NHS were told in every setting we visited. Because such disconnects appeared to account in one way or another for many instances of low SCR use (see Section 10.1), our qualitative findings represent an attempt to capture what has been called the 'workaday world' of unscheduled NHS care in all its messiness and complexity and explain the goodness (or poorness) of fit of the SCR in relation to this.[113] To that end, we sought what qualitative researchers call a 'maximum variety sample' – that is one that is not necessarily statistically representative so as to capture a spread of examples and viewpoints. For example, we deliberately oversampled in 'major' and 'resus' sections of A&E.

6.2.2. All organisations approached consented to participate and welcomed our team. No manager or clinical director refused to be interviewed, though some did not reply or were unavailable when we visited. Clinical staff were very busy, sometimes with very sick patients, but most tried to accommodate us. Of 77 clinicians approached, ten declined to have us shadow or interview them (reasons included too busy, forgotten smart card, and not interested; several gave no reason). Five patients of 246 approached declined to participate in the study, and in four further cases the researcher chose to leave the room or was asked to do so by the clinician before the patient was called in or during a sensitive phone conversation. Because of the pace of activity, it was not practicable to ask patients their reasons for refusal.

[NN] Some sites showed longer consultations when a SCR was accessed but lack of a consistent effect between sites suggests this is not a simple causal relationship. Qualitative data (see Section 6.8) suggested that when data held on the SCR were poorly matched to the scope of practice of the clinician (for example when a nurse who was not a trained prescriber opened a SCR which listed multiple medications), a time-consuming effort to make sense of the data sometimes ensued.

6.2.3. The Appendix gives details of the staff interviewed, demographics of the 214 clinical cases and 23 call handler cases and the distribution of these cases between sites. In sum, we interviewed a wide range of staff in all sites, from receptionists to clinical directors and with a predominance of front-line doctors, nurses and pharmacists. Our dataset of 237 patient encounters had an even gender balance, broadly reflected the age distribution and ethnic mix of the local population with a skew towards very young children, and included mild, moderate, severe and life-threatening illness. Half the patients were on prescribed medication or had known allergies (i.e. there might have been some information on their SCR had it existed).

6.2.4. Most clinical encounters we observed did not involve the SCR. As the title of this report implies, reasons for this were multiple, complex and tied to the situated detail of the encounter itself (the 'micro' level illustrated in Figure 3.1, paragraph 3.4.3) and the organisational context in which it occurred (the 'meso' level in the same figure). Sometimes the patient did not have a SCR (e.g. was 'out of area' or registered with a GP who was not participating). Sometimes the patient's SCR status was unknown for technical reasons (e.g. temporary failure of key technologies needed for viewing the SCR). Mostly, however, non-access of the SCR was for essentially human reasons – usually because the organisation, despite having achieved technical go-live and being signed up as a participating site, had decided "not to push" the SCR.

6.2.5. Reasons for a semi-official strategic-level decision "not to push" the SCR varied between organisations. Most commonly, it was said that following initial enthusiasm and effort by the organisation, staff had lost motivation because of a "low hit rate". At the time of our fieldwork, about half the patients in participating PCTs were registered in GP practices which had uploaded data to create SCRs, but many patients attending unscheduled care settings were 'out of area', hence the hit rate for finding a SCR on any patient was estimated by staff as closer to one in three or one in four. In other organisations, the logistics of accessing SCRs were considered prohibitive or the SCR was "not a priority" because other sources of data were felt to be as good as or better than the SCR. These issues are discussed further in Sections 6.5 and 6.6.

6.2.6. In the rest of this chapter, we try to explain variation in SCR access between different unscheduled care settings, professional groups and individuals. We also explore the consequences ('benefits' and potential tradeoffs) of occasions when the SCR was used. We reflect briefly on whether the SCR might have made a difference in clinical encounters when it was not used. In short, there appears to be no single, simple explanation of why the SCR was used in so few encounters. Rather, explaining what is, thus far, limited use and modest impact of the SCR requires a detailed understanding of unscheduled care and the socio-technical network in which this technology is – somewhat precariously at the time of writing – embedded.

6.3. Who attends unscheduled care and why?

6.3.1. As described later in this section, the SCR sometimes appeared to contribute surprisingly little to the management of a presenting problem in the settings we studied. In order to explain this finding, it is necessary to explore the patterns of illness and consulting behaviour outside normal GP consulting hours. A person who sought 'unscheduled' healthcare had a number of choices, including:

- Phone the national NHS advice line NHS Direct (note however that at the time of this fieldwork NHS Direct were not participating in the SCR programme)

- Phone the local GP out-of-hours (OOH) service (or occasionally, turn up in person without phoning first)
- Turn up in person to a nurse-led walk-in centre
- Turn up in person to an A&E department

6.3.2. NHS Direct and nurse telephone triage at the GP out-of-hours service both fed into the same access routes locally. Call handlers routed most calls directly to a clinician except when it was clear that a home visit (e.g. to a terminally ill person) was essential or when the caller preferred to come in and be seen ('base visit'). The way telephone advice worked was that the call handler took the caller's number and flagged the case as a 'call back' on the on-screen list of pending cases. Doctors and nurses in the centre scrolled down this list on their own computer, and used their judgement to prioritise cases on the basis of brief free text notes made by the call handler.

1 year old infant. Caller's voice not audible to researcher

Call handler: "Right, what's the problem?"

Listens. Writes free text: `Blocked nose, vomiting. Saw GP a month ago, not better.`

Call handler: "Any temperature?"

Writes free text: `No temperature. Had MMR jab last week.`

Call handler: "Eating and drinking OK?"

Writes free text: `Not eating but drinking.`

Call handler: "Is he normally fit and well?"

Writes free text: `Normally fit and well`

Call handler: "Any past medical history?"

Writes free text: `No past medical history`

Call handler: "Any allergies?"

Writes free text: `No allergies`

Call handler: "OK what I need to do is get a GP to call you back."

Flags call on system for 'routine call back'

Call handler in GP OOH centre (FN29/#219) [OO]

6.3.3. Callers who spoke to a GP or nurse were given self-care advice or advised to attend for a base visit, attend the walk-in centre to be seen by a nurse, attend A&E or see their own GP the next day. Rarely, a call handler called a 999 ambulance or assigned a GP home visit. Most of our sample of 214 patients seen by clinicians in unscheduled care were self-referred and almost exactly half were sent home (or in the case of telephone advice, advised to stay at home) without onward referral. However, a substantial minority were referred from, or referred on to, other parts of the local health community. The picture was thus one of multiple routes into the system and multiple routes for cross-referral after the primary contact.

6.3.4. Some patients seeking unscheduled care were classified by staff as clinical emergencies. Nine of the 53 patients we saw in A&E, for example, were unconscious

[OO] As with all the patient encounters reported in this document, clinical details in this case have been systematically fictionalised (see paragraph 3.3.11). The notation here refers to a particular set of field notes (e.g. 'FN15' and a particular individual – where patients are denoted with a hash (e.g. '/#23') and members of staff with a tilda (e.g. '/~03').

or had severe chest pain, though this finding should be interpreted in the light of the fact that we had directed our A&E fieldwork towards 'major' cases (in whom the SCR might be more relevant). Of 133 encounters in the walk-in centres and GP out-of-hours centres, two had acute chest pain (FN07/#97, FN03/#31), one impending airways obstruction (FN05/#60) and one was a possible surgical emergency (FN29/#211). In several other patients, a symptom (typically pain) which had been going on for hours or days had become substantially worse. Three patients had run out of medication, and in two of these (asthma, FN05/#56, and glaucoma, FN05/#59), an immediate prescription was needed to prevent a possible emergency. Another patient (FN06/#67) sought the 'morning after' pill and was already close to the 72-hour deadline.

6.3.5. More commonly, unscheduled care was sought when a patient's symptoms or relatives' concerns had reached a point where prompt assessment or reassurance was required. Typical cases were a child with a rash (parents wished to exclude meningitis even though the child was not especially unwell, FN09/#93) and an elderly person whose relatives were concerned about general deterioration (FN04/#63). Sometimes, patients had left the problem for a day or two but it had not got better, and may have been prompted by a third party to be seen without delay. For example, with one small child seen on a bank holiday (FN03/#32), the grandmother had come round for tea and judged that the child's condition needed urgent assessment.

6.3.6. Almost a quarter of our sample of 214 clinical encounters were patients who described themselves as not having major symptoms but wanting to *check* that the problem was nothing serious. Clinicians sometimes used the term 'worried well' for such encounters. For example, case FN16/#155 was a young child who had tripped over in a school playground earlier in the day and could not remember which part of his body he had bumped. There were no signs of injury but the mother had been advised by school staff to get the child checked out as this was 'policy'.

6.3.7. Some people used the unscheduled care service to see a doctor of nurse without missing work or domestic responsibilities (e.g. FN05/#58) or because opening times were more convenient than their own GP's (e.g. FN29/#203). One child had missed a non-urgent X-ray appointment the previous day and was brought to A&E complaining of pain in the relevant region; nurses suspected that this was an attempt by parents to get the procedure done at a more convenient time (FN18/#185). Some people used the service as a way of saving money (e.g. to get a prescription for a medication that could be bought over the counter).

"Out-of-hours has moved away from urgent care. It's more patient choice now."

Senior OOH GP, while discussing several examples of patients who had chosen to attend this centre rather than consult their own GP (FN29/~02)

"In theory we only visit the elderly and the disabled, but it's not like that in reality (laughs). People who claim they've got no transport and no money for a taxi also get home visits"

OOH GP interview on way to home visit (FN11/~02)

6.3.8. As in 'in hours' GP encounters, some patients' main reason for attendance was formal or informal sanction of illness. Some, for example, sought a certificate to cover intended non-attendance at work the next day (e.g. FN16/#162, low back pain), while others sought to sanction *wellness* because they hoped to attend work (e.g. FN11/#76, rash, parent needed note for child to be accepted in workplace nursery).

6.3.9. Some patients attended for a second opinion, and particularly to challenge a diagnosis given by another health professional. For example, we saw one small child whose mother had been told by her GP that the child was suffering from infected scabies (FN03/#22). By attending a different GP at the out-of-hours centre, the mother sought to confirm her own (correct) lay diagnosis of chickenpox and also ask whether the medication prescribed for the 'wrong' diagnosis was safe to give. This case illustrates how the currency of the out-of-hours encounter may not be information (the diagnosis passing from the knowledgeable clinician to the ignorant patient or carer) but authorisation (this parent brought the child to confirm what she already suspected).

6.3.10. Some patients contacted the out-of-hours clinic to seek medication which they believed they needed and which their own GP had refused to supply. Patient FN03/#106, for example, sought antibiotic eye drops for a mild red eye and was disappointed when the out-of-hours GP backed up their own GP in declining this request. Clinicians found these negotiations time-consuming and stressful, especially when they occurred over the phone.

"He kept saying 'just give us a prescription, give us a prescription."

OOH call centre nurse debriefing with researcher after difficult phone call with parent of young child, complaining of cough (FN11/#80)

6.3.11. 'Simple' physical problems presenting in unscheduled care sometimes masked complex social, mental or emotional ones. Excess alcohol (FN14/#147), domestic violence (FN04/#39), risk of violence to staff (FN106/#3), major life events (e.g. bereavement, FN29/#209), serious financial difficulties (FN29/#236), serious mental health problems presenting as minor physical symptoms in the patient (FN11/#79) or as their 'sick' child (FN29/#203), dual diagnosis (mental health problems as well as drug and alcohol dependency, FN13/#116) and weak social networks (lives alone, nobody to look after her, FN126/#13) were all evident in our dataset, though this study was not designed to provide quantitative estimates of their prevalence. Clinicians were generally alert to these complexities but the social aspects of the case were often poorly captured by the technologies, which were typically designed to record coded diagnoses and provide clinical decision support for 'textbook' medical or nursing problems.

6.3.12. In a single case in our sample of 237 encounters, the contact may have been an attempt by a drug-dependent individual to obtain an additional supply:

Patient has "run out of" sleeping tablets. The patient's Adastra record shows two previous prescriptions given by out-of-hours doctors for these tablets but there is no SCR available. GP refuses to prescribe any more and advises see own GP. But records indicate that this strategy has been successful on previous occasions.

Field notes GP OOH clinic, phone consultation (FN05/#55)

6.3.13. In the above example, the absence of independent information on whether, when and how many sleeping tablets had been prescribed by the regular GP created strategic possibilities for this patient in the unscheduled care setting. The patient did not have a SCR, and it is not possible to say with confidence whether the prescribing behaviour of the out-of-hours GP (or any of the previous ones consulted) would have been influenced by 'objective' information on the person's current medication from a SCR.

6.4. Primary care settings: GP out-of-hours and walk-in centres

6.4.1. The GP out-of-hours services in Bolton, Bury and Medway were run from modern, purpose-built, well-equipped buildings with the nurse-run call centre in one room and GP consulting rooms nearby. Walk-in centres were staffed by nurses, most of whom were licensed to prescribe a limited range of drugs using disease-related group (DRG) protocols. In Bolton, the walk-in centre was co-located with a GP surgery, though its opening hours were longer. In Bury, the walk-in centre was in the same building as the GP out-of-hours centre, making cross-referral of patients from nurses to GPs very straightforward. Towards the end of this study, Bury had begun to host a smaller, privately-run GP out-of-hours service in the same building.

6.4.2. Almost all patients seeking GP out-of-hours care did so by telephone call. Call handlers did not have access to SCRs or even to information on whether the patient had a SCR. Clinicians could not access the SCR of a caller unless their smart card had been authorised for the session and until the administrative details of a particular call (e.g. confirming the patient's name and address and finding their record on the Personal Demographic Service) had been checked by the call handler. This was the so-called 'separation of roles' introduced to prevent unauthorised access (or, more accurately, to make unauthorised access dependent on collusion between a clinician and a non-clinician – see Section 8.5).

6.4.3. The clinical case load in the GP out-of-hours consultations was broadly similar to that seen in patient-initiated consultations in mainstream general practice. Most patients, for example, had (or were concerned they might have) acute infectious illness (e.g. tonsillitis, urinary tract infection), acute non-infectious illness (e.g. allergic rash) or acute-on-chronic illness (e.g. a deterioration in diabetes control). Several patients attended for management of 'old' injuries (e.g. removal of stitches). One patient attended with central chest pain because the walk-in centre was located near the main shopping centre where the pain had come on (FN07/#97).

6.4.4. All the unscheduled primary care sites used the same software (Adastra), and when patients were referred on from the walk-in centre to the GP out-of-hours centre, the same Adastra electronic record was accessible to both. At the time of our field work (April 09-January 10), the Adastra software had been upgraded so that the clinician could link directly with the SCR from an on-screen icon (the 'integrated Adastra solution', see Section 5.6). This allowed the SCR to be accessed in less than one second (compared to a previous visit by our team when the same task had involved collapsing a window, going into a different piece of software and entering password details again – taking around 35 seconds). With the upgraded software, we did not observe a single instance of a clinician saying it was too much trouble to access the SCR.

"We've come a heck of a long way. It was a long and drawn-out process before."

OOH call centre nurses in group interview (FN11/~01)

6.4.5. Different types of clinician used electronic records differently. Decision support algorithms ('vomiting', 'head injury', 'urinary tract infection' and so on, made by a separate software company and embedded in the Adastra interface) designed for triage nurses were available. Some but not all nurses made extensive use of these, and this sometimes led to very lengthy conversations with long lists of questions, leading to an 'overcomplete' set of answers that obscured key particularities[PP] and which sometimes appeared to overshadow the nurse's own clinical judgement.

[PP] Overcompleteness of information leading to loss of overview is a well-described safety problem in electronic patient records.[114]

6.4.6. Experienced nurses generally made selective use of decision support algorithms and sometimes ignored them altogether. For example, a call centre nurse dealing with a call that had been triaged as 'back pain' (FN11/#79) quickly ascertained that the patient had multiple medical needs and was feeling suicidal, so she immediately aborted the back pain algorithm and assigned the call to a high-priority GP home visit. Doctors almost exclusively used 'free text' boxes and chose to over-ride when offered an algorithm.

6.4.7. Strong emphasis was placed on creating an audit trail which could be called upon in the event of a complaint or critical event. For example, all telephone calls in the out-of-hours centres we visited were tape recorded and nurse supervisors listened in to consultations periodically while also checking what was recorded on the Adastra software. The culture of accountability appeared to be positive, supportive, clinically led and locally run. Staff saw it as a normal and expected part of their job. [QQ]

"We're audited every month on whether we are doing our job right. […] No-one has a problem with it. [Nurse who does the audit] is very fair, she knows all of us and the conditions we work under, and she writes little comments. She's a very experienced nurse, she's lovely."

OOH call centre nurse interview (FN09/~2)

6.4.8. Nurses in two of the three the out-of-hours call centres told us that they had been advised to access the SCR of all consenting patients where one was present. They usually complied with this because they considered it good clinical practice to have information on medication and allergies available when advising the patient over the phone (especially since other sources of information were relatively sparse in this context). However, we observed cases where nurses said they were accessing the SCR in order to generate 'access data'. Sometimes, the nurse obtained consent to view the SCR while speaking to the patient, but did not actually access it until after she had completed the call (e.g. FN09/#88), as if calling up the SCR was a task to remember to do, but not one that was integrated into clinical work.

6.4.9. Overall, call centre nurses felt positively about the SCR since it offered some additional information for what was for them a very simple access procedure (ask a short question to gain consent, and then click on an integrated tab). Since they were already sitting at a terminal and logged onto the Spine via their smart card, the operational challenges for this group of staff were minimal. But most call centre nurses interviewed felt that it rarely influenced their own management of the case.

"Often there's nothing much on there. […] It's more useful for the doctors as they prescribe."

"Social information would be useful, such as if someone lives alone, if the GP doing the visit can just let themselves in, if someone is in a wheelchair…"

"There's nothing wrong with it, it's just how relevant it is to each practitioner"

"If someone has chest pain, we just call the ambulance, there's not time to look at the SCR."

OOH call centre nurses in group interview (FN11/~01 to 04)

6.4.10. In a high proportion of the calls dealt with by call centre nurses, the patient was advised to come in and see the GP. Often this was the action recommended by an

[QQ] The use of clinical records to create an accountability trail, and the tension between 'clinical' and 'for the record' notes is not a new finding, nor its it restricted to electronic records. It was first described in 1967 by the medical sociologist Harold Garfinkel in a classic paper subtitled *Good organisational reasons for bad clinical records.*[115]

algorithm in the Adastra system, but the nurses also had their own rules of thumb and seemed to err on the side of getting a doctor's opinion (see case FN29/#204 in paragraph 6.4.16). It is more difficult to make a confident and safe diagnosis without seeing the patient, so the 'default' of offering a base visit was understandable. It probably explains why we never observed a case in which the information on the patient's SCR made a difference to whether the patient was invited to come for a base visit, nor one in which a nurse felt that a SCR would have changed her decision if present.

6.4.11. The SCR was not directly accessible on home visits. GPs were driven to home visits in a car which contained a 'rugged laptop' with Adastra software so that the GP could look up the patient's details and enter data while travelling to the next visit. Some cars also had a printer. Some in-car laptops were somewhat old-fashioned – staff referred to them as "Breville toasters" (FN05/~02) because they were large, cumbersome and opened up like a sandwich maker – though we were told that more modern versions were about to be introduced. At the time of our fieldwork, the Adastra system on all home visit laptops did not link with the SCR on the Spine, partly because the remote solution had yet to clear CFH's Common Assurance Process (paragraph 4.3.18). We understand from Adastra that this hurdle has now been cleared.

6.4.12. Call centre nurses who allocated a home visit could cut and paste the contents of the SCR into the patient's Adastra record before the GP went on the visit, and they had been explicitly asked to do this. We did not see this happening (we only observed 4 home visits in total, and in none of these did the GP feel that a SCR would have changed management). GPs told us that if there had been relevant information from the SCR, the nurses would have pasted it in. Call centre nurses gave examples of information they had previously pasted from the SCR into Adastra (e.g. one nurse said she had pasted a medication record from a patient who had been "very drunk", FN05/~02). However, they expressed concern that once pasted into Adastra this information "would always stay" and would not be subject to the same strict access controls as the SCR. For example, the driver of the car taking the GP to house calls routinely looked at the Adastra records on the laptop to plan the next journey while the GP was inside visiting the patient.

6.4.13. GPs and nurses in most out-of-hours and walk-in centres routinely asked the patient's consent to view the SCR if they intended to access it, and this appeared to be fairly easily integrated into their consulting routine.

"No-one has ever said no." – OOH call centre nurse interview (FN09/~01)

"I don't think patients mind us looking at their records. Most patients will tell you their most intimate medical problems, more so than face-to face."

OOH call centre nurse interview (FN09/~02)

6.4.14. However, some staff felt resentment that they had to ask permission, and associated this additional task with anxiety, especially since the consent model had recently changed from one allowing them free access to the SCR.

"Before, we could look at records without worrying, now we have to worry about generating alerts. Nobody wants to get into trouble for breaking confidentiality".

OOH call centre nurse in group interview (FN11/~01)

6.4.15. We did not find any instances in the GP out-of-hours or walk-in centre settings of clinicians failing to access a record when they judged it to be clinically indicated because of fear of breaching access controls. However, our data did suggest that

gaining point-of-care consent to view the SCR was sometimes problematic because most patients did not know what the SCR was. Hence, the full consent procedure required a fairly lengthy explanation as well as a question. Most clinicians had developed a workaround for this problem, referring to the SCR as "information from your GP" or "your GP record". Whilst all patients consented when asked, most were surprised at the question, and some did not appear to understand it. In the following example, the staff member initially frames the consent issue as a question, but when the caller expresses confusion the issue is reframed as a *statement*, and the "OK" response therefore has ambiguous meaning.

3 year old [ethnic minority] child.

Nurse: "Is it ok if I access her Summary Care Record from her GP?"

[No reply.]

Nurse: "I have access, if you give me permission, to her GP record."

Mother: "Oh, OK."

OOH call centre, phone consultation (FN09/#92)

6.4.16. Some clinicians accessed SCRs before calling patients back in order to orient themselves to the case. They answered 'yes' to the question of whether the patient had given consent. When asked to justify this, they said that if the patient sought care from the service they were obviously consenting to staff accessing their record. In many cases the information on the SCR was tangentially helpful (but not essential) in orienting the clinician. In the following example, the SCR gives some 'significant negatives' (no known allergies and no recent medication), which were later confirmed by the patient's parent:

14 year old female, has already been logged by call handler as 'stomach upset'. Caller's voice not audible to researcher

Clinician accesses SCR before calling patient. SCR shows amoxicillin (prescribed 2 months ago), ibuprofen (5 months ago), amoxicillin (6 months ago). No allergies or adverse reactions listed.

Clinician: "So she's got tummy troubles. Diarrhoea and vomiting… I see… and high temperature? What is her temperature? [caller gives value] Okay, have you given her anything?..... Where is the pain? Left side, I see. And she's not eating or drinking. No. Any joint aches, muscle aches? Arms, legs, back? Any medications? No, okay. Any allergies? No. Okay I think she should be seen by a doctor. [logs call for base visit which call handler will organise].

Clinician enters codes on Adastra `'diarrhoea'` *and* `'vomiting'`

Advice call, OOH centre (FN29/#204)

6.4.17. We were later told that strict information governance controls had been judged unworkable in some parts of this centre in an earlier pilot phase.[RR]

6.4.18. In summary, some primary care settings using the integrated Adastra interface appeared to have successfully introduced the SCR as 'business as usual'. In Section 6.7 and 6.8 we consider examples of benefits and possible trade-offs ('disbenefits') of SCR use in this setting. In relation to consent issues in the unscheduled primary care encounter, both GP and nurse consultations occurred in the context of a clear,

[RR] Glancing through the record to orient oneself before calling the patient into the consulting room (or making a phone call to them) is common in medical and nursing care and not viewed as poor practice. Yet the SCR consent model requires this sequence to be reversed. When the consent model changed, routine accessing of the SCR for 'orientation' was abandoned in more than one setting (e.g. district nursing [paragraph 7.6.6] and mental health community care [paragraph 5.3.20]).

readily understood, one-to-one clinical relationship (albeit brief and transient), and also in a culture where patients were routinely told (or expected to be told) what was happening to them and why. In this context, trust was high and staff responsibilities clear. The patient's consent to view the SCR was relatively easily sought and readily given, though it was perceived as a hassle by front-line staff and some felt that the disadvantages of asking patients outweighed the advantages. Staff were aware of the possibility of access alerts but were not, in general, put off by them. This contrasts with the situation in secondary care, which is discussed in the next section.

6.4.19. The staff we shadowed in primary care settings were confident in using the SCR and broadly positive about the benefits it offered. We had few direct refusals, but it is possible that staff who felt negatively towards the SCR might have made themselves scarce when we were seeking help with the ethnography. We had tangential encounters with primary care staff who did not know about the SCR at all or who, even after completing a training course, appeared confused about how to use it.

6.5. Secondary care settings

A&E departments

6.5.1. Both A&E departments visited (Bolton and Bury) were sited in busy district general hospitals and had adjacent admission wards, the Medical Assessment Unit (MAU) and/or Acute Medical Receiving Unit (AMRU), where patients were transferred while waiting for investigations or for a bed in the main hospital. The A&E departments used a different software system from the main hospital (Ascribe Symphony); at the time of our fieldwork this did not interface directly with the SCR.

6.5.2. The challenges of trying to access the SCR in A&E departments were greater than in primary care settings. Around half the patients seen in the A&E departments had a SCR but we only saw this being accessed on a single occasion, by a senior A&E doctor, to show the researchers how "useful" it was.

"The SCR is no problem here. There's plenty of terminals, plenty of printers. All the doctors – except the locums – have Spine access via their smart cards."

A&E senior clinician (FN04/~01)

6.5.3. Apart from this individual (a champion for the SCR), nobody we interviewed said they used it regularly and very few had heard of it. Our isolated example mirrors the findings in CFH's own quantitative dataset (Figure 6.1, paragraph 6.1.3), which suggests that up to March 2010 fewer than 30 SCRs were being accessed per week in all non-Adastra settings combined.

While sitting watching by the main computer terminal, had this conversation:

Junior doctor: "What are you doing here then?"

Researcher: "I'm doing research into electronic records."

Junior doctor: "Oh brilliant, I use them all the time. Ask me anything you like."

Researcher: "Do you use the Summary Care Record?"

Junior doctor: "What's one of them?"

Field notes, A&E (FN04/~03)[SS]

[SS] A reviewer of a draft of this report pointed out that once an integrated interface to the SCR is included in routinely used software in A&E, the SCR is likely to be viewed as part of the standard record and not as a separate piece of technology.

6.5.4. Whereas in unscheduled primary care encounters, the care pathway was simple and linear (the patient went from a space that doubled as the reception area and waiting room to the consulting room, and a single document was generated – the Adastra electronic record), the A&E experience involved a non-linear patient pathway which crossed multiple locations within the hospital and generated multiple documents, both paper and electronic. The patient journey for a typical major admission is shown in Figure 6.2, along with documentation produced along the way.

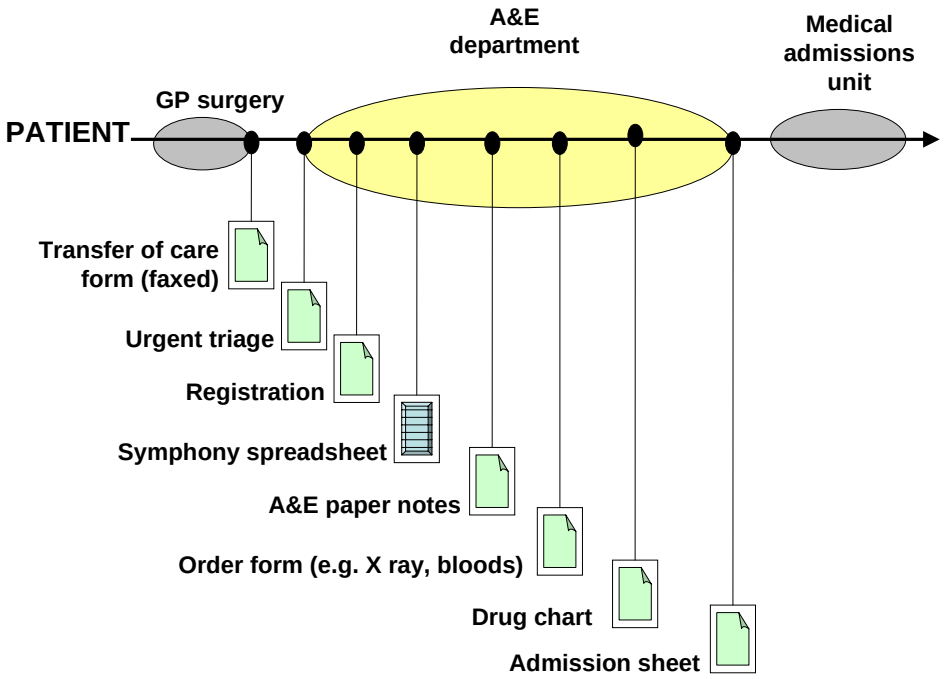


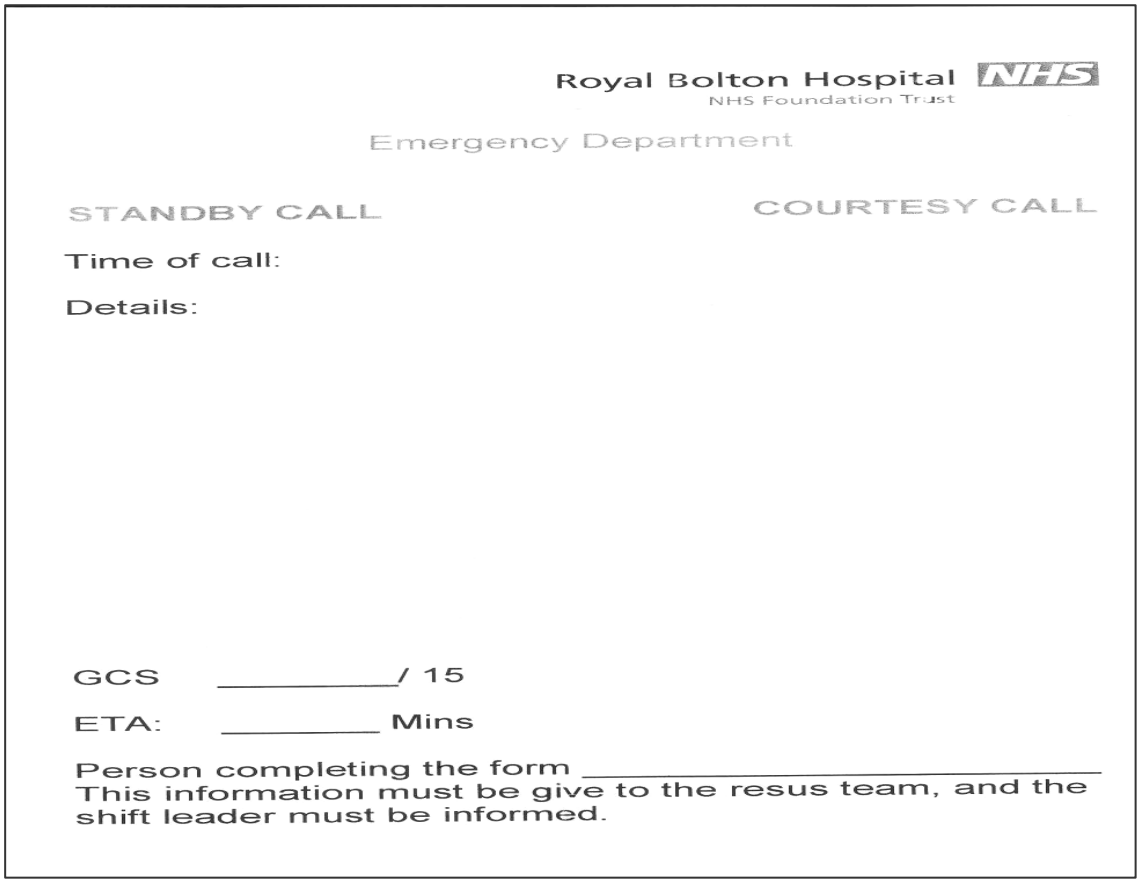
Figure 6.2: Typical patient journey for 'major' case in A&E, Bury[TT]

6.5.5. Paper documentation in A&E served not only to record data but to structure where the patient was and what was being done by whom. For example, a patient would not be placed in a queue to be seen until registration documents had been generated, and they could not be admitted to the Medical Admissions Unit until transfer paperwork was complete. If a patient was in the X-ray department, their paper temporary record was physically moved to a plastic bin attached to the wall labelled 'in X-ray'.[UU] A referral to the medical team was achieved by (a) telephoning the relevant member of that team and (b) placing the patient's paper record in the plastic bin on the wall labelled 'awaiting medics'. When the medics arrived, they took all the temporary records out of 'their' bin and looked through them to prioritise cases in order of urgency. The paper record thus allowed an incoming team to locate the patient within the large A&E department, prioritise all pending cases, and orient themselves to what other staff had done – all in a matter of seconds.

[TT] This diagram was inspired by a similar one by Carsten Østerlund.[116] His two-year study of A&E departments in the USA demonstrated that paper documents, including printouts of the electronic record, served as structuring devices which enabled and constrained the complex movement of the patient between different physical spaces and professional teams.

[UU] The use of 'bins on walls' (for which the generic term used by organisational sociologists is 'artefacts') to structure and prioritise cases in the fast-paced A&E department was also described by Østerlund in his US study.[116] He offers a lengthy and cogent argument as to why such physical artefacts would be hard to replace with electronic structuring devices. Note that the 'bins on walls' arrangement makes it possible to consider the patient's clinical data not only as an intrinsic dataset, but also in comparison with other patients in the queue (i.e. when assessing the relative urgency of several cases). This is a good example of what Berg has called the 'ecological flexibility' of paper.[117]

6.5.6. Both Bolton and Bury A&E departments contained examples of low-tech forms that had been invented by front-line staff and subsequently formalised. For example, the form in Figure 6.3 was designed to support the common situation in which the ambulance service phoned through outline details of an urgent case on a 'red phone' to warn A&E staff to prepare to receive the patient.


Royal Bolton Hospital NHS
NHS Foundation Trust

Emergency Department

STANDBY CALL COURTESY CALL

Time of call:

Details:

GCS _____/ 15

ETA: _____ Mins

Person completing the form _____
This information must be give to the resus team, and the shift leader must be informed.

Figure 6.3: Example of 'home grown' paper document used to support care in A&E (GCS = Glasgow Coma Scale; ETA = expected time of arrival)

6.5.7. The computer terminals in A&E were in constant use, with multiple staff members queuing for their turn to access one or other databases available on the hospital intranet or a web portal. In all, 32 different databases were accessible from the home screen of the terminals in one A&E department. These included Lorenzo (inpatient records), PACS (image database such as X-rays and scans), outpatient letter archive, ECG and other cardiology reports, bed occupancy and a contact database of bank nurses. Most staff made regular use of three or four of these databases but no single individual could talk us through more than a handful.[VV]

6.5.8. Much of the clinical case load of the A&E department contrasted dramatically with the primary care settings we visited. The following field notes from an A&E encounter illustrate the complexity and pace of activity:

[VV] Professor Lucy Suchman would probably call this an example of an 'arena of activity' – a personally ordered, edited version of a complex environment with which an individual is familiar, just as a regular supermarket shopper builds a mental map of particular aisles and shelves for an efficient, personally tailored shopping trip.[118] Suchman has shown that collaborative work involving computers in complex, information-dense environments necessarily involves such personally edited spaces – hence it is a positive and expected finding that staff 'know' some databases but not others.

Diabetic coma. Semi-conscious patient unable to give own history. Found by son to be less responsive this morning → 999. Given urgent blood glucose test on arrival. Found to be in [high-glucose coma] so has been referred to medics. Much activity round this patient. Nobody free to talk at length to me about her.

Staff whom I observed interacting with patient over a 10-minute period: three staff nurses, one health care assistant, one F1 doc, one F2 doc, two middle-grade medical docs (? registrars), one staff grade A&E doc, one pharmacist, one clerk.

A regular patient at this hospital so has LOTS of info on the internal [electronic] systems including outpatient letters (but latest is five months ago), blood tests (ditto) and clinical examination, etc. Her medication is [list of five cardiovascular drugs and two diabetes drugs with dosage schedule]. Junior doc is putting another arterial blood specimen into the blood gas analyser in the corner of the room.

Everyone is contributing bits to the record (temporary paper folder) which is on a trolley table at the end of the bed. Multiple information sources are being used (most of which have been placed on this table e.g. by printing out from computer terminal in corner of room): Ambulance referral form, old clinic letters (from the ALS database), old blood tests (from 'path results' database), patient's previous A&E record (from Symphony database), TPR [temperature, pulse, respiration] chart, drug chart. Computer screens show oxygen level and ECG monitor. Patient's [main] paper notes soon appear and are flicked through by various docs.

Each staff member uses different information sources and draws the information from these together by writing an entry on paper. Docs write free text clinical notes on A4 sheets which look the same as the ones I used when a junior doc 25 years ago except there are now some infection control prompts as a footer. Junior doc writes a long structured clerking including a detailed examination, then a senior comes along and writes a sentence or two to summarise the problem, emphasise key points, and give a clear order for next steps. Other juniors look at what the junior wrote; other seniors just look at the senior's entry.

Field notes from A&E (FN04/#42)

6.5.9. The above patient (whose details have been fictionalised, see paragraph 3.3.11) was in the resuscitation wing of A&E ('resus') in a large bay surrounded by high-tech equipment (cardiac monitor, blood gas monitor, suction). When we first saw her she had been in the building for just over half an hour. Already, a full clinical clerking and examination had been done, written up and filed in a temporary folder; two drips had been put up; baseline blood tests had been sent and results obtained; a process had been established for close monitoring of vital signs (pulse, breathing etc); urgent drugs and fluids had been ordered (by the doctors) and administered (by the nurses), a portable X-ray picture had been taken; judgements made about which letters and summaries held on the various hospital databases were worth printing; and an internal referral made to the medical team. The patient's conscious level had improved dramatically (i.e. she had begun to recover rapidly on the treatment given) and arrangements were being made for her transfer to the Medical Admissions Unit.

6.5.10. This example shows the A&E system of care at its best. A life-threatening emergency was managed in a sophisticated way with all available staff and technologies played to their respective strengths. Physical space was arranged to maximise access to the patient and create an 'information dense' area at the foot of the bed where attending staff could gain a quick overview of the problem (including studying paper records, taking in graphical displays from the monitors, and brief conversations with other staff around the bed) before providing their own input. The patient's clothing had been removed and a gown put on loosely so that in the event of deterioration (e.g. a

cardiac arrest), no time would be wasted accessing key body sites. Curtains had been pulled back out of the way.

6.5.11. This patient did not have a SCR but none of the staff managing her checked whether she had one or not. In terms of the information needed to manage this case, the list of current medication had already been provided by the ambulance staff (supplied as a handwritten ambulance summary form which was on the table at the foot of the bed, and which in turn had been completed using information obtained from the patient's relatives before leaving her home), but it was not relevant to emergency management. Even the fact that the patient was on insulin (hence possibly at risk of diabetic coma) did not substantially alter front-line emergency care since every unconscious patient, whether known to be diabetic or not, was routinely given a fingerprick blood glucose test on arrival.

6.5.12. The key items of information being used to make the diagnosis and shape the unfolding work of emergency care were the minute-to-minute readings of the various technical equipment (ECG, blood oxygen levels, blood gas levels), the TPR chart (pulse, blood pressure, fingerprick blood glucose levels), and the results of laboratory tests, X-rays and so on undertaken in the last few minutes. The reason why the patient was being transferred to the Medical Admission Unit was because these new data were already showing a rapid trend towards recovery. Witnessing this scene, the non-clinical researcher on our team saw something akin to chaos but to the clinically qualified researcher, the various inputs made much sense and indicated successful, evidence-based, tightly coordinated emergency care.

6.5.13. The A&E department was oriented around the needs of the sickest patients. But the same attitudes, rules of thumb and work processes were evident throughout the department and shaped and constrained the care of all patients. Even when seeing patients with minor medical conditions, clinician-patient interactions typically involved multiple staff members, multiple interruptions and an 'open' rather than 'private' consulting space.

6.5.14. The physical layout of the A&E department meant that the closest thing to privacy that most patients got was a curtain pulled around them. Efforts were clearly being made to shift this culture – for example via clip-on signs saying "please close curtains – respect patients' dignity". But these signs were often to be found on the floor after staff had pulled the curtains apart to gain access. It was a normal and expected part of business as usual for staff members to come into cubicles, ask one or two questions or undertake a task (e.g. take blood), and exit again.

6.5.15. In summary, our findings suggest that the sophisticated division of labour, fast pace and technical orientation in the A&E department saves lives but these (perhaps necessary) features of emergency care mean that both physical preconditions for SCR accesses (e.g. a single clinician using a single terminal) and emotional preconditions (e.g. interpersonal trust and an atmosphere of privacy) are not easy to achieve and may serve as barriers to accessing a nationally stored record.

Medical Assessment Unit and pharmacy

6.5.16. The Medical Assessment Unit (MAU) had a number of four-bedded bays and the standard supporting infrastructure of a hospital ward (administration desk, nurses' station, treatment room, work terminals, sister's office etc). It housed non-surgical patients who were awaiting transfer from the A&E department to a regular hospital ward. The purpose of the MAU was partly to ensure that the patient had somewhere more comfortable to wait than the busy A&E setting (and also perhaps to help meet the important 'four hour target' for getting patients through A&E).

6.5.17. The clinical caseload on the MAU was heavily skewed to patients with multiple and serious medical conditions. Of our sample of 30 patients, for example, the mean age was only 60 but all were on multiple medications and eight had chronic disabilities. Typically, MAU patients had at least one (and often two or three) of the following: chronic heart disease, chronic chest disease, severe arthritis, a neurological condition (e.g. multiple sclerosis), a mental health problem, drug or alcohol dependence, diabetes with complications or cancer – as well as an acute exacerbation of one of these conditions. In short, they were both acutely (recent onset) and chronically (long-term) sick.

6.5.18. Whereas the priority in the A&E department had been to stabilise the patient (for which real-time, rapidly changing data on the patient's physiological state was the main information need), the task in the MAU was to gather all the necessary background information (known as a "full medical clerking"), make a definitive diagnosis and initiate treatment. Much work was undertaken here by junior doctors and pharmacists (see below) to ascertain the patient's full history and medication. Patients typically stayed on the MAU for between four and 24 hours.

6.5.19. Despite the complex medical needs and uncertain medication status of many patients in the MAU, the SCR was accessed in only one of 30 patients reviewed by our team. This surprised us, and appeared to be for several different reasons. In one site, a semi-official decision had been made "not to push" SCR accesses until the programme was further underway. In an earlier phase, the organisation had put resources into training juniors, issuing smart cards, and encouraging them to access and use SCRs, but when they did so only around a third of patients had a SCR (the much-lamented "low hit rate"). Furthermore, in some cases the information on the SCR was incomplete – in particular, the date listed on the SCR medication record was the date a prescription had been initiated rather than the date the drug was last prescribed (we were told that this 'date last issued' problem was in the process of being corrected but would involve a change to the contract with BT so was not seen as imminent). At the time of our fieldwork, staff were waiting for more SCRs to be created and for the date of last issue problem to be fixed.

6.5.20. Hospital pharmacies were among the busiest departments we visited in our fieldwork. Senior staff described them as seriously understaffed and told us that a high proportion of front-line staff were part-time or temporary. These staff included qualified pharmacists and 'pharmacy technicians' – people without a full pharmacy qualification who had been trained to check and issue medication under supervision.

6.5.21. Most patients whose medication details were sought by the hospital pharmacists were on the MAU. Pharmacists had limited involvement in most A&E cases because when all went well the patient was either discharged on no medication or transferred out to the MAU fairly promptly, and pharmacy work on the main wards consisted of checking and supplying medication prescribed within the hospital. This explains why the original plan in Bolton, for SCRs to be used by pharmacists on all wards, was subsequently changed to include only the MAU. When we visited Bury, the hospital pharmacy was making very little use of SCRs.

6.5.22. One pharmacist told us that even when a patient's SCR was present, she always telephoned the GP surgery *"because we get better information by phoning the GP"* (FN01/~02).[WW] However, it was also because the pharmacists saw their role in

[WW] Note the crucial distinction made by this pharmacist between data and information (data in context). By phoning the GP the pharmacist can not only find out the patient's medication and allergies, but also learn additional contextual factors which make these data meaningful.

relation to newly-admitted patients as gathering what was often partial information from multiple sources and drawing together as complete a picture as possible taking into account inconsistencies between them.[XX]

6.5.23. In A&E and MAU, the consent to view model was more problematic than in primary care, for three reasons. First, multiple clinicians were dealing with the patient in a rapidly changing and largely unpredictable sequence. Second, the physical location of the patient was changing rapidly. During admission, for example, a patient would typically be transferred to different sections of the A&E department, have a spell in the X-ray department, be transferred to MAU, and then go to a ward (perhaps a day later). In each location a different team took partial or interim responsibility for the patient and required access to their record. Third, as described above, A&E culture appeared to place less emphasis than primary care culture on seeking consent.

6.5.24. Another reason why the consent-to-view model was viewed by many as unworkable in the hospital setting was staff concerns about the possibility of access audits, which were perceived as being undertaken by distant authority figures who did not know them personally or understand the details of their work routines.[YY] There had apparently been a substantial reduction in the willingness of non-medical staff to access a patient's SCR since the consent-to-view model was introduced, partly because of general staff reluctance and partly because, in some cases, organisations or departments had imposed additional access controls. In case FN22/#03, for example, a pharmacist who could not wake a drowsy patient on the MAU told the researcher that she was not allowed to select the 'emergency' icon on the SCR access page because of an internal hospital rule. The issue was *"with the Caldicott Guardian"* – in other words, a request had been put to the relevant authority to get the rule changed, but nonetheless it was currently constraining practice.

6.5.25. In case FN22/#01, a limited English speaker who was confused, the MAU pharmacist had asked the patient if she could view his SCR and he had consented, but she felt he had not really understood the question, so she decided not to access the SCR – especially since the patient appeared to have brought his medication with him. This example highlights several 'grey zones' not anticipated by designers or policymakers: consent was equivocal, the clinician's access privileges were equivocal (at least in that she had a legitimate clinical relationship with the patient but this relationship did not 'count' under the organisation's locally-imposed rules), and the clinical need for viewing the data was also equivocal. Given these uncertainties, the pharmacist understandably decided not to access the SCR.

6.5.26. In contrast, MAU doctors appeared confident using the emergency over-ride. We shadowed one senior doctor who said he always used the 'best interests of patient' over-ride even when the patient had given consent, justified on the grounds that he would not be accessing the SCR at all unless it was in the patient's best interests (though he did not actually access any SCRs when we were shadowing him).

Bolton Community Unit

6.5.27. The Community Unit was a ward in Bolton hospital staffed by nurses with close links to primary care (especially the patient's GP). The staff explained that patients have

[XX] This description of their role resonated with the account given by district nurses in paragraph 7.2.5; both these groups of professionals likened their role to that of the fictional detective character Sherlock Holmes.

[YY] This contrasted with the situation in primary care, where (for example) call centre nurses viewed the general auditing of their performance as a formative and supportive process done by known, trusted colleagues (paragraph 6.4.7), and were in no doubt that they had a legitimate relationship with any patient who phoned the centre, hence concerns about access alerts rarely discouraged them from accessing SCRs in the course of their work.

medical needs but also significant social needs (e.g. not ill enough to need full hospital inpatient services but not coping at home because of an acute condition).

