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SUMMARY CARE RECORD EARLY ADOPTER PROGRAMME

**An independent evaluation by University
College London**

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Preface

It has been both a privilege and a challenge to lead the independent evaluation of the Summary Care Record Early Adopter Programme in England.

It has been a privilege because the questions raised by this project are fundamental to the performance of healthcare systems in the 21st century. These questions include how to harness the potential of IT to support efficient, seamless healthcare, especially for patients with complex needs; how (if at all) to make sensitive personal data widely accessible in a vast, bureaucratic and geographically dispersed organisation; how and to what extent clinicians should share uncertainties and risks with patients; how to support vulnerable members of society to make appropriate, informed choices; and how to manage competing policy 'must-dos' from a limited budget.

It has been a challenge because the evaluation centres around a number of critical tensions: between central control and local emergence; between private-sector investment and public-sector values; between accessibility of data and protection of privacy; between algorithmic models of the clinical encounter and its messier, less predictable reality; between formal protocols and informal workarounds; and between blissful ignorance and effortful, informed choice. An early finding of this evaluation was that many stakeholders tended to polarise these tensions into simplistic and morally absolute dualisms ('bad' central control versus 'good' local emergence; 'bad' technical designers versus 'good' caring clinicians, and so on), and demonise what they characterised as the 'other side'. These entrenched positions preclude effective dialogue. It is time to move on from them.

A key audience for this report is NHS Connecting for Health – at least in the sense that they paid for it and helped pose the official research questions set out in paragraph 2.3.3.. But there are other audiences, and wider questions. Shared electronic patient records have been strongly backed by the current government and opposed by a number of lobbying groups. This evaluation, was commissioned (as part of the broader Connecting for Health Evaluation Programme) after a Ministerial Taskforce report,¹ though it might have been commissioned anyway. When we were awarded the contract, we were asked to focus mainly on the implementation of the Summary Care Record as a technology. But the political context proved impossible to ignore, since as an anonymous reviewer of an earlier draft of this report pointed out, “[The] SCR programme has acted as a lightning rod for concerns over politics, health service management, the cost of NPfIT and shared records in general.”

There are many people who wish to develop an informed opinion on the Summary Care Record – patients who wonder whether to 'opt in', 'opt out', or take some middle ground option; citizens who question how their taxes are being spent; GPs who struggle to redefine what 'confidentiality' means in the information age; investors who wonder whether this latest NHS IT project is a risk too far; and the responsible press, who wish to cover an important story beyond the obvious soundbite headlines. All of them must first engage in a debate about how the critical tensions set out above (which will never go away, because they are *inherent* to the complexity of the problem) play out in different situations and settings. The debate must address what large-scale networked electronic records mean for each of us personally and for the National Health Service generally. This report does not seek to prejudge the outcome of that debate, but to illuminate the issues in a way that informs it.

Professor Trisha Greenhalgh OBE
April 2008

1. Executive summary

Background and context

- 1.1. The Summary Care Record (SCR) is a centrally stored health summary created (currently) from a person's general practitioner (GP) record. It contains details of medication, allergies and adverse reactions and is accessible on a secured Extranet – known as N3 – which will offer connectivity to a wide range of National Health Service (NHS) staff. It is intended to support care when other records are unavailable or incomplete (e.g. emergency and unscheduled care). HealthSpace is a separate, Internet-accessible technology that allows patients to record and organise their own health data, and via which they will be able to view their SCR. People do not have to have a SCR but if they do not want one, they must actively opt out. HealthSpace is also voluntary but people must opt in. People with no Internet access may ask their GP for a printout of their SCR.
- 1.2. The SCR and HealthSpace form part of a wider programme within the Department of Health, known as the National Programme for IT (NPfIT), which is delivered centrally via an organisation called NHS Connecting for Health (CFH) and locally by Strategic Health Authorities and Primary Care Trusts. The NPfIT is very ambitious in size and scope. It has been both praised (because modern, efficient IT systems are seen as linked to quality and safety in healthcare, and because contracts with IT suppliers were drawn up in a way that passed much of the risk to the private sector) and criticised (for being too ambitious, too centrally driven, too closely linked to political goals, and too focused on 'technology push' at the expense of wider socio-technical change).
- 1.3. CFH is a large, hierarchical organisation whose work on the SCR has been characterised by detailed planning, tight monitoring, extensive documentation, and frequent reporting. CFH has had negative coverage by some sectors of the press in the past, which has led to a somewhat defensive and controlling approach to the release of information.
- 1.4. The SCR and HealthSpace are being introduced in six Early Adopter sites across the UK, of which this evaluation studied four. Each consisted of a Primary Care Trust, participating GP practices, and linked unscheduled care settings (e.g. Accident and Emergency department, walk-in centre, out-of-hours service, and minor injuries unit).
- 1.5. This evaluation used mainly but not exclusively qualitative methods, comprising around 1500 hours of ethnographic observation within CFH and the Early Adopter sites; 250 interviews with NHS staff; some 2500 pages of correspondence and documentary evidence; interviews and focus groups with 170 NHS patients and carers; and incorporation of relevant surveys and statistics produced by others. Details of data collection, analysis and synthesis are described in the main report.
- 1.6. Stakeholders (including politicians and taxpayers) expect the investment in the SCR to reap a number of benefits including improved patient safety (especially reduction in medication errors and adverse reactions); improved quality of care, especially in the acute situation and in particular for vulnerable groups (e.g. limited English speakers); better efficiency of care (e.g. reduced duplication of tests, faster patient throughput); better coordination of care (hence fewer unnecessary hospital admissions); more informed and engaged patients; and improved openness and trust between patients and health professionals.

Implementation in the Early Adopter sites

- 1.7. Key stages in implementing the SCR programme in Early Adopter sites were set-up (establish management and governance infrastructure; recruit staff); preparation (ensure that practices meet minimum data quality standards; raise public awareness of the SCR; and provide patients with an opportunity to opt out if they did not wish to have a record); creation of SCRs from GP records (coordinate the timetable in which successive practices 'go live', also referred to as 'the upload'); and deployment (support SCR use in emergency and unscheduled care). Some PCTs introduced HealthSpace at the same time as the SCR; others addressed these tasks separately.
- 1.8. All PCTs studied appeared to be well-managed organisations with strong leadership and a tradition of ICT innovation. They made good progress in the set-up period, though this was hard work all round. Much preparatory work was undertaken by PCTs and GP practices to improve data quality for the SCR, and this linked with wider national incentives on primary care data quality. Whilst many participating practices began with mediocre data, the process for data quality improvement was good, and rapid progress was made in many (though not all) practices. Participation in the SCR programme appeared to be a strong incentive for data quality improvement initiatives that had wider relevance to PCTs and GP practices.
- 1.9. The first Early Adopter site began preparation in spring 2007 and the first SCRs were created in June 2007 ('go-live'); deployment in unscheduled care settings began on a limited scale in October 2007. In the second site, the first records were created in October 2007 and deployment began in February 2008. In the third and fourth sites (where most GP practices were served by different software suppliers), go-live had not been achieved by end April 2008. A major problem was failure of some but not all software contractors to deliver key technologies to agreed schedules.
- 1.10. When the SCR was first deployed in unscheduled care settings, there were a number of technical glitches and operational problems with the SCR (and more widely, with the Clinical Spine Application on which it is held). In a project of this scale and complexity, this is not surprising, but even relatively minor problems sometimes led to long delays and considerable frustration in all participating organisations.
- 1.11. As of end April 2008, the SCR of 153,188 patients in the first two sites had been created. A total of 614,052 patients in four Early Adopter sites have been sent a letter informing them of the programme and their choices for opting out of having a SCR (or limiting access to it). Of these, 4961 (0.81%) have actively opted out of having a SCR and 154 (0.03%) have asked for data on their SCR not to be shared.
- 1.12. There was some resentment amongst participating PCTs that CFH allegedly pushed forward on a tightly-managed, largely non-negotiable timetable for implementing the SCR despite the immaturity of technical solutions. Some GP practices and unscheduled care providers felt that they were pushed excessively by PCTs. Some but not all clinicians' leaders believed they were not adequately consulted, and generally attributed this to time pressure rather than hostility from the PCT. It was recognised that CFH were under pressure to redress what had been described by a House of Commons Committee as a "*worrying lack of progress*" on the NPfIT.
- 1.13. The SCR was introduced at a time when a number of media stories reported large-scale data loss by government and the NHS. There were also questions from professional bodies about whether a GP who creates a SCR from a patient record is 'breaching confidentiality', especially if there is no clear evidence that the patient has received, read and understood correspondence about it.

Critical factors influencing the progress of the SCR programme to date

- 1.14. Material properties and attributes of the technology [negative mediator]
 - a. The SCR is currently an immature technology which staff have described as “*clunky*” and which currently interfaces poorly with other ICT systems. Many staff have given up using it “*until it works better*”.
 - b. There is wide variability amongst NHS staff on whether they feel the SCR has significant benefits, though most are broadly enthusiastic.
 - c. The SCR is widely seen as “*too complex*”, to the extent that many see it as unworkable in its current format.
 - d. The SCR is seen by some GPs as incompatible with a fundamental part of their professional role and identity – protector of patient confidentiality.
 - e. The ‘observability’ of the benefits of the SCR is more apparent to some users (mainly A&E and OOH staff) than others (mainly GPs and their staff who create the record), though there is some overlap between these groups.

- 1.15. Concerns of potential adopters [negative mediator], which include:
 - a. GPs who are participating (or considering participation) in the SCR programme worry about workload, especially in the phase 2 upload in which selected aspects of patients’ medical history will be added to the record by explicit consent. Much uncertainty surrounds how phase 2 (which has only just begun in two practices) will play out in practice.
 - b. Some GPs are also concerned about the ethics and legality of creating a SCR on a patient who has not given full informed consent. These concerns have led at least two GP practices to withdraw from the Early Adopter Programme.
 - c. The practicalities of SCR use, such as time taken to access it and how it will align with existing work roles and routines. Early usage in unscheduled care settings suggests that job roles and patterns of interaction between healthcare staff sometimes have to be rethought. This is not necessarily a bad thing but it may temporarily delay efficient use of the SCR.

- 1.16. The impact of interpersonal influence [positive mediator], including:
 - a. ‘Champion’ roles such as the GP National Clinical Leads for the NPfIT (who traveled the country to hold a series of well-received ‘engagement events’ for their colleagues), and ‘local champions’ (GPs and managers who sold the idea of the SCR to their colleagues and encouraged participation).
 - b. Data quality facilitators (DQFs), who visited GP practices and provided bespoke, flexible support and training to help practices achieve the necessary accreditation for inclusion in the programme.
 - c. Interpersonal influences on patients, including family, NHS staff (especially GPs), trusted advisers in community organisations, and other patients.

- 1.17. Antecedents for innovation in participating organisations [positive mediator], including:
 - a. Strong leadership, clear strategy, and a tradition of similar projects in IM&T.
 - b. Slack resources (i.e. spare human and technical capacity) that could be used to buffer the stress of innovation. Our data suggest that the impact of technical and operational glitches was magnified by the fact that organisations were already running at or close to maximum capacity, with limited slack to buffer them.

- 1.18. Organisational readiness for the SCR [positive mediator], including:

- a. Innovation-system fit. All PCTs studied had assessed the implications of the SCR and made an explicit strategic link between introducing it locally and improving patient care (most usually, to develop emergency and out-of-hours services).
- b. Tension for change. All PCTs studied had varying reasons to be dissatisfied with the status quo and saw the SCR as helping solve a specific problem (e.g. overcrowded A&E department, high burden of need in long term conditions).
- c. Specific preparedness, especially in relation to data quality accreditation.
- d. Sufficient resources (time, money, staff) specifically allocated to the project.

1.19. Operational aspects of the implementation [positive mediator], including:

- a. Good project management and the devolution of operational decision-making to teams charged with delivering on the project. When micro-management from the centre was perceived to have occurred, it was widely resented.
- b. Successful recruitment and retention of high quality staff who had both relevant skills (e.g. project management, ICT), experience (in the NHS), and personal qualities (especially interpersonal skills and flexibility). Where continuity of key staff was lost, or where these staff lacked credibility or engagement with local teams, project momentum suffered.
- c. Enough (but not too much) training for front-line staff at the right time in a real working environment. The IT literacy of many NHS staff was low. Formal training by CFH, whilst of a high standard and well evaluated by participants, did not always have a positive impact on the ability of staff to actually use the system. This was partly due to time lags in deployment but also highlights the need for ongoing, local, on-the-job training that takes account of both individual learning needs and the contextual practicalities of particular roles and routines.
- d. Real-time monitoring of progress e.g. via collection of, and reflection on, performance statistics.

1.20. The wider context [negative mediator], especially:

- a. The high political profile of the SCR programme ensured that it remained high on the strategic priority list, but this also created a climate of pressure that sometimes had negative impact. For example, local project leaders struggled to align political timescales with the pace of clinical engagement and the readiness of technical solutions.
- b. Negative publicity from a small but hostile sector of the press and pressure from some vocal lobby groups engendered anxiety in both staff and patients and (at times) defensive reactions from CFH.

The patient perspective on the SCR and HealthSpace

1.21. In over 100 interviews conducted by our team with patients in Early Adopter sites, a high proportion of them did not recall having received information about the SCR or HealthSpace. This was despite an extensive public information programme that had included individual letters sent from PCTs or GP practices, posters, leaflets, roadshows, and liaison events with voluntary sector groups.

1.22. Most patients saw both benefits and disbenefits to having a SCR. They described a process of weighing the former against the latter when making their personal choice. Key factors influencing this choice included the nature of any illness (especially whether it was likely to lead to emergency care needs); past and present experience of both healthcare and government surveillance; the person's level of engagement and health literacy; and their trust and confidence in the primary healthcare team, the wider NHS, and the government. People who had had personal experiences relevant to a decision about the SCR (such as an error in their medical record, an adverse

reaction to a drug, or an episode of loss of consciousness) tended to have strong views about it one way or the other. Those without direct personal experience had often never thought about it and took a more neutral or undecided view.

- 1.23. Seven focus groups were held with people with particular communication needs and/or whose record might contain sensitive information. Participants were, overall, more positive about the SCR than advocates who claimed to speak for 'vulnerable groups'. This seemed to be because whilst the potential risk (of disclosure of confidential information) was higher in individuals with serious illness, so were the perceived benefits of having a SCR. Most people, particularly those with potentially stigmatising illness (mental health problems, HIV) generally wanted to have a SCR but (importantly) also wanted to control who had access to it at the point of care.
- 1.24. A person's trust (or lack of trust) in a member of NHS staff appeared to be a property of the relationship with a particular individual rather than of that person's formal role or job status, and varied considerably with the individual patient. This suggests that generic role based access controls may be less suited to supporting patients' choices than consent at the point of access.
- 1.25. In contrast to an anticipated benefit of the SCR – that it will increase trust and openness between patients and clinicians – both patients and staff in our interviews described scenarios in which they might use the SCR to assist in negotiations when they did *not* trust the other party. Patients, for example, anticipated that the SCR would confirm that they had genuinely been ill on a previous occasion, or were really on the tablets they claimed to be on. Staff hoped that the SCR would provide an objective account of what the problem was, when otherwise they would only have the patient's fallible version. But others worried that the SCR might lend false objectivity to inaccurate entries by staff, with far-reaching consequences. These findings suggest an important agenda for further research into the role of the SCR in mediating (or substituting for) trust between patients and healthcare staff.
- 1.26. Misconceptions about the SCR were common amongst patients, especially confusion about what data it contained and who would have access to it. The most serious misconception was confusion between the SCR and the detailed general practice record. For example, a number of people believed that they would be able to use their SCR to check the detail of a recent consultation with their GP.
- 1.27. In this evaluation, levels of interest in HealthSpace amongst patients and the public were low. Uptake of HealthSpace is currently very low, with only 0.12% of those invited to open an account actually completing the process. Most people were not interested in recording their medical data or accessing their SCR via HealthSpace, and some saw HealthSpace as potentially undermining an existing good relationship with their GP (because of the implication that it could be used to check up on the GP's performance). Some people, however, saw the potential for HealthSpace to support self-management and lay care for those with chronic and serious illness.
- 1.28. In contrast to the claims of campaign groups that the introduction of the SCR is an affront to civil liberties, many people readily admitted to being "*not bothered*" whether they had a SCR or not, but if anything they welcomed it because it meant that there was less need for them to remember what was wrong with them or what medication they were on. Particularly in people with low health literacy, lack of interest in seeing their own health data appeared to be the key moderating factor which explained the mismatch between the decision to have a SCR (for most people 'yes' or 'don't care') and the decision to have a HealthSpace account (for most people 'no').

Comment

- 1.29. The hoped-for benefits of the SCR (notably improvements in the quality and safety of care and the opportunity for patients to be more actively involved in their care) remain unproven, but this is not surprising since there has not yet been sufficient opportunity to demonstrate them.
- 1.30. All Early Adopter PCTs studied in this evaluation scored highly on organisational antecedents for technology-supported change, organisational readiness for the SCR, and operational aspects of managing the project. They faced, and successfully overcame, numerous challenges in different aspects of the programme. It should be noted that these sites had been selected for key characteristics that seemed to account for their success. PCTs that come on board subsequently may have weaknesses that were not apparent in the Early Adopters.
- 1.31. The SCR raises important ethical and practical questions. It has potential benefits and potential disbenefits. Public debate up to now has tended to be conducted by the minority of individuals with extreme views (positive or negative) and been somewhat simplistic, polarised and tied to hypothetical situations. It is time to focus the debate on how the balance between benefits and disbenefits might play out for different individuals in different circumstances, and how these may change over time.
- 1.32. At this early stage in the deployment of the SCR, our findings do not support the *a priori* use of any particular definitions or metrics of success. In our view, any 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 the fitness for purpose of such metrics must be continually questioned as the programme develops. The justification for this is set out in Section 7.2.
- 1.33. The SCR team within CFH has been criticised (in our view, justifiably) for taking a narrow and instrumental focus on implementing a technology rather than a broader and more developmental focus on socio-technical change. A shift to a more socio-technical perspective would change the SCR programme considerably – for example, the SCR would no longer be seen as an end in itself (with ‘success’ measured in terms of number of records created and extent of use) but as a means to other ends (with ‘success’ being defined in terms of a range of locally relevant ends, for which the SCR would be provided as a resource). This important potential change in the scope of the programme is discussed further in Section 7.3.
- 1.34. The SCR programme was approached by CFH via what many management academics would view as an outdated model of change – centrally driven, project-oriented, rationalistic, with a focus on documentation and reporting, and oriented to predefined, inflexible goals. More contemporary models of change (which are programme-oriented and built around theories of sensemaking, co-evolution and knowledge creation) include soft systems methodology, technology use mediation and situated action. Their advantages are discussed further in Section 7.4.
- 1.35. Some stakeholders wanted this evaluation to “*measure the workload*” associated with the creation, deployment and maintenance of the SCR. Whilst this was seen by some as a simple exercise in accounting for time spent on SCR-related tasks, the evaluation revealed a more complex and less easily quantifiable picture. Workload for the SCR overlaps with other work (most obviously, the duty of all doctors to maintain accurate and up-to-date patient records); it will vary with the choice of consent model; and it will increase with the assiduousness of efforts to encourage patients to consider their choices. Workload is discussed further in Section 7.5.

- 1.36. There is a widespread desire from patients and staff for a simpler consent model. The current model (referred to as a 'hybrid') is one of implied consent (opt-out) for the initial phase 1 upload of medication, allergies and adverse reactions, and express consent (opt-in) for any additional uploads. The ethical and practical challenges of changing the consent model are discussed in Section 7.6.
- 1.37. Whilst the technical security measures of the SCR appear to meet high standards, and whilst nobody is yet known to have 'hacked' into the N3 network, there remain unresolved questions raised by experts about whether a series of linked smaller systems would be safer than a large single system, and whether the plans for operational security will be fully enforceable in the busy environment of the NHS. Security is discussed further in Section 7.7.
- 1.38. There is a tension between tightly defining the intended use (or a limited set of uses) for the SCR so that there is clarity on the specification, and encouraging (or even permitting) end users to develop additional uses. Data from this evaluation suggest that a narrowing of intended use cases would be welcome, at least in the early stages of deployment. The reasons for this are discussed in Section 7.8.
- 1.39. The SCR was specifically intended to help address the "inequalities agenda" – that is, improve health outcomes especially for such groups as the disempowered, the socially excluded, those with communication difficulties, the very elderly and the very sick. Our data suggest that despite commendable efforts on the part of CFH and participating PCTs to address the needs of these groups, there is much work still to be done. Examples of unresolved challenges are given in Section 7.9.
- 1.40. We found numerous examples of confusion and miscommunication between PCTs and CFH over "national" versus "local" responsibility for particular parts of the programme, and also a limited tendency for PCTs to communicate laterally with one another. This may be partly because the NPfIT Local Ownership Programme was introduced part-way through this evaluation, but we suspect that the tension between centre and periphery should be addressed proactively rather than left to resolve with time. This is discussed further in Section 7.10., which includes reference to a more radical model of 'local ownership' currently being discussed in the USA.

Points for stakeholders to consider

- 1.41. In view of the finding that choices about the SCR are personal, context-bound and change with time (i.e. that there is no universal 'right' choice), we suggest that all citizens (to the extent that they are able to) might ask themselves two questions:
 - a. Am I happy for selected information from my GP record to be made available for access by NHS staff in an emergency or when my full records are unavailable?
 - b. If not, do I know my options for opting out or withholding selected items?
- 1.42. Carers and advocates of people whose ability to make choices or communicate in English is limited (including people with frail elderly relatives, and those who interpret for limited English speakers) might consider presenting key information about the SCR and HealthSpace to them so as to help them consider the above questions.
- 1.43. We encourage patients, carers, patient organisations, and the voluntary sector to take an active part in public debate on how to address the needs and support the choices of different groups. People in an advocacy role should note a key finding of this evaluation: that many 'vulnerable' individuals were more positive about the SCR and HealthSpace than people who sought to speak on their behalf.

- 1.44. We suggest that NHS staff ensure they know about the SCR and can explain to patients how it will be used in different circumstances and the options for opting out.
- 1.45. Organisations involved in the implementation and early deployment of the SCR should note the important if unsurprising finding from this evaluation that success appears to depend on good leadership, clear strategy, efficient project management, attention to human resource issues (especially retention and training), thorough groundwork (especially around data quality), facilitation, and monitoring of progress.
- 1.46. Participating PCTs should consider developing links with other PCTs (for example, via exchange visits, bulletin board, workshops, learning sets and so on) so that mutual support and informal exchange of resources and ideas can occur.
- 1.47. Professional organisations and advisory bodies should note that the findings of this evaluation suggest that it would be inappropriate to impose context-free rules or recommendations about the use of the SCR, and that as in other aspects of clinical care, professional judgements should be made with attention to context and the needs, wishes and understanding of the patient.
- 1.48. The BMA should note that the evaluation team tried but has so far failed to produce clear answers to the ethical and practical questions its members have raised about the SCR. To some extent, the expectation for simple and generalisable answers to complex and contingent questions was unrealistic. However, greater clarity on some questions, especially workload for phase 2 uploads, is likely to emerge with time.
- 1.49. At an operational level, given that the implementation of the SCR continues to unfold, we suggest that the SCR Programme Board and Advisory Group pay urgent attention to four tasks:
 - a. Reflect on the distinction between ‘project management’ and ‘programme management’ set out in Section 7.11. of the main report, and consider shifting to a more flexible and adaptive approach to change as outlined in Section 7.4.
 - b. Review the current ‘hybrid’ consent model for the SCR, which is widely seen as overly complex and unworkable (and which many GPs and Caldicott Guardians see as unethical), and consider alternative models, notably ‘consent to view’, that have been shown to be acceptable and successful in comparable programmes elsewhere (see Section 9.4.).
 - c. Review the programme’s tendency to scope creep and consider developing a tighter definition of what the SCR is to be used for, at least until key decisions (such as the content of the phase 2 upload) have been agreed.
 - d. Ensure that ‘benefits realisation’ work is more balanced, e.g. by considering how the tension between benefits and disbenefits plays out in different situations.
- 1.50. At a more strategic level, we suggest that the NPfIT National Programme Board consider carefully the finding of this evaluation (which confirms previous observations by academics and policy analysts) that ‘technology push’ is being prioritised at the expense of attention to wider socio-technical change and that this is, in the opinion of the evaluation team, a major risk to the success of the NPfIT. Should the Board seek to address this, it follows that fundamental changes are needed to the structure, culture and preferred change model of the NPfIT.
- 1.51. We suggest that the NPfIT National Programme Board consider uncoupling HealthSpace from the SCR programme. In the view of the evaluation team, stakeholders in HealthSpace should prioritise optimising the design and use of this technology in specific, clearly-defined use scenarios (e.g. supporting self-care in one

or two chronic conditions) before attempting to offer it to NHS patients more generally. To this end, partnerships with patient organisations and voluntary sector groups (which are already in place and being further developed) are strongly encouraged.

- 1.52. All those who set expectations for the SCR programme (government, programme planners, National Audit Office, and so on) should note that if the NHS is to attend to socio-technical aspects of the SCR in a way that embeds the programme effectively and maximises the chance of long-term sustainability, a more emergent and negotiable framework of timescales and deliverables will be needed.

2. Introduction

2.1. Background and context

- 2.1.1. “Computers are everywhere; you can’t get away from them,” said a patient we interviewed last month in an out-of-hours centre waiting room. This sentiment captures the unprecedented expansion of ICT in numerous aspects of public and private life in recent years. We access the Internet in coffee bars; we pay our household bills from our sitting rooms. And if we get ill, the doctors and nurses looking after us may soon be able to access key information from our personal medical record from any networked computer in the NHS.
- 2.1.2. Across the world, doctors who have struggled to work out what is wrong with an unconscious patient (or, more prosaically, to treat a visiting temporary resident who has forgotten what their little white tablets are called) share a dream that in the not-too-distant future there will be a universally accessible electronic patient record (EPR), linked to all the person’s healthcare providers and protected by appropriate access controls. As Prime Minister Tony Blair expressed it in 1998, “*If I live in Bradford and fall ill in Birmingham then I want the doctor treating me to have access to the information he needs to treat me.*”² In this dream, clinical care, especially in the emergency setting, will be better informed; fewer medical errors will occur; handovers between clinical teams will be smoother; limited English speakers and those with low health literacy will receive as high a standard of care as everyone else; and as the efficiency of care rises, its costs will fall.
- 2.1.3. The dream of a comprehensive, universally accessible EPR has not yet been realised on any significant scale anywhere in the world (though as the examples in Section 9.4. illustrate, some teams are coming close). Not only is the dream elusive; there are many examples worldwide of it returning to haunt those who try to achieve it.³ In general, the larger the scale of a healthcare IT project, the greater its chances of failure.^{4,5} This is because healthcare information systems are complex; they require large amounts of metadata (i.e. data about the data); and they raise unique technical, administrative and security challenges – the more so if interoperability between all parts of the system is required.^{4,6} The EPR has been likened to Disney’s *Sorcerer’s Apprentice* – a broom that is conjured up to ‘do medical work’ but which multiplies far beyond the original vision and exhausts its master in efforts to control and contain it.⁷
- 2.1.4. Yet the dream persists – partly because we are all excited by the potential of computers (which are linked in the policy unconscious with a ‘modern’ and ‘fit-for-purpose’ NHS⁸⁻¹²), partly because human error and poor coordination across the numerous interfaces in today’s complex health economy account for thousands of avoidable deaths every year,¹³⁻¹⁵ and partly because the most vulnerable members of society (the poor, those with communication barriers, the very elderly, 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.¹⁶⁻¹⁸ If Mr Blair becoming indisposed in Birmingham is the individual-level problem for which the universally-accessible EPR is the solution, then inefficiency, clinical error, poor coordination, poor continuity and inequality of access are the equivalent system-level problems it is intended to solve.
- 2.1.5. This, broadly, was the logic behind the National Programme for IT (NPfIT), an ambitious programme of work intended to deliver the EPR dream for the NHS in England.¹⁹⁻²¹ (Comparable programmes in Scotland and Wales are described in

Section 9.4.). The story of the NPfIT, of NHS Connecting for Health (CFH^A), the body charged with delivering it centrally, and of various precursor programmes and bodies including the NHS Information Authority (NHSIA) has been documented in detail elsewhere.^{6:22-24} In summary, large sums of money were invested in a programme widely described as “*the world’s largest civilian IT project*”, which had a number of key components:¹²

- The Spine, a national, central database that holds demographic, clinical and other information;
- The National Network for the NHS (N3), which would provide the secure infrastructure to allow electronic data exchange between organisations;
- The Personal Demographic Service (PDS), which would store demographic details (name, date of birth, address etc) of all NHS patients;
- Picture Archiving and Communication Systems (PACS, a paperless archive for X-rays and other digital images);
- Choose and Book (an electronic booking service for hospital outpatient appointments);
- Electronic Prescription Service (EPS, for transferring paperless prescriptions between GPs and community pharmacies);
- The Summary Care Record (SCR), which would be held on the Spine and contain essential clinical information needed in emergency and unscheduled care situations;
- Local Detailed Records (LDRs)^B, for example the record held by the patient’s GP, which would hold more extensive clinical information;
- The Secondary Uses Service (SUS), which would integrate data from different sources and make it available for audit and research purposes.

2.1.6. An important dimension of the NPfIT is the Connecting for Health Evaluation Programme (CFHEP). This was set up in April 2006, led by Professor Richard Lilford’s team at the University of Birmingham with the goal of commissioning, managing and following through a programme of research on behalf of CFH, influencing longer-term national research programmes to develop capacity in relevant areas, and informing the research uses of computer-held data in the NHS. To this end, a series of evaluation projects were commissioned (and some are still to be commissioned) to assess the usability, actual usage, functionality and impact of pilot and delivered systems within the NPfIT; provide informative and timely feedback to all relevant parties on what works, for whom, and how systems can be improved; disseminate findings widely; and promote an evaluative culture and evaluation capacity within CFH and the NHS. The SCR evaluation thus forms part of a wider programme of research which is both empirical (seeking findings from current projects) and methodological (seeking to generate knowledge about methods that will inform other evaluations).

2.2. The Summary Care Record and HealthSpace: in brief

2.2.1. The Summary Care Record (SCR) is a centrally stored summary of key medical details that is created from a person’s existing NHS record (initially, the one held by their GP) and made available to NHS staff in emergency and unscheduled care

^A The official name of the organisation is ‘NHS Connecting for Health’ but it is almost universally referred to as ‘Connecting for Health’ or ‘CFH’ except in official documents. For the sake of plain English, we have chosen to use the abbreviation ‘CFH’ throughout this document.

^B The term ‘Local Detailed Record’ was used with different meanings by different people. Some used the term to refer to the standard GP record; others used it more specifically to denote detailed records that were *locally* shared (typically including detailed community, child health and GP data). In this report we have tried to avoid unqualified use of the term ‘LDR’.

situations (A&E departments, GP out-of-hours clinics, and walk-in centres). It is comparable to (but differs in important respects from) the Emergency Care Summary in Scotland and the Individual Health Record in Wales (see Section 9.4.). It will initially contain details of medication, allergies and adverse reactions.

- 2.2.2. The SCR is currently being introduced across England in six 'Early Adopter' sites (of which four were studied in this evaluation).^C We were advised by CFH that several sites (rather than just one or two) were selected in what was called a 'flotilla' approach, in anticipation that there may be delays in the production of software by some technical suppliers. It is intended that a SCR will be created on every NHS patient who does not opt out (see below). It will link to the Personal Demographic Service (see paragraph 2.1.5. above).
- 2.2.3. Extensive technical safeguards have been built into the SCR and HealthSpace to prevent unauthorised access (e.g. by hackers). Role-based access controls restrict access to NHS staff with a legitimate relationship to the patient. All accesses of the SCR are logged and audited, and unauthorised accesses trigger automated alerts. These measures are discussed further in Section 3.5.
- 2.2.4. The current consent model for the SCR is one of implied consent or 'opt-out' (i.e. unless a person explicitly withdraws consent, their record will be created). Patients may choose one of three main options: 'don't store' (a blank SCR will be created; nothing will be placed on the record beyond the demographic details that are already on the Spine); 'store and share' (a full SCR will be created) or 'store but don't share' (a full SCR will be created but explicit consent must be obtained from the patient every time a health professional wishes to access it).
- 2.2.5. At the time of writing (April 2008), the information held on the SCR is limited to current medication, allergies and adverse reactions (the 'phase 1 upload'^D), but a minimum clinical dataset (e.g. whether someone is diabetic – the 'phase 2 upload') is being developed and added in selected sites. The content and purpose of 'minimum dataset' is the subject of ongoing negotiation and uncertainty at both local and national level.
- 2.2.6. Being introduced approximately in parallel with the SCR is HealthSpace, an Internet-accessible health record which enables people to input their personal medical details (such as blood pressure readings). HealthSpace also serves as a front end for NHS patients to access their SCR from home or from a public-access Internet connection. For storing their own medical details, individuals must create a *basic* HealthSpace account; in order to access their SCR, they must create an *advanced* account.

2.3. Aim and scope of this evaluation

- 2.3.1. This evaluation was commissioned via a competitive bidding process in March 2007 and officially ran from 1st May 2007 to 30th April 2008. Its aims were:
 - a. To assess the usability, usage, functionality and impact of the SCR in Early Adopter sites, and place this in context.

^C At the time of writing, one of the six sites selected had not yet signed the Memorandum of Understanding and is thus technically a 'potential' Early Adopter, but is included in SCR Implementation Board agendas and minutes.

^D The content of the phase 1 upload (medication and allergies) was developed after extensive consultation with professional bodies, especially the Royal College of General Practitioners, and was chosen partly because the accuracy of data in these fields was considered fairly high in most GP practices.

- b. To set the stage for the step-wise inclusion of further sites and further data sources.
 - c. To provide timely feedback to stakeholders.
 - d. To contribute to the generation of an evaluative culture within CFH and the NPfIT.
- 2.3.2. This evaluation was relatively small scale, comprising a one-year project with 2.5 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 (which is the responsibility of CFH; see also the detailed reports on the NPfIT produced by the National Audit Office²³ and Public Accounts Committee²⁴) and the individual NHS organisations involved in the programme.
 - b. Large-scale surveys of public awareness and opinion about the SCR and HealthSpace (for which CFH commissioned TNS UK and results are obtainable directly from CFH²⁵).
 - c. Local project management and monitoring, undertaken by the participating Primary Care Trusts in collaboration with locally based CFH staff, which included (for example) a detailed 'lessons learned' report for each Early Adopter site.
 - d. The work being undertaken by departments within CFH (and those in Strategic Health Authorities and PCTs), which seeks to identify and apply suitable metrics to monitor the success of implementation and the clinical and economic benefits of the SCR.
 - e. Public education and information about the SCR and HealthSpace, which are the responsibility of CFH's Communications Department and local PCTs.
 - f. Monitoring patient enquires to national helplines, which was the responsibility of NHS Direct.
- 2.3.3. The research questions for this evaluation were as follows:
- a. At the 'micro' level, what is the usability, usage, functionality, fidelity of implementation, and impact of the SCR in Early Adopter sites? What is the range of variability in all these phenomena within and between different Early Adopter sites, and what factors (in what combination) might explain this variability?
 - b. At the 'macro' level, what is the social, political, technological and economic context into which the SCR (as part of the NHS Care Records Service within the NPfIT) is being introduced? How does this context shape, enable and constrain micro level usability and usage – and how, conversely, does the experience at micro level impact on macro level issues?
 - c. What aspects and dimensions of the implementation of the SCR are seen by different actors and stakeholders as important? How (if at all) might these key dimensions be expressed as standards and aligned with one another? To what extent can measures be developed that are valid, applicable in practice, able to discriminate reliably between high, medium and low success, able to be applied in different geographical sites and healthcare contexts, and responsive to change?
 - d. What can we learn from this project about how best to evaluate the NPfIT and the work of CFH more generally?

2.4. Evaluation approach

- 2.4.1. We used Utilisation-Focused Evaluation, developed by Professor Michael Quinn Patton.²⁶ This approach is popular for large-scale evaluations of social interventions

in the USA, and has been used in Britain for programmes outside healthcare,^E but has not previously been used in e-health research. It is different from, but has parallels with, other interpretive approaches such as realistic evaluation²⁷ and what Paul Bate has described as ‘studying quality qualitatively’.²⁸ Patton defined programme evaluation 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].

2.4.2. Utilisation-Focused Evaluation is centrally concerned with the uses to which evaluation ‘products’ might be put and by whom. Before an evaluation begins – and as a critical part of its design – three questions must be addressed:

- What is the *purpose* of this evaluation?
- Who are the *audience(s)* for the evaluation?
- What *use* will the audience(s) make of the evaluation?

These questions are addressed in Section 2.6. (Key stakeholders and what they expect from the evaluation).

2.4.3. The utilisation-focused approach requires that, rather than an evaluation team being ‘commissioned’ as external experts to produce a set of ‘evaluation findings’ that can be ‘fed into’ a change process, the evaluators must enter a partnership with key stakeholders so as to facilitate ongoing learning and change. Utilisation-focused evaluators must be:

- *Active* in deliberately and calculatedly identifying intended users of their evaluation and focusing useful questions;
- *Reactive* in listening to intended users and responding to what they learn about the particular situation in which the evaluation unfolds; and
- *Adaptive* in altering the evaluation questions and designs in the light of their increased understanding of the situation and changing conditions.

2.4.4. A meaningful evaluation must strike a balance between illumination (‘formative’ focus) and judgement (‘summative’ focus). There is an inherent tension between, on the one hand, engaging fully with local and national teams and providing ongoing information that will be useful to them in real time and, on the other hand, seeking to provide an objective and dispassionate assessment of the project’s success. We have intentionally erred towards illumination so as to serve the judgements of all stakeholders (see Preface and paragraph 2.6.2.). Illuminative insights from the evaluation are presented in this report, but have also been fed back to CFH and participating PCTs periodically while the evaluation was ongoing.

2.4.5. One specific expectation of this evaluation was that we would help to identify some valid indicators or metrics (both qualitative and quantitative) to measure the “success” of the SCR as it is rolled out beyond the Early Adopter sites. The inherent problems of metrics in general, and the pros and cons of specific metrics for the SCR, are considered in Section 7.2.

^E For example, the Higher Education Funding Council is using Utilisation Focused Evaluation to assess the impact of the CETL (Centres for Excellence in Teaching and Learning) programme.

2.5. Methods, data sources and analysis

- 2.5.1. Ethical approval was obtained from Thames Valley Multi-centre Research Ethics Committee in January 2007 (06/MRE12/81 and subsequent amendments).^F An External Advisory Group to oversee the management and governance of the evaluation was set up with a lay chair and representatives of clinicians, patients, professional bodies (British Medical Association and Royal College of Nursing), and academic peers (see Acknowledgements for membership details). This group met four times during the one-year evaluation. In addition, and at the request of the BMA, an ad hoc sub-group of the BMA was convened to consider our emerging findings, and met three times over the year. The latter had no formal governance role but provided important feedback about issues that were pertinent to BMA members (see paragraph 2.6.5.).
- 2.5.2. In line with the requirements of Utilisation-Focused Evaluation (see previous section), we took a mixed-method approach – that is, we used a wide range of collection methods and data sources so as to capture as rich a picture of the programme as possible from as many angles as possible. We collected some of the data ourselves, and also used data collected by others. The methods and data sources are described in detail in Section 9.1., and a reflection on the evaluation method is provided in Section 8.
- 2.5.3. We chose to evaluate four of the six Early Adopter sites, partly because of our own resource constraints and partly because slippage in the last three sites meant that there was little to evaluate there within our timeframe. We spent most of our time in the first two sites (Bolton and Bury).
- 2.5.4. Quantitative (numerical) data used in this evaluation included:
 - a. Closed-item questionnaire items developed by our own team for interviews with staff in participating PCTs (paragraph 9.1.3.) and NHS service users (paragraph 9.1.7.).
 - b. Publicly available data on population demographics, socio-economic deprivation and burden of disease (including Office of National Statistics www.ons.org, community health indices www.communityhealthprofiles.info, annual public health reports from PCTs, and deprivation indices.²⁹
 - c. Regular uptake statistics produced by CFH and participating PCTs e.g. on the proportion of records created by a given date.
 - d. The TNS UK Tracker Surveys of public attitudes to the NPfIT and SCR.²⁵
 - e. The GP Patient Survey 2007.³⁰
- 2.5.5. Qualitative (non-numerical) data sources included
 - a. A total of 250 interviews with staff involved with the SCR project (see Appendix, paragraphs 9.1.1. to 9.1.3.).
 - b. Approximately 1500 hours of ethnographic observation (paragraph 9.1.4.).
 - c. Approximately 2500 pages of documentary data (paragraph 9.1.5.).
 - d. Brief interviews with 103 patients or carers (NHS service users; paragraphs 9.1.6. and 9.1.7.).

^F Strictly speaking, because this project is classed as ‘service evaluation’, it is explicitly outwith the NHS Research Management and Governance Framework (i.e. MREC approval is not needed). However, because we seek to undertake further analysis of data collected for this evaluation with a view to publishing research papers in academic journals, MREC approval was sought at the outset of the study.

- e. Seven focus groups involving a total of 67 people who had potentially stigmatising conditions and/or difficulties accessing health care (or who represented such people; paragraphs 9.1.9. *et seq*).
 - f. A small 'mystery shopper' telephone survey of the NHS Information Line (paragraph 9.1.11.).
 - g. An analysis of the foreign-language leaflets produced by CFH (paragraph 6.1.9.).
- 2.5.6. In accordance with standard governance procedures for biomedical research, we prepared information sheets explaining the purpose and nature of the evaluation to potential participants, so as to ensure that all input was given with full informed consent. 'Special' information sheets and consent forms were used for people judged to have low health literacy. Copies of these forms are available on request.
- 2.5.7. This study generated large amounts of qualitative data of different forms (e.g. field notes, documents, interviews, informal stories) as well as some quantitative data (e.g. closed-item questionnaires, monitoring statistics). All data were processed (anonymised, indexed, and coded) and stored either manually in paper files or electronically. 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); (b) these first-order analyses were integrated further using narrative synthesis, so as to produce a coherent, multi-level interpretation of the story in each Early Adopter site; (c) insights from individual case studies were synthesised further in a cross-project analysis. 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 interim presentations to participating PCTs and incorporation of their feedback into our interpretations.

2.6. Key stakeholders and what they expect of the evaluation

- 2.6.1. A striking early finding was that different stakeholders (see Section 2.4.) held very different views about the purpose of the evaluation, different expectations for it, and different views on what methods were 'rigorous' and 'valid'. The picture is complex and fluctuating, but broadly speaking, there are a number of overlapping groups of stakeholders, whose expectations are set out below.
- 2.6.2. Connecting for Health:
- a. The NHS Care Record Service Programme Board within CFH expects the evaluation to provide clear guidance, based on lessons learned from the Early Adopter phase, that will inform the wider roll-out of the SCR (initially in what are known as 'Fast Follower' sites and then more widely).
 - b. There is also hope that the evaluation will provide preliminary data to support the argument that the SCR has clear benefits for patients and is worth the substantial investment, both to date and committed.
 - c. CFH recognises, however, that many of these benefits will not have been realised within the short time frame during which the SCR has been in use (around four months and on a very limited scale). Box 1 summarises the original benefits anticipated by CFH.
 - d. A more recent list of benefits supplied by CFH included the additional hope that GPs would have "*more honest and open relationships with patients*".

Box 1. SUMMARY OF BENEFITS OF THE SCR AS ORIGINALLY ENVISAGED BY CFH³¹

PATIENT SAFETY

- Reduction in adverse drug reactions due to allergy (hence fewer hospital admissions, shorter length of stay, less litigation)
- Reduction in errors due to illegible or missing information (ditto)

ACCESS AND RESPONSIVENESS IN THE ACUTE SITUATION

- Prompt and appropriate assessment by the primary care out-of-hours service
- Prompt and appropriate assessment in A&E departments
- Prompt and appropriate assessment by NHS Direct
- For those with limited English fluency, flagging of language/support needs

CLINICAL CARE (ESPECIALLY OF LONG TERM CONDITIONS)

- Better co-ordination of care between different professionals and sectors, especially in situations when patient is seen in an unscheduled care environment
- Easier and more cost efficient management of acute exacerbations of long term conditions such as diabetes and asthma
- Reduction in emergency admissions
- Reduction in GP visits
- Better medicines management (e.g. when someone is admitted to hospital they can use their existing medication supply rather than throwing it away and prescribing from scratch)
- Reduction in repeat tests/procedures ordered because of missing information
- Faster throughput e.g. may help to achieve the 18-week wait for outpatient appointments

THE PATIENT EXPERIENCE

- More informed and engaged because of access to own record via HealthSpace
- Better understanding of medication so perhaps better compliance with medication
- Less need to keep repeating own medical history to new clinicians/administrators ('corroboration rather than interrogation')
- Greater control over what information is being stored or shared

2.6.3. Primary Care Trusts and other local stakeholders:

- a. Stakeholders in Early Adopter PCTs had mixed expectations of the evaluation. A few (erroneously) saw us as consultants hired by CFH to assure accountability of funds. Others (reasonably) wanted us to confirm to CFH that they had worked hard and done a good job in difficult circumstances (e.g. that they had done their best to inform patients of their choices). Most commonly, people (rightly) viewed the evaluation as an opportunity for them to comment on what had gone well and feed honest criticism back to CFH in an anonymised and constructive way.
- b. Stakeholders in PCTs considering joining the SCR programme, like CFH, expect some clear advice on how to prepare for and progress with the next phase of the SCR programme, and in particular, pragmatic advice on what to do, in what order, and what approach to change might be best.

2.6.4. Government and those responsible for governance:

- a. Ministers and MPs expect the concerns raised about the SCR by the Ministerial Taskforce,¹ Public Accounts Committee,²⁴ and House of Commons Health Committee³² in relation to the SCR programme (see Section 3.1.) to be addressed.
- b. The Information Commissioner and his/her Department (www.ico.gov.uk) expect findings that will help them fulfil their statutory responsibility to ensure that "...the

NHS takes its responsibilities seriously and that patients are provided with all of the information and choices they need to have to be able to make informed decisions about their health records.”

2.6.5. Professional bodies:

- a. The British Medical Association has explicitly advised its members who are not involved in the Early Adopter programme to await the outcome of the evaluation (see (<http://www.bma.org.uk/ap.nsf/Content/ncrs2>). Senior BMA members have a number of concerns, including: [i] are the government’s assurances about the security of the system justified?; [ii] is the current implied consent model legal (i.e. are doctors breaking the law by creating SCRs for patients without explicit consent), under both English and EU law?;^G and [iii] do role based access controls work in practice? The BMA is also seeking to develop a code of practice with CFH, with input from defence organisations on liability issues around uploading information onto the SCR.
- b. The Royal College of Nursing has similar concerns and expectations to those of the BMA, but with a focus on nurses. A particular concern is that whilst nurses make up a much larger fraction of the NHS workforce than doctors, and use computers to a comparable extent, they are mentioned relatively rarely in official documents and have relatively low representation at strategic level in the NPfIT. There is an expectation that the evaluation will highlight the role of nurses in the use of the SCR and ensure that designers and policymakers take this into account.
- c. Professional organisations and advisory bodies for doctors and nurses have broadly reflected the concerns of the BMA. Interim advice from defence societies advises doctors to satisfy themselves that their patients have received, read and understood the information about the SCR before assuming ‘implied consent’. Clarity on this issue would therefore seem a priority for the evaluation.

2.6.6. Patients and their advocates:

- a. Many people are asking questions about whether the SCR programme is a worthwhile use of public money; some of those people hope that this evaluation will make a judgement on this point (see paragraph 7.1.2.).
- b. Some individual service users (NHS patients and carers), especially those with residual concerns, are likely to draw on this evaluation to make their own choices about whether to have a SCR and/or a HealthSpace account.
- c. Voluntary sector self-help and advocacy groups (e.g. the Terrence Higgins Trust, Mental Health Foundation, Asian Women’s groups) seek factual information that will help them advise their members on the basis of informed, impartial judgements. There are numerous such groups and each is, of course, concerned to ensure that their particular membership is included.
- d. Statutory bodies with a remit to represent and advise patients and the public (e.g. Patient Advice and Liaison Services, Local Involvement Networks), and health education organisations (e.g. Expert Patient groups), may draw on this report when preparing advice and information materials for their clients.

2.6.7. Academics and scholars:

- a. There is much interest in this evaluation from fellow academics – both for the empirical findings (what generalisable findings will we generate about the value

^G The legality of the SCR, on which we are not qualified to pronounce, was effectively upheld in the House of Commons Health Committee Report, though as witnesses cited in that report suggested, the legal status of an implied consent model will only become apparent when a test case is brought.³²

and implementation of large-scale IT programmes in healthcare?) and for methodological insights (what lessons will we produce about the evaluation of such programmes in general?). Whilst our team has considered both these questions, they will be the subject of further academic papers and have not been addressed in this report.

- b. The British Computer Society Health Informatics Forum is a multidisciplinary community of IT scholars and practitioners working at the applied end of computer science in healthcare settings. The BCSHIF produced a detailed paper on the NPfIT in December 2006, whose main message was that *“There is no such thing as an IT project, merely business change projects mediated by ICT”* – and that the NPfIT was in danger of failing because of weak business planning across the NHS.⁶ More recently, a group of 23 senior computer scientists (‘NHS23’), mostly academics and linked to the British Computer Society, have voiced serious concerns about the NPfIT.^{5;33;34} There is, perhaps, an expectation by this group that the evaluation will air some reservations and key lessons which BCS and NHS23 have attempted (many feel, unsuccessfully) to get across to the Department of Health.

2.6.8. Campaigners and lobbyists:

- a. Civil liberties groups, e.g. the Big Opt-Out Campaign (www.nhsconfidentiality.org) perhaps expect factual information to support particular arguments (such as evidence of harm due to inaccurate or incomplete records, or lack of evidence that the SCR programme has produced value for money).
- b. Some individual GPs feel passionately opposed to the SCR programme; they may or may not be linked to official campaigns. If there is any expectation of the evaluation from these groups, it is probably similar to the above.^H

^H We approached two such GPs but neither was willing to give an interview.

3. The national context

3.1. Recent official documents

3.1.1. In June 2006, the National Audit Office published a review of the NPfIT,²³ in which it praised both the procurement process (see paragraph 3.3.2.), and the overall programme management by CFH, but questioned the escalation of the project budget to an estimated £12.4 bn.

3.1.2. In December 2006, a Ministerial Taskforce chaired by Harry Cayton, the NHS Summary Care Record Taskforce, set out a number of key issues relating to the SCR, of which six were particularly prescient of subsequent problems and challenges:¹

- a. Doubt about the case for the SCR as essential to modern clinical care.
- b. Resentment by clinicians, especially GPs, that they had not been adequately consulted.
- c. Low public trust in Government IT programmes in general and in the confidentiality, reliability and security of patient record systems in particular.
- d. Lack of agreement between key stakeholders between an 'opt-in' (explicit consent) model and an 'opt-out' (implied consent) one.
- e. Lack of clarity about operational aspects, including what information would go onto the SCR (the 'minimum dataset'), who would be allowed to access it, how 'free text' data would be uploaded, and how 'opt-outs' would be handled.
- f. Concern about informing, educating, engaging and involving patients.

3.1.3. The Ministerial Taskforce made a number of recommendations including the setting up of an independent advisory group to oversee the SCR programme (this became the Summary Care Record Advisory Group, SCRAG) and an independent evaluation. A number of other recommendations made by the Taskforce, were in retrospect somewhat ambiguous. For example:

- a. The SCR implementation should be *"as straightforward and practical as possible"* but also that its roll-out should be linked with a second complex technology (HealthSpace) and that it should be accessible by a range of different clinicians from multiple access points (including the emergency ambulance service and NHS Direct).
- b. The implementation should unfold at a pace *"commensurate with clinical engagement"* but also that it should occur *"as soon as possible so that its benefits are realised"*.
- c. Informed, empowered patients should drive the SCR programme (for example, by accessing their own record via HealthSpace and asking questions about the accuracy and completeness of data) but also that the SCR should be *"implemented in a way that ensures equity of access to its benefits"* by those with low health literacy, difficulty communicating, difficulty accessing healthcare, those who lack a complete GP record, and frequent users of the out-of-hours service.

These contradictions reflect tensions that are inherent to any complex change project involving the introduction of a new technology that must also align with other changes and technologies.

3.1.4. In March 2007, the House of Commons Public Accounts Committee questioned the amount of money being spent on the NPfIT and asked uncomfortable questions about the auditing of those funds and the value for money of the programme. The

PAC commented (page 6): *“We are concerned that leadership of the Programme has focused too narrowly on the delivery of the IT systems, at the expense of proper consideration of how best to use IT within a broader process of business change.”*²⁴ Whilst it was not within our remit to consider value for money of the wider NPfIT, we have considered the question of whether the ‘business change’ aspect of the SCR implementation has been adequately addressed.

3.1.5. In September 2007, the House of Commons Health Committee published a report on electronic patient records (EPRs) in the NHS.³² The report took account of an extensive consultation with stakeholders and was widely seen as credible and balanced. The report included the following points relevant to this evaluation:

- a. Overall, it was felt that EPRs have the potential to bring huge benefits to patients, giving them greater control over their own healthcare, but these benefits are dependent on active involvement of stakeholders, especially doctors.
- b. The Committee was *“dismayed”* that arrangements for creating and adding information to the SCR were unclear, and had been poorly communicated to patients and clinicians.
- c. The Committee was in favour of an implied consent model for basic information and an explicit consent model for more detailed information. However, after hearing evidence from patients and patient groups (who were confused about the two-stage consent model), it concluded that *“much of the controversy over privacy and consent arrangements for the SCR would have been avoided if Connecting for Health had communicated its plans more clearly to patients.”*
- d. The Committee expressed concern that *“the complexity of the SCR appears to be increasing. This will make the SCR more difficult to use, particularly in emergency situations. The Department [of Health] must be clear about the purpose of the SCR, and it must ensure that the record is easy to use.”*
- e. After reviewing extensive submissions from suppliers and technical advisers about the technical security of the SCR, and from clinicians and lobbyists about how security would play out in practice, the Committee concluded that more rigorous evaluation of both technical and operational (i.e. human elements of) security for the SCR is required.
- f. The Committee believed that widely publicised delays in the delivery of the CRS, which have eroded public confidence in the NPfIT, were partly due to *“a worrying lack of progress on implementing local systems”*. It recommended that a more localised approach should be taken by CFH in order to speed up the implementation of the programme (see paragraph 3.3.6. and 7.10. for a discussion on how this policy has been operationalised).

3.2. NHS Connecting for Health

3.2.1. Many previous publications have commented on the distinct structure, culture and management style of CFH,¹ and suggested that these characteristics account partly or wholly for the fortunes of the NPfIT.^{6;24;35;36} In this evaluation, we have gained much experience of the style of working of the SCR teams within CFH, and have also been struck by the tendency of some stakeholders to blame all sorts of problems on “CFH” or its staff. We have tried to ask *why* relevant sections of CFH are organised and run the way they are, to question the alleged link between CFH and a range of

¹ CFH is a large and diverse organisation of which our team only studied a small part. Whilst our interviewees in the Early Adopter sites, as well as the press and lobby groups, tended to criticise (or less commonly, praise) “CFH” in general, our analysis should be seen as pertaining only to those sections of CFH that were involved in the development and delivery of the SCR programme. These included various designated SCR project teams as well as the Communications Department and relevant higher-level strategy boards.

perceived characteristics of the SCR programme, and to consider what needs to change and how.

- 3.2.2. CFH, the delivery arm of the Department of Health for the central aspects of the NPfIT, is a large, complex and geographically dispersed organisation, to which many staff have moved (temporarily or permanently) from the NHS, DoH or management consultancy firms. The central departments of CFH are perceived by staff as an exciting, fast-paced environment close to the heart of government. CFH is divided into numerous subdivisions and departments. The approach to change management in many (though perhaps not all) departments appears to be highly rationalistic (identify problem → diagnose cause of problem → make plan → implement plan → measure impact). For example, the task of training and supporting PCTs to deliver the NPfIT is described on CFH's website thus: *"The Capability and Capacity project undertook a proof of concept review and gap assessment to determine the position across the NHS with respect to this, and delivered an Investment Case in October 2007, setting out the recommended actions to address the gaps identified."*
- 3.2.3. Our ethnographic findings (see Appendix, paragraphs 9.1.4. and 9.1.5., for details of data sources) suggest that the general culture of teams working on the SCR programme within CFH appeared to be one of command and control (described by a senior CFH executive as *"discipline"* and by one PCT informant as *"extremely pushy"*^J). Senior staff on the programme appeared oriented to pushing projects forward at a pace set out in an over-arching Gantt chart (the 'plan on a page' or POAP); they favoured tight performance management of staff and frequent reporting against pre-set standards and milestones. This contrasts markedly with the structure and culture of the NHS (a highly dispersed and fragmented organisation with a strong tradition of resistance to 'command and control' management).
- 3.2.4. We were given five different versions of CFH's organisational chart by staff working on the SCR programme, and in these, four different people were flagged as having ultimate responsibility for the programme.^K This confusion was perhaps partly due to the speed with which the project had grown, the fluid nature of early roles and responsibilities, the hierarchical nature of CFH (in which staff always feel answerable to someone senior) and the fact that the SCR is nested within the wider NPfIT. Nevertheless, the inability of CFH's own staff to tell us who was running the programme aligned with our own impressions that there was a focus on operational management at the expense of strategic leadership.
- 3.2.5. Almost all CFH staff interviewed for this evaluation were very well qualified. They worked very hard, far beyond their contracted hours, and perceived their working conditions as stressful. Middle management staff appeared to be seen as interchangeable and geographically mobile within the SCR programme (for example, we interviewed someone from London who had just been told *"you're working in Leeds from next week"*). Whilst "good interpersonal skills" appeared to be a standard line on job descriptions, we saw little evidence that staff were selected, developed or

^J These comments represent the extremes of a continuum of perceptions. Most participants in the Early Adopter sites experienced the pressure from CFH as uncomfortable; they were divided in their views on whether this was a worthwhile price to pay for working towards key targets and milestones.

^K We are not suggesting here that there were multiple versions of the official organisational chart in circulation. The five 'charts' we received were all sketched by individuals who sought to help us get oriented in what we described to them as our familiarisation phase, and were accompanied by suggestions of whom we should approach for different aspects of the evaluation (of the general format *"X chairs this committee but if you want an action, go to Y"* or *"let me tell you a story about how things work round here"*). This naturalistic data reflected the informal, embodied and enacted versions of the organisational hierarchy and routines rather than the formal lines of accountability or standard operating procedures. In case study research, discrepancies between 'formal' and 'informal' versions of the organisation are an important source of higher-order insights about organisational culture and subcultures.³⁷⁻³⁹

rewarded for such skills. Our data suggest that generally speaking, the emotional and sense-making aspects of work (buy-in, team spirit, airing feelings, achieving a common vision, reflecting) had relatively low priority within the SCR programme. These organisational features may partly explain our findings that PCT informants often portrayed the interpersonal skills of CFH staff negatively (“*relationships are not X’s strong point*” or “*Y didn’t really click with people on the ground*”).

- 3.2.6. Communications was a well resourced part of the SCR programme and was taken seriously (and often somewhat nervously, given negative press coverage in the past). We found that much work went into getting the language right so as to avoid producing “press bait”. For example (and with many exceptions) CFH staff tended to give ‘set piece’ Powerpoint presentations about the SCR programme that had been checked by seniors (described by one PCT informant as “*the double glazing talk*”) and from which they were uncomfortable deviating. Whilst we do not condone this defensive approach to communications, our data confirm that demonising and caricaturing CFH’s management of the NPfIT has become something of a sport for lobbyists and some sectors of the press.
- 3.2.7. The strategic direction of the SCR programme was not helped by the presence of multiple committees and advisory groups. Groups to which the evaluation team were asked to study and/or present to included:
- a. The Care Records Service Programme Board (an executive group which directed the SCR programme plus a number of other programmes within the NPfIT, which met two-monthly).
 - b. The SCR Implementation Board (the “hands-on” executive board for the SCR programme, which met fortnightly initially and then monthly).
 - c. The SCR Operations Management Group (the management committee, which met weekly).
 - d. The SCR Advisory Group (SCRAG, the official non-executive group charged with advising the programme, which met three-monthly).
 - e. The Clinical Reference Panel and Patient Reference Panel for the SCR (both of which met 6-weekly).
 - f. The HealthSpace Implementation Board and HealthSpace Reference Panel (which met approximately two-monthly).
 - g. We were also asked to report to several groups whose remit spanned the whole NPfIT and who regularly discussed the SCR (and sought to have strategic input to it), including the National Advisory Group (NAG, comprising three separate sub-groups of clinicians advising the NPfIT – doctors, nurses and professions allied to medicine, each of which met separately every three months) and the Voluntary Sector National Advisory Group for the SCR (VSNAAG, with membership from a number of patient and advocacy organisations, which met three-monthly).
 - h. In addition, each PCT had a Project [executive] Board with representation from CFH, and an Implementation Board.

In our experience, communication between the different CFH committees was sometimes poor, and duplication of activity common. Whilst we acknowledge that each of these committees and boards had a different remit, our data show that there was much duplication of activity^L and communication between the different groups was not always good.

^L For example, one person who attended the SCR Implementation Board as well as the Operations Management Group told us that both groups went through “*the same agenda*”. Two CFH staff told us they routinely sent a junior to certain committee meetings because whilst the agenda items were important, everyone knew that key decisions were made by a higher committee.

- 3.2.8. Co-ordination between the different CFH departments in relation to the SCR programme was identified by many informants both within and outside the organisation as weak. In some but not all teams, there seemed to be limited understanding of, or respect for, the work of other teams in the same organisation. For example, technical groups appeared to work largely independently from those working in front-line clinical settings, and vice versa, and these teams also worked separately from the information governance team.
- 3.2.9. A 'knowledge portal' to support the national rollout and local change management for the SCR has been developed by CFH's Clinical and Business Change Programme. It has now been incorporated into the public-access CRS site, and contains a wealth of resources intended to *"support clinical engagement and clinical benefits delivery of the SCR"*. These resources appear to be well designed and include guidance documents; software tools for demographics, business process mapping, performance monitoring and risk management; and a series of training modules including 'IM&T planning', 'business processes', and 'public information programme' (in preparation). Given the quality of these resources, we were somewhat surprised to find that very few people in participating PCTs were using them regularly. Of a 'straw poll' of 16 PCT informants whom we judged might have found the resources useful, six were not aware of their existence, five were aware but had never accessed the site, one was waiting to be sent the link, three had accessed it (once each), and one used the site regularly. Several said things like *"I am aware of these [resources] but don't have time to access them"*.
- 3.2.10. Our data suggest that the characteristics set out above have led to a hierarchy of the sort of knowledge that is valued by teams working on the SCR programme within CFH, and how this knowledge flows (or fails to flow) in the organisation. In general:
- Explicit knowledge (e.g. standard operating procedures, reports) appears to be valued over tacit (e.g. know-how embodied by particular individuals, hunches, organisational memory);
 - Timetabled reporting of predefined data fields appears to be valued over sharing information that has come up spontaneously;
 - Vertical flow (top down command and bottom-up reporting) appears to be valued over lateral flow (information exchange between individuals of similar rank or role);
 - Email appears to be the preferred mode of communication;
 - Quantitative data appears to be valued over qualitative;
 - When appointing staff, formal qualifications and objective measures of performance appear to be valued over experience (e.g. previous experience in the NHS), local knowledge (e.g. of a particular PCT patch) or emotional intelligence.
- 3.2.11. Almost all technology projects over-emphasise the technology itself over the social aspects of its introduction and use. Whilst it has become something of a cliché within CFH that *"the SCR project is 10% technological change, 90% business change"*, many staff in strategic positions in the SCR programme did not appear to understand what this means. For example, one conference presenter from CFH introduced a talk on business change with that statement but later in the same presentation said *"We want to ensure that when Fast Follower PCTs want to adopt [the SCR], they can switch on an off-the-shelf solution."* To some extent (but by no means universally within CFH):
- 'Business change' appears to have been equated with 'business processes';
 - 'Business processes' appear to have been equated with 'business tools';

- 'Business tools' have been subcontracted out to freelance consultants (who seem to have done a good job within their brief);
- There is an assumption that once the tools have been applied, business change will be unproblematic;
- Thus, even the 90% of work that CFH recognises as *non-technological* is still seen as essentially *technical*.

3.2.12. The highly rationalistic approach to change taken by CFH teams in relation to the SCR programme, together with an explicit and concerted effort to control the language of the programme, has marginalised concepts such as uncertainty, paradox, and emergence, and made it difficult for wider stakeholders to address these phenomena. Problems such as the inevitable trade-off between accessibility of data and protection of privacy, the mismatch between the technical model of clinical work and the messier, coal-face reality of that work, and the fact that a new cohort of children turns 16 every month, for example, are dismissively blamed on CFH's "*poor planning*", "*lack of clarity*" or "*lack of attention to detail*" rather than being seen as inherent issues that will never go away and which it is everyone's responsibility to deal with.

3.3. Financing and contracts for the NPfIT

3.3.1. The NPfIT is a substantial national investment and involves complex relationships with both the local NHS (via Strategic Health Authorities [SHAs]) and software suppliers. The business and financial detail is beyond the scope of this evaluation and has been extensively addressed by the Public Accounts Committee.²⁴ Briefly, the NPfIT is said to be costing £12.4 bn in the ten years to 2013-14, comprising £1.9 bn for "*central expenditure*", £0.2 bn for Choose and Book, £0.2 bn for the Picture Archiving and Communication Service, £0.6 bn for the National Care Records Service (the SCR and Local Detailed Records); £0.9 bn for the N3 broadband service; £0.3 bn for "*other central contracts*"; £3.4 bn for "*[centrally allocated] local NHS expenditure*"; and £8.3 bn for "*[locally devolved] local expenditure*".