"The patients are the ones in a clinical grey zone. We have the people with mobility needs which the orthopods don't want to take, and the people with medical needs which the medics don't want to take, and the people with non specific head injuries which the neurosurgeons don't want, that sort of thing."

Hospital doctor explaining caseload on the Community Unit (FN13/~01)

6.5.28. Patients on the Community Unit were admitted either directly via their GP (with a referral letter or Transfer of Care form) or via A&E or the MAU, in which case their medication and allergies were ascertained from various information sources (patient, ambulance form or green bag, GP practice) by pharmacists, junior doctors or the Unit nurses. The SCR was not in use in this Unit because of the hospital's informal policy of "not pushing" accesses until the hit rate was higher and the accuracy problems resolved. Staff considered that once this problem was overcome, the SCR would be an important source of information on medication.

6.5.29. When we visited the Unit we were introduced to three patients and told about a fourth. Three were in their 80s and rehabilitating from a fracture, an infection and an exacerbation of diabetes; a younger patient had a non-specific musculoskeletal problem. Two of the four (FN17/#167 and FN17/#168) had had adverse reactions to medication administered since entering the hospital. In one of these, it was likely but not certain that this was a previously documented allergy that would have been listed on the patient's GP record. However, whether it would have been listed on the patient's SCR would have depended on whether the GP practice had entered it as a coded data item rather as free text or as a scanned-in discharge letter.

6.6. Ambulance and community settings

Ambulance Service

6.6.1. Bolton and Bury hospitals were both served by North West Ambulance Service, which had been formed in 2008 from the merger of four smaller local services. The service was extremely busy and the caseload broadly reflected the 'major' cases seen in A&E (see Section 6.5). Calls were classified according to urgency – 'Level 1' (urgent – needs to be seen within 8 minutes); 'Level 2' (moderate – see within the hour) and 'Level 3' (non-urgent – essentially serving as transport for patients referred to A&E by GPs but not seen as time-dependent emergencies).

6.6.2. National strategy had identified 'Level 3' ambulance calls as a potential use scenario for the SCR. A Project Initiation Document between CFH and North West Ambulance Service was signed off in October 2007 for the use of the SCR in ambulance control centres, and technical go-live in these centres was achieved in December 2008.[ZZ]

6.6.3. When asked about the SCR, front-line ambulance staff appeared to know nothing about it (*"Summary Care Record – is that the yellow ticket thing in the back of the*

[ZZ] As also illustrated by the SHAs (Section 5.1), it was not uncommon for top management to have a view that the SCR programme was happening while front line staff considered that it was not happening. However, as a CFH senior executive pointed out to us (FX11), there is a big difference between a 'hard' (technical) go-live in which it is confirmed that all the boxes and wires are in place and connected up, and a 'soft' go-live in which people, processes and interactions all support the use of the SCR. The ambulance service was a good example of a go-live that had not progressed from 'hard' to 'soft'.

BNF[AAA]?" – FN12/~04). When we explained what the SCR was to a group of them in an informal discussion during a short break, they did not feel that it would help them or that it would be possible to incorporate electronic access to the SCR into their job.

6.6.4. Several ambulance staff had reacted with amusement to the idea of attempting to access an electronic record while "on a job" (dealing with an emergency call). Later, we asked managers why staff had found the idea of the SCR amusing,[BBB] and they explained that front-ambulance work is complex, unpredictable and above all, tightly target-driven – especially the need to get to a Level 1 call within 8 minutes. Use of the SCR "on a job" was seen as impractical, low-priority and potentially conflicting with over-riding performance targets.

6.6.5. The statement *"It's got to be practical"* was made independently by four out of the six ambulance staff interviewed for this study, suggesting that the practical, material properties of equipment and artefacts took high priority in the service. When we asked how they found out what medication a patient was taking, their responses suggested that they placed great trust in what they saw with their own eyes and handled directly, and were cynical of distant, official sources of data.

"One of the crew will look round for the repeat prescription form or take a Tesco bag and go whoop and sweep all the bottles into it. In fact we designed our own bag, it's a green bag now."

"The accuracy of it, usually, is that unless someone is supervised very closely they don't take half of it. The ones on the table by the armchair go in the bag. Then you can go to the kitchen drawer and there's the ones she don't take. We've found drawerfuls of stuff."

"…and then there's the fridge system. Generally, if there's anything special for this patient, something they're on, it will be in a bottle in the fridge."

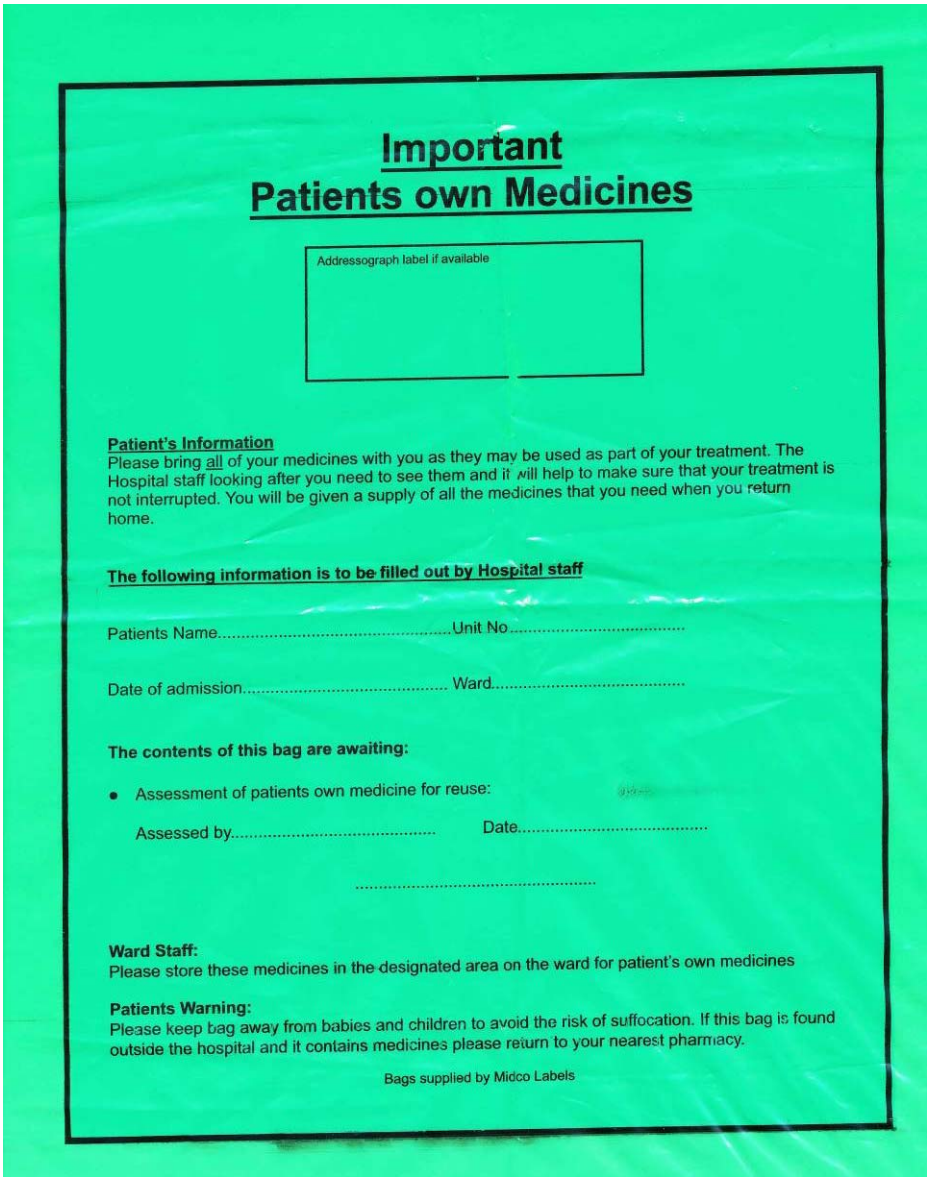
Ambulance service managers (FN12/~05 and 06)

6.6.6. The green bag designed by front-line staff in the North West Ambulance Service is shown in Figure 6.4. The bags were viewed as very fit for purpose and 'foolproof'. In contrast, electronic solutions for ascertaining patients' medication were seen as less likely to give accurate data, less practical, more vulnerable to failure and a waste of money.

6.6.7. Neither full-size ambulances nor fast-response cars were equipped with the type of computer screens needed for viewing SCRs. However, we understand from CFH that the intention was never to offer SCR access in ambulances but to make SCRs available in the central control centre (a setting to which we did not gain access), and to focus on Level 3 calls which are not subject to the 8-minute target. If that is the case, there is no reason why front-line ambulance staff ought to know about this technology or why the 8-minute target would be a barrier to SCR use. However, we did not have access to the relevant business case or project initiation documents so could not confirm details. The latest version of the Full Business Case for the SCR still talks about "emergency ambulance services" (page 28 and 76[84]) and does not mention the restriction to Level 3 ambulance callouts.

[AAA] BNF – British National Formulary, a book of drug formulations and dosages which includes a tear-out yellow form for reporting suspected adverse drug reactions to a national surveillance centre.

[BBB] In organisational sociology, the use of humour by staff members is seen as data, since it can indicate what is perceived to be absurd or incongruous in the organisation.[119]



Important
Patients own Medicines

Addressograph label if available

Patient's Information
Please bring all of your medicines with you as they may be used as part of your treatment. The Hospital staff looking after you need to see them and it will help to make sure that your treatment is not interrupted. You will be given a supply of all the medicines that you need when you return home.

The following information is to be filled out by Hospital staff

Patients Name..... Unit No.....

Date of admission..... Ward.....

The contents of this bag are awaiting:

- Assessment of patients own medicine for reuse:

Assessed by..... Date.....

.....

Ward Staff:
Please store these medicines in the designated area on the ward for patient's own medicines

Patients Warning:
Please keep bag away from babies and children to avoid the risk of suffocation. If this bag is found outside the hospital and it contains medicines please return to your nearest pharmacy.

Bags supplied by Midco Labels

Figure 6.4: Green bag invented by ambulance staff to 'scoop up' patient medication

6.6.8. The North West Ambulance Service had its own contact database, which central control office maintained, and which had the capacity to flag both clinical alerts and high-risk situations for staff. This was perceived by the people we interviewed as imperfect but still extremely useful. It did not interface with any other system.

"We've got a database of our own. It flags up a violent patient. Say I go to a council estate and I go to a flat in that estate and someone punches me in the face, I'm going to come back and put that on my database so if one of our lads or lasses goes there again they know, there's a violent person in there. And also vulnerable adults. Yesterday, I went to a girl, she had a [describes serious acute illness]. And I came back after that job and I put on the database, vulnerable adult, so that next time when she gets like that, she'll get a proper paramedic crew, not a technician crew."

Ambulance service manager (FN12/~05)

6.6.9. Despite some cynicism towards the SCR programme, many ambulance staff interviewed felt that at some stage in the future, there would be a "better" database, fully interoperable with other information sources they might need to access in the

NHS and more complete and accurate than their own current local system. They did not, however, view the NPfIT as equating with this future ideal.

Community Diabetes Service

6.6.10. Community services in Bury operated a Community Diabetes Service, a component of which was a consultant-led, multi disciplinary team diabetes clinic operating at several sites within the Bury area. We visited one such clinic which was held in a purpose-built health centre co-located with a GP surgery.

6.6.11. Referrals from GPs and other health professionals were sent either electronically on a template via the GP software package Vision or via a paper template. Referrals were triaged by clinicians within 72 hours of receipt, and if considered appropriate patients were seen in clinic with an appointment allocated via the Choose and Book online booking service. Additional information was faxed on a Transfer of Care form. The service was delighted to participate in a pilot study of SCR access.

6.6.12. When we visited this setting, the SCR was not being used. Feedback from the multidisciplinary team was that although in essence the SCR was a useful tool, as with everything it needs to be applied in the appropriate environment, and a non-acute community diabetes clinic was not such a place. The team considered that diabetes patients presenting to A&E or seen by paramedics may benefit greatly from staff accessing their SCRs. Another problem was that a multidisciplinary community team looking after patients with chronic disease often work with multiple providers and across multiple sites. In such circumstances data access becomes an issue, with variable access as people use their swipe cards in different primary, secondary and community care environments. With prevailing financial pressures and the very limited data accessible on the SCR at the time, the team made the decision that the SCR project should not be pursued.

6.7. Benefits at the front line

6.7.1. As Section 4.2 shows, policy documents and business plans describing the vision for the SCR were built on the assumption that it was likely to add value in six areas (and that this added value was measurable and quantifiable). The SCR would:

a. Make unscheduled care *better* (by improving clinical decision-making);
b. Make unscheduled care *safer* (by reducing the risk of harm);
c. Make unscheduled care *more efficient* (by making the consultation faster);
d. Reduce *onward referrals* (especially, keep patients out of hospital and thereby reduce hospital-acquired infections);
e. Make care *more equitable* (by being particularly useful for patients unable to communicate or advocate for themselves); and
f. Improve *patient satisfaction* (by meeting their needs more closely).

6.7.2. In contrast with these clearly defined hopes for what the SCR would achieve, and bearing in mind the caveat about the programme being at a very early stage (paragraph 1.4), a striking finding from our detailed qualitative study of 214 clinical encounters was that any ‘added value’ associated with the SCR (measured directly when a SCR was present and accessed, or indirectly in terms of possible ‘missed value’ when it was unavailable) was considerably more subtle than policy documents assumed. The impact of the SCR was also far more difficult to isolate out from other

factors in the consultation than either we or other stakeholders had anticipated. The remainder of this section should be read with this caveat in mind.[CCC]

6.7.3. Very rarely, the SCR was the only source of drug information available. However, in only one such case (FN03/#24) was knowledge of the patient's current medication needed to manage the presenting problem. One of the 214 cases studied (FN13/#126) was an unaccompanied unconscious patient with no reliable information on medication, allergies or adverse reactions. This individual did not have a SCR and only limited information was available to the doctors treating her. This real example, while not supporting any statistical statements about how common such cases are, substantiates the ubiquitous hypothetical case in policy documents of the patient who presents to NHS services with a life-threatening illness and no way of communicating their medication and allergies to health professionals.

6.7.4. We observed a number of cases in which the SCR provided data which either usefully confirmed information provided by the patient or added additional information to this, though in some of these cases we considered that the benefit was marginal. In just over 10% of cases where a SCR was not accessed, we judged that *had it been available* and *had it contained all the data expected*, it *might have* added significantly to the consultation. However, the impression that the SCR 'might have added value' represents considerably weaker evidence than 'did add value', as the examples in Section 6.8 show.

6.7.5. Unsurprisingly, the SCR appeared to add value (or, when not available, was most missed) when the problem related to medication (e.g. a patient seeking to renew a supply of regular medication) or allergies (a patient with an unexplained rash). The SCR seemed to add particular value when the patient suffered from multiple medical conditions ('comorbidity'). The quantitative data supplied by Adastra (Section 6.1) confirm that the SCR was significantly more likely to be accessed when the patient had more than one coded diagnosis. In our own qualitative study, the SCR also appeared more likely to be accessed when patients were taking multiple medications ('polypharmacy'), though we were not able to interrogate the Adastra dataset to confirm this impression quantitatively. The following is a fictionalised example of such a case:

Patient: "I got a high temperature since last night, and 3-4 weeks I'm tired and sleepy. Yesterday I get stink in my urine. Very worried about stink. Horrible."

GP: "Pain? Burning?"

Patient: "Yes. Last week my GP sent a sample, gave antibiotics. Sample was clear, so sent second sample, he got no result yet. Three weeks ago had an antibiotic and felt a bit better. GP has arranged scan to kidneys, but it's two months away."

GP: "Other medical problems? Diabetes?"

Patient: "No,"

GP: "Allergies?"

Patient: "Penicillin."

GP: "What happens?"

Patient: "10yrs ago, I had penicillin, fell down, everything look black, then doctor looked."

[CCC] Elsewhere, we have offered a critique of research on electronic patient records (EPRs) in which we question the widely accepted gold standard research design is an experimental comparison of the general format 'EPR present' versus 'EPR absent'.[12] As we set out in Section 3.4, our theoretical position is that the SCR is socio-technically embedded and does not, in and of itself, *cause* improvements in quality, safety or efficiency of care. Hence, while we have done our best in this evaluation to answer the research question in a way that meets the expectations of those who view the technology in causal terms, we ask readers to note our own philosophical misgivings about such a framing.

[GP seeks consent and accesses SCR, which shows Allergies: Penbritin 1998.]

GP [to researcher]: "Do you know what Penbritin is?"

Researcher: "Penicillin I think."[DDD]

[Medication list on SCR includes:

12 weeks ago: Trimethoprim 200 bd (6)

9 weeks ago: Nitrofurantoin 100 bd (10)

7 weeks ago: Trimethoprim 200 bd (10)

3 weeks ago: Nitrofurantoin 100 bd (10)

GP: "OK I'll give you ciprofloxacin".

GP OOH consultation (FN03/#24)

In this example, the out-of-hours GP said that he would have prescribed trimethoprim if the SCR information had not been available. The SCR also added important weight to the patient's somewhat atypical account of a penicillin allergy – though importantly, the GP said afterwards that he would have accepted the patient's account of this allergy even if it had not been corroborated by the SCR.

6.7.6. Another situation where the SCR appeared to add value (or, if absent, was missed) was for medically unexplained symptoms (i.e. generalised, non-specific symptoms such as tiredness, aches and pains, blurred vision and so on). These are common in general practice and often present out-of-hours, not least because patients with such symptoms may seek a prescription and their GP may have turned them down for one.[120] The following (fictionalised) consultation was for a middle-aged man with limited English, whose 11-year-old child was translating.

Child: "He's got pain in chest, cough, green phlegm, sore throat. Had TB in past but saw his GP and told he don't got none now. And pains in back and legs."

GP: "What's the main problem now?"

Child: "[translates for patient who moves his head around. Child explains, pointing to dad's chest] His head hurts when he moves his head to the left and when he moves it to the right."

GP: "Does it hurt when he takes a deep breath?"

Child: [translates for dad who gives long description in own language]

Child: "Yes, and when he cough, it hurt a lot."

GP: "Has he got any medical problems?"

Child: "For one and a half years he has bad chest. And asthmatic as well."

GP: "But what's the problem now?"

Child: [without asking patient] "Sore throat for a day and his chest is worse. His blood pressure also goes low at times, he thinks."

GP: "Are these two problems related?"

Child: "No, cos he had it yesterday. And he has an ulcer as well."

GP: "What does he take for this?"

Child: "Ranitidine. [pause] He's got psoriasis too, puts cream on it."

GP: "Is the asthma well controlled?"

Child: "His breathing was bad yesterday."

GP: "What inhalers is he on?"

Child: "Blue and brown."

GP: "What dose does he take?"

[DDD] Actually, Penbritin is a brand name for amoxicillin, a penicillin-related antibiotic which would have a similar if not identical allergy profile. The GP confirmed this using the electronic BNF.

Child: [translates for dad, who replies] "Doctor told me, four times each. He had a headache yesterday."

GP: "How are his bowels?"

Child: "I don't understand."

GP: "Does he go to toilet OK?"

Child: [translates, dad replies] "Yes."

GP: "Right, I think your dad's got a virus."

Child: "When he stands up his eyes go blurry."

GP: "I'll take your dad's blood pressure."

[GP measures BP sitting then gets patient to stand and repeats. Listens to chest – clear]

GP: "He doesn't seem to have uncontrolled asthma."

Patient: [in English] "I have pain all over body, too tired."

[speaks more in own language]

Child: "He asks for medication."

GP: "What's he been taking?"

Child: "Paracetamol."

GP: "That's good but I can give you some co-codamol, which contains paracetamol and something a bit stronger for his muscle pains. If his symptoms are no better he should see his GP. If asthma gets worse use his blue inhaler more frequently."

Patient: [looks very unhappy]

GP: "Is that alright with him?"

Child: [without translating] "Yes."

GP OOH consultation, no SCR available (FN03/#20)

6.7.7. The above case illustrates that primary care cases may involve multiple symptoms and issues, none of which point unambiguously to where the problem lies. The role of the out-of-hours clinician is not to address every symptom but to make a 'what to do next' decision for the perceived here-and-now problem. This patient probably seeks an antibiotic for a simple respiratory tract infection, but the multiple chronic symptoms, along with the language barrier, obscure the clarity of this diagnosis and place the GP under additional pressure to prescribe. The GP pieces together a picture of what is going on using information from both the child interpreter and the clinical examination. Once again, the absence of the SCR may not have changed the management of this patient (unless, importantly, he had a rare allergy to co-codamol), but had the medication list been available on the screen, the consultation would almost certainly have been easier and the child interpreter would have been under less pressure. Note also that the NHS standard of offering professional interpreters cannot be fulfilled in unscheduled care, and the use of family member interpreters or ad hoc interpreting by bilingual staff is routine in this setting.

6.7.8. All clinicians interviewed in the primary care setting cited examples of how the SCR had added information that made an unscheduled care consultation "easier" – especially when, as in the above example, there was some barrier to communication. Typical examples given were confused patients, elderly patients on multiple medication (especially those in nursing homes), limited English speakers, and those who were under the influence of recreational drugs or alcohol. No clinician could recall an example of when the SCR had made a 'life or death' difference, though many considered that such instances might occasionally occur.

Researcher: "Can you give me your best example of where the SCR has helped you, made a real difference?"

GP: "I can't do that, it's never made a life-or-death difference. It has two uses: drugs and allergies! The drug history gives you the past medical history. I don't think it's changed my practice, it gives me a little more information."

GP OOH interview (FN03/~1)

6.7.9. These clinician impressions of the SCR 'adding some value but not in a life-or-death way' and 'making consultations easier' were strongly supported by our own observations. The following fictionalised transcript is from a telephone conversation between an out-of-hours GP and an 80 year old patient (whose SCR was not accessible) who had had a 'funny turn'.

Patient: "I got up to take a tray into the kitchen. I was losing my balance, but I managed to get to the kitchen, put the tray down, and got back to the chair. I sat down, kept falling asleep. I was trying to follow the film but I just kept nodding off. So my daughter came round, and I'm on these high blood pressure pills. She measured my pressure, it was very low, 93/50. It's usually 150/90 odd. I'm on a lot of blood pressure medications."

GP: "Has this happened often?"

Patient: "I'm now walking around OK"

GP: "Has it happened before?"

[doesn't reply]

GP: "Have you been drinking enough? It's a very hot day"

Patient: "I've had two or three tumblers of water and a cup of tea. I'm normally going to the toilet weeing but today I haven't been"

GP: "Can you read out your medications?"

Patient: "Well I've got arthritis, and she's given me metatrexate [methotrexate] and Froobin [Froben]"

GP: "What?"

Patient: Froobin. Froobin.

GP: "Oh, OK" [opens eBNF on computer to look up names of drugs]

Patient: "And I have a problem with the blood pressure, I'm on Rampril [Ramipril], 10 at night, manoxady [minoxidil] and atnol [atenolol], 25mgs one morning and none [? one] at night. She's put me on silver statin, 40mgs, um [reads from box] sirnvastatin. And something spiro lactune"

GP: "Spironolactone?"

Patient: "Yes"

GP: "Have you done?"

Patient: "What?"

GP: "Have you told me all of them now?"

Patient: "Yes"

GP OOH phone consultation (FN03/#35)

6.7.10. The above conversation took around ten minutes as the patient was hesitant with the drug names. Like many patients in this study, she had allocated new names to her medication so they made more sense (we met patients who had named their medications after TV celebrities – e.g. 'Oprah Mezole' instead of omeprazole, 'the Michael Jackson pill' instead of Microgynon). In some instances these names were readily matched with generic drug names but in others (e.g. 'manoxady' for 'minoxidil'), the GP had to search for several minutes to identify the likely medication.

The GP in the consultation above was very patient and eventually gained all the data he needed from the elderly patient, but an accurate SCR would have made this consultation easier and considerably faster. Note, however, that it would not have made it safer because the GP chose to spend time seeking the information from a hesitant patient rather than rush to a decision.

6.7.11. We were repeatedly struck by the skill of experienced out-of-hours clinicians to deduce what medication the patients were taking in the absence of objective information. In the following example, an elderly patient attends the walk-in centre with chest pain that has been present for about 24 hours.

Nurse: "Are you on any medications?"

Patient: [laughs heartily and gets an anti-coagulant therapy booklet out, hands it to nurse]

Nurse: "You're laughing" [looks at booklet] "So you're on warfarin?"

P: "Yes. Rim.."

Nurse: "Ramipril?"

P: "Yes"

N: "Are you on anything else?"

P: "Ad.."

N: "Atenolol..?"

P: "No"

N: "Amlodipine?"

P: "That's the one. Sometimes I think I'm a bit thick.."

N: "No, no, it's not you, they just make up these long names that no-one can remember. Do you have any allergies?"

P: "No"

Walk-in centre consultation (FN07/#97)

6.7.12. Although the patient in the above example is very unwell (an urgent ambulance has already been called), the nurse manages to create a supportive atmosphere and offers prompts which allow her to identify her medication. Hence, whilst the SCR would have *added to the nurse's confidence* in managing the condition here, it would not have *changed* that management.

6.7.13. We found it difficult to decide whether a SCR had added value even when it was present and accessed, and we found it even more difficult to say whether a SCR, had it been present, *would (or might)* have added value. This was mainly because many unscheduled care consultations involved a combination of medical and social need and were characterised by a high degree of uncertainty and ambiguity. In the following example, the patient (an elderly woman with chest pain) has no SCR and the GP is attempting to give telephone advice to a relative who is anxious about the patient and confused about what medication she is taking:

GP: "Can you tell me how long the chest pain has lasted?"

Son: [asks patient] "Just today."

GP: "Where is the pain?"

Son: "Left side."

GP: "Does it spread to the left arm and jaw?"

Son: [asks patient] "She's not sure."

GP: "Does she have a spray for angina?"

Son: "I'm not sure what it's for, asthma or angina. Should I give her the purple one?"

GP: "No, we don't know what's in it. Is she on aspirin?"

Son: "She's on God knows what. There is aspirin in it I think."

GP: "I'll send someone out but if she gets really bad, call an ambulance."

GP OOH phone consultation, no SCR available (FN03/#50)

6.7.14. In this example, one possible 'spray' would be GTN (a treatment for angina) but the GP decides against advising the son to give this because "we don't know what's in it". Another 'spray' (such as salbutamol for asthma) could potentially make a cardiac condition worse. The GP also rapidly weighs up the pros and cons of advising the son to give aspirin in this uncertain clinical scenario and decides against this. *If* the patient was having a heart attack *and* was not taking any medication that interacted with aspirin *and* was not already taking aspirin, then taking an additional aspirin in this acute stage could increase her chances of survival by up to 20%. However *if* the diagnosis was something other than a heart attack (such as an ulcer), aspirin could potentially make the problem considerably worse.

6.7.15. The above case illustrates how clinicians tended to err on the side of caution in the absence of reliable information on medication.[EEE] The SCR, even if it had been present and contained an accurate current medication list, would not have made care safer because the care provided was not unsafe. The added value of a SCR in this case is more subtle: it *might* have allowed the doctor to instruct the relative more confidently on interim management (and hence, lessened the stress felt by both the relative and the doctor), and it *might* have indicated that the patient was already on aspirin. But since many patients on aspirin buy it over the counter, the SCR might also have misled the GP. Even if he had known for sure whether she was taking aspirin, this probably would not have changed the advice he gave. It would merely have eliminated one out of a number of uncertainties in the scenario.

6.7.16. The extent of 'added value' from the SCR depended on the nature and quality of other data sources. It was clear from the consultations we observed that clinicians in unscheduled care draw on multiple sources of information including verbal descriptions from the patient, repeat prescription slips, boxes and bottles of medication (usually physically present during home visits), previous entries on the electronic record (especially the out-of-hours software Adastra) and Transfer of Care forms (structured summaries generated from the local GP record). These sources varied with the setting and were often but not always adequate.

"For us it's lovely when we get a SCR as we've got nothing at all except what the patient tells us."

Walk-in centre nurse interview (FN06/~3)

GP: "Do you take any medications?"

Patient: "Yes, something for me blood pressure. They're all in there" [points at a plastic bag opposite the couch, which partner gets for him]

GP OOH home visit (FN11/#85)

6.7.17. Sometimes the SCR served mainly as a non-specific measure of how sick the patient was rather than providing data that directly impacted on the clinical decision. In one case, for example, a patient in her 50s telephoned the GP out-of-hours centre saying that she needed an urgent home visit because she had run out of cough mixture (FN29/#209). This request caused some exasperation amongst the call handlers but when the case was picked up by the duty nurse, it was clear from the patient's SCR

[EEE] All doctors in training are taught the principle *primum non nocere* (first, do no harm), and we observed on a number of occasions doctors and nurses 'holding back' from active intervention in situations of high uncertainty.

that she was on multiple medication for several life-threatening medical conditions. The combination of a seemingly trivial request and a 'serious' medication list in a relatively young patient aroused the nurse's suspicion and she prioritised the case when planning her call-back work. The patient turned out to be near-suicidal following a recent life event, and the nurse had no hesitation in allocating an urgent home visit (which was what the patient had initially asked for). The apparent influence of the SCR here was to increase the priority of the call-back, but since the nurse would have spoken to the patient within a few minutes anyway, it is hard to conclude definitively that the SCR made care 'better' or 'safer'. However, having the full list of medication available when dealing with a complex and sensitive call-back appeared to make the encounter less stressful for the nurse.

6.7.18. Bearing in mind our own misgivings about framing the question in the format "What are the benefits of the SCR?" (see footnote to paragraph 6.7.1), we believe we have shown limited direct and indirect evidence that the SCR may improve the quality and safety of care in a minority of cases in which it is accessed, and also that in complex cases, it may improve the clinician's confidence and make the unscheduled care consultation easier. We found no evidence that the SCR changed onward referral in our sample but our study was not capable of excluding an impact on this aspect of care that occurred less frequently than once every 200 or so encounters. If efficiency of the encounter is measured *quantitatively* in terms of consultation length, we found no consistent evidence of an impact of the SCR. However, if efficiency is measured *qualitatively* in terms of clinician confidence, the SCR may increase this.

6.7.19. We initially tried to measure whether the use of the SCR had contributed significantly to patients' satisfaction but abandoned this because we found it impossible to judge. In the case of the phone call with a distressed patient (paragraph 6.7.17), for example, it is entirely speculative whether this individual was more satisfied than she would have been had the medication list not been viewable by the nurse.

6.7.20. The SCR appeared to have most impact in more serious cases. Cases in which we felt confident that the SCR had no impact were often suffering from minor illness or no illness at all. The finding that the SCR makes no contribution to care in "most" unscheduled care cases should be interpreted in the light of the important finding discussed in Section 6.3 that the denominator for such cases includes a significant fraction of people who are attending primarily to confirm that there is nothing seriously wrong with them.

6.7.21. In sum, our empirical data lend support to the claim that the SCR may improve the quality and safety of care, and that it may be particularly useful when there are communication difficulties and in patients with complex medication regimens (hence, in sicker patients). However, it did not appear to influence length of consultation or onward referral.

6.7.22. These general conclusions, drawn from detailed qualitative cases observed directly by our team, are not intended to serve as a statistical survey of the frequency of benefits. However, the general impression that benefits appeared more subtle and contingent than early policy documents and business plans had anticipated was strongly supported by other data, including quantitative analysis (Section 6.1); interviews with front-line staff; feedback (both orally and on structured reporting sheets) provided to CFH by local NHS managers and clinical leads; 'risks and issues' documents prepared as background to board meetings; and activities undertaken locally and nationally to address perceived lack of emerging benefits.

CFH staff member: "What's needed is two or three people [in each SHA] for nine months and one for a further 12 months, and the same resource level in PCTs split across the different workstreams."

SHA Lead: "The way the SHAs see it, there's not enough benefits to put that much resource into it."

SHA Programme Leads meeting, January 2009

SHA Lead: "we're not getting any evidence of benefits from places where it's being used routinely"

SHA Programme Leads meeting (in the context of a discussion on whether the SCR produces financial savings), July 2009

The CFH Viewing Strategy Report (November 2009 draft) referred to confusion in relation to benefits and to lack of transparency on this issue.[FFF 17]

"As a result of local NHS organisations perhaps having insufficient resourcing available, both people and financial, as well as there being a lack of perceived benefits there is a risk that the NHS will not fully meet the SCR deployment targets as set out in the SCR business case and the NHS Operating Framework."

Risks and issues document presented to CFH Programme Board, November 2009, page 19

6.8. Risks at the front line

6.8.1. We noted a number of risks associated with the SCR as it was used in clinical care, none of which led to significant harm to the patient in the cases observed:[GGG]

a. The SCR was sometimes 'blank';
b. The SCR medication record was sometimes incomplete and/or inaccurate;
c. The SCR record of allergies and adverse reactions was sometimes incomplete and/or inaccurate;
d. Conversations about consent occasionally seemed to surprise or confuse the patient;
e. Information on the SCR occasionally seemed to surprise or confuse the patient;
f. Information on the SCR occasionally seemed to distract the clinician into 'studying the record'.

6.8.2. A clinician who used SCRs regularly told us: *"So many of the records I open, they're blank. The message pops up 'record is blank'. Nothing on it."* (walk-in centre nurse interview, FN06/~04). A record that is described as 'blank' by the software means that the patient has opted out of having a SCR. Patients who are on no medication and have no known allergies would have a record with no content, but the system would not then give the message 'blank'. Official CFH statistics suggest that fewer than 1% of patients have opted out of having a SCR, yet of some 30 attempts by clinicians to access SCRs in our presence, one (FN04/#42) routed to a screen message 'this record is blank'. In that case, the patient insisted that they had not

[FFF] We were asked not to include direct quotes from this document because it was a "draft". Lack of transparency in this context appears to refer to (a) lack of clear evidence of benefits from the early adopter sites and (b) lack of clarity in communication material on precisely what benefits were expected. As Table 5.1 shows, the benefits of the SCR were often depicted as self-evident and/or a foregone conclusion.

[GGG] Note: the risks considered in this section are the risks associated with successful implementation of the SCR, not the risks that might serve as barriers to its introduction. See paragraph 2.5.11.

opted out. One explanation for this is that a temporary technical glitch in the software was incorrectly flagging records as blank, which had the unintended consequence of eroding clinicians' confidence in the system.

6.8.3. Medication prescribed recently by anyone except the GP was not recorded on the version of the SCR that was being used at the time of our fieldwork. Examples of medication lists that did not routinely appear on the SCR are shown below:

a. Medication prescribed by an out-of-hours GP but not yet added to the SCR by the patient's regular GP;

2 year old child with 'high fever'. Was seen by GP in this out-of-hours centre two days ago and prescribed penicillin. SCR shows various medications given by own GP (chloramphenicol eye drops 2 weeks ago, amoxicillin 1 month ago, clotrimazole 4 months ago, ibuprofen 5 months ago) but not the penicillin he's on currently. However, this medication is shown on the Adastra record.

Field notes on OOH call centre phone consultation (FN29/#201)

b. Medication prescribed under DRG protocols by nurses in walk-in centres (FN07/#99, antibiotic for urinary tract infection);

c. Medication given over the counter by a pharmacist:

Patient phones out-of-hours centre for painful red eye.

Nurse: "Is it OK if I access your GP medication record?"

Patient: "Yeah, sure"

[SCR has nil relevant]

Patient: "I got these eye drops from the chemist, Optrex, they haven't helped"

Nurse: "Is it the ordinary Optrex or the Optrex for infected eyes?"

Patient: "I've no idea, and my eyes are so blurred I can't read it"

OOH call centre phone consultation (FN05/#64)

d. Strong (opioid) painkillers obtained abroad (FN16/#154));

e. Medication initiated recently in hospital outpatient department (triple therapy for helicobacter; FN07/#98);

f. Medication taken by the patient but prescribed to someone else (patient brought to A&E by ambulance with an overdose of non-steroidal anti-inflammatory drugs thought to have been prescribed for a relative, FN12/#112);

g. Medication prescribed to the patient more than 6 months ago and restarted by them without consulting GP:

Parent of small child calls out-of-hours centre. "Vomiting but not all the time."

Family have recently returned to [country of origin] for one-week holiday. Mum got medication in [country of origin], antibiotic plus cough medicine. One month ago mum had given the child a different antibiotic, from an old supply she had.

Field notes on OOH call centre phone consultation (FN29/#206)

6.8.4. Examples of medication shown on the SCR as 'current' but not being taken by the patient included:

a. Medication that had been stopped but still appeared as a current drug because it had not been actively moved to 'past drugs' (FN29/#212, eye drops);
b. Medication that had been prescribed and dispensed but which the patient had not taken at all (FN56/#05, lost asthma inhaler);

6.8.5. To this list might be added medication that had been prescribed but was not being taken as directed, as this example from a patient without a SCR shows:

Mental health patient. Had dosette box (brought in by ambulance staff) showing very selective consumption of prescribed medications. He did not take the large white ones at all and had already eaten most of the red ones for future days.

Field notes from A&E (FN13/#116, no SCR available)

6.8.6. We encountered examples of allergies which had apparently been entered on the GP record (perhaps as free text) but which did not appear on the SCR:

88 year old woman, coughing green sputum.

Call handler note reads: `GP sent spec last week, unable to get result as surgery closed. Allergic to one medication, tri-something, not sure exact name.`

Nurse opens SCR before calling patient. SCR shows Repeat meds: losartan. Acute meds: hydroxocobalamin. Allergies: nil.

[…]

Nurse asks about the allergy. Speaks very gently, coaxing her: "Now can you try to remember exactly what you're allergic to, take your time."

Patient (very slowly): "tri, tri, trimethoprim. I'm allergic to that. I'm pretty sure."

Nurse advice call, out-of-hours centre (FN29/#210)

6.8.7. We also found at least one example of a *perceived* allergy (i.e. a drug to which a patient believed themselves to be allergic) which had been transferred from the GP record to the SCR.

Nurse: [viewing SCR]. "Oh you're allergic to penicillin."

Patient: "Yes, when I was a very little lad I came out in a really horrible rash, was ill for quite a while, they told my mum I shouldn't ever have it again."

Nurse: "I'll give you another antibiotic, erythromycin."

77-year-old patient seen in walk-in centre in 2009 (FN06/#65)

The above patient would have been 14 when penicillin was first introduced into general practice the UK (1945), and a penicillin rash would be unlikely to make a child "ill for quite a while". The "horrible rash" may have been due to a reaction to sulphonamide, an antimicrobial that was widely prescribed in the 1940s and which typically causes a generalised illness with a widespread rash that lasts several weeks. Thus, whilst the SCR in this case *appears* to corroborate the patient's account of an adverse reaction, it may have merely ossified an inaccuracy.

6.8.8. Importantly, clinicians using the SCR did not show blind trust in data held on it. Variable data quality is a fact of life in clinical care. Any notion that the SCR would offer 'perfect' data (always complete, always accurate, always accessible) was unrealistic from the outset, and a key risk identified by our team when we began this study was that clinicians might behave *as if* data were complete and accurate when in reality they were neither. Indeed, a key safety measure in any clinical encounter is the extent to which the clinician has a *realistic* view of the data quality and takes appropriate precautions.[2] Our ethnographic findings suggest – reassuringly – that even though the SCR had only recently been introduced, front-line clinicians were already developing rules of thumb to assess the quality of the data on it. Most

commonly, the clinician asked the patient as well as consulting the SCR, and made a judgement about which source was likely to be the more reliable.

"I had a lady yesterday said, 'My doctor said I was allergic to penicillin but I've had it since and I'm not allergic, and I don't want them giving me erythromycin as it makes me sick.' Well I looked her up on the SCR and she was still down as allergic to penicillin."

Walk-in centre nurse interview (FN06/~01)

"We get people who say they're not allergic to anything, but then you look at their SCR, and the patient is allergic to statins"

Walk-in centre nurse interview (FN04/~01)

6.8.9. In both the above examples, the nurse has to make a judgement call: should she trust the patient's account over the SCR or vice versa? Penicillin allergy is notoriously overdiagnosed. A confident description by a patient of having taken penicillin without ill effect is highly credible. Erythromycin makes a lot of people sick. In the first case, then, the patient's account is likely (though not 100% certain) to be "right". The typical adverse reaction to statins (strictly, intolerance rather than allergy[HHH]) comprises vague muscle aches that come on insidiously and/or an abnormality on a blood test – something very different from the acute rash or vomiting which lay people would typically associate with a drug allergy. A GP may discontinue a statin on these grounds without conveying to the patient that they have had a reaction to the drug. Hence, *in this particular case*, the SCR may be more likely to be "right" than the patient. Reassuringly, these nurses were demonstrating the ability to shift their trust judiciously between the patient and the SCR.

6.8.10. We found that when a clinician accessed the SCR, this sometimes generated conversations which the patient was not expecting. Because the clinician viewing the information was not the person who prescribed the medication, it was sometimes unclear why the drug was given. This could generate awkward moments in the conversation, as the following exchange shows. Here, the SCR has been accessed with the patient's consent in order to see which medication the GP gave her when she last had the problem.

Patient attends with headache, possibly migraine. Part way through consultation her child asks to go to the toilet.

[Patient exits. Nurse and researcher look at SCR together. It shows that she has had medroxyprogrsterone a month ago and diclofenac four months ago. The nurse asks the researcher what medroxyprogrsterone would have been given for, and both speculate on some possibilities. The patient re-enters the room to find nurse and researcher studying the computer screen]

Nurse: "Why did you have the hormone treatment?"

Patient: [anxiously] "Nope, I've never had hormones." [stands up and begins to study screen] "Not me."

[longish pause while nurse studies SCR and considers how to deal with this]

[HHH] The issue of 'intolerance' to a medication is an interesting example of the ambiguity of data when transferred to new contexts. A reviewer of a previous draft of this report commented: "On EMIS if one wants to code an intolerance, it would be entered as 'allergy' and a free text next to this coded entry would say what the intolerance is e.g. headache, nausea, cough. But it is not possible (or at least if it is, few people are doing it) to code an 'intolerance' as distinct from an allergy. So when using the EMIS 'allergy list' (with access to the linked free text) the clinician makes a judgment based on the need for the medication versus the likelihood and potential severity of the intolerance (for example, one warns a patient that he may get diarrhoea on an antibiotic or drowsiness on a strong painkiller like he did last time). However, if only the *coded* data are sent on the SCR (without free text), then many intolerances would appear as allergies, giving the impression that the medication should not be given in any circumstances."

Nurse: "You had some tablets about three weeks back, were they for the periods?"

Patient: "Oh yeah, to stop my period, it wouldn't stop. That was awful."

Nurse: "Did they work?"

Patient: "Yeah it was fine."

Walk-in centre consultation (FN06/#68)

6.8.11. In the above consultation, the mismatch between what was expected and what was found was minor. The nurse was attuned to the breach in smooth communication and swiftly initiated a 'repair'. However, this example illustrates how introducing information which neither the patient nor the clinician can make sense of could potentially threaten the delicate trust relationship in the out-of-hours consultation.

6.8.12. We identified one critical event where there was confusion about whether the patient had been opted out.

"Last week we had a young lad in with mum, the blood tests had got him possibly glomerulonephritis [kidney disease]. I accessed his SCR, with patient and mum's permission, and it popped up 'patient has denied access'. I said to mum, 'so you said you don't want us to see your son's record'. And mum said no, I filled out the form, because with him being ill and having tests, I did really want him to have it. The way mum was talking she wasn't going to rest till she'd had it sorted out. She wasn't anxious she was indignant. She was marching from here right to the [GP] surgery to get it altered!"

Walk-in centre nurse interview (FN06/~2)[III]

6.8.13. Numerous explanations are possible for this case. Did the mother misunderstand the consent form, opting out when she meant to opt in? Was human or technical error involved in flagging the record inappropriately? Had the father opted the child out without telling the mother? Perhaps the mother had changed her mind and was now seeking a face-saving excuse. Whatever the explanation, information about consent to view a child's SCR had generated confusion and distress for both parent and staff.

6.8.14. We encountered examples of non-medical staff apparently becoming diverted into studying what was on the SCR. This is evident in the following transcript:[JJJ]

Nurse: "So you've cut your toe?"

Patient: "Yes"

Nurse: "Right, I've got access to your Summary Care Record, can I look at it?"

Patient: [looks blank]

Nurse: "Your Summary Care Record, from your GP... your medications."

Patient: "OK, OK"

Nurse: [Looks at SCR] "You're on ferr..(ferrous sulphate?). Are you anaemic?"

Patient: "No, for acid problem."

Nurse: "OK. And are you on tol…tolterodine?" [reads off SCR]

Patient: "What for?"

Nurse: "I don't know" [pause] "Are you on anything apart from the iron?"

Patient: "Yes. I'm on triple therapy for helicobacter, started last week"

Walk-in centre consultation (FN07/#97)

[III] This fictionalised case was reported under our research governance procedure to the patient's GP.

[JJJ] As in the example in paragraph 6.4.15, the clinician's request for consent to view the SCR is reframed as a *statement* when the patient did not respond to a direct *question*. Again, the response was "OK".

6.8.15. In the above case, the nurse became diverted from doing a simple wound dressing into a largely irrelevant conversation about specialist medication (which was, incidentally, complicated by the fact that the helicobacter therapy did not appear on the SCR). In this encounter, the time spent was relatively small, but the case illustrates how information on the SCR may not save time, especially when the data held are poorly matched to the scope of practice of the clinician.

6.8.16. Our data thus suggest that on occasion, the SCR may be incomplete, inaccurate or potentially misleading. However, our study was not designed to provide a quantitative estimate of this problem and our data suggest that clinicians who make regular use of the SCR do not treat the data on it as necessarily complete or accurate. Rather, they treat the SCR in much the same way as they treat the multiple other data sources available to them – they make a situated judgement about the likely trustworthiness of the data and factor this into their decision-making. These examples beg the question of the extent to which information may become ambiguous and/or untrustworthy when it is transmitted to new contexts and use settings – a theme we consider in Section 11.5.

6.9. Summary: The socio-technical chain needed for SCR use

6.9.1. To try to capture the multiple interacting explanations for situations when the SCR was not available, not accessed or accessed but not found to be helpful, we developed the concept of a 'socio-technical chain' with multiple precarious links. This is loosely analogous to the 'cold chain' needed to maintain integrity in vaccine supply. If just one of the links in the chain is broken, the patient's SCR will either not exist at all or will be inaccessible, incomplete or otherwise unhelpful.

6.9.2. Figure 3.1, paragraph 3.4.3, shows diagrammatically the numerous interacting factors, both social and technical, which influence the use (or non-use) of the SCR in an individual encounter. The 'socio-technical chain' might be conceptualised as a particular combination of people, technologies and connections in this network (whether operating at macro, meso, or micro level) which are relevant in a particular encounter.

6.9.3. The socio-technical chain for the SCR is complex and includes numerous links, for example:

a. Macro-level links (e.g. national level policy, public trust, professional norms and values, legislation and case law, advice from Information Commissioner) are all broadly supportive of the use of the SCR);
b. Meso-level links in the patient's GP practice (e.g. there is buy-in to the SCR programme, support of the practice Caldicott Guardian, a SCR-compatible software system, the practice has achieved 'readiness' including data quality accreditation, successful go-live, regular updates from local system to Spine);
c. Meso-level links in the provider organisation (e.g. organisation has Spine access, organisation's routines and procedures are compatible with SCR access, supporting technology is installed and working, there is sufficient capacity e.g. terminals, smart card readers, there is active encouragement for staff to view SCRs);
d. Prior micro-level links relating to the patient (e.g. patient is eligible for NHS care and has not opted out of a SCR);

e. Prior micro-level links relating to the clinician (e.g. clinician is trained, motivated, in possession of functioning smart card and with the right access privileges in this organisation);
f. Prior micro-level links relating to the SCR (e.g. medication, allergies and key clinical data have been entered on local GP record in the relevant data fields and have been uploaded to the SCR); and
g. Micro-level links relating to a particular encounter (SCR-held data are relevant *on this occasion*; clinician chooses to access SCR and has smart card *on this occasion*; patient consents to viewing at point of care; clinician has skills to interpret SCR-held data *in the context of this encounter*).

6.9.4. Whilst the notion of a socio-technical chain is a useful heuristic for considering the many things that must come together for an informative SCR to be available and used in a clinical encounter, it does not comprise our definitive analysis of the programme. In Section 10, we offer further theorisation of the macro, meso and micro elements of the socio-technical system.

7. Mobile SCR: The Bolton District Nurse PDA pilot

7.1. Background and context

7.1.1. Between May and September 2008, BT supported a pilot study in which district nurses were issued with Portable Digital Assistant devices (PDAs) so they could access the SCRs of the patients they visited on their rounds. We describe this sub-project in some detail because it highlights a number of critical issues for the wider SCR programme. In particular, the PDA pilot illustrates three things:

a. The complex and somewhat unstable socio-technical network (both local and national) within which the SCR technology was being introduced;
b. The way the project was shaped and constrained by both 'macro' issues (e.g. relations between CFH and suppliers) and 'micro' ones (e.g. perceptions and actions of front-line staff); and
c. The complex nature of clinical work (especially nursing work) and how this work comes to be represented (or not) on the electronic patient record.[KKK]

7.1.2. CFH was under pressure to demonstrate benefits from the SCR within a very tight timescale. A number of small-scale pilot projects were established in Bolton and Bury in 2008-9 aimed at achieving 'early wins' in this regard. From CFH's perspective, the Bolton district nurse PDA pilot was one such initiative. Because district nurses are attached to GP practices, the PDA pilot could be focused on nursing teams linked to participating practices, in which the 'hit rate' for SCRs would be close to 100%.

7.1.3. From BT's perspective, this pilot was separate from its main Spine and NASP (National Application Service Provider) contracts (Sections 2.3 and 5.6) and linked to a broader programme of research to explore possible opportunities for the use of PDAs by 'mobile' health professionals. BT's original plan had been to pilot their prototype PDAs in Birmingham but that site had very few SCRs, so the project switched to Bolton and came to align with CFH's quest for 'early wins', though this was a somewhat uneasy alliance. Socio-technical linkages in this sub-project were complex. Key technologies included the Spine (made and maintained by BT under contract to the DoH), the PDAs (made by BT but not under contract, and *lent* to the PCT), the local GP records (made and maintained by GPSoC suppliers) and the Lorenzo contacts database for district nurses (made and maintained by CSC Alliance). Shared local detailed records had not been introduced.[LLL]

7.2. The district nursing service in Bolton

7.2.1. NHS district nurses cover mostly housebound patients and provide a wide range of clinical services (e.g. dressing leg ulcers, reviewing diabetes control, checking that patients recently discharged from hospital are coping).

[KKK] Academic readers may be interested our in-depth theoretical and methodological paper on studying 'big IT' in healthcare, in which this case study is briefly discussed.[68]

[LLL] This sub-project raised interesting questions about who, *de jure* and *de facto*, is responsible for the part of the patient's record that is stored on the SCR. For the duration of the pilot, the PDAs through which SCRs were accessed were *held* by district nurses but *owned* by BT. The SCRs themselves were *created* by the patient's GP using software provided by GP system suppliers and *'hosted'* by BT on the Spine. SCR data are apparently officially 'owned' by the Department of Health (the data controller for the SCR under the Data Protection Act). These complexities are taken up in Section 8.2.

7.2.2. The service took referrals from multiple sources (GPs, hospitals, social services and self-referrals from patients). Referrals usually came by fax and were processed by a clinical nurse manager who assigned a priority and allocated a particular nurse to it. Urgent referrals required immediate allocation of a staff member, who may need to divert from less urgent regular duties. The service was thus highly complex and unpredictable – a fact which perhaps came as a surprise to CFH.

"We were well into the pilot before they looked at our business processes" (FN30/~01).[MMM]

7.2.3. District nurses considered their patients holistically as having health and social care needs, not easily separated. The care they provided was multifaceted, and some was subtle and hard to measure (e.g. emotional support, troubleshooting). Many felt that neither GPs nor managers fully understood this, and that much of their skilled input was a "hidden service", not captured by the closed codes on the contacts database.

"The problem the patient has been referred for is often the least of the patient's problems. Something seemingly straightforward like administering eye drops can turn into a long visit when other problems need to be dealt with, whereas a visit to an end-of-life patient can be quick when they have good family support." (FN24/~01)

7.2.4. The nurses perceived the service to be struggling with high and rising demand and to be under-resourced. Two mobile telephones were available for each team of 15-20 front-line staff. The limited mobile phone supply was a bone of contention, especially since socio-economic deprivation is strongly linked to poor health and a high proportion of visits were in areas with high rates of crime and social need.[NNN]

"We're a vulnerable service, because we never know what we're walking into, there's always the risk of violence" (FN24/~02)

7.2.5. The district nurses saw a crucial aspect of their role as drawing together information on a new referral from the patient and various NHS and social care records to produce a complete picture of the individual's situation and care needs. "Doing a review", as this process was called, typically comprised piecing together fragments from multiple sources, none of which was 100% complete or accurate, and cross-checking these against each other.

"Once a new patient has been taken on, the hunt for information begins. This includes having a look in the patient's home for other medications they might be on. It's like being Sherlock Holmes. Hospital discharge letters for example only contain hospital medication, but no information about what else the patient is on." (FN24/~01)

7.2.6. The district nurses occupied a part insider, part outsider position in GP practices, and to some extent this helped to *resolve* the inherent tension in the SCR programme between 'keeping patient data confidential' and 'making data accessible throughout the NHS'. District nurses are PCT employees (hence, in that sense, are not 'practice staff') but they are attached to one or more GP practices and formally contracted to look after the patients registered at those practices (hence, in that sense, they are very much 'practice staff').[OOO] The PDA pilot was thus almost unique amongst all the SCR sub-projects in raising no major information governance issues at a hypothetical level (but see paragraph 7.4.3 below on *perceived* information governance barrier).

[MMM] Because this study involved interviews with small numbers of people, we have omitted potentially identifying details of our sources and described all informants as 'district nurses' whether front-line or managerial.

[NNN] The number of physical attacks on district nurses was probably low, but the *fear* of attack was understandably high.

[OOO] It is typical but not invariable, for example, for district nurses, health visitors and other 'attached' staff at a GP practice to have a pigeon hole in the practice reception area and for them to ask receptionists to provide print-outs of relevant patient details. Whilst a Caldicott Guardian (paragraph 4.4.4) in a GP practice might object to data on 'their' patients being accessed by NHS staff outside the practice, they could not reasonably object to the practice's own district nurse having this access.

7.3. The PDA device and how it was introduced and used

7.3.1. The PDA device supplied by BT is shown in Figure 7.1. Not all of its functions were operable – for example, it offered telephone and camera functions which had been disabled by BT as they wanted the pilot to focus on the SCR-related performance of the device. 30 devices were provided and were used by team leaders doing initial assessment visits and by other team members if available.

Figure 7.1: PDA device used for Bolton district nurse pilot

7.3.2. In a preparatory phase, the nurses attended a 3-hour training session by a BT or PCT trainer. Training was held at the weekend and nurses' time funded from the district nursing budget. Trainers (who had little or no experience in clinical settings) relied heavily on click-through Powerpoint presentations. In one session the Spine was down for maintenance – but even when it was running, the trainers stopped at the 'legitimate relationship' screen (Section 8.5).

"It was all right, but we should have gone through a patient… the scenario.. the actual machines weren't working, they were like dummies, so if we'd had a patient we could have worked through.. it would have been much better…" (FN25/~06)

7.3.3. Initial attempts to use the devices uncovered a number of technical problems but these were relatively swiftly resolved.

"There were several patches that needed to be put on, there were loads of technical glitches, all the smart card readers had to go back at one point, and staff lost a bit of confidence in the product" (FN30/~03)

"Once it was working it worked very well" (FN30/~01)

7.3.4. In an ad hoc meeting outside the formal training sessions, some nurses decided to access their own SCRs to gain familiarity with the live system. This 'workaround' immediately revealed inaccuracies in the SCRs. Their feedback led to a technical audit which found that the SCRs of patients in some practices were not being regularly updated due to a bug in the GP software. Whilst the bug was promptly fixed, the nurses' confidence in the quality of the data held on SCRs was not fully restored. This was perhaps not a bad thing, since as one interviewee put it:

"…the SCR might make people [nurses] more prone to rely on one source of information, whereas they'd normally cross-check" (FN25/~05)

7.3.5. As the district nurses became familiar with the SCR, they tended to use it to supplement other information sources as part of the 'Sherlock Holmes' task of building up a full, up-to-date picture of the current state of the patient.

"Here's one example we had. A patient was discharged [from hospital], the nurse popped in, and the medications on the discharge note were incompatible with the ones she was still taking from the GP which the nurse could see on the SCR. The hospital had obviously not realised what the GP had given, and the nurse was able to sort it out then and there. That's where the SCR can be useful 'cos if there's missing information, you can usually find it. They [hospital] will tell you the patient's had an appendicectomy but they won't tell you they've got other needs, they might have cancer of the pancreas or a whole load of other things wrong with them but if that wasn't part of this admission they won't tell you it." (FN30/~01)

7.3.6. Different nurses used the PDAs differently in their day to day work. Some who attended the training did not go on use the PDAs at all. Some, especially the team leaders, used them to access the SCRs of most or all patients while doing home visits. Some explored the full functionality of the PDA device and made creative use of it to assist them with other aspects of their role in ways that may have been unanticipated by its designers. For example, one found that he could look up names of unfamiliar drugs on an internet-based formulary, and also accessed online patient education materials to support a discussion on prognosis and treatment options with a housebound patient. Another said she used the PDA in her car to access Google maps and find the address of the next patient.

7.3.7. The district nursing manager found a very different use for the devices. The PDAs had GPS (satellite navigation) which linked to a central 'diary' from which she could track her staff.

"[the best benefit was] knowing where my nurses were and how to organise my workflow. Equalising the caseloads, how much time do they spend travelling, we have no idea about that. [With the PDA] you could manage your work as it came in, if you got a call you would be able to redirect staff to where they were needed. Say I've got an assessment come on my fax at 10 am and I look on the GPS diary, I could phone them and say, go along and see this person." (FN30/~02)

7.3.8. One nurse described how a colleague had accessed the SCR via her PDA in a power struggle with an out-of-hours GP:

[Nurse] mentioned the case of a patient who had been prescribed antibiotics on a Friday by his GP, didn't collect them and was then visited by one of her DN [district nurse] colleagues on Saturday. This nurse wasn't a prescriber, but she returned to the DN office at [---], which they share with the OOH [out-of-hours] GPs, and asked a GP to prescribe it. This GP "didn't believe" that the patient had been prescribed the antibiotic, but could be convinced when the DN showed him the medication list on her PDA. This saved either the patient having to go to OOH or the GP having to make a home visit, and the patient got his antibiotics more quickly. They agreed that the OOH GP obviously didn't think of using his computer to access the SCR.

Field notes from focus group discussion (FN25/~03)

7.3.9. The above case was taken up by CFH's Communications department and used to prepare a brochure about the benefits of the SCR, in which the technology was presented as a neutral container of essential 'facts' for clinical care ("*Using her mobile device she was able to look up the Patient's SCR to see which antibiotics the patient had been prescribed. With this information she was then able to contact the Out-of-hours GP who issued a new prescription for the antibiotics. This meant the patient received the correct treatment quickly and prevented a further GP home*

visit."[121]) but issues of power, trust and jurisdiction between the different professionals went unacknowledged. An alternative interpretation of the story is that the SCR and linked PDA device were a somewhat technology-heavy way of getting an out-of-hours GP to take a district nurse's account of a patient's illness seriously.

7.4. Explaining high and low use of the PDA

7.4.1. The highest users of the PDA device were, unsurprisingly, those who considered themselves confident with the technology and were keen to innovate. The PDA aligned with such nurses' identity and values (as a mobile workforce, they saw a mobile technology as very appropriate). Working in an organisation where they were not routinely given a simple mobile phone, they felt valued and rewarded when given the more technically sophisticated PDAs. High users of the PDA commented that they felt it increased their credibility in the eyes of the patient, partly because they could show the patient his or her own record at the bedside. It is possible, but only a hypothesis at this stage, that a demonstrable link with the main NHS records system made the nurses seem more a part of the trusted NHS system in the patient's eyes.

7.4.2. We did not interview any non-users of the PDAs, but focus group participants told us of others who had made only limited use of them. One reason for this was the PDA's material properties. For example:

a. It was considered to be "the wrong size" – neither small enough to fit into a pocket nor large enough to be used like a PC.

   "It consists of the main device itself, which is basically the screen, and a clip-on magnetic keyboard. If you were trying to type, you couldn't comfortably type with both hands because the screen would fall off the keyboard." (FN25/~05)

b. It had to be used with an external smart card reader which connected to the PDA via short-range wireless technology ('Bluetooth'). The nurses already had smart cards for using Lorenzo so they just needed to be authorised to use these cards on the SCR viewer. The Bluetooth had a range about the size of an average room, so the nurses had to take both the reader and the PDA with them. If the PDA was taken outside that range, it would switch off (this was an intentional security feature). It would also switch off if it was idle for more than a few minutes, hence was somewhat difficult to use during the clinical encounter.

   "They were a bit of a faff really, quite cumbersome in some respects" (FN25/~03)

c. The PDAs had to be returned to base every evening to be recharged, hence the hope that they would save a return journey was not realised.[PPP]

d. The nurses were also concerned about the infection risk of using the PDA at the patient's bedside. The keyboard was 'raised' (hence hard to clean), and whilst they had been given antiseptic wipes to use on it after every visit, these did not seem to work very well. For infection control reasons the high-tech PDA and its smart card reader were carried round in a plastic Tupperware box.

[PPP] A recurring theme in our data, and also in studies undertaken by others,[116;122] was a "fantasy of placelessness" – i.e. the unrealistic expectation that technology would eventually allow work to happen in a way that was no longer tied to particular physical places and spaces. In fact, as the PDA example shows, even 'mobile' technologies are often highly constrained in terms of the spaces and places which support their use.

Whilst these related to an early prototype which we understand is being refined by BT, they illustrate how physical properties like size, texture, 'fiddliness', ease of connectivity and ease of cleaning had a significant influence on adoption and use.[QQQ]

7.4.3. Another reason for low use of the SCR, which in this pilot was quickly picked up and addressed by nurse managers (but which could prove a barrier in other, less closely monitored, environments), was that front-line staff *perceived* a problem of access rights. The PDA trainers, who had received information governance training from BT, were aware of the importance of *not* accessing 'real' records during the sessions and of the serious consequences of triggering an alert (possible dismissal from their job). The nurses, on the other hand, had a clinical relationship with the patients in their care but this was so second-nature to them that when expressed in formal terms ('legitimate relationship'), some did not understand the meaning and concluded either that the technology did not work or that some distant authority had blocked its use.

"One of the big problems I encountered was people ringing me and saying 'it won't come on, it won't come on.' But when we got to the bottom of it with a lot of them, it was the way that they'd trained us when you got to the legitimate relationship screen, they'd absolutely petrified everyone into being convinced that we could not go past this screen. So people were saying 'well, I can get on it, but I can't get any further, so there is no record.' Once they had realised, peoples' response was: 'Oh, I didn't realise I could go past that screen, because the man said not to go past it.' It was inferred that you haven't got a legitimate relationship, and he didn't really explain that the reality obviously was that if you're seeing that patient you obviously have a relationship. And that held us up for a couple of weeks." (FN24/~01)

7.4.4. The unfamiliar nature of the PDA technology and some nurses' initial lack of confidence in using it occasionally eroded the patient's trust in the nurse – or at least, this was a fear expressed by some of them. The following reaction to the PDA contrasts markedly with the perception by the more confident nurses that accessing the patient's SCR via the PDA at the bedside *increased* their credibility in the patient's eyes (see paragraph 7.4.1 above).

"When I went to a patient the first time we used it, I felt like I wasn't quite sure where I should be going….and they're looking at you…" "….and they expect you to know what you're doing. But obviously if you don't know what you're doing with one part of the care, then they think 'God, they really don't know what they're doing'. And even if they're not thinking that, you're thinking that they think that." (FN25/~05 and ~06)

7.4.5. Of 339 SCR accesses during the five-month pilot period, 57 triggered an alert, suggesting that the clinician did not have a legitimate relationship with the patient (see Section 8.5). These alerts were all sent by email to the Caldicott Guardian of the PCT, who checked the reasons for them (by contacting the individuals involved and/or checking the Lorenzo contacts database) and produced an audit. None of the alerts indicated a genuine information governance problem. Rather, they were caused by a mismatch between the model of nursing work built into the SCR technology and the reality of that work. Examples of this model-reality gap included:

a. A district nurse sometimes wished to discuss a case with a senior colleague, perhaps by telephone. In such circumstances, the senior nurse used her own smart card to access the patient's SCR, but would not record on the Lorenzo

[QQQ] Again, this finding aligns with the wider literature. See for example Davis's Technology Adoption Model which adapts Rogers' diffusion of innovations theory for technologies by adding attributes such as 'ease of use'.[123] For the more philosophically inclined, Dant's theory of material interaction draws on the phenomenological work of Heidegger to consider how people may 'embody' the technologies they use most fluidly.[124] We discuss the material aspects of EPR technologies, and the relative neglect of this topic in research in this field to date, in our recent theoretical paper.[68]

system that she had seen the patient, so there was no obvious clinical relationship.

b. A nurse might enter contact information on Lorenzo several days after the one on which she accessed the patient's SCR. It was not uncommon, for example, for nurses to see patients on a Friday but not log the contact until the following week.
c. A nurse might look at a patient's SCR in advance of a visit and discover that the patient was not at home when she got there (e.g. because they were in hospital).

7.5. District nurses' suggestions for improving the mobile SCR

7.5.1. The nurses did not generally distinguish between the PDA through which they could access the SCR and the SCR itself. In relation to the PDA, numerous suggestions for improving its usability and ease of use were fed back to BT and are not listed here. We describe below the suggestions made in relation to the SCR.

7.5.2. The most pressing need perceived by the district nurses was to increase the clinical content of the SCR. Some nurses interviewed (like many doctors interviewed in other parts of the evaluation) felt that although the clinical content was currently limited, at some future date the SCR would contain all the information needed to manage the patient (and that there would be no inaccuracies or omissions).

"If you had this all-encompassing record...[...] so you had a complete picture of that patient."

"…if someone is a rapist, violent or psychopathic"

"…a note about the surroundings, like if the steps were slippery"

"…it would be good to be able to send a prescription directly to the pharmacy."

"We should access the Path Lab results, so we can give blood, urine results to the patient"

"It could also be used to make referrals, including for equipment"

"it could link with telehealth"

Focus group participants, when asked what information the SCR should contain (FN25/~03-06; FN30/~01)

7.5.3. Another bugbear for the nurses was that they could not enter data on the SCR. The principle of 'read only' access by anyone except the patient's GP had been hotly debated by various committees and panels. Having a single point of data entry aligns with research evidence that if multiple data entry routes were provided, data quality would be at risk.[2] The decision had been made using examples of junior doctors in the A&E department, and the district nurses felt, perhaps with good justification, that this rule should not apply to them.

"If you're trusted to prescribe, and you've been through a very rigorous education in order to do it, then you should be trusted to add to the SCR." (FN24/~01)

7.6. The end of the pilot

7.6.1. BT withdrew the PDAs in September 2008 – a time which, intentionally or not, corresponded with when considerable hunger for the product had emerged amongst front-line nurses. There was not, however, a business case within the PCT for

continuing the deployment. Some nurses felt somewhat cheated when the PDAs were withdrawn, and were surprised by the 'commercial' behaviour of the supplier (*"They got everything they wanted, but we didn't get what we wanted",* FN25/~01).

7.6.2. From the perspective of CFH, the PDAs were a tool through which the district nurses could access the SCRs, thereby demonstrating 'proof of concept' of the SCR in the context of district nurse work. They saw BT's withdrawal of the PDAs as a relatively minor and temporary issue, since once proof of concept was demonstrated, the SCR programme would (many staff believed) reach a 'tipping point' and PCTs would be required to support it – which would include buying or hiring PDAs for all its mobile staff. This assumption is reflected in policy documents about IT systems generally:

"The intent is to identify the essential functionality that will create a pull effect from clinicians who see it as useful and valuable in conducting day-to-day business. This will create a 'tipping point' in the acceptability and demand for the strategic IT systems."

NHS Informatics Review, page 26[48]

7.6.3. Some CFH staff viewed the PDAs as a relatively simple, off-the-shelf technology through which the 'real' product (the SCR) would be viewed by the nurses. Minutes of project meetings from the run-up to the PDA pilot suggest that both CFH and PCT staff anticipated that the cost of these devices would be modest and that CFH assumed it would be met from PCT budgets. They did not appear to fully recognise that the PDA's cost in business terms was much greater than its production cost.[RRR]

7.6.4. As BT pointed out, the PDAs were not a freestanding technology. The price for the project incorporated the cost of the PDAs as well as the costs of providing the service, including substantive changes to Spine for the security, identity management, audit, single log on, increased input and output channels, and extra storage that would be needed for PDA access to Spine.

7.6.5. Overall, the district nurses and managers were positive about the PDA pilot and keen for it to continue. Some of this enthusiasm may have been what is known as a 'Hawthorne effect' (people tend to feel positive and perform well when they perceive that conditions are improving and someone is measuring that improvement). In addition, many appeared to conflate current benefits of the SCR with the benefits of some future, imagined SCR that would be more complete, accurate and easy to use. These issues, along with wider questions of incommensurabilities between the political, technical, commercial and clinical worlds are addressed in Chapter 10.

7.6.6. A tightening of protocols around the new consent model meant that the district nurses, many of whom had become local champions for the SCR, could not even access patients' SCRs from their terminals at the base centre before they went on their visits. This was because unlike patients contacting the GP out-of-hours centre, very few district nursing patients were self referrals.

Researcher: "What's happened with the SCR here now?"

Interviewee: "It's died a death. We managed to get it onto everyone's machine and they would look at it before they went out on visits. But it fell by the wayside because we can't get the permissions needed. The patient now needs to give consent before the nurse looks at the record. But it's good to look at the record before you see the patient, to get oriented, to plan what to take, and sometimes it's useful speak to the GP beforehand." (FN30/~2)

[RRR] In response to an earlier draft of this report, CFH advised us that "The main reason not to proceed with the pilot was due to NHS Infrastructure Policy not to support non-windows PDAs to view clinical data, but to only support windows based devices,"

8. Wicked problems

8.1. Introduction

8.1.1. As indicated in Section 4.3, CFH staff took a highly systematic approach to the operational detail of the programme. Problems identified in boards and committees were minuted on a spreadsheet and named individuals allocated to actioning them. The first item on most agendas was a review of numbered action points from the previous meeting. Recurring agenda items included:

a. Content and scope of the SCR;
b. Data quality;
c. Consent;
d. Information governance;
e. "Technical" problems;
f. Children; and
g. Training.

8.1.2. These (and other) complex problems that recurred in CFH meetings had a number of common characteristics:

a. They spanned the different 'worlds' of different stakeholder groups (Section 10.1);
b. They involved a tension between different philosophical models of reality ('hard', rationalistic, factual versus 'soft', contextualised, interpretive);
c. They tended to include a claim on contested resources (i.e. not everyone agreed that money or time should be spent 'fixing' them);
d. They were vulnerable to multiple external influences, some of which were not under the control of the people charged with 'fixing' them;
e. They had complex interdependencies with other parts of the programme;
f. They produced unanticipated ramifications elsewhere in the system; and
g. They appeared to be exacerbated by the scope and scale of the programmes.

8.1.3. As the examples below illustrate, resolution of these problems proved challenging. This was partly because of the scale and complexity of the programme and partly because key influences were outside the control of key agents. But it was also because these were 'wicked problems' – i.e. they did not have a universal right answer or generic protocol. Rather, they required deliberation and attention to the detail of a particular situation, and they tended to recur in new guises even when a previous iteration of them had apparently been 'fixed'.[125]

8.2. Content and scope

8.2.1. A widespread perception of scope creep emerged early in the programme despite what appeared to be a clear and unambiguous definition in official documents: [1]

"The SCR is designed to provide a summary of clinical information which would be deemed useful in the event of urgent or unscheduled care for a patient, particularly when other sources of information may not be readily available. […] The over arching aim is that the SCR will contain only significant aspects of a person's care, those deemed to deliver benefit to a patient when receiving urgent and unscheduled care."

Summary Care Record Scope Document, page 4[126]

8.2.2. This simple definition masks considerable complexity and ambiguity. Even basic 'level 1' content (medication, allergies and adverse reactions) means different things to different people in different situations. 'Enriched' content (selected clinical details added to the SCR by the GP) and 'level 2' content (summaries from A&E, inpatient, outpatient, and out-of-hours; the Health and Social Care Common Assessment Framework; and patients' contributions via HealthSpace) are open to differences in interpretation and application, and also different options for entering information on different systems in different coding languages.

8.2.3. There was disagreement on the extent to which it was either possible or desirable to standardise the content of the SCR. One reason for this is that 'content' is not synonymous with an unambiguous quantum of data. Rather, candidate 'content' for any electronic record must be selected, interpreted, organised and entered into a particular data field as either code or free text – and that process requires multiple subtle human judgements. Upstream of this, the record must be designed with a particular architecture, coding structure and functionality so as to make writing and reading of particular entries possible. Currently, the SCR is created by uploading data fields from one of a number of different GPSoC systems (Section 5.5). Level 2 content will involve uploading from other systems (e.g. Ascribe Symphony), though usually as documents rather than coded entries.

8.2.4. Some senior staff felt that common technical standards and clinical definitions (desirable) should be carefully distinguished from operational rigidity (undesirable). They perceived CFH as having begun to shift from a 'more rigid' to a 'less rigid' view of the SCR's functionality as the programme matured (or, perhaps, that this shift was linked to internal cultural changes consequent on a change of leadership in CFH):

"Recently many senior people in CFH have 'got it' – or else they got it all along but now feel they have the freedom to say they've got it. 'Ruthless standardisation' was a Richard Granger [previous Director General of CFH] expression. His line was that we can simplify the contracts and make things cheaper by assuming that everything – for example an X-ray, an outpatient appointment – will be the same whatever the context. […] But whilst this may be true of some processes, it's not true of most. […] Take two extremes. In an A&E situation in which junior doctors are on rotation, there's lots of bank nurses and a high turnover, it makes sense to make every hospital in the country follow a common procedure as this will save lives. But when you get into the professor of diabetes' office there's little or no added value, probably no lives saved. Medicine is significant part art. It isn't an accident that people are not all using the same system or processes."

Senior CFH executive, NPfIT, exit interview, date withheld (FX06)

8.2.5. Various groups were set up at national level (e.g. National Clinical Content and Requirements Board, National Clinical Reference Panel) to consider the challenges of capturing illness and clinical work in a meaningful way on electronic records. This linked to wider regulation and performance management initiatives in the NHS (paragraph 2.2.8), the Secondary Uses Service (SUS) for clinical data and parallel work on data standards for shared records undertaken by professional bodies.[127;128] Several groups considered the question of an 'exclusion dataset' – i.e. a list of items (e.g. relating to sexual health) to be automatically excluded from SCR uploads.

8.2.6. The RCGP Health Informatics Group upheld the ideal of a complete, accurate, timely and consistent summary created in a largely automated way from particular data fields. But it also pointed out the following inherent problems with that ideal:

"Any summary is dependent on the record structure, this varies from GP system to GP system:

- *In the current GP clinical systems, summaries are completely different from each other with no shared 'standard' concept of a summary content or structure*
- *The content of the clinical summary depends on the context of the patient, the author and the reader*
- *Therefore patients have a crucial role to play in deciding what constitutes a meaningful medical summary for them"*

RCGP recommendations on GP component of the SCR (page 2)[127]

8.2.7. The RCGP recommendations implicitly recognised three types of data: 'hard' data which were stable and largely independent of context, and for which it was possible – theoretically at least – to provide automated uploads (e.g. medication, allergies and adverse reactions[SSS]); 'soft' data which were unstable and highly context-dependent, and which required active patient input and a manual upload process (e.g. end of life preferences); and 'grey' data which lay between these two extremes and which were best dealt with using a semi-automated upload process with consent from the patient (e.g. significant past and current medical problems). Transfer of free text alongside coded items would help allow data to be interpreted in context, but there were

"….problems with line breaks, line wrapping, different capacities of different information structures to hold text and danger of truncation (and even of excess text turning up in completely unacceptable places), loss of formatting, handling of 'odd' characters like the tilde, different ways of locating text (e.g. in a 'box' as part of a form or as local system coded 'free text entry' with problem linkage to a heading)."

RCGP recommendations on GP component of the SCR (page 3)[127]

8.2.8. The RCGP also recognised the history of interoperability glitches between the different record systems in relation to a long list of seemingly 'hard' data items including laboratory test results and screening recalls. They recommended that these items should not form part of a routine upload to the SCR, but suggested that specific laboratory values (e.g. a haemoglobin value in a patient with anaemia) might be transferred manually along with contextual information.[127]

8.2.9. These SCR-specific recommendations, along with a more recent document focusing on local detailed records drawn up in collaboration with other bodies including patient organisations and CFH,[128] saw the tension between customisation (to both the individual and the local healthcare context) and conformity (to national or even international standards) as a circle that could never be squared.[TTT] In other words, the inability to transfer meaning at the computational level was seen by clinical content panels as inherent to the complex and context-bound nature of clinical data.

8.2.10. However, those who worked one degree removed from clinical content panels seemed to anticipate that the SCR would at some stage be instrumental in 'tidying up' clinical content – and were disappointed when this problem refused to be fixed.

"A rich electronic patient record is much more than just a string of data items. 'Clinical content' consists of concepts with their associated context along with the rules that health professionals use to make sense of it."

Clinical Content Assurance leaflet distributed by CFH at Annual Clinicians Conference, July 2009

[SSS] Even 'hard' data such as these fields proved surprisingly difficult to tame, as evidenced by the fact that an early guidance document limited to these three fields ran to 33 pages.[129]

[TTT] Nor should we expect it to be squared, since this tension is inherent and stems from the uniqueness of individuals and the unpredictable, exception-filled and context-sensitive nature of clinical work. The inherent tension between customisation and standardisation is addressed further in Section 11.3.

8.2.11. The above statement assumes that finite, unambiguous sets of both 'concepts' and 'contexts' can be determined a priori – something that is contested by many computer scientists.[130] It is probably no accident that the idea of a standardised, national minimum dataset was abandoned in favour of 'local enrichment'.

"The minimum data set has gone by the wayside. It was too difficult [at national level], it's now been left to local…we won't come up with a national consensus, not even a local one, but the problem needs to be addressed somewhere."

CFH staff member, National Implementation Board, February 2009

8.2.12. In early 2010, CFH board meetings and communications placed increasing emphasis on forthcoming 'level 2' content in which the SCR would change from being an extract from the patient's GP record to a repository for entries from different provider organisations. Level 2 content was seen as high priority despite continuing difficulties defining and operationalising level 1 content. There seemed to be several reasons for this. First, executive-level staff who made the decision did not appear to be closely versed in the ongoing challenges with uploading level 1 content and assumed these would shortly be 'fixed'. Second, feedback from front line staff had suggested that low usage of the SCR and limited evidence of 'benefits' were partly attributable to limited data available on it.[17] Finally, it was anticipated that GPs who remained resistant to participating in the SCR programme would be more likely to cooperate if the SCR contained material that would augment the records in GP practices.

8.2.13. The 'level 2 content' issue also impacted significantly on questions of information governance. Clinical Leads raised concerns on behalf of front-line clinicians as to whether they would be held responsible for data entered onto the SCR by someone else, and were reassured that they would not be asked to take responsibility for the "errors" of others. But there was no clarity on the detail.

"Unfortunately it is not clear who the data controller is for shared electronic health records. It would seem that the data controller of each participating organisation has a role and the idea of a 'data controller in common' has been proposed, where the data controllers of each participating organisation have a shared responsibility for the total contents of the shared electronic health record. It is not clear how current legislation supports this concept or how it could be organised in practice.

RCGP recommendations on shared electronic records (page 23)[128]

8.2.14. At the time this report was submitted, level 2 uploads to the SCR appeared to have been put on hold in most if not all settings because of the '93C3' problem described below (paragraph 8.5.24). We remain concerned that senior staff who are pushing forward on this issue appear to be making light of the technical, semantic and ethical complexities that are likely to emerge.

"We need to get them [GPs] to understand that the SCR is a vehicle, but once you've got it working you can reshape it".

CFH staff member, Clinical Directorate, December 2009

8.2.15. This executive-level tendency to reify the SCR as a neutral container for unproblematic content that would grow organically by an ill-defined 'enrichment' process contrasts markedly with the attitudes of front-line staff, who saw issues of content, consent, information governance and technical security as interdependent:

"There's a lot of fear as to who's getting access to what records, which is why the majority of people now are tending to set everybody to implied consent and not enrich the records"

Trainer for GP system supplier, February 2010 (FS13)

8.2.16. We do not have a simple answer to the question of whether it will ever be possible to define a value-neutral set of clinical content for the SCR, but our qualitative data include numerous examples raised by clinicians which support our general conclusion that this task becomes increasingly difficult as one moves from high-level principles to the front-line detail of individual cases, if only because of the practical impossibility of second-guessing every potential ambiguity or misinterpretation.

8.3. Data quality

8.3.1. In an earlier report, we identified two dangers associated with low data quality: a direct risk to clinical care from incomplete, inaccurate or misleading data; and an indirect risk when clinicians decide not to use the SCR because they do not trust the quality of the data on it.[2] 'Data quality' in this context is about the *process of entering data*, since poor-quality data on electronic records are often plausible and not easily identified post hoc. We observed that whilst incentive schemes to improve data quality in GP practices were open to gaming (i.e. 'fixing' the data items that counted towards payments), such schemes can also provide impetus for genuine and significant improvements in data quality. Our empirical work showed that key prerequisites for an ongoing, practice-wide effort to improve data quality were the culture of the organisation; clear data quality targets and dedicated resources for working towards these; and a positive relationship with local data quality facilitators.[UUU]

8.3.2. Data quality work for the SCR programme was initially aligned with the IM&T DES (Information Management and Technology Directly Enhanced Service), a national programme of support, training and incentives for GP practices based on the nationally accredited PRIMIS and CHART tools.[95] Funding for the IM&T DES was provided by the Department of Health from April 2007 to March 2009 but despite lobbying from CFH National Clinical Leads it was not renewed thereafter,[VVV] leaving no dedicated funding stream to support SCR-oriented data quality work by practices. Data quality was subsequently flagged as a recurring 'red risk' in SCR Programme Board meetings.

8.3.3. CFH did not have the funds to resource a SCR-specific data quality scheme and also felt (probably rightly) that aligning with existing schemes would be a more effective strategy. Three candidate schemes were considered – Paperlite (a PCT scheme in which practices who met the standard were allowed to shred some components of the paper record, thus freeing up storage space); the QOF (Quality and Outcomes Framework, a financial incentive scheme from the DoH which rewarded particular elements of administrative and clinical performance); and guidance from the Royal College of General Practitioners on "data fit for sharing".[128]

8.3.4. However, none of the alternative data quality schemes was ideally fit for purpose. The Paperlite standard was differently interpreted and applied in different localities, and neither it nor the current QOF directly addressed the particular data items that were being added to the SCR. The Primary Health Care Special Interest Group of the British Computer Society was emphatic that *"It is disingenuous to suggest that Paperlite accreditation as currently applied offers any reassurance as to the fitness of*

[UUU] This last requirement is particularly important because good quality data are the product of good quality processes. Searching for "bad" data and fixing these *post hoc* has limited value because the most dangerous data are plausible (hence not readily spotted in an audit) but incorrect. We explore this issue further in our separate report on data quality.[2]

[VVV] See Section 2.2 for an account of the changing economic context of the NHS. In short, money was tight.

records for sharing or indeed use within a practice."[131] RCGP guidance was not linked to a financial incentive scheme. CFH Clinical Directors sought to negotiate changes to the QOF with the DoH, but since 'QOF points' were in limited supply and known by policymakers to be powerful levers for change, the SCR faced considerable competition from other policy streams. There was also a question of how to ensure practices which had met a national or local data quality standard were maintaining data quality in an ongoing way.

8.3.5. After requests from SHA Programme Leads and Clinical Leads for a "data quality statement on CFH letterhead", CFH produced an Interim Requirements Statement. Some perceived this as little more than a 'holding' statement and others did not feel it was workable so set about producing their own local guidance. At the time of writing, CFH boards and directorates were discussing the finding that many SCRs had been found to contain incomplete or inaccurate data. But an answer to the question of how to assure data quality after the demise of the IM&T DES – a question on which, arguably, the success of the programme depended – was still awaited.[WWW]

8.4. Consent

8.4.1. The complex initial consent model was the single most common issue raised by stakeholders in our Year 1 evaluation (Section 2.5). We recommended that CFH should consider requiring all staff to ask a patient's consent to view their record at the point of care.

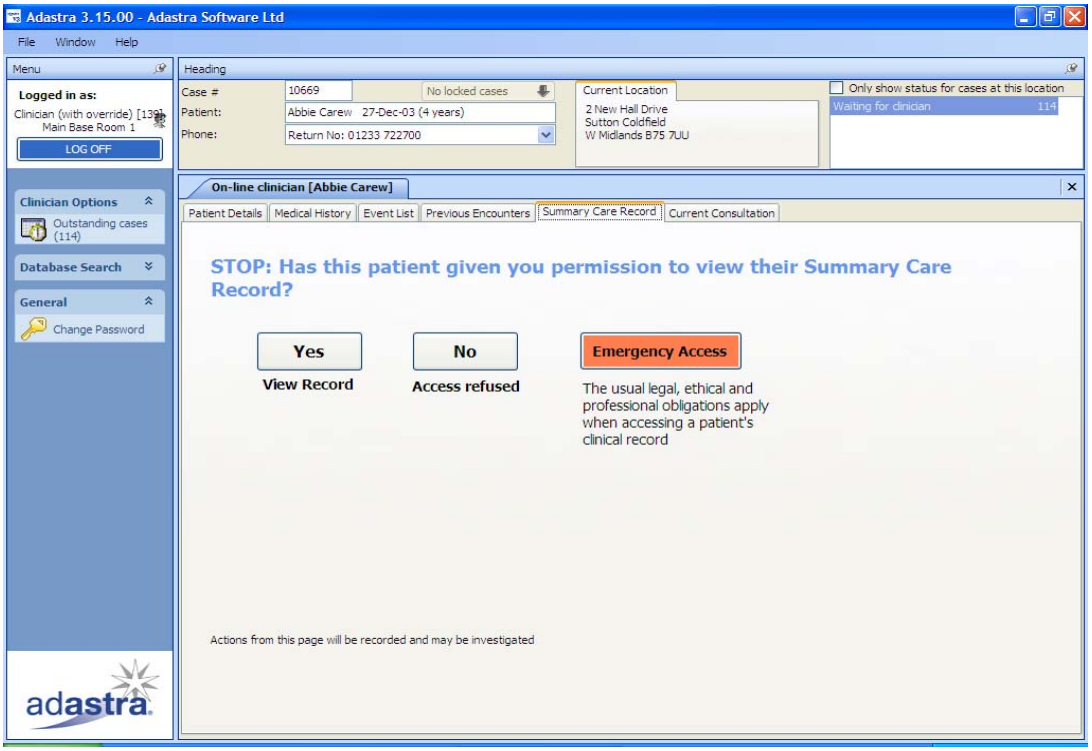


Figure 8.1: The 'permission to view' screen (Adastra version)

8.4.2. The solution proposed by CFH involved both a technical change – the insertion of a preliminary page with the text 'Stop: has this patient given you permission to access

[WWW] At the time of writing the latest guidance could be accessed via this link: http://www.connectingforhealth.nhs.uk/systemsandservices/scr/staff/impguidpm/dq

their SCR?' and three response options: 'yes', 'no' and 'emergency' (Figure 8.1) – as well as a behavioural change (staff would be trained to ask consent at the point of care and encouraged to follow a set of guiding principles[132]) and a technical system for auditing unauthorised accesses (Figure 8.2). In addition, an 'ask me once' option was proposed in which one clinician could document the patient's blanket consent for all future accesses by all staff in the organisation. These changes were seen as 'simplifying' the consent model, mainly because the new model no longer involved the confusing 'store but don't share' option.

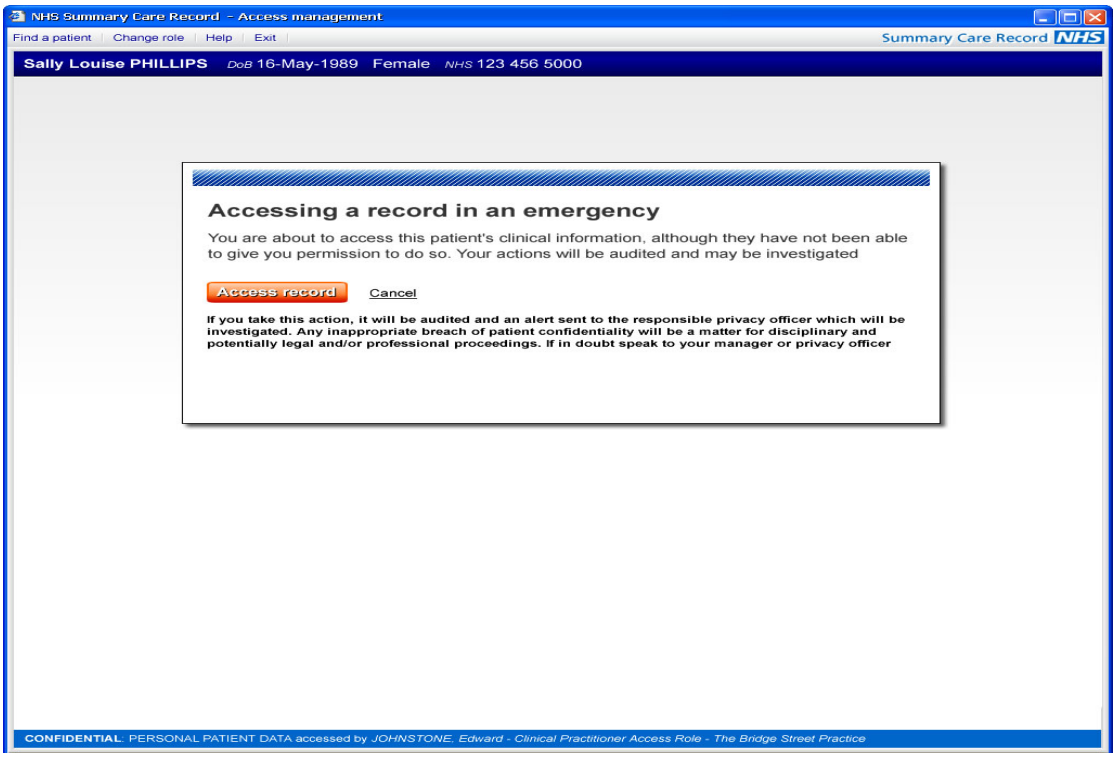


Figure 8.2: The 'emergency access' screen (SCR viewer version)

8.4.3. In practice, however, implementing the change to the consent model proved to be a complex and expensive task, and it was several months before the new model was operational. This was partly because technical changes had to be 'designed in' rather than 'bolted on' to the software and partly because any changes to the software required changes to legal contracts with BT (see Section 5.6). In addition, CFH was treading a delicate path with public and professional opinion (and with the Information Commissioner) and had to be seen to be responding sensitively to minority voices who viewed 'consent to view at point of care' as a significant civil liberties issue and/or as delicate legal ground.

"… we were going forward with a new consent model, looking at ramifications of that, looking at what needed to change technically, working with users to see how things would operate on the ground. I guess the challenge in this environment is always that things are subject to a high degree of scrutiny, when things done on a national scale that brings a different order of magnitude in terms of that scrutiny. The challenge for the SCR programme is having the flexibility to change when change is needed, but without it being a major media event and being seen as a climbdown."

Senior CFH executive, SCR programme, February 2010 (FX15)

8.4.4. In retrospect, it is debatable whether the change to the consent model for the SCR (which the BMA had recommended and civil liberties groups had demanded) required a fundamental change to the SCR technology. Even some senior staff within

CFH were uneasy about the technology-heavy solution developed to what was essentially an issue of human trust. In addition, the highly politicised context in which the SCR consent model changed led to it being uncoupled from the consent model for sharing and viewing the local detailed record.[XXX]

"Once you've started commissioning systems it takes a lot of time and money to push any change through. To be honest I wonder if it [technical change to consent model] was worth the candle. I was all for making it [consent to view] a courtesy thing. In Scotland the clinician says 'May I look at your summary record?' .CFH decided it had to be changed formally in the system. There were perceived constraints between choices about sharing the SCR and choices about sharing the detailed record. Then they said maybe they should make them totally disconnected. The two choices were intermingled, the decision was made to separate them out into two completely discrete choices – one for the SCR and one for the detailed record. Ideally we'd have started with a clean sheet, but the sheet we had had already been scribbled on."

CFH senior staff member (FX07)

8.4.5. Our formative feedback as well as CFH's own monitoring statistics suggested that the introduction of 'consent to view' for the SCR was associated with a significant reduction in accesses by some NHS staff and with the development of workarounds by others (e.g. answering 'yes' to the consent question without actually asking the patient – see paragraph 6.4.16). CFH senior staff found it difficult to comprehend why the new 'simple' consent model set out on their business process maps was meeting operational difficulties at the clinical front line:

"The understanding <u>in this room</u> is that the patient is asked at every point!"

"It's not a detailed conversation, just a simple one 'are you aware' – 'yes, that's fine', they should only have a detailed conversation once."

CFH staff in SCR Programme Board meeting, October 2009

8.4.6. Thus, whilst much work was done to produce normative guidance for NHS staff about how consent should ideally be obtained,[132] CFH had little control over whether or how staff asked consent in practice. This issue proved pivotal at the clinical front line (see paragraphs 6.4.16 and 7.4.3 for empirical examples and Section 10.5 for analysis).

8.4.7. There was no consensus on what kind of consent was needed for addition of the 'enriched' dataset to a patient's SCR (paragraph 2.4.2). Some GPs wrote to ask permission and/or invited patients to make an appointment. Many wrote again to patients to tell them that the content of the SCR had changed (and incurred unanticipated costs).[YYY]

SHA Lead: "Our PIP letter didn't talk about enrichment. GPs are wanting to go down the explicit consent route for now, until they see it's too much work, then they might change their minds. … It means we'll need another letter"

[XXX] As this report went to press changes to the access screen were being negotiated, so as to soften the message to front-line staff. The draft new wording is "Please ask the patient - Can I view your Summary Care Record today". In response to an earlier draft of this report, CFH pointed out that the consent screens on the SCR were modelled on the screens used in the Scottish Emergency Care Summary and were also produced with clinical consultation.