3.3.2. Whilst it has (we were told) always been planned that the NPfIT would be "*locally owned and delivered*", there were considerable economies of scale (estimated at £4.5 bn) to be gained by negotiating software contracts nationally. CFH drove a hard bargain with the large software companies; contracts were signed very rapidly (described by one witness to the Public Accounts Committee as "*at breakneck speed*" [page 11]²⁴) with the alleged advantage that this would reduce risks from technology obsolescence (and also fit in with political pressure to deliver the NPfIT as soon as possible). Questions have been raised (but not answered definitively) about whether speed of procurement was achieved at the expense of depth and detail of planning, and whether national procurement of so-called local solutions was sensible.²⁴ What is not disputed is that a large amount of the burden of risk for the NPfIT was successfully transferred to the software companies, a move described by one senior CFH informant as "*brilliant*" of the executive who pushed it through.

3.3.3. Local delivery of the NPfIT by SHAs was originally organised around five implementation groups or 'Clusters' (North East, North West, Midlands, Southern, London and Eastern). CFH's plan was for software providers to compete for the contract to be a Local Service Provider (LSP) in one or more Clusters. A LSP contract was worth around £1 bn, and a financial competence clause was included in the contract, so bidders were limited to large IT companies (Fujitsu, BT, Accenture, and CSC). The providers of GP software (EMIS, TPP, InPractice Systems, iSoft, HealthySoft) were important (though much smaller) players in these contracts, and

there was much negotiation to develop 'LSP consortia' comprising a large company shouldering the financial risk (but with the potential to make large profits) plus an established GP system supplier.

- 3.3.4. One of the largest providers (Accenture) which had successfully bid for two LSP contracts, subsequently pulled out of the programme (because of the high-stakes contracting process and high degree of uncertainty surrounding the programme), transferring its share of the business to CSC. For this reason, three of the original Clusters have merged, leaving London (supplied by BT), Southern (supplied by Fujitsu) and North, Midlands and East (NME, supplied by CSC).
- 3.3.5. In the phase where consortia were being formed, EMIS, the provider of around half the country's GP software systems, was left without a partner for a LSP contract. Accenture developed an arrangement whereby GP practices were incentivised by PCTs to change from their existing system supplier to TPP (Accenture's partner supplier), which created serious instability in the market. CFH's response was to pay for all GP system licences centrally and to regulate a market place – an arrangement that became known as GPSoC ('GP systems of choice'). CFH's relationship with EMIS throughout this process was somewhat awkward (its chief executive was said to be more interested in the 'big players' and to have initially dismissed EMIS's product as "*a legacy system on a ransom strip*") but eventually a deal was done under GPSoC in which EMIS agreed to work towards developing interoperability with GP2GP and the CRS. However, EMIS has its own priorities and timetable (for example, it is currently working on a major upgrade to its existing GP system), so lack of alignment with CFH's timetable for the SCR has been a risk for some time.
- 3.3.6. Both the Public Accounts Committee (paragraph 3.1.4.) and the House of Commons Health Committee (paragraph 3.1.5.) made strong recommendations that the NPfIT must become more localised.
 - a. The shift from central to local responsibility was termed, somewhat ironically, the National Programme for IT Local Ownership Programme (NLOP).
 - b. Executive responsibility for delivering the NPfIT (including "*realising the benefits*" of the SCR programme) was officially transferred to the three new Local Programme for IT Boards (paragraph 3.3.4. above) on 1st April 2007.
 - c. The hope is that NLOP will make the NPfIT more strongly embedded in local healthcare and training strategies and more closely aligned with local priorities.
 - d. Our data suggest that whilst NLOP has clearly been welcomed by both CFH and the SHAs, it has not been without teething problems. For example, CFH staff have intimated that SHAs have been somewhat slow to take up their new responsibilities.
 - e. However, SHA informants feel that as well as unnecessary delays with the transfer of funds, they have been "*dropped in it*" (meaning, left to implement what is essentially still a nationally driven programme in all but name).

NLOP is discussed further in paragraph 7.10.

3.4. Data quality

- 3.4.1. A separate report on data quality for the SCR programme is currently in preparation by our team and will shortly be submitted to CFH. The remainder of this section provides a preliminary summary of the issues covered in that report.

3.4.2. The main data quality standards in use in GP practices at the time that selection for inclusion in the Early Adopter SCR programme was occurring were:

- a. The Quality and Outcomes Framework (QOF), a national system of financial incentives and rewards for various clinical and administrative targets in general practice. To win QOF points, practices are required to collect data on both the process and outcome of care across different disease groups and dimensions of management. There is some evidence that the QOF has begun to have a positive impact on patient outcomes.¹⁶
- b. Primary Care Information Service (PRIMIS+, www.primis.nhs.uk/), a national programme of training and quality improvement for GP practices in relation to ICT. PRIMIS is an academic group based in Nottingham which has a contract with the Department of Health. The group has produced a series of semi-automated audits using a tool known as 'CHART' (Care and Health Analysis in Real Time), which have proved popular and credible amongst many GP practices and which are widely used as tools for data quality improvement initiatives (and also by PCTs to monitor practices' progress in this sphere). An interactive example of a CHART audit is accessible from the PRIMIS website.
- c. Paperlight, an accreditation process that ensures GP surgeries are able to work exclusively with computerised patient records. In order to qualify for Paperlight accreditation, practices must have: complete patient records on the computerised clinical system; policies to ensure those records are maintained; regular audits to validate those records; a software system that is accredited under GPSoC^M; data security measures and business continuity provisions.
- d. The IM&T DES (Information Management and Technology Directly Enhanced Service) was a dedicated funding stream negotiated nationally by the National Clinical Leads (see paragraph 5.4.5.), which incentivised GP practices to put in the major effort needed to improve data quality. The first IM&T DES ran from 1st April 07 to 31st March 08, and has recently been extended till March 09.

3.4.3. The challenge to improve data quality in primary care, and the potential benefits associated with this challenge, occurred on a much wider canvas than the specific SCR programme. Before the SCR programme began, many PCTs had already appointed their own 'generic' data quality facilitators (DQFs) to support IT development in GP practices. CFH also provided specific DQFs for the SCR programme. It is also worth noting that the existence of the SCR, and participation in the SCR programme, appeared to provide a strong incentive to practices to work on improving their data quality.

3.4.4. There are, broadly, four sets of requirements for clinical data (largely tied to four groups of users). There are: service planning and commissioning uses; research uses; clinical care uses; and patient access. When considering the adequacy of the data quality standards and processes for the SCR programme, we chose to focus on the clinical care use scenarios, as we felt that this was the area in which the most immediate and direct risks existed. This is because:

- a. In the research setting, and in the planning and commissioning settings, risks from poor data quality are relatively low. When dealing with population data it is always possible to place confidence intervals around the aggregated data obtained. The higher the quality of data, the tighter those confidence intervals would be. Nevertheless, even fairly approximate data would have some indicative value and could lead to the development of useful models. Judicious use of such data can still support good planning and research outcomes.

^M GPSoC = GP Systems of Choice, a limited selection of approved software systems for use in GP practices (paragraph 3.3.5.)

- b. In the patient access situation, the risk centres around the credibility gap that would arise should the patient see mistakes (real or perceived) in their SCR. The more categories of information placed on the SCR, the more scope there is for error. There is a risk of this credibility gap arising, not only if data do not accurately reflect the patient's real record but also if the SCR and HealthSpace do not meet the expectations of the patients. This may affect the patient's level of trust in the competence of their clinicians, but their health is unlikely to be directly affected.
 - c. In contrast, in the clinical care setting, confidence intervals cannot be applied to individual data items in a patient's record. An individual patient record must contain a data item, or a 'not known', for each of the headings in the SCR. The penalties of acting on an incorrect entry are potentially very grave. For this reason, we conclude that the highest priority in ensuring data quality should be in providing data for the purposes of clinical care.
- 3.4.5. Few clinical records (paper or electronic) are 100% complete or accurate, and it is an established part of clinical practice to work on the assumption that data may be incomplete or inaccurate. For example, just because a patient has no *recorded* allergies doesn't mean they have no allergies. If the data held in the SCR are known, or generally perceived, to be of poor quality, then it is likely that clinicians will choose not to consult the SCR. Thus the risks associated with poor quality data in the clinical setting are not so much that clinical error will increase (although that is a real possibility), but that the SCR might fail to deliver any benefit to users because clinicians fail to trust or use it.
- 3.4.6. Data on the SCR are, at present, drawn from a single data source: the GP-held record. If data on the GP record are poor then the SCR will be inaccurate, incomplete and therefore untrustworthy. Data quality is undoubtedly a prerequisite for producing a meaningful SCR, but there is uncertainty as to whether current standards are fit for purpose. Most data quality standards in current use were designed for supporting individual clinicians treating individual patients. In contrast, the SCR is intended to be shared between users in a variety of different contexts. Whilst much research has been undertaken on data quality, studies to date have not addressed the specific question of the problems that arise from interpreting inaccurate or incomplete data in cross-contextual use.
- 3.4.7. Previous research on data quality standards tends to discuss the completeness and accuracy of data. However, it is impossible to define an absolute meaning for these terms: data can only be defined as 'complete' or 'accurate' with respect to some particular use of the data. No studies have so far addressed this. At the time of writing, there remain three major uncertainties relevant to data quality:
- a. What will be the main (and the potential supplementary) uses of the SCR?
 - b. What information will the SCR contain?
 - c. By what mechanism will patients be able to restrict access to certain parts of their SCR (e.g. will it be possible for data to be held in a 'virtual sealed envelope' without a clinician seeing a flag that something has been withheld)?
- 3.4.8. In the absence of a clear and limited set of use cases for the SCR, and some sort of 'hierarchy' within these use cases (e.g. what are the most and least important uses), it is inherently impossible to determine a single set of prescriptive data quality standards. If the potential uses of the SCR are to remain flexible and open ended, specifying prescriptive data quality standards will continue to be problematic.
- 3.4.9. However, even in the absence of prescriptive data quality standards, it is possible to make reasonable statements about 'better' or 'worse' data quality. If good data are

defined as those which are 'fit for purpose', for example, then a working definition of poor quality data might be 'data that could mislead a clinician in one or more contexts of use', and a working definition of good quality data might be 'data that lead to better decision making in one or more contexts of use'. Note that these definitions, whilst pragmatic and defensible even in the absence of specific use cases, do not lead directly to quantifiable measures of data quality.

- 3.4.10. Audit measures, such as the ones in the CHART system (see paragraph 3.4.2. above), do result in quantified outcomes. Queries of the GP record can determine where data are possibly absent or materially incorrect, for example where a record of a prescription (e.g. digoxin) is present but the appropriate diagnostic code (e.g. atrial fibrillation) is not. These audits are not, in and of themselves, sufficient to assure data quality. Firstly, it is only possible to generate audit queries of the 'drug-diagnosis correlation' type for a limited subset of data items. For most clinical data, no meaningful rule based queries can be constructed. Secondly, because the current plan is for the SCR is to be used in a variety of settings, it is not possible to determine *a priori* which data need to be audited. Finally, audits such as the CHART queries only reveal the state of one particular set of data at one particular point in time.
- 3.4.11. These audits do, however, point to underlying problems with the data capture process. Once these problems have been identified, it is then possible to determine the source of the problems (e.g. problems with the process of data entry or coding) which can then be addressed by process improvement interventions: for example, drawing up protocols for data capture or designing and targeting staff training courses. GP practices do not necessarily have the skills to carry out process improvement interventions. Even where practices have staff that are skilled in both IT and data quality, they may need support in carrying out CHART and other audits, analysing them, and identifying which of the practice's processes and procedures to target for improvement. To this end, the role of the data quality facilitator (DQF) has been developed. We discuss data quality audit and the importance of 'hands-on' input from the DQF further in paragraph 5.4.7.
- 3.4.12. In our separate report on data quality in the SCR programme, we have recommended that in the absence of prescriptive data quality standards driven by a limited, clearly defined set of use cases, the best possible standards of data quality are likely to be obtained through the use of ongoing audit and intervention cycles as described above. In other words, we believe that the current approach to data quality is the one of choice. Whilst this is a relatively costly approach, and requires a cohort of skilled DQFs that are able to engage with the practices, we believe that such an approach is the only way to assure the clinical usability of data in the SCR.

3.5. Security issues

- 3.5.1. Personal medical data is private and sensitive. Security in relation to the SCR can broadly be divided into technical security (properties of the software which prevent unauthorised access) and operational security (processes and procedures that guard against the impact of human error or malice). This section sets out the strategy and procedures for security in the SCR programme; later sections (see especially Section 7.7.) present our findings on how these play out in practice.
- 3.5.2. Protocols for ensuring the operational security of the SCR include a number of measures, many of which also apply to local detailed records:

- a. Access to the SCR system requires users to insert a valid NHS smartcard as well as entering a user name and password.
- b. Smartcards are issued to NHS staff on a personal (not-to-be-shared) basis; they are only issued following a registration process which requires users to present identification and to be sponsored by a senior member of their organisation (for example, the senior partner in a GP practice).
- c. Role based access control – i.e. users accessing the SCR system are only able to view information relevant to their job role, so clinical information is not generally accessible to someone in a purely administrative role. It is increasingly recognised, however, that many so-called ‘administrative’ roles (e.g. compiling test results on behalf of a doctor) do require access to clinical data and that access controls must be sufficiently fine-grained to reflect this reality.
- d. Users can only access information about a patient after specifying a legitimate relationship with them, for example ‘best interest of patient’, ‘public interest’, plus free text box to enter details, e.g. ‘Admission to Bolton A&E’.^N
- e. The SCR system includes the capacity to produce a detailed audit trail indicating who has accessed patient information, and also (if it has required the breaking of a seal or an individual ‘legitimate relationship’ claim) for what purpose. This information is accessible by privacy officers and Caldicott Guardians and we understand that it can be made available to patients on request.
- f. The SCR includes the capacity to ‘seal’ selected items of information which patients do not wish to be shared. At the time of writing this report, the system for this was not yet functional. It is envisaged that a clinician will be able to see that there is additional information there but which can only be accessed with explicit consent at the time (or, exceptionally, without such consent in a ‘break glass’ scenario); such accesses would trigger an information governance alert and audit trail.
- g. Penalties for attempting to access information unlawfully are serious and include the possibility of dismissal and/or a custodial sentence.

3.5.3. We are not qualified to undertake an independent check on the claims made by CFH and its suppliers about technical security. It is worth quoting extensively from the House of Commons Health Committee Report, which drew on interviews with senior executives from CFH and the software suppliers (page 37):³²

- a. *“Officials acknowledged that no system of information storage can be considered entirely secure, and stated that “different vulnerabilities” affect paper and electronic storage systems. Richard Granger pointed out that security risks are being mitigated by the use of experienced suppliers who also work for the security services, by introducing functionality incrementally with thorough evaluation, and by ensuring compliance with HL7 international infrastructure standards.*
- b. *“The new systems will be protected by state of the art security measures capable of providing far greater protection than has ever been the case previously. The NHS patient database (the Spine) will reside within a fully private network known as N3. The Spine system and database can be accessed only from within this private network. Should an attacker somehow gain access to the NHS private network they would then have to break through three separate layers of tiered architecture—each tier being protected by twin firewalls (of different manufacture) to access the database. The firewalls are supported by intrusion detection*

^N In reality, most ‘legitimate relationships’ are created at the outset of the provision of care (e.g. when a patient registers with a GP), so these do not have to be manually logged at every encounter. Whilst ‘self-claiming’ a legitimate relationship is currently the norm for accessing a patient’s SCR, it is envisaged that the legitimate relationship will eventually be built into the interoperability of the systems so that (for example) a call centre nurse will not have to re-enter reasons for the legitimate relationship every time she accesses a SCR from the Adastra out-of-hours system.

- systems and other multiple security measures, which monitor network traffic routinely and raise an alert on the detection of suspicious activity.
- c. “BT, the supplier of the national systems, offered strong assurances about technical security levels, arguing that unlawful access to the National Data Spine would be “near impossible” without the assistance of a registered user, i.e. without a breach of operational security. Patrick O’Connell, Managing Director of BT Health, told the Committee that BT has an ongoing programme of internal testing to ensure that systems cannot be infiltrated. BT also stressed the inevitability of a trade-off between the level of system security and the practicalities of making systems user-friendly, particularly to busy clinicians.”
 - d. “Witnesses argued that the creation of a nationally accessible system, rather than a series of smaller, local systems, would increase the risk of security breaches. The UK Computing Research Council stated that: ...a single system accessible by all NHS employees from all trusts maximises rather than minimises the risk of a security breach. It increases the number of patients affected by the worst case breach...In short, it provides both a bigger target and a larger number of points of attack than a series of smaller systems.
 - e. “The British Computer Society took this point further, arguing that higher levels of security would be achieved by storing information in a “distributed database” rather than on centralised storage systems. Such a system would allow clinicians to search a range of local databases for information about a particular patient which could be drawn together into a ‘virtual’ record when required, rather than being permanently stored in one place.”

3.5.4. The various security measures for the SCR have been summarised by CFH in a diagram (Figure 1 below).

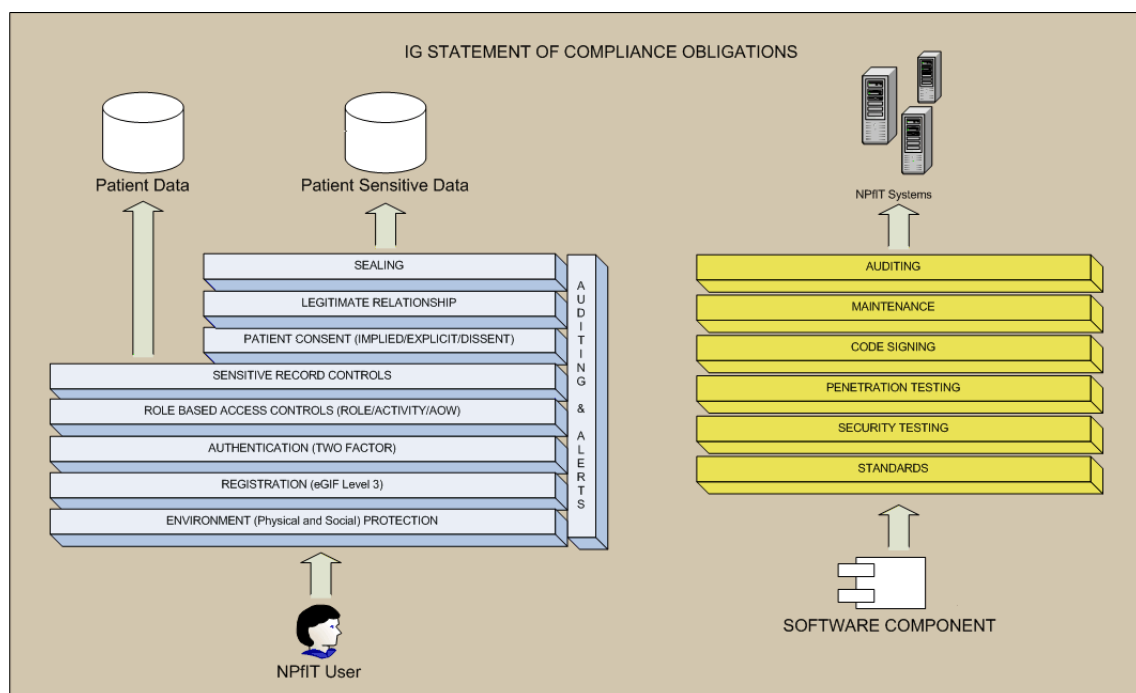


Figure 1: Information governance diagram supplied by Connecting for Health

4. Case studies of Early Adopter sites

4.1. Selection and description of the Early Adopter sites

4.1.1. Early Adopter sites were selected from volunteers in a competitive application process on the basis of six main criteria (each scored on a 2- or 4-point scale):

- a. Size (not too large) and stability (low cross border patient transfers) of the population.
- b. At least 60% of population registered at practices with a single GP System Supplier.
- c. A track record in similar ICT-based initiatives (especially Choose and Book).
- d. Good data quality in GP practices (PRIMIS, IM&T DES [Section 3.4.] or an equivalent local initiative) and willingness to work on data quality.
- e. Single unscheduled and/or emergency care settings that could take part in the implementation (i.e. by viewing the SCR via the Clinical Spine Application (CSA)).
- f. Good partnerships between the NHS, professional bodies, practices, primary care system supplier(s) and unscheduled care provider(s). Buy-in from the Local Medical Committee and patient representative groups was specifically required.

4.1.2. Based on 2006/7 data from the Office of National Statistics²⁹ and Community Health Profiles, the catchment populations of Bolton, Bury and South Birmingham were of slightly higher than average ethnic mix, and higher than average levels of illness; the population of Dorset had the opposite characteristics (Table 1).

	England average	Bolton	Bury	South B'ham	Dorset
Setting	-	Urban	Urban	Urban	Rural
Population (000)	-	270	183	383	430
Deprivation ranking 2007 (using ONS Index of Multiple Deprivation, where low rank means more deprived)	177 (out of 354)	51	122	10	325 (East) 210 (West) 247 (North)
% of children achieving 5 A*-C GCSEs 2005-6	58%	51%	59%	59%	62%
% of population above 65 ^o	15.9%	14.9%	14.8%	14.5%	24.5%
% of population below 15	18.9%	20.3%	20.2%	22.0%	16.4%
% minority ethnic groups	8%	10%	10%	29.6%	3%
% of adults describing themselves as 'in poor health'	7.8%	9.8%	8.8%	10.5%	6.0%
Number of people claiming benefit for mental health disability (per 1000)	27.4	42.9	38.2	36.6	21.4
% of children living in poverty (low-income households)	21%	24%	19%	39%	13%
Patient satisfaction with access to GP services 2006/7 ³⁰	86%	87%	87%	85%	93%

^o Data on age profile of populations are based on the 2001 Census, and do not take account of more recent changes to PCT boundaries. More recent data showed similar relative profiles but did not allow comparisons across sites.

4.2. Case study 1: Bolton

Local context and demographics

- 4.2.1. Bolton is a large town north of Manchester, with a population of about 270,000. It lies within North West Strategic Health Authority. As Table 1, paragraph 4.1.2., shows, the population is young and one-third live in areas of high socio-economic deprivation; the size of the minority ethnic population (mainly from the Indian subcontinent) is fairly small and stable on the whole, although higher in some areas, and there has been a recent increase in immigrants. There is high unemployment, lower than average levels of education and literacy, relatively poor health, and low life expectancy, especially around the centre; although there are also some more affluent areas.^{29,40}
- 4.2.2. Bolton PCT was established in 2002² and there are 57 GP practices, as well as one nurse-led walk-in centre and an out-of-hours service (although some GPs provide their own out-of-hours care). The majority of practices use the InPS system, although a significant number are with other providers (14% HealthySoft, 9% iSoft and 9% EMIS). Primary care services were described in the Annual Public Health Report as “less good than the national average” and in need of investment. Efforts are being made for improving access to services and reducing inequalities.⁴¹ The local district general hospital is the Royal Bolton.

Why the PCT got involved and why it was selected

- 4.2.3. The PCT has a strong tradition of innovation and history of investing in ICT (e.g. Choose and Book, Community Lorenzo, e-Prescribing), which has partly been driven by innovative GP practices. Both the previous and the current Chief Executive are supportive of the NPfIT. Inclusion in the Early Adopter programme was seen as aligned with the PCT’s explicit strategy of investing in IM&T to improve patient care and outcomes. The Royal Bolton Hospital also has one of the busiest A&E Departments in Greater Manchester, and the SCR was seen as aligned with the aim of reducing inappropriate admissions (because it would provide more information on which to base the admission decision). Additionally, there was a sense of “it was going to happen anyway”, so being an Early Adopter gave the PCT the opportunity to influence the project and receive support that would not be available later.
- 4.2.4. Bolton was selected as an Early Adopter site by CFH because it was a medium sized PCT with a single secondary/unscheduled care provider; most practices (68%) were using a single GP software provider (InPractice); data quality in GP practices was relatively good; there was significant local enthusiasm and buy-in; it was close to Leeds where key CFH staff were based; the population was fairly stable (hence patient turnover in GP practices was fairly low); and there was perceived to be a manageable amount of cross-border patients (though we were subsequently advised by Bolton A&E that the actual figure was 21%). Even though Bolton scored lower than Bury (see next section) overall, it was chosen as the first Early Adopter site because it had a higher number of Choose and Book referrals.

How the SCR implementation unfolded in Bolton

- 4.2.5. With Bolton being the first site nationally to go live with the SCR, there was a sense of ‘pioneering excitement’ as well as considerable uncertainty as to what would be involved in the project. There were also concerns about what the workload would be and when it would occur. (“The PCT knew very little”; Bolton “took a massive leap of faith” – lead GPs). Both CFH and the PCT wanted to move forward with the project

quickly, because upcoming local elections meant that patients needed to be mailed before the compulsory 6-week 'election purdah'. Monthly SCR implementation board and fortnightly implementation team meetings were established quickly, and have been well attended. Both have representation from general practice and A&E, but until recently not from OOH or the WiC.

- 4.2.6. The PCT was relatively well resourced for the project. There were five data quality facilitators (DQFs) to help the practices achieve early accreditation, and three full-time and one part-time trainer for SCR training. The communications side of the project was run by the Bolton PCT and Royal Bolton Hospital communications lead, with support from the PCT communications manager, who took over when the former left at the end of 2007. A full-time project manager was appointed and funded by the grant provided by CFH. IT aspects were managed by the PCT's IM&T Department in liaison with CFH and suppliers.
- 4.2.7. Initially, it was expected that most if not all GP practices would sign up to the Early adopter programme. Five 'engagement' events were held where national GP leaders visited Bolton to explain the project and answer questions. Three-quarters of Bolton practices attended such an event, and used it mainly to acquire more information and ask detailed questions. Two practices who had volunteered early were chosen for wave 1, also because one used the prevalent GP system InPractice, while the other used another system (iSoft). The GP champions from these practices became heavily involved in the implementation of the project, working closely with and advising the CFH team, and one was later appointed as a clinical lead.
- 4.2.8. The first wave 1 practice went live in June 2007. Nine more practices signed up for the second wave, but others expressed concerns, mostly over the implied consent model, protection of confidentiality, and workload.
- 4.2.9. Depending on their progress with the IM&T DES, practices experienced significant workload to achieve Paperlight accreditation. Some informants felt that data quality was *the* stumbling block to signing up more practices. The need to complete the IM&T DES ahead of schedule to be able to go live caused problems for some practices, and discouraged others from signing up for the project.
- 4.2.10. Whereas the SCR specific workload for the wave 1 practices was very high because of their role in shaping the project (there were numerous meetings to attend, for example), wave 2 practices reported very little work associated with the initial creation of SCRs.
- 4.2.11. Practices in the earlier waves felt under considerable pressure from CFH. This was resented ("*it was madness, we were rushed and pushed around.*" – practice manager). Despite this, phase 1 had to be delayed by several months in many practices because of the immaturity of the technology. This was particularly the case for the iSoft practices, and staff were not always informed of cancelled dates. For most InPS practices, the upload was fairly smooth with little impact on the practice. However, a number of practices experienced a significant slow-down of their system post go-live. At the time of writing (April 2008), 22% of Bolton patients have a SCR.
- 4.2.12. The two wave 1 practices in Bolton have very recently begun adding further information to records (the so-called 'phase 2 upload', see paragraph 2.2.5.). They have chosen to target patients with chronic diseases (e.g. diabetes), and letters are being sent out to patients on practice disease registers. Patients who agree to a further transfer of information from their record can tick a box and sign for their GP to add information without them having seen it, or alternatively, request a print-out of

the current data before committing themselves. In one of the practices over a third of mailed patients have now opted to have their record 'enhanced'.

Deployment in unscheduled care settings

- 4.2.13. Deployment of the SCR in unscheduled care settings has only recently begun. Although almost a quarter of Bolton's patients have a SCR, the unscheduled care population is skewed towards practices that have not been part of the SCR programme (generally in more deprived areas, with lower data quality). This means that a much smaller proportion of patients who seek out-of-hours care actually have a SCR, so the 'hit rate' when a clinician checks for the presence of a SCR is very low.
- 4.2.14. The OOH triage nurses began accessing the SCR in October 2007, and the OOH GPs followed in February 2008. Most have now been trained but some who work part time have not yet received training. In December 2007 the OOH service was taken over by the PCT from a private company, and underwent major organisational changes, which posed short-term challenges for the deployment of the SCR while also offering longer-term opportunities (for example, a strategic plan for staff development and training is now in place, as well as regular quality control audits). Use of the system in the OOH centre is currently low for technical reasons. Access to records is tedious, as NHS numbers need to be copied and pasted manually from the OOH software (Adastra) to the CSA. This seemingly minor hurdle has put staff off accessing the SCR (*"It has to be part and parcel of the system that you're using; you want to be into it in a couple of clicks"* – OOH GP). Additionally, there are pressures to meet targets, and accessing a patient's SCR adds to consultation time (*"you're up against the queue"* – nurse). Plans have recently been drawn up to make records available in the cars taking GPs on home visits.
- 4.2.15. The main Bolton walk-in centre (WiC) went live in December 2007. Computers were not used there at all prior to the SCR being introduced, and equipment had to be installed. This was welcomed, but the SCR is not accessed much, mainly because of technical problems (slow access), but also because the attending population mostly presents with trivial illness or minor injuries, and most are not on regular medication. The WiC often gets very busy (we have seen queues so long there is standing room only in the waiting area, though we have also seen the WiC almost empty), and at busy times it is not seen as feasible to take time out to look up a patient's SCR.
- 4.2.16. In A&E, the SCR has been available for access since January 2008. Deployment in A&E was held back somewhat by the promise in the CRS Confidentiality Leaflet (Appendix, paragraph 9.3.1.) that clinical records would not be accessed by receptionists. In some NHS environments (and Bolton A&E was one), this promise was at odds with existing work routines, in which administrative staff regularly access clinical data to support doctors and nurses in their work. A&E is a highly complex environment with constant time pressures, and direct access of the SCR by clinicians did not appear workable. Whilst this situation was being considered, records could be accessed by healthcare assistants (HCAs). However, HCAs are not available during the night when resources tend to be most stretched, and are often not easily reachable by clinicians. Plans to revert to the original plan for an extended receptionist role, allowing them to print out records along with other information about the patient are now under discussion, which would fit with existing working practices.
- 4.2.17. The hospital pharmacy will also begin accessing records once a new fix to the software has been installed. Pharmacy staff expect great benefits when they have gone live because new prescriptions need to be checked against existing drugs, and it will save them from constantly having to phone GP surgeries for this information. Access to the SCR via hand-held computers by district nurses is also being explored.

4.2.18. One challenge in all unscheduled care settings in Bolton (as elsewhere in the NHS) is that there is not a culture of regular usage of smart cards. Whereas most GPs now carry their smart cards with them and log in at the beginning of each surgery, staff in unscheduled care settings did not have this habit and did not always have their smart cards with them when they turned up to work. In some ways this was not surprising given that the technical limitations of the SCR are seen as precluding its routine use anyway. A management decision has been made to wait until more records have been created and current technical issues have been resolved before putting pressure on staff always to use their smart cards.

Public engagement and information

4.2.19. There was considerable anxiety from both CFH and the PCT about the wording of the leaflet that would be sent to patients informing them of the project. The leaflet (reproduced in Appendix, Section 9.3.) underwent numerous iterations following input from CFH, PCT staff and Early Adopter practices. Both wave 1 and 2 practices commented that they had been prepared for high numbers of patient enquiries, which consequently built up expectations, but turned out to be an “*anti-climax*” as there was little interest from patients.

4.2.20. The two wave 1 practices wrote to their patients themselves, whereas wave 2 patients were written to by the PCT. No difference in patient response (enquiries and opt-out numbers) was reported. After the first two waves had been mailed, the PCT wrote to the remaining population (even those registered with non-participating practices) because it was felt that there needed to be widespread awareness of the project prior to running an information campaign – a move which they admitted in retrospect was ill judged.

4.2.21. 'Road shows' (information events) with the CFH information trailer were arranged in the town centre and Middlebrook Retail Park in the West of Bolton. The town centre shows attracted some attention from passers-by, whereas Middlebrook was very quiet. About 20 information sessions were held in the Lever Chambers Centre for Health, the PALS office and one rural practice, and were attended by a small number of patients. Presentations to minority ethnic groups (e.g. Somali women's and Polish group) were said to have been well received.

4.2.22. Additionally, there was local radio and press advertising, and the PCT also sent regular press releases to the Bolton News. There was wide coverage of the project locally, which ranged from critical articles voicing the concerns expressed by some of the GPs (“*GPs fear online records at risk from hackers*”) to more positive stories (“*Patients can log on to see their records*”). Information was also made available on the PCT website, and SCR and later HealthSpace posters were displayed in GP practices.