[YYY] In response to an earlier draft of this report, CFH asked us to add this comment: "The first consent model that we tried to put through had GPs consulting patients before allowing significant medical history to be added to the core data set of Medication and allergies. This was always unworkable from a workload perspective and also not ever going to be achievable in secondary care. With the move to express consent before viewing the record in 2008 our advice lessened to implicit consent to enriching records. However many GPs are simply not confident enough to add more information without asking patients specifically. We built software that enabled GPs to go at their own pace – i.e. to switch patients on opportunistically individually. But [the software] also allows practices to move to enrichment against groups of patients if they feel ready. This evolving confidence is alien to PCTs way of working and they prefer a direct protocol that instructs practices to enrich records."

CFH staff member: "That's where Communicator comes in, it only takes a second on email to ask the patient if it's OK"

SHA Programme Leads Forum, December 2009

8.4.8. Unsurprisingly, problems with consent tended to emerge in situations where the patient lacked capacity to consent, as case FN22/#03 (paragraph 6.5.24) illustrates. The question of whether (if at all) a third party might consent or dissent on behalf of the patient had only just begun to be addressed when this report was submitted:

"At today's meeting of the X--- region SCR Steering Group, concern was expressed about possible '3rd party consent' being used to create or access (legitimately) a SCR of a person who is not capable, for whatever reason, of carrying out that action. The concern revolved around the apparent fact that where this may occur there is no note made as to what relationship the 3rd party may have with the patient."

Email sent to evaluation team by patient representative on SCRIE Evaluation Advisory Group, February 2010

8.4.9. The question of consent in those with impaired cognitive capacity was also seen as an important issue by some defence societies, who suggested that their members should consider contacting such patients and taking additional measures to ensure that literature sent in the public information programme was fully understood. This begs the question of how a GP might assess cognitive capacity in a patient they may never have met.

"The general principle being that no patient should be 'surprised' to learn that their confidential records have been shared and someone other than their GP practice may have access to their medical record – albeit that person must seek specific permission before viewing the records."

Representative of doctors' defence society in feedback on draft of this report, March 2010

8.5. Information governance

8.5.1. Personal health data are extremely sensitive. A minority of people viewed the SCR programme as an attempt by government to encroach on the privacy of vulnerable citizens (see our Year 1 report[1] and Section 5.8 of this report). The system had to be secure – and seen to be secure.

"We will take appropriate steps to make sure we hold records about you – both paper and electronic – securely and only make them available to people who have a right to see them. We will keep a record of everyone who accesses the electronic information the NHS Care Records Service holds about you. You will be able to ask for a list of everyone who has accessed records that identify you, and when they did so.[ZZZ] There may be times when someone will need to look at information about you without having been given permission to do so beforehand. This may be justifiable, for example, if you need emergency care. We will tell you if the action cannot be justified. We will take action when someone deliberately accessed records about you without permission or good reason. This can include disciplinary action, ending a contract, firing an employee or bringing criminal charges. We will tell you if this happens."

NHS Care Records Guarantee 2009

[ZZZ] This is not strictly correct, since the automated audits will only indicate, at best, which smart card was inserted in the machine at the time the access was made.

8.5.2. CFH documents depicted information governance in straightforward terms as comprising three elements: system measures such as firewalls, passwords and automated alerts for unauthorised access; organisational measures such as policies, procedures and training; and individual behaviours such as use of smart card and personal password and respect of confidentiality and privacy. From 2009-10, all NHS organisations were expected to undertake an annual information governance review.

8.5.3. This clear commitment to service users and seemingly robust approach to achieving it masked considerable operational challenges which were played out at SHA, PCT and provider organisation level (see Chapter 5) and at the clinical front line (Chapters 6 and 7 and Section 10.5). We found widespread confusion about information governance issues amongst front-line NHS staff and frustration with the message perceived to be coming from CFH that these issues were straightforward and unambiguous. They saw two ironies here: first, that 'simple' information governance procedures tended to be presented in jargon and using complex algorithms (see Box 8.1 below) and second, that the insoluble tension between sharing data and protecting privacy was either not recognised or deliberately glossed over. As one nurse put it, *"I go hot and cold on access – I can see advantages and disadvantages in sharing data"* (FS11).

8.5.4. Information governance was seen as the remit of the NPfIT as a whole. Smart cards and role based access controls, for example, were not peculiar to the SCR programme. However, subtly different approaches were taken to the detail of information governance in different settings (for example, the SCR and local detailed records had different consent models). Furthermore, there was a tension between national and local governance: some issues discussed below were considered impossible to resolve at national level and were delegated to regional or local level, sometimes leading to variation in practice across the country.

8.5.5. Aside from data quality and consent to view (covered in the previous two sections), a non-exhaustive list of wicked problems in information governance included:

a. Role based access controls;
b. Audits and alerts about possible unauthorised access;
c. Deleting SCRs;
d. 'Release 2' content; and
e. People who opted out and then chose to opt back in again.

Role based access controls

8.5.6. In order to access the Spine (hence, the Personal Demographic Service and/or a SCR), a staff member had to log in using a personal smart card in which were inscribed security controls linked to his or her NHS role. There had to be confirmation of a 'legitimate relationship' between clinician and patient. This could be done by an administrator when the patient registered for the encounter ('patient self referral') or by the clinician during the encounter ('clinician self claim').[AAAA] The former approach was preferred, first because the administrator could assign a legitimate relationship for an entire group of clinicians (e.g. all nurses in a walk-in centre) and also because the person confirming the legitimate relationship was not the one viewing the SCR ('separation of roles'), hence an unauthorised access would require collusion

[AAAA] Based on our observations at SHA Programme Leads meetings, these terms were widely misunderstood, perceived as counter-intuitive (perhaps partly because the terms 'referral' and 'claim' had a different meaning here from the ones generally understood in the NHS) and confused with one another (even CFH staff sometimes used the terms 'patient self-claim' and 'clinician self-referral' in presentations).

between a clinician and an administrator. In addition to all this, the patient had to consent to the clinician accessing their SCR.

8.5.7. Role based access controls were typically handled by the local PCT, and involved an administrative officer putting the appropriate roles on a person's smart card before issuing. Also entered on the smart card was an identifying code (NACS – national administrative code service) for the person's place(s) of work. Staff who moved organisations had to return their smart card for change of NACS code. SCR access had to be entered on the smart card as an 'additional activity'. Administering role based access controls was perceived to be labour-intensive and backlogs were common – e.g. if the officer went on holiday or a new cohort of junior doctors started. Locum, short-term and agency staff often lacked functioning smart cards.

8.5.8. Different IT suppliers interpreted national standards and guidance for role based access controls (and other information governance issues) in subtly different ways, hence different software solutions offered different prompts, different instructions and different options on pull-down menus – a problem picked up by CFH in its internal review of barriers to SCR uptake (Section 4.6). Some CFH staff expressed hope that different suppliers would voluntarily align their approach in subsequent upgrades.

Audits and alerts

8.5.9. A key security feature of the SCR was the facility to create an audit trail whenever a patient's SCR was accessed, using a special piece of software called the Enhanced Reporting Service ('ERS'). The Care Records Guarantee gave patients the right to request a report on who had accessed their SCR. Audit trails were also envisaged to be useful in case of complaints or when investigating a particular clinician's behaviour. An 'alert' was generated when the clinician used the emergency access route e.g. when a patient was unable to give consent (see Figure 8.2, paragraph 8.4.2). Alerts were viewable through a Transaction Event Service ('TES') viewer.

8.5.10. The facility inscribed in SCR software to generate a list of all staff who had accessed a particular record or, alternatively, which records had been accessed by a particular staff member was presented in official documents and by CFH staff in positive terms (as a 'security feature' and a manifestation of 'empowerment'). But as the empirical data presented in Chapter 6 illustrate, some NHS staff viewed the SCR's powerful audit trail and alert features in sinister terms as intrusive and personally stressful.[BBBB]

8.5.11. CFH envisaged that all organisations would appoint a privacy officer who would support the work of the Caldicott Guardian by reviewing alerts and seeking explanations from the relevant clinician. In practice, this role was problematic:

a. Not all NHS organisations had a privacy officer and even when they did, these duties tended to be an 'add on' to the person's existing work;
b. In very small organisations (e.g. singlehanded GP practices) there was no individual to take on the privacy officer role;

[BBBB] The link between large-scale IT systems and surveillance of individuals by organisations and the state has been extensively explored in the academic literature. In particular, Michel Foucault introduced the term 'panopticon' to depict the loss of personal and professional privacy and the far-reaching shifts in the nature of power and trust as automated 'audit trails' become a fact of life.[133] He also used the term 'govenmentality' to depict how staff in an organisation may not only accept the idea of the panopticon uncritically but also unconsciously take on and legitimise the 'policing' role implicit in the design of such systems. Other research teams have drawn on Foucault's work to study how networked electronic patient record systems linked to a planned increase in managerial surveillance of clinical practice are sometimes accepted[134] and sometimes vigorously and successfully resisted[135] by front-line staff.

c. If an organisation did not have a privacy officer, alerts would apparently be directed to a privacy officer in a 'central' organisation (e.g. the PCT) who would (according to front-line managers) have limited power to investigate them;
d. In settings which linked to different organisations (e.g. GP out-of-hours clinic serving several PCTs), it was sometimes unclear which privacy officer would receive alerts in particular circumstances (or alerts would be received by the SHA where the privacy officer might have insufficient context to interpret them);
e. Large organisations (e.g. hospital trusts) had many departments but a single privacy officer. The alert did not tell the privacy officer which department the access was made from (it only gave the name of the staff member);
f. In the case of a patient seeking access details for their SCR, the request may need to be sent to the privacy officers in several different organisations;
g. The TES viewer was considered by some privacy officers as counter-intuitive and difficult to use, and some perceived "technical problems" with the alerts, hence this task was unpopular with some.

8.5.12. The gap between CFH's 'model' of the privacy officer role and the reality playing out at the managerial front line led to much frustration.

"Don't worry too much about the detail, it's all a bit abstract." (CFH presenter)

"They think they can just train someone up and say 'you're now a privacy officer', it doesn't work like that. You can't just have a central privacy officer for a local health community, that doesn't make sense." (SHA Programme Lead)

SHA Programme Leads Forum, August 2009

8.5.13. A recurring issue in CFH board meetings was the practicalities of alerts – and in particular that far more alerts were being generated than the system designers had anticipated, leading to a build-up of alert reports in PCT back offices. Reasons for this were multiple and included:

a. Large numbers of alerts were said by some informants to be triggered when staff accessed SCRs to look up the patient's name, address or date of birth on the Spine's Personal Demographic Service (i.e. when staff did not wish to view the clinical data on the SCR but used the SCR application as a 'workaround' to find demographic details);
b. Some staff used the 'emergency' consent option indiscriminately (perhaps as a workaround to avoid the need to ask consent);
c. Clinical work was often collaborative, hence more than one staff member might access the record but not confirm consent in each case (a problem that was sometimes but not always overcome by authorising a group of staff via 'patient self referral' rather than individual staff members via 'clinician self claim');
d. In at least one early adopter site, alerts were sometimes triggered even when a legitimate relationship had been logged because this relationship 'lapsed' immediately (due to a technical glitch) rather than remaining for five days.

8.5.14. One proposed solution was that only a sample (e.g. one in 10 or one in 100) alerts might be investigated by privacy officers. Another solution was for CFH to produce "additional guidance" for PCTs in the form of business process maps (Box 8.1). At the time of writing, the maps listed in Box 8.1 were all in development, and were to be added to maps for 14 other business processes (e.g. see Section 8.7 on children). Whilst we have no particular issue with the steps set out in any of the business process maps, our overall impression was that information governance for the SCR was at risk of becoming bureaucratised in a way that front-line staff saw as unworkable. As CFH staff acknowledged on introducing a further iteration of one set

of maps to the Clinical Leads, *"Here are some more. You're going to lose the will to live."* (Clinical Directorate meeting, July 09).

BOX 8.1: BUSINESS PROCESS MAPS IN DEVELOPMENT BY CFH FOR MANAGING ACCESS AND CONTROL OF SUMMARY CARE RECORDS

Process 12 Accessing a Patient's Summary Care Record
Process 13a Self-Claim Legitimate Relationship
Process 13b Self-Referral Legitimate Relationship
Process 13c Emergency Access Legitimate Relationship
Process 14 Alert Matching Self-Claimed Legitimate Relationships
Protocol 15a Managing Generated Alerts
Protocol 15b Interval Management of Alerts
Protocol 16 Caldicott Management Process
Protocol 17a Patient requested Audit Report
Protocol 17b Caldicott initiated Audit Report
Protocol 18 Staff Audit Report

8.5.15. A further area of confusion was how (if at all) the SCR would ever interface with the Secondary Uses Service (SUS) which used de-identified patient data to produce aggregated statistics for public health reports, commissioning, research and so on. At the time of our evaluation the SCR had no feed into SUS and none was planned (indeed, it was said that the technical design of the SCR made secondary uses impossible). However, some NHS staff interviewed considered that if information governance hurdles could be overcome, the SCR could potentially allow PCTs to generate aggregated clinical data on their populations without going through GP practices – and that if this was not going to be possible, they were much less interested in the SCR as a solution.

Deleting SCRs

8.5.16. A person's right to choose not to have a SCR created from their local NHS record was officially recognised by CFH.[CCCC] Problems arose, however, when a SCR had been created but a person (or their GP) wished all or some of the material on the SCR to be deleted. This could occur when:

a. The person's SCR had originally been created 'in error' (e.g. when their opt-out request had not been actioned);
b. The person changed their mind (e.g. having discarded unread the original letter inviting them to opt out, they subsequently became aware of their choices);
c. The person discovered what they considered to be inaccuracies on their record (or particular items which they wished had not been uploaded);
d. A GP entered information on the wrong patient's local record which was subsequently uploaded onto that person's SCR;
e. A GP practice, having initially joined the programme and uploaded data to create SCRs on its patients, subsequently reconsidered its position and sought to withdraw those records.

8.5.17. If data held on the SCR were agreed to be inaccurate, these could be corrected as part of the routine updating of SCRs from local records. However, if the patient wished a particular entry to be *removed*, this was more problematic. The general

[CCCC] Civil liberties campaigners and concerned professionals considered that this 'right' was paid little more than lip-service by CFH. They felt, for example, that an opt-out form should have been included routinely in the public information programme and a less "threatening" message included in the letter explaining the implications of not having a SCR.

advice from CFH in this situation was that single entries on the SCR could not be deleted, though the patient may exercise their right to remove the entire record.

8.5.18. Once a SCR had been created, it was difficult to wipe it from the Spine. However it was possible for the record to be 'withdrawn', meaning that the data remained on the Spine but were not routinely viewable (i.e. the clinician would see the message "this record is blank" as in case FN04/#42, paragraph 6.8.2). However, this solution did not satisfy civil liberties campaigners, especially in relation to records created 'in error', which they argued should be properly deleted from the Spine.

8.5.19. The SCR displayed the latest summary from the GP record; previous uploads were stored centrally. Corrections to the SCR would only over-write the current version of the summary, not previous stored versions. The implications were complex (Box 8.2).

Box 8.2: Extract from advice document 'Withdrawal of GP Summaries' supplied by CFH to SHA Programme Leads, July 2009

"Actions Following Withdrawal of a GP Summary
If the withdrawn GP summary didn't replace either an initial GP summary or a previous GP summary update when it was sent, then no further action is necessary.

If the withdrawn GP summary replaced an initial GP summary or a previous GP summary update when it was sent, then a new GP summary update needs to be sent for the patient, otherwise the patient will no longer have a visible GP summary in their Summary Care Record.

If the patient is no longer registered at the practice which requested the withdrawal, then the practice will not be able to send a GP summary update. The patient's new practice will need to be informed for the appropriate action to be taken."

8.5.20. Like all NHS records, the SCR had medico-legal status. The Information Commissioner had recently advised that a SCR could be permanently deleted if it could be shown that it had not been accessed and there were no circumstances in which it "should have been accessed". A senior clinician in CFH was designated the final arbiter of whether a SCR could be permanently deleted, though front-line staff interviewed by our team felt that the issue had not been satisfactorily resolved.

'Release 2' content

8.5.21. Release 2 (or level 2) content was material added to the SCR by sources other than the person's GP practice (see paragraph 2.4.3). Whereas consent to upload level 1 content from the GP record had been widely discussed and detailed procedures developed (e.g. the public information programme, opt-out forms and so on), there was no clarity on how consent for adding level 2 content would be sought.

8.5.22. As the examples in Chapter 6 illustrate, level 2 content was likely to be generated in unscheduled care settings and added to the SCR by a person whom the patient did not know and at a time when they were unwell or anxious, hence issues of consent and trust were inherently problematic. Whilst there is already an established system for sending electronic updates from primary care out-of-hours settings to the patient's GP, few NHS organisations require staff to seek explicit consent for this – but Release 2 of the SCR will require such consent.

8.5.23. At the time of this evaluation, a high proportion of the population (around 20% across the country) were registered with GPs whose systems were not SCR-compliant and who would therefore not have a SCR created by their GP. However, once level 2 content is introduced, these patients may have a SCR created in other care settings.

"On the subject of managing patient expectations, X--- PCT have PIP'd [mailed] 100% [of the population] and now we're told we won't have [SCR compliance from] EMIS PCS, although we had to write to them anyway because of Release 2. In that case, where does Release 2 consent come from?"

SHA Lead at Programme Leads Forum, December 2009

Managing opt-outs (and opting back in)

8.5.24. Opt-outs are currently managed at practice level by 'flagging' a patient's local record using a particular Read code ('93C3'). The 93C3 flag on the GP system means that a patient's SCR still exists as an empty file but GP content is not uploaded to it (the 93C3 code effectively means "no data on this patient may leave the practice"). Anyone seeking to view the SCR of such a patient will get an 'opted out' message. In the future, when level 2 content becomes operational, non-GP content could be added to 'empty' SCRs of patients treated in other settings. It was recognised that at this point, the opt-out 'flag' would need to be held on the Spine rather than (or as well as) on the patient's GP record.

8.5.25. Opted-out patients might subsequently change their minds and wish to have a SCR. Opting a patient back in involves a simple manoeuvre (for example, depending on the system, a 'toggle' switch) by an authorised member of staff. If such a switch were done after the opt-out flag had been placed on the Spine, the patient's SCR might come to contain entries from all sources *except* their GP record because the GP had not switched off the 93C3 flag. Because of the way the initial opt-out flag had been designed, the patient would not be able to check the level 2 content on their SCR via HealthSpace.

8.5.26. Various discussions were held about how to "migrate the flag" from the local GP-held record to the Spine. An automated migration would require a substantial amendment to the contract with the supplier (Section 5.6) hence had time and resource implications (and we understand would not be possible until the SCR business case had been approved). A number of interim solutions were considered:

a. Migrate all 93C3 flags manually (seen as a possible option since most GP practices only had a handful of patients who had opted out). However, GPs were considered likely to ask for payment for this work and perhaps not prioritise it;
b. Require all NHS staff to seek consent for uploading any level 2 content to the SCR every time (seen as unworkable);
c. Run a further national public information programme to inform patients of the problem (seen as unaffordable – or at least, financially unjustified);
d. Introduce a new 'business process' which would require patients who sought to change from dissenting to consenting status to write to their GP, and perhaps allowing only restricted groups of staff to action these requests (seen as resource-intensive).

8.5.27. A recurring item in programme meetings was a hypothetical scenario which came to be referred to as the 'flip-flop consent issue'. This issue was differently interpreted by different stakeholders and we did not get consistent accounts of the problem, but we set out our understanding of it here. A clinician claiming a legitimate relationship with the patient might, for either benign or malicious motives, temporarily toggle a patient's SCR to 'consented', view the record, and then toggle back to 'dissented' – all without triggering an access alert.

8.5.28. The potential for a 'flip-flop' scenario had come to light allegedly because an individual from within the medical profession had accessed their own 'opted out' SCR

to highlight the flaw in the system (demonstrating, for example, the absence of an access alert). CFH acknowledged the flaw and took it seriously. However, they were frustrated that the problem had emerged not in the course of NHS business as usual but as an artificial 'test case' by a medically qualified civil liberties campaigner.

"The problem is that if the scenario happens, it would be breaching what we had promised the Information Commissioner […] there's a reputational risk […] statements are true for now, but not for the future."

"It's only true if people are doing things they shouldn't be doing." [DDDD]

CFH executive staff in SCR Programme Board meeting, October 2009

8.5.29. After much discussion, a long-term solution was envisaged to be a technical upgrade to the systems (in which a member of staff 'flip-flopping' a patient's record would be automatically detected), but in the short term a bureaucratic manual fix was proposed:

"It was agreed at the SCR Programme Board that additional RBAC [role based access control] constraints should be put in place so that a change of consent status from dissent to consent would require a patient signature and be completed through a back-office function requiring a separate and tighter RBAC role. Requiring two separate roles to complete the process would make it impossible for one clinician to move the patient from consent to dissent and back to consent again. In addition, a letter could be provided to the patient each time there was a change of consent status." [EEEE]

SCR Programme Board Briefing Paper on 'flip-flop consent', August 2009

8.6. "Technical" problems

8.6.1. The design and development of the SCR technology and the software needed to view it was by no means complete when the national roll-out began. On the contrary, "technical" delays loomed large in the meetings of the SCR Programme Board, the SHA Programme Leads Forum and the Clinical Leads Forum – and were often flagged in red on Gantt charts. The main "technical" (which in reality, of course, were socio-technical) issues underlying delays or perceived delays were the nature of contracts with suppliers, specification, interoperability, 'bugs', security and information governance, and supplier capacity.[FFFF]

8.6.2. The nature of the original contracting process with LSPs (Section 2.3) was perceived to have created a particular legal and cultural context that pervaded all parts of the programme, even those that were not directly linked to the original LSP negotiations. The situation was made more complex by the coexistence of other systems alongside NPfIT products, the fact that local NHS organisations had considerable leeway on whether and when to join the programme and the wide variation in care processes both within and between NHS organisations.

"We are busy making road maps of how the applications roll out, how do they conform to the grand plan or not. Each change at policy level, [we ask] do the contracts actually reflect these, and when will they come through? Then the question on the implementation side, when does a particular trust hop on the roundabout, which options will it choose, will it take the SCR application, will it take Lorenzo, will it

[DDDD] This comment reveals a somewhat naïve assumption that all staff can be expected to behave according to standard operating procedures.
[EEEE] Whether this proposed workaround will be an effective security measure in practice is currently unproven.
[FFFF] A similar set of issues emerged in the HealthSpace programme (Chapter 9). See in particular Section 9.5.

go for TPP….? It's partly the complexity of decision-making in the NHS, the lack of standardisation of care processes, whereas most commercial organisations will produce a much simpler range of widgets."

CFH staff member (FX07)

8.6.3. The GPSoC agreement (Section 5.5) from 2007, reflects a fiercely defended right of GP practices to choose the software system for local records (GPs are not NHS employees but independent contractors and have a culture of being autonomous "small businesses"). Some staff in CFH admitted that they would prefer to deal with one large supplier GP system than with several smaller ones, all of whom had to be treated in subtly different ways. This was partly because of perceived economies of scale and partly because many small suppliers made for a more complex market.

"The thing for me that's been such a big learn is just how incredibly complex the environment is that we're trying to deliver change into. You'd expect there to be some kind of standardisation across the piece."

CFH senior staff member, SCR programme (FX14)

8.6.4. Reasons for "technical" delays in go-live dates for GP practices were often multiple and complex. In addition to software issues (below), practices or PCTs may not have completed necessary technical work prior to upload; practice staff may not have been given relevant smartcard privileges; dates for train-the-trainer sessions may not have been communicated to suppliers (leaving suppliers unaware that a practice was ready to upload) and CFH documents were allegedly sometimes out of date. When several practices declared themselves 'ready' in close succession, some would have to wait because the suppliers did not have the capacity to support parallel go-lives.

8.6.5. CFH and SHA staff sometimes equated delays in the delivery of software solutions with poor supplier performance:

"The suppliers seem to be notoriously poor when it comes to planning. […] We've had and still get lots of examples where they say we deliver this for testing by then, and then dates change, maybe it's a cultural thing. Perhaps from their perspective it's not that critical whether it comes on in January or March…"

CFH staff member, SCR programme (FX14)

8.6.6. CFH staff, who were tied to predefined delivery dates, expressed frustration when these dates slipped and often talked in terms of "managing" or "putting pressure on" suppliers and lamented that getting suppliers to deliver, so often a rate limiting step, was outside CFH's control. Suppliers were depicted by some staff – especially those new to the programme – as disorganised, fickle and un-cooperative.

"We're continuing to push [supplier X] as hard as we can"

CFH staff member, SHA Programme Leads Forum, January 2010 (FF16)

"We've got no control over [supplier Y]" - CFH staff member, SCR programme (FX13)

"[supplier Z] won't play ball" - CFH senior CFH executive (FX15)

8.6.7. An alternative explanation is that CFH and suppliers had different expectations of how definitive delivery dates for new software releases can ever be and how long it takes to develop a robust product in a field as complex as healthcare. In the suppliers' view, the nature of software development did not allow exact predictions of when a product would be ready. They felt frustrated when this inherent uncertainty was interpreted as lack of organisation or commitment by some senior CFH staff.

"*We take a best guess. Because we've deployed a lot of software in the past, we'll base our assumptions on previous roll-outs of a similar nature. And we tend not to*

agree specific dates as such, we'll always try and work towards those days, and we'll always try to meet the dates, but we'll never say 'yes, we'll definitely meet those dates."

GPSoC supplier (FS14)

"*You could actually argue that it took two years for the issues to come out from version 1, so maybe the delay wasn't really a delay."*

GPSoC supplier (FS13)

8.6.8. Suppliers admitted that when put under pressure for an agreed delivery date, they were sometimes tempted to release a product before they were fully confident. The downside of this was that documentation was not always complete or problems occurred that could have been averted given additional development time.

8.6.9. Achieving interoperability with the multiple other systems in the NHS, some but not all of which were old and established ('legacy' systems), was seen by all parties as one of the programme's major challenges. The limited memory and slow running speed of some local systems meant that introducing new functionality sometimes tipped the system beyond its smooth running capacity.

8.6.10. 'Bugs' are inevitable in software, and almost by definition do not come to light until a test version of the product is released and been running for some time.

"It [new release] is never perfect. We know that because we run our own processes for testing products, we run alpha tests on a small number of sites, 4 or 5, we run beta.. 20 or 30, but once you go from 4 or 5 to 20 or 30 you invariably hit problems. And then once you go to [full] roll-out, you hit another set of problems. […] It's only when you've rolled it out to everyone and they've been using it for 2 months, it's then that you can say 'this product works'".

GPSoC supplier (FS02)

8.6.11. Thus, as well as known and predictable incompatibility between the SCR and legacy systems, 'bugs' meant that particular versions of one software package (e.g. a new upgrade) would prove after release to be incompatible with particular versions of another, leading to an *unanticipated* loss of function. The inevitability of such problems was recognised to some extent by CFH in assigning First of Type status to contexts where two software systems interfaced for the first time. Organisations implementing FoT projects were given more resources, allowed more time to implement and expected to help collect lessons to inform refinements (hence there was some competition over who would be selected for a FoT deployment). The FoT approach was a positive move to allow lessons to be learnt. But one uneventful FoT deployment did not mean that all subsequent deployments in subtly different environments would necessarily go smoothly – and if the problems appeared in subsequent practices, resources to address them did not automatically follow.

"it [uploading] is gonna take us as long as it takes – GPSoC supplier (FS02)

8.6.12. In the FoT deployments, there was a general sense of 'all hands on deck' and that suppliers, CFH, the PCT and the practice were all united around a common task (generating lessons to inform further deployments). Front-line managers felt that subsequent deployments were characterised by an assumption that all would go according to plan, and when something did not, each stakeholder tried to 'fix' what they saw as their part of the problem without engaging with the bigger picture:

"….sorting this out is taking forever and a day…it's not only stopping the SCRs but we've got local pressure to get the other CFH products going and this is holding

everything else up. We've got PCT people, [LSP supplier] people, [GPSoC supplier] people all separately looking at the problems, we need one individual to own this."

SHA Lead, SCR Programme Leads Forum, February 2009 (FF07) [GGGG]

8.6.13. One particularly troublesome 'bug' which emerged at deployment stage was known as the 'EMIS 2000 problem'. The EMIS LV SCR solution met unforeseen problems on many machines that were running the Windows 2000 operating system. EMIS had undertaken in-house testing of their SCR solution with the test version of the Spine. Everything appeared to work and CFH's witness testing team approved the product. But problems later emerged at GP practices including the upload in the FoT and subsequent practices even after the 'bug' was thought to have been fixed. The experience led both EMIS and CFH to reflect hard on the testing process.

"*We weren't involved in the decision which sites to use, they were decided by CFH. Now they asked us if there was any reason not to use them, which is fine, but they go to the PCTs and organise at which sites they're gonna do things. […] There is a slight difference in opinion ..,. when you get full roll-out approval, which they would give us at the end of the FoT period, because they deem they've done enough, they've proven the software and therefore they see no reason why it can't now just go out to everybody. We may not have had that approved."*

EMIS informant (source code withheld)

"We had focused very much on the functionality, we hadn't focused enough on the deployment aspects. Whilst we knew there were infrastructure problems that had been identified, EMIS was able to fix them straight away, and what we didn't do was join the dots up and say 'hmm, all these infrastructure problems have been identified, what does that actually mean for national deployment?', and we didn't make that connection, that was a mistake on our part."

Senior CFH executive, exit interview, date withheld (FX14)

8.7. Children

8.7.1. The care of children is inherently ambiguous because of the tension between the rights of the parent and the rights of the child, and in the digital age, this is further compounded by the generic tension between sharing data and protecting privacy. It is reasonable for a parent to have a say in their child's care – but the widely-cited Gillick case established a legal precedent for a child (whatever their age) who was deemed competent to make their own decisions to be treated *without* parental consent and for the medical records of that child to be withheld from the parent.

8.7.2. Some high-profile cases of children who died of murder or neglect had prompted an official report by Lord Laming in March 2009, which exhorted the prompt sharing of data between agencies and sectors.[136] There was active speculation within and beyond the DoH about a proposed 'ContactPoint' database to support this goal.[HHHH] 'At-risk' children may have parents who maliciously seek to restrict sharing of

[GGGG] This quote might equally apply to the Salford integrated records pilot in Section 9.5. Indeed, the preconditions for this kind of deadlock were evident in many parts of the NPfIT, and included multiple stakeholders from multiple different 'worlds' (Section 10.1), the fragmented nature of the NHS along with the prevailing illusion that it is a 'single organisation' (see Section 2.2), the complex technologies involved and the lack of tightly-specified use cases.

[HHHH] ContactPoint holds the name, address, date of birth, GP, school and parental details of all under-18s, and is intended to assist professionals reach children they suspect are at risk. It was introduced in January 2009 and is said to have been plagued by delays, 'bugs', and security breaches during testing.[137] Ironically, it has been suggested that particularly vulnerable children (e.g. those whose parent is fleeing abuse) should be excluded from the database.

information that may incriminate them, so it was seen as important for all staff to question the right of a parent to 'opt their child out' of an electronic database.

8.7.3. Against that background, a number of issues relating to children recurred at board level in CFH and SHAs. First, there was the ongoing need to inform all children who were about to turn 16 of the existence of the SCR and invite them to opt out. One PCT was very active in this area, working with GP practices to develop systems for notifying 'rising 16s' and with schools to encourage regular showing of an information DVD and promote discussion in the relevant year groups. However, this task was resource-intensive and was not undertaken by all PCTs. A much simpler solution had been proposed at national level: SCRs might "automatically" be created on children under 16 (SHA Programme Leads Forum July 2009) – a suggestion which drew protests from civil liberties groups.

8.7.4. Second, a child who turned 16 might decide at that point to opt out of having a SCR. If his or her SCR had ever been accessed, it would have to be retained indefinitely as a medicolegal document (i.e. it could never be permanently deleted). This was viewed by civil liberties groups as highly inappropriate given the designated status of children as a 'vulnerable group' (see paragraph 5.8.7).[109]

8.7.5. Third, there was the question of what to do if a parent sought to opt their child out of having a SCR. It was decided that in such cases, GPs should be required to look up the child's record and decide whether it would be in their best interests to deny this right. Letters sent as part of the public information programme were inconsistent in how they presented the rights of children to opt out (or be opted out by parents).

8.7.6. Fourth, there was the question of the circumstances in which a parent might be denied access to their child's record via HealthSpace. A parent does not have an automatic right to see their child's SCR, and will only be allowed to view it via HealthSpace if special approval is given by the child's GP. At a hypothetical level, child protection would occasionally require a parent to be denied this access, but this would surely be achieved only at the expense of a large grey zone in which state authority might be imposed (and parental rights and responsibilities undermined) on the basis of limited evidence and/or social stereotyping.

8.7.7. CFH produced a series of business process maps (see paragraph 8.5.14) covering the action to be taken when a parent sought to opt a child out, when a child sought to opt out without parental consent, when a parent sought to view their child's SCR and so on. Opt-outs required (among other things) a written request from the parent and a log to be maintained at the practice of all such requests. CFH also placed the following advice on its website:

"A competent child is entitled to agree to an SCR, and an informed decision of this sort should be respected. Where the child lacks competence and a parent wishes to dissent then they should not generally be prevented from using the available controls to safeguard the child's confidentiality, including dissent to the creation of an SCR. However, there may be specific circumstances where a clinician feels that the best interests of the child concerned may justify the creation of an SCR and he/she is not persuaded by the arguments made to support dissent. The individual making the request must be informed of this decision and it should be made clear that dissent to having an SCR is a choice that is provided at the discretion of the NHS and does not constitute a legal right."

CFH 'FAQs for clinicians' accessed 28th February 2010
http://www.connectingforhealth.nhs.uk/systemsandservices/scr/staff/faqs/mpsfaqs

8.7.8. CFH's business process maps and FAQ advice were met with exasperation by front-line staff, who considered them simplistic and unworkable. It later came to light that practices were following official instructions inconsistently. Many had no record of parental opt-outs and some had apparently authorised these without checking the child's record (Clinical Directorate, July 2009). As a result, it was not possible to prepare reliable national-level statistics on numbers of children opted out by parents.

8.7.9. The reduction of this highly complex area to a series of decision algorithms and simplistic, procedural advice arguably failed to acknowledge that 'query child protection' issues in unscheduled care are almost invariably characterised by uncertainty, ambiguity, incomplete or conflicting information, contested entries in the record and strong emotions.[138] Furthermore, despite the FAQ response, national-level policymaking groups had failed to reach agreement on this issue (in particular, the National Clinical Reference Panel had allegedly crossed swords with the National Information Governance Board) and it was acknowledged by some members of these groups that the deadlock reflected major legal and ethical complexities.

"Potentially you might be faced with vulnerable children, which is why you need somebody to do the assessment".

"I'm worried we're creating a system that says 'you can always check who's viewed your record, unless we don't want you to'".

"It would need input from the Caldicott Guardians".

"That would already by covered under 'access to records'".

"You're not covered because you're looking at records from across organisations".

Discussion in Clinical Directorate, December 2009

8.7.10. Despite the numerous unresolved (and arguably unresolvable) questions about how the SCR might be used to record suspicions or hunches about child protection issues, there was considerable board-level interest in offering the SCR as a tool for implementing the recommendations of the Laming report. Whilst it was not clear how it would interface with the proposed cross-sector ContactPoint database, work on the business case for what was envisaged as a possible substantial expansion of the scope of the SCR had already begun by the time this report was submitted.

8.8. Training

8.8.1. Training was recognised as a high priority from the outset. CFH saw it as comprising a number of key packages:[95]

a. SCR Concept Training – to describe the SCR and what it might be used for;
b. Preparing for the SCR – an introductory session intended to be used in the early stages of implementation;
c. GP System Supplier Training – instructor-led sessions to either PCT training team or GP practices, or as seminars co-hosted by CFH and the PCT;
d. SCRa (SCR application, previously known as Clinical Spine Application or CSA) Training – to show staff how to access SCRs via a freestanding viewer;
e. Planning and Reporting Tool (PRT) Training;
f. Information Governance Training – for Caldicott Guardians and privacy officers to ensure appropriate management of audit trails and access alerts; and
g. HealthSpace Registration Training – for staff charged with processing applications from patients for advanced HealthSpace accounts (Chapter 9);

h. Various aspects of Clinical Leads Training – including introduction to the NPfIT and SCR, how to engage fellow clinicians and how to handle the media.

8.8.2. In all the above, explicit learning objectives were set and click-through Powerpoint presentations, self-study packs and/or e-learning packages developed and distributed by CFH's Communications department. Training was delivered by instructors from software suppliers, third-party training organisations or PCT staff, often as part of a 'cascade' (train-the-trainers) model. Some stakeholders expressed disappointment at this approach – i.e. the apparent assumption that once the standard slides had been shown, training pack followed and 'frequently asked questions' gone through, all real-world problems and ambiguities relating to the topic would be solved. Yet whilst official materials provided valuable background and factual details, these were no substitute for hands-on practice in a live system and did not necessarily equip the learners to address the topic in the real world.

"I think they [trainers] found it absolutely astonishing… the job that we do. They were quite shocked really what we're involved in." – District nurse (FN24/~01)

8.8.3. The training-reality gap occurred partly because training topics embraced wicked problems – i.e. ones which were inherent to the complexity of the programme and had no universal answers. As the previous sections in this chapter have illustrated, often the only way to progress such problems was by deliberating on what was the best way forward in a particular local situation. This was apparent, for example, in the district nurse PDA pilot training (Section 7.3), when the nurses felt so unprepared after an official training session on a 'dummy' system that they set up their own ad hoc training sessions in which they accessed their own SCRs and discussed real problems encountered (e.g. inaccuracies due to a previously unidentified 'bug').

8.8.4. A recurring challenge in delivering training was coping with a changing baseline. Training too early or late in relation to a go-live was by definition ineffective, and go-lives were often subject to unpredictable changes (Section 8.6). Many front-line staff – especially junior doctors and nurses – were on short-term contracts or rotations, and some senior managers felt that the resource needed to keep all front-line staff trained in SCR use could be better spent in other ways. PCTs had limited resource for SCR training, and local rules were often developed to allocate this.

"Training support will only be provided out of this project's resources for new locations. Existing GP practices and SCRa deployment sites will need to make their own arrangements for training to cope with further releases of the Spine or GP Practice software upgrades."

From project brief for an early adopter PCT (source code withheld)

8.8.5. As well as the considerable demand on financial resources, training also competed for the scarce resource of staff time, and was sometimes seen as interfering with direct patient care.

[Two clinical staff in a small department] were expressing their frustration to the consultant at yet another IT training course. This time it's 3 half days for Lorenzo training. One had just received an email. "They say, pass this on to your staff. But we <u>are</u> the staff. This is impinging on patient care. We can't just cancel the clinics."

Field notes from ethnography in NHS organisation (FN15)

8.8.6. Policy changes and software upgrades also brought a need for re-training, as the example in Box 8.3 shows.

Box 8.3: Extract from Interim lessons learnt report from early adopter PCT, December 08

Training on how to use the [GPSoC] system in the context of the [revised] consent model and how it is supported by the software was provided by the local Vision trainers. The [GPSoC] trainers were supported by resources from CfH. CfH provided awareness training for the SCR Application through a "train the trainer" approach. This was cascaded to the Sector Training Team who then passed this training, along with other materials, onto the locally deployed sites. The additional materials included system training guides, PowerPoint presentations and a web-based "demonstrator".

Findings: There was a heavy reliance on the local [GPSoC] trainers to provide all system training to GP Practices. There was no training environment to utilise to deliver this training. Instead, this had to be completed using screenshots on a PowerPoint presentation. The PCT took on all the concept training for their own community following some "train the trainer" handover and this worked well, with local people who knew their environment taking the initiative. The training content changed frequently as policy changed, having a knock on effect to staff that had received the training and had to be re-visited to make sure they were up to date. We found that whilst the Sector Trainers provide excellent training for "project delivery" they are, currently, unable to provide training for "business as usual", i.e. to train in the light of changes arising from new releases of software.

Recommendations: There is a need to resolve how business as usual training for newly-released software will be handled so that the Trusts within the SHA can become self-sufficient in this area.

8.8.7. Some informants considered that official training packages for the SCR programme, as with other components of the NPfIT, were pedagogically superficial, consisting of little more than instruction on which button to press or which standard 'frequently asked question' to access for particular topic areas. They felt that not only did training in the fundamental principles of health informatics not occur, but that even senior training advisers within CFH allegedly failed to recognise the need for this:

"I see health informatics as about the preservation of meaning as data are transferred to different parts of the system. But the prevailing view in CFH, especially amongst those who lead on training, is to define health informatics in terms of building competency to use IT."

Technical adviser to large IT supplier (FS12)

8.8.8. The culture of delivering training in discrete topic-based packages focusing on standard processes, procedures and responses was viewed very negatively by some critics. One ex-CFH senior training officer considered this approach to underlie many of what s/he perceived to be the NPfIT's failures (as with all 'exit interviews', the response should be interpreted in the light that people who have left an organisation may have undeclared reasons for feeling negatively about it):

Researcher: "What were the main barriers to you achieving your objectives when you were at CFH?"

Interviewee: "A disappointing marginalisation of trainers and developers generally within the NHS; a tendency to separate ICT training from other aspects of ETD [education, training and development] – even statutory and mandatory ETD; an un-nuanced understanding by managers about how ICT could help them to meet their targets and transform service; a prevalent risk-averse culture which suppresses useful information flowing from less-than-successful practice, a 'not invented here' syndrome that reduced the potential of one Trust or local health community to learn from another on the often spurious grounds of local differences, and finally an overwhelmingly technicist ideology within CFH which marginalised learning (along with cultural change, business process design and change management) in favour of a preoccupation with systems implementation, what has been described as a 'GANTT chart culture,' and heavy-duty (often adversarial) contractual negotiations."

CFH senior staff member, exit interview, date withheld (FX12)

8.8.9. As noted in Section 5.1, we were somewhat surprised that whilst staff in participating SHAs and PCTs enjoyed making informal contact with their opposite numbers at meetings organised by CFH, they had little contact with one another outside these meetings. Many said they would have liked to take materials (e.g. protocols) which other organisations had produced and modify them for local use, and some asked CFH staff to coordinate this. This suggestion was consistently rejected, probably because passing round unstandardised and unapproved local materials ran directly counter to CFH's 'controlled document' culture (see example paragraph 4.3.17). Front-line staff rarely challenged this decision and were probably unaware of the literature demonstrating how valuable such informal exchanges of 'reusable artefacts' can be in the implementation of complex innovations.[82]

8.8.10. In June 2007, soon after commencing this evaluation, we submitted a paper to CFH emphasising the importance of promoting informal, lateral support amongst organisations who were attempting to implement the SCR and HealthSpace programmes.[139] In this, we drew on the research on Quality Improvement Collaboratives[140] and 'soft networks' (closed-membership email fora) in healthcare,[141] and also on a systematic literature review which highlighted the importance of 'soft' knowledge transfer in the diffusion of complex innovations.[82] CFH did set up a knowledge-sharing portal and bulletin board to be accessed by local implementation teams, and they also organised regular meetings for both Clinical Leads and SHA Programme Leads. But in all these initiatives, the focus came to be on the vertical exchange of highly formalised information such as structured checklists, reporting tools and click-through Powerpoint presentations that had been signed off by the Communications department. We reflect further on training issues in Section 11.5.

9. HealthSpace

9.1. Early strategy 2007-2009

9.1.1. The HealthSpace programme underwent multiple changes (strategic, economic and technical) during the period covered by this evaluation. This section should be read with this context in mind.

9.1.2. HealthSpace sat part-within and part-without the NPfIT. On the one hand, because of the strong policy-level link between the NPfIT, patient choice and the quality improvement agenda (see Section 2.2), components of HealthSpace which allowed the patient access to the SCR and Choose and Book were central to the NPfIT and were originally considered to lie *within* its £12.4 billion budget allocation. On the other hand, components of HealthSpace intended to support a person's self-management of their health and illnesses (which broadly approximated to the functions for which a 'basic' HealthSpace account sufficed) were often viewed as lying outside the strategy and budget of the NPfIT and more closely linked to plans for supporting long term condition management outlined in the Next Stage Review.[27] However, the documents to which we had access did not always make the distinction in these terms.

9.1.3. Our early research on HealthSpace (paragraph 9.3.1) found that both patients and NHS staff were disappointed with the limited content of the original release of the technology and wanted more information and greater functionality. Long before our interim report on this was submitted to CFH in late 2008, plans were being put in place by CFH to expand and extend the original HealthSpace programme (hence, they viewed our interim findings as relating to an already-obsolete release).[61]

9.1.4. CFH supplied us with three relevant documents in relation to HealthSpace for this evaluation period:

a. A 41-page Strategic Outline Case for HealthSpace Extension, version 2.4, dated 23rd October 2007;[58] and
b. A 124-page Outline Business Case for HealthSpace Extension, version 1.2, dated 8th October 2008;[142] and
c. A 9-page document containing extracts from a paper submitted to the Delivery Oversight Board in late 2009, which we understand formed the basis of the programme of work that was approved for funding during 2010.

9.1.5. The Strategic Outline Case for HealthSpace Extension referred to four policy and policy-related documents: *Health Reform in England: Update and Next Steps (2005), Better Information, Better Choices, Better Health (2004)*, *Choosing Health*, *(2004)* and *Our Health, Our Care, Our Say (2005).*[5;9-11]

"The need for more information and increasingly easy access to this information to support patients in making their choices will become vital. High-quality information that is accessible and adaptable to individual needs will ensure that choice is meaningful and will assist patients, especially those living with long-term conditions, to manage their own health."

Health Reform in England 2005, cited in Strategic Outline Case for HealthSpace, page 10[11]

9.1.6. It also referred to a 2007 House of Commons Health Committee Report:

"HealthSpace is an excellent addition to the SCR programme and has huge potential to improve the safety and efficiency of care by allowing patients to check

the accuracy of their SCR and to access detailed information about their own health. In order to take fuller advantage of HealthSpace, we recommend that Connecting for Health …trial the use of HealthSpace for patients, particularly those with long-term conditions, to record their own measurements of key health information..."

House of Commons Health Committee Report on the Electronic Patient Record 2007, cited in Strategic Outline Case for HealthSpace Extension, page 10[143]

9.1.7. From the outset, then, an expanded HealthSpace programme was seen as closely aligned with several elements of government health policy (see Section 2.2) including

a. Personalisation of care (by supporting choice, the extended HealthSpace would help shift NHS care beyond the 'one size fits all' approach and allow it to be adapted to individual needs);
b. Self-management of long-term conditions (by entering their own health data onto HealthSpace, and also by accessing their SCR via an Advanced HealthSpace account, patients would be better able to manage their chronic illness, thereby increasing empowerment);
c. Accountability, quality improvement and safety (patient input, supported by high-quality, accessible information, would drive up quality in the NHS – for example, data quality errors in GP-held records would be spotted by patients accessing their SCR via HealthSpace and they would seek to get these corrected); and
d. Efficiency (frequent implicit, though rarely explicit, links were drawn between greater engagement of the patient in his or her own care and reduced need for input by NHS staff – in particular, that a greater degree of self-management would reduce the level of NHS resources needed for managing long-term conditions).

9.1.8. The Darzi Review presented HealthSpace as closely linked to the promotion of health literacy.[IIII]

"Achieving the strong partnership that characterises personalised care is only possible through greater 'health literacy'. Too few people have access to information about their care or their own care record. We will change this. We will expand the educational role of the NHS Choices website. We will introduce HealthSpace online from next year, enabling increasing numbers of patients to securely see and suggest corrections to a summary of their care records, to receive personalised information about staying healthy, and to upload the results of health checks for their clinician(s) to see".

Darzi Review (High Quality Care for All, page 41)[20]

9.1.9. In order to support these high-level goals, it was initially envisaged that HealthSpace Extension would offer six inter-related functions:

a. Information – i.e. data extracted from the patient's medical record such as test results, clinic letters, care pathways, treatment history, as well as details of 'alerts' (the patient would be able to see whether NHS staff has accessed their SCR without authorisation);
b. Making appointments – the facility to book a GP appointment or change a hospital one;
c. Repeat prescriptions – the facility to send a request to their GP to renew their medication;

[IIII] The apparent conflation in the Darzi review of the provision of information websites and self-management tools with the development of the capacity of individuals to use these tools was, in our view, a non-sequitur and is listed in Table 11.2 as one explanation for the fortunes of the programme to date.

d. Stating preferences – the facility to upload a birth plan, living will, 'donor card', and other treatment preferences;
e. Easier NHS access – the facility to email one's GP and gain access to locally held records; and
f. Self care, including linking to assistive technologies and telehealth.

9.1.10. A number of additional functions for HealthSpace Extension were subsequently added in the Outline Business Case:

a. Communicator: a secure email-type function for contacting their GP and other practice staff;
b. Updates (appointment reminders, test prompts); and
c. Privacy and Security (the facility to view an audit trail of attempts to access the record by NHS staff and permit selected third parties access to the HealthSpace account).

9.1.11. Early strategy documents located HealthSpace very specifically in relation to other technologies in the NPfIT. The Strategic Outline Case saw three key components to the NHS vision for more and better information for patients. One was 'Information Services' (general health information and details about the NHS, accessed via the website NHS Choices and an associated phone advice service, including but not limited to NHS Direct). The second was 'Personal Transaction Services' (specific information about the patient's own health) which HealthSpace Extension was envisaged as providing. The third was the Summary Care Record. All these, it was proposed, should have 'seamless' interconnectivity from the patient's perspective.[58]

9.1.12. This triple package (HealthSpace plus NHS Choices plus the SCR, all interconnected) was thus positioned as the solution to a very particular problem: that *"information on a patient's care is often fragmented and maintained in several different systems"* (page 13),[58] and also as necessarily linked to one another.

> *"HealthSpace needs to be developed in a way which enables it to form an element of the portfolio of public online services complementary to the other elements. That portfolio package must provide services to the patient that are personalised, secure and apparently seamless. Without those features, which can only be delivered by all the elements being offered in a joined up manner, the take up of these services will be damaged with the risk of wasted investment. Thus there is a need for a suitable investment in the development of the HealthSpace service to ensure that it provides that key element in the portfolio of on-line services."*
>
> Strategic Outline Case for HealthSpace Extension (page 13)[58]

9.1.13. The Strategic Outline Case considered various eventualities, including the likely uptake of HealthSpace (estimated at "significantly more than 5%" of the over-16 population) and an option appraisal of whether the additional functionality should be introduced incrementally or as a 'big bang' (all at once). The document concluded that there appeared to be significant advantages in providing a series of enhancements over a two-year period (Financial Year 08-09 and 09-10).

9.1.14. The Outline Business Case set out the anticipated benefits of HealthSpace (Box 9.1). It estimated the proportion of the population that would actively use HealthSpace would reach "approximately 10%" of over-16s" (page 13) after five years and explored various options for procurement and implementation of HealthSpace Extension. [JJJJ]

[JJJJ] As set out in the terms of reference for this evaluation (paragraph 3.1.7) it was beyond our brief to comment on the financial aspects of the business case, and furthermore, these aspects were considered by CFH as commercial in confidence.

BOX 9.1: ANTICIPATED BENEFITS OF HEALTHSPACE EXTENSION AS SET OUT IN OUTLINE BUSINESS CASE OCTOBER 2008[142]
Benefits to patients who use HealthSpace: • Better informed about their own conditions • Better able to manage their long term conditions • Better communication on medication management • Simpler access for making appointments • Need to visit the clinician less • Electronic access to clinician advice independent of surgery opening times • Empowered in relation to their own healthcare • Carers of HealthSpace users, including those in nursing care homes, can access the users' HealthSpace records and so are better able to care for them appropriately
Benefits to the NHS: • Improved patient/ clinician communication and interaction • Better use of clinicians' time, enabling clinicians to do more • Information in advance of appointments results in more effective use of consultation time • The time for appointments is not wasted by improved attendance by patients with less DNA's • Reduced pharmacological risks • Better use of primary care resources • A clinician can be confident that relevant information is reaching the patient and that it is delivered in a secure way • A clinician with the patient's authority can access the patient's clinical information via the patient's own HealthSpace account • Patient management is independent of surgery opening times

9.1.15. The Strategic Outline Case for HealthSpace Extension was approved by CFH's Agency Management Board and formally noted by the Department of Health's Capital Investment Board (CIB) in October 2007. However, the Outline Business Case was not approved from the NPfIT budget. This was apparently partly because many of the 'extended' functions were seen to lie outside the scope of the NPfIT and partly because *"they [DoH executives] couldn't justify spending that kind of money in a recession"* (senior CFH executive, HealthSpace programme, FX01).

9.2. Implementation efforts 2008-9 and change of strategy 2009-10

9.2.1. The operational infrastructure for local implementation of HealthSpace overlapped closely with that for the SCR (Section 4.3). Some policy documents and executive letters referred to NHS organisations' duties in relation to "The SCR and HealthSpace". Work at SHA and PCT level on benefits realisation, training, public information programme, information governance and so on was common to both programmes.

9.2.2. Progress on the HealthSpace programme during the period 2008-9 was slower than on the SCR, and by the time this report was submitted many SHAs had not got as far as planning the detail of the implementation.

"I'm a bit mystified, I don't know where that's gone. I think it's a bit stuck. [...] I'd say that philosophically and strategically we [CIOs] get it, but it's happening over the next four or five years, at that point when this new digital strategy gets going, that's when HealthSpace will start to come into play."

SHA Chief Information Officer (FJ24)

9.2.3. A significant issue for PCTs was how to manage registration. A basic account could be created online but there was no online option for registering for an advanced account. Patients had to seek authentication from a PCT front office or their GP. Once this had been signed off, forms were sent to a national back office in Exeter and patients sent a personal security access card (Figure 9.1) – the system would prompt for particular squares on the matrix using a random number generator.

	A	B	C	D	E	F	G	H	I	J
1	T	W	3	M	K	Q	D	A	6	Z
2	4	V	T	T	V	D	2	1	X	C
3	4	M	B	H	O	3	9	J	L	T
4	S	7	K	D	9	I	R	1	B	G
5	J	C	H	K	5	8	F	J	C	B

Figure 9.1: Healthspace security access card

"…they have to do the first part themselves, which is doing the basic [HealthSpace] registration. And that gives them an application number which, to do the advanced registration, they can actually do part of that themselves. But to finish the registration off they need to come in to, like the front office, because we check all their identification documents that they need. I have to sign to say that I've seen the three proofs of ID. One's got to be a photograph, like a passport. One's got to be, to have a proof of address so that can be a photograph, driving licence, or a utility bill, something like that. And then they've got to have a third one, which is definitely like a utility bill that's current; it's got to have been issued in the last 3 months so I have to check all that and check that the face matches the name and that their address is the one that they're registered at the doctor's with, even. So I have to do that. And then they get, when I've okayed it, they sign the form and then I give them – it's like a little credit card but it's got codes on – and when I've sent the paperwork off to the [national] back office, they then write to the patient and confirm that they've now got their advanced registration and send them a code that they work out with this card, and that gives them access to their record then."

Administrator, PCT HealthSpace front office (SR10)

9.2.4. This registration and authentication process was recognised by CFH as cumbersome and complex, and this was felt to account for much of the low uptake of advanced accounts. Another bugbear was that the Exeter back office was perceived as having a low threshold for rejecting applications (e.g. if a wrong date was entered or a line of address mis-spelt). When this happened, back office staff allegedly shredded the

entire application, requiring the patient to start again from scratch (and in some cases, incur a fee from their GP for a second signature).

9.2.5. CFH felt that uptake of HealthSpace depended on introducing online registration and more 'user friendly' functionality. To this end, they set up an online survey to which some 11,000 people (recruited mainly from the NHS Choices website) responded, and just under 6000 complete replies were analysed. In this survey, which is not reported in detail here at CFH's request (because CFH may publish it subsequently), a majority of responders said they would use at least one of the various services offered as options at least monthly, with people with long-term conditions anticipating most frequent use.[KKKK]

9.2.6. We understand that a proposal for a scaled-down version of the HealthSpace programme, [financial data deleted at the request of CFH], was submitted to the Delivery Oversight Board of the DoH in late 2009 and approved for one year's funding from January 2010. The modified HealthSpace programme proposed to:

a. Introduce an online registration and authentication service;
b. Introduce functions in which more than 50% of responders to the survey expressed interest (health updates, test results, appointment booking, recording preferences e.g. diet, accessing SCR and advance directives); and
c. Explore the possibility of parents accessing their child's health record online.

9.2.7. At the time this report was written (March 2010), the HealthSpace team were cautiously celebrating the recent approval of this business case and putting in place an operational machinery to implement it.

9.2.8. The HealthSpace programme was smaller than the SCR programme and had a less complex governance structure. It shared the high-level governance structures (e.g. National Programme Board and Summary Care Record Advisory Group, see Section 4.1) and also initially had a separate HealthSpace Reference Panel with representation from both clinicians and patients. However, this panel was suspended in late 2008 pending approval of the original business case.

9.3. Use and non-use of HealthSpace by patients

9.3.1. In 2008, as part of our Year 1 evaluation, we conducted interviews and multi-media data analysis (audio, video and screen capture) on 21 people who had expressed interest in having a HealthSpace account. Because uptake of HealthSpace in early adopter sites was much lower than originally predicted, we did not complete this work until after our Year 1 report had been published. We submitted an internal report to CFHEP in September 2008 and a final version (following peer review) in December 2008. The main findings of this early evaluation of use of HealthSpace were:

a. Interest in the study was low and it took six months to recruit 21 participants who agreed to try HealthSpace;

[KKKK] This survey raises questions about whether the sampling frame (mostly Internet users who were currently seeking health information online) was representative of the wider population and what significance to attach to the fact that around 40% of people who commenced the survey did not complete it. The accuracy of prospective users' predictions about how and how frequently they 'would' use the technology is also questionable, and it should also be noted that the closed response options did not include the statement 'I would not use HealthSpace for anything'. These limitations notwithstanding, the systematic effort by CFH to capture users' views and feed these into the redesign of a technology that had not proved popular should be acknowledged.

b. All these participants (even two whose job included teaching IT skills) found the HealthSpace website confusing, difficult to navigate, and counter-intuitive. Most tried to abandon their effort to access it before they succeeded in registering. Note that this finding refers to an earlier version of the site which was subsequently improved in response to feedback;

c. All participants were disappointed at the limited content of HealthSpace. Some were shocked and angry to find that no information at all was available on their 'basic' HealthSpace account unless they entered it themselves, and that (at the time of the study) their Summary Care Record would only contain information on medication and allergies. Despite the prior leaflet and explanation from the researcher, most participants were expecting to find much more detail about their medical condition, particularly narrative detail from recent consultations with their GP. Seven of the 21 expected to see their entire GP-held medical record and two expected to see hospital records as well;

d. All were confused by the concept of 'basic' and 'advanced' accounts and the dual registration process. As one expressed it, the term 'basic' implied that certain key information ("*blood pressure readings, height, weight and glucose levels")* would be available, whereas the 'advanced' account would surely contain *"more clinical records and more in-depth information."*

e. Participants failed to see the added value of HealthSpace for managing their (or someone else's) condition. Many offered examples of simpler ways of achieving the same goals (*"write it in a diary"*, *"use an Excel spreadsheet"*). Some also pointed out that the "self-monitoring" of health data involves a complex interaction between patient and health professional; the process of entering and accessing the data cannot be meaningfully separated from the wider care relationship.

"I don't know why you would document it here, because there's no one else looking at it, there's only you looking at it. So I don't understand why you'd want to put your own allergies down because you'd know yourself wouldn't you. …… It's a bit faffy really. …I suppose if I asked a nurse, erm, she would ring me with the blood results ' what was my cholesterol like, what was this' then you could do some of that. You could use your glucose, you could use your cholesterol, you wouldn't know the blood type and your blood pressure. But again it's only recording it, you would need to know why you were recording it, what's good and what's bad, don't you, and then you'd have to get. You could ask your nurse and then put it in your target. 'What's a good level, what's a good cholesterol to have?' and then put it in a target. I don't know whether people would use it".

Person who tried HealthSpace (HS14).

9.3.2. Difficulty recruiting people to demonstrate or talk about their experiences using HealthSpace persisted throughout the evaluation period. This seemed to be because potential participants, despite having opened a HealthSpace account, were not actively using it and reluctant to be quizzed on why this was.[LLLL] Reasons given by non-users of HealthSpace included lack of interest in managing their health in this way, a perception that health information was the realm of health professionals and lack of interest or confidence in using IT.[3]

[LLLL] Whilst recruitment to any research study can be challenging, our difficulties with HealthSpace were unique in over 80 researcher-years' combined experience. In seeking a sample of HealthSpace users, we used numerous approaches including leaving letters and posters in PCT front offices, asking administrators and clinicians to ask verbally and pass on written information about the study, and approaching national patient organisations and local support groups. Our work was bound by the Research Governance Framework for Health and Social Care and our professional codes of conduct which precluded 'cold calling' potential participants or putting any kind of pressure on them to participate.

9.3.3. When we later tried to add to our early sample, many people admitted they were disappointed in the complex access controls and limited functionality of the latest release of HealthSpace but did not want to be interviewed about this as part of a formal research study. One person described the 'sleeping gym membership' phenomenon: registering for HealthSpace, accessing it once, then losing interest. Our study was not designed to quantify this phenomenon. Because of the consistent message from people that they were not interested in using HealthSpace, we shifted our research question to "What approaches to organising personal health data *are* people with chronic conditions using – and if they are not using any, why not?"

9.3.4. The remainder of this section describes ethnographic ('shadowing') studies on a sample of 20 people with diabetes ranging in age from 13 to 69. Some also had cardiovascular disease, kidney disease, thyroid disease, chronic lung disease, arthritis, chronic disability from stroke, or visual impairment. Their educational level varied from school leaver to postgraduate degree; more than half had left school at the minimum school leaving age; two were from minority ethnic groups. None were initially using HealthSpace but three registered for a basic account after we suggested they might like to try it. The ethnographies (which comprised several hours' observation, usually on two or three occasions) revealed limited insights into how HealthSpace was being used but mainly insights into its *non-use* – in particular, how this technology (and planned upgrades) may or may not help with the lived reality of chronic illness.

9.3.5. A striking finding from spending around 150 hours shadowing our 20 people with diabetes was the ongoing *work* needed to manage the condition – which included paying close attention to the timing and nature of meals, undertaking and recording the results of fingerprick blood glucose testing, considering how to adjust medication dosages to take account of food intake and energy expenditure, and organising and attending various healthcare appointments (doctor, nurse, optometrist, podiatrist, education and so on), which often involved trying to negotiate time off work . For some people, these various tasks seemed to dominate and constrain their lives and were felt as a constant burden; others saw them more as an inconvenience. Many had relatives (especially partners or parents) who supported this 'diabetes work' and in some cases the patient was passive while the relative(s) took most of the decisions and actions.

9.3.6. Some participants were already using personalised ways of documenting and monitoring their condition, though these were not necessarily technology-based. Some had special 'DAFNE' diaries which they had been given on an intensive self-management course ('dose adjustment for normal eating'). The DAFNE course covers a challenging syllabus of insulin dosage adjustment depending on blood glucose readings, food intake and exercise levels (as one participant put it, *"the only way you can make adjustment to anything that needs treatment is by looking for the pattern, and you can only do that with a diary" – DE01*). Several participants had attended the local DAFNE course and were committed to intensive monitoring in principle, but none used HealthSpace to support this activity. They told us of a 'DAFNE graduates' website where they could input blood glucose readings and obtain graphs and other visualisations of aggregated results.

9.3.7. Other participants used less structured (and considerably less sophisticated) paper records. These ranged from a standard exercise book (in which readings were typically recorded as free text, one line per reading) to ad hoc entries in personal diaries or written on any available piece of paper. One housebound participant jotted her home blood glucose readings in the margins of magazine articles.

9.3.8. Some people regularly exchanged telephone or text messages with their diabetes specialist nurse. Some phoned or texted their results through on the same day and received advice on adjustments to medication or diet (*"they have an emergency number for worries"* – DE07). One locality had a popular 'Care Call' service whereby an administrator phoned the patient once a month to ask for blood glucose readings and passed these to a nurse who later called the patient back with advice.

9.3.9. Some people appeared to lack the necessary health literacy or IT literacy required to use a technology-based personal health organiser. Others collected data on their illness but did not do anything with these data – either because they felt it was not their place to study the figures or because they appeared to lack the ability, motivation or confidence to *reflect* on the values they obtained. This lack of reflexivity may be a highly significant factor explaining non-use of HealthSpace in some participants:

I ask X if she keeps a log of her blood sugars. She says she only keeps them in the blood sugar monitoring kit and once she's given the figures to Care Call she deletes them from the monitor. Her partner Y says she should put those on the computer. X (looking a bit bewildered) says "I suppose I should". I ask Y why he thinks this. "In all things our assessment of the future is based on the past – whether it's uphill or downhill, you can do something about it before it's too late." He laughs and suggests that X is "a bit resistant".

Field notes from shadowing person with diabetes (DE08)

"What would I do with that information [data entered on HealthSpace] then? It's there for somebody else to analyse but I wouldn't bother with it."

Person with diabetes (DE02)

9.3.10. A number of people used Microsoft Office (Word, Excel, Outlook), which they found very accessible, readily updated and easy to print off.

[showing researcher on own computer] "That's a word document which I use when, if I'm going for a hospital appointment, I find more and more medical appointments these days for diabetes or whatever ask for a list of your current medication you're on. […] So I've found myself got into the habit of whenever I'm going for a health orientated appointment with a professional I'll take, I will print off the list from the word document and take it with me, rather than trying to remember because I'm on quite a lot of stuff."

Person with diabetes (SR11)

9.3.11. When these users were asked whether they would like to try HealthSpace instead, they said no, because it had no advantages over simpler technologies and was less accessible (e.g. required Internet access and password). Indeed, password access was perceived as a major barrier to any technology ("*I've ordered prescriptions over the internet but I keep forgetting my password so now I fax the request*" – DE02).

9.3.12. Some participants had no access to computers or saw them as serving some other purpose in their lives – typically games, shopping, social networking or using 'Skype' to make low-cost telephone calls. Many home computers were low-specification and had limited memory and functionality.

We finally get on to the internet after 15 minutes. It was a free laptop when they took out a contract with AOL broadband.

Field notes on visit to home of person with diabetes (DE08)

9.3.13. Many participants preferred to use personal contact when they needed information:

I ask what she would do if she needed information. She says she would ring the diabetic clinic at the hospital or she would just drop in (she lives round the corner from the hospital) because you're allowed to do this without phoning first. If there is nobody there they'll tell you when to come back.

Field notes from shadowing person with diabetes (DE03)

"I've never had a question that the diabetes nurses can't answer."

Person with diabetes (DE08)

"There's another person in my class who's got diabetes."

Teenager with diabetes when asked where they would get information (DE09)

"If people round here want to know about a hospital they'll ask other people. They won't look at information on the hospital on the internet."

Person with diabetes (DE07)

9.3.14. Some people used (or would have liked to use) software linked to blood glucose testing machines. One participant told us of a previous blood glucose machine which he was able to plug into his personal computer and download several days' readings, which were presented to him graphically (and which he could print out to show the nurse). He had found this extremely valuable. When the machine ceased functioning, he was disappointed that the one his PCT had agreed to fund did not have the functionality to feed data into his PC, and he had to revert to using a paper diary.

9.3.15. HealthSpace self-management software had competition from applications for digital personal organisers (iPhone 'apps'). Some 'apps' were freely available, having been developed by an IT-literate person with diabetes and put into the public domain for altruistic reasons. Other 'apps' were from commercial vendors (usually priced very competitively at around £2) who offered resources such as food values on a branded website. Examples are given in Table 9.1. Whereas there was little enthusiasm for HealthSpace when we introduced the idea, there was much more interest in the iPhone apps and some people were keen to try these, though interestingly, in follow-up visits or phone calls few had actually done so and only one person was using such an application regularly. Participants with iPhones who did not use 'apps' said they would prefer to use a meter which automatically captured blood glucose data rather than requiring manually transfer of readings from glucose meter to iPhone.

TABLE 9.1: EXAMPLES OF iPHONE APPLICATIONS TO SUPPORT DIABETES SELF CARE

Name / url	Functions
Glucose Buddy http://www.oneapponecause.com	Enter and analyse blood glucose data List medication Enter food values and activity values. Generates graphs and emails to health professional or carer
Islet 2.0 http://www.iabetics.com	Enter blood glucose, insulin, food and exercise data. Backdate and email CSV files. Generates graphs with high, average and low values on an hourly, daily, weekly or monthly basis.
Glucose Charter http://glucose-charter.com	Enter and analyse blood glucose data. Website offers food database to assist in dietary choices.
Diamedic Log http://www.martoon.com/diamedic/	Enter and analyse blood glucose and insulin dosage

9.3.16. Some people monitored their condition predominantly or exclusively via bodily perceptions and tended to value knowledge generated from their own symptoms and experience over codified knowledge provided by health professionals. Some individuals tended to assume (perhaps incorrectly) that in the absence of particular alert symptoms, their illness (diabetes, high blood pressure) was well controlled.

I ask about re-using the [insulin] needle. He says the nurse says you should change them each time but he doesn't do that. He says he has been injecting so long he knows when the needle is sharp. He reckons one needle lasts 10 injections. He says other diabetics do this too.

X--- is aware when his blood sugar is going high. He feels physically uncomfortable and "jittery". He can't relax and he feels it affects his taste buds.

Field notes from shadowing person with diabetes (DE01)

9.3.17. The needs of many people with diabetes were not primarily for codified data (e.g. biomarkers such as blood glucose) but for practical knowledge of 'how to live' with their condition, especially what to do in a one-off (e.g. wedding) or emergency (e.g. 'hypo') situation, and for emotional support. They tended to get this from other people with diabetes (e.g. local patient group, Facebook, chat rooms). Box 9.2 shows examples of messages posted on a Facebook site run by a patient organisation.

9.3.18. Many participants in this sample also had relatives with diabetes and shared both information and support.

He talks to his brother quite a bit about diabetes. His brother has not been able to go on a DAFNE course because the PCT in [town] where he lives doesn't provide it. He's sent his brother all the materials from the DAFNE course. The diabetes is a bond with his brother.

Field notes from shadowing person with diabetes (DE06)

9.3.19. Some participants had regular contact with a health professional via ordinary email:

X says he has a good relationship with health care professionals, he emails them with queries. He gave the example of needing information on a forthcoming long-haul flight. He emails BJ, the diabetes nurse specialist at Y--- hospital with travel times and time differences and asks what's the best way of dealing with this. BJ provides a very detailed diabetes schedule for the journey. X says not many people do this.

Field notes from shadowing person with diabetes (DE01)

9.3.20. Participants on insulin (half the sample) took various approaches to the possibility of sudden unconsciousness (from a 'hypo'). Two wore 'Medic-alert' necklaces. One had ensured that staff in his office had had "health and safety" training (by which he meant an ad hoc session in which he had explained what to do if he began to lose consciousness), and parents lobbied for school staff to receive training. Insulin-treated participants complained about lack of availability of 'partner training' locally. Many partners demonstrated a high level of current knowledge about diabetic emergences, particularly the signs displayed by *their* partner and what treatment s/he tended to respond to, and said they had picked this up over the years.

9.3.21. Some participants' lives were constrained by poverty, adverse physical environment (e.g. poor housing), environmental stress (e.g. fear of crime or eviction), family stress or serious disabilities related or unrelated to their condition (e.g. depression, stroke). Monitoring and managing their diabetes competed with these other problems for emotional and material resources and was rarely top of the priority list.

Box 9.2: Postings on a diabetes patient organisation public-access bulletin board (identifying details fictionalised)

Hi
the best way to get out of a low, is sugar and milk. trust me... and also quick question... can anyone tell when there blood levels are high, cus its obvious when there low but my doctor said i couldnt tell when they are high,, but i can :D :D ... can anyone else?????

Hi All,
i was wondering if some one could give me some advice about the pumps. i am 32 and a type one. i have tried everything under the sun to control my levels. i eat well, work out and take good care of myself AND still i cant get control myself. i feel rather alone and scared esp after reading some things online ref...

> Hi i'm in the same position as you,i just cant get my sugars under control (its been an uphill struggle for 22 yrs).I have asked my consultant about a pump for several yrs but she always just ignored me...but finally last aug she said she would consider it !! In nov i was told that i have been accepted, but that there is a 2yr waiting list..so i'm waiting. I've read that it is very hard work at first but the benifits are well worth it. My advise to you would be to first of all speak to your G.P/consultant/D.L.S [Diabetes Liaison Sister] and see what they say. If you meet all the NICE requirements (which it sounds like you do),keep on asking your consultant. Once you have got your consultants backing, your local PCT have to fund it! but in some areas they drag their feet because they dont want to part with the money. If this happens speak to your local MP (that's what I'm doing) and just keep on nagging. try looking at these websites :-www.nice.org.uk/TA151 www.input.me.uk...
>
> Try our online diary - record your glucose levels and the carbs you are eating online so they are all in one place http://diabeticfriend.co.uk/ I found it really useful to understand my levels while I was pregnant. Xxx

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After my last check at hospital clinic they were concerned about my blood preesure as it was a tad on the high side and am already on medication for it. They asked my GP to keep an eye on it. First reading 155/70, 2 weeks later 152/70. I told receptionist that was too high as a person with diabetes should not have a reading that high, not above 130

> Maybe if you brought a blood pressure machine. Take it daily and show your GP the results when you see them again. Personally I dont always rely on the receptionists. Good luck and hope you are settled soon.

I just gave my 4 year old daughter 8 units of novorapid instead of 8 units of lantus can any1 let me know wot 2 do.

> Been there! If you have any milkshake or juice or junky food I'm sure she can manage something.....x
>
> I gave my son 28 units of novorapid by mistake 1 night, it was a very long nite, making sure he was ok, won't make that mistake again

9.3.22. Only one participant mentioned lack of trust in computer held data (in the context of opting out of a supermarket clubcard). As the above examples show, the main reasons for not undertaking self-monitoring were that people were disinterested, too

busy, not capable or confident in using the technology, or considered self monitoring inappropriate. For those who did self-monitor, HealthSpace was not perceived as having any relative advantage over existing paper or technological alternatives, and as having a number of significant disadvantages, particularly low ease of use. As we noted on one participant we revisited:

She has looked at HealthSpace since I first interviewed her but she hasn't done anything with it.

Field notes from shadowing person with diabetes (DE08)

9.3.23. In summary, these findings show that 'self management' is a much more complex, dynamic, and socially embedded activity than original policy documents and technical specifications appear to have assumed. The quote below highlights not just one patient's disappointment with current functionality but also the idealistic expectation that the HealthSpace site was going to provide whatever he wanted to find there.

"[I imagined] it would be like having a briefcase with all your papers contained. So you can pull out - if I wanted to know how to deal with hypos, it would be there. Or carb counting, pull that leaflet out. But at the moment since the inception of HealthSpace I have personally lost credibility in it. It's had a severe impact on my beliefs in the HealthSpace benefits. No promises on HealthSpace have transpired. […] You start making your arrangements elsewhere. I don't go to HealthSpace because I know there is nothing there. The user name and password for the basic and key codes for the advanced and there's nothing there for me, rather than go through that palaver, I just don't go there."

Person with diabetes (DE01)

9.4. The Communicator pilot

9.4.1. This section describes interviews and observations with users of the Communicator function of HealthSpace (see paragraph 2.4.10). Communicator was piloted in three GP practices – two in London and one in Bury. All three lead GPs had a longstanding interest in IT and had worked with their PCTs on IT-supported quality initiatives. At the time of the pilot two were working part-time for CFH. All participating practices were well-equipped with IT and had a history of IT-based innovation.

9.4.2. Fewer patients than anticipated signed up to use Communicator, despite personal invitations, letters, posters and 'what's new' messages on practice websites. Fewer than 100 patients (of a combined list size of around 25,000) expressed interest over a six-month period and were given the paperwork to send off to open an advanced HealthSpace account. It is not known how many actually did so, since the patient's GP is not notified when a person opens an account.

9.4.3. Patients who expressed interest were asked by practice staff if they would be interviewed by our team. We were given 20 names and interviewed 13 patients plus two partners who helped them use the technology (or used it for them). The other 7 changed their minds or were unobtainable.[MMMM] Age of interviewees ranged from 25 to 77 (median 48); 9 were female; three were from non-white minority ethnic groups and two from mainland Europe. To protect confidentiality in this small sample, we have fictionalised clinical conditions and omitted details of age, gender and ethnicity.

[MMMM] We were conscious that recruitment to this study was occurring through enthusiasts for the technology who were in an unequal power relationship with the patient by virtue of being their GP. We made particular effort to emphasise that people should feel under no obligation to participate and that their clinicians would not be told who had withdrawn at this stage.

9.4.4. When we asked GPs and practice managers why recruitment was slower than originally anticipated, most felt it was because people were put off by the relatively complex registration process for advanced HealthSpace accounts (see Section 9.2) or because the practice offered comparable services (e.g. simple email, online appointment booking through GPSoC software). One GP felt that ideally, patients would be recruited opportunistically for Communicator follow-ups where clinically indicated, but this was not currently possible.

"If I could say in the context of a clinic consultation, I will follow you up using Communicator, it would be great. But because it's [registration] such a complex drawn out process, you can't do it like that."

GP Communicator user (CP19)

9.4.5. Bearing in mind the small and atypical sample, patients using Communicator generally felt positively about this technology. They described the registration process as *"pretty straightforward"* and *"easy if you can use email"*, though two had had their applications turned down by the national back office for reasons that were unclear. Many felt that their IT literacy was higher than that of their contemporaries (*"my friends call me clever clogs"* – 69 year old Communicator user[NNNN]), and almost all attributed their relevant skills to IT training received at work. Two carers said that the patient did not have the skills to register or use the technology themselves.

9.4.6. Lead GPs tried to engage their fellow clinicians in using Communicator but enthusiasm was limited. It is part of the functionality of Communicator that the clinician must 'accept' a patient before message exchanges may occur between them, and other staff in the practices rarely completed this step.

9.4.7. Box 9.2 shows the different uses which service users made of Communicator.

BOX 9.2: HOW PATIENTS AND CARERS USED COMMUNICATOR

SOCIO-EMOTIONAL

- Avoiding a difficult, inconvenient or expensive trip to the surgery (e.g. saving on cab fare or carer)
- Maintaining emotional contact with own GP during a severe illness
- Maintaining contact with own GP when frightened to go out of the house
- Conveying distress (easier than seeing the doctor face to face when feeling low)
- Asking for advice, reassurance or instruction for apparently minor problems
- Bypassing a receptionist who is perceived as unsympathetic, obstructive or untrustworthy

CLINICAL

- Sending pictures (e.g. of a rash)
- Informing the GP of a symptom or problem before attending in person
- Informing the GP of a symptom or problem instead of attending in person (especially telling them whether a problem has or has not cleared up)
- Seeking emergency advice or care
- Sending updates on chronic disease biomarkers (e.g. blood glucose levels in diabetes)

ADMINISTRATIVE

- Booking appointments

[NNNN] Whilst we have identified a few 'silver surfers' (older people confident in using the Internet) in the course of this evaluation, our overall impression was that older people were generally less confident or interested in Internet based solutions than younger people, often markedly so. This accords with findings from the National Household Survey (2009) that 64% of the over-65s have never used the Internet.[144]

- Ordering repeat prescriptions
- Asking for (or receiving) test results
- Bypassing a busy or inconvenient reception process

9.4.8. Patients saw Communicator as offering continuity of care with a GP who was popular (hence hard to get an appointment with) and who only worked part-time. For many, emotional continuity with "their" GP was more significant than transfer of particular items of knowledge or advice. Some felt they already had a special relationship with a particular GP, usually because of many years' continuity of care. Thus, whilst the original vision for Communicator saw it as supporting a chronic disease management service in which clinical staff were largely interchangeable, many users were going through an *acute* illness (or an acute exacerbation of their chronic illness) for which they needed temporary 'extra' support from a known and trusted personal doctor.

"My hair started to fall out, and I went out and got a wig. Dr N replied it's a good idea to get a wig. I'm not doing a long rigmarole, and it's not that I've got a problem, I'm just letting her know how things are going. It's nice that she knows about the wig."

Patient CP12, recently diagnosed with cancer

9.4.9. A minority of patients considered Communicator a "safety" measure for use in emergencies (despite having apparently been instructed *not* to use it in this way).

"In an emergency, I would email." [Researcher suggests this is inadvisable as doctor only works two days a week in surgery] "In an emergency it would only work during those two days, but on other days we'd have to use the normal method, ringing up."

Patient CP05, chronic illness[OOOO]

9.4.10. Contrary to expectations that Communicator would 'empower' patients, some appeared to use it as a means of becoming more dependent on their GP, seeking instructions or affirmation when they might otherwise have made their own decision.

"I was quite impressed, I think it's wonderful to be able to type a message to my doctor and he can answer me: 'Do X Y or Z'. I suppose I have blind faith in my doctor. I've never had the inclination into looking up the details of what my medication consists of. […] I ask doctor if it's safe to take with the other medicines"

Patient CP04, chronic illness

"I talked to her [i.e. sent a Communicator message] when I had flu. After she came to see me, prescribed antibiotics, then I let her know that the temperature had gone down. I immediately got a response saying she was pleased that the antibiotics were working and my temperature was down."

Patient CP08, chronic illness and disability

9.4.11. The GPs who led the Communicator pilot appeared unusual in that they actively sought to maintain communication with their patients outside the hours they were contracted to work for their practice. They did not appear to find messages intrusive and often answered them from home or during breaks at their other workplace. In contrast, other GPs who had decided against using Communicator were concerned that messages from patients would be stressful and potentially uncontainable.

"When I was very ill, Dr T [Communicator user] gave me her mobile phone number and told me to call her on her mobile if I was worried, anytime, she said just call me."

Patient CP03, chronic illness, frequent exacerbations

[OOOO] This worrying misconception was reported to the patient's GP under our research governance procedure.

9.4.12. Patients who made most use of Communicator considered that their doctor "didn't mind" receiving messages and would deal with the problem quickly. Others made selective use of the technology, only sending messages they considered "essential".

"It's nice to be able to get in touch with the doctor directly. I can get hold of the doctor quicker than going through receptionist, that's their job isn't it, to protect the doctor."

Patient CP03, chronic illness

"I can communicate with the doctor day or night…he must be wondering why I'm not using it"

Patient CP04, chronic illness, sends 2-3 messages per week, checks account several times daily to see if doctor has replied

9.4.13. In contrast, some patients felt less comfortable using Communicator and were concerned that they might offend the doctor (e.g. by using the wrong form of address) or intrude on the doctor's private time.

"I know myself how emails encroach on your time, my gut reaction is how is the doctor going to cope with this workload? […] To be honest, I fear for the other doctors in the practice if this was foisted on them!"

Partner CP13, would "never" use Communicator

9.4.14. In summary, efforts to introduce Communicator in three GP pilot practices produced examples of patients whose access to their GP, overall care and satisfaction appeared to be significantly enhanced by this technology, but such cases were rare. Even in these highly selected volunteer practices, and especially more widely, questions remain about the acceptability of Communicator to patients and staff and how its use could be aligned with the culture and routines of general practice.

9.5. The Salford Integrated Records patient access pilot

9.5.1. The local shared record initiative in Salford was set up by a consultant diabetologist who had a longstanding interest in shared care, electronic records and patient involvement. The vision was that primary, secondary and community care would all have access to a core dataset about patients with four long term conditions – diabetes, coronary heart disease, chronic kidney disease and stroke (which often occur together) – thus reducing fragmentation of care and inefficient use of resources. Records had been shared for diabetes patients since 2006; those with other long term conditions were added in 2009. The Salford Integrated Record for diabetes was used regularly by the multidisciplinary foot clinic, antenatal clinic, diabetes clinic and emergency teams at the hospital, and by primary and community care teams, each of whom could call up a different customised view of the data held.

9.5.2. Record systems in the different organisations were linked using a 'middleware' solution made by the software supplier Graphnet. Middleware sits between applications that may be working on different operating systems. Being interoperable with both, it allows one 'incompatible' system to read from another (*"We take a feed from the GP's, and we take a feed from the hospital"* – PCT project manager, SR09).

9.5.3. Graphnet is a major IT supplier to the NHS but is not part of the NPfIT. An estimated 18 million electronic patient records are hosted on Graphnet software (see http://www.graphnethealth.com/). Whilst in one sense Graphnet was a competitor to

systems introduced as part of the NPfIT, the company was cautiously positive about a partnership with CFH.

"I'd prefer if we're going to have something like this [patient access to a Graphnet record], I'd prefer it if it was not owned by Microsoft, if it was neutral so to speak, so in principle I'm keen to work with HealthSpace."

Senior executive, Graphnet (SR22)

9.5.4. The Salford shared diabetes record, which used a standard dataset, was popular with both hospital clinicians and GPs. The SIR had been closely designed around the detail of clinical care, in which patient involvement was strongly emphasised:

"We want to use that [patient access to SIR] in conjunction with care planning. That's our idea, and we want to advocate it to people so that…and we don't know how that will work, the idea is that they would get all their tests and sort of, mechanical things done, and then they would look at their results themselves and have a think about what their key issues were [before jointly discussing a care plan]. The way we set up the new version of the record is that the agreed care plan appears on the record"

Hospital consultant (SR15)

9.5.5. The consultant worked actively with the local Diabetes Patients' Forum and initially explored various possibilities for adding a patient view to the system (including an existing interface designed for kidney patients or asking GPs to print out the record on request). These solutions were rejected in favour of HealthSpace, partly because the latter was considered to be a "more strategic" option (i.e. since it appeared to be the emerging official brand for patient access to records). The consultant approached CFH and was initially turned down as this project was not part of the original business case, but CFH later decided this would be a worthwhile pilot which might open new avenues in other projects. Talks began in late 2008.

9.5.6. At a patient 'Have Your Say' event organised by the diabetes service, top priorities for improving services identified by brainstorming groups were: (a) improve access to services (podiatry, dietetics and eye checks); (b) improve the quality of diabetes care by GPs and practice nurses; (c) improve the quality and quantity of information about diabetes; (d) improve signposting of support services such as 'Care Call' (paragraph 9.3.8); (e) ensure that everyone is offered a personal care plan; and (f) ensure that GPs do not 'ration' blood testing strips. Access to their own electronic record was not raised as a specific priority, but some people wanted access to blood test results.

9.5.7. The Diabetes Patients' Forum strongly encouraged their members to sign up for the pilot, and eight registered for an advanced HealthSpace account in anticipation of joining the scheme. But when they tried to log on to the SIR system, all but two of these eight got an error message.

"…after a couple of weeks I got the customary letter, and the card and what have you, and my password and all that was sorted out, I did all that, but like I say, the times I've tried to get on to it, it keeps coming up with the same thing, 'your GP isn't launched yet, your GP isn't taking part in this yet.' is all it says. […]

"I'm questioning that, as to why, via my GP with the GP manager and the surgery manager, she said, 'Oh I don't know nothing about that, I've never heard about it.' - So I said to her, 'Ring X--- at [PCT front office for HealthSpace], and she'll tell you all about it because I want to get involved in it'."

Person with diabetes (SR04)

9.5.8. Despite the error message, this person's GP *was* participating in the pilot. When our researcher interviewed a PCT manager a few days later he checked the system, found it 'working', and suggested that the problem may be with the patient:

"Well there's definitely data in the table for the Y--- surgery, so I don't know why the person can't see that, maybe if they check their password, make sure they've done their permissions correctly…."

PCT project manager (SR09)

9.5.9. Another patient with the same access problem contacted the HealthSpace helpdesk, who attributed the problem to either the GP or to local IT support at the PCT:

"…and they took it all on board and they were very nice and then they said I'll ring you back, which they did, and they said this isn't a HealthSpace problem, this is, it looks like it's a local problem so it's probably, this is what they said, it's probably because either your GP hasn't uploaded his, your records onto the HealthSpace website yet, or it's something to do with the IT people on your local NHS area who are responsible for erm, who are responsible for getting your doctor's records onto the HealthSpace site."

Person with diabetes (SR11)

9.5.10. In the early stages of the pilot, two patients initially managed to log onto the system and access their SIR shared record. They valued the information and liked the design of the site which they found easy to navigate.

"I've found it useful to get my blood glucose results that I do need, when I couldn't get an appointment to see the doctor quickly, erm, because I want, because I work I don't want to be taking time off work just to go for a blood glucose result."

[showing interviewer own SIR record via HealthSpace] "And this is all the information they've got of my medical records. […] Blood pressure, cholesterol, blood glucose levels, eye check, feet check…. [Interviewer: "Does that say it's been done those checks? Does it give you a date?"] "Yeah. And this is about diet, exercise, smoking drinking, all the things you shouldn't do, weight, height. And this is a list of all the medication, when I last had the prescription."

Person with diabetes (SR12)

9.5.11. But information sometimes led to confusion and anxiety, which necessitated an additional appointment, as the following example shows:

"I went to see the practice nurse, and I took the health care records that I showed you last time that I printed off. You had to show her, because I was concerned about certain things on it, and she didn't know anything about it; she'd never heard of HealthSpace, she didn't know what it did, so I was a bit, at a bit of a loss. […] And I just assumed that everybody who worked in the health service knew what it was. […] And I asked her, I showed it to her, and I asked her about the thing that was concerning me which was the chronic kidney disease…"

[Interviewer: "It said stage 3?"]

"Stage 3. And she said, 'Oh, that's way they write it.' apparently there's 5 stages, and as you get older your kidneys deteriorate anyway, and stage 3's not bad because most people are in stage 2 anyway by the time they're my age. And she said it can go back to stage 2 anyway. […] Well, I felt quite relieved, that it wasn't something that was going to kill me within the next 6 months."

Person with diabetes (SR05)

9.5.12. This patient clarified the problem from their own perspective and accepted that the "error" they had perceived in their record was a misunderstanding. The patient felt that whilst the hospital diabetes team (who initiated the scheme) supported patient access, not all primary care staff were equally positive. However, the small numbers in this study do not allow any conclusions about how common such attitudes are.

[Interviewer: "Yes, okay. So what did the [practice] nurse think about it all?"]

"I don't think she was too happy about it, because I don't know how professionals like people being able to access all this information. I don't think they're over keen on it."

[Interviewer: Right. That was your impression?]

"That was my impression. You know, sort of, 'well, why do you want to do that?'"

Person with diabetes (SR05)

9.5.13. After a slow start attributed to difficulties with short-term IT staff, the project continued for a few months, though only two patients accessed their SIR. A server upgrade was planned for mid 2009 to increase capacity prior to widening the scheme. Sadly, a 'bug' appeared in the new server which made the system run slowly from the clinician end and blocked patient access entirely. After tests by a subcontractor to CFH, the bug was attributed to "browser incompatibility" of the upgrade, and CFH decided to turn off the link between HealthSpace and the SIR until this had been fixed.

"We worked with Graphnet and Salford PCT to try and resolve what the issue was. Er we did spend a few weeks trying to get to the bottom of where the issue lay. And then, until mid-July [2009], and Graphnet, they basically acknowledged that further testing wasn't going to achieve anything and that they would need to implement a fix within their system. […] So the work that has been going on since mid-July has been, well basically, waiting for Graphnet to implement this fix. And also waiting for additional test accounts to be created so we could test the performance level of the records."

Staff member, HealthSpace team (SR17)

9.5.14. From the clinicians' perspective, the key problem was how the Graphnet middleware was interfacing with the HealthSpace application. The diabetes centre had contracted Graphnet to create dummy patients on the new SIR system and undertake testing, but that work could not go ahead until the HealthSpace link was turned back on.

"Basically it seems to be a Graphnet/Connecting for Health axis that is required to resolve it."

Hospital consultant (SR20)

9.5.15. However, CFH's link with Graphnet did not involve a direct contract, so little direct dialogue was occurring:

"The relationship is between the PCT and Graphnet, we don't have a relationship with Graphnet as such, in that we don't have any contractual relationship with them. The contractual relationship would be between the PCT and Graphnet."

Staff member, HealthSpace team (SR17)

9.5.16. From Graphnet's perspective, the main problem was the very stringent standards and testing requirements imposed by CFH and the associated costs (which had not been anticipated by all parties when the project was set up). CFH required 'penetration testing' (i.e. systematic testing to see if the system could be hacked into, see paragraph 4.3.18) but considered that the cost of this testing should be borne by the PCT and/or Graphnet. Hence, whilst the problem was articulated in technical terms ("waiting for Graphnet to implement this fix"), the delay was more to do with costs and contracts and a clash of perspective on whether the additional 'testing' was actually necessary.

"As far as we're concerned we've done everything we need to do, and it's back to them. Is it overregulation? Is it overtesting? Probably a bit of both. We've done our bit ages ago and for some reason it's not moving ahead."

Senior executive, Graphnet (SR22)

9.5.17. Different stakeholders in this small but complex project had different views on what exactly was being 'tested'. It was not actually the *components* of the system that needed testing but how the live system functioned in real time. But interestingly, each stakeholder talked in terms of their own component "working fine" and expressed suspicion about components which other parties were responsible for:

"…the pen[etration] testing people came along, and classically communications errors got in the way. The people from [a small private company, subcontracted to CFH] who came to the testing weren't briefed properly and we weren't either. We said to them, we need to understand exactly what you want to do and if you think we should do something more around security. We were expecting them to access HealthSpace and make sure it was secure, see if it was all working. But they assumed they were coming to look at our end, not check their end."

"It seemed reasonable, but they then wanted to test the live system, it's in operation across the patch and we didn't want them jeopardising the whole system as it's up and running. I was happy to let them have access to HealthSpace but then they started up with 'we just want to let this tool run on your network' and we said 'yes well no thank you, it's a live network' and then we thought we didn't realise what they had been told to do was to be targeted towards a live system, and they hadn't realised either. So they went away again."

Staff member, PCT (SR23)

9.5.18. The HealthSpace SIR project had been driven by local clinician and patient enthusiasm. It had a somewhat 'ad hoc' status – for example, it was not managed using the PRINCE 2 tools that were expected methodology for 'official' IT projects within the PCT. Perhaps for this reason, an IT manager at the PCT who had been identified by HealthSpace staff as the central contact for the project locally saw this work as a "side issue" and their own involvement in it as peripheral.

"…because the HealthSpace part from our perspective was never a formal project, if it had been a formal project, part of…, if it had been part of Salford Integrated Records, PID [project initiation document] and business case, that we were formally integrating HealthSpace then...[…] , it's always been kind of like a side thing. […]. I'm only vaguely involved – I just see the emails ... so X like just kept me up to date with what was going on really."

"What's happened is you've got somebody who's very enthusiastic and wants to implement it but then not gone down formal channels and obviously there's a clinician there who's very keen and you can see the benefits of doing it for his patients but then fundamentally it then gets undermined."

PCT IT manager (SR19)

9.5.19. The above quote is particularly ironic given the overall emphasis on 'benefits realisation' within the NPfIT and the early indications that patients with diabetes greatly valued access to their integrated record. In summary, despite enthusiasm from patients, clinicians, the PCT, Graphnet and CFH, and a great deal of work that was undertaken by all parties, challenges relating to information governance and complex commercial relationships are yet to be overcome in this promising project.