HealthSpace

4.2.23. The PCT initially expected to publicise HealthSpace at the same time as the SCR, but then decided against it on the basis of workload concerns and the fact that since the HealthSpace technology was still being refined, there would not be any tangible benefits for patients. Once the first two waves had gone live, a HealthSpace registration office was opened in the public health section of the central Bolton library in October 2007. A minimal advertising programme was run with leaflets in practices and articles in the local press, and did not attract much attention. Out of 60,000 patients who have a SCR, only 66 have gone through the various steps of opening an advanced HS account. The main reason for this low number (even lower than

other Early Adopter PCTs) appears to be a lack of awareness and interest and/or the fact that HealthSpace is only [seen as] relevant to people with serious, chronic or multiple health problems (see Section 6.3.). Currently, patients who have consented to having more information added to their records are being targeted to consider a HealthSpace account. However, interest remains low. The patient perspective is covered in detail in Section 6.

4.2.24. Despite the high investment in the public information programme and regular articles in the press, there was little awareness of the SCR and low interest in it (see Section 6.). However, our own fieldwork suggests that when the SCR was explained to patients, most were not concerned about sharing data, and many thought that records were already shared.

4.2.25. As of April 2008, 237,759 people have been mailed and opt-out numbers have been very low (2295 people, 0.97% of the mailed population), although slightly higher than in the other Early Adopter PCTs. This may have been a result of critical articles in the Bolton press, activities of the opt-out campaign and Bolton being the first Early Adopter site.

Clinical engagement and incentives

4.2.26. In terms of clinical engagement, the initial process for engaging GPs was felt by many informants to have been rushed, and as a result buy-in suffered (*"We were running too quickly with the stakeholder engagement"* – PCT informant). However, many practices still described their attitude towards the project as *"positive but cautious"* – it was not that they were opposed to the project but they were unsure about the workload involved and wanted reassurance about how the information on the SCR would be used.

4.2.27. In addition, some GPs did not want to go against the advice of the Local Medical Committee, which at one stage recommended not taking part. The PCT had written to all Bolton patients about the SCR programme, regardless of whether their practice was involved or not, and there was some quite vocal resistance from a few local GPs. Concerns from these and other GPs were around security of the system and the protection of patient data, as well as the cost of the project. However, most GPs in Bolton believed that the SCR could bring significant benefits to patients, though they were not always comfortable with the implied consent model.

4.2.28. Bolton practices who were involved early on received a one-off payment, and plans to make the project a Local Enhanced Service (LES, see paragraph 5.8.9.), which would generate payment according to the number of records created, are being explored. Once upgrades to the GP software have been released, a third wave of practices is planned to go live.

Summary

4.2.29. As the first site nationally and with a lot of uncertainty because of the project still evolving at a fast pace, Bolton was generally able to take the pressures in their stride because of a committed core team, close alignment with a wider strategy of IM&T development, and a well-resourced team of support staff. However, because of the tight schedule, there was little time to engage clinicians after the decision had been made to become an Early Adopter site, and in any event the technical immaturity of solutions and associated delays showed that the haste had been premature.

4.3. Case study 2: Bury

Local context and demographics

- 4.3.1. Bury comprises a collection of six towns north of Greater Manchester, and lies within North West Strategic Health Authority. As Table 1, paragraph 4.1.2., shows, life expectancy is slightly lower than the national average and there are higher levels of chronic disease. Levels of education and literacy are similar to the national average. The minority ethnic population is small and stable, although there has been a rise in immigration in recent years.
- 4.3.2. The PCT was created in 2002, and there are 32 GP practices (all using InPractice as the GP system), as well as two nurse-led walk-in centres and one out-of-hours service. Primary care services are generally considered good, although areas for improvement have been identified. Recently there has been an increase in investment in IM&T, and there are plans to establish new 'primary care centres' to provide more services in the community. The local district general hospital is Fairfield General. However, about one in six A&E attendances from Bury residents are to other hospitals.

Why the PCT got involved and why it was selected

- 4.3.3. The PCT has a culture of innovation and a recent track record of IM&T projects (Choose and Book, GP2GP, e-Prescribing, Community Lorenzo). Taking part in the Early Adopter programme was seen as another opportunity to use new technologies to improve patient care and outcomes. The Chief Executive is very supportive of the project, which was seen as closely aligned with the wider aim of integrating unscheduled care provision. Keen lead clinicians have been involved from the beginning and have played a significant role in driving the project. Others involved in implementation are also keen (*"People are really up for it"*). There was also a sense of *"it was going to happen anyway"*, so being an Early Adopter gave the PCT the opportunity to shape the project and receive support that may not be available later.
- 4.3.4. Of 56 PCTs who applied to be included in the Early Adopter programme, Bury came top in terms of formal assessment criteria (see paragraph 4.1.1.). It is a medium-sized PCT with a single secondary/unscheduled care provider; 100% of practices are using a single GP software provider (InPractice); data quality in GP practices was relatively good; there was significant local enthusiasm and amenability; it was close to Leeds where the CFH support team were based; and adjacent to Bolton.

How the SCR implementation unfolded in Bury

- 4.3.5. Bury was the second Early Adopter site, and there was both excitement and uncertainty about what would be involved (though less uncertainty than in Bolton). The timescale proposed by CFH for conducting the initial public information programme and achieving the first uploads was seen as unrealistic (*"we were shocked"*) and the PCT argued for it to be changed so as to achieve buy-in from practices prior to the mail-out to patients. Senior PCT staff and lead clinicians also worked hard to gain buy-in from the Local Medical Committee, as well as from local MPs (on the advice of CFH).
- 4.3.6. The project initiation document was approved in March 2007. Fortnightly SCR Implementation Board and weekly Implementation Team meetings were established, which were moved to monthly and fortnightly after the patient mail-out.

Representation from general practice and the secondary care providers was invited, although it proved difficult to recruit GP representatives onto the Implementation Team.

- 4.3.7. A full-time project manager was provided by CFH, and the PCT seconded a part-time assistant project manager, paid for by the PCT's Early Adopter budget. The PCT had one data quality facilitator (DQF) and two other staff helping with data quality work, but this proved inadequate and another full-time DQF was seconded from CFH.^P The technical aspects of the project were managed by Bury's IM&T lead, and training was provided by trainers from the NPfIT Greater Manchester North East sector with support from a CFH-appointed consultant.
- 4.3.8. Communications were led by the NPfIT Greater Manchester North East sector communications lead, with support from the PCT communications manager, both of whom later left the project. The new PCT communications manager then took over this role, but in retrospect, the PCT felt that a dedicated communications resource would have been useful for the first year of the project. The patient letter used was based on the template provided by CFH, also used by Bolton, although edited by each project's communications lead.
- 4.3.9. A number of 'engagement events' were arranged, but attendance from practices was low, so these were followed up with individual visits to some practices.
- 4.3.10. Twenty-three practices were recruited for the first wave, with another just missing the deadline and being allocated to the second wave. Patients in participating practices were mailed June and September 2007 respectively (the first wave mail-out had to be delayed slightly because of the requirement not to implement potentially contentious changes around the time of local elections). The remaining 11 practices did not wish to sign up for the project, at least for the time being, for various reasons ranging from concerns over workload; competing priorities; IT problems; failure to meet data quality standards; or staff objections to the project. Even amongst practices who agreed to participate, not all clinicians were comfortable with the opt-out consent model, as records would inevitably be created without patients' knowledge or explicit consent.
- 4.3.11. The first practice to go live was that of a lead GP who had been involved at national level in the project even before the PCT became an Early Adopter site. Initially there were minor delays as a result of software non-readiness, but it was mainly the upload itself that took longer than expected. However, after this the records of patients at most the remaining practices were uploaded fairly swiftly, although technical problems with the current version of the InPractice GP system have meant that at the time of writing, several practices were still waiting. Two of the six practices that had uploaded and were interviewed experienced a significant slow-down of their system post-upload.
- 4.3.12. One of the first practices to go live felt that CFH and the technical staff involved in the go-live did not fully appreciate the extent of the disruption to their core business (providing care to patients), and felt *"invaded... [like] having builders in the house"*. However, later practices in Bury did not feel so disrupted.

^P CFH asked us to add this comment: *"It would be helpful to outline why NHS CFH provided resources to the Early Adopter PCTs. As it was an Early Adopter programme it was in all parties' interests to learn from the experience and achieve as much progress as possible through the period of the Early Adopter programme."*

Deployment in unscheduled care settings

- 4.3.13. Bardoc, the GP out-of-hours (OOH) provider, officially went live with the SCR in February 2008. Staff have generally shown enthusiasm for the SCR as an idea for the near future, but technical difficulties (the SCR is slow to boot up and is not yet fully integrated with the Adastra system) have prevented regular access. Many of the doctors also still need to be trained on the system, which is not an easy task given the large numbers of staff and unsociable hours worked. Current problems with the N3 connection are expected to be resolved when Bardoc moves to new premises. There is a feeling among some staff that for records to be accessed routinely, the spine viewer would need to be integrated into Adastra, and records would need to be checked automatically rather than manually by the clinician.
- 4.3.14. Fairfield A&E started accessing records in March 2008, and preliminary data suggest that this has been broadly successful. The decision was made for the two 'target chasers', whose role includes helping to ensure that the 4-hour target is met as well as consultants and senior nurses, to access records. The 'target chasers' already had access to clinical records because their role included printing off diagnostic test results from a computer and bringing them to the attending clinician. Adding the additional task of accessing the SCR where clinically relevant was very easy to integrate with existing work processes. It is also worth noting that at the time of writing, the project is still very new, and there is considerable goodwill and enthusiasm among staff.
- 4.3.15. The WiC teams in Bury were initially sceptical about benefits, but have become more positive and are in the process of preparing their data for go-live.
- 4.3.16. Whilst there has not been a systematic programme of data quality improvement in emergency and unscheduled care settings, we found that data quality is also an issue in these settings. For example, prior to go-live, Bury OOH centre invested considerable time and effort into populating their database with NHS numbers, which were not previously used in this setting.

Public engagement and information

- 4.3.17. The project was launched with local and national media briefings. The local press was happy to publish press releases, but otherwise provided little coverage of the project. The patients of all practices that had signed up to the project were written to by the PCT. In addition to a patient letter, NCRS guarantee leaflet and order form for alternative formats, the pack included a HealthSpace leaflet. Although patients were told that they had the choice of not having a SCR or limiting what would be shared, the information pack did not provide information on how to opt out (though it did state where to get more information). After the mail-out, two information centres were opened for the duration of the 16 week campaign, one in the centre and the other in the south of the borough. Attendance at these centres was poor, and after the first four weeks, staff availability was reduced. Those who attended mostly wanted to opt out of having a SCR.
- 4.3.18. In addition, a CFH information trailer featuring a local GP (who attended in person) was available in various locations in the borough. These 'road shows' were found to be a useful way of approaching the public and gauging their awareness. Drop-in sessions were held in a few practices, and information about the project was placed on the PCT website as well as on the websites of several local practices. Presentations to various community and voluntary sector groups, including minority ethnic groups, were made and appear to have been well received. These

presentations were not focused entirely on the SCR, but linked with other communication programmes running at the PCT at the same time.

- 4.3.19. The PCT also sent regular press releases to the local newspaper. The radio advertisements that had been produced by Bolton were used, but were played on a station hardly known in the South of Bury. This is a good illustration of the problems of 'targeting' mass media message – the stations listened to in South Bury could not run the advertisement because they are broadcast right across Greater Manchester, but a more 'local' station did not map well to the project catchment area. Posters about the NCRS, SCR and HealthSpace were also placed in GP surgeries, unscheduled care settings, pharmacies, colleges and other public buildings.
- 4.3.20. To date 118,750 patients have been mailed. The opt-out rate is low with 779 patients (0.66%) choosing not to have a SCR and 119 (0.1%) asking for 'store, don't share'.

HealthSpace

- 4.3.21. In contrast with the approach taken in Bolton, the PCT decided to link the SCR and HealthSpace in their public information programme, on the grounds that the two technologies were clearly related, and HealthSpace might be seen as a "selling point" for the SCR. HealthSpace registrations were initially taken in the town centre and in Whitefield in the south of the borough, which is located with the PALS and PPI services. Discussions are also being held with local libraries to offer the option to register for HealthSpace there.
- 4.3.22. Interest in HealthSpace by people in Bury has been poor. Of over 90,000 patients with a SCR, only just over 100 have had an advanced account created. This number is somewhat higher than Bolton's, but significantly lower than Dorset's. Individuals who have registered have tended to be elderly. The registration process is described as "*complicated and tedious*". Currently there are renewed efforts under way to raise awareness of HealthSpace and encourage people to register and try it out.
- 4.3.23. As described in detail in Section 6., patients in Bury generally showed little awareness of the project and little interest in it. Many appear not to have read the letters, and did not understand that a record would be created automatically unless they opted out. A GP commented "*patients don't have a clue*". The very low opt-out rate (0.6% at the time of writing) may partly be explained by lack of engagement by patients, though in our own survey, when we explained the SCR to patients, most showed enthusiasm for having a SCR or "*did not mind*".

Clinical engagement and incentives

- 4.3.24. Bury was initially characterised by a relatively low level of interest from GP practices. Many were concerned about workload and the uncertainties of the project. However, most were already involved in other CFH projects (especially Choose and Book or GP2GP). Through individual discussions with practices by PCT staff, a high sign-up of 75% (24 out of 32) was eventually achieved. This was partly because the PCT allowed practices the option of deferring a decision on the upload of phase 2 information (the so-called 'minimum data set', paragraph 2.2.5.). The 'phase 1 only' option was taken up by ten practices.
- 4.3.25. Reasons practices gave for becoming involved in the SCR programme included the contribution the project could make in improving patient care; and a wider interest in sharing information with colleagues. Many practice managers said that they thought the SCR was "a good idea", and one GP "*did not want to be left behind*". Some also felt that as an Early Adopter practice they would receive support which would not be

available later on. Practices spoke highly of their good relationship with the data quality facilitator and the SCR project manager, implying that interpersonal influence had played an important part in their decision to join the project.

- 4.3.26. However, a number of the practices told us that, in retrospect, they felt they had been to some extent coerced into the project (*"we had our arms twisted"*). Some also expressed a sense of 'innovation fatigue' (*"Bury always wants to be the first in everything"* – said by two different practice managers). Depending on their progress with the IM&T DES, many practices experienced significant workload, especially to achieve Paperlight accreditation, which was one of the prerequisites for commencing the phase 1 upload.
- 4.3.27. At the time of writing, practices are waiting for information from the PCT regarding the second phase of the SCR upload. The feeling is that *"it's all gone a bit quiet"* (practice manager), and most practices have not made plans for how to deal with a possible increase in workload.
- 4.3.28. Lead clinicians and managers from A&E and OOH were involved in the project from the beginning, and have been very supportive. They feel that are regularly presented with patients about whom they have insufficient information, and would welcome access to selected data from GP records (as well as medication, allergies, and adverse events, they would like to see main medical diagnoses, immunisations and key treatments received). However, slippage in the planned 'go-live' date has led to frustration. At the time of writing, unscheduled care settings have only just begun accessing the SCR, and the system is fully functional only in A&E.
- 4.3.29. Concerns over the (lack of) success of the public information programme, together with the prevailing political situation surrounding extended GP working hours^Q led one practice to withdraw from the programme and another three to put the project on hold. As discussed above, the workload for GPs themselves for phase 1 uploads has been negligible, but (depending on the consent model chosen) is likely to be higher for phase 2, so the PCT anticipates a period of further negotiation.
- 4.3.30. One practice carried out an informal survey of 50 patients, and found (as we did) that understanding of the SCR was very limited. This concern was shared with the PCT and CFH, and additional support for engaging the local community was offered. However, amidst the wider pressures discussed above, this offer was not taken up, and the practice has now formally withdrawn from the Early Adopter programme.

Summary

- 4.3.31. Overall, participants in Bury describe their involvement in the Early Adopter programme as a success, and attribute this to good project management and good support from key staff (especially the project manager and data quality facilitator). However, the high levels of clinical engagement were achieved via a compromise (practices could, and many did, opt to defer a decision on the phase 2 upload), and there are now significant winds of dissent amongst some practices who initially signed up. Clarity on the definitive consent model, and advice from professional bodies on the legality of creating records when patients remain ignorant of what is going on, may help the programme regain momentum in terms of go-live.

^Q Senior informants in the BMA advised us that the SCR programme was politicised by some of its rank and file members as a negotiating issue in the 'extended working hours' debate. Put crudely, the alleged link was that if the government drove too hard a bargain over extended opening hours of GP surgeries, the GPs had decided that they would not play ball with the SCR programme. Whether or not this was true, it was a 'hot issue' in the medical press in late 2007.

4.4. Case study 3: South Birmingham

Local context and demographics

- 4.4.1. South Birmingham was a medium-sized Early Adopter site; its population is significantly younger than the national average, significantly more deprived; and there are more minority ethnic residents (see Table 1, paragraph 4.1.2.). Unemployment is high and levels of education and literacy are lower than the national average. Relative to the other sites studied, it has very high levels of illness.
- 4.4.2. There are 64 GP practices. GPSS coverage is predominately EMIS (73%), plus InPS (15%) and iSoft (12%). Emergency care services are provided by two hospitals: Selly Oak (UHBFT) and Birmingham Children's Hospital, as well as CRIS, (the Community Rapid Intervention Service) and the OOH provider (Badger). South Birmingham PCT also contains two community hospitals, Moseley Hall, and West Heath.

Why the PCT got involved and why it was selected

- 4.4.3. The project lead is seen as *"a forward looking IT lead"*, and the PCT is involved in a number of other IM&T initiatives. South Birmingham's reasons for applying to become an Early Adopter PCT were primarily to improve patient outcomes and efficiency by using the SCR to achieve a greater level of collaboration between the various clinical teams and greater integration of the ICT systems deployed across the local health economy (e.g. A&E, OOHs etc). The SCR was seen as fitting into the PCT's Integrated Service Plan for LTCs (patients with long term conditions).
- 4.4.4. More specifically, the SCR is seen as a support tool in developing the Practice Based Commissioning Agenda by enabling access via mobile devices used by the community nursing team when they visit patients in their own homes. As part of the SCR Early Adopter programme, South Birmingham has agreed to pilot the use of the SCR in a mobile environment. BT has agreed to supply 20 mobile devices to the community nurses and the pilot is to run for six months. As well as capturing the benefits of the SCR in a mobile environment, the PCT aims to test out a different consent model by *"driving consent"* via their district nurses (i.e. gaining explicit consent opportunistically when the nurses see patients).
- 4.4.5. South Birmingham was selected as an Early Adopter site because of the enthusiasm expressed by the PCT to be involved, the high percentage of practices using one GPSS system supplier (EMIS), the fact that they have only two A&E departments (one of which is specialist paediatric), and no boundary changes were anticipated.

How the SCR implementation unfolded in South Birmingham

- 4.4.6. The PCT recognised the need for additional resources to support the project. A full-time SCR communication lead was recruited from within the PCT, and CFH supplied a project manager, three data quality facilitators (DQFs) and a trainer. A Project Board was set up and work streams identified. The Project Board is chaired by the chair of the Professional Executive Committee and made up of the director of ICT, the SCR project manager, the Head of Communications, the Data Quality lead, a GP, a patient representative, the head of Community Nursing, the general manager of the OOH service, the PCT programme manager, and the LTC programme lead. In recent months representatives from the LMC and SHA have also been included. The Project Board meets monthly and Implementation Team meetings with the various work

streams meet weekly and is seen to be valuable, giving *“everybody the opportunity to know what everybody else is doing...especially because everything changes so fast”*.

- 4.4.7. Towards the end of April 2007, letters were sent inviting GP practices to the CFH SCR engagement event held in May. The event resulted in four practices agreeing to participate in the project, including the largest practice in the PCT with over 20,000 patients. The initial Project Board meeting was held in June when the PID was formally accepted. The PCT received £170,000 from CFH to pay for additional expenditure including the purchase of plasma screens for practices participating in the SCR which the PCT use as part of their information programme. At the same time, discussions began with CFH about piloting mobile devices using the SCR, and the Project Initiation Document for mobiles was signed off in December 2007.
- 4.4.8. Clinical engagement (see below) and concept training with practices continued until the end of March 2008, by which time 45 out of the 64 practices were on board. Our interviews with practices suggest that workload for practice staff has been “minimal”, though practices did not consider the workload associated with the IM&T DES as part of the SCR programme. However, some expressed uncertainty and apprehension about the additional workload implications for the phase 2 upload.
- 4.4.9. Practices were divided into three waves: for the first (4 practices), letters informing patients were sent out in August 2007; for the second (8 practices), letters were sent in September 2007. The potentially lengthy delay for the EMIS solution was becoming apparent, so the third wave was rescheduled for November 2007 and reduced to the two non-EMIS practices, with the remaining practices and the public information programme put on hold. The creation of records from the non-EMIS first wave practices was delayed (and at the time of writing had not yet happened) due to technical glitches with both the iSoft and InPS systems. The PCT anticipates that the initial go-live will take place soon after the end of April 2008.
- 4.4.10. The PCT began the IM&T DES and Paperlight training by helping each practice individually. It soon became obvious that this would take too long and so group workshops and drop-in sessions for practice managers were offered instead. The training drew a good response and 59 practices are currently doing the IM&T DES. Of these, 28 have so far been Paperlight accredited. According to the PCT lead, *“we already have some patient benefit in terms of better data quality”*.

Public engagement and information

- 4.4.11. A detailed communications plan was produced by the PCT Head of Communications by July. Local MPs and press were briefed and CFH provided a ‘road show’ which was located at various events including the PCT Annual General Meeting. The SCR communications lead oversaw the mailout to patients. The mailout also included an additional leaflet based on a design derived from a diagram on a CFH mouse mat summarising three possible choices (don’t store, store but don’t share, store and share). Patients were given numerous options for obtaining information including the local PALS telephone line, NHS Direct Information Line, and the PCT web site. The letter also included times of information sessions held within their GP practices. The sessions were staffed by PALS, and although not many patients attended, sessions were well received by both GP staff and the patients who did attend.
- 4.4.12. South Birmingham had a proactive patient representative, with strong links to Expert Patient groups, on their project board. He assisted the PCT by promoting the SCR and HealthSpace among patient groups with a view to engaging reluctant practices through patient power.

- 4.4.13. Many patients assumed that data sharing was already taking place, and concerns were mainly about security, especially after press reports about government data losses. The PCT also held a SCR presentation at one of the regular fortnightly PALS events, as well as to patient forums in some GP practices. To date 62,762 patients have been mailed, and the opt-out rate has been low with 477 patients (0.76%) choosing not to have a SCR and 6 (0.01%) asking for 'store, don't share'.
- 4.4.14. As well as information sessions and the PALS information line, the PCT provided participating practices with a large plasma screen with a rolling presentation about the SCR developed by the PCT. This also informs patients about other current PCT health promotion campaigns (e.g. blood pressure, anti-smoking). Nursing homes were contacted by either the practices themselves or in some cases by the PCT. South Birmingham has a large university student population and plans to conduct an information campaign on campus during Freshers Week in September 2008.

HealthSpace

- 4.4.15. The PCT decided to treat HealthSpace as a separate programme rather than run it parallel with the SCR. It was felt that making patients aware of both SCR and HealthSpace at the same time might be confusing and be too much of an additional strain on PCT resources. The HealthSpace Project Initiation Document was signed off in November 2007. A HealthSpace user group was set up and the Director of Public Health has been appointed as sponsor for the project. Once the go-live of the first practice takes place, the PCT plans to conduct HealthSpace registrations within the practice reception area, targeting specific patient groups (those with chronic, long term conditions). The PCT will hire health trainers to give demonstrations and register patients. *"We're waiting to see how it goes, if uptake turns out to be a trickle, then might re-consider, have more general advertising, perhaps move front office into local libraries, nothing's been decided yet, it's still under discussion at the PCT"*.

Clinical engagement and incentives

- 4.4.16. The approach adopted by the PCT to engaging GP practices was based upon individual consultations with practices and securing their voluntary agreement to participate. This approach had been discussed and agreed with the Local Medical Committee. Initially, engagement was seen as *"challenging"*. However, by mid July 2007, the situation had improved and of the first dozen practices contacted, only two declined to participate, mainly due to concerns about patient confidentiality.
- 4.4.17. Overall, the practices interviewed in this evaluation were positive about the SCR. They feel that the project has been *"well managed by the PCT"* and that *"the PCT has been very supportive and responsive"*. The main reasons given for deciding to take part was the assumption that it was going to happen eventually anyway and *"there's no knowing how much PCT support will be available to practices later on"*.
- 4.4.18. A major setback to South Birmingham's involvement occurred when the first large 'flagship' practice withdrew commitment because of concerns about confidentiality.

Summary

- 4.4.19. South Birmingham is one of the most deprived areas in the country, with high rates of long-term illness. The PCT signed up for the SCR as part of a wider strategy to improve care for long term conditions. The main problem to date has been the delays in creating SCRs, mainly because the EMIS solution is not yet ready, and also because of residual technical problems with other suppliers.

4.5. Case study 4: Dorset

Local context and demographics

- 4.5.1. Dorset is the largest of the four Early Adopter sites in both population and area. It is predominately rural with farming, tourism and leisure its main industries. As Table 1, paragraph 4.1.2., shows, Dorset is an affluent part of the country and its population is relatively elderly but relatively healthy. The main hard to reach groups are gypsies and travelers (estimated population 2400–3000, but could be much higher) and prisoners (just over 2000). There are some pockets of socio-economic deprivation, and PCT figures show that these are almost exclusively in the Weymouth and Portland areas due to a concentration of prisons and halfway houses for recovering alcoholics and drug addicts concentrated within this area.
- 4.5.2. Dorset PCT was formed in October 2006, as a result of a merger between South West Dorset, and South and East Dorset PCTs. There are 60 GP practices, 77% EMIS GPSS, 15% InPractice, and 8% iSoft. There are 11 Community Hospitals, and eight nurse-led Minor Injuries Units, co-located within the Community Hospitals, most are open from 8 to 8 pm daily. There are three A&E departments: Royal Bournemouth Hospital, Dorset County Hospital, and Poole Hospital. The out-of-hours service is operated by the Dorset Ambulance NHS Trust.

Why the PCT got involved and why it was selected

- 4.5.3. According to the project lead, as well as wanting to get involved at an early stage so as to influence the national rollout, the main reason for applying to become an EA was his view of the SCR as *“a continuation of Dorset’s aborted ERDIP project it felt as if we had already done half the work anyway”*. The main benefits of the SCR for Dorset was described as *“tying it in with Practice Based Commissioning, to keep people in their own homes...”*.
- 4.5.4. CFH informants described Dorset as *“an ideal springboard for the SCR”*. Most practices were on the same system, and Dorset GPs were said to be already *“intellectually there”* (because of their earlier ERDIP experience in 2002 – see Appendix paragraph 9.4.1.). Data quality in Dorset was also seen as *“better than most”*. There was support from the Local Medical Committee, which was also attributed to participation in ERDIP.
- 4.5.5. Whilst Dorset’s past experience with ERDIP was seen as beneficial, concern was raised by CFH at the outset that the PCT was perhaps underestimating the amount of work that would be involved in implementing the SCR, especially in terms of the public information programme. Other initial concerns were its distance from Leeds and not being co-terminous with a single secondary care provider.

How the SCR implementation unfolded in Dorset

- 4.5.6. The Project Initiation Document for the SCR programme was approved by the Dorset Informatics Board, and subsequently by the SCR Project Board, in April 2007. The Project Board meets bi-monthly, and the project team meets fortnightly. In comparison to other Early Adopter PCTs, Dorset Project Board was initially quite large group (23 people, including 5 patient representatives). However, by the third meeting, the newly appointed Chair decided to review the membership of the Board in the light of CFH’s desire to *“find out whether public benefits are being realised”*, and a number of members, including the patient representatives, were asked to

stand down in favour of representatives of the anticipated main users of the SCR, the MIUs, A&E, district nursing and OOHs.

- 4.5.7. Detailed project planning began in May 2007. At that time, neither a project manager nor a full time data quality facilitator (DQF) was in post, though they had been appointed by June. Unlike the other Early Adopter sites, Dorset PCT did not appoint a dedicated person to handle communications about the SCR. Instead, the project manager found herself responsible for all forms of communication except external media press releases (which were dealt with by the PCT press officer).
- 4.5.8. Practices were initially scheduled into five waves. Due to the technical delays with the EMIS system, it was decided to include only the six non-EMIS practices (InPractice and ISoft) in the first wave. Data quality accreditation and concept training for the initial six practices began in May 2007 and was completed by July. The PCT mailed patients on 16th and 17th July along with a press release which led to coverage in several local newspapers and local BBC. Unfortunately, the mail out for one of the practices had some incorrect addresses which had to be re-sent.
- 4.5.9. A second mail-out took place in August, consisting of a further seven practices in the Weymouth area. Although still relatively low, the opt-out rate increased significantly in parallel with media stories about the government data losses. The continuing uncertainty about the delivery of the EMIS solution, together with the 'data loss' stories in the press, made the PCT decide to hold off on their third wave mail-out and instead amalgamate it with wave 4 in January 2008.
- 4.5.10. At the time of writing (April 2008), Dorset PCT has completed the mail-outs for 25 GP practices, representing a total of 154,215 patients. In total, 1,289 patients (0.84% of the mailed population) have decided to opt out of having a SCR, and 8 Patients (0.005%) have opted for the 'store, don't share' status. Eleven practices have received data quality and Paperlight accreditation.
- 4.5.11. Technical problems affecting ISoft & InPS go-live (see Bolton and Bury case studies) have delayed the uploading of the wave one practices, which were scheduled to go live in December. The first go-live is now expected to take place in June 2008, and the date for the second wave uploads remains uncertain. Meanwhile, data quality accreditation and concept training continues for the remaining practices. The PCT project lead has yet to see live versions of any of the GP systems or CSA.
- 4.5.12. On the whole, GP practices have confirmed the PCT's view that workload was "*not a major issue*" for them as far as the initial go-live was concerned. Several practices did, however, express the view that the data quality work was more than they had anticipated. Many greatly valued the high level of data quality support that had been given initially, but some felt that the support was neither sufficient nor timely. Aside from data quality work, additional workload consisted of dealing with patient opt-outs (considered "*negligible*" by most practices), and handing out information packs about the SCR to newly registering patients.
- 4.5.13. Quantitative estimates by practices for the total amount of work that has been involved up to now ranges from 10 hours to 6 days and appears dependent on the number of staff within the practice that required concept training and the extent of work needed to fulfill the data quality IM&T DES and Paperlight accreditation requirements. These estimates broadly accord with our own observations in practices in Dorset.
- 4.5.14. There is, however, considerable concern in Dorset about GP workload for the phase 2 upload of the minimum data set (and/or transferring of any further data once the

phase 1 upload has taken place). There are also concerns about the consent model to be used. Between 30% and 50% of practices have not committed to uploading the minimum data set and instead are adopting a cautious 'wait and see' approach until there is more clarity as to what the workload implications on GP practices will be. The PCT acknowledges that they may need a LES (see paragraph 5.8.9.) *"once things start to move forward"*.

Deployment in unscheduled care settings

4.5.15. Because of delays in go-live, the SCR has not yet been deployed in emergency or unscheduled care in Dorset. The PCT is approaching plans for such deployment cautiously and on a geographical basis, implementing one small community at a time, *"in case we make a catastrophic mistake it's best made on a small scale"*. Initially, the PCT will target the two MIUs in the surrounding area of the six wave one practices. The MIUs are staffed by nurses; some are small and have no receptionist. They currently only use written records and do not have smartcards. CSA application training in the two MIUs is scheduled to take place when ready to go live, and as with GP practice training, will consist mainly of 'concept training' by a visiting consultant.

4.5.16. The OOH service is the responsibility of the South West Ambulance Trust, and triage is handled centrally at St Leonard's Hospital. Some informants have expressed doubts as to whether the triage nurses will have the time to access the SCR (a concern that may indicate a more general need to review roles and routines in parallel with the introduction of SCR use). The local A&E department will not be connected until the EMIS practices are live with the SCR, as prior to this there will not be a critical mass in the system.

Public engagement and information, and HealthSpace

4.5.17. The letter sent to patients was similar to that used in Bolton and Bury. Patients were sent information about the SCR and HealthSpace registration at the same time. Because of Dorset's rural environment, there was no central location to direct patients to. The PCT invited patients to SCR information sessions, together with the option for HealthSpace registration, within a number of participating GP practices.^R Locations and times of the drop-in information sessions were included in the letter and patients could attend any of them, regardless of whether or not it was their own GP practice. A total of 53 sessions were held, staffed by various people from the PCT. As of end March, 639 people had attended one of the sessions. As noted in the other Early Adopter sites, patients who wanted to opt out did not want to discuss it, *"they don't trust the government and you can't argue about trust"*.