9.6. Conclusion

9.6.1. The findings reported in this chapter should be interpreted in the light of the caveat that the version of HealthSpace evaluated had much lower functionality and greater access hurdles than are intended for the next release. Whilst we made considerable efforts to recruit a larger sample of respondents who had registered for HealthSpace

and to identify ways in which this technology was being used to support self management, our sample was small and offered limited direct evidence from HealthSpace users. The nature of the evidence means that conclusions can only be tentative. Indeed, it could be argued that our findings only pertain to the particular version of the technology which we evaluated and that future releases will need a separate evaluation.

9.6.2. We believe that our findings deserve to be taken seriously even when the limitations above are acknowledged – most significantly because we were not evaluating HealthSpace as a technology but as a programme. The empirical data presented here as well as our previous work[3] represent a substantial body of evidence on the widespread current disinterest in a centrally stored personal health record and on the diverse needs and priorities of people with chronic illness.

9.6.3. The method used in this study was developed explicitly to overcome the pro-adoption bias which is ubiquitous in the health services research literature. We have previously shown that researchers tend to restrict their analysis of the adoption of innovations to individuals who have adopted and are willing to give an interview or fill out a questionnaire.[82] The ethnography of 20 people living with diabetes, whilst a small sample, generated rich insights about the diverse approach to 'self management' (and 'non management') amongst people with just one long term condition. Whilst these findings are preliminary, they suggest that a standardised, relatively non-customisable solution for supporting self management may have inherent limitations which are unlikely to be 'fixed' by an upgrade to the software.

10. Analysis

10.1. The socio-technical network in context

10.1.1. In order to analyse this complex case study, we draw on the theoretical framework described in Section 3.4. First, we map, in broad-brush terms, the overall socio-technical network of the programmes[PPPP] and outline the macro (social and institutional) context in which this network was evolving. Next, we consider how macro-level forces influenced the meso level of the structure, culture, resourcing and ways of working of the organisations involved, particularly CFH. We then consider key people (dispositions, perspectives and activities of individuals who were pivotal in the programmes) and technologies (the material properties of, and assumptions built into, the SCR and HealthSpace, and why these were important). Finally, we reflect on how the 'success' of the programmes depended not only on large-scale issues such as policy decisions but also on the situated actions of particular individuals in particular circumstances, and on how these actions fed back on the wider system in both anticipated and unanticipated ways.

10.1.2. The socio-technical network for the SCR and HealthSpace programmes was large, heterogeneous and characterised by complex interdependencies. Whilst all parts of it were influenced to some extent by all others, it is worth teasing out the key configurations for a number of key tasks: design, implementation, governance, front-line use and evaluation.

10.1.3. The design network comprised professional advisers, technical designers (based variously in CFH, commercial IT companies and academic institutions) and technical components from which the record architecture, data models, clinical content and exclusion dataset for the SCR emerged. Individuals and groups in this network struggled with questions of scope (i.e. on what counted as a 'summary' for urgent care – and for other use cases as ideas for these emerged); how such a summary would be coded, organised, presented and updated; the extent to which it could or should be created 'on the fly' for different use cases; how the record should be built; and the interoperability standards via which it would interface with GP systems, the Spine and unscheduled care software. Talk and action in the design network drew on technical language and specialist skills – clinical, computational and often both. As ethnographer Susan Leigh Star has observed, studying the design of large-scale IT systems presents challenges for the qualitative researcher because of an unusual type of 'strangeness':

> *"….the design of networks and their import for various communities, the fierce debates about domain names, exchange protocols, or languages. Theirs is not the usual sort of anthropological strangeness. Rather, it is an embedded strangeness, a second-order one, that of the forgotten, the background, the frozen-in-place."* (page 117)[145]

10.1.4. The implementation network comprised

- Civil servants and policymakers who developed the 'benefits' case for the SCR and HealthSpace, thereby securing substantial central funding and a place for the programmes in NHS policy and the Operating Framework;

[PPPP] The SCR is generally thought of as being linked to the N3 network and local record systems (i.e. the term 'network' means the technical infrastructure of the NHS). The analysis described in this section shifts the emphasis to the *socio-technical* network of the programmes, which includes the SCR and HealthSpace, linked technologies, the people who design and use the technologies, and the people who seek to critique or block their introduction (see Figure 3.1, paragraph 3.4.3).

- National-level managers and clinical negotiators who created financial incentives to support various SCR- and HealthSpace-related workstreams in provider organisations;
- National and local communications staff plus mailhouse contractors who ran the public information programme;
- PCT managers, GP practice staff and supplier support staff who orchestrated 'go-lives' in GP practices;
- Trainers, helpdesk support staff and 'super users' who provided formal and informal training for staff in SCR use;
- People and technologies less closely aligned with SCR-related work – for example, the British Medical Association (national) and Local Medical Committees (local), and strategically placed GPSoC suppliers – whose power to 'resist' implementation of the SCR and HealthSpace was considerable.

10.1.5. The governance network was particularly heterogeneous and complex. It comprised

- Professional bodies concerned with clinical and ethico-legal standards (e.g. Royal College of General Practitioners, Royal College of Nursing, Medical Defence Union, National Patient Safety Agency);
- Legal and quasi-legal bodies with an information governance remit (most notably the National Information Governance Board and the Information Commissioner's Office);
- Regulatory and advisory bodies who set national and international technical security standards (e.g. ISO 27000 series);
- Committees within CFH which oversaw governance and/or selected particular security features, and technical staff who sought to build these into the system;
- Contractors and subcontractors who undertook the different security testing measures;
- Business analysts who developed business process maps for investigating possible security breaches;
- PCT back office staff who processed applications for smart cards and oversaw role based access controls
- Staff at regional and national level who dealt with audit and alert reports escalated from local level;
- Caldicott Guardians, privacy officers and others in NHS organisations who undertook (or found it impossible to undertake) audits of 'unauthorised accesses'.

10.1.6. The front-line use network comprised

- NHS staff who sought to use the SCR in their clinical work;
- Patients whose SCR was being accessed (or not);
- Local and/or web-based software systems through which staff might gain access to the SCR, along with the terminals and smart card readers in front-line clinical settings;
- Local administrators who granted authorisation and call handlers who located patients on the Spine (thus achieving 'separation of roles' for accessing patients on the Spine – see paragraph 6.4.2);
- Patients and carers who attempted to use HealthSpace to help manage their illness;
- NHS staff and systems who enabled individuals to register for a HealthSpace account; and
- Relatives and friends who supported the individual in their efforts to 'self manage' (including accessing their SCR if they chose to do so).

10.1.7. As indicated in Section 3.1, the evaluation network comprised a number of groupings, official and unofficial, who deliberated in a highly contested space on what counted as 'success' in the programmes and how this should be measured:

- DoH policymakers and business planners in CFH, SHAs and PCTs who sought to define and measure the 'benefits' of the technologies;
- The various teams and systems within CFH tasked with monitoring the programme (including capturing ongoing performance data on SCR uploads and use, and analysing these data);
- Official bodies such as the Audit Commission and Public Accounts Committee which considered the extent to which the programmes were delivering value for money;
- The media, lobbyists and publishing machinery which produced narratives or counter-narratives about the system being (allegedly) insecure, illegal, an affront to civil liberties, behind schedule, a 'waste of money' and so on;
- Public-facing staff in CFH, especially the Communications department who produced press releases and information materials about the progress of the programmes, plus senior executives who whose remit included mitigating "reputational risks", and equivalent staff in NHS organisations;
- Patients and service users, whose increased satisfaction with care was an explicit benefit anticipated by policymakers;
- Our own team, contracted to produce an 'independent' evaluation (which should be seen as part of the network rather than objectively set apart from it, not least because many stakeholders made decisions with our evaluation in mind).

10.1.8. During the period covered by this evaluation, this complex socio-technical network was dynamic and unstable. At any time point, there was a particular alignment of people who were developing and implementing the technologies, using them (or not), training and supporting others to use them (or not), and monitoring the security and performance of the system with a greater or lesser degree of success. Sometimes the technologies 'worked' in particular settings, and at other times they did not 'work' – either because particular technical components of the network failed (or had never been put in place), or because people in the network *chose* to behave in particular ways (e.g. because they felt ethically compelled to do so) or were *prevented* (socially or materially, locally or nationally) from behaving as they would have wished to.

10.1.9. In some settings (e.g. some but not all GP out-of-hours centres), there appeared to be an overall trend towards stability of the network (i.e. the SCR appeared to be seamlessly interoperable with local systems and becoming accepted 'business as usual' in these organisations) while other parts (e.g. hospital and ambulance settings, use of HealthSpace and Communicator) were characterised by continuing instability.

10.2. Organisations and their worlds

10.2.1. The attempt to roll the SCR and HealthSpace out nationally spanned five very different 'worlds' – political, clinical, commercial, technical and academic – with different institutional logics, as well as the personal world of the patient.[146;147] Differences in norms, values, priorities and ways of working between these worlds, and imperfect attempts to bridge these differences, accounted for much of the instability in the socio-technical network – and this in turn explained many of the challenges and frictions encountered as the complex collaborative tasks of design, implementation, governance, front-line use and evaluation were pursued. The situation was further complicated by the fact that some of these 'worlds' were

experiencing internal tensions of their own and revisiting long-held traditions and value hierarchies.

10.2.2. The political world of the government and civil service embraced strong neo-liberal norms and values. Health was viewed at least partly in economic terms (rather than, for example, as a human right); the principle of the cradle-to-grave welfare state on which the NHS had been founded (Section 2.2) was being questioned; and public sector organisations were expected to undergo grass-roots restructuring to introduce efficient business processes and strong governance (by which was meant a machinery for auditing how well their expressed goals were being pursued).[34;39] In this world, the SCR programme was an exercise in delivering measurable and worthwhile gains in health outcomes and improving value for money in the NHS. Pressure to identify and demonstrate benefits (preferably 'cash-releasing' ones) from an IT system which was widely reported to have cost several billion pounds of taxpayers' money became progressively more intense as the country entered a period of economic recession.

10.2.3. Neo-liberal ideology did not, of course, go unchallenged in the political world. For one thing, the commitment to providing high-quality healthcare for all, free at the point of delivery, was a near-universal value amongst the British people and one which all political parties were effectively obliged to sign up to. For another, critics of the government saw 'informating' the public sector as more about surveillance and central control than about transparency and free-market choices.[148] The charges of 'creeping privatisation' and 'database state' were powerful political gibes. Policy documents were careful to emphasise accessibility, equity and personalisation of care alongside effectiveness, efficiency and accountability.[20;48]

10.2.4. The clinical world was defined by professional norms and values: high standards of care, autonomy, integrity, honesty, respect for the privacy and dignity of the patient, reflective practice (identifying and addressing ongoing learning needs and consulting colleagues where necessary) and commitment to furthering and defending the profession (be it medical, nursing, pharmacy etc). In this world, the SCR programme was an initiative to improve care standards. Poor records, poor record-keeping and breaches of confidentiality are recurring themes in complaints and malpractice claims against clinical professionals. Conversely, good records (complete, accurate, legible, secure) are widely viewed as a marker of high professional standards and competent care. After the removal of the 24-hour commitment from GP contracts in 2004, unscheduled care settings had a reputation of being one of the last areas of unregulated care in the NHS, in which clinicians with variable levels of training and skill made unmonitored decisions on unfamiliar patients on the basis of limited data.[25] It was hoped that the SCR would serve to support various professionally-led improvement initiatives which would help bring standards of quality and safety in unscheduled settings closer to those achieved in routine 'in hours' care.

10.2.5. The clinical world was experiencing a number of internal conflicts relevant to this analysis (Section 2.2). First, as a result of several high-profile scandals, the clinical professions were shifting from an ethos which emphasised clinical freedom and self-regulation to one which espoused explicit performance standards and an external (or at least, externally auditable) system of regulation.[149] Second, the rise in evidence-based medicine (decision-making based on mathematical estimates of probability and risk derived from large-scale quantitative research studies) fundamentally redefined the nature of clinical practice. Its emphasis on standardisation of care and use of decision support tools meant that clinical work was increasingly framed as an exercise in probabilistic decision science (and, detractors claimed, uncritical protocol-following, overseen by distant authorities who had never met the patient) rather than

as an intuitive art whose essence is humanistic and largely unmeasurable.[150;151 QQQQ] Finally, new technologies along with a shift towards team-based care threatened to render traditional notions of privacy and confidentiality in the clinical relationship obsolete. Since the dawn of medicine, secrets shared with one's doctor have been secure because (and to the extent that) one's doctor could be trusted The advent of distributed electronic records required a significant reframing of confidentiality from 'trust in a particular professional' to 'trust in the system' – the latter embracing both technical security and the trustworthiness and fallibility of large numbers of unknown NHS staff.[152]

10.2.6. In sum, at the time of this evaluation, clinical norms and values represented an active battleground between (on the one hand) traditionalists who defended clinical practice as art, upheld 'old-fashioned' professional virtues and the sanctity of the therapeutic relationship, many of whom were opposed to the SCR programme; and (on the other hand) modernists who defended medicine as [decision] science and sought to introduce greater standardisation, regulation and transparency – many of whom were in favour of the SCR. Importantly, most clinicians aligned with neither pole but struggled to find an acceptable middle ground. Professional organisations to some recognised these inherent tensions in contemporary, technology-supported clinical work and few if any made categorical statements about what their members 'should' do (indeed, one professional body contacted our team to ask for advice and another deferred making a statement about the SCR pending the publication of this report).

10.2.7. The norms and values of the commercial world were those of private-sector business: competitiveness, efficiency, quality workmanship, customer orientation, value for money and return on investment. But again, under this broad umbrella there were tensions, particularly between 'small business' and 'big business' values and business styles. Small businesses tend to favour personal relationships with local customers, responding flexibly to their needs and providing relatively informal after-sales service, often in the context of a small niche market. Big businesses tend to emphasise corporate branding, growth, market share, and formal contracts with large customers. The SCR and HealthSpace were potentially a source of substantial income to both large LSP suppliers and the smaller suppliers to primary care organisations, and they brought the promise of 'preferred provider' status for both software and training contracts. But these programmes were also considered by some to be a significant business risk (Section 2.3).

"They [senior executives] live in a world of contracts and requirements."

Technical adviser working for large ICT supplier (FS12)

10.2.8. The technical world was defined by the norms and values of design ('the science of the artificial'[153]) such as innovativeness, elegance, closeness to specification, functionality and practicality. In this world, the SCR programme was a software development project, for which the key task was bridging the 'model-reality gap' – that is, ensuring that the functionality of the system captured the vagaries of what Crabtree has called the 'workaday world'.[113] Because clinical work, especially in unscheduled settings, is complex, unpredictable, exception-filled and strongly influenced by social as well as medical factors (see paragraph 6.3.11), and because the settings in which such care is delivered are geographically and organisationally fragmented, software that supports unscheduled care in a seamless and integrated way is extremely difficult to design and build.[RRRR]

[QQQQ] The comment of a senior CFH executive "medicine is significant part art" in relation to the challenges of standardising care protocols with the support of electronic records (paragraph 8.2.4) is telling here.

[RRRR] Such design challenges are also highly unusual. In most IT projects, systems are built for routinised 'use cases' and include a relatively narrow repertoire of scripts for the most important exceptions. The notion that *most* cases will be exceptional in some way is something which software designers who lack familiarity with clinical work may have trouble

10.2.9. The approach taken by designers in the SCR programme was based on conventional design assumptions – that technical design is a specialist task, separate and separable from use of the product in practice or the assignment of meaning to the product by users, and that whilst repeated iterations and field testing are required, development is fundamentally a process of 'engineering'. An alternative set of norms and values underpin the 'co-design' approach favoured by interpretivist and critical software designers, who view software development as a process of organic socio-technical growth and negotiation of meaning.[16;155] At the time of this evaluation, the field of software development, like that of clinical practice, was undergoing an internal struggle over fundamental values, as illustrated by the left and right hand sides of the 'agile manifesto':

"We are uncovering better ways of developing software by doing it and helping others do it. Through this work we have come to value:

- ***Individuals and interactions** over processes and tools*
- ***Working software** over comprehensive documentation*
- ***Customer collaboration** over contract negotiation*
- ***Responding to change** over following a plan*

That is, while there is value in the items on the right, we value the items on the left more."

From http://agilemanifesto.org/

10.2.10. The academic world was defined by the norms and values of scholarship: clarity of concepts and research questions, robust empirical methods and critical awareness of the possibility of bias. Researchers in health services research (and those in management and information systems) polarised around a philosophical tension between positivism and interpretivism. Quality in the positivistic tradition is defined in terms of objectivity, use of quantitative (and broadly technical) empirical methods which often involve checklists or standardised metrics, large sample sizes and reproducibility.[156] Quality in the interpretivist tradition is defined in terms of reflexivity, use of strong theory with flexible (often qualitative) methods, consideration of multiple interpretations, and the 'hermeneutic circle' in which observations about parts of the system are continually and iteratively related to an emerging understanding of the system as a whole.[157;158] Our own position, at least in relation to this particular evaluation, was strongly interpretivist, as the footnote linked to paragraph 6.7.2 makes clear.[SSSS]

10.2.11. The personal world of the patient corresponds to what Jurgen Habermas has called the lifeworld – the informal world of family and community, governed by the practical rationality of shared cultural understandings and practices.[159] Habermas contrasted this with the world of the system – the formal world of industry, economy and state which is governed by the technical rationality of rules and procedures. He suggested that there is a tendency for modern institutions to *colonise* the lifeworld by replacing practical rationality with a logic that is formalised, instrumental and non-negotiable. Much has been written about the tendency of the 'voice of medicine' to colonise the 'voice of the lifeworld', and patient centred clinical care is alert to this danger.[160] Thus, as well as the direct and tangible risks of incomplete and inaccurate data, the SCR also brings a more abstract risk – an risk of colonisation of the lifeworld by such

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understanding. But as clinician and academic (and, latterly, IT consultant) Marc Berg has shown, healthcare work is irrevocably personalised, exception-filled and context-bound, and because of this *"the nature of health care work sets natural limits to the possibilities of IT to revolutionize this work."*[154]

[SSSS] Our philosophical position as evaluators will be addressed more fully in a forthcoming academic paper. See also Chapter 12 (Epilogue).

things as consent procedure, access controls and the complex system of surveillance now needed to assure 'privacy'.

10.2.12. CFH's world was political in the sense that its activities were – arguably – a paradigm example of the new public management (paragraph 2.2.8) in action.[161] A strategic case and then a business case were generated in standard Department of Health format: highly structured, formalised and presenting arguments which rested on the anticipated return on investment in terms of cash-releasing and non cash-releasing benefits, the systematic and largely quantitative assessment of options for achieving these, the robustness of governance structures, the soundness of business processes and the exhaustive identification and mitigation of potential risks.

10.2.13. CFH's world was also to some extent commercial. For one thing, its raison d'être was to buy IT solutions from commercial suppliers and support their deployment in the NHS. CFH's relationship with software suppliers was mediated through legal contracts (either directly or via subcontracts with the LSPs), and internal CFH documents relating to the programmes were typically labelled 'commercial in confidence'. Many of CFH's staff, from junior managers to the Director General, had a background in the commercial IT sector and/or management consultancy rather than in the NHS – and many brought a piece of this culture with them (as evidenced by somewhat disparaging remarks made by NHS staff about 'pin striped suits').

10.2.14. At the time of this study, CFH appeared to be generously resourced and to have considerable 'organisational slack' in terms of staff, time, space, and funding that could be diverted relatively quickly into new workstreams as these emerged. 'Organisational slack' in this context is a term used by management academics to refer to financial, human or other resources that can be channelled into new projects without compromising existing ones.[82] The availability of organisational slack has been shown to be a critical success factor for complex innovation projects.[82]

10.2.15. NHS provider organisations operated largely in the clinical world, though GP practices, as small businesses who were contractors rather than employees of the NHS, also showed characteristics of the commercial world (e.g. they often sought to negotiate a fee for SCR- and HealthSpace-related tasks). Apart from the very evident presence of patients and the material infrastructure of clinical work, most norms, values, systems, protocols, procedures, standards and allocation of time and resources were all oriented first and foremost to delivery of patient care. Save for designated business managers, staff in these organisations considered form-filling, business planning, purchasing IT systems and being trained to use these systems as something tangential to and even competing with their core business (see paragraph 8.8.5), though *using* IT systems was viewed by most as an integral part of clinical care. As one clinician put it when commenting on the PRINCE 2 approach, *"The problem is the mindless effect this management style has on everybody, they can't think straight when told to do things in this way"* (FM04). But as indicated above, even within the clinical world there were no easy answers to the question of whether or how to participate in sharing patient data in large distributed record systems.

10.2.16. NHS organisations had very limited organisational slack. Indeed, some parts of the service (notably GP practices, hospital A&E departments, hospital pharmacies and the ambulance service) appeared to be suffering from what one sociologist has called a 'time famine' – where the amount of work substantially exceeds the time available such that stressful compromises are continually required.[162] In the latter part of the evaluation period these organisations came up against a shrinking budget in real terms. The SCR and HealthSpace programmes, with their promise of 'better, safer, more efficient' care at some stage in the future, faced stiff competition from the here-and-now demands of sick patients in the waiting room.

10.2.17. Commercial software companies bridged the technical and commercial worlds, seeking to achieve high-quality designs for a limited outlay of time and resource. They were strongly customer-oriented and sought to provide them with 'must-have' and 'nice-to-have' functionality, but as Sections 5.5 and 5.6 showed, different customer groups viewed the value and priority of the SCR very differently and the GPSoC suppliers in particular had a business model that did not align unproblematically with the SCR. The 'big business' suppliers appeared to have a business-oriented relationship with CFH and their NHS customers, mediated through formal design specifications set out in legal contracts (and, for refinements, official variations to contract). In contrast, some 'small business' suppliers had been started by front-line GPs with an interest in IT and had a tradition of 'co-creation' of software solutions with sentinel provider practices or clinical user groups. To some extent, these smaller companies had one foot in the clinical world.

10.3. People and what influenced them

10.3.1. Implementing the programmes depended on people – both at national level and at the clinical and managerial front line. The people in this programme brought different beliefs, values and motives to their work ('normative' influences), and their actions were also shaped and constrained by such things as job descriptions, access privileges and the functionality and limitations of technologies ('causal' influences). But the story was more complex than one based on crude cultural stereotypes or formal organisational roles. For one thing, the commonalities across the different stakeholders – and in particular their shared vision for the SCR – were as important as the differences between them. For another, most individuals occupied more than one 'world' and held multiple (and sometimes conflicting) values.

10.3.2. The people who proved most pivotal in the programmes were those who not only held 'boundary roles' (working between different organisations) but who also managed to align – to some extent at least – the complex and competing institutional logics which characterised the programme. An implicit requirement of boundary roles was the ability to speak the different 'languages' of the political, clinical, commercial and technical worlds and to have credibility and voice in more than one stakeholder organisation. A prominent finding in our data was the large amount of *work* involved in the SCR and HealthSpace programmes, the difficulty and complexity of this work, and its critical dependence on the qualities and capacity of individuals in boundary roles. Some staff appointed to boundary roles struggled to deliver the complex input required of them. But many engaged actively in what Latour and his colleagues have called 'translation', which involves four stages:[163]

a. Problem construction: defining a problem for which the SCR and/or HealthSpace offered a solution;
b. Selling the idea: getting others to accept this problem-solution link;
c. Enrolment: defining key roles and practices in the socio-technical network; and
d. Mobilisation: engaging others in fulfilling the roles, undertaking the practices and linking with others in the network.

10.3.3. The most senior boundary roles were the National Clinical Directors (paragraph 4.3.9a). Their translation efforts were evident, for example, in the following:

a. Contributing to national groups writing policy and strategy, including the Ministerial Task Force,[33] the NHS Informatics Review,[48] and the Darzi Review;[20]

and seeking to influence policies which had not initially included the SCR or HealthSpace but for which these might be seen as an aid to implementation (e.g. Laming Report on Child Protection,[136] End of Life Care Strategy;[104]
b. Collaborating with professional bodies and patient organisations to produce joint statements of principles and guidelines on shared records;[128]
c. Ensuring that key issues were tabled, discussed and signed off at board-level meetings within CFH and the SHAs, and followed through at Clinical Leads and SHA Programme Leads forums;
d. Organising clinical engagement events, including securing local opinion leaders to speak and finding a budget to reimburse attenders;
e. Publishing in clinical journals[164-166] and healthcare management journals[167] and distributing these articles as the 'evidence base' to different target audiences;
f. Working with CFH Communications department to produce 'proof of concept' resources, press releases, ministerial briefings and other materials; and
g. Attempting to mobilise funds from a variety of sources for SCR- and HealthSpace-related work (data quality, regional public information programme).

10.3.4. CFH's National Implementation Managers held another key boundary role. Successful NIMs spoke (or rapidly learnt) the language of cash-limited SHAs and PCTs and that of clinically-oriented, time-starved provider organisations. Their input to the programme was as much about building a bridge between these worlds and that of CFH as it was about handing out business process maps or escalating unresolved problems to the centre.

10.3.5. Local Clinical Leads occupied the clinical world. Almost all had a foot in the technical world (i.e. they were keenly interested in IT) but few moved in the political or commercial worlds. In contrast to the National Clinical Directors who often held (or had previously held) roles in medical or nursing politics and/or on the boards of software companies, few Local Clinical Leads held such positions either locally or nationally. Furthermore, whilst all the National Clinical Directors were seasoned senior clinicians and appeared to hold 'expert opinion leader' status amongst their clinical colleagues, many Local Clinical Leads were non-principals in general practice. Their experience was largely restricted to general practice, so they had limited understanding of other settings and limited time to get to know these settings. Given this background, it is perhaps unsurprising that whilst some Clinical Leads mobilised considerable local support for the SCR, others had less success.

10.3.6. The ability to work across different worlds came more easily to some than others, but even the most insular CFH staff responded to repeated exposure to the reality of the various other 'worlds'. In the early stages of the national roll-out, for example, CFH's response when NHS staff aired their frustrations about wicked problems at the front line was to send the 'tools' back to the national office and request more and better business process maps, spreadsheets, checklists and so on. But a more mature and responsive relationship gradually developed between CFH staff and front-line implementation staff, born of a developing understanding of one another's 'worlds'. Similarly, relationships between CFH staff and GP system suppliers have matured. At the outset, the expectation of CFH had been for tightly-specified solutions by non-negotiable delivery dates. By late 2009, many CFH staff had begun to recognise and accept that software development for complex specifications by small companies with limited slack is characterised by inherent unpredictability and that it was in CFH's interests to insert some flexibility into the timetable. However, towards the end of the evaluation period it was our interpretation that with a forthcoming general election there was increased pressure to demonstrate benefits within a tight time period, and some of this newly-acquired flexibility was put on hold.

10.3.7. SCR implementation depended on NHS staff: those in GP practices whose cooperation was needed to upload patients' data to create SCRs and those in unscheduled care organisations from whom front-line use was needed. The ethnographic descriptions in Chapters 6 to 9 illustrate how relatively small differences in normative and causal influences on individuals (see paragraph 10.3.1) explained wide variations in outcomes (e.g. whether a GP practice signed up to the SCR programme or whether an organisation that had achieved 'hard [technical] go-live' went on to achieve the more challenging 'soft [human] go-live'). We analyse three such examples in more detail in Section 10.5.

10.3.8. The largest group of people on whom implementation of the SCR and HealthSpace programmes depended were NHS patients. Given the potential noted above for these technologies and the procedures associated with their use to increase the 'colonisation' of the (informal) lifeworld by the (formal) system, it might be concluded that patients and citizens have much to lose (as well as, potentially, much to gain) from this technology and that many would have strong views for or against. In fact, our data show that whilst a minority felt strongly about these technologies, most were disinterested or unengaged.[3] Because of the implied consent model, 'unengaged' patients lent passive support to SCR implementation because public opt-out rates were low (hence 'hit rate' potentially high). But with HealthSpace, which required active input to register, 'unengaged' patients could effectively bring the programme to a standstill.

10.4. Technologies and what was inscribed in them

10.4.1. The SCR and HealthSpace were evolving technologies. Their position in the socio-technical network was also evolving and different versions embodied different assumptions and values. In this section, we consider three versions of the SCR: the original release ('Release 1') with level 1 content (paragraph 2.4.3), the 'permission to view' screen linked to the new consent model (paragraph 8.4.1), and the future ('Release 2') version. We consider only the current version of HealthSpace since new functionality is at an early stage of development.

10.4.2. The SCR and HealthSpace had been designed from a medical perspective and embodied the assumptions of a medical model of illness. Central in the SCR's data model were three predefined, coded fields – drugs, allergies and adverse reactions – all of which would impact significantly on 'textbook' cases of unscheduled illness. The SCR design also assumed that GP practice staff would consistently enter (or perhaps, soon begin to enter) these key data onto the local detailed record in the prescribed coded fields rather than as free text or scanned-in documents.

10.4.3. Central to HealthSpace's data model were various biomarkers of disease (or the risk of disease) – such as weight, blood pressure, blood glucose level and so on – which a 'textbook' self-managing patient with a long term condition would be seeking to monitor over time. The HealthSpace design assumed that patients were sufficiently interested in their own biomarkers to enter the data regularly and that these biomarkers were an accurate reflection of the patient's illness or risk status. The Communicator function of HealthSpace assumed a GP who was comfortable with the unpredictable and uncontained nature of messages from patients – and also that patients were comfortable seeking their GP's input in this way.

10.4.4. These inscribed assumptions about the nature of illness and the behaviour of patients and staff did not match reality, and they accounted in considerable measure

for people's non-adoption, partial adoption and abandonment of the technologies. In contrast to 'textbook' patients, individuals seeking unscheduled care included those who were not ill at all, not 'medically' ill or not significantly ill, and those whose medical or nursing needs were complicated if not completely overshadowed by various types of social need (paragraph 6.3.11), none of which were directly informed by data held on the SCR. GPs and their staff typically entered some but not all key data in coded fields. Some but not all (and in our sample, very few) patients with long term conditions monitored and managed their illness using the types of data envisaged in the design of HealthSpace. Many did not monitor their condition at all, but others monitored it in non-textbook ways that were based more on tacit, embodied knowledge than anything that could be codified on HealthSpace.

10.4.5. The model-reality gap in the SCR (e.g. the fact that medication listed on it was not always a faithful representation of what the patient was taking) meant that clinicians soon adjusted their level of trust in the data it held. In the clinic and at the bedside, the SCR was just one more possibly-incomplete, possibly-inaccurate source of data whose provenance and reliability had to be weighed against that of other data sources at the moment of decision-making. As with all the other data sources used in clinical care, the SCR's inherent limitations did not render it useless – they just meant that human processing and judgement was required to make each data item meaningful and assign a here-and-now value to it.

10.4.6. The original version of the SCR allowed the clinician direct access to the main data fields. As set out in Sections 2.5 and 8.4, resistance from professionals, the public and (most significantly) the Information Commissioner to the 'implied consent' model led our team to a recommendation that staff seek consent to view the SCR at the point of care. The next release of the SCR included a 'permission to view' screen (Figure 8.1). Thus, powerful institutional messages about autonomy, trust, surveillance and performance management came to be inscribed in the SCR technology in a way that few stakeholders (our own team included) fully anticipated when the redesign decision was made.

10.4.7. At the time of writing, 'Release 2' of the SCR (which will offer the facility for non-GP staff to enter the level 2 data listed in paragraph 2.4.3) is being much discussed in strategic level meetings and technical development work for this release is well underway though Release 2 is said to be on hold pending a solution to the 'flip-flop consent' issue (paragraph 8.5.27). Leaving aside the technical challenges associated with Release 2, the assumptions being built into it include a complex set of behaviour patterns and skills in relatively junior (often short-term) staff in different provider organisations. In particular, Release 2 appears to assume that these staff will be able and willing to make judgements about what some other clinician in some other organisation might find useful in some unknown encounter in the future.

10.5. Critical conjunctures

10.5.1. The devil, as we said in the title, is in the detail. To the extent that non-adoption, partial adoption and abandonment of the SCR and HealthSpace technologies occurred, this could often be explained by the micro-level actions and inactions of individuals in particular situations and settings – in which they interpreted (perhaps imperfectly) and enacted the conflicting institutional 'worlds' described in Section 10.1 within the social, material and technical constraints of their local setting. In this section, we look at three examples of such 'critical conjunctures' – by which we mean combinations of events or circumstances on which the fortunes of parts of the

programme appeared to turn.[81] The examples below are not exhaustive but have been selected to illustrate the principle that it is particular people in particular here-and-now circumstances, responding to both normative and causal influences (paragraph 10.3.1) who make adoption *or non-adoption* happen. We consider:

a. A GP practice decides not to sign up to the SCR programme;
b. Staff cannot apply 'training' to the workaday world; and
c. Role based access controls prove counterproductive.

Critical conjuncture 1: GP practice does not sign up to SCR programme

10.5.2. Most GP practices chose to be part of the SCR programme but a significant minority opposed it. Interviews undertaken for our Year 1 report suggested that many staff in 'participating' practices had residual concerns about the dangers of distributed records and that conversely, many staff in non-participating practices saw great potential in the SCR (indeed, some were on national and local strategy groups charged with implementing it). Every GP practice has faced – or will face – a critical conjuncture in which the perspectives of all its staff (which are typically ambivalent, unstable and based on strong feelings and/or an incomplete knowledge base) must be distilled into a single, organisational-level decision at a particular time point: yes (this practice will participate) or no (we will not participate).

10.5.3. In the practices we studied, this decision was never made by a simple vote, nor was it made autocratically by a senior partner. Sometimes, all partners were broadly in favour and consensus was quickly reached. At other times, disagreement within the practice was played out as a discussion (and occasionally as an overt confrontation) between two individuals, one of whom was a champion for the SCR (who articulated the arguments in favour of data sharing) and one of whom was reluctant (who articulated the arguments against data sharing). Whether an individual member of staff was 'for' or 'against' the SCR was sometimes influenced by whether he or she held an 'IT lead' role or a 'Caldicott Guardian' role – but this may have been because prior values and interests had influenced taking on these roles in the first place.

10.5.4. Typically, both the 'pro-SCR' and 'anti-SCR' voices saw their stance as a moral one and sought to draw support from within the practice (and sometimes beyond it – for example by citing professional guidance or statements by the Information Commissioner, or by contacting the press) for their 'side' of the argument. The four stages of translation outlined in paragraph 10.3.2 were evident in this process. The 'pro-SCR' voice articulated the issue in terms of a problem (e.g. poor quality out-of-hours care, lack of integration in the NHS, poorly informed patients) for which the SCR was the solution; they placed this problem-solution link on various formal and informal agendas within the practice; they attempted to allocate roles for SCR go-live preparations (usually structured around CFH's 'readiness' checklist); and they tried to mobilise staff into the activities allocated. The anti-SCR voice, on the other hand, offered a competing problem-solution dyad: the *problem* was the potential for harm if protected data were allowed to go outside the practice and the *solution* was for the practice to actively resist the SCR programme. They, in turn, sought to sell this idea and mobilise practice staff and professional colleagues into a 'resistance' movement.

10.5.5. In the early months of the SCR programme, around half the GP practices in early adopter sites opposed the programme. Over the ensuing two years, around two-thirds of these non-participating practices changed their decision and joined the programme. As Figure 10.1 shows, the initial 'anti' arguments included a social component (the validity and fairness of the 'implied consent' model) and a technical component (the security of the IT system). Once the change to the consent model had been implemented, the critical conjuncture at GP practice level could be revisited

– and for most practices, the decision swung in favour of participating. But whilst this change resolved a problem that lay upstream in the socio-technical chain, it created other problems downstream, as critical conjuncture 3 below shows.

Half of GPs refuse to put patients' records online

DOCTORS across the country are reluctant to follow Bolton GPs and upload patients' medical records on to a national electronic database.

Almost half of family doctors surveyed by the research organisation Medix said they would refuse to upload information without a patient's explicit consent.

Just 11 per cent of those questioned said they would follow guidelines and upload the information unless a patient objected.

The summary care records, which are an online version of patient's records, were launched in Bolton earlier this year.

So far, almost 50,000 Bolton patients have their details on the system which can be accessed by staff in the out-of-hours service at Landmark House. The move has been controversial in Bolton, with some GPs expressing concerns about confidentiality.

Dr John Tabor, a GP at the Kildonan Medical Practice in Horwich, said: "These records will be accessible to a lot of people in the health service and I'm very concerned about security. I would be more than happy to upload my patients' records if they had opted to have this done, but I don't think it is fair people have to opt out."

Other GPs believe the summary care records will be of benefit to patients.

Dr Liaqat Natha, of the Kearsley Medical Centre, said: "We volunteered to be involved in this project as we wanted our patients to be the first in the country to benefit from having a summary care record and also the ability for our patients to register for Healthspace to enable them to see their own summary care record whenever necessary."

Figure 10.1: Press coverage of non-adoption by GP practices in early adopter PCTs (Bolton Evening News 21st November 2007)

Critical conjuncture 2: Staff cannot apply 'training' to the workaday world

10.5.6. In almost all the field sites we visited, we encountered staff who, despite having received formal training, were not accessing SCRs. Many had never attempted to do so. Some claimed to have lost or forgotten their smart cards; others said they "didn't see the point" of the SCR or admitted that they had not found the training useful (or had forgotten key details). Here, we consider this third explanation. In paragraph 7.3.2, we described a click-through Powerpoint training session which district nurses found had prepared them inadequately for the task of accessing real patient records. It is worth unpacking this incident as it reveals much about the 'clashes' between the different institutional worlds.

10.5.7. Trainers usually came from the software suppliers, and some were freelance IT trainers contracted in to cover busy periods. They occupied the technical-commercial world and saw their role as 'demonstrating the technology'. Many viewed real patient cases as relatively uniform and unproblematic (see quote paragraph 8.6.2 on most commercial software applications being developed for a *"simpler range of widgets"*).

10.5.8. In the example in paragraph 7.3.2, the trainer viewed his task as showing the nurses which buttons to press and did not consider it particularly problematic that he could not access live records. His 'textbook' model of nursing work comprised a series of decision algorithms. He saw learning largely in terms of transfer of facts – particularly 'concept training' (paragraph 8.8.1) which formed the basis of the supplier's training contract with the PCT and the PCT's memorandum of understanding with CFH.

10.5.9. The district nurses, in contrast, occupied the clinical world (specifically, the close-to-the-patient, socially embedded world of community nursing). They were very aware of the uniqueness of every patient and the complex, unpredictable, exception-filled and unclassifiable nature of much of their case load. Their knowledge was predominantly embodied, practical and situated – what has variously been called

'personal knowledge' or 'body pedagogy'.[168;169] They saw a sanitised, non-live, proof-of-concept demonstration as conveying very little 'knowledge'.

10.5.10. The nurses' response was to get together and access their own SCRs – and in this situation, 'training' occurred through playing with the technology alongside informal discussion and knowledge exchange with their peers. Through this practical and highly personalised learning based on their own experiences as patients and data subjects, they soon discovered the real-life SCR in all its possibly-incomplete, possibly-inaccurate detail.

10.5.11. Interestingly, nurses who explored the potential of the SCR technology and became confident users were not put off by its limitations - they quickly learnt to use their intuitive, practical judgement when using it in patient encounters. Others, however, never overcame their perception of the SCR as the 'disembodiment' of clinical knowledge and thus of little relevance to their nursing work.[37]

Critical conjuncture 3: Role based access controls prove counterproductive

10.5.12. In paragraph 6.5.24 (case FN22/#03), we briefly described an incident on a hospital Medical Assessment Unit in which a pharmacist attempted unsuccessfully to wake a newly-admitted (perhaps semi-comatose) patient to seek consent to access his SCR. The hospital she worked in had imposed a rule that only the doctors could use the emergency over-ride icon (Figure 8.2, paragraph 8.4.2). In the circumstances, the pharmacist chose not to access the patient's SCR (indeed, she was effectively stopped from doing so by the organisational protocol).

10.5.13. This case illustrates a number of competing institutional logics and how they played out through the decisions and actions of front-line staff. The need (or perceived need) for tight access controls had emerged in the context of a highly politicised debate about individual privacy rights in relation to 'government' databases.

10.5.14. The wording of the emergency access page, which talks explicitly about surveillance, performance management and even disciplinary action, is a good example of the audit and regulatory practices which critical academics complain are being increasingly introduced across the healthcare field[37;39] and (at a higher level of abstraction) of what Bowker and Star have called *"software [as] frozen organisational discourse"*.[170] The severe wording of the text in Figure 8.2 contrasted with the gentler form of words used for the Emergency Care Summary in Scotland in a much smaller and less overtly politicised programme.[TTTT]

10.5.15. The wording of the SCR access screen is probably at least partly attributable of the huge scale of the SCR programme – what a blogger in the Computer Weekly online magazine called the First Law of the Bleedin' Obvious: *"The risk of the loss or misuse of personal information is directly proportional to the product of the number of records in that database and the number of authorised users of that database"*. [171] Because the risk that someone, somewhere in the English NHS might make an unauthorised access was (statistically at least) moderately high, the software was designed to incorporate a particularly uncompromising warning.

10.5.16. Somewhat ironically, this pharmacist did have a legitimate relationship with the patient and was eligible to use the emergency over-ride as designed by CFH. She

[TTTT] The Scottish Emergency Care Summary is discussed in paragraph 9.4.2 of our Year 1 report.[1] The wording used for the ECS access screen was: "You must ask the patient for permission before viewing their clinical data. Your details will be recorded and monitored, and the patient's practice will be able to see that you have looked at this record."

would also likely have been aware of guidance produced by the National Prescribing Centre about the importance of checking patients' medication carefully in circumstances like this.[172] This guidance came from the clinical world and stemmed from rising awareness of the dangers of medication errors. Thorough checking of the medicines of newly-admitted patients was a task pharmacists took very seriously and devoted a great deal of time to. Indeed, this task defined their professional role.

10.5.17. But in this particular case, the pharmacist was *prevented* from being guided by her professional norms or following the emergency access route envisaged by designers and policymakers, because her organisation had imposed additional access controls and barred all staff except doctors from going past this screen. This rule was, perhaps, counterproductive, since of all the staff who might access the medication list of a newly-admitted patient, the MAU pharmacist is probably the most key. As a result, the very patients who were not able to convey details of their own medication were also the ones whose SCRs were effectively inaccessible to the people whose job it was to check the drugs. It is unlikely that the patient would have known or cared about staff access privileges to his SCR (indeed, he may well have assumed, incorrectly, that the pharmacist already had access to his full GP-held record).[3]

10.5.18. The counterproductive access controls in operation in this hospital had the short term impact of limiting the pharmacist's ability to perform her professional role. They may also have had a more subtle, longer term effect on the social order of the organisation: they served to reinforce an organisational stereotype of doctors as more trustworthy than other clinicians and the legitimacy of placing managerial controls on clinical work. But in the highly sensitive political context of the programme and the various data loss stories in the media at the time, it was not uncommon for NHS organisations to operate tight internal access controls.

10.5.19. A similar example of access controls proving counterproductive is given in paragraph 7.4.3 in relation to the very high alert rate generated by district nurses in the PDA pilot. This example again highlights a clash of institutional logics – between the clinical world of nurse-patient relations (in which ethics were to do with professional norms and virtues) and the political world of the new public management (in which ethics were to do with external standards and controls and technology-assisted audits). Whilst the SCR technology was designed to capture rare instances of unauthorised malicious access, the unintended consequence of this 'security feature' was a huge increase in managerial surveillance of clinical work. The mismatch between what the alert designers thought nurses did (the 'textbook' encounter which was undertaken alone and immediately logged on the database) and what they actually did (the messy, unpredictable workaday world which involved consulting peers about cases and logging them some time after the encounter) was made explicit and generated secondary work for the auditors (who had to investigate the alerts) and the nurses (who had to defend their actions).

11. Discussion

11.1. Defining success and realising benefits

11.1.1. Early strategy documents predicted that the SCR would deliver better care (improved clinical decision-making), safer care (especially, reduced medication errors), more efficient care (quicker consultations), more equitable care (in patients unable to communicate or advocate for themselves), reduction in onward referral, and greater patient satisfaction. HealthSpace would deliver personalisation of care, empowerment, accountability, quality improvement, safety, reduced NHS costs and improved health literacy. Business plans were clear that rollout should occur quickly in order to realise benefits as soon as possible.

11.1.2. Bruno Latour, writing about a large-scale technology programme in France which had spanned political, professional, technical and commercial worlds, said *"By definition, a technological project is a fiction, since at the outset it does not exist"* (page 23).[173] [UUUU] At the time the initial strategy and business cases were written, stakeholders appear to have shared a number of expectations which went largely unquestioned at the time.[6;60;60;86;86;87] These documents depicted the SCR and HealthSpace as near-universally accessible to staff and patients and as offering information that would be complete, accurate, unambiguous and appropriate for clinical and personal decision-making – which in turn would lead to the benefits listed in the previous paragraph.

11.1.3. Individuals from disparate interest groups thus initially united around this compelling outline vision. In this vision, the technologies – for many stakeholders at least – did not come with significant and ongoing material limitations, interoperability issues, training and support needs or information governance challenges. Their various connections within the socio-technical network (and the data they would contain) were imagined as simple and non-contentious: the SCR and HealthSpace would be accessible, more or less, to whoever needed to use them and contain whatever information that person needed to know.

11.1.4. Given these unrealistic expectations, the first releases of the technologies were destined to disappoint. They were – at least compared to the utopian original vision – difficult to access both socially and technically, and 'clunky' to use. Their content was sometimes incomplete, inaccurate, ambiguous or irrelevant to the user's current information needs. HealthSpace was perhaps even more disappointing than the SCR, since in the basic account version it contained no information at all until the user had entered key data themselves.[VVVV] Both technologies required much work to implement and to learn to use. They created new possibilities for both staff and patients – but these possibilities sometimes came with unanticipated and unwelcome changes to the nature of the social relationships they had been designed to support.

11.1.5. There is no simple or universally agreed metric for measuring success. Large IT programmes are socially and politically embedded; their 'success' and 'failure' are open to contestation.[174] Table 11.1 shows 28 measures and metrics used by different stakeholders for the SCR programme. Each offers a different view of progress, and for each, different stakeholders interpret its significance differently. For example:

[UUUU] The fact that the technology does not exist even as a specification is not necessarily a bad thing. Indeed, 'growing' the technology organically from the vision is the very basis of the 'agile' methodology described in paragraph 10.2.9.

[VVVV] This caveat might have been in the specification and the public information programme, but as our early fieldwork showed, it was not in the typical HealthSpace user's head when they first sought to access their account.

a. Our data support some benefits anticipated in early strategy documents. In particular, we found isolated examples of better quality care and more equitable care, though these benefits appear uncommon. Our data are consistent with (but did not directly demonstrate) a benefit of the SCR on safety. *However*, our findings did not support a significant impact of the SCR on onward referral; they did not support a significant impact of the SCR on consultation length; and it was impossible to isolate out an impact on patient satisfaction in any meaningful way;
b. Almost 9 million people have been mailed about the SCR programme. *However* the question of whether this represents real momentum in the programme or merely an attempt by NHS organisations to take up a 'free postage' offer is disputed;[wwww]
c. The public opt-out rate is extremely low. *However*, the extent to which this represents informed consent or merely lack of engagement is disputed;
d. 43% of all GP practices use the EMIS LV record system. This is described as 'technically compliant' with the SCR and Full Rollout Approval has been given. *However*, practices and PCTs complain that attempted uploads are associated with complex technical problems and progress fixing these is perceived as slow;
e. A million records had been created by January 2010 and the number is now rising at a rate of over 20,000 per week. *However*, the original plan was for distributed electronic records to be accessible by NHS staff and/or patients by 2005,[99] 2007[32] and 2010.[47]
f. 25 NHS provider organisations have achieved technical go-live for viewing SCRs. *However*, many of these sites are a long way from 'soft' go-live (i.e. records are not being accessed in these organisations to any significant degree);
g. Overall, around 4% of clinical encounters in participating primary care out-of-hours centres (and 22% of those in which a SCR is available) now involve a SCR access, and rates are rising in some settings. *However*, this figure masks considerable variation between sites and clinicians;
h. Leaflets and DVDs offering opinion leader endorsement and 'good news stories' are in circulation. *However*, there are few robust examples of real past or current real benefits as opposed to the opinion leaders' belief in potential future benefits.