4.5.18. Just under 500 people in Dorset (0.31% of those mailed in the information programme) have registered successfully for an advanced HealthSpace account. Although this number is extremely low, it is significantly higher than in either Bolton (0.03%) or Bury (0.1%). Recognising that a HealthSpace 'front office' for patient registration would need to continue indefinitely (an inefficient use of staff time), the PCT are considering paying practices per HealthSpace patient registration, and/or appointing a part time peripatetic registrar.

Clinical engagement and incentives

4.5.19. Clinical engagement seems to have gone well in Dorset. The two clinical engagement events held in May 2007 were judged by local GPs to be extremely

^R Initially, the PCT had approached the GP practices to undertake the HealthSpace registrations, but they were unwilling to take on this additional workload without payment.

positive events, and the LMC were “on board”. The local clinical lead and project manager visited each GP practice individually to give them an overview of the SCR and the clinical lead sent letters to practices encouraging them to take part. In their view, “*engagement with each GP practice on a one to one basis is imperative*”.

- 4.5.20. Of the 60 GP practices in Dorset, five or six remain undecided whether or not to take part; a further five have not been included due either to inability to meet the data quality standards or GP system incompatibility. One practice withdrew from the project, after the mail-out to patients, in direct response to the MTAS data loss story (in which junior doctors’ job application details were found to be visible on a public access Internet site) and has decided not to participate “*until security is improved*”.
- 4.5.21. Practices reported an element of coercion in that they were told they would get support from the PCT if they joined early, but support would not be there for those who participated later in the programme. In the event, some practices felt that the initial support from the PCT, especially with regards to the IM&T DES and Paperlight, was not maintained. Although most practices interviewed felt that the SCR would benefit their patients, uncertainty was expressed as to whether it was worth both the time and money being spent on it. There is currently frustration among practices about the lack of communication from the PCT since the mailouts. Anticipated dates for ‘go-live’ are said to be repeatedly being postponed without any reasons being given, and as one interviewee put it, “*it feels like a black hole*”.
- 4.5.22. Some Dorset participants feel that there has been a lack of leadership on the part of CFH which has led to “*the difficult issues, the tricky issues not being tackled*”, and “*lack of clear responsibilities in the national team for policy decisions*”. They wonder whether the project is “*more locally owned than it should be*”. Of particular concern is the opt-out procedure that Dorset has adjusted to fit in with their local circumstances (a two-part opt-out form which the patient has to bring back to the surgery for counter-signature is not practicable in rural areas where patients live many miles from the surgery, so a simpler form that does not require a counter-signature on part B has been devised). The PCT is concerned that either they or the practices could be held legally responsible, so they would like CFH to ratify their decision.
- 4.5.23. More generally, there was some suggestion that CFH staff were more interested in sites that were closer to Leeds (hence easier for them to get to). They have had very few visits from CFH, and have felt isolated and neglected in comparison to the amount of support that other Early Adopter sites have received. They commented on the lack of shared learning from the other Early Adopter sites, and wondered whether this was a deliberate (quasi-experimental) move by CFH, “*they let us go our own way, make our own mistakes...reinventing the wheel*”.
- 4.5.24. Other concerns raised include the lack of resources within the PCT for a project of this scale, in particular lack of a dedicated communications lead, suitably qualified data quality facilitators, insufficient staff for the SCR and HealthSpace information sessions, insufficient specialist staff to deal with the measurement of benefits. and as of end March 2008, no replacement for the outgoing project manager.

Summary

- 4.5.25. Dorset is a largely affluent rural area with good primary care services and a recent tradition of shared electronic records (ERDIP), which has generated considerable local enthusiasm for the SCR. Clinical engagement is high, as is frustration that technical solutions are not yet ready.

5. Cross-case analysis

5.1. Theoretical framework

5.1.1. In this section, we present an analysis across the four PCT cases, using a multi-level model of diffusion of complex innovations in healthcare developed previously by our team in a systematic literature review (Figure 2),⁴² and supplemented by more recent work on the importance of ICT innovations in organisational change efforts⁴³ and the routinisation of complex innovations.⁴⁴ ^S

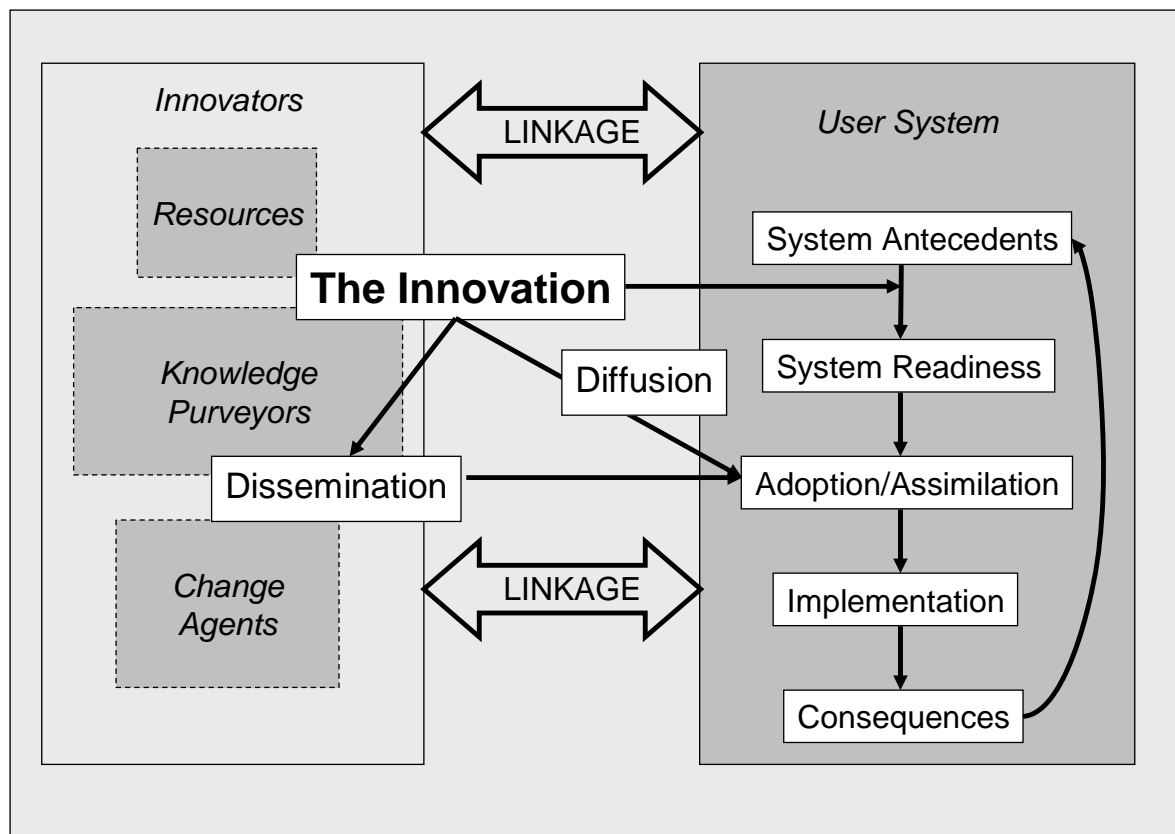


Figure 2: Summary of theoretical model for considering the diffusion of complex innovations in healthcare organisations (adapted from Greenhalgh et al⁴²)

5.1.2. The analytic framework considers the dynamic interaction between:

- The innovation itself (both its material properties and its attributes in the eyes of potential adopters).
- The individual adopters and the nature of their adoption decision.
- Communication (both mass media and interpersonal influence).
- The organisational context (both general innovativeness and readiness for specific innovation).

^S In this report, which is intended mainly for a non-academic audience, we have deliberately not included large numbers of academic references. Interested readers should see the extensive reference list in our previous paper,⁴² but are also welcome to contact the authors with specific queries.

- e. The processes of implementation and routinisation by which the innovation becomes business as usual, including inter-organisational communication and benchmarking.
- f. Linkage (formal and informal) between different parts of the system.
- g. The wider context (e.g. socio-political climate).

5.1.3. In the paragraphs that follow, we offer brief evidence from the literature about each component of the framework and then consider how this component played out in the case of the SCR programme. We focus mainly on the SCR but include some comments on HealthSpace where relevant. We have in places referred forward to the section on The Patient Perspective (Section 6.).

5.2. Material properties and attributes of the SCR

5.2.1. Research evidence suggests that to be successfully and widely adopted, a technology must have appropriate material properties e.g. it must have the necessary functionality and work smoothly and efficiently under real conditions of use.⁴²

5.2.2. The SCR technology is still under development. In Section 2.1., we described a vision for the SCR that assumed a number of material properties – rapid and easy accessibility in a wide range of use scenarios, intuitive user interface, seamless interoperability with other components of the NPfIT, and 100% reliability. The current reality is very different, with staff describing the technology as “*a beta version*”, “*clunky*”, and “*still has significant bugs*”. Some end users have decided not to use it at all until a more definitive version becomes available.

5.2.3. HealthSpace is an even less well developed technology. One of the most consistent findings of the evaluation was users’ frustration with the technical process of both registering for, and using, HealthSpace.

5.2.4. Research evidence suggests that six attributes have been shown to account for variability in the levels of adoption of innovations:⁴²

- a. Relative advantage. Unless an innovation has a clear relative advantage over previous practice in the eyes of potential adopters, it will not be adopted (or will be quickly abandoned). Relative advantage is the single most significant factor accounting for variability in innovation adoption.
- b. Complexity. A complex innovation whose introduction cannot be broken down into simpler components is less likely to be adopted.
- c. Compatibility. An innovation that is viewed by potential adopters as compatible with their existing values and ways of working is more likely to be adopted.
- d. Trialability. An innovation that can be tried out on a limited basis ‘without obligation’ has a greater chance of being successfully adopted.
- e. Observability. An innovation whose benefit is clearly observable to its adopters has a greater chance of successful adoption.
- f. Potential for reinvention. Innovations that include the capacity for end-users to customise and adapt them are more readily adopted than those with fixed characteristics and applications.

5.2.5. A key finding of this evaluation was wide variability in the perceived relative advantage of the SCR.

- a. Some clinicians (e.g. the ‘champions’ referred to below) saw huge potential benefit in having a patient’s drugs, allergies and key diagnoses readily available in the unscheduled care setting.
 - b. Others (a small but vocal minority) saw no value whatever and were cynical of the ‘benefits’ list circulated by CFH (Section 2.3.).
 - c. Most NHS staff felt that the SCR was a “*good thing*” (but they were of course from a self-selecting sample of organisations who had volunteered for the project), though even in this sample, many felt that the benefits (or the trade-off between benefits and operational hassle) of the SCR were unproven.
 - d. Whilst patients had only a hazy view of what the benefits of the SCR might be, most saw it as “*a good idea*” or talked in general terms about greater efficiency or safety of care (see paragraph 9.2.2.).
 - e. Perceptions of relative advantage varied considerably with an individual’s role and setting. In general, those working in A&E departments and other emergency settings saw distinct advantages (describing the SCR as “*a godsend*”); those working in mainstream primary care had much more variable perceptions and in particular, wondered if it was worth the expense and hassle of the SCR programme.
 - f. Perceived relative advantage of the SCR was higher in Dorset, where there were recent memories of a previous shared record system.
- 5.2.6. A recurring theme in our fieldwork was a perception that the SCR (along with its required conditions of use) is too complex. Specifically:
- a. The consent model was almost universally described as “*too complicated to work in practice*”. This is discussed further in the Discussion, Section 7.6.
 - b. The opt-out model (which required a form to be filled in by the patient plus a counter-signature from a clinician) was also described as excessively complex (and in rural areas, highly impractical).
 - c. The lack of interoperability (for example, the need to cut and paste demographic details from Adastral to the CSA to call up a patient’s record) made the use of the SCR in the out-of-hours clinics “*too fiddly*”.
 - d. In some (but interestingly, not all) unscheduled settings, the practicalities of role-based access controls introduced an unworkable layer of operational complexity (see paragraph 5.8.11. below).
- 5.2.7. In terms of compatibility with existing values, whilst some participants saw the SCR as enhancing the quality of care and the professionalism of staff, a significant minority saw it as fundamentally eroding the essence of their work and their professional identity. This was most evident amongst GPs.
- a. Some GPs felt strongly that their role was to “*protect*” their patients’ data rather than “*pass it to the government*”.
 - b. Other GPs argued that contemporary healthcare requires a radical change in how ‘confidentiality’ and ‘privacy’ are defined (from a property of the individual doctor-patient relationship, mediated by the human qualities of the doctor, to a property of the whole system, mediated by technical and operational security measures).
- 5.2.8. The SCR was not readily triable. A GP practice had to either sign up to participating in the Early Adopter roll-out or decline to do so. One PCT, however, chose to require practices only to sign up for phase 1, allowing them to delay phase 2 uploads (creating the so-called ‘enriched’ Summary Care Record with key diagnoses), perhaps as an attempt to build in something approximating a ‘trialability’ phase. Whilst this led to (apparently) high levels of engagement, some clinicians and PCT staff believe that it may lead to practices stalling at the second hurdle.

- 5.2.9. In terms of observability, an inherent problem with the SCR is that its anticipated benefits (see paragraph 2.6.2.) would not be readily observable by the people involved in the initial creation of SCRs except to the extent that some of these individuals also work in out-of-hours clinics or other unscheduled care settings.
- 5.2.10. The SCR does not currently have marked potential for reinvention, though there is ongoing dialogue between designers and end-users. The main reason given by PCTs and GP practices for wanting to be involved in the Early Adopter programme was “*we wanted to influence what happened*” and in some cases the thing they most wanted to influence was the actual design of the SCR (including its operational aspects such as the consent model).
- 5.2.11. Against the above six criteria, HealthSpace scores somewhat differently:
- The perceived relative advantage of HealthSpace is much lower than that of the SCR (a common comment by patients and staff was “*I can’t see the point of it*”).
 - In its present iteration, HealthSpace is also complex – a feature largely attributable to the tight security measures (which may be difficult to change).
 - It is not overly compatible with existing values and ways of working (but see Discussion, paragraph 7.3.8.).
 - The observability of HealthSpace’s benefits remains to be demonstrated, since this attribute concerns whether patients will perceive a worthwhile impact when they use the technology themselves.
 - One strength of HealthSpace is that once registration hurdles are overcome, it is easily triable.
 - Another potential strength is that there are plans for patients to be able to customise (‘reinvent’) HealthSpace to their own preferences and needs.

5.3. Individual adopters and the adoption decision

- 5.3.1. Research has shown that adoption of an innovation is a process, not a one-off event. Adopters have concerns, and these change through the adoption process.⁴²
- In the pre-adoption phase, concerns generally centre on the “what’s in this for me?” question (how much will it cost, will it make work, will it save me time, etc?).
 - Once people have begun to use an innovation their concerns generally shift to the practicalities of use (how do I make it work?; when and how should I use it?).
 - When use of an innovation is well established, concerns tend to focus on ideas for modifying the innovation to improve fitness for purpose or extend its potential.

In this section we focus on initial concerns that appeared to influence the adoption decision; concerns about practicalities are covered in Section 5.8.

- 5.3.2. The main initial concerns of GP practices in Early Adopter sites were workload and the ethics of consent.
- Some (but only a minority) of GP practices who chose not to take part in the SCR upload cited workload as their main issue. Workload is discussed further in the Discussion, Section 7.5.
 - Initially, GPs were concerned that their own workload would be high, with patients making appointments to discuss their choices, but it soon became apparent that very few patients wanted to discuss the options with their GP and that the main workload issue was the administrative burden of meeting data quality standards.

- c. GP practices remain concerned that an ‘opt in’ consent model for the phase 2 upload will generate a large workload for clinicians since this may involve a personal discussion with every patient. Because the phase 2 upload has only recently begun in one or two practices, and because different approaches are being piloted, we have not yet been able to quantify this workload precisely (but see Section 7.5.).
 - d. Other concerns included whether the implied consent model was legal, whether patients understood the choices they were being asked to make, whether the record was technically and operationally secure, whether participation in the programme would erode patients’ trust in the practice, and the risk of the system grinding to a halt during the upload.
- 5.3.3. The main initial concern of staff in unscheduled care settings was technical functionality and the ability of staff to use the SCR.
- a. There was concern about the need for smooth interoperability of the SCR software with existing systems (e.g. Adastral).
 - b. Against a background of relatively low levels of IT skills amongst staff in unscheduled settings, much work was put into training, so that the large numbers of (often part-time) staff would be competent and confident in using the SCR.
 - c. Another key concern was how the SCR would fit in with existing staff roles and work routines (see next point).
- 5.3.4. Research has shown that individuals’ decisions to adopt innovations in organisations can be either collective (everyone in a particular group must decide to adopt or not), authoritative (the individual is told to adopt), or contingent (the individual may choose to adopt the innovation but only after the organisation has sanctioned it).⁴²
- 5.3.5. Our data suggest that a PCT’s decision to become an Early Adopter site was generally made by the Chief Executive and/or the Board, on the basis of a proposal by a senior staff member (e.g. the IM&T lead), and that PCT staff were generally fully signed up to this decision. Whilst the individual adoption decision for PCT staff was thus authoritative, we did not encounter significant dissent from these staff.
- 5.3.6. GP practices’ adoption decisions were made in a variety of ways – either collectively (e.g. typically by the partners plus the practice manager, with or without consultation with staff) or, more rarely, authoritatively (by one or two senior doctors). This had a number of knock-on effects:
- a. There was no option for a contingent adoption choice (i.e. an individual in a participating practice could not choose to be a non-adopter). This led to some reluctant conscripts (especially amongst administrative staff, who may not have been involved in the “collective” decision) and also to dissent (and in some cases, bad feeling) among the doctors in the practice.
 - b. Where resistance to their practice’s involvement in the SCR programme came mainly or wholly from the Caldicott Guardian,^T this individual usually successfully argued the case for the entire practice to withdraw its expression of interest.

^T All NHS organisations are required to have a Caldicott Guardian. The Department of Health website (www.dh.gov.uk) defines the role thus: “A Caldicott Guardian is a senior person responsible for protecting the confidentiality of patient and service-user information and enabling appropriate information-sharing. The Guardian plays a key role in ensuring that the NHS, Councils with Social Services responsibilities and partner organisations satisfy the highest practicable standards for handling patient identifiable information.” It would appear that some Caldicott Guardians interpret this as inconsistent with their participation in the SCR Programme.

- c. Where resistance came from someone with no formal role in information governance (e.g. a 'less keen' GP), that individual was generally carried along with the practice's decision and tended to take on a role of passive acquiescence (or less commonly, resistance) rather than active protest.

5.4. Communication and influence

- 5.4.1. Research has shown that mass media, if carefully targeted, can be highly effective at raising awareness of an innovation, but that the actual decision to adopt is almost always made as a result of interpersonal influence (see paragraph 5.4.4. *et seq*).⁴²
- 5.4.2. Communication with the public about the SCR programme was taken very seriously both by CFH and the PCTs, partly for legal reasons (creating a record on an implied consent model would be far less defensible if the patient had not been offered the opportunity to opt out) and partly because of strong pressure from particular staff (notably Caldicott Guardians) and lobbyists. Much effort was put into designing and distributing letters and posters about the programme (see Appendix, Section 9.3.), liaising with local and national newspapers, and targeting messages to local radio. Roadshows were also held in town centres and other busy locations. These were intended to link with national efforts, including the NHS Information Line.
- 5.4.3. Overall, the impact of the mass media elements of the public information programme (PIP), as it was known, was disappointing (see Section 6.). Low awareness amongst some sectors of the public despite the PIP was due to some combination of the following, and is considered further in the Discussion (paragraph 7.9.3.):
 - a. The message (perhaps not clear enough, or not presented in an interesting enough way).
 - b. The medium (does anyone read 'mailmerge' letters that arrive on the doormat?).
 - c. The sender (some practices felt that the letter would have been more likely to be opened and read if it had come directly from the person's GP than if it came from the PCT, though interestingly, in sites where a mailshot went from GP practices this appeared to make little difference to response rates).
 - d. The recipient (people with low levels of engagement or health literacy were a particular challenge).
- 5.4.4. Research has shown that interpersonal influence from another adopter is, on average, 70 times as effective as mass media communication in influencing someone to adopt an innovation.⁴²
 - a. Influence is more likely if the individual is homophilous (similar social and educational background) with the potential adopter and/or an established opinion leader.
 - b. Other interpersonal influence roles include the champion (someone who feels passionately for [or against] an innovation and tries to influence others to adopt [or not]) and the change agent (someone hired to drive change by influencing others).
 - c. It is seen as good practice to appoint established opinion leaders and champions as change agents.
- 5.4.5. A good example of interpersonal influence in this project was the role of the National Clinical Leads for General Practice.

- a. When work on the SCR programme was beginning, two GP NCLs for the NPfIT (Gillian Braunold and Mike Pringle, both GPs themselves and nationally recognised opinion leaders) were appointed to liaise between the profession and CFH and be accountable to both. They were sponsored into CFH by BMA and Royal College of General Practitioners respectively. They travelled the country to explain what the programme was about, hear the concerns of their fellow GPs, and try to make their audiences more receptive to the plans for the NPfIT.
- b. These 'clinical engagement events' were described by most participants as very useful. The NCLs were well liked as people and considered extremely credible, though their style drew some criticism ("*evangelistic*").
- c. More recently, a number of additional NCLs have been appointed (to a team led by Gillian Braunold) with a remit that includes influencing and supporting their fellow GPs. They have been selected for their personal qualities and credibility as well as for their IT experience and skills.
- d. The NCL role was perhaps particularly successful because it combined the advantages of both 'expert' and 'peer' opinion leader (both GB and MP were also hands-on GPs) and included an explicit change agent remit.
- e. There were also NCL roles for nurses and professions allied to medicine, though their role at the early stages of the programme (creating SCRs from GP records) was less prominent than those of the GP leads.

5.4.6. Another important interpersonal role was that of 'local champion'.

- a. All the participating PCTs had at least one GP enthusiast who made a strong link between developing IT infrastructure in primary care and improving patient care, and who typically became a 'super user' (with early and sophisticated use of the innovation in a way that others could learn from). Local GP champions often held other roles in quality and professional development (such as GP trainer, appraiser, or member of the PCT Professional Executive Committee), and framed the SCR programme as part of their wider quality role across the PCT.
- b. There were also champions in a management role (usually with a nursing background), who energetically pursued a vision of "*making the service better for patients*", especially in relation to out-of-hours care.
- c. Despite the popularity and success of the NCL engagement events, many local champions believed that GP practices' decision to be part of the SCR Early Adopter programme, and their continuing commitment to it, had more to do with ongoing interpersonal contact from local leaders than to one or two events in which national experts were present ("*it wasn't as if they [GPs] showed up to the engagement event and a little light went on in their head*" – local clinical lead).

5.4.7. Our data showed (somewhat surprisingly perhaps) that the role of the data quality facilitator (DQF) was very much one of interpersonal influence.

- a. As described in Section 3.4., the task of improving data quality across several thousand records is laborious and never-ending, since new patients register all the time.
- b. The technical aspects of data quality (running audits, amending records, identifying and meeting training needs) can be addressed either as a gaming exercise (fix the particular things that are causing the audit to indicate a problem e.g. too many hysterectomies recorded) or mindfully⁴⁵ (use the example highlighted by the audit to gain insight into a more generic problem e.g. induction of new staff into coding routines).
- c. Almost all the participating practices we visited took a 'mindful' approach to data quality, and all attributed this approach to the personal support of the DQF.
- d. When we asked an open-ended question "*tell me about the data quality in this practice*", the response was often expressed in terms of the interpersonal

dimension of the work rather than the technical tasks (“we’ve got a *great relationship with the data quality facilitator from the PCT*”).

- e. Our empirical findings support the conclusion that if DQFs are remote, inflexible or lack credibility, their interventions will not suffice to improve data quality. For example, in interviews with a practice IT lead, it became apparent that there had been no discussion with the DQF for some time. The IT lead volunteered that the first DQF appointed had been flexible and “*prepared to get their hands dirty*”, but that the latter two had not been flexible enough. ‘Flexibility’ in these cases consisted mainly of being available to visit the practice out-of-hours, as this is when queries needed to be run due to the volume of data at the practice.
- f. One PCT felt they had had “*dreadful problems*” with the three DQFs assigned to the SCR programme, each of which had lasted only a few weeks and then left by mutual agreement. In each case, the individual was perceived as having poor interpersonal skills, limited knowledge of what data quality in GP practices was all about (“*X was a generic project manager with no NHS experience, now what use is that?*”), and an overly technical approach to their role.
- g. The repercussions from DQFs’ lack of effective engagement with practices were apparent in several of the site visits and interviews. For example, one practice had an IT lead who was a highly skilled individual with many years’ IT experience. However, it was evident that there were several CHART queries that were not being used in the practice, as their purpose had not been explained. When asked about their contact with DQFs, the IT lead stated that the first DQF had been very helpful, but that there had been two others in the meantime, neither of which had been flexible enough (see point e. above).
- h. In another practice, the manager complained of CHART queries that “*Partners spent about four hours each going through the list*” (i.e. the list of records that CHART had flagged). This practice manager had not been trained to see the CHART queries as diagnostic, nor to change their procedures in the light of what is revealed. As a result, this person claimed that “*Data quality is not better than it was before...it hasn’t improved data quality... just created a lot of extra work*”. This case illustrated that without skilled input from the DQF, CHART queries may well be a “waste of time”.

5.4.8. Interpersonal influence was evident in many patients’ decision to have a SCR (or not).

- a. Our patient survey showed that human sources (family members, friends, receptionists) often played a more important role in making a decision about the SCR than official information.
- b. In one PCT, a knowledgeable, pro-active patient champion who strongly supported the SCR provided a credible source of information for others at Expert Patient groups and appeared to have strong influence on the decision of others with long-term illness.
- c. In the same PCT, the PALS office also provided a source of credible and trusted individuals based in the local community whom some patients consulted for advice.

5.4.9. A key interpersonal influence on patients was the critical role of the GP (and to a lesser extent, other practice staff) in encouraging (or discouraging) them from having a SCR.

- a. We observed wide variation in the opt-out rate in different practices, and differences were readily accounted for by the attitude and behaviour of the GP.
- b. Practices who gave their patients a strong positive steer typically had opt-out rates of around 0.3%.

- c. One non-participating practice in an Early Adopter site, in which a GP handed out letters reminding patients of data loss scares and alleging slack use of smart cards by NHS staff claimed that they had been “*inundated*” by patients wanting to opt out. Official CFH statistics put the opt-out rate at 6.7% in that practice.
- 5.4.10. Interpersonal influence was also evident in the community engagement events, where PCT staff and local GPs worked flexibly with voluntary sector groups (for example, minority ethnic groups or chronic illness support groups), to develop communication plans for their members.
- a. The most common approach to community engagement was attendance at a scheduled regular meeting of a voluntary sector group, and these groups appeared to value personal input highly (for example, the chief executive of the PCT turning up to answer questions).
 - b. Drop-in sessions at GP surgeries were not widely attended but were valued by those who did.
 - c. A travelling ‘trailer’ in which a local GP attended to answer questions in person was seen as especially valuable by those who attended.

5.5. Organisational antecedents for innovation

- 5.5.1. Research has shown that organisations are more or less innovative (i.e. more or less able to identify potential innovations from elsewhere and introduce them in-house).⁴² Differences in innovativeness between organisations are explained by:
- a. Structural factors (large, well-resourced organisations with flat management structures and semi-autonomous working groups are more innovative than small or hierarchical ones with centralised management and tight budget pressures).
 - b. Absorptive capacity for new knowledge (organisations with a sound existing knowledge base and experience with previous similar projects [including ‘failed’ ones] are more innovative than those without such capacity).
 - c. Receptive context for change (innovative organisations tend to have strong leadership, visionary staff in key positions, good managerial relations, effective data capture systems to gain timely feedback on performance, and a supportive, risk-taking climate).
- 5.5.2. The structural dimensions of the participating PCTs and GP practices did not appear to have a major influence on the success of the SCR programme.
- a. Both large and small PCTs, and large and small practices, coped similarly with the programme, as did both traditional GP practices (e.g. with a clearly identifiable senior partner who made most of the decisions) and those organised less hierarchically.
 - b. However, the case studies illustrated the absence of what is known as ‘organisational slack’ in both GP practices and emergency and unscheduled care settings. ‘Slack’ means spare resources (money, time, physical space, expertise) that can be channeled into new projects. The fact that even a relatively straightforward technical procedure (go-live) produced major internal disruption for some practices (who felt “*invaded*”) may be less to do with the inherent intrusiveness of the procedure than with the absence of spare time, spare staff

capacity and so on. Our fieldwork in both WiCs, OOH and A&E departments illustrated that the time, space and skills available were all already in full use.^U

5.5.3. Our data strongly affirm the importance of absorptive capacity for new knowledge at both PCT and practice level.

- a. All PCTs described themselves as “*innovative*” in terms of ICT, and had a strong track record of comparable projects.
- b. Many but by no means all participating GP practices were also well-established pioneers in the development of IT (first wave practices in some PCTs said that they had also been the first practice to go computerised some 20 years previously).
- c. This long tradition of IT innovation meant that the organisations generally had extensive formal expertise (at both executive and ‘hands-on’ levels), informal organisational know-how, technical infrastructure, and links with support organisations (they were, for example, typically on first-name terms with contacts in software supply companies).
- d. In GP practices where this was not the case, the organisation was less proactive and required considerably more support from the PCT.

5.5.4. All PCTs studied in this evaluation had what we would describe as a receptive context for change.

- a. All had strong leadership and a clear strategic vision for the PCT’s medium-term direction.
- b. Managerial relations were overall very good (a typical comment by staff was “*this is the best PCT I’ve ever worked in*”), and we were, overall, impressed by the commitment of staff at all levels.
- c. In one or two cases, key posts were occupied by individuals who lacked necessary managerial skills or who were lukewarm about their current work and looking for another job. In such situations progress on the project in question was palpably slowed.
- d. All the PCTs in the evaluation, and many of the GP practices, had a climate conducive to experimentation and risk taking. In particular, failed projects tended to lead to reflection (what can we learn from this?) and efforts to address system features rather than to blaming of individuals. Many PCTs, for example, had had ‘open and honest’ reflection on their involvement in Choose and Book.
- e. All PCTs also had good data capture systems and a tradition of analysing data on their performance. The capacity of GP practices in this regard was variable.

5.6. Organisational readiness for the SCR

5.6.1. Research has shown that as well as being generally innovative, an organisation must be ‘ready’ for a specific innovation in order for it to be successfully assimilated. ‘Readiness’ has a number of dimensions including:

- a. Innovation-system fit (including absence of competing priorities).
- b. Tension for change (i.e. people are uncomfortable with the status quo).
- c. Support and advocacy.
- d. Specific preparedness.
- e. Resources (time, staff, money).

^U Perlow has described the phenomenon of ‘The time famine’ and how this drastically constrains organisational work; this phenomenon should not be underestimated in relation to the demands placed by the NPfIT on NHS staff (many of whom come to projects with the explicit but probably unrealistic expectation that the use of new technologies will *save* time).⁴⁶

- 5.6.2. Because of the close fit between PCTs' wider development strategies (e.g. IM&T development, integration across the health economy) and the SCR programme, competing priorities were not generally a major problem at PCT level (though there were minor tensions, for example in one PCT all other ICT training was put on hold while SCR training sessions were run). However, at individual practice level, preparing for SCR go-live and informing patients of their choices was just one of dozens of projects vying for clinical and managerial attention, and some participating practices struggled with partners or other staff who did not see the problem for which the SCR was supposed to be a solution (but see next point).
- 5.6.3. Tension for change was palpable in several of the participating PCTs. A good example of this was the vision in one PCT for developing an integrated out-of-hours service to replace the previous fragmented one. In relation to the latter, staff talked about unacceptable patient experiences (long waits, questionable clinical care, poor premises, loss of dignity) and financial waste (e.g. through unnecessary acute admissions). They appeared unified in a vision to develop a "*state-of-the-art*" out-of-hours service with a new building (currently under construction), well-trained professional staff, efficient infrastructure, and seamless communication across the various interfaces (including ambulance service, NHS Direct, and innovative outreach and in-reach links with secondary care). 'Readiness' for the SCR rode along the rails laid down for this wider programme of work.
- 5.6.4. The main aspect of specific preparedness for the SCR was data quality (including Paperlight accreditation).
- a. Much of the ground work for the SCR go-live comprised efforts to improve general data quality. This was a huge task which was described to us as "*exhausting*", and on which practices spent considerable time and resources.
 - b. Whilst many informants in the early stages of the evaluation intimated that data quality in some practices was "*dreadful*", there was also a much wider ongoing initiative (both nationally and locally) to improve this situation (for example via PRIMIS training, see paragraph 3.4.7., and via PCT-led initiatives in certain "*flagging*" practices).
 - c. Importantly, the data quality work for the SCR was seen as synergistic rather than at odds with their wider data quality work ("*a very useful exercise anyway*", "*helped us with the QOF^v*"). This was presumably because CFH and the PCTs used existing 'off the peg' data quality standards to select practices for the SCR programme.
 - d. The question of whether a more bespoke data quality metric should be applied is a difficult one – on the one hand, it would be more fit for purpose but on the other hand, it would place SCR data quality efforts out of step with other data quality work. This question is one that our team are addressing in a separate report (plus see Section 3.4.).
- 5.6.5. A critical dimension of 'support and advocacy' that was well recognised by both CFH and the PCTs from the outset was clinical engagement.
- a. The crucial role of both National Clinical Leads and local champions has been described above (paragraph 5.4.4. *et seq*). Overall, these had a strongly positive impact on clinical engagement.
 - b. In some PCTs there were also 'negative champions' – people who opposed the SCR programme and who had a varying degree of influence. A specific question used in the selection process for Early Adopter PCTs was "*is the Local Medical*

^v Quality and Outcomes Framework, see paragraph 3.4.2.