[wwww] Some front-line staff complained to us that some metrics listed in Table 11.1 were "political" targets more than true measures of the progress of the programme. It is certainly true that towards the end of the evaluation period, and with a general election looming, there was much effort put into the regional public information programme, including an offer from CFH to fund the whole cost of it.

TABLE 11.1: MEASURES AND METRICS OF SUCCESS IN THE SCR PROGRAMME (as of 1st March 2010)				
	Measure or metric	Stakeholder(s) using this metric	Extent of 'success' according to this metric	Comment
BENEFITS REALISATION				
1	Better care (i.e. improved clinical decisions)	CFH, NHS organisations, professions, press, patients, official auditors	Our qualitative findings confirmed an impact of the SCR on clinical decision making for the minority of patients who have complex needs and/or taking multiple medication	Overall, there is very limited evidence that benefits identified in early policy documents have yet been realised. See paragraph 11.1.2 for comment on initial expectations for the SCR
2	Safer care (i.e. reduced risk of harm, especially medication errors)		Our qualitative findings were consistent with, but did not actually demonstrate, a positive impact of the SCR on patient safety.	Serious harm is a rare event, hence a much larger dataset than the one we collected would be needed to exclude a significant reduction in harm.
3	More efficient care (shorter consultations)		There was no consistent effect on consultation length, but in 2 of 3 sites SCR use was associated with significantly longer nurse consultations	These findings should be interpreted with caution because of risk of confounders (encounters in which SCR is used differ in unmeasured ways from those in which it is not)
4	More equitable care (for patients unable to communicate or advocate for themselves)		Our qualitative findings were consistent with the conclusion that the SCR adds particular value when the patient has communication difficulties or has multiple illnesses or medications	The ability of the SCR to add value in such situations is crucially dependent on data quality, discussed in Section 8.3.
5	Reduction in onward referral (ambulance callouts, A&E attendances, admissions)		Our qualitative findings showed no impact of the SCR on onward referral	NHS staff tended to err strongly on the side of caution and refer on to the next stage in the system when there was the slightest doubt.
6	Greater patient satisfaction		We found the impact of the SCR on patient satisfaction impossible to measure	The impact of the SCR on satisfaction was impossible to isolate out from other contributory variables. To do this would need a large, randomised study
7	Improved clinician experience (consultations easier and less stressful, especially in patients with complex needs)	Front-line clinicians, professional bodies	Our qualitative findings were consistent with significant added value from the SCR on clinician confidence and reduction in the perceived stress of seeing patients without full records	This benefit of the SCR is particularly hard to measure, especially using quantitative metrics
8	Value for money	Official auditors	Beyond the scope of this evaluation	See Terms of Reference paragraph 3.1.7

BUSINESS MILESTONES				
9	Sign-off of business case and/or allocation of interim resource	CFH, DoH	Business case signed off by DoH Capital Investment Board and Minister of Health but not by HM Treasury	Non-approval of business case is seen as biggest risk to programme by CFH
10	'Proof of concept' (demonstration of the technology in a non-live setting)	CFH, technical designers	Technical demonstration in non-live environment seen as successful	A recurring complaint from NHS staff was trainers' focus on 'proof of concept' rather than use of live system
11	Number of PCTs who have begun some activity on SCR programme	CFH, SHAs, PCTs	50 PCTs have commenced public information programme	Many PCTs were keen to take advantage of a one-off offer of central funding to undertake the public mailout before end March 2010.
12	Mailshots (absolute or relative number of people sent a letter)	CFH	8,853,358 people have been sent a letter about the SCR	
13	'Opt out rate' (proportion of people who actively state that they do not want a SCR)	CFH, civil liberties lobby, critical press	% of opt-outs has remained below 1% throughout the programme	High opt-out rate was identified as a risk to the programme but this has not materialised. New releases of the SCR change the nature of what people are opting into or out of
14	Number of PCTs / GP practices who have begun to create SCRs	CFH, SHAs, PCTs	16 PCTs have at least one GP practice which has gone live with SCRs. 201 out of 8390 GP practices have gone live.	Several PCTs have sent letters to take advantage of funding offers but have no current plans to commence SCR creation
15	Proportion of GP practices using local record systems that are compliant with the SCR	CFH, GPSoC suppliers	80% of GP practices use systems that are SCR-compliant in theory but half these use a system (EMIS LV) which at the time of writing had yet to support an unproblematic automated 'go-live'	EMIS LV is the GPSoC system with the largest market share. The question of compliance 'in practice' as opposed to 'in theory' is a recurring issue in at the operational front line. As Section 5.5 showed, GP system suppliers have limited incentive and capacity to prioritise SCR compliance over other development work.
16	Achievement of go-live in a 'First of Type' (FoT) GPSoC system	CFH, technical staff, GPSoC suppliers	Four GPSoC systems (INPS, TPP, iSoft Synergy and EMIS LV) have had FoT uploads to the Spine. EMIS LV required manual correction of technical glitches	
17	Proportion of GP practices using a particular GPSoC system who have gone live	CFH, GPSoC suppliers	Proportion of practices supplied by GPSoC systems which have gone live: TPP (7.1% of supplier estate), INPS (4.5%), iSoft (4.5%) and EMIS LV (0.6%)	Go-lives with TPP, INPS and iSoft are now occurring in a largely automated way. There is concern about supplier capacity to support go-lives if programme expands rapidly
18	Proportion of GP practices in a participating PCT who have signed up to the programme in principle	CFH, BMA, RCGP, press	% of GP practices committed to participating in principle in SCR programme rose from approximately 50% to 85% in early adopter sites since 2008	Change in consent model was probably the single most significant factor explaining this shift

19	Proportion of GP practices in a particular PCT who have gone live	CFH, BMA, RCGP	% of 'gone live' GP practices rose from 18% to 44% in the first early adopter site and from 50% to 76% in the second between April 2008 and February 2010.	Change in consent model was probably the single most significant factor explaining this shift
20	Number of SCRs created	CFH, press, official auditors	1,243,911 SCRs have been created	CFH's internal target of 'one million SCRs' was reached on 12th January 2010
21	Number of unscheduled care sites achieving 'hard' (technical) go-live	CFH, SHAs, PCTs	25 sites are now technically live for viewing SCRs	There is a big difference between 'hard' and 'soft' go-live (see footnote to paragraph 6.6.2). Technical go-live alone does not result in any SCRs being accessed. See Section 6 for examples of disconnect between 'hard' and 'soft' go-lives.
22	Number of unscheduled care sites achieving 'soft' go-live (regular use of the SCR)	CFH, SHAs, PCTs	National data not available. 5 of 13 viewing sites in the early adopter PCTs we visited were technically live but not accessing SCRs	
23	Absolute number of hits (e.g. total number of SCRs accessed)	CFH, press, official auditors	14,266 SCRs have been accessed. Expressed as a proportion of all encounters, access rate varies from 2 to 20% in GP out-of-hours and walk-in centres and is below 0.1% in secondary care settings	In some but not all GP out-of-hours centres access rate for the SCR is rising steadily over time. See Section 6 for detailed qualitative analysis of this finding.
24	'Hit rate' (proportion of patients for whom a SCR is found when the clinician looks for it)	NHS organisations, front-line staff	'Hit rate' in early adopter sites has risen from around 10% in 2008 to 50-75% now, depending on the particular site and setting	Some NHS organisations in early adopter sites perceive a hit rate that is lower than the actual hit rate (i.e. believe hit rate *would be* low so are "not pushing" the SCR)
25	'Slippage rate' (i.e. pace of progress in any given indicator compared to original predictions)	CFH, government, press, public	Policy documents in 2000 predicted an integrated NHS record system with patient access to own record by 2004/5.[99] In 2002 the milestone shifted to 2007 [32] and in 2007 to 2010.[47]	Whilst 'slippage' has negative connotations, managers and front-line staff were critical of what they viewed as its flip side: ruthless pursuit of 'political' targets which was perceived as hindering socio-technical change efforts
COMMUNICATION SUCCESS				
26	Opinion leader endorsement (senior clinicians recommend SCR)	CFH	Communication material produced by CFH cited senior clinicians claiming that the SCR was in use and associated with benefits	Claims were typically made in vague terms and focused more on future, hoped-for benefits than established ones
27	'Good news stories' (anecdotes of patients helped by SCR)	CFH	Communication material produced by CFH described patients who benefited from SCR being accessed	Very few such stories were produced despite several requests to front-line staff and PCT managers
28	Lack of 'bad news stories' (no examples of SCR linked to poor care, harm or security breaches)	CFH	We encountered examples of the SCR containing incomplete or inaccurate data but no harm resulted. No stories of serious security breaches emerged	The SCR programme remains politically sensitive and vulnerable to 'bad news stories'

11.1.6. Table 11.2 shows 14 measures and metrics used for the HealthSpace programme. Again, each offers a different picture of progress, and for each there is a caveat. For example:

a. Funding for the HealthSpace programme has been approved from the Next Stage Review stream within the DoH, which supports (among other things) the development of services for long term conditions. *However* the long-term future of the programme has not yet been assured;
b. The HealthSpace technology 'works' in the sense that people can, if they wish, create a basic account, and over 110,000 people across the country have done so. *However*, people who have attempted to use their basic HealthSpace account to manage their health and who are willing to talk about it seem hard to find. We identified only a handful of such people, all of whom were disappointed in the current functionality;
c. The advanced HealthSpace account 'works' in the sense that people can, if they wish, register for this facility and access their SCR. *However*, the uptake of advanced accounts is low (2219 accounts have been created to date), and almost no data exist on whether or how people are using these advanced accounts. We know of no examples yet of improvements to data quality as a result of patients accessing their SCR via HealthSpace;
d. The Communicator function of HealthSpace 'works' in the sense that patients with an advanced account who are registered with participating practices can, if they wish, send and receive messages to and from their GP. Some have done so and valued the extended access and convenience of this service. *However*, enthusiasm for Communicator appears to be low amongst both staff and patients and unanswered questions remain about the acceptability of this service beyond highly selected volunteers;
e. Our qualitative data do not substantiate many of the benefits anticipated in early strategy documents. Specifically, there appears to be limited evidence so far for increases in access and choice, and no evidence for improved quality or safety of care, reduced NHS costs or improvements in patients' ability to self-manage a long term condition;
f. Leaflets offering opinion leader endorsement and 'good news stories' about HealthSpace are in circulation, some of which feature 'ambassador patients' who strongly endorse this technology. *However*, these individuals appear to be unusual and our own sampling frame failed to identify people who felt similarly about the current release of the technology.

11.1.7. We were asked to point out that the above conclusions should be interpreted in the light of the fact that the HealthSpace programme is at an earlier stage of development than the SCR programme. The findings to date do not exclude the possibility of an upsurge in use and a concomitant increase in benefits – especially since further functionality is planned in the next release.

11.1.8. In the light of the modest benefits so far demonstrated, it is instructive to reflect on the original vision and plans for the SCR and HealthSpace. In the early stages of the programmes, these technologies existed in political speeches, policy documents, strategic outline cases and committee agendas – but they did not exist as a material form or a firm design specification. As Section 4.1 shows, the original option appraisal for the SCR rejected a slow, 'organic' implementation model because the benefits (which were assumed to be self-evident) would take longer to be realised. Similarly, HealthSpace strategy documents (Section 9.1) depicted the benefits of this technology in definitive rather than potential terms and sometimes in the present rather than future tense.

TABLE 11.2: MEASURES AND METRICS OF SUCCESS IN THE HEALTHSPACE PROGRAMME (as of 1st March 2010)				
	Measure or metric	Stakeholder(s) using this metric	Extent of 'success' according to this metric	Comment
BENEFITS REALISATION				
1	Personalisation of care (by supporting choice and improving access)	CFH, SHAs, PCTs, patient organisations, official auditors	Some patients use HealthSpace to access Choose and Book to arrange an appointment at a convenient time. No data are available on SCR accesses via HealthSpace. Fewer than 100 patients in 3 pilot practices emailed their GP via Communicator. Those who have done so greatly value the facility	Choose and Book is accessible online via HealthSpace but it is possible to use Choose and Book by telephoning an access line. Low numbers of patients taking up the offer to use Communicator, and limited interest of many GPs in offering this service, may be explained by changes to the GP-patient relationship afforded by the technology.
2	Patient empowerment and improved health literacy (by improving the person's ability to manage their illness)		There is currently no evidence to support this claim. Our ethnographic studies suggest that patients with low health and/or IT literacy and low ability to manage their illness do not use *or wish to use* HealthSpace and that most of those with high health and IT literacy choose alternative products such as iPhone apps. Findings suggest that empowerment may be *reduced* in Communicator users	The use of personal health organisers appears to *require* but does not appear to *produce* high health literacy and IT literacy. Our findings do not exclude an untapped market of individuals with long term conditions who *would* use HealthSpace if its functionality changed, nor do they exclude an increase in self-management motivation and skill that might come with regular use of such technologies. Our limited sample of patients using Communicator included several who seemed to email their GP rather than seeking other information sources or making a decision
3	Accountability, quality improvement and safety (via patient input to the data quality improvement cycle)		There is currently no evidence to support this claim. We identified a patient who viewed a local shared diabetes record via a middleware solution and considered that the record was inaccurate, but a more likely explanation was the person's limited understanding of medical jargon	Whilst our findings do not exclude a potential impact of patient input to improving data quality, they do raise the possibility of an unintended consequence of significant numbers of patients being alarmed by, and seeking to contest, entries which were not expressed in lay language
4	Reduced NHS costs (self-management would reduce cost of managing long-term conditions)		There is currently no evidence to support the claim that self-management via HealthSpace reduces or has the potential to reduce NHS costs	See previous row. It is possible (but speculative) that efforts to promote self management by HealthSpace could *increase* the burden to the NHS
5	Value for money	Official auditors	Beyond the scope of this evaluation	See Terms of Reference paragraph 3.1.7

BUSINESS MILESTONES				
6	Sign-off of business case and/or allocation of interim resource	CFH, DoH	Original business case not approved; interim funding given from Darzi Next Stage Review	Funding has been allocated for one year from January 2010 to link with long term conditions work in DoH
7	'Proof of concept' (non-live demonstration of technology)	CFH, technical designers	Technical demonstration in non-live environment seen as successful	The technology 'works' but potential users appear disinterested in it
8	Number of PCTs who have begun activity on HealthSpace	CFH, SHAs, PCTs	14 PCTs have included HealthSpace in their public information programme for the SCR	Many PCTs were keen to take advantage of a one-off offer of central funding to undertake the public mailout before end March 2010; 14 of 33 chose to include information about HealthSpace in this.
9	Mailshots (absolute or relative number of people sent a letter)	CFH	Exact figures not available but estimated 500,000	
10	Number / proportion of people in the country who have registered for a basic HealthSpace account	CFH, SHAs, PCTs, patient organisations	110,000 people have registered for a basic account. Very few people were willing to talk about their experiences with HealthSpace. Of those who were, all were disappointed with its current functionality.	Registration for a basic HealthSpace account may be done online. There is almost no data on whether or how people who have registered for HealthSpace are using their account.
11	Number / proportion of people in participating PCTs who have completed paperwork to register for an advanced account		No direct data available on how many people have started to create an advanced account. Indirect data suggest that around 9000 people have begun the paperwork and 3100 have brought it in for sign-off.	This step cannot currently be done online; it requires sign-off by the person's GP or a PCT front office. Paperwork is processed in a national back office. The forthcoming online registration may possibly lift a significant barrier to uptake
12	Number / proportion of people who have activated their advanced HealthSpace account		2219 people have activated their advanced HealthSpace account and are technically 'live' for accessing their SCR from home	Once Exeter back office has approved application, patient has to activate the account online. Attrition rate between starting an application and activating one is about 75%
13	Number / proportion of people who have used their HealthSpace account to access their SCR		No data available. We did not identify a single person who used HealthSpace to access their SCR.	We tried to obtain quantitative and qualitative data on this but had limited success. However a lag might be expected between creating SCRs and patients seeking to view their SCR, hence findings do not exclude a future rise in interest
COMMUNICATION SUCCESS				
14	Opinion leader endorsement (service users and/or clinicians recommending HealthSpace in communication materials)	CFH	Communication material produced by CFH cited patients with long term conditions and their clinicians who describe how HealthSpace has helped manage the condition and empowered the user	Whilst patient 'ambassadors' for HealthSpace have been identified by CFH, they appear to be unrepresentative of the wider population of people with long term conditions

11.2. Change: PRINCE and waterfall

11.2.1. We commented previously that CFH's model of change appeared centrally driven, project-oriented, rationalistic, with a focus on documentation and reporting, and tied to predefined, inflexible goals.[1] We contrasted this with programme-oriented models built around theories of sensemaking, co-evolution and knowledge creation.[XXXX]

11.2.2. PRINCE 2 methodology ('Projects IN Controlled Environments') was described as a "de facto standard in UK government" (see http://www.prince2.com/what-is-prince2.asp). NHS organisations were expected to produce PRINCE 2 style business plans and lock their roll-out efforts to a locally-tailored benefits agenda. As Table 5.1, paragraph 5.1.18, shows, anticipated benefits were sometimes concretised further as the details of local implementation plans were fleshed out at SHA level.

11.2.3. PRINCE 2 appeared to be an efficient business tool for managing the parts of the programme that could be controlled, isolated into discrete work packages and 'managed' in the conventional sense of the word. But the sheer complexity of the socio-technical network, its embeddedness in wider institutional structures and the fact that many risks were outside CFH's control meant that this "de facto standard" had limited impact in many parts of the programme (see Chapter 8 for examples).

11.2.4. Even at the level of the small, contained work package, PRINCE 2 was not always fit for purpose. Many implementation challenges linked to people's deeply-held norms, values and meaning-systems and to practical and material factors such as access to resources. This sat oddly with PRINCE 2's process-oriented methodology. Tasks represented on flow charts involved dealing with people who might be expected to have an emotional perspective on an issue (e.g. a patient who discovered an error on their record, a staff member asked to do something not on their job description), but they were depicted almost exclusively in procedural terms (see Figure 4.2, paragraph 4.3.15) and left questions like "where am I going to get the money/time for this?" or "how do I deal with people's feelings?" unanswered. A key challenge was to *humanise* the PRINCE 2 processes – for example by influencing others to care about them or developing workarounds for problems that did not appear on the charts.

11.2.5. There was a palpable tension in the programme between two polarised models of software development: the 'waterfall' (large-scale, top down, pre-specified, inflexible) model preferred by CFH and the large system suppliers and 'agile' (small-scale, bottom up, emergent, flexible) model preferred by NHS organisations and small suppliers. This was, perhaps, an inevitable and insoluble paradox. On the one hand, the domain of use for the technologies was too complex and unpredictable for a waterfall model to be assured of success, but on the other, the programme was too large and had too many stakeholders for 'agile' methods to be applied effectively.

11.2.6. There is a related ongoing debate in the computer science community on what has been called the 'cathedral versus bazaar' question. The 'cathedral' model assumes that software is best built in-house by a large, reputable supplier who can assure standards and be held to account if anything goes wrong, and who in return keeps the patent for the product. The 'bazaar' model advocates open source software,

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XXXX In response to an earlier draft of this report, CFH said, "It is not accurate to say that PRINCE 2 is followed by the book. CFH follow an internal delivery framework which uses a combination of PRINCE 2 and Managing Successful Programmes which is applicable for large scale change programmes." In response, we searched our entire dataset (including strategy documents, business plans, agendas and minutes of meetings, 200+ interviews, field notes and correspondence) and could find no reference to 'Managing Successful Programmes' save for a single meeting between the UCL team and CFH in which we were assured that MSP was being used. In contrast, a search for 'PRINCE 2' found over 100 documents.

whose underlying code is placed in the public domain. Anyone may modify the code but must do so according to agreed (evolving) standards and place the modified code back in the public domain. Open source products tend to be released early and contain numerous 'bugs' but these are rapidly fixed as hundreds of people experiment with the code. Early experiences with open source software were variable but there have been some notable successes in recent years – notably the Linux operating system and two widely-acclaimed electronic patient record systems: Vista, used in the US Veterans Health Administration (http://www.vistasoftware.org/) and OSCAR, used in Canadian primary care (http://www.oscarcanada.org/). Protagonists of open source software see it as cheaper, less financially risky and 'self-fixing'; opponents say quality control is too unpredictable for products on which life or death may depend.[YYYY]

11.3. Tensions of scale

11.3.1. It might be argued that two key aims of NHS IT policy – to (on the one hand) centralise control over the specification, procurement, resource management, performance management and delivery of the information and IT agenda and (on the other hand) put the patient at the centre and 'personalise' care – are, to some extent at least, mutually exclusive. The notion of a 'national' IT programme that was 'locally owned and delivered' was viewed by many front-line staff with a mixture of confusion and amusement, and there was much unfinished business over which organisations would pick up unforeseen recurrent costs associated with maintaining the programmes. Efforts of local teams to find creative new uses for the SCR sat in uneasy tension with implicit or explicit allegations of 'scope creep'.

11.3.2. Hanseth has argued from a mathematical perspective that networked electronic record systems are not unproblematically scalable.[90] The tension between standardisation (which helps stabilise the socio-technical network) and contingency (which reflects and responds to local needs and priorities) can never be resolved; rather, it must be actively and creatively managed – and this gets harder as the network gets bigger. Others have predicted from a perspective which draws on complexity theory that over-assiduous efforts to 'standardise' or 'integrate' on a sizeable scale will create disorder (hence generate work) elsewhere in the system.[175]

11.3.3. A recent systematic review found that because of unpredictability, unintended consequences and the loss of potential for using information in a locally meaningful and situated way, many large-scale networked EPR systems have proved to be less efficient, less cost-effective, less safe and the information they contain less trusted, than smaller, more local systems – though whether this is *inevitably* the case is a question on which researchers disagree.[12] In relation to the NPfIT, one academic observed that *"One can (with difficulty) achieve any two of (a) high security, (b) sophisticated functionality, and (c) great scale – but achieving all three is currently (and may well remain) beyond the state of the art"* (page 230).[176]

11.3.4. The massive scale and virtual nature of the SCR programme, along with the struggles of the Information Commission to apply data protection legislation in a way that keeps pace with technological innovation, has created new ambiguities about who now 'owns' patients' medical records, who is responsible for assuring the quality and confidentiality of the data on those records and in what circumstances consent

[YYYY] Interested readers may like to follow a prospective study in which a designer released an open source product in 2000 and is blogging its fortunes while reflecting on the cathedral-bazaar tension: http://catb.org/~esr/writings/cathedral-bazaar/.

should be asked for sharing these data. In the pre-digital era, NHS records were said to be the property of the Secretary of State for Health, and the legal guardian of the data was the patient's registered GP (or in hospitals, the relevant consultant). But the *information* on those paper records was treated as 'owned' by the patient, who had to consent before it was shared beyond the immediate clinical team providing care. Such consent was considered to be implicit when (for example) GPs and consultants exchanged letters, so in practice it was rarely sought.

11.3.5. The hardware and software of the NPfIT are 'owned' by various participating organisations (BT, for example, own the parts of the N3 network which lie outside GP surgeries or hospitals, but NHS organisations own the infrastructure within the buildings). The question "who is the guardian of the data on the SCR?" awaits a test case under the Data Protection Act. The official answer is apparently the Department of Health as the 'corporate' data controller for the SCR, though patients may still assign this role to their GP and GPs will seek the rider "…but the GP will not be held responsible for entries or unauthorised accesses by third parties". SCRs are potentially accessible by thousands of NHS staff, and because of legitimate public concerns about security a complex system of access controls and audit trails was inevitable. It was probably also inevitable that human work to support these measures would come up against capacity constraints in the NHS and (in some settings) prove unworkable. Pressure is likely to increase as the SCR changes (under the planned 'Release 2' functionality) from being read-only by everyone except the patient's GP to being a 'container' onto which numerous staff in different organisations will be encouraged to enter data (albeit mostly in document format).

11.4. Risks revisited

11.4.1. It is clear that risk was taken very seriously within CFH and the approach to it was highly systematic. Option appraisals and risk assessments accounted for much of the text in strategy documents and business plans. These cases were constructed by allocating a numerical score to different predefined subcomponents and adding these together to get a single overall score for the programme. As described in Section 4.6, risks which emerged in the implementation of the programmes were also managed using PRINCE 2 methodology (Section 11.2):

"Risks and issues are recorded in a risk and issue log as soon as they are identified. They are then assigned an owner and a manager. Risks and issues are formally reviewed every 2 weeks in a team meeting and the mitigating actions tracked in the log. High level risks and issues are reported at senior management level within the National Programme Office."

Outline Business Case for HealthSpace Extension (page 14)[142]

11.4.2. In the original Full Business Case (February 2008), the SCR programme was given a risk score of 56 on a composite scale in which anything over 40 was classified as 'high risk'. The risks identified and proposals for mitigating them are listed in Table 11.3 along with our assessment of what has happened in the programme to date.[ZZZZ]

[ZZZZ] See Section 4.1 and footnote to paragraph 4.1.3. A new version of the Full Business Case for the SCR was produced in September 2009 and at the time of writing awaits approval by Her Majesty's Treasury. In that document, the risk assessment is revised. However, the phase of work we were evaluating was informed mainly by the business case whose risk assessment is analysed here.

TABLE 11.3: RISKS IN THE SCR PROGRAMME			
	RISKS IDENTIFIED IN ORIGINAL BUSINESS CASE[60]	MITIGATION STRATEGY	DID THIS RISK MATERIALISE AND IF SO, WHAT HAPPENED?
1	Delay in provision of compliant GPSoC systems	Start with "compliant" suppliers, review deployment schedule against supplier readiness throughout and adjust timetable if necessary	Yes. Continued review of schedule did not alter the fact that CFH had little control over when suppliers delivered
2	Delay in provision of systems in primary and secondary care that can support level 2 functionality	Close management of suppliers and direct involvement of these in the development of level 2	Yes. CFH did not have the power to "closely manage" suppliers
3	Uptake of HealthSpace advanced accounts greater than expected	Contract out registration process	No
4	Uptake of HealthSpace advanced accounts lower than expected	Continue existing public information programme	Yes. Public information programme had little impact on demand for HealthSpace
5	Staff in NHS organisations do not undertake the work required to implement SCR, due to other work demands, "professional resistance" or lack of recognition of benefits	"Active communication regarding benefits and importance of SCR … continuing engagement between NHS CFH and CIOs … letting peer pressure and general positive feedback of SCR sway staff"	Yes. Active communication and CIO engagement engendered some local support for SCR. However, lack of firm evidence of the hoped-for benefits had an attenuating effect on local enthusiasm and peer pressure was minimal
6	Opt-out rate higher than expected	Active communication on benefits and importance of SCR, use of "peer pressure"	No. Low public opt-out rate may active, informed sign-up to the SCR but may reflect ignorance or apathy
7	Consent model contested by GPs	Monitor early adopter experience carefully and act accordingly	Yes. Strong initial resistance was greatly reduced when consent model changed.
8	Support services (e.g. information line) unable to support roll-out	Monitor demand for services carefully	Yes but when this happened, alternative providers were quickly found
9	Unacceptable performance of local NHS infrastructure results in low use of system	"Advise local health communities in advance of impact that SCR access will have on local infrastructure"	Yes. Not all impacts on local infrastructure were predictable. Advance advice did not mitigate impact of this risk
10	Unacceptable performance of Spine	Thorough testing in high-volume environment	As far as we could assess, not to a significant extent at the time of writing
11	"Some NHS users do not take advantage of access to patient records on SCR, due to factors such as impact on business processes, perceived lack of benefit and the system not being easy to use"	"Promote benefits to the NHS and ensure new business processes are fully understood by staff"	Yes. Promotion of benefits created dissonance amongst staff who did not see these benefits materialising. Training in business processes had limited impact due to inherent limitations of PRINCE 2 methodology (Section 11.2).
12	"System as designed proves not to meet user requirements adequately"	"NHS CFH to explicitly manage new requirements through existing change control process and enforce requirement stability, plus use CCN budget built into the business case"	Yes. New requirements emerged and the 'contract change note' procedure proved bureaucratic, un-agile and unpopular.
13	Security breaches	Robust assurance processes, clear implementation guidelines	Yes (see '93C3' issue paragraph 8.5.24). Information governance procedures were perceived by some staff as bureaucratic, intrusive and threatening and by others as unworkable within existing resource.
14	Legislative and regulatory changes place pressure on programme	Early dialogue with users and suppliers should this occur	As far as we could assess, not to a significant extent at the time of writing
15	Spine and/or LSP contract reprocurements are delayed	Extend contracts to tide over until reprocurements are complete	Impossible for us to assess because key documents were not available to us

11.4.3. A number of mission-critical risks identified in the original Full Business Case, including whether suppliers would deliver solutions on time and whether NHS staff would adopt and use the new technology, were outside CFH's control and could not be effectively mitigated.[AAAAA] Other significant risks, such as a major squeeze on NHS finances, were not identified. Benefits of the SCR technology were assumed to be self-evident and it was anticipated these would produce early positive feedback in the system. But the SCR did not produce significant benefits in early deployments and if anything, staff enthusiasm for the technology attenuated as the work unfolded.

11.4.4. Early business cases assumed that security breaches could be 'designed out' by a combination of state-of-the-art technical features and strict information governance procedures. In fact, breaches occurred because of human ignorance, fallibility or deliberate efforts to subvert the system. CFH tended to write these off as aberrations rather than acknowledge that such instances were an inevitable consequence of giving large numbers of staff access to a database with large numbers of records.

11.4.5. The potential need for a change in consent model was anticipated at the outset but efforts to mitigate the risk had unforeseen consequences. A change which reduced resistance to the SCR in one part of the system (GPs who were considering uploading data to create SCRs on their patients) led to increased resistance in another part of the system (front-line staff in unscheduled care organisations). More generally, as Section 8.4 showed, the numerous unforeseen problems associated with implementing a 'simple' design change in order to increase stakeholders' acceptance of the technology were paradigmatic of the complex and sometimes brittle links between clinical, technical, commercial and political worlds (Section 10.1).

11.4.6. At the outset, it seems that implementation of the SCR was viewed in terms of "deployment" of a technology and risks were depicted largely (though not exclusively) in mechanistic terms. The 'socio' element of socio-technical change appears to have been poorly understood and inadequately explored. For example, *affective* barriers (e.g. perceptions by key stakeholders that the SCR was unethical, a waste of money, a diversion from more important tasks, a symbol of the 'database state' and so on) were combined in the generic category of "professional resistance" and seen as mitigated by "peer pressure" and "general positive feedback of SCR".

11.4.7. In a recent interview, a senior executive on the SCR programme acknowledged that whilst human issues had been identified in early strategy documents, their impact on the programme had not been fully anticipated:

Researcher: "What did CFH anticipate at the outset would be the major challenges?"

Interviewee: "Most of the discussion within the programme was around where the information would come from how it would get onto the Spine. The broader issues that later emerged around consent and so on were certainly recognised as issues at the beginning, but the detail was not fully thought through at that stage."

CFH executive, February 2010 (FX15)

11.4.8. We did not have access to the original strategy document or business plan for the version of HealthSpace which we were evaluating. The risks set out in the Outline Business Care for HealthSpace Extension (which evaluated the programme as 'medium risk' with an overall score of 39) are summarised in Table 11.4. We have omitted risks linked to parts of the programme that were subsequently abandoned or uncoupled. Since the extended functionality of HealthSpace has not yet been introduced, our assessment in Table 11.4 should be viewed as preliminary.

[AAAAA] In response to this statement, CFH commented: "Risks may be outside the CFH organisation therefore requiring alternative responses and mitigation strategies, but they are not out of CFH's control."

TABLE 11.4: RISKS IN THE HEALTHSPACE PROGRAMME[142] *(note: risks associated with functionality that was subsequently abandoned, and with the development of linked parts of the NPfIT, are not considered here)*			
	RISKS IDENTIFIED IN OUTLINE BUSINESS CASE	MITIGATION STRATEGY	DID THIS RISK MATERIALISE AND IF SO, WHAT HAPPENED?
1	"Inadequate specification of requirement and failure to identify key features by patient groups, HealthSpace team and stakeholders"	Maximise consultation with users and demonstrating how system could affect them prior to completing specification	Yes. The HealthSpace functionality evaluated appeared poorly matched to needs of patients with long term conditions. We note functionality will be upgraded in next release
2	Capacity and capability of supplier inadequate and lack of partnership in working relationship	Include testing of supplier capability and testing capacity at procurement stage	Full data not available to us. Salford pilot met significant problems with testing (see Section 9.3)
3	Costs of integrating Communicator into wider HealthSpace Extension development underestimated	Identify Communicator requirements and design approach during supplier procurement and pass some of the risk of integration onto supplier	Data not available to us
4	Costs of registration and authentication system development greater than estimated	Achieve optimum balance between type of technology and security benefits	Data not available to us
5	HealthSpace given low priority by CFH and/or PCTs	communication within and beyond CFH to "demonstrate benefits of HealthSpace and its place in NHS policy & IT strategy"	Yes. Communication programme had little impact on priority given to HealthSpace by CFH or PCTs
6	Operational difficulties setting up registration process	Ensure that communication programme to PCTs identifies importance of registration process to success of project.	Yes. Identifying the importance of the registration process did not mitigate the operational complexities associated with it
7	Competition from other health organiser products limits uptake of HealthSpace by patients	"Ensure that HealthSpace option chosen contains all the features that users want"	No. Uptake of HealthSpace was very limited but there was relatively low demand for any personal health organiser
8	"NHS [staff] users resist using the system e.g. as a consequence of not seeing value of the service or of a perception that it interferes with working practices"	Focus communication programme on PCTs and GP practices and pharmacies, to demonstrate benefits of HealthSpace	Yes. A key finding of the evaluation was lack of positive engagement by NHS staff. Communication programme had little impact on this
9	Helpdesk service inadequate	Focus on Helpdesk staff training and management of service	No. Limited interest meant back office was underused
10	Poor service performance due to infrastructure failure	Obtain technical advice, using data from comparable projects, for sizing of servers and infrastructure	No
11	Security breaches, data loss, identity theft	Ensure registration and authentication security matches highest industry standards	No
12	Political agenda changes	Monitor political agenda and policy changes	Not to a significant extent at the time of writing but general election imminent
13	Supplier defaults on contract/timescales due to internal changes e.g. insolvency	Make soundness of supplier a mandatory selection criterion; use features such as parent company guarantees and escrow within contract	Not as far as we could ascertain

11.4.9. Bearing in mind the early stage of the programme and the limited data available to us, two significant issues are evident. First, the original strategy for HealthSpace assumed that the benefits of this technology were self-evident. Second, the architects of the programme appeared to have seriously overestimated the level of public interest in personal health organisers in general and HealthSpace in particular.

11.4.10. In summary, some but not all risks in the SCR and HealthSpace programmes were identified at the outset and successfully mitigated. But a number of mission-critical risks could not be mitigated and/or were not identified or fully explored. It is worth commenting that the standard DoH approach of assessing options and risks by a highly formalised process of assigning quantitative scores to subjective data about complex issues may have lent a spurious objectivity to the risk assessment process and diverted attention from systematic *qualitative* methods such as deliberation or defending one's ideas in front of an audience.

11.5. Where is the wisdom?

11.5.1. TS Eliot's rhetorical question *"Where is the wisdom we have lost in knowledge? Where is the knowledge we have lost in information?"* is one on which the fortunes of the SCR and HealthSpace programmes appeared to turn. Two areas of knowledge appeared particularly significant: the knowledge held on the SCR and HealthSpace technologies and the knowledge pertaining to the progress of the programmes.

11.5.2. As we noted in Sections 2.5 and 4.2, the prevailing view of many stakeholders in these programmes, notably of a number of CFH senior executives, was that knowledge comprises (or ought to comprise) stable and discrete data items that can be formalised, stored, transmitted and manipulated (e.g. aggregated to produce summaries and trends). Knowledge about the patient can thus be placed more or less unproblematically on the SCR and/or HealthSpace, which serve as a 'containers'. It follows that removing knowledge from its context and distributing it to new geographical and social contexts is essentially a technical task, albeit one requiring human work to develop standards, codes and data models. It also follows that 'completeness' and 'accuracy' are the key quality dimensions of knowledge.

11.5.3. An alternative perspective on knowledge holds that much of it is tied to particular people, contexts, experiences and practices; that 'facts' are intrinsically value-laden, representing not a 'view from nowhere' but a particular representation of reality, produced and presented for a particular social purpose, and about which people have positive, negative or ambivalent feelings.[BBBBB] 'Knowledge' in this broader sense has an important social component and is difficult if not impossible to extract from its context or the people who know it, and much meaning may thus be lost when data from different origins are aggregated.[168;177] Dimensions of provenance (the context in which a data item was produced, the audience for whom it was produced and the purpose for which it was produced) become critical aspects of quality which strongly influence the extent to which a particular data item can be trusted.

[BBBBB] Consider, for example, the hypothetical case of a mother who seeks a letter from her general practitioner to confirm that her child is suffering from attention deficit-hyperactivity disorder (ADHD) in the context of an attempt to get the child 'statemented' so as to gain additional support for him in school. The child might be found to meet 'objective' diagnostic criteria for the condition at that time the letter is written. But had it not been for the context (only 'statemented' children are allowed extra staffing support in state schools), the child might not have been brought to the GP in the first place – or the GP might have made different subjective judgements about the significance of the child's behaviour. In this case, the codified diagnosis of 'ADHD', produced for a particular audience at a particular time, might come to be placed on the child's SCR. At some future date this decontextualised 'data item' could be viewed by staff in a very different context (e.g. child protection) and acquire a different and perhaps more sinister meaning.

Ambiguities and apparent conflicts in data may be explained by considering different meanings which data items hold in different contexts.

11.5.4. Our theoretical perspective introduced briefly in Section 3.4 (and explained in more detail in a separate paper[13]) proposes that electronic records are best viewed not as passive containers of information but as (in one sense) active players which 'shape' knowledge by requiring particular data items to be entered in particular formats – and which, as Section 10.4 argued, typically embody assumptions about social roles and relationships. This approach also places central emphasis on what human actors 'know', especially such things as opinions, attitudes, tacit or embodied knowledge, norms, values, feelings and what the person believes will be the consequences of a particular action in a particular situation.

11.5.5. Data fields represented in the version of the SCR which we evaluated (medication, allergies and adverse reactions) represent the 'hard' (codifiable, relatively uncontested, relatively context-independent) end of the clinical data spectrum. The forthcoming 'Release 2' content (Sections 2.4 and 8.2) is likely to include material that is 'soft', context-dependent and potentially contestable. The rationale for the SCR and approach to its content and scope appear to have taken limited account of the Law of Medical Information: *"the further information has to be able to circulate (i.e. the more diverse contexts it has to be usable in), the more work is required to disentangle the information from the context of its production. The question that then becomes pertinent is; who has to do this work, and who reaps the benefits?"*.[14]

11.5.6. A clinician's choice of whether to access a patient's SCR and trust the data they find on it depends on at least two things: completeness and accuracy of data held *and* the extent to which the clinician considers that this *type* of data can be trusted.[2] The latter might be influenced by personal views about trustworthiness of electronic records in general (see quotes from ambulance staff in paragraph 6.6.5) and by past experience of using such records. It is by no means a foregone conclusion that data held on SCRs will be trusted in geographically or professionally distant contexts even when such data apparently meet a particular data quality standard. A nationally *stored summary* record may hold less intrinsic potential for conveying the contextual detail essential for engendering trust than a nationally or locally *shared* record, since with the latter it is likely to be clearer who has entered data for what purpose.

11.5.7. The ethnographic findings in Section 9.3 and in particular the examples of knowledge exchange amongst people with diabetes on an online self-help bulletin board (Box 9.2, paragraph 9.3.17) illustrate the difference between the narrowly factual, abstracted and stable knowledge ('knowing-that') which HealthSpace was designed to collect and the embodied, richly contextualised, practical and ephemeral knowledge ('knowing-how') which appears to be needed for effective self-management.[178] Box 9.2 also suggests that self-management knowledge has an affective and moral dimension and is embedded in complex questions of power and control (e.g. who has the authority to classify a data item as 'normal' or 'abnormal'?). Philosopher Martha Nussbaum has cogently if controversially argued that knowledge stripped of its embodied, emotional and political dimension is necessarily impoverished.[177] To date, national policy on self-management for long term conditions, and state-sanctioned self-management technologies, have (in line with mainstream medical thinking) tended to equate self-management knowledge with a dataset of biomarkers. At a time when questions are being asked about whether to continue, transform or replace the HealthSpace programme, debate might be productively expanded to embrace more radical perspectives on what self-managing patients need to 'know'.

11.5.8. The 'knowledge as data items' perspective underpins the particular approach to implementation taken in these programmes – namely, that if data on local activity are systematically captured on 'assessment tools' and 'progress charts' and returned in a timely fashion, top management will be able to maintain a meaningful picture ('dashboard') of the state of play and subsequent decisions will be well-informed. Perhaps reflecting the spirit of such an endeavour, we experienced the culture of CFH as valuing explicit knowledge over tacit; structured reporting over informal information-sharing; quantitative over qualitative data; and formal qualifications over experience (e.g. in the NHS) or local knowledge (e.g. of a particular PCT patch).

11.5.9. Much wisdom may have been lost in this approach to knowledge. 'Facts' passed up the management hierarchy, though rarely false, were sometimes not the full picture, since good news is known to make this journey more readily than bad.[179] The assumption that knowledge was effectively captured and made complete by codifying, documenting and approving it meant that other forms of knowledge (knowing the ropes, knowing what was said around the water cooler, knowing how to play Joe to his strengths) were rarely tapped to their full potential.

11.5.10. The conceptualisation of knowledge as data items which are added together to make information is very prevalent in the healthcare field and underpins the assumption that the more knowledge is available (and the more people it is available to), the better informed (and the more 'empowered') the user will be – just as more money inevitably makes you richer.[CCCCC] An alternative view holds that whilst this is sometimes the case, it ceases to be true as the nature of the data moves from 'hard' (e.g. 'blood pressure 160/90' or '3476 letters mailed') to 'soft' (e.g. 'penicillin rash as a baby' or 'clinical engagement') and the system moves from simple to complex.

11.5.11. One 'wicked problem' in the SCR programme was clinical content (Section 8.2). Numerous groups tried to define and list (in a generalisable, unambiguous way) such things as 'core content', 'the enrichment dataset' and 'the exclusion dataset'. As Bowker and Star have shown, such tasks are often taken on by groups who anticipate a relatively straightforward if laborious piece of work at the clinical-technical interface – but they find that, however tight the definitions, ambiguities persist (indeed, they multiply as various what-ifs are proposed and explored), and the need for local tailoring and situational judgement always remains.[182]

11.5.12. Some academics have argued that in any large complex system, information is inherently ambiguous, confusing, untrustworthy and ungovernable. As Haridimos Tsoukas has put it in a classic paper entitled 'The Tyranny of Light':

> *"Contrary to how knowledge was viewed in pre-modern societies, knowledge now tends to be understood as information, that is as consisting of objectified, commodified, abstract, decontextualized representations. The overabundance of information in late modernity makes the information society full of temptations. It tempts us into thinking that knowledge-as-information is objective and exists independently of human beings; that everything can be reduced into information; and that generating ever more amounts of information will increase the transparency of society and, thus, lead to the rational management of social problems. However… the information society is riddled with paradoxes that prevent it from satisfying the temptations it creates. More information may lead to less understanding; more information may undermine trust; and more information may make society less rationally governable."* (page 827).[15]

[CCCCC] The maxim 'knowledge is power' is attributed to the 16th century philosopher Francis Bacon. Many contemporary scholars consider this a somewhat simplistic and outdated equation. For more contemporary and critical perspectives on the relationship between knowledge and power in the context of large-scale IT programmes, see these references.[15;180;181]

11.5.13. Most criticisms of the SCR and HealthSpace programmes to date have been couched as technical ('wrong underlying design'), operational ('poor programme management') or economic ('poor value for money'), and solutions proposed in terms of better design, better business processes or tighter financial management. Programmes of work have begun to address all these areas of criticism. But the arguments presented in this section suggest that some problems that have dogged the SCR and HealthSpace programmes to date are essentially philosophical and ethical rather than strategic or operational.[DDDDD] If that is the case, the urgent question for public debate is not "Why have the benefits of these technologies not yet been realised?" but "To what extent were these programmes built on an inadequate conceptualisation of what knowledge is, a privileging of facts over values, a failure openly to debate what is reasonable and an unrealistic expectation that a defined input would produce a predictable output in a complex system?".

[DDDDD] A US academic paper analysed the Presidential Commission report on the Challenger spaceship disaster.[183] The report had concluded that the primary cause was 'failure of the pressure seal in the aft field joint of the right Solid Rocket Motor' and the 'contributing cause' was 'a serious flaw in the decision making process leading to the launch of [the] flight'. The academics argued that this official report had *"privileged the technical and procedural over the cognitive and ethical"* and hence marginalised the role of rhetoric and deliberation in making complex decisions in unpredictable environments.

12. Epilogue

12.1. This section was written after we had circulated draft sections of this report to the various stakeholders listed in Section 3.1 and received feedback from them. As we had anticipated, reactions to our draft report were mixed. Leaving aside numerous stylistic suggestions, typographical errors and correction of factual details (for which we were grateful), our respondents raised five substantial themes which we set out here with the aim of opening up debate on this unfinished story.

12.2. First, questions were asked about our research design and methods. We had chosen a predominantly qualitative, emergent design which made minimal use of checklists and measurement tools. Our study, some observed, was uncontrolled. Our sample size – at least in relation to the number of accesses of the SCR and Healthspace we observed directly – was said to be too small. We had focused too much, critics said, on subjectively-assessed phenomena such as people's values and feelings and the 'worlds' of participating organisations – and not enough on the hard metrics (Tables 11.1 and 11.2) which could have informed definitive statements on the programmes' success. We had failed to take due account of surveys commissioned by particular stakeholders (in which clinicians had reported benefits from the SCR and thousands of people had expressed their interest in using an enhanced version of HealthSpace). Perhaps we should have used a step-wedge design to compare 'early adopters' systematically with 'fast followers'.[184] Perhaps we should have calculated a number-needed-to-treat (i.e. how many people would need to use the SCR or HealthSpace in order for one to benefit). We had strayed from the protocol set out in our original proposal, and had developed theory on the fly.