Committee [LMC]^W on board?”. A key finding from the evaluation was that whilst the official LMC spokesperson (e.g. the chair) will give a ‘corporate’ LMC view (that the LMC is, for example, “*supportive*”), individual LMC members have their own personal views and where these are negative (or even neutral or undecided), actual LMC “support” will be ambivalent or passive rather than active.^X

5.6.6. In terms of financial resources, CFH provided between £100K and £200K per PCT for set-up costs and some but not all PCTs offered financial support for practices.

- a. All PCTs had limited budgets for the SCR, but these do not generally seem to have been limiting (though PCTs had many ideas about how they would have spent additional funding had this been available). Importantly, they were usually able to draw on other ‘pots’ to provide small amounts of bridging funding where needed.
- b. The £2000 set-up grant that was made available in one PCT (Bolton) for participating practices was greatly welcomed. In PCTs where this was not offered, some informants told us that the lack of financial incentive had been the deciding factor in their decision not to participate.
- c. The IM&T DES was another very welcome source of funding for practices (see paragraph 3.4.7.).
- d. In one PCT, some practices have said they will only participate in the phase 2 upload (see paragraph 2.2.5. and 5.3.2.) if dedicated funding is forthcoming, unless the SCR programme moves to a less labour-intensive consent model (e.g. consent to view, see Discussion, Section 7.6.).

5.6.7. The existence of good (or at least, fair and rapidly improving) data quality in the participating PCTs and GP practices, and also the culture of monitoring and reporting imbued by CFH, meant that the capacity (or at least the potential) to evaluate the SCR programme was present from the outset. It was possible, for example, for PCTs to produce statistics (using a somewhat crude ‘red’, ‘amber’ and ‘green’ classification) on where each practice lay on the road to achieving the data quality standard. Whilst producing these statistics was met with varying enthusiasm by different staff members, all PCTs did produce them, and this aspect of readiness was readily and dynamically evaluated by people at the front line of the project.

5.6.8. Because the SCR programme is at a very early stage, this section has focused mainly on the readiness of the primary care organisations (PCTs and GP practices) to be involved in the initial creation of SCRs. We have less data on the readiness of the different unscheduled care organisations (A&E departments, walk-in centres, GP out-of-hours clinics) for the SCR, though our preliminary findings suggest that tension for change, innovation-system fit, preparedness in relation to data quality, support for the SCR by influential individuals, and the level of resources that could be channeled into its implementation, varied between different unscheduled care organisations.

^W Local Medical Committees are official bodies representing the interests and concerns of GPs. They have been in existence for at least 50 years and their role varies widely in different areas. They are typically described as powerful, insular, politically conservative, and oriented mainly to protecting the interests (and income) of GPs. In reality, many LMCs have evolved to take a much more contemporary role; they are actively involved in local development initiatives and have extensive links with other professions and organisations locally. What is not in doubt is that the LMC is a body to have ‘on board’ in any change initiative involving GPs.

^X One PCT, initially shortlisted for the Early Adopter programme, and with a very keen Professional Executive Committee, withdrew because of intense lobbying by a small number of GPs opposed to the programme.

5.7. Linkage between different parts of the system

- 5.7.1. Research has shown that innovation is more likely when there is early and ongoing linkage between the developers of the innovation, the change agents charged with promoting its adoption, and the intended end users.⁴² A key aspect of this linkage is developing a shared language and frame of reference through which the purpose and context of the innovation can be discussed and negotiated.
- 5.7.2. Our data suggest that 'linkage' activity in the development and customisation of the SCR technology could be substantially strengthened. For example, in Section 5.2., we comment on the "*clunky*" nature of the current version of the SCR, but perhaps more surprising and significant than the immaturity of the technology is the process by which problems appear to be addressed. CFH has a large and well qualified technical team, and software suppliers have put considerable resources into technical support. However, our impression was that technical problems tended to be assessed fairly briefly on site and then taken back to CFH's technical base (the National Integration Centre or NIC, known as "*the sandpit*") for fixing. On the basis of the few examples we were told of, dialogue between coal-face users of the software and technical support staff seems to have focused on the technology itself rather than the conditions and practicalities of its use. One GP who visited the NIC to talk to technical staff expressed surprise that "*we were having to explain to them how it worked rather than the other way round, yet until that point I thought they were the experts*".
- 5.7.3. Research has shown that just as individual adopters are influenced by opinion leaders and pick up facts and tacit knowledge from their peers, so organisations benchmark themselves against other organisations and transmit 'organisational learning' amongst themselves.⁴² Linkage between organisations can occur both formally (in quality improvement collaboratives, conferences, learning sets and so on), informally (via exchange within individuals' social networks or between spouses), and serendipitously via 'boundary spanners' (someone with a foot in more than one camp).
- 5.7.4. Formal mechanisms for PCTs and practices to link with one another and share learning were relatively rare in this project, but when they occurred they were greatly valued.
 - a. When PCTs were asked towards the end of the evaluation period whether they had learnt much from other Early Adopter PCTs, most said they had not. One informant felt that "*I think they [CFH] were trying to keep us away from each other*" (a reference, perhaps, to CFH's preference for knowledge to pass vertically rather than horizontally, as described in paragraph 3.2.10.) but others felt that not contacting fellow PCTs had been a local choice ("*we couldn't learn from X--- PCT, they're very different from us and we had to work it out ourselves in a way that was relevant to us.*").
 - b. One or two networking events were organised by CFH to bring people from different Early Adopter PCTs together. These appeared to be greatly valued by participants ("*I've met people facing the same problems as I'm facing*") and formal evaluations (by end-of-workshop questionnaires) were highly positive.
 - c. As described in paragraph 5.4.5., the engagement events with the GP NCLs were also highly valued, and appeared to spark discussions and local activities that continued beyond the event itself.
- 5.7.5. Linkage between individuals appears to have had some influence on the SCR programme. For example, in one PCT the practice managers from several GP

practices had regular meetings and some individuals had close friendships. The SCR was a regular topic of discussion and much tacit knowledge was exchanged. Importantly, this social network worked both ways: when one practice began to have misgivings about its involvement in the SCR programme, doubts quickly spread to neighbouring practices through this informal network.

- 5.7.6. In general (but not universally), GPs who worked regularly in the out-of-hours service were keen to see the SCR implemented because they were both ‘creators’ and ‘end users’ of the SCR, and the latter role added motivation for the former. This is a classic ‘boundary spanning’ phenomenon, and, as in other research studies, appeared to be a powerful lever for change. Interestingly, some GPs who did not want to participate at practice level were quite happy to access records in OOH.

5.8. The implementation and routinisation process

- 5.8.1. Research has shown that implementing a complex innovation, and making sure it becomes business as usual, is a highly non-linear process, typically characterised by numerous shocks and setbacks.⁴² Critical success factors for implementation include the following:^{42,44}

- a. Leadership and project management.
- b. Devolved decision-making to front-line teams.
- c. Human resource issues, especially the selection, retention, continuity and training of staff.
- d. Ongoing funding.
- e. Attention to practicalities, especially in relation to operationalising routines.
- f. Communication within and across the organisation.
- g. Inter-organisational networks.
- h. Feedback on performance.

- 5.8.2. Informants described the local leadership and project management of the Early Adopter programme as good. In general, delays in the project were due to technical immaturity, not to poor leadership or management at PCT level.

- 5.8.3. The issue of ‘devolved decision-making’ raises the wider question of whether and to what extent (and in what way) the SCR programme is currently “*locally owned and delivered*” (paragraph 3.3.6.). When asked towards the end of this evaluation year what single change they would wish to make in the programme, the most common response by PCT informants was “[CFH should] just give us the money and let us get on with it”.^Y The implications of this suggestion are addressed in the Discussion (see Section 7.10.).

- 5.8.4. In terms of staffing, we encountered a few examples of PCTs who were unable to recruit appropriate staff locally, and other examples of staff seconded from (or recruited by) CFH who proved unpopular with PCTs. In general, however, we were impressed with the quality of the individuals appointed to key roles and it was clear that these individuals contributed in large part to the programme’s successes. Continuity of staff was a problem in some areas, especially when local recruitment failed and individuals were seconded short-term from CFH to cover gaps, and where this occurred, the momentum of implementation often suffered. These examples

^Y We understand that funding for the SCR programme in PCTs who are not Early Adopters will be found locally, and not channelled through CFH.

raise questions about the scalability of the programme to areas where there are skills shortages (e.g. in project management, ICT, and NHS-relevant data quality work).

- 5.8.5. Training was a major challenge for PCTs, mainly because slippage in the project led to a mismatch between staff receiving training and them needing the skills they had been taught. The model of training used, at least for the initial 'concept training' was that a CFH-appointed consultant made themselves available to PCTs and visited for an afternoon whenever needed. The quality of the training provided by these consultants was widely praised, but there were concerns about the underlying model. Whilst an intensive one-off session was seen as extremely useful to get people through the basics, our informants identified several problems:
- a. Arranging for staff to attend a pre-arranged session to link with a visiting external trainer is a complex way of organising something that's actually pretty simple.
 - b. Training needs arise continuously and many involve special personal circumstances (e.g. people off sick on the day of training; part time staff who cannot make certain days; people who seek refresher or confidence-building input on a one-to-one basis; people who were fine at the training event but cannot make it work in their own office, and so on).
 - c. Training merges with staff support and performance management – for example, the best way to address a slip-up in performance may be to provide immediate, just-in-time training followed by close supervision and monitoring.
 - d. Team training in the work environment may be more effective than individual training away from the work environment.
 - e. Very formal and comprehensive training, especially in the early stages, can be perceived as too complex, confusing and “*off-putting*”.
- 5.8.6. For all the above reasons, PCTs were keen to take greater ownership and control of staff training. Various 'cascade' models were tried but some found these difficult to implement (mainly because people were taking on a semi-formal training role on top of their other duties). A suggestion from one PCT was that a particular administrator (who was clearly already a 'super user' of the SCR herself) should be trained as a trainer. This individual was said to have a number of selling points: she lives locally, has worked in the PCT for many years (“*knows all about our ropey systems*”), knows key staff well and is well liked, can work flexibly, has high credibility amongst staff, and has a proven track record in actually using the technology. This point is taken up in the Discussion (paragraph 7.10.2.).
- 5.8.7. The dependence of successful routinisation on effective communication (both formal and informal, and both within the organisation and between organisations, at least according to the research literature) raises unanswered questions about how to develop and support such communication channels both within primary care and in the wider health economy (e.g. A&E staff). We have noted some preliminary interest in a 'learning set' model, and there are also various resource-sharing initiatives being discussed in both Early Adopter and Fast Follower sites. At the time of writing, however, all these are still at the 'ideas' stage.
- 5.8.8. Ongoing feedback on performance is crucial to routinisation efforts. We have already seen the powerful impact of quantitative feedback on the morale and motivation of front-line staff. For example, when press reports were suggesting that public trust in the NPfIT was being seriously eroded, staff working on the SCR programme were greatly reassured when statistics showed that opt-out rates had only “doubled” to less than 1% of the population. Staff involved with HealthSpace registrations in one PCT (where recruitment has been very low) were elated when feedback showed that the 100th individual had just completed the process of creating an advanced account. In our view, this type of ongoing feedback will be an important lever for improving

usage statistics in unscheduled care settings, though it is probably too early in the programme to say what data should be collected or how and when it should be fed back to staff.

5.8.9. At the time of writing there is uncertainty about the long-term future of dedicated funding for the PCTs involved in the SCR programme. In particular, the IM&T DES (paragraph 5.9.4.) was originally a non-recurrent initiative for 2007-8, and has just been extended to 2008-9. Many PCTs are talking about offering a LES (Locally Enhanced Service) – i.e. comparable financial incentives negotiated at local level.

5.8.10. The practicalities of when, how and in what circumstances to use the SCR were the main preoccupation of staff working in organisations that had begun to deploy it. Doctors and nurses in unscheduled care settings appear to have developed a set of personal unwritten rules about where the SCR would add value, and restricted their attempts to access it to these situations. For example:

- a. Nurses in walk-in centres said they would only use the SCR *“if I was going to prescribe anything, which isn’t very often”*.
- b. GPs in out-of-hours clinics, and doctors in A&E, had typically decided to use it for patients *“on long lists of medication, confused, unconscious, or who don’t speak English”*.
- c. Nurses in call centres felt they would call up the SCR for limited English speakers and for people whose problems were not readily resolved with information already available (either from the patient or from existing out-of-hours records).
- d. A&E nurses had also begun to use the SCR very selectively, most commonly to seek out key items of information that were not available from other sources but which were necessary to build up a full clinical picture, for example *“if someone says ‘I know I’m allergic to an antibiotic but I can’t remember which one’”*.²

5.8.11. A key issue around SCR deployment in unscheduled care settings was the practicalities of the routine associated with SCR access, and in particular, how role based access controls (paragraph 5.8.11.) would fit with this routine.

- a. In one A&E department, for example, there is a well-established ‘target chaser’ role which already involves logging onto a computer and bringing blood test results or other clinical information from the record to the attending clinician. In this setting the SCR was described as *“no more of a problem than any other aspect of medical records”*.
- b. In another A&E department, however, accessing the SCR could not easily be linked to an existing routine, so new roles and responsibilities are currently being developed and operationalised.

5.9. The wider socio-political environment

5.9.1. Research suggests that innovation in organisations is more likely when there is a ‘following policy wind’, a conducive socio-political climate, and specific incentives and mandates at national level.

² These data should be interpreted in the context that at the time of the evaluation, very few staff in unscheduled care settings had had much experience with the SCR, partly because of slippage in the implementation plan and partly because a technical glitch at the interface with the out-of-hours computer system (Adastra) was being addressed. Despite their limited experience, however, staff seemed to have remarkably clear ideas about the situations in which they would use the SCR once it was *“working properly”*.

- 5.9.2. The official policy wind from the Department of Health was certainly blowing in the direction of the SCR (so much so that the programme was in our view overtly politicised – for example, dates for sending letters to patients were delayed because of ‘election purdah’), but a number of other social and political forces were operating in the opposite direction. In particular, headlines of the general format ‘government department loses sensitive private data’ had hit the press at exactly the time of the initial letter going to patients in the Early Adopter PCTs, resulting in measurable ‘blips’ in the number of people attending their GP surgery or contacting the NHS Information Line with queries about information security.
- 5.9.3. In addition, there was a strong civil liberties movement arguing for less state control of private data, as well as specific opt-out campaigns that were led or endorsed by senior doctors. Some of these doctors framed their opposition to the SCR programme as a moral crusade and distributed emotive ‘opt out’ materials to their patients. Some sectors of the medical press gave extensive coverage to small incidents which (allegedly) “*proved*” that the whole Early Adopter initiative was a fiasco. All this contributed to a climate of uncertainty which made some participants in the Early Adopter programme uneasy. Other participants, however, dismissed the impassioned opposition of their professional colleagues as due to unfortunate but rare personal experiences and the more dramatic press coverage as “*rubbish*”.
- 5.9.4. The main financial incentive that helped get practices to the starting block for the SCR programme was the IM&T DES (Directly Enhanced Service), described briefly in paragraph 3.4.7., though this was not initially designed as a lever for the SCR programme.
- 5.9.5. Another aspect of the wider environment to note here is the demography of the population (getting older) and the focus of healthcare, which is shifting (for example) from acute to chronic illness, from uniprofessional to multiprofessional care, and from one-off episodes of care to ‘the patient journey’. Within that wider context, electronic records, and the SCR in particular, were generally seen to have important advantages.

6. The patient perspective

6.1. Impact of the public information programme

- 6.1.1. The extensive public information programme ('PIP') for the SCR was described in Section 4 in the individual PCT case studies. As well as a letter sent to every patient whose record was to be created, the PIP included posters, leaflets, 'road shows', talks to community groups, and radio and newspaper coverage. A confidentiality pack including the Care Records Guarantee (a leaflet assuring people of both technical security and controls over who would access their record) was sent out on request. Both CFH and participating PCTs put considerable energy into this part of the SCR programme.
- 6.1.2. Our wider field work suggested that GP practices in particular had major concerns about the impact of the public information programme, and many did not feel that the low opt-out rate could be interpreted as meaning that patients had received the letter, understood it, and made an informed decision. One practice manager expressed this well: *"I think the elderly were more confused about what it was all about. We haven't had any elderly patients ask me questions or opt out. I think they just put it [the letter] to one side and ignored it. I went to see my mother, she's 86, she got her letter, I saw it open on the table and I asked her 'have you read that? ..and she replied 'can't be bothered'..she just ignored it.."*
- 6.1.3. An independent 'tracker' survey was commissioned by CFH in early 2007 (before the public information programme began), undertaken by the market research company TNS UK. In this, just over 200 interviews were conducted in both Bolton and Bury amongst members of the public.²⁵ The tracker survey asked closed questions (i.e. the person had to pick an answer from a list) and indicated very low awareness of the Care Records Service in these sites. More than a quarter of people believed that their medical record was already held centrally, and half had never thought about where their records are held. The tracker survey also showed marked differences by social background, with professional groups much better informed than manual workers and the unemployed. A second tracker survey was conducted in late 2007; the data are awaiting further analysis and were not available to us. A third survey is also planned.
- 6.1.4. We conducted an interview survey in two Early Adopter sites of a total of 103 NHS service users (patients, carers and patient advocates). Our sample was intentionally skewed towards users of out-of-hours services, and contained a higher proportion of manual workers, unemployed, and those with low health literacy^{AA} than the tracker survey. We used a short list of open questions (i.e. we asked a question and wrote down the free text response). We also conducted seven focus groups comprising a total of 67 people with potentially stigmatising illness (mental health service users, HIV positive people), difficulty accessing health care (limited English speakers, and people on a drug rehabilitation programme, and advocates of vulnerable groups including a domestic violence charity) and extremes of age. The demographic details of these participants are described in the Appendix (paragraphs 9.1.6. to 9.1.9.). The detailed results are also in the Appendix (paragraph 9.2.1. *et seq*). We summarise the findings below.

^{AA} The World Health Organisation (www.who.org) defines health literacy as *"the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health"*. See Appendix, paragraph 9.1.8., for how we measured it in this study.

- 6.1.5. By the date of our individual interviews, at least 95% of the population in our sample area should have received a letter informing them that the SCR was being introduced in their area. Only about one person in 7 in the walk-in and out-of-hours centres, and just under half in the GP surgeries and A&E departments, claimed to have received this letter. Only 8 of the 103 individuals interviewed had definitely heard of HealthSpace.^{BB}
- 6.1.6. Awareness of the SCR was higher in those with high health literacy (one in two aware) than those with medium or low health literacy (one in four aware). Very few people recalled having binned the letter as “junk mail” though many agreed that this could have happened. Many believed (wrongly) that electronic records were already shared between health professionals either locally or nationally. Nobody with low health literacy recalled any information about HealthSpace.
- 6.1.7. Because of key methodological differences between the tracker survey (conducted before the Public Information Programme) and our own (conducted after it), it would be inappropriate to treat these as ‘before and after’ data. However, it is clear that many individuals in the Early Adopter sites remain unaware of the SCR Programme, and that this is a particular problem in those with low health literacy.
- 6.1.8. We also conducted a small ‘mystery shopper’ survey of the NHS Information Line in November-December 2007 (see Appendix, paragraph 9.1.11. for details of questions asked and paragraph 9.2.4. for detailed findings). In summary, the advice given by NHS Information Line staff was generally accurate and highly consistent (staff were working from prepared templates). However, staff did not appear to use flexibility or judgement (for example, if we did not understand the answer, it was simply repeated). We were somewhat concerned that questions about the security of the SCR were answered by an assurance about the high technical security of the system, and the possibility of human error or corruption was dismissed by some staff. These findings were fed back immediately to CFH, and we understand that further training has now been given to Information Line staff.
- 6.1.9. We asked bilingual individuals to comment on foreign language leaflets. Each leaflet was shown to (a) someone without higher qualifications who was working in a manual job, and (b) someone with a medical or research degree (in one case a medical student). Some leaflets were well translated and made sense; others appeared to have been translated by someone who did not understand the sense of the English version and had done a literal, word-for-word translation that made no sense in the other language. For example, the Arabic leaflet had translated the word ‘surgery’ (meaning GP surgery) as ‘operation’.
- 6.1.10. Our focus group participants viewed the official educational DVD setting out the benefits of the SCR with some amusement, and described it as “*unrealistic*” and “*propaganda*”. (That is not to say that the DVD does not mention any disbenefits at all, merely that these were not seen as being portrayed realistically or in a balanced way).

^{BB} HealthSpace was not as widely advertised as the SCR, so low awareness of this technology is perhaps unsurprising. It is also worth noting that none of our interviewees mentioned ‘rival’ technologies to HealthSpace (e.g. Googlehealth or the HealthVault technology offered by Microsoft) either. However, the rapid and recent emergence of competing technologies for managing personal health data from the commercial sector could lead to substantial changes in public awareness of, and attitudes to, these technologies (and perhaps, also to how they view their own responsibilities in relation to collecting and managing such information). We plan to study these social trends over the next two years.

6.2. What influences a person's decision to have a SCR?

- 6.2.1. In our survey and focus groups, most people were positive about the SCR and felt happy that if they did nothing, one would be created for them. But few were unequivocally in favour of the idea. Rather, people described a process of weighing perceived benefits (set out in the Appendix, paragraph 9.2.2.) against disbenefits (paragraph 9.2.3.) for them personally and, where relevant, their dependent relatives. For example, many people argued that they had nothing much wrong with them; that their personal health information (especially about medication and allergies) was not that sensitive; and that whilst nothing these days is 100% risk-free, the accessibility of medical details in an emergency situation was well worth the trade-off.
- 6.2.2. As the tables in paragraphs 9.2.2. and 9.2.3. show, many perceived benefits (especially accessibility of medical data in an emergency) and disbenefits (security, potential disclosure of stigmatising information) of the SCR were unsurprising. The more interesting data concern how participants saw the balance between 'benefits' and 'disbenefits' playing out in different situations, which we discuss below.
- 6.2.3. The most commonly cited factor influencing the decision to have a SCR was personal experience. People who had experienced an adverse drug reaction, an episode of loss of consciousness, lost medical records, or a 'near miss' medical error, and those with serious or complex health problems (especially those with multiple co-morbidity) tended to view the SCR very positively. In contrast, those who had been the victim of mistaken identity (in the NHS or outside it), an incorrect medical diagnosis, or identity fraud (e.g. stolen credit card) tended to be opposed to it. When a relevant personal experience had occurred, people generally developed firm views on the SCR one way or the other, whereas those who lacked such experience were often undecided or disinterested. In the focus groups, we observed a shift in participants' perspective from 'undecided' to more firmly 'for' or 'against' as they deliberated over real (or alleged) scenarios.
- 6.2.4. Many participants (including some who identified themselves as advocates of vulnerable groups) assumed that someone with a potentially stigmatising illness (e.g. HIV, mental health problems) would not want a SCR. But most respondents who actually suffered from serious long-term illnesses felt that the risk of disclosure of their condition to a third party was outweighed by the benefits of having an accessible record. Two people spontaneously disclosed their own epilepsy, for example, as a reason why they were strongly in favour of the SCR "*in case I collapse*". Some HIV positive people felt that the benefits of the SCR outweighed the risk of disclosure of their HIV status; others (especially those with more than one potentially stigmatising condition) felt the opposite.
- 6.2.5. The intention of the developers of the SCR was that it would increase patient empowerment, especially when accessed by the patient via HealthSpace. To a limited extent, our findings supported this. Numerous participants said they would value sight of their SCR "*to see what the doctor/nurse wrote about me*", and believed that the SCR would contain explanations and clarifications of what had been said in a consultation or why they had been sent for a test. Advocates of limited English speakers suggested that the latter valued the written word (particularly numerical data) over oral explanations as these would be more readily assimilated by someone with partial English. A few people anticipated approaching their GP to correct factual details.
- 6.2.6. However, one of the most common perceived benefits of the SCR in the eyes of patients was its potential to reduce the need to fill out forms or remember what

medication they were taking. In some cases a long and complex medical history was cited, but some participants appeared keen to put the onus for knowing their details and making decisions about their care onto the health professional. For example, 8 of 46 people interviewed in the walk-in centres, all of whom we judged to have low health literacy, gave “*not bothered*” or “*don’t care*” responses to the question “*Would you like to have a SCR?*”. In contrast to those who had not yet made up their mind, these people were very clear that they *did not wish to make a decision*. One person said they had a right to say they had no view. Several admitted that the reason they had no view was because of limited capacity to understand (“*I can’t get my head round it*” – walk-in centre attender).

- 6.2.7. The SCR was seen by some respondents as a ‘legitimising’ artefact. We heard many examples, for example, of GPs refusing to prescribe medication that the patient “knew” they should be taking (for example, when an outpatient letter had not yet arrived). These accounts were presented as the GP imposing his or her own version of reality on the patient, and SCR was seen as a mechanism for shifting the power balance in favour of the patient’s version. Two people, both walk-in centre attenders, felt that the main benefit of the SCR was “*to prove I’m not a liar*”, because a condition (such as a child’s fever) that had been documented on the SCR could not easily be contested by a health professional. However, another participant felt that the SCR was useful “*to stop patients lying about what they’re on*” (this person worked in a chemist shop and claimed that customers often say they are on no medication when they are actually taking things that could react with over-the-counter medicines).
- 6.2.8. The theme of legitimation frequently occurred when participants lacked trust in doctors and the NHS. In situations where trust was high, the need to legitimate an account was seen as explicitly unnecessary. At one GP surgery, for example, there was strong resistance to the idea of HealthSpace as patients appeared to feel that this would undermine their good relationship with the GP (“*It’s a terrific surgery so there’s no need for something like HealthSpace*”).
- 6.2.9. Some participants wondered whether the possession of a SCR would itself become a legitimising factor in healthcare, and whether people who had chosen not to have one would become second-class citizens (“*will they be treated as a flaming nuisance by the reception staff?*” – focus group for advocates of vulnerable groups).
- 6.2.10. Our data suggest that the SCR is likely to have somewhat unpredictable effects on access to health care. Advocates of limited English speakers said that the SCR might make it easier for disempowered minority ethnic groups to access and register with a new GP, since some GPs allegedly used lack of the proper paperwork (e.g. proof of identity) as a reason not to register a patient (see Section 6.4.). However, they also felt that the presence of a SCR would enable an unscrupulous GP to preview someone’s record before accepting them, and selectively turn away those with complex, expensive-to-treat, or poorly controlled diseases.
- 6.2.11. People with chronic illness described frustrating experiences in hospital outpatients when their paper records had been unavailable and they had had to have repeat blood tests, X-rays, or come back on another day, and anticipated that the SCR would make such experiences a thing of the past. Many assumed that their SCR would necessarily be complete, accurate, and universally accessible. They saw a link between these aspects of the record and quality of care (“*I would like to go to somewhere and be treated properly, with all my record*” – participant in HIV focus group).
- 6.2.12. But other participants felt that far from protecting against staff error, the SCR was likely to magnify the impact of such error, since its use would require sophisticated

skills and consistent practices. They also felt that the quality of data on the SCR would only be as good as the data quality standards and practices that support its creation and maintenance. We heard many examples from people with chronic illness of NHS staff who were tired or overworked (hence unlikely always to use the SCR as intended), and stories of doctors who had (allegedly) failed to take note of adverse event warnings on existing electronic records.

- 6.2.13. Mental health service users were concerned about the dismissive attitude of NHS staff towards them in general, and some had little confidence that the SCR would be used as intended. Some pointed out that their condition (and their ability to give a credible account of themselves) fluctuated; having their illness documented on a SCR might enable them to be taken seriously in an emergency rather than turned away as “*stroppy*”. Others, however, were concerned that a diagnosis on the SCR might lend false objectivity to impressionistic or one-off assessments, especially of a person’s mental state, thereby colouring the judgement of others in the future.
- 6.2.14. Many interviewees and focus group participants exhibited a positive attitude towards the SCR that was linked to implied trust in the honesty and motives of NHS staff. But this was by no means universal, and many stories were shared of both clinicians and receptionists who were depicted as unprofessional, undertrained, or lazy. Several participants who were NHS staff had decided not to have a SCR themselves to prevent access by “*nosey*” colleagues. Trust was strongly related to age, with some younger people distinctly cynical of the motives of GPs, and to continuity of care (“*I’m perfectly happy for anybody at my doctor’s to look at my records because I know everybody at my doctors. I’m more [than] happy for them to have my files, but anybody else, no.*” – participant in drug user focus group). In general, older and better-trained people were trusted more (medical students were mistrusted more than receptionists, for example).
- 6.2.15. In our focus groups, people who might be classed as ‘disempowered’ (chronically sick, poor, socially excluded and/or with limited education) generally wanted to have a SCR but also wanted control over which individuals had access to it.
- 6.2.16. An important finding of this evaluation was that trust or lack of trust appeared to be a property of the person’s relationship with a *particular* health professional or administrator, rather than a property of the person’s official role. Trust was strongly linked with continuity of care and familiarity with particular members of staff (“*I’m perfectly happy for anybody at my doctor’s to look at my records because I know everybody at my doctors. I’m more happy for them to have my files, but anybody else, no.*” – participant in drug rehab focus group).
- 6.2.17. Some people felt that the SCR was a bad idea “*on principle*”, and viewed the intention to create one as an infringement of their rights (though interestingly, not everyone who held such a view had opted out of their own SCR being created). Many of these people were opposed to large-scale computerised databases in general and drew explicit parallels with government plans to introduce identity cards and the clamp-down on social security fraud (which some people saw as covertly linked to the SCR).
- 6.2.18. Some people were concerned that once consent for a SCR had been given, pressure would build from a host of public and private sector organisations to access the data, and the government would be able to change its own rules and governance procedures in the future (“*...we’ve got no power over it. It’s a genie that once it’s open, there’s nothing we can do*” – participant in HIV focus group).

6.2.19. Whilst individuals opposed to the SCR “*on principle*” were often vocal (they accounted for around half the speaking time in focus groups and tended to give lengthy and emotionally-charged interviews), they only accounted for one in 12 of our sample. Most participants were aware of (or were reassured to learn of) the extensive security measures, role-based access controls, and audit trails that have been built into the SCR programme (see Section 3.5.). Not a single participant felt that these measures would guarantee the security of their data, but they felt that the small risk of identity fraud, exposure or blackmail was worth taking. They contrasted personal health information (seen as a low security risk) with their bank details (much higher risk), and some people with serious illness joked that nobody would want to steal their identity.

6.3. Explaining the low uptake of HealthSpace

6.3.1. The government’s vision for HealthSpace was summarised by Lord Hunt in the recent House of Commons Health Committee Enquiry (page 28): “...*the great advantage of HealthSpace is...there will be a whole host of information about health, and my own view is that it has huge potential in helping people take control of their own health.*”³²

6.3.2. Statistics collected by CFH show that uptake of HealthSpace has been very low. Only around one person in 300 (0.33%) who has been sent a letter inviting them to register for a basic HealthSpace account has actually done so, and just over one in a thousand (0.12%) has activated an advanced HealthSpace account. The proportions vary between different Early Adopter sites, with people in Dorset, for example, four times as likely to register for HealthSpace as those in Bolton. Nevertheless, uptake of HealthSpace is currently running at a very low level in all Early Adopter sites.

6.3.3. As paragraph 9.2.3. shows, the overwhelming reason for people in our sample not wanting a HealthSpace account was disinterest in their own health record, and in a few cases an active distaste for seeing information about their illnesses. For most people, the personal risk-benefit equation (see paragraph 6.2.1.) came out *in favour* of having a SCR but *against* having a HealthSpace account.

6.3.4. Many of our respondents were unsure of the purpose of HealthSpace, describing it as “*pointless*”, “*irrelevant*” and not fit for purpose. One person said of their personal health information “*I would just rather write it down in the diary or just hide it underneath my bed or something*”. There was, however, a small but important minority of people who saw the value of HealthSpace for monitoring their own or a relative’s chronic illness, and several people said that whilst they would not want a HealthSpace account themselves, they could see its value for certain other people.

6.3.5. Several people said that they preferred to discuss their health issues with their own GP or nurse (or in one case, a favourite receptionist). We interviewed one person who had signed up for a HealthSpace account, accessed their record, and was now trying to de-register because they had found it far less comprehensive and useful than they had expected. Uptake of HealthSpace is discussed further in Section 7.9.

6.4. Misconceptions about the SCR and HealthSpace

6.4.1. A number of misconceptions about the SCR and HealthSpace were revealed in this study (Table 2 below).

MISCONCEPTION	COMMENT
1 Doctors and nurses already have the ability to access a patient's full medical record wherever they are in the NHS.	This facility does not exist except on a limited local basis in some areas.
2 The SCR and HealthSpace will contain detailed medical information which will (for example) enable a person to clarify what the GP said in the last consultation or why a test was ordered.	The SCR will focus mainly on current medication, allergies and adverse reactions. As currently planned, it will only contain very brief medical details.
3 If a SCR is created, it will contain an accurate and complete account of current illness and will always be accessible to healthcare staff, making lost records or missing data a thing of the past.	The SCR is unlikely to be universally accessible because of technical and operational hurdles. Its future accuracy and completeness are unknown.
4 'Opting out' of the SCR means that a person will no longer be registered on the Personal Demographic Service. Hence, opting out will protect against identity fraud.	All NHS patients will be registered on the PDS. Identity fraud (while highly unlikely) is therefore a theoretical possibility even for patients who have opted out of the SCR.
5 The SCR will be cross-linked to the Social Security system, making it possible for the government to check up on sickness and incapacity benefit claims.	No such plans have been announced.
6 The SCR will enable people to remain registered with a GP even when they move out of the area.	A patient who moves out of area will still be expected to register with a new GP.
7 An advanced HealthSpace account will allow a patient access to their detailed medical record.	HealthSpace only allows access to the SCR, not the detailed medical record.
8 The SCR will contain details of sexually transmitted infections (STIs) and/or a person's sexual orientation.	Information on sexual orientation is not part of the minimum dataset; STIs treated at specialist clinics will not be on the GP record, and STIs treated by the GP would not normally be on the minimum dataset.
9 The SCR will improve access to GPs for vulnerable groups because proof of identity and current address will no longer be needed to register.	The SCR will not change the requirements for registering with a GP.
10 The SCR will allow the patient to legitimise an account of illness (for example, that they were genuinely sick on a particular day in the past).	The SCR is unlikely to contain sufficient detail to adjudicate in contested accounts of illness.
11 The SCR could be easily hacked into.	Extensive technical security measures and access controls are in place, making hacking unlikely though not impossible.
12 Patients will be able to make corrections to their medical record directly via HealthSpace.	As currently planned, corrections will only be possible indirectly.

6.4.2. Importantly, many people do not understand the difference between the PDS (a demographic database), local detailed records (LDRs), and the SCR. They have limited understanding of what data are currently shared, or what technical and access control measures are in place to protect their data.

7. Discussion

7.1. *Between the poles: Towards a more sophisticated policy debate*

- 7.1.1. The later sections of this Discussion address what we feel to be the most important policy-level questions arising from the evaluation. We have not given easy or absolute answers to any of them. In many cases, the reason for this is not merely that our own team has not found the answer to the question *yet*, but that a simple, universal answer is *not possible*, even by people more skilled and better resourced than us. This section explains why.
- 7.1.2. At the outset of this evaluation, CFH made clear to us that we had been contracted to evaluate *“an Early Adopter phase, not a pilot”*, and that our findings would be used to *“inform the wider roll-out of the programme”* (hence, implicitly, that it was not our role to seek to reverse the original high-level policy decision to fund the programme). Nevertheless, the main question which many stakeholders (see Section 2.6.) wanted us to answer was *“Should large amounts of public money have been put into the SCR programme in the first place?”*.
- 7.1.3. This question (and the fact that so many people expected us to answer it) illustrates an important point about the nature of policymaking. The NPfIT (and the Care Records Service in particular) is a ‘wicked policy problem’. That is, it raises complex questions to which many people expect science to provide ‘objective’ answers but which are actually questions about social priorities, and which therefore require citizens and policymakers to deliberate about ethics and values as well as about scientific and technological ‘facts’.⁴⁷ A key issue is how problems are framed by different interest groups,^{CC} since framing determines which ‘facts’ are viewed as important by different stakeholders and how we should collect, interpret, and respond to those ‘facts’. What, for example, should be classed as a ‘scandal’ or an ‘early win’ in the Early Adopter programme? What should we count as a ‘robust measure of success’ or ‘clear evidence of failure’? The contested nature of these most fundamental of definitions is something which science alone cannot resolve.⁴⁸
- 7.1.4. An early finding of this evaluation was that those who felt strongly about the SCR – champions and change agents on the one hand; lobbyists and conscientious objectors on the other – had a tendency to frame issues in terms of simplistic and morally absolute dualisms, and to cite selected ‘facts’ in support of their position. Furthermore, our interpretation was that these people unconsciously sought to blame a host of problems on what they characterised, disparagingly, as the ‘other side’ – the government, CFH, the press, *“the privacy fascists”*, *“single issue campaigners”*, and so on. This mutual demonisation, to which some sectors of the press have contributed with a lamentable lack of criticality, has to a large extent overshadowed sensible debate.
- 7.1.5. We were initially surprised to discover, for example, that CFH had an active Benefits Realisation Team for the SCR but no equivalent team charged with documenting and disseminating its disbenefits or risks. That is not to say that CFH dismiss the latter entirely, merely that potential ‘benefits’ are pursued, documented and disseminated with great enthusiasm by one department whereas ‘disbenefits’ appear to be the

^{CC} To illustrate what we mean by ‘framing’, here is an example from a different field. Are the Beijing Olympics “a celebration of sporting excellence” or “an attempt by China to buy political credibility with key allies”? Those seeking to persuade others of either of these positions will amass ‘facts’ to support their argument, but a ‘meta-policy’ question is “why have particular frames been chosen by different stakeholders, and what does this tell us about the complexities of this wicked problem?”.⁴⁸

responsibility of an entirely different (and somewhat less proactive) department.^{DD} As a result, the official line from CFH sometimes presents the benefits of the SCR as simple, generalisable, context-free, and without significant qualifiers. Early Adopter PCTs were occasionally also guilty of taking a very one-sided perspective. For example, one interviewee described an uncomfortable scene in the waiting room of a GP surgery, in which a Powerpoint presentation on the benefits of the SCR was playing on a plasma screen in a continuous loop. The GP commented *“it’s apparently ours for life and we haven’t got the ability to change it”*.

- 7.1.6. At the opposite pole, campaigners claim that the disbenefits of the SCR (risk of inaccurate information, malicious access, or the affront to civil liberties associated with an ‘implied consent’ model) always or almost always outweighs its benefits. ‘The Big Opt-Out’ campaign (see www.nhsconfidentiality.org), for example, warns the public that once the SCR goes live, *“everything you tell your GP ... will be sent to BT”* and exhorts them to download a pro forma letter to opt out of having a SCR. The website of a GP practice opposed to the SCR says *“EVERY SINGLE PATIENT SHOULD OPT OUT OF THE NHS DATABASE WITHOUT DELAY”*. Just as a unilateral focus on ‘benefits’ erodes the credibility of CFH in the eyes of the public and other stakeholders, so a one-sided focus on ‘disbenefits’ makes it difficult to take these campaigns seriously. Polarised claims on both sides tend to be simplistic, entrenched, moralistic, and generate more heat than light.
- 7.1.7. Most individual patients and staff, and a number of professional organisations and advisory bodies, rejected a simplistic framing of the SCR as either a “bad thing” or a “good thing”, and saw its benefits as individual, contingent, liable to change with circumstances, and offset by risks (see paragraph 6.2.1.). For example, most service users in our interviews and focus groups described weighing potential benefits and risks against one another, and taking account of personal circumstances, when making the decision about whether to have a SCR or HealthSpace account themselves.
- 7.1.8. Those who rejected a polarised position recognised (to some extent) that the SCR brings a number of inherent tensions. For example:
- a. Increased accessibility of data brings greater risks to security.
 - b. Increasing the options for using the SCR opens up new opportunities, but at the cost of greater complexity and confusion.
 - c. A long letter about the SCR may be thrown away unread; a short letter may not contain all the information that people need to make an informed choice.
 - d. Waiting until everyone is on board may increase ‘engagement’ but if we wait too long, the train may never leave the station.
 - e. A quick and dirty solution may ‘work better’ than following the standard operating procedure, but it may contain unforeseen threats to safety and/or raise unacceptable ethical or legal problems.
 - f. An opt-out consent model is less time-consuming and achieves the ‘critical mass’ needed for access by unscheduled care, but may not be seen as ethical; an opt-in model is more time-consuming, may not achieve critical mass, but more widely accepted by clinicians and lobbyists.

^{DD} There is an extensive ‘risk register’, which documents the risks associated with implementing the project (i.e. the risk that the SCR might not be rolled out as planned), but this is of course a very different thing from risks associated with the SCR (for example, that a person might withhold key medical information from their GP for fear that it could be shared with a third party).

7.1.9. Tensions are inherent to complex systems; there are no simple solutions to them; but attempting to unpack them can potentially raise the level of debate to a more sophisticated plane. The remainder of this Discussion attempts to illustrate how these tensions can play out differently in different personal, social and organisational situations. As indicated above, and in the hope of sparking a much-needed wider debate on the issue of electronic patient records, we have chosen to express this complexity as a series of questions with ‘no easy answers’.

7.2. How should we measure ‘success’ in the SCR programme?

7.2.1. Much work has been done both by CFH and by Early Adopter PCTs on developing ‘metrics of success’. Whilst these metrics have superficial plausibility, they tend to seek to quantify phenomena whose causes are complex, which occur against a shifting baseline, and whose validity (and causal link to the SCR) is likely to be challenged. For example, one of numerous tables of possible metrics suggests that once the SCR has been introduced, “*Ability to provide urgent care outside of A&E increased due to improved access to patient information*” might be measured in terms of “*% of all urgent cases treated entirely in community*” and “*Number of A&E attendances avoided due to increased access to patient information*”.

7.2.2. An international authority on the evaluation of medical information systems, Professor Marc Berg, invites his readers to go beyond the quest to nail the benefits (or expose the harms) whenever a new technology is introduced in a social system. Indeed, he argues that the very terms “success” and “failure” are unhelpful when considering large-scale IT programmes in healthcare.⁴⁹ This is because such programmes are inevitably charged with political significance (positive or negative, depending on one’s allegiance). Standards that define success, and measures of how far such standards have been reached, can and will be manipulated by interest groups (see paragraph 7.1.3. above). Would the SCR be a “failure”, for example, if 5 percent (or even 50 percent) of the population chose not to have a SCR? Would it be a “success” if firm evidence were produced that x deaths had been prevented (if so, what would be the value of x?) or that out-of-hours clinicians felt that there was less uncertainty when dealing with patients who cannot remember their medication list (if so, by how much would uncertainty need to be reduced to make the programme worthwhile?).

7.2.3. At this early stage in the roll-out of the SCR, our findings do not support the *a priori* use of any particular definitions or metrics of success. In our view, any 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 the fitness for purpose of such metrics must be continually questioned as the programme develops.

7.2.4. For example, if “implementing the SCR” is seen as an end in itself, then “success” might reasonably be measured in terms of the proportion of records created (and actively in use) by particular predefined dates. If, on the other hand, the SCR comes to be seen as supporting a broader strategic vision for a local health economy (see Section 7.3. on socio-technical change), then “success” might be better measured much more flexibly, in terms of how the SCR contributes to particular locally-defined outcomes.

7.2.5. One inevitable side effect of a programme having a high political profile is that it tends to be judged in terms of direct, measurable deliverables in the here-and-now rather than being seen as a longer term investment and/or as something that might

co-evolve with other developmental projects. As described in Section 3.1., CFH has been formally criticised for “delays” in the NPfIT, and inability to deliver on time is a favourite criticism of the hostile press. But this begs the question: to what extent *should* the SCR programme be judged on keeping to a rigid programme and predefined timetable rather than on how well it justifies a more emergent or negotiated set of goals and milestones?

- 7.2.6. For example, our findings show that few people currently wish to keep a record of their personal health data to be accessed via the Internet. But very few participants in this study had previously thought about HealthSpace, and those with chronic illness (or who informally took responsibility for the chronic illness of someone else) were much more positive about its potential than those with few or no health problems. Just because people do not currently wish to take responsibility for their own health does not necessarily mean that we should not encourage them to do so. But it does mean that if the SCR and HealthSpace are to support ‘empowerment’ and ‘engagement’ (see paragraph 7.9.1.), considerable work must be done in fields such as health promotion, public understanding of science, and citizenship.

7.3. The SCR: ‘Plug and play’ technology or socio-technical change?

- 7.3.1. In Section 3.1., we summarised the recommendations of recent reports from the Ministerial Taskforce on the SCR,¹ Public Accounts Committee,²⁴ and House of Commons Health Committee.³² These had acknowledged the need for wider social and organisational change (including clinical engagement, patient empowerment, the ethics and practicalities of consent, and the need for new care models and business processes) to be addressed in association with the implementation of the SCR. As the four case studies in Section 4 illustrate, these wider dimensions went a long way to explaining the fortunes of the programme in each of the Early Adopter sites.
- 7.3.2. In paragraph 3.2.11., we were critical of what we perceived to be CFH’s over-emphasis on the ‘technology push’ aspects of business change at the expense of a deeper engagement with wider social and organisational change.^{EE} In the eyes of many critics, this lack of attention to what is known as the ‘socio-technical’ perspective is the single most problematic aspect of the NPfIT, and one which many predict will lead to its downfall.^{5;6;34} These criticisms are not ill-informed and deserve to be taken seriously. But whilst it is relatively easy to point out the need to go beyond the technology, it is not so easy to identify the specific steps that CFH should take to achieve such a fundamental shift in emphasis. This section makes some preliminary suggestions which we hope will be picked up for further discussion both within and beyond CFH.
- 7.3.3. The task for which we were contracted was to “*evaluate the implementation of the SCR in Early Adopter sites*” – an explicit ‘technology push’ brief. But interviews with strategic-level decision-makers in these sites suggest that whilst most are broadly positive about the SCR, they do not frame their role as “*implementing the SCR*” (though they have, to a greater or lesser extent, learnt to talk the language of implementation and align with CFH’s milestones and targets). Rather, local policymakers have a host of strategic priorities for which the SCR is seen (variously) as instrumental, irrelevant, or interfering.

^{EE} A reviewer of an earlier draft of this report commented: “*This really needs the historical context of NPfIT being set up to procure IT to enable a modernisation programme being led by the Modernisation Agency. When that [the Modernisation Agency] was abolished, an organisation set up to procure IT, i.e. do the technical change, was also left by default to do the social change. It was not either staffed or organised to take that on.*”

- 7.3.4. For example, some PCTs are working hard to develop an integrated out-of-hours service, increase the quality and efficiency of this service, and reduce unnecessary emergency admissions. The SCR is part of that vision – indeed, it is seen as an essential component of it – but the timescale of introducing the SCR is secondary to the timescale of restructuring the out-of-hours service, recruiting and training staff to run it, developing integrated care pathways for different emergency and unscheduled care scenarios, and (in some cases) building new premises to support the new service models. This is a good example of a vision for socio-technical change (i.e. change that requires, and is underpinned by, new technologies, but which is not initiated in order to implement those technologies).
- 7.3.5. This raises the somewhat radical question *“To what extent should the implementation of the SCR be framed, undertaken and evaluated as a freestanding programme?”* Perhaps, if socio-technical change is an important goal, it would be better for CFH to offer the SCR in a flexible and responsive way to local policymakers as a means to other ends. For example, instead of meeting a set of external criteria oriented around ‘readiness for the SCR’, PCTs would be required to produce and justify a coherent business plan and strategy for some ulterior purpose that includes the SCR as a component.
- 7.3.6. The disadvantage of such a radical model is that, as the critics themselves point out, a technology push model *“may be the only way NPfIT can be done, as the NHS is so large, complex and differentiated that it is difficult to get users to lead and agree a project”* (page 13).³⁴ This begs the question of whether attention to the wider socio-technical dimension is a luxury that can only work for smaller, simpler projects.
- 7.3.7. In paragraph 5.2.7., we pointed out that the SCR is viewed differently by different NHS staff in terms of its compatibility with existing values. ‘Compatibility’ begs the question of whether (and to what extent) the values by which health professionals have traditionally defined their role and identity should change. Specifically, should GPs be encouraged to move beyond a traditional view of confidentiality (a property of the individual doctor-patient relationship, assured by professional virtues) and engage with the more contemporary view (i.e. that in these days of interprofessional care and inter-organisational care pathways, confidentiality *should* become a property of the system, assured by technical and operational security measures)? From a narrowly technological perspective, this question is beyond the scope of the SCR programme; from a socio-technical perspective it lies at the very heart of that programme.
- 7.3.8. As a final example of the potential for broadening the work of CFH to embrace socio-technical change, it was clear from our evaluation that one factor explaining the low uptake of HealthSpace is that this technology is currently not overly compatible with the existing values and ways of working of either clinicians or patients. However, to some extent this is because many patients and staff are more comfortable with a paternalistic model of care in which the health professional owns the data and makes the decisions. Whilst the absolute numbers of patients who intend to use HealthSpace to manage their own chronic illness are currently tiny, a socio-technical approach to the development of this programme would seek to build on this small base and systematically challenge the ‘paternalistic model’ as well as merely increasing the number of users.
- 7.3.9. As pointed out in Section 7.2., a socio-technical approach will require a radical re-framing of the metrics for success. Specifically, such metrics will need to be more emergent and revised iteratively in response to ongoing evaluation. Delivery timescales will need to be revised (in some cases, radically) so as to align better with

the much longer timeframes known to be associated with achieving successful social change. And most importantly, politicians will need to recognise that requiring CFH to “go beyond the technology” at the same time as keeping strictly to predefined goals and milestones (see Section 3.1.) is both philosophically and practically impossible.

7.4. The change model: ‘Make it happen’ or ‘let it emerge’?

- 7.4.1. A common criticism of CFH by participants in this study was that PCTs felt “pushed” at a pace they found uncomfortable. GP practices made similar criticisms of their PCT, and senior CFH executives commented that the punishing pace of change was actually set by government because of the high political profile of the CRS programme. Leaving aside the fundamental problem of immaturity of technical solutions, there is a question to be addressed about the extent to which roll-out should be undertaken at a pace and style consistent with ‘softer’ aspects of social and organisational change rather than as dictated by an over-arching Gantt chart.
- 7.4.2. The question of what sort of change model is ‘better’ depends to a large extent on local context and priorities. In one Early Adopter PCT, for example, a project manager with a collaborative, relationship-building style left and was replaced by one with a more managerial, goal-oriented style. Whilst the latter was less popular with some individuals (at least initially), the project moved forward more quickly. In the example of the DMICP system (the networked electronic patient record system used in the British military, described in Appendix, paragraph 9.4.4.), roll-out was strictly timetabled and broadly successful (though not without problems) – but the military are a self-selected sample who are more accepting of ‘command and control’ management.
- 7.4.3. It was pointed out to us by both senior CFH staff and PCT participants that the NHS is well known for its reluctance to accept an imposed pace and style of change. The fact that some Early Adopter PCTs saw clinical engagement (and especially the ambivalent or lukewarm support from Local Medical Committees) as the rate limiting step of the SCR programme, and that at least one practice has decided to withdraw from the programme after initial enthusiasm, suggests that the balance between ‘make it happen’ and ‘let it emerge’ may currently be too far towards the former approach, though we certainly do not have firm evidence that the latter approach would necessarily meet with greater uptake.
- 7.4.4. The academic literature on change management recognises a general tension between ‘managed roll-out’ versus ‘organic emergence’.⁴² This follows from a more fundamental ontological tension (that is, a tension in what people see to be the nature of reality) between a rationalist, ‘clockwork’ universe and a more constructivist, ‘organic’ one. If the universe is seen as fundamentally rationalist, then an ‘intervention’ (such as a training programme) might be expected to produce an ‘outcome’ (such as efficient and confident use of a new technology) in a more-or-less predictable way, which allows for detailed planning and a change model geared around predefined milestones and outcomes. Much of the current CFH approach to ICT development and implementation is predicated on such a world view.
- 7.4.5. An especially problematic feature of change programmes predicated on a rationalist view of the universe is the tendency to ‘compartmentalise’ problems rather than taking a holistic approach. In paragraph 5.7.1., we reported that when technical problems arose, there was a tendency to undertake a brief assessment on site and then send the problem to a specialist centre where technicians with limited experience of front-line healthcare settings would work on a solution. This “back to

the sandpit” approach was not popular, and it was evident that technical solutions were often emerging for a long time and of variable utility when they did emerge.^{FF}

- 7.4.6. A number of alternative approaches to change management, all based on a constructivist model, might be considered by CFH. One is Peter Checkland's 'soft systems methodology' approach to information systems development. Checkland has argued that change is fundamentally a process of sensemaking and negotiating interpretations between different stakeholders. Individuals and groups construct different interpretations of the world. The purpose of a soft systems intervention is to achieve 'accommodation' between conflicting world views which allows purposeful action to be taken without necessarily getting all players to agree.⁵⁰
- 7.4.7. Another constructivist model of information systems development, proposed by Orlikowski's team, in the USA, is technology use mediation or TUM. A brief summary of the academic literature on TUM follows.
 - a. TUM is defined as *“deliberate, ongoing and organisationally-sanctioned intervention within the context of use that helps to adapt new communication technology to that context, modifies the context as appropriate to accommodate that use of the technology, and facilitates the ongoing effectiveness of that technology over time.”* (page 424).⁵¹
 - b. When a specialist technology (such as the SCR) is introduced, considerable 'contextualising work' is needed to reconcile the properties of the technology with existing organisational practices (for example, deciding which functionalities of the software to activate and/or how to reconfigure certain organisational routines). Such contextualising has been found to be necessary even with so-called 'plug and play' technologies (and indeed, may be even more necessary, because of the social design assumptions embedded in the software).
 - c. TUM is subtly different from standard implementation support such as on-the-job training or job redesign, and from the modifications that all end users make to adjust a technology to their particular needs. It is where a subset of organisational members (who are 'super users' of the technology themselves) take officially-sanctioned actions in order to make ongoing and episodic adjustments both to the technology itself and to the institutional properties of the organisation on behalf of all users.
 - d. TUM was initially developed in the commercial software industry, but is seen as offering particular advantages in the healthcare setting, because organisations are often constrained by strong institutional pressures such as the requirements of regulatory agencies and/or normative pressure from professional bodies.⁵²
- 7.4.8. A third theoretical model of emergent change, which both CFH and participating PCTs might consider, is work at the interface of three key disciplines:
 - a. The philosophy of knowledge, in particular the key distinction between 'mode 1' (factual, abstracted and readily codified) knowledge and 'mode 2' (applied, tacit and socially negotiated) knowledge;
 - b. Theoretical approaches to organisational development that place the circulation of knowledge as central (e.g. Senge's work on 'the learning organisation'⁵³ or Nonaka and Takeuchi's work on 'the knowledge creating organisation'⁵⁴); and
 - c. The work of Lave and Wenger on situated learning (that knowledge, especially about ICT applications, cannot be detached from its context of use) and communities of practice (networks of people who share a common interest,

^{FF} CFH asked us to point out that *“The suppliers have competing priorities and there is no traditional financial levers over the GP System Providers as there are in other IT projects.”*

identity and purpose and who share knowledge in creative and largely informal ways).⁵⁵

In our interviews with PCT participants, there was some enthusiasm for a 'learning set' approach to the change effort associated with the SCR, and such a model would link with the above theoretical perspectives. This is an option we will seek to pursue further in the next two years of the evaluation.

7.5. Workload: What are the questions, and how definitive are the answers?

- 7.5.1. A number of stakeholders wanted this evaluation to *"measure the workload"* associated with the creation, deployment and maintenance of the SCR. Whilst this task was seen by some as a simple exercise in accounting for time spent on SCR-related tasks, the evaluation revealed a more complex and less easily measurable picture. For one thing, it was recognised very early on that *"it's always harder for first of breed"*. The very first PCT, and the very first practices in each PCT, and the very first practices using each different GP software system, found the going tough. This is partly because for the pioneers, everything is new; every process and every item of documentation must be developed from scratch; and there must be ongoing negotiation about who will undertake what role and interact with whom – and partly because 'first of breed' comes up against the technology at its most immature and least tested stage. Furthermore, if lessons are to be captured from 'first of breed' to make life easier for their successors, documentation must be particularly thorough and meetings particularly frequent (*"It's been meetings upon meetings upon meetings we've had to attend"* – local clinical lead). The difference between the reflections of a first-wave practice (*"it nearly killed us"*) and a third-wave practice (*"Has the upload happened yet? To be honest I'm not sure, I know the PCT were going to come and do it sometime this week"*) captures the full range of workload experienced by GPs.
- 7.5.2. Secondly, the SCR did not exist in isolation. The *"exhausting"* task of improving data quality to achieve Paperlight or IM&T DES accreditation (a prerequisite for inclusion in the Early Adopter programme) was something that most participating practices had on their to-do list anyway, because it linked with the Quality and Outcomes Framework (and hence with practice income) and also because few GPs disputed that good patient care in the 21st century is built on (among other things) accurate and up-to-date data.
- 7.5.3. Thirdly, new technologies are associated with changes in the nature of work (and also who does it). Hence, the 'workload' associated with the SCR is not merely *"how long does it take someone of which minimum rank to do task X with the plug-in technology?"* but *"what key roles and routines (both traditional and novel) are linked to the use of the new technology, and how do these combine to impact on key outcomes?"* An important finding of this evaluation has been that new technologies make staff roles and work routines visible and open to question. Collaborative health care requires clinicians to work with administrative staff and allied professionals in systematic and mutually supportive ways, and technology can both support and constrain such collaborative work.⁴⁴ The mismatch between the idealised statement in the SCR confidentiality leaflet (paragraph 9.3.1.) and the reality of clinical work in some unscheduled care settings (where people with a receptionist role were already regularly accessing other clinical records, with no associated scandal or patient protests) illustrates this point. The different experiences of the two A&E departments

that have so far deployed the SCR shows that where the new technology aligns well with existing roles and routines (and/or when nobody shouts “foul” when the SCR throws existing roles and routines under the spotlight), excess ‘workload’ associated with the SCR may be minimal.

- 7.5.4. Fourthly, the evaluation found that once the ‘first of breed’ phenomenon has passed, a major determinant of workload was the level of uncertainty deliberately or inadvertently created by GPs and practice staff. We do not necessarily condone those practices who raised no questions about the ethics of the consent model and reassured all patients with advice such as *“it’s all quite safe love, I’ve got one myself”*. However, our data show that those practices that actively encouraged their patients to consider their options very carefully reported far more enquiries and opt-outs than those who did not. This variability of workload with the assiduousness of efforts to get patients to consider their choices explains why practices who would, statistically at least, be defined as ‘outliers’ in their stance towards the SCR (for example those whose GPs are actively campaigning against the NPfIT) report very high levels of personal enquiries and opt-out requests from their patients. This finding begs the question, *“to what extent should GPs be generating uncertainty about the SCR amongst their patients?”*; and perhaps the answer is *“to some [or to a large] extent, otherwise informed consent is impossible”*. Only once that question is answered can ‘workload’ begin to be quantified.
- 7.5.5. Finally, a common complaint from participating GPs, which was linked to wider concerns about the consent model (see Section 7.6.), was that an ‘opt-out’ model for phase 1 along with an ‘opt-in’ for phase 2 would generate large amounts of work for GPs, since patients might (very reasonably) wish to spend an entire ten-minute consultation viewing their GP record and telling their GP which information they were happy to have placed on their SCR. Furthermore, some patients would wish to do this for every future item of data that was added to their GP record. However, on the basis of very preliminary findings from the two or three GP practices who have started the phase 2 uploads, it appears that consent for populating the ‘enriched record’ (e.g. with key diagnoses and test results) is being given without lengthy deliberation or dedicated appointments. This may, however, be because GPs have carefully chosen what one described as *“the low hanging fruit”* (i.e. their most trusting patients with chronic disease), and/or those with high health literacy. The only valid conclusion at this early stage is that the workload for phase 2 remains unknown but that it is likely to be heavily influenced by the definitive consent model.
- 7.5.6. If, as we believe, a meaningful and objective measure of the ‘workload’ associated with the SCR is not (or at least, not currently) possible, what useful information can we give those who seek to negotiate on this point? Here are some facts.
 - a. In the 36 practices where workload was studied either by our direct observation or using detailed self-reporting by practice managers, and not including work on data quality, the estimate of overall workload varied from less than an hour to 30 person-hours in total. The points below show how this is broken down:
 - b. In phase 1, workload for GPs (except for those who were local champions or ‘first of breed’) was widely described as *“negligible”*. Workload fell to practice managers (organising and attending meetings, collecting opt-out figures to send to the PCT, explaining options to patients, allaying patients’ anxieties about government data loss stories, and *“making sure the receptionists understood everything”*) and receptionists (attending training, processing opt-out requests, including scanning opt-out forms into records, and processing communications about the SCR with newly registering patients). Explaining options to patients and dealing with queries was generally judged to be a manager’s role (*“We tried*

- to limit it and take it away from reception because they were panicking" – manager of practice that had had 10 enquiries and 60 returned letters).*
- c. Dealing with newly-registering patients will be ongoing, and will of course vary with the population turnover of the practice; Early Adopter PCTs were selected for their stable populations, so receptionist workload in areas with high patient turnover may be considerably greater.
 - d. PCT staff who work closely on clinical engagement (and who do not themselves stand to gain from any financial deal with GP practices) consistently told us that unless there is a LES (Locally Enhanced Service, see paragraph 5.8.9.), enthusiasm for the SCR programme will wane.

7.6. Consent: Is there a simpler and less onerous model?

- 7.6.1. One of the most consistent findings of this evaluation has been a request by both patients and staff for simplification of the consent model.
 - a. The current model (referred to as a 'hybrid') is one of implied consent (opt-out) for the initial phase 1 upload of medication, allergies and adverse reactions; and express consent (which CFH prefer to describe in terms of 'choices': 'don't store', 'store but don't share' or 'store and share') for any additional uploads, including a standard 'minimum dataset' in the phase 2 upload plus any further additions.
 - b. This model was developed by various working groups within CFH, with a high level of patient representation.
 - c. Seeking express consent for a phase 2 upload would of course raise awareness of the SCR amongst patients, but in a somewhat laborious way.
 - d. One reason for supporting the hybrid model was the anticipation that with an initial opt-out phase, a much higher proportion of the population would end up included in the system than would be achieved by an opt-in model.^{GG}
- 7.6.2. Whilst the 'hybrid' model may not seem overly complex, and whilst it creates an element of flexibility that could benefit vulnerable groups, we encountered numerous examples of clinicians who were both perplexed by, and dismissive of, the multiplicity of options.
- 7.6.3. The current consent model has been marketed as aligned with the 'choice' agenda.
 - a. *"Patients have choices. They can decide whether or not to have a summary care record and, if they decide to have one, whether or not it is shared. They can change their mind at any stage."* – CFH background document on the consent model.
 - b. In paragraph 6.2.15., we presented an important element of our analysis of patient data, which suggested that people who might be classed as 'disempowered' generally wanted to have a SCR but also wanted control over which individuals (as opposed to which 'generic' roles or situations) had access to it.
 - c. For these individuals, the key choice appears to be not whether any particular *item* of information (or indeed, the record as a whole) is classified as 'share' or 'don't share' but whether they trust any particular *individual* with access to their record at a particular point in time. This finding leans us towards recommending a 'consent to view' model (see examples from other jurisdictions in Appendix,

^{GG} A CFH staff member made the following comment on a draft of this paragraph: *"It is critical that the share choice is appreciated as having a far wider implication than just SCR - it is far more of an opt-out of the wider NHS CRS programme as a whole."* Simplifying the consent / choice model for the SCR would apparently have important ramifications for the use of local detailed records, which would not be easy to address.

Section 9.4.), though we feel that this provisional suggestion should be verified through further consultation with patients.

- 7.6.4. Health information systems academics and ethicists have argued that implied consent (*"if we don't hear from you, we'll upload your record"*) is only informed consent (and only ethical) if there is evidence that the patient has read and understood their mail and also that they know what is on their record.⁵⁶⁻⁵⁸ This evaluation has confirmed the results of a small survey undertaken by one erstwhile Early Adopter practice (which subsequently withdrew from the programme) that many patients who were sent a letter (plus leaflet and information on where to go for further information) remained ignorant of the basic issues. The fact that much of the individual resistance within GP practices has come not from IT-ignorant 'laggards' but from Caldicott Guardians (see paragraph 5.3.6., who are generally the most information-literate members of staff and certainly the formal custodians of the practice's data) adds weight to the argument that the current consent model should be urgently reviewed.

7.7. The key to security: Fixing technology or managing people?

- 7.7.1. Official assurances about the security of the SCR have tended to focus on the technical security of the systems (for example, one publication distributed by an Early Adopter PCT at a community engagement event stated, *"Connecting for Health's position on this is that the programme of work is proceeding as designed particularly as the **systems** it is developing and deploying provide very high levels of patient record security."* (our emphasis). But technical measures alone can not ensure security, as by their nature they must allow numerous users some level of access.
- 7.7.2. To address fully the need for security, the social aspects of the system must be addressed, by minimising the possibility for human error and by applying sanctions where data are accessed inappropriately and malevolently. CFH is aware of this, and there are, on paper at least, detailed measures in place for limiting access to those with a legitimate relationship with the patient, and producing and policing audit trails of inappropriate access.
- 7.7.3. Despite these measures, most security questions raised by independent commentators have concerned the risk of human error. They point out that the NHS is a uniquely busy institution operating under pressing physical and administrative constraints, with one of the largest and most diverse workforces in the world and in an environment that is freely accessible to the public. Staff turnover is rapid and the demands of many roles high. Much work occurs outside regular office hours (and this will be particularly true of work involving the SCR). The enforceability of both personal smart cards role based access controls in such an environment has been questioned,³⁴ and our own observations in this evaluation confirm that there is a mismatch between what the official operational measures assume and what is likely to occur in practice, especially at busy times.
- 7.7.4. Deliberate inappropriate access to patients' electronic records (for example, of celebrities) by NHS staff has undoubtedly occurred. It is inevitable, in any organisation of considerable size, that there will be those who seek inappropriate access to records whether for personal gain or through simple curiosity. We believe that though the social aspects of system security have been considered by CFH, they are still to be fully addressed at an operational level. There is an urgent need for workable measures to reduce the risk of human error, and these must take into

account the operational environment in which the SCR will be accessed. Furthermore, an effective and credible system of routine audit and sanctions for inappropriate access is essential. The object of these measures would be twofold: to deter deliberate access to records where there is no legitimate reason, and also to ensure that the security of the SCR remains credible to patients. This is an especially pressing requirement in the light of recent data losses by various bodies, government departments and private companies alike.

- 7.7.5. In summary, whilst the technical security measures of the SCR appear to meet high standards, and whilst nobody is yet known to have 'hacked' into the Spine, questions remain about whether a series of linked smaller systems would be safer than a large single system and whether the plans for operational security will be fully enforceable in the busy environment of the NHS.

7.8. New uses of the SCR: Creative deployment or scope creep?

- 7.8.1. A recurring criticism of the SCR in this evaluation was that it was *"trying to be all things to all men"*. It is a basic rule of software engineering that the client should specify the 'usage scenarios' as tightly as possible in order to make the design of a bespoke product possible.
- 7.8.2. Analysis of historical documents reveals a tendency to 'scope creep' from the outset of the SCR programme. For example, a witness in the House of Commons Health Committee commented: (page 26): *"The notion that you could introduce a Summary Care Record and then use it as the Local Care Record, because it had the flexibility to enable local care groups to upload whatever information they wanted to and could agree to actually share amongst themselves, looks to me like a specification creep that is highly likely to undermine the security policies that are being put in place..."*³²
- 7.8.3. On the other hand, a positive aspect of local emergence is that end users develop ideas for new applications of the SCR and new functionality (which links with the attribute of 'reinvention' described in paragraph 5.2.4.). For example, as this report went to press, at least one hospital pharmacy was poised to start using the SCR to avoid the thankless and time-consuming task of telephoning GP surgeries to check a patient's current medication before issuing new medicine. It is hard to condemn this local creativity – especially since it is a good example of where the SCR might save time and improve efficiency. Nevertheless, there is a balance to be struck between having a single, well-defined use scenario and allowing local teams to develop multiple potentialities.
- 7.8.4. It is worth noting that the developers of the Emergency Care Summary in Scotland (see Appendix, paragraph 9.4.2.) attribute its success to a very simple, clearly defined and essentially non-negotiable use scenario (emergency care). They described continually having to resist the enthusiastic ideas of their end users (community pharmacists, for example, put a strong case for having access to the ECS). That is not to say that all developments were rejected outright, (a new addition is about to go to pilot, whereby a Palliative Care Summary can be added to the ECS with the explicit consent of the patient) but that the development of ECS was carefully controlled until after the 'basic' ECS had become fully operational across Scotland. Consultations are now taking place with stakeholders to examine which extensions of users and data could fit with the aims, benefits and aspirations of the ECS.

7.8.5. Whilst it is difficult to be prescriptive, the scale and complexity of the SCR programme, even for the 'core' usage scenarios set out in original strategy documents, mitigates against the development of multiple additional functions. As Randell has put it (page 230), *"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."*⁵

7.9. Hard to reach groups: Inverse care in the Information Age?

7.9.1. The inverse care law states that people most in need of health care are least likely to seek it or receive it, especially when economic interests are involved.⁵⁹ Despite the fact that both CFH and participating PCTs explicitly saw the SCR programme as supporting the care of the disempowered, the chronically sick, and the socially excluded (see the Ministerial Taskforce Report for a powerful 'inequalities' vision, for example¹), this evaluation has revealed a number of examples of the inverse care law. The examples in this section are not intended as criticism of the considerable efforts made both nationally and locally to identify and address the needs of 'hard to reach' groups (for example, the dozens of meetings with community and patient groups described in the case studies in Section 4), but to illustrate that despite these efforts, a vast agenda of work remains.

7.9.2. Our own observations suggest that those actually attending for emergency and unscheduled care in Early Adopter sites appear to be far less likely to have a SCR than the general population in those sites (see paragraph 4.2.13.), though the deployment has not been running for long enough to produce quantitative access statistics. The inequality appears to be due to a number of things:

- a. GP practices who signed up for the Early Adopter programme are often (but not always) sited in more affluent areas.
- b. Patients registered with such practices may be less likely to seek emergency or unscheduled care (perhaps because they are better cared for overall and/or have better self-care skills and resources, so fewer 'emergencies' arise).
- c. People seeking emergency and unscheduled care are less likely to be registered with a GP at all.
- d. People seeking emergency and unscheduled care are more likely to be registered with a GP outside the area.

7.9.3. The dramatic differences in awareness of the SCR programme in people with high health literacy compared to those with low health literacy following the public information programme (paragraph 5.4.3.) suggests that the needs of the latter must be specifically targeted.

- a. Our empirical work showed that news articles were perceived as easier to understand than the patient letters by many patients with low health literacy (and had led to awareness when the letter was not recalled at all).
- b. Marketing and communications scholars talk about 'audience segmentation' (dividing the target audience up by key demographic, cognitive and other characteristics, and tailoring different messages to different segments of the audience).
- c. There is a trade-off between completeness of information and the length of the message, but as one practice manager said, *"If I was to do it over again, I would need to direct the letters better. Different letters for different patient groups."*

- 7.9.4. In paragraph 6.2.6., we presented our finding that a small but significant proportion of people in Early Adopter sites, and especially those with low health literacy, were 'not bothered' whether they had a SCR or not. These people appeared to feel that that the SCR was a good thing because it *reduces* personal responsibility for health. This finding is open to a number of interpretations (for example that these individuals did not wish to engage with the research) and requires further confirmation. If people genuinely view the SCR as a way of abrogating responsibility for their health, this links not with the assumed 'empowerment' agenda that was said to underpin the introduction of the SCR and HealthSpace¹ but with the 'lack of engagement' agenda which Sir Derek Wanless warned could potentially undermine the success of numerous public health initiatives in the UK.⁶⁰ In participants with low health literacy, lack of engagement appeared to be the key moderating factor which explained the mismatch between the decision to have a SCR (almost all 'yes' or 'don't care') and the decision to have a HealthSpace account (almost all 'no').
- 7.9.5. There is a growing research literature on the health risks associated with low health literacy (it has a strong association with a wide range of risk behaviors and physical, mental and social problems), and on how best to support those with low health literacy.⁶¹⁻⁶³ Initiatives that promote informed, empowered self-care are inherently geared to those with the ability and motivation to manage their own health, and might even be said to discriminate against those who are "*not bothered*" (motivational block) or "*can't get my head round it*" (cognitive block). It is also true that a tax on cigarettes discriminates against smokers but is also in the long run good for them. If the SCR and HealthSpace are to be used (as originally envisaged) as tools in reversing the depressing (and worsening) health outcomes associated with low health literacy and social exclusion, much remedial work will need to be undertaken on both the cognitive and motivational dimensions of health literacy.
- 7.9.6. The apparent lack of engagement of hard-to-reach groups (which is based on a relatively small sample and needs to be confirmed in other studies) has implications for the consent model (see Section 7.6.) – in that if someone chooses not to engage (or is unable to engage) with the issue, the legality of informed consent may be in doubt.
- 7.9.7. Another aspect of the inverse care law is the 'digital divide': computer use is disproportionately a privilege of the affluent and educated. This was demonstrated in the tracker survey in Bolton and Bury, where both ownership and use of computers was strongly associated with higher socio-economic status, younger age, and absence of long-term illness or disability.²⁵ This contrasts with the most commonly cited use scenario for the SCR (an elderly person on a long list of medication) and the anticipated main user group for HealthSpace (people with long-term illness, especially the housebound elderly). It should also be noted, however, that in our survey, not having access to a computer was a relatively rare reason for not wanting a HealthSpace account, and that many younger adults were keen on the idea of HealthSpace as they saw it as a way of keeping track of an elderly relative's illness.
- 7.9.8. At this relatively early stage in the development of HealthSpace the only certain conclusion is that dialogue and development work must continue in partnership with potential users of the technology, and that this work must extend beyond the 'usual suspects' of Expert Patient groups and retired businessmen. We are cautiously impressed with preliminary plans of CFH for a very active patient voice in the next phase of HealthSpace development (which includes several targeted projects with people with long term conditions), and are also beginning to explore creative initiatives both nationally and locally (in which, for example, health trainers are being introduced to HealthSpace with a view to canvassing interest amongst target groups).

7.10. “Local ownership” of a national programme: contradiction in terms?

- 7.10.1. The balance in responsibility for the SCR between CFH and the PCTs was associated with confusion. On the one hand, PCT participants in this evaluation complained that they felt pressured and constrained by CFH. We were also told (in some cases by the same informants) that CFH failed to provide national level resources (e.g. templates for posters) or a clear steer for what they saw as ‘national’ controversies and issues (e.g. how they should respond to a standard letter sent by an activist to all PCTs in the Early Adopter programme).
- 7.10.2. On the other hand, CFH staff gave us examples of national level resources that the PCTs had rejected or chosen not to use (“because they wanted to do it their way”) and in some cases complained that key decision-makers in the PCTs worked on an incorrect assumption that they needed to keep “running to the centre”. A good example of this is the misunderstanding about staff training in one PCT (see paragraphs 5.8.5. to 5.8.6.). The PCT had experienced a centrally-driven training model for the SCR as constraining, and asked us to broker a ‘training the local trainers’ model to CFH in this report. When we raised this with CFH, however, we were told that such a model was already in place, and they were surprised that the PCT was not using it.
- 7.10.3. Overall, our impression was that the centre-periphery tension is due partly to the fact that, despite in principle supporting local ownership of the SCR programme, CFH staff were somewhat constrained by their own hierarchical organisational structure, a technical and rationalistic rather than developmental and constructivist model of change, the desire to maximise the success of the Early Adopter programme, and an inefficient approach to the generation and circulation of knowledge (Section 3.2.).
- 7.10.4. It is also worth commenting on the relative lack of lateral exchange or mutual support between PCTs. The fact that if an activist sends a letter to all the Early Adopter PCTs, it would be sensible for that individual to receive a consistent reply from all of them does not necessarily mean that that reply needs to be drafted by someone in CFH. Another option would be for the chief executives (or press officers) of the PCTs to collaborate *without* the input of CFH. Informants in each of the four PCTs in this evaluation used the metaphor of “sending knowledge up before they send it back down [to another PCT]” but none had a clear reply to the question “why don’t you just get together and discuss things between yourselves?” (That is not to say that such exchange never happened, merely that it was relatively sparse and ad hoc rather than frequent and systematic).

Box 1. CURRENT DIVISION OF RESPONSIBILITY IN THE NATIONAL PROGRAMME FOR IT LOCAL OWNERSHIP PROGRAMME

CFH’s MAIN RESPONSIBILITIES (acting as an agent for the NHS)
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- | |
|--|
| <ol style="list-style-type: none">1. Overall financial management, commercial strategy and clinical direction of NPfIT2. Capability and capacity building to support the NHS3. Maintain, manage and report on overall plan, progress, risks, issues, costs4. Maintain consistent benefits realisation framework5. Produce and maintain business cases on behalf of the NHS |
|--|

STRATEGIC HEALTH AUTHORITIES’ MAIN RESPONSIBILITIES

Delivering & implementing the NPfIT, including
--

- | |
|--|
| <ol style="list-style-type: none">1. Approve supplier requirements, commercial proposals, business cases and finance |
|--|

2. Ensure clinical governance
3. Service management strategy
4. Monitor benefits realisation

NHS TRUSTS' MAIN RESPONSIBILITIES

1. Develop credible deployment plans and Project Initiation Document (PID)
2. Allocate resources (people, money, time)
3. Undertake preparation, readiness and risk assessment
4. Address data quality, integrity and migration
5. Ensure staff / clinical engagement

7.10.5. The above points suggest that there is a job to be done achieving clarity about the role of CFH (as currently constituted) and the participating PCTs. But there is also a more fundamental question that goes beyond the SCR programme – concerning whether a radically revised version of NLOP might include the potential for the entire NPfIT to shift to a more decentralised ‘federation’ of linked record systems, each with a much higher degree of local ownership than is currently accorded to SHAs. As others have recently pointed out, the NHS in England may officially be a single organisation, but in reality it operates in a highly differentiated way, and the current division of labour within NLOP (See Box 1 above) may make timely progress with locally-driven IM&T projects impossible in practice.^{4;34} In the USA, a network of academics and IM&T practitioners called Connecting for Health (no relation) has described a range of alternative models based on distributed systems, and – importantly – characterised a very different role for the centre (that of coordinator and “adoption catalyst”, including setting and monitoring standards for interoperability).^{34;64}

7.11. How should the risks in the SCR programme be managed?

7.11.1. According to the Public Accounts Committee, the NHS Care Records Service is predicted to cost around £0.6 billion before the SCR is fully up and running, and that does not count the set-up costs of the N3 network or other “*central costs*” (see paragraph 3.3.1.).²⁴ Large-scale IM&T initiatives in healthcare are in danger of becoming ‘runaway projects’ into which stakeholders continue to pour money even when the project is sunk.⁶⁵ A legitimate question is “*what are the risks and how can these be contained?*”

7.11.2. Complex systems (of which the NHS is an example) are inherently stochastic rather than deterministic (in other words, knowing all the properties of the system does not allow one to predict what will happen next). In his excellent book ‘The Innovation Journey’, Andrew Van de Ven observed (based on two decades’ empirical work studying innovation, mostly in healthcare) that large-scale innovation in complex systems does not progress in a linear way. Rather, it happens in spurts, interspersed with other periods of not much happening and even backward movement. The innovation journey is punctuated (indeed, it may be largely driven) by a series of “*shocks*”. Given the inherent non-linearity of complex innovation, and especially of complex ICT projects, such a course should not, therefore, be interpreted as evidence that something has gone wrong or that the programme is necessarily off course.

- 7.11.3. We are concerned that to some extent (and within the limits of our own competence to judge – we are academics, not experts on financial investment or business management) the existing arrangements for governance and risk management assume that the system operates by deterministic laws (and that hence, for example, every problem has a solution that just needs to be worked out and put in a ‘standard operating procedures’ manual, the policing of which will effectively manage the risk). But the system into which the SCR (and the NPfIT more widely) is being introduced is – *and always will be* – characterised by too much inherent uncertainty to justify such an approach.
- 7.11.4. ‘Project management’ is fundamentally different from ‘programme management’. A project is a circumscribed initiative with predefined, measurable endpoints towards which managers work systematically, fixing anything along the way that interferes with the agreed goal. A project may be complicated (multiple interacting elements and sub-projects) but it is not *complex* (inherently non-linear and unpredictable).⁶⁶ Programme management is about bringing together multiple elements in iterative and adaptive ways against an ever-changing background context, towards a more abstract goal (e.g. “improve access to health records in emergency settings” rather than “implement the SCR”). The abstract programme goal requires continually redefining and negotiating throughout the innovation journey, but such a goal is better able to transcend system shocks (such as shifts in technology specification or prevailing IT policy). The skills of project management relate to planning, organising, monitoring, adjusting, documenting and reporting. Those of programme management include negotiation, sensemaking, synthesis and (above all) situational judgement.
- 7.11.5. On the basis of the findings in this evaluation, we feel that the single most important contribution to risk management in the SCR programme is to shift the emphasis from ‘complicated project’ to ‘complex programme’. This will require a shift away from (implicit or explicit) fixed timescales and talk of the project (sic) being “behind schedule”. It will also require leaders and senior managers to have both the skills and the mandate to take a more adaptive and context-sensitive approach to defining and executing the programme than has been the case to date.

8. Reflections on the evaluation

8.1. Was the approach to evaluation valid?

- 8.1.1. The approach taken in this study was a radical departure from previous evaluations of large-scale ICT projects in the NHS.^{67;68} It was explicitly based on an interpretivist rather than rationalist philosophy, and privileged qualitative rather than quantitative methods. Much has been written about the place of interpretivist philosophy in information systems research (see, for example, Orlikowski and Baroudi's landmark paper from 1991⁶⁹ and Walsham's more recent justification of the approach for the kind of study we sought to undertake^{70;71}), about the strength of qualitative methods when the field of enquiry is uncertain or contested,⁷² and about the added value of mixing qualitative and quantitative data.⁷³
- 8.1.2. Many qualitative studies in healthcare are impoverished by weak (or absent) theory. We concur with Ken Judge that in a complex field of enquiry we do not merely need qualitative (or, better, mixed qualitative and quantitative) methods, but 'strong theory, flexible methods'.⁷⁴ The use of a robust, multi-level theory on diffusion of complex innovations in healthcare organisations (developed from a literature systematic review⁷⁵) not only enabled us to analyse the data systematically, but also helped inform and shape our strategy for data collection. Having said that, the very rich dataset collected for this study (set out in detail in the Appendix) will lend itself to a number of further analyses (for example, using theories of technology structuration⁵¹), from which academic papers are planned.
- 8.1.3. A good illustration of how a qualitative approach can promote *interpretation* (rather than mere description) is the treatment of conflicting data. In a quantitative study, if data are conflicting, the general assumption is often that one set of data must be incorrect; the next step is often to collect a third set of data (perhaps a larger sample, or with more precise equipment); and the conclusion is often that "more research is needed". In qualitative enquiry, "conflicting" data leads to a search for explanations, and thence to *higher-order* data (that is, data at a higher level of abstraction than the raw data which appear to conflict). Here are two examples.
- When we enquired about training, informants in one PCT gave us the impression that the standard training model was that CFH sent in consultants, who were great trainers but a hassle to organise, and that they would prefer to have the autonomy to do in-house training (paragraphs 5.8.5. to 5.8.6.). In contrast, staff from CFH told us that the training model was largely led by the PCTs and that CFH training consultants only did initial 'concept training'. The "conflicting data" in this case led us to the higher-order insight that there was a problem between CFH and the PCTs over what aspects of the programme were led centrally and what were led locally – an issue which we discussed in Section 7.10.
 - Another example of "conflicting data" was the (initially somewhat confusing) finding that some GP practices described the CHART audits (part of the PRIMIS data quality programme, see paragraph 3.4.2.) as extremely useful while others saw them as "a waste of time". This led us to ask (through a qualitative technique known as 'progressive focusing') "*what is it about the practices who find CHART a waste of time, compared to those who find it helpful?*". Detailed ethnographic observation of individuals undertaking CHART audits in both sorts of practice, as well as the application of Epstein's theory of 'mindful practice' (paragraph 5.4.7.⁴⁵), led us to one of the most important insights of this evaluation – that CHART audits can be *either* very useful *or* a waste of time, depending on the level of understanding and the quality of facilitation by DQFs.

8.2. Did the evaluation answer the research questions?

- 8.2.1. The research questions set at the outset of this evaluation have been reproduced verbatim in Section 2.3.3. We take them in turn.
- 8.2.2. At the 'micro' level, we believe that the evaluation was overall very successful in analysing the usability, actual usage, functionality, fidelity of implementation, and impact of the SCR in Early Adopter sites (to the extent that deployment had actually begun). It also allowed us to describe and analyse variability in all these phenomena within and between different Early Adopter sites, and to derive a set of factors that explained this variability (see Section 5.), and also a summary of critical mediators in the Executive Summary, paragraphs 1.14. to 1.20.). Whilst these factors were largely derived from previous theory, we used our data to question and refine the theory (for example, the theory predicted that large organisations would be more successful than small ones in implementing the SCR, but our data showed otherwise).
- 8.2.3. At the 'macro' level, our approach was also largely successful in contextualising the SCR programme within the prevailing social, political, technological and economic context, and in illustrating how this context shaped, enabled and constrained micro level usability and usage (see, for example, Section 5.9. plus our analysis of CFH, Section 3.2.).
- 8.2.4. The evaluation was very successful in allowing us to map stakeholder expectations and values (see, for example, paragraph 2.6.2. *et seq*), but only partially successful in meeting these expectations for the evaluation. One area where we were unable to meet expectations was in exploring specifically the role of nurses in the creation and deployment of the SCR. This was not because we unconsciously excluded nurses (indeed, we explicitly asked to interview and observe them), but because the task of creating records in GP practices, and of overseeing this process, appeared to fall to managers and GPs respectively. Nurses were much more involved in the deployment of the SCR at the point of unscheduled care, but because this phase had barely begun when the report was written, we only captured preliminary data.^{HH} The role of nurses will be explored specifically in the next phase of the evaluation.
- 8.2.5. We were much less successful in our goal of developing standards and metrics based on the values and interests of different stakeholders, for reasons we discuss in Section 7.2. In retrospect, we were unrealistic in expecting to produce such metrics, which our analysis (along with literature review) has shown are best approached developmentally and iteratively by the teams themselves.
- 8.2.6. Finally, we believe that the evaluation has produced some important lessons for evaluation scholars about how to illuminate and inform large-scale programmes of ICT development that occur in a politically sensitive environment. For example:
 - a. A strong theory of evaluation, Patton's Utilisation Focused Evaluation²⁶ (as well as additional theory for data analysis) allowed us to clarify both for ourselves and for our stakeholders what the evaluation would and would not cover, and how.
 - b. Mapping the stakeholders and articulating their expectations was an effective way of alerting us to potential areas of contestation, and modifying our approach as we went along.

^{HH} On our visit to Scotland to see the more established Emergency Care Summary in use (paragraph 9.4.2.), we interviewed far more nurses than doctors and noted that a high proportion of encounters where the ECS was accessed were nurse-led.

- c. Building relationships with stakeholders allowed us (where appropriate) to challenge their expectations and negotiate a compromise in what we were expected to deliver.
- d. A strong and broad-based advisory group, with representation from many (though not necessarily all) stakeholders, provides an essential sounding-board for emerging findings and a vehicle for identifying and addressing controversies in the findings.

9. Appendix

9.1. Details of data sources and methods

9.1.1. The data sources for this evaluation are summarised in paragraphs 2.5.3. and 2.5.5. Further details of selected sources are given below. In total, 38 GP practices in four Early Adopter sites (11 in Bolton, 12 in Bury, 8 in South Birmingham, and 7 in Dorset) were studied. Interviews were conducted to explore the perspective of staff involved in the SCR project. The demographic characteristics of this sample are shown in Table 3 below. A total of 250 individuals were interviewed; several of these were interviewed on more than one occasion but we have only counted them once in the table below. Around half of the interviews were lengthy (lasting between 30 and 60 minutes); others were brief (5-20 minutes).

	Source of recruitment						Total
	CFH	Bolton	Bury	South B'ham	Dorset	Other*	
Gender							
Male	20	22	22	18	12	21	115
Female	15	41	29	12	13	25	135
Employed by (or contracted to)							
CFH	35	8	4	2	2	0	51
PCTs (not incl. PALS)	0	8	10	8	7	11	44
GP surgeries	0	26	20	14	15	7	82
Unscheduled care	0	18	15	0	0	8	41
Other (e.g. voluntary sector, PALS)	0	3	2	6	1	20	32
Role							
Executive /strategic [A]	13	7	4	5	3	5	37
Managerial/facilitator [B]	16	21	21	8	10	10	86
Administrative [C]	1	6	6	0	4	2	19
Senior clinical [D]	5	5	7	6	5	3	31
Front-line clinical [E]	0	21	11	7	3	8	50
Patient or advocate**	0	3	2	4	0	18	27
Total	35	63	51	30	25	46	250

* includes participants from Strategic Health Authorities, Fast Follower PCTs and those in Early Adopter PCTs not included in our case studies (i.e. Bradford, South West Essex), military, Scotland/Wales, ERDIP sites, campaigners, national-level voluntary sector, etc.

** Not including patients interviewed for patient survey (see paragraph 9.1.6.).

[A] e.g. chief executive, senior manager; [B] e.g. practice manager, trainer, data quality facilitator, technical support; [C] e.g. receptionist; [D] e.g. doctor or nurse involved in strategic level decisions about the SCR; [E] e.g. other doctor / nurse, healthcare assistant, pharmacist

- 9.1.2. For preliminary staff interviews, we initially used an unstructured approach – i.e. we asked the person to talk about their experience of the SCR without any prompts, or began with the question “*What questions do you think I should be asking you?*”. As we built up a preliminary picture of the issues, we shaped our interview schedule into a more conventional semi-structured format. Box 2 shows a typical semi-structured interview schedule for a preliminary interview; the questions were adapted for different individuals and contexts. A few staff interviews were tape-recorded and transcribed, but in most cases we made detailed contemporaneous notes and typed them up immediately after the interview. This approach was chosen because we found that people spoke more freely and honestly, especially about sensitive issues, when they were not being taped.

Box 2. SEMI-STRUCTURED INTERVIEW SCHEDULE FOR A TYPICAL EARLY INTERVIEW WITH MEMBER OF STAFF INVOLVED IN THE EARLY ADOPTER PROGRAMME

[Explain purpose of research; obtain informed consent to interview]
 Please describe your role in this project.
 How has the project been going so far?
 What do you think have been the main things influencing the implementation of the Summary Care Record locally? Why do you think that is?
 How do you relate to / work alongside [person X]? What do you think their role in the project has been?
 What would you describe as the main difficulties or challenges so far?
 Have you had any critical incidents (things you've been concerned about)? If so, please describe what happened and how you felt about it.
 Tell me more about [picking up on something the person has raised]
 If you were doing this work again, what changes would you make and why?
 What have you learnt from your involvement in this project?
 What else do you think I should be asking you about?

- 9.1.3. At a later stage in the evaluation, when analysis of preliminary interview data had given us a good map of the territory we were exploring, we moved from an ‘open ended’ approach (allowing the interviewee to stray onto different topics if they wished) to a more semi-structured approach with a consistent list of questions. Box 3, for example, gives a typical semi-structured interview schedule for interviewing staff at participating GP surgeries and Box 4 gives a comparable schedule for staff at non-participating surgeries.

Box 3. SEMI-STRUCTURED INTERVIEW SCHEDULE FOR A TYPICAL LATER STAFF INTERVIEW FROM A PARTICIPATING GP PRACTICE

[Explain purpose of research; obtain informed consent to interview]
 1. BRIEF BACKGROUND TO PRACTICE
 How many staff (doctors, nurses, admin, other)
 Number of patients? Any specific characteristics /stands out in your patient population - (Prompt: for instance, large minority ethnic population (which), university students, larger than average elderly, diabetic etc).
 How would you categorise the practice & attitude of staff in relation to IT? (Prompt - Has the practice been involved in any other IT projects? Do you use C&B? /IT literacy/Interest - any differences between GP Partners, other staff, nurses, reception/admin?)
 2. INTERVIEWEE'S STORY

How were they approached by PCT (Prompt by whom/ what did they know/ what were they told?)
How was decision taken to become involved as EA Practice? (Prompt: Who was involved in the decision making?)
Was everyone in Practice in agreement? Any dissension (if yes, by who/what were the issues/how resolved?)
Has it all gone as expected? If different, how? How? Any critical events?
In hindsight, do you feel you were given enough information as to what was involved?

3. WORKLOAD

Estimate of amount of time has practice as a whole/ individual members of staff/ spent up to this stage?
Which aspects have been most time consuming? For whom?
What about data quality? How far have you got? How much work is/was involved, who did it? How much support did you get? From whom?

4. PATIENT CONSENT

What have been the main enquiries and issues/concerns for patients? (prompt: any differences in terms of age/ethnicity/ specific patient group)
How have they been dealt with, by whom?
How is the practice dealing with patient consent for the second stage of the upload? Any thoughts on resource implications for next stage of implementation?

5. BENEFITS/ DISBENEFITS

What do you see as the main benefits of the summary care record?
What do you see as the main disadvantages or risks?
What are your thoughts on HealthSpace? Benefits/ drawbacks?

6. RELATIONSHIP WITH THE PCT/CFH

What are your thoughts about the way PCT/CFH has gone about the implementation process up to now?
How have they supported you for the SCR? Was this sufficient? Anything specific lacking?
What about training? Were you happy with it in terms of form/ quality/ quantity/ timing?
Has your relationship with PCT changed in anyway since implementation of SCR, (better/worse, in what way?)

7. GENERAL

And finally, to wrap up, what is your perception of how things have gone so far, has it met your expectations? Anything you feel has not gone as you expected? Better/worse? Why, in what way?
Anything you would like to add?

Box 4. SEMI-STRUCTURED INTERVIEW SCHEDULE FOR A TYPICAL LATER STAFF INTERVIEW FROM A NON-PARTICIPATING GP PRACTICE

[Explain purpose of research; obtain informed consent to interview]

1. BRIEF BACKGROUND TO THE PRACTICE

(as above)

2. INFORMATION ABOUT SCR

How did you first hear about the summary care record?

How were you invited to become involved? By whom? (By letter, personal contact, etc) How is your relationship with the PCT?

What was your impression of how the PCT handled this?

Did you attend any engagement events? Your reaction?

How was the decision not to become involved in the project made?

At what point did you decide not to take part?

What made you decide not to take part? (security issues/patient confidentiality issues, or the way it's being implemented, consent model, work load etc?)

Who was involved in the decision-making? Was there any disagreement within the practice?

How did you inform the PCT of your decision?

How was this responded to?

3. GENERAL ATTITUDE TOWARDS TECHNOLOGY

Have you been involved in any other IT projects?

What is your experience with Choose & Book?

Have you dealt with Connecting for Health before?

4. PATIENTS

Have you had any patients asking about the SCR, whether or not your practice is involved? (If yes, what did you tell them?)

How do you think the SCR will affect patients?

5. POSITIVE ASPECTS

Do you see any benefits or potential benefits in the summary care record?

Is there anything that would make you change your mind?

Which criteria would make you feel that the SCR is successful in [your PCT]?

6. GENERAL

How do you expect the SCR project will go?

Would you like to add anything? Is there anything else I should have asked you?

What would you like to see in the evaluation?

9.1.4. To generate ethnographic data, one or more members of the evaluation team attended a meeting or visited a field site and made free text notes, which were subsequently typed up and analysed (see below). Table 4 shows the sources of these data. Note that one hour of ethnographic observation tends to generate 3-6 pages of field notes.

Table 4. ETHNOGRAPHIC DATA USED IN THIS EVALUATION		
	No. of hours of ethnographic observation	Key sources of ethnographic data
Connecting for Health Formal meetings Informal meetings Conferences	150 150 100	Committees, working groups, team meetings, phone-ins, presentations, informal contacts with CFH staff
Bolton PCT GP practices Unscheduled care settings	200 200 100	Project board meetings, team meetings, engagement events, training events, waiting rooms, consulting rooms, call centres
Bury PCT PCT GP practices Unscheduled care settings	100 150 50	As above
South Birmingham PCT PCT GP practices Unscheduled care settings	20 0 0	As above but less emphasis on unscheduled care settings because SCR not yet in use
Dorset PCT PCT GP practices Unscheduled care settings	20 40 0	As above but less emphasis on unscheduled care settings because SCR not yet in use
Comparative settings Scotland UK Defence	20 10	Strategic centres, reception areas, waiting rooms, consulting rooms, call centres
Wider context Voluntary sector Other patient groups Other	60 60 60	e.g. Community group meetings, Expert Patient meetings, campaigns and conferences not part of official SCR programme
Total	1500 hours	

9.1.5. We collected extensive documentary data which were analysed alongside our ethnographic notes and interviews (see below). Table 5 shows the sources of these data.

Table 5. DOCUMENTARY DATA USED IN THIS EVALUATION		
	No. of pages of documentary data (approximate)	Key sources of documentary data
Connecting for Health Letters and emails Official documents Official communications