12.3. Others disagreed. They considered our rejection of a protocol-driven search for impact statistics and quasi-experimental comparisons in favour of a richly contextualised, sample-of-one, perspectival and at times contradictory national case study as a significant strength of the evaluation. They liked the fact that we had evaluated more than just the technologies and had sought to explore (but not 'fix') the programmes' many uncertainties and ambiguities. These people felt we had over-emphasised, not under-emphasised, the quantitative parts of our dataset and that our qualitative sample was quite large enough to justify the cautious conclusions drawn from it. They shared our concerns about the study designs, sampling frames, and item validity of surveys undertaken by other stakeholders. They pointed out that unlike much healthcare research, organisation and management academics have long recognised the importance of balancing empiricist methodologies with interpretive and qualitative ones. These respondents commended us for taking a flexible approach to method and for seeking to build theory from emerging data. One anonymous reviewer of a conference abstract cited this quote from a landmark study (published in 1993) of organisational change in a turbulent external environment:

"Stigma attached to 'post-hoc theorizing,' 'data mining,' and dust-bowl empiricism are handed down across generations of researchers. In short, researchers are indoctrinated to think first, then act. But as our study progressed, one research design parameter after another slipped the shackles of experimental control and started behaving like a variable."[185]

12.4. Second, respondents prompted us to consider whether our overall approach to evaluation had been reasonable and fair. We had chosen to identify key stakeholders in the programmes and to treat their differing and at times conflicting perspectives as research data. Some described this approach (at least inasmuch as it was perceived as criticism of their own contribution) as "inappropriate", "irrelevant" and "unjustified". They felt the report was too discursive, too focused on parochial detail and too long.

Some said it lacked the abstracted generalisations expected by editors of international journals. Others described our approach as "remarkable", "compelling", "sophisticated" and as providing a worked example of evaluation scholarship whose implications extended beyond the particular topic covered and the shores of the UK. These respondents wanted us to write more and disseminate widely.

12.5. These contrasting views are only partially explained by partisan interests or by the age-old question of whether qualitative or quantitative research designs produce better science. They address the legitimacy of the evaluation and our warrant as evaluators. The Connecting for Health Evaluation Programme (CFHEP) has generally laid claim to a *scientific* legitimacy. It is led by an internationally ranked epidemiologist who has published guidance for doing "objective", "robust" and "scientific" evaluations which rise above political interests;[184] and its governance structures are oriented to anonymous peer review of the kind conventionally expected for scientific papers. Politicians anticipated that the CFHEP would produce hard facts (see for example Hansard, 25th June 2007). Press reports on our own work have tended to highlight numbers and to present these as things which we – as clever (or not-so-clever) scientists – have "measured".

12.6. Whilst our work was bound by the terms of reference of the wider CFHEP, our particular theoretical and methodological approach is actually making a different and more radical claim to legitimacy: that of *democratic evaluation*. Back in the 1970s (and summarised in a more recent paper[186]), Barry Macdonald identified three evaluation approaches for government-sponsored programmes: bureaucratic, autocratic and democratic, which represent different levels of independence from the state. Using this taxonomy, the CFHEP has explicitly distanced itself from the *bureaucratic* model (in which management consultants produce evaluations which directly serve political ends) and promised an *autocratic* model (in which academic experts use systematic methods to produce objective reports that are published independently). In the *democratic* model, evaluators undertake not only to produce competent science but also to engage, explicitly and reflexively, with the struggle over ideas, values and priorities which is the hallmark of democratic deliberation. Thus, our warrant as evaluators stems as much from our efforts to give voice to all 'sides' and to surface the power relationships and complex ethical dilemmas in these programmes as it does from our ability to identify appropriate samples, make precise scientific measurements and draw conclusions that are justified by our data.

12.7. Third, respondents were divided on whether this evaluation will be made public too soon or too late. Some said if only we had waited six more months, the tipping point might have been reached and the benefits of these technologies could have been far more evident.[18] Indeed, since relatively few SCRs had been created by the time of our main phase of fieldwork (mid to late 2009), and since it would have taken additional time for clinicians to begin accessing these on a regular basis, this study (arguably) should have expected to demonstrate substantial benefits *yet*. Others said this work should have been published sooner. Our interim reports, submitted in mid-2008,[1;2] were based on data collected in four early adopter sites, before SCRs were being regularly accessed in clinical care. Perhaps, suggested some, we should have made key findings on the use of the SCR at the clinical front line public before a major expansion of the programme occurred in late 2009. We are no more qualified to stipulate the "right" time to release an evaluation of an unfolding national IT programme than any other stakeholder group. This question is equally pertinent to the other ongoing CFHEP evaluations, and perhaps it is time to debate it.

12.8. Fourth, some respondents felt we should have compared the SCR and HealthSpace programmes with other electronic record initiatives throughout the world and drawn lessons about critical success factors. If we were to do this rigorously, we would

need to access (and perhaps collect) raw empirical data rather than relying on published reports. We would also have to buy into the assumption that it is possible to identify critical success factors which are more or less universal across different contexts. With these caveats in mind, we offer some comparative examples below.

12.9. National shared record programmes between primary and secondary care exist in Scotland, New Zealand and Denmark.[187-194] In Denmark, for example, all the country's GP practices, hospitals, pharmacies and laboratories are linked via a single national network and electronic transfer of prescriptions, laboratory results, letters and email messages is the norm, though (perhaps significantly) there is no centrally held summary record. These national schemes differ in some fundamental technical features, but all attribute their success to a similar combination of factors: a pace of progress commensurate with levels of engagement and tension for change; early and frequent dialogue between key stakeholders to develop a culture of collaboration; systematic attention (e.g. via focus groups or discussion networks) to potentially contentious issues; strong peer influence (e.g. through clinical IT user groups); careful alignment of incentives for both individuals and organisations; transparency in monitoring and evaluation; and balancing central and local leadership. Interestingly, all these countries have populations of around 5 million, though whether this figure is a critical ceiling or a coincidence is speculative.

12.10. The US Health Maintenance Organisation Kaiser Permanente offers an electronic record system which includes 'My Health Manager', a personal health organiser through which members may access parts of their centrally-held record including laboratory results, medication, allergies, immunisations, past clinic visits and key diagnoses; it also includes a secure email connection.[195;196] By mid 2008, 2.4 million of Kaiser's 8.7 million members had registered for My Health Manager, most commonly to request repeat prescriptions. In a survey of 10,000 members, restricted to those who had accessed the site two or more times in six months, with a response rate of 17% (skewed towards those with degree-level qualifications), most perceived the technology as useful and easy to use.[195] Whilst this finding appears to demonstrate significant uptake and use of a technology not dissimilar to HealthSpace, the sample is systematically skewed and the context is very different from the UK. US healthcare, for example, is not delivered through a 'cradle to grave' welfare state and the British public has been criticised for its 'low engagement' in managing health in ways expected by policymakers,[197] though we could not identify systematic comparative studies between the two countries. Physicians working for Kaiser are paid per encounter, whether this occurs via email or face to face, and patients may telephone their physician rather then visiting in person. In short, this particular comparative study raises more questions than it answers about HealthSpace's 'proof of concept', particularly in relation to the take-up rate.

12.11. Finally, respondents were divided on whether we should be more or less prescriptive about what should happen next. We listed some recommendations in paragraphs 1.50 *et seq* of the executive summary, mostly in the format of "things that need to be debated further". Some critics viewed our lack of firm recommendations on the future of the SCR and HealthSpace programmes as a cop-out. Our response to them is that we were contracted by the DoH to undertake an evaluation to "inform the wider roll-out" of the technologies. We were not contracted to offer judgements on whether and in what way the programmes should continue – and some stakeholders argued that our position required us *not* to offer direct recommendations for policy and practice. Mindful of these sensitivities, we chose to offer tentative recommendations as a starting point from which the programmes' many stakeholders could choose to engage with and deliberate on the "what next?" question. Particularly given the timing of this publication (the final version of this report will be submitted before the 2010 UK general election but not released until after it), we stand firm on this position.

12.12. Notwithstanding the point made in the previous paragraph, we note the request from many respondents for some more general advice – aimed at designers, clinicians, policymakers, commercial suppliers, academics and citizens – on how large-scale electronic record programmes might be better specified, designed, pursued and evaluated. We agree that generic learning points from this study could be further drawn out. In particular:

a. The *idea* of a nationally stored electronic record is seductively simple, but any programme to develop and implement such a record is likely to be embedded in multiple institutional worlds (e.g. political, commercial, technical, clinical/professional), and frictions between these worlds should be anticipated;
b. As the scale of an IT programme increases, so will its operational complexity, the work needed to implement it and the incidence of 'wicked problems' (Chapter 8). This is perhaps true for all IT programmes, but it is particularly true for electronic health records because of their institutional embeddedness;
c. The multiple stakeholders in shared electronic record programmes do not merely need to be 'engaged'. They need to enter productive partnerships in which they work towards a shared understanding of the programme and the goal of accommodation (though not necessarily consensus) between their respective 'worlds'. Whatever the chosen development model, this accommodation process is likely to take time, to depend on the input of key 'boundary spanning' individuals and to resist an externally mandated pace of change;
d. The question of whether there is a critical level – in terms of both size of population and scope of use – beyond which a shared electronic record programme will fall victim to its own complexity has not yet been answered;
e. There is (to date, at least) no universal 'best' model for the design of a nationally stored or shared electronic record. Neither a classic 'waterfall' (large-scale, top-down, pre-specified) nor a classic 'agile' (small-scale, bottom-up, incremental) approach is ideally fit for purpose. That said, it is clear that technical solutions need to be developed alongside a close and detailed study of the 'workaday world' of front-line clinical care and that, conversely, relevant work practices and routines need to be shaped incrementally to fit the technologies;
f. Health information systems tend to be developed as part of a wider ambition to transform healthcare. But this does not absolve developers from the requirement to understand current practices and the practitioners who embody them, and to craft systems in a way that supports and strengthens key work practices;
g. Change must be resourced, and key incentives must be developed and aligned. In particular, our findings suggest that those who put in the work to create records (including the essential ground work to ensure that data feeding into shared records are 'fit for sharing') may not be the ones who benefit from the widespread accessibility of those records;
h. Qualitative research methods, applied in the context of a critical and democratic evaluation philosophy, offer untapped potential for unpacking the complexities in large-scale electronic health record programmes, though they do not offer quick fixes or easy answers.

12.13. It is, perhaps, telling that the complexity of both the process and the products of this evaluation were viewed as a curse by some and a blessing by others. We hypothesise that diversity of responses to this report are not due solely to the need to demonstrate the legitimacy of a rich, qualitative evaluation. Instead, we should consider this evaluation as addressing two distinct audiences: those who are in search of tractable, concrete solutions and those who are more concerned with the complex, fluid and contradictory world into which those technical solutions are introduced and out of which useful and valuable systems in practice may emerge.

13. APPENDIX: Descriptive statistics on data sources

TABLE A1: STATISTICS ON FRONT-LINE STAFF INTERVIEWED (N=67)	
A&E Departments (Bolton and Bury)	
Consultant	2
Junior doctor	8
Staff grade doctor	3
Nurse	4
Total A&E staff interviewed	17
Medical admissions unit	
Consultant	1
Junior doctor	1
Pharmacist	3
Total MAU staff interviewed	4
Hospital based community unit	
Nurse	2
Out-of-hours centre	
Call centre nurse	8
GPs	7
Manager/director (1 GP, 1 nurse by background)	3
Call handler / receptionist	3
Total out-of-hours centre staff interviewed	21
Walk in centre	
Nurse	7
Receptionist	2
Manager	1
Total walk-in centre staff interviewed	10
Diabetes outreach centre	
Clinician (1 consultant, 1 nurse, 1 dietician)	4
Receptionist	1
Total diabetes outreach centre staff interviewed	5
Dental access centre	
Nurse manager	1
Dentist	1
Total dental access centre staff interviewed	2
District nursing service	
Nurse manager	2
Front-line district nurse	4
Total dental access centre staff interviewed	6

TABLE A2: DEMOGRAPHIC STATISTICS ON PATIENT ENCOUNTERS OBSERVED (N = 237)		
	Clinical cases (N = 214)	Call handler cases (N = 23)
Age		
0-5	41	3
6-17	22	4
18-64	103	7
65+	48	6
Missing data	0	3
Gender (% female)	52%	50%
Ethnicity		
White British	185	18
South Asian	24	0
Other (Africa, Middle East, Other European)	5	1
Missing data	0	4
Currently on prescribed medication and/or has known allergies (i.e. there would be relevant information on SCR		
No	107	4
Yes	106	11
Missing data	1	8

TABLE A3: SETTING AND STAFF MEMBER OF PATIENT ENCOUNTERS OBSERVED (N = 237)	
Ambulance service / Ambulance personnel	8
A&E (9 in 'Resus', 22 in 'Major', 22 in 'Minor')	
Consultant	4
Junior doc	35
Staff grade doctor	12
Nurse	2
Total A&E	53
Medical admissions unit	
Junior doctor	21
Pharmacist	9
Total MAU	30
Hospital based community unit	
Nurse	5
Out-of-hours centre	
Call handler	23
Call centre nurse phone advice	36
GP base visit	26
GP phone advice	12
GP home visit	4
Total out-of-hours centre	101
Walk-in centre	
Nurse	32
Diabetes outreach centre	
Consultant, dietician, specialist nurse (patients seen by all 3)	4
Dental access centre	
Dentist	5

TABLE A4: STATISTICS ON PREVIOUS ENCOUNTERS FOR THIS EPISODE (N=237)		
	Clinical cases (N = 214)	Call handler cases (N = 23)
None (patient self-referred)	133	7
Walk-in centre (nurse sent patient on to A&E or out-of-hours GP)	9	0
GP (e.g. own or out-of-hours GP sent patient on to A&E, saw GP but wanted 2nd opinion or condition deteriorated)	18	7
A&E (patient previously seen in A&E and re-presented to A&E or other unscheduled care provider with same problem)	6	1
Call centre (call handler or nurse advised patient to attend walk-in centre, A&E or out-of-hours GP)	34	1
Ambulance/paramedic (999 call, patient brought to A&E)	7	0
Other hospital department (e.g. patient became unwell while attending outpatient appointment, diverted to A&E, recently discharged and presented in community)	4	2
Dental access centre (patient re-presented to dental access centre with same problem)	3	0
Other community provider e.g. nursing home, district nurse, pharmacist, hospice	0	6

TABLE A5: STATISTICS ON ONWARD REFERRAL AT CLOSE OF THIS EPISODE (N=214)		
	Clinical cases (N = 214)	Call handler cases (N = 23)
None (patient sent home, perhaps with instructions on what to do if deteriorates)	106	0
Admit to hospital	45	0
A&E	20	0
GP out-of-hours centre phone advice (from nurse or doctor)	0	14*
GP out-of-hours centre attendance ('base visit')	26	5
GP home visit	7	4
Hospital outpatient appointment	3	0
Dental access centre (patient seen in DAC advised to return for further treatment)	2	0
See own GP in the morning	1	0
Not yet decided at time of encounter	4	0

* many 'advice' calls by nurses in the GP out-of-hours centres were converted to base visits after the nurse had spoken to the patient.

TABLE A6: MAIN SOURCE OF DRUG/ALLERGY INFORMATION IN PATIENT ENCOUNTERS OBSERVED (N=214)	
Patient (often via repeat medication list from GP)	103
Parent/carer (ditto)	57
GP (letter/fax/Transfer of Care form)	13
Other NHS organisation	6
Medication or packaging (e.g. dosit box, ambulance green bag)	20
SCR	4
SCR and patient (i.e. patient knew but good to confirm)	4
Known to A&E clinicians ('frequent flier')	1
Hospital discharge letter	1
No reliable source (unconscious and unaccompanied, SCR unavailable)	1
Adastra (from previous attendance at same walk-in centre)	2
Missing data	2

14. Glossary

AMRU	Acute Medical Receiving Unit
ASSIST	Association for Informatics Professionals in Health and Social Care
BCSHIF	British Computer Society Health Informatics Forum
CFH	NHS Connecting for Health
CFHEP	Connecting for Health Evaluation Programme
CHART	Care and Health Analysis in Real Time
CIB	Capital Investment Board of Department of Health
CRS	Care Records Service
CSA	Clinical Spine Application
DCR	Detailed Care Record
DES	See IM&T DES
DRG	Disease Related Group
DMICP	Defence Medical Information Capacity Programme
DOH	Department of Health
ECS	Emergency Care Summary (Scotland)
ERDIP	Electronic Development and Implementation Programme
EHR	Electronic Health Record
EMIS	Egton Medical Information Systems
EPR	Electronic Patient Record
GP	General practitioner
GPSoC	GP Systems of Choice
GPSS	General Practice System Suppliers
HCA	Health care assistant
ICT	Information and Communications Technology
IM&T	Information Management and Technology
IM&T DES	Information Management and Technology Directly Enhanced Service, a national programme of support, training and incentives for GP practices based on the nationally accredited PRIMIS and CHART tools[95]
INPS	InPractice System
JGPITC	Joint GP IT Committee of the General Practitioners Committee (of British Medical Association) and Royal College of General Practitioners
LDR	Local Detailed Records (these include the GP held record, pharmacy record, out-of-hours record etc)
LMC	Local Medical Committee
LSP	Local Services Provider
MAU	Medical Admissions Unit
MIU	Minor Injuries Unit
N3	National Network for the NHS
NCL	National Clinical Lead

NCRS	National Care Records Service
NHS	National Health Service
NLOP	National [Programme for IT] Local Ownership Programme
NPfIT	National Programme for Information Technology
OOH	Out-of-hours
PAC	Public Accounts Committee
Paperlite	A PCT data quality scheme in which practices who met the standard were allowed to shred some components of the paper record
PCT	Primary Care Trust
PDS	Personal Demographic Service
PEC	Professional Executive Committee (of PCT)
PID	Project Initiation Document
POAP	Plan On A Page
PRIMIS	Primary Care Information Services
PSA	Public Sector Agreement
QOF	Quality and Outcomes Framework, a financial incentive scheme from the DoH which rewards particular elements of administrative and clinical performance in GP practices
Read codes	A widely used electronic coding system for GP held clinical data
RCN	Royal College of Nursing
SCR	Summary Care Record
SHA	Strategic Health Authority
SNOMED	Systematised Nomenclature of Medicine Clinical Terms, the clinical coding system used in the SCR
SUS	Secondary user service
WiC	Walk-in Centre

15. References

(1) Greenhalgh T, Stramer K, Bratan T, Byrne E, Russell J, Mohammad Y et al. Summary Care Record Early Adopter programme: An independent evaluation by University College London. http://webarchive.nationalarchives.gov.uk/20071001182424/http://www.pcpoh.bham.ac.uk/publichealth/cfhep/002.shtml. London: University College London; 2008.

(2) Byrne E, Kalra D, Stramer K, Greenhalgh T. Data quality evaluation for the Summary Care Record. http://webarchive.nationalarchives.gov.uk/20071001182424/http://www.pcpoh.bham.ac.uk/publichealth/cfhep/002.shtml. London: University College London; 2008.

(3) Greenhalgh T, Wood GW, Bratan T, Stramer K, Hinder S. Patients' attitudes to the Summary Care Record and HealthSpace: qualitative study. BMJ 2008; 336(7656):1290-1295.

(4) Greenhalgh T, Stramer K, Bratan T, Byrne E, Mohammad Y, Russell J. Introduction of shared electronic records: multi-site case study using diffusion of innovation theory. BMJ 2008; 337:a1786.

(5) Department of Health. Our health, our care, our say: a new direction for community services. London: The Stationery Office; 2006.

(6) Department of Health. Direction of Travel for Urgent Care: A discussion document. London: The Stationery Office; 2006.

(7) Darzi A. Our NHS, Our Future. London: The Stationery Office; 2007.

(8) Darling A. Comprehensive Spending Review. London: HM Treasury; 1998.

(9) Department of Health. Better Information, Better Choices, Better Health: Putting information at the centre of health. London: The Stationery Office; 2004.

(10) Department of Health. Choosing Health: Making healthy choices easier. London: The Stationery Office; 2004.

(11) Department of Health. Health Reform in England: Update and Next Steps. London: The Stationery Office; 2005.

(12) Greenhalgh T, Potts H, Wong G, Bark P, Swinglehurst D. Tensions and paradoxes in electronic patient record research: A systematic literature review using the meta-narrative method. Milbank Quarterly 2009; 87(4):729-788.

(13) Greenhalgh T, Stones R. Theorising big IT programmes in healthcare: Strong structuration theory meets actor-network theory. Social Science & Medicine 2010; 70:1285-1294.

(14) Berg M, Goorman E. The contextual nature of medical information. International Journal of Medical Informatics 1999; 56:51-60.

(15) Tsoukas H. The tyranny of light. The temptations and the paradoxes of the information society. Futures 1997; 29:827-843.

(16) Checkland P, Holwell S. Information, systems, and information systems: making sense of the field. Chichester: John Wiley & Sons; 1998.

(17) Davidson C. SCR Viewing Strategy End Project Report, Final version (0.8). London: NHS Connecting for Health; 2010.

(18) Gladwell M. The Tipping Point: How Little Things Can Make a Big Difference. New York: Little Brown & Co; 2002.

(19) Department of Health. The NHS Plan: A plan for investment, a plan for reform. London: NHS Executive; 2001.

(20) Darzi A. High Quality Health for All: NHS Next Stage Review Final Report. London: The Stationery Office; 2008.

(21) Bodenheimer T, Wagner EH, Grumbach K. Improving primary care for patients with chronic illness: the chronic care model. Part 1. JAMA 2002; 288:1775-1779.

(22) Greenhalgh T. Primary Health Care: Theory and Practice. Oxford: Blackwells; 2007.

(23) Tudor Hart J. NHS at 50. Thoughts from an old GP. National Health Service. Lancet 1998; 352(9121):51-52.

(24) Wong G, Bentzen N, Wang L. Is the traditional family doctor an anachronism? London Journal of Primary Care 2009; 2:93-99.

(25) National Audit Office. The Provision of Out-of-Hours Care in England. 16th Report of Session. London: The Stationery Office; 2007.

(26) Thompson C, Hayhurst C, Boyle A. How have changes to out-of-hours primary care services since 2004 affected emergency department attendances at a UK District General Hospital? A longitudinal study. Emerg Med J 2010; 27(1):22-25.

(27) Darzi A. NHS Next Stage Review: Our Vision for Primary and Community Care. London: The Stationery Office; 2008.

(28) Hoffmarcher MM, Oxley H, Rusticelli E. Improved health system performance through better care coordination. Health Working Paper No. 30. Paris: OECD; 2007.

(29) Pevalin DJ. Socio-economic inequalities in health and service utilization in the London Borough of Newham. Public Health 2007; 121(8):596-602.

(30) Shah SM, Cook DG. Socio-economic determinants of casualty and NHS Direct use. J Public Health 2008; 30(1):75-81.

(31) Goddard M, Smith P. Equity of access to health care services: theory and evidence from the UK. Soc Sci Med 2001; 53(9):1149-1162.

(32) Department of Health. Delivering 21st century IT support for the NHS. London: Department of Health; 2002.

(33) Cayton H. Report of the Ministerial Taskforce on the NHS Summary Care Record. Available on www.connectingforhealth.nhs.uk/resources/care_record_taskforce_doc.pdf. London: Connecting for Health; 2006.

(34) Greener I. The three moments of New Labour's health policy discourse. Policy and Politics 2004; 32(3):303-316.

(35) Smith R. All changed, changed utterly. BMJ 1998; 316:1917-1918.

(36) Marshall M, Davies H. Public release of information on quality of care: how are health services and the public expected to respond? J Health Serv Res Policy 2001; 6(3):158-162.

(37) Nettleton S, Burrows R, Watt I. Regulating medical bodies? The consequences of the 'modernisation' of the NHS and the disembodiment of clinical knowledge. Sociology of Health and Illness 2008; 30(3):333-348.

(38) Power M. The Audit Society: Rituals of Verification. Oxford: Oxford University Press; 1997.

(39) Harrison S. New Labour, modernisation and the medical labour process. Journal of Social Policy 2002; 31(465):485.

(40) Darling A. Modern Public Services for Britain: Investing in Reform. Comprehensive Spending Review: New Public Spending Plans 1999-2002. London: HM Treasury; 1998.

(41) Newman J, Vidler E. Discriminating customers, responsible patients, empowered users: Consumerism and the modernisation of health care. Journal of Social Policy 2006; 35:193-209.

(42) Ling T. Delivering Joined-Up Government in the UK: Dimensions, Issues and Problems. Public Administration 2002; 80(4):615-642.

(43) Vidler E, Clarke J. Creating Citizen-Consumers: New Labour and the Remaking of Public Services. Public Policy and Administration 2005; 20(2):19-37.

(44) Wanless D. Securing Our Future Health: Taking a Long-Term View. London: HM Treasury; 2002.

(45) Department of Health. Information for health: An information strategy for the modern NHS 1998-2005. London: NHS Executive; 1998.

(46) Department of Health. Building the Information Core. London: Department of Health; 2000.

(47) Department of Health. Connecting for Health: A guide to the National Programme for Information Technology. London: The Stationery Office; 2005.

(48) Department of Health. The NHS Informatics Review Report. London: The Stationary Office; 2008.

(49) Appleby J, Crawford R, Emmerson C. How cold will it be? Prospects for NHS funding: 2011–17. London: King's Fund; 2009.

(50) Anonymous. Leviathan stirs again. Economist 2010; 23rd-29th January:22-24.

(51) Martin S, Smith PC, Leatherman S. Value for money in the English NHS: Summary of the evidence. London: Health Foundation; 2006.

(52) Public Accounts Committee. Financial Management in the NHS: Report on the NHS Summarised Accounts 2007–08 Twenty-second Report of Session 2008–09. London: Stationery Office; 2009.

(53) House of Commons Health Committee. The use of management consultants by the NHS and the Department of Health. Fifth Report of Session 2008-9. London: Stationery Office; 2009.

(54) Office of National Statistics. Public Service Productivity: Health care summary. Donwloadable from http://www.statistics.gov.uk/articles/nojournal/HealthCare_290108.pdf. London: ONS; 2008.

(55) Department of Health. NHS 2010 - 2015: from good to great. Preventative, people-centred, productive. London: The Stationery Office; 2009.

(56) Anonymous. David Nicholson predicts tough NHS pay negotiations. Health Service Journal 2010; 22nd January:00.

(57) National Audit Office. Department of Health: The National Programme for IT in the NHS. Report by the Comptroller and Auditor General, HC 1173. London: The Stationery Office; 2006.

(58) Howlett P. Strategic Outline Case for HealthSpace Extension. London: Connecting for Health (internal document); 2007.

(59) Public Accounts Committee. The National Programme for IT in the NHS: Progress since 2006. Second Report of Session 2008-09. London: Stationery Office; 2009.

(60) Beale P. Full Business Case for Summary Care Record Implementation, Including Patient Access Via Advanced HealthSpace Accounts, Version 0.5. London: Department of Health; 2008.

(61) Jordan M. HealthSpace Extension: Statement of Requirements, Version 0.7, October 2008. London: Connecting for Health internal document; 2008.

(62) Klecun E, Cornford T. A critical approach to evaluation. European Journal of Information Systems 2005; 14:229-243.

(63) Cooke N. SCR Evaluation: Addressing the points to consider. Downloadable from http://www.connectingforhealth.nhs.uk/systemsandservices/scr/documents/evalresponse.pdf. London: Connecting for Health; 2008.

(64) Patton MQ. Utilization-focused evaluation: The new century (3rd edition). London: Sage; 1997.

(65) Yin RK. Case study research: design and methods. (2nd ed.) . London: Sage; 1994.

(66) Stake R. Qualitative case studies. In: Denzin N, Lincoln Y, editors. The Sage handbook of qualitative research. London: Sage; 2005.

(67) Gomm R, Hammersley M, Foster P. Case study method. London: Sage Publications; 2000.

(68) Greenhalgh T, Stones R. Theorising big IT programmes in healthcare: Strong structuration theory meets actor-network theory. Social Science & Medicine 2010; in press.

(69) Blommaert J. Discourse: a critical introduction. Cambridge: Cambridge University Press; 2005.

(70) Grant D, Iedema R. Discourse analysis and the study of organisations. Text 2005; 25(1):37-66.

(71) Iedema R. The medical record as organizing discourse. Document Design 2003; 4(1):64-84.

(72) Atkinson P, Hammersley M. Ethnography: principles in practice. 3rd edition. London: Routledge; 2007.

(73) Glaser BG, Strauss AL. The constant comparative method of qualitative analysis. In: Glaser BG, Strauss AL, editors. The discovery of grounded theory. Chicago: Adline; 1967.

(74) Woods L, Roberts P. Generating theory and evidence from qualitative computerised software. Nurse Researcher 2004; 8 VERIFY YEAR(2):28-41.

(75) Winter R. Fictional-critical writing: an approach to case study research by practitioners. Cambridge Journal of Education 1986; 3:175-182.

(76) Greenhalgh T, Russell J, Swinglehurst D. Narrative methods in quality improvement research. Qual Saf Health Care 2005; 14(6):443-449.

(77) Weick K. The generative properties of richness. Academy of Management Journal 2007; 50(1):14-19.

(78) Gabriel Y. Storytelling in organisations: facts, fictions and fantasies. Oxford: Oxford University Press; 2000.

(79) Car J, Black A, Anandan C, Cresswell K, Pagliari C, McKinstry B et al. The impact of eHealth on the quality & safety of healthcare: a systematic overview & synthesis of the literature. Available from: http://www.pcpoh.bham.ac.uk/publichealth/cfhep/pdfs/NHS_CFHEP_001/NHS_CFHEP001_eHealth_report_Full_version.pdf. Birmingham: Connecting for Health Evaluation Programme; 2008.

(80) Giddens A. The constitution of society: outline of the theory of structure. Berkeley, CA: University of California Press; 1984.

(81) Stones R. Structuration theory. Basingstoke: Palgrave-Macmillan; 2005.

(82) Greenhalgh T, Robert G, Macfarlane F, Bate P, Kyriakidou O. Diffusion of innovations in service organisations: systematic literature review and recommendations for future research. Millbank Quarterly 2004; 82:581-629.

(83) Wacquant L. Bourdieu. In: Stones R, editor. Key Sociological Thinkers (2nd edition). London: Palgrave Macmillan; 2007.

(84) Beale P. Full Business Case for Summary Care Record Implementation, Version 0.7. London: Department of Health; 2009.

(85) Darling A. Comprehensive Spending Review. London: HM Treasury; 1998.

(86) Beale P. NHS Summary Care Record Implementation Strategic Outline Case. London: NHS Connecting for Health; 2007.

(87) Meyer A. Summary Care Record: Supporting High Quality Care for All. Version 1.1. Available in full text on http://www.connectingforhealth.nhs.uk/systemsandservices/scr/documents/care4all.pdf. London: Connecting for Health; 2009.

(88) Smith J. Building a safer NHS for patients: Improving medication safety. London: The Stationery Office; 2004.

(89) Monteiro E. Integrating health information systems: a critical appraisal. Methods of Information in Medicine 2003; 42:428-432.

(90) Hanseth O. Integration-complexity-risk: the making of information systems out-of-control. In: Ciborra CU, Hanseth O, editors. Risk, complexity and ICT. Oslo: Edward Elgar; 2007.

(91) Department of Health. The NHS in England: The Operating Framework for 2009/10. London: The Stationery Office; 2008.

(92) Department of Health. The NHS in England: The Operating Framework for 2010/11. London: The Stationery Office; 2009.

(93) Department of Health. Informatics planning 2009-10 for the NHS in England. Downloadable from http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_091437. London: The Stationery Office; 2008.

(94) Department of Health. Informatics planning 2010-11 for the NHS in England. Downloadable from http://www.dh.gov.uk/dr_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_110336.pdf. London: The Stationery Office; 2008.

(95) Arvaniti A. NHS Summary Care Record and HealthSpace Readiness Assessment Guidance Version 1.0. London: NHS Connecting for Health; 2008.

(96) Bratan T, Stramer K, Greenhalgh T. "Never heard of it" – Understanding the public's lack of awareness of a new electronic patient record. Health Expectations 2010; 00:00.

(97) Hayes G. Independent Review of NHS and Social Care IT. Commissioned by Stephen O'Brien MP. London: House of Commons; 2009.

(98) BMA Press Office. BMA calls for roll-out of electronic patient records to be suspended. Press release, 10th March. London: British Medical Association; 2010.

(99) Department of Health. The NHS Plan: An information strategy for the modern NHS. London: NHS Executive; 2000.

(100) Exworthy M, Berney L, Powell M. How great expectations in Westminster may be dashed locally: the local implentation of national policy on health inequalities. Policy & Politics 2003; 30(1):79-96.

(101) Checkland K. National Service Frameworks and UK general practitioners: street-level bureaucrats at work? Sociol Health Illn 2004; 26(7):951-975.

(102) Iles V. Addressing both national and local accountabilities: effective relationships between SHAs and PCT boards. Downloadable from http://www.reallylearning.com/ConversationsAboutTrust.pdf. London: Nuffield Trust; 2005.

(103) Pawson R, Greenhalgh T, Harvey G, Walshe K. Realist review--a new method of systematic review designed for complex policy interventions. J Health Serv Res Policy 2005; 10 Suppl 1:21-34.

(104) Department of Health. National End of Life Care Programme. London: The Stationery Office; 2008.

(105) Boehm B, Turner R. Balancing Agility and Discipline: A Guide for the Perplexed. Boston, MA: Addison-Wesley.; 2003.

(106) Anonymous. New rules for big data. In special supplement Data, Data Everywhere, 27th February. Economist 2010;14.

(107) Ministry of Justice. Coroners and Justice Act. Downloadable from http://www.justice.gov.uk/publications/coroners-justice-bill.htm. London: The Stationery Office; 2009.

(108) Thomas R, Walport M. Data Sharing Review Report. London: Ministry of Justice; 2008.

(109) Anderson R, Brown I, Dowty T, Inglesant P, Heath W, Sasse A. Database State. York: Joseph Rowntree Reform Trust; 2009.

(110) O'Reilly D, Stevenson M, McCay C, Jamison J. General practice out-of-hours service, variations in use and equality in access to a doctor: a cross-sectional study. Br J Gen Pract 2001; 51(469):625-629.

(111) Salisbury C, Hollinghurst S, Montgomery A, Cooke M, Munro J, Sharp D et al. The impact of co-located NHS walk-in centres on emergency departments. Emerg Med J 2007; 24(4):265-269.

(112) Department of Health. Chief executive's report to the NHS. Statistical supplement. www.dh.gov.uk/assetRoot/04/13/58/41/04135841.pdf. London: The Stationery Office; 2006.

(113) Crabtree A. Designing collaborative systems: A practical guide to ethnography (computer supported cooperative work). London: Springer; 2003.

(114) Ash JS, Berg M, Coiera E. Some Unintended Consequences of Information Technology in Health Care: The Nature of Patient Care Information System-related Errors. J Am Med Inform Assoc 2004; 11(2):104-112.

(115) Garfinkel H. "Good" organizational reasons for "bad" clinic records. In: Garfinkel H, editor. Studies in ethnomethodology. Englewood Cliffs, NJ: Prentice Hall; 1967. 186-207.

(116) Østerlund C. Documenting dreams: patient-centered records versus practice-centered records. PhD thesis. MIT Sloan School of Management; 2002.

(117) Berg M, Toussaint P. The mantra of modelling and the forgotten powers of paper: a sociotechnical view on the development of process-oriented ICT in health care. International Journal of Medical Informatics 2003; 69:223-234.

(118) Lave J. Cognition in Practice. Cambridge: Cambridge University Press; 1988.

(119) Czarniawska B. A narrative approach to organization studies. Qualitative research methods series 43. London: Sage; 1998.

(120) Katon WJ, Walker EA. Medically unexplained symptoms in primary care. J Clin Psychiatry 1998; 59 Suppl 20:15-21.

(121) Connecting for Health Communications Department. District Nurses in Bolton are given a helping hand to deliver faster treatment with Summary Care Records. Downloadable from http://www.connectingforhealth.nhs.uk/systemsandservices/scr/documents/dnurses.pdf. London: Connecting for Health; 2008.

(122) Jensen TB, Aanestad M. Hospitality and hostility in hospitals: a case study of an EPR adoption among surgeons. European Journal of Information Systems 2007; 16(6):672-680.

(123) Davis FD. Perceived usefulness, perceived ease of use, and user acceptance of information technology. Mis Quarterly 1989; 13(3):319-340.

(124) Dant T. Materiality and Society. Maidenhead, Buckinghamshire: Open University Press; 2004.

(125) Gibson B. Framing and taming 'wicked' problems. In: Lin V, Gibson B, editors. Evidence-based health policy. Oxford: Oxford University Press; 2003.

(126) Clay R. Summary Care Record Scope. Downloadable from http://www.connectingforhealth.nhs.uk/systemsandservices/scr/documents/scrscopel.pdf. London: Connecting for Health; 2009.

(127) RCGP Health Informatics Group. GP Summary Component of the NHS Summary Care Record. Downloadable from http://www.scimp.scot.nhs.uk/documents/RCGPSummaryCareRecordGPSummaryFinal.pdf. London: Royal College of General Practitioners; 2007.

(128) RCGP Health Informatics Group. Informing Shared Clinical Care: Final Report of Shared Record Professional Guidance Project. London: Royal College of General Practitioners and Connecting for Health; 2009.

(129) Horsfield P, Sibek S. Representation in Electronic Patient Records of Allergic Reactions, Adverse Reactions, and Intolerance of Pharmaceutical Products. Downloadable from https://svn.connectingforhealth.nhs.uk/svn/public/nhscontentmodels/TRUNK/ref/NPfIT/Allergy_ADR_Intolerance%20v%201.2Final.doc. London: Connecting for Health; 2006.

(130) British Computer Society Health Informatics Forum. The way forward for NHS health informatics: where should NHS Connecting for Health (NHS CFH) go from here? Downloadable from http://www.bcs.org/upload/pdf/BCS-HIF-report.pdf. London: BCS; 2006.

(131) Primary Health Care Specialist Group of BCS. Report of Clinical Special Interest Group on topic: "What accreditation process should be used by PCTs before GP practices are allowed to upload data to the Summary Care Record (SCR)?". London: British Computer Society; 2009.

(132) Braunold G. Principles for Implementing Permission to View for the Summary Care Record to support the diversity of care settings in the NHS. Downloadable from http://www.connectingforhealth.nhs.uk/systemsandservices/scr/staff/aboutscr/documents/principles.pdf. London: NHS Connecting for Health; 2009.

(133) Foucault M. Power/Knowledge: Selected Interviews and Other Writings 1972-1977. New York: Pantheon; 1980.

(134) Bloomfield BP. Power, Machines and Social Relations: Delegating to Information Technology in the National Health Service. Organization 1995; 2(3-4):489-518.

(135) Timmons S. A failed panopticon: surveillance of nursing practice via new technology. New Technology, Work and Employment 2003; 18:143-153.

(136) Laming L. The Protection of Children in England: A Progress Report. London: The Stationery Office; 2009.

(137) Murray J. Why the delay in launching database? Guardian 2008 Sep 2.

(138) Bannon M, Carter Y. Protecting children from abuse and neglect in primary care. Oxford: Oxford University Press; 2002.

(139) Greenhalgh T. Notes on collaborative support networks for Early Adopter PCTs who are attempting to implement the Summary Care Record. Discussion paper submitted to CFH. London: University College London; 2007.

(140) Øvretveit J, Bate P, Cleary P, Cretin S, Gustafson D, McInnes K et al. Quality collaboratives: lessons from research. Qual Saf Health Care 2002; 11:345-351.

(141) Russell J, Greenhalgh T, Boynton P, Rigby M. Soft networks for bridging the gap between research and practice: illuminative evaluation of CHAIN. BMJ 2004; 328(7449):1174.

(142) Howlett P, Beale P. Outline Business Case for HealthSpace Extension. London: NHS Connecting for Health; 2008.

(143) House of Commons Health Committee. The electronic patient record. Sixth report of session 2006-7. London: The Stationary Office; 2007.

(144) National Household Survey. Internet Access: Households and Individuals. Accessible on http://www.statistics.gov.uk/StatBase/Product.asp?vlnk=5672. London: Office of National Statistics; 2009.

(145) Star SL. Infrastructure and ethnographic practice: working on the fringes. Scandinavian Journal of Information Systems 2002; 14(2):107-122.

(146) Currie WL, Guah MW. Conflicting institutional logics: a national programme for IT in the organisational field of healthcare. Journal of Information Technology 2007; 22:235-247.

(147) Young K. 'Values' and the policy process. Policy and Politics 1977; 5(3):1-22.

(148) Anderson R. Confidentiality and connecting for health. Br J Gen Pract 2008; 58(547):75-76.

(149) Donaldson LJ. Clinical governance: a mission to improve. Clin Perform Qual Health Care 2000; 8:6-8.

(150) Harrison S, Wood B. Scientific-bureaucratic medicine and UK health policy. Review of Policy Research 2005; 17(4):25-42.

(151) Timmermans S, Berg M. The gold standard: The challenge of evidence-based medicine and standardization in health care. Philadelphia: Temple University Press; 2003.

(152) Montgomery J. Personal information in the National Health Service: the demise or rise of patient interests? In: Lace S, editor. The Glass Consumer: Life in a Surveillance Society. London: National Consumer Council; 2005. 187-204.

(153) March S, Smith G. Design and natural science research on information technology . Decision Support Systems 1995; 15:251-266.

(154) Berg M. The search for synergy: interrelating medical work and patient care information systems. Methods of Information in Medicine 2003; 42:337-344.

(155) Oudshoorn N, Pinch TE. How users matter: the co-construction of users and technology. Cambridge, MA: The MIT Press; 2005.

(156) Pfeffer J. Barriers to the Advance of Organizational Science: Paradigm Development as a Dependent Variable. The Academy of Management Review 1993; 18(4):599-620.

(157) Judge K, Bauld L. Strong theory, flexible methods: evaluating complex community-based initiatives. Critical Public Health 2001; 11:19-38.

(158) Klein HK, Myers MD. A set of principles for conducting and evaluating interpretive field studies in information systems. Mis Quarterly 1999; 23(1):67-93.

(159) Habermas J. The theory of communicative action. Boston: Beacon; 1987.

(160) Mishler EG. The Discourse of Medicine: Dialectics of Medical Interviews. Norwood, N.J.: Ablex; 1984.

(161) Lane J-E. New Public Management. London: Routledge; 2000.

(162) Perlow LA. The time famine: Towards a sociology of work time. Administrative Science Quarterly 1999; 44:57-81.

(163) Callon M. Some elements of a sociology of translation: domestication of the scallops and the fishermen of St. Brieuc Bay. In: Law Je, editor. Power, action, and belief: a new sociology of knowledge. London: Routledge; 1986.

(164) Davies M, Eccles S, Braunold G, Winfield M, Thick M. Giving control to patients. Br J Gen Pract 2008; 58(548):148-149.

(165) Thick M, Davies M, Eccles S, Braunold G, Winfield M, Pujara M et al. Connecting for health. Br J Gen Pract 2008; 58(548):204-205.

(166) Tait C, Braunold G, Jeeves R, Hopwood L, Thick M. Summary Care Record – the Bury experience. European Journal of Palliative Care 2009; 16(3):124-126.

(167) Braunold G. Age of consent. Health Serv J 2008; Suppl:9.

(168) Polanyi M. Personal Knowledge: Towards a Post-Critical Philosophy. Chicago: University of Chicago Press; 1958.

(169) Shilling C, Mellor C. Cultures of embodied experience: technology, religion and body pedagogics. Sociological Review 2007; 55(3):531-549.

(170) Bowker GC, Timmermans S, Star SL. Infrastructure and organizational transformation: classifying nurses' work. In: Orlikowski WJ, Walsham G, Jones M, DeGross JI, editors. Information technology and changes in organizational work. London: Chapman and Hall; 1995. 345-370.

(171) Stevens T. Privacy 101: Introducing the Laws of the Bleedin' Obvious. Available on http://www.computerweekly.com/blogs/the-data-trust-blog/2009/03/privacy-101-introducing-the-la.html. Computer Weekly 2009; March(3).

(172) Clyne W, Blenkinsopp A, Seal R. A guide to medication review. Keele: National Prescribing Centre; 2008.

(173) Latour B. Aramis, or love of technology. Translated by Catherine Porter. London: Harvard University Press; 1996.

(174) Berg M. Implementing information systems in health care organizations: myths and challenges. International Journal of Medical Informatics 2001; 64:143-156.

(175) Berg M, Timmermans S. Orders and their others: On the constitution of universalities in medical work. Configurations 2000; 8:31-61.

(176) Randell B. A Computer Scientist's Reactions to NPfIT. Journal of Information Technology 2007; 22(3):222-234. Available at www.palgrave-journals.com/jit/journal/v22/n3/full/2000106a.html.

(177) Nussbaum M. Upheavals of thought: The intelligence of emotions. Cambridge: Cambridge University Press; 2001.

(178) Fentl J. Knowing-How and Knowing-That. Philosophy Compass 2008; 3(3):451-470.

(179) Handy C. Gods of management: The chanigng work of organisations. Oxford: Oxford University Press; 1995.

(180) Hardy C, Clegg SR. Some dare call it power. In: Clegg SR, Hardy C, Nord WR, editors. Handbook of Organizational Studies. London: Sage; 1996.

(181) Willcocks LP. Michel Foucault in the Social Study of ICTs: Critique and Reappraisal. Social Science Computer Review 2006; 24(3):274-295.

(182) Bowker GC, Star SL. Sorting things out: classification and its consequences. Cambridge, MA: The MIT Press; 1999.

(183) Gross AG, Walter M. The *Challenger* Disaster And The Revival Of Rhetoric In Organizational Life. Argumentation 1997; 11(75):93.

(184) Lilford RJ, Foster J, Pringle M. Evaluating eHealth: how to make evaluation more methodologically robust. PLoS Med 2009; 6(11):e1000186.

(185) Meyer AD, GOes JB, Brooks GR. Organizations reacting to hyperturbulence. In: Huber GP, Glick WH, editors. Organizational Change and Redesign. New York: Oxford University Press; 1993. 66-111.

(186) MacDonald B, Kushner S. Democratic Evaluation. In: Mathison S, editor. Encyclopedia of Evaluation. Thousand Oaks, CA: Sage; 2004.

(187) Pagliari C, Donnan P, Morrison J, Ricketts I, Gregor P, Sullivan F. Adoption and perception of electronic clinical communications in Scotland. Inform Prim Care 2005; 13(2):97-104.

(188) Protti D, Bowden T, Johansen I. Adoption of information technology in primary care physician offices in New Zealand and Denmark, part 1: healthcare system comparisons. Inform Prim Care 2008; 16(3):183-187.

(189) Protti D, Bowden T, Johansen I. Adoption of information technology in primary care physician offices in New Zealand and Denmark, part 2: historical comparisons. Inform Prim Care 2008; 16(3):189-193.

(190) Protti D, Bowden T, Johansen I. Adoption of information technology in primary care physician offices in New Zealand and Denmark, Part 3: Medical record environment comparisons. Inform Prim Care 2008; 16(4):285-290.

(191) Protti D, Bowden T, Johansen I. Adoption of information technology in primary care physician offices in New Zealand and Denmark, Part 4: Benefits comparisons. Inform Prim Care 2008; 16(4):291-296.

(192) Protti D, Bowden T, Johansen I. Adoption of information technology in primary care physician offices in New Zealand and Denmark, part 5: final comparisons. Inform Prim Care 2009; 17(1):17-22.

(193) Protti D. Comparison of information technology in general practice in 10 countries. Healthcare Quarterly 2007; 10(2):107-116.

(194) Edwards J. Denmark's achievements with healthcare information exchange. Case study G00139713. Available from http://www-03.ibm.com/industries/ca/en/healthcare/files/gartner-case_study-denmarks_achievementswHIE.pdf. Stamford, Conneticut: Gartner Industry Research; 2006.

(195) Silvestre A-L, Sue VM, Allen JY. If you build it, will they come? The Kaiser Permanente model of online health care. Health Aff 2009; 28(2):334-344.

(196) Chen C, Garrido T, Chock D, Okawa G, Liang L. The Kaiser Permanente Electronic Health Record: Transforming and Streamlining Modalities of Care. Health Aff 2009; 28(2):323-333.

(197) Wanless D. Securing the Public Health: Taking a long term view. London: Department of Health; 2004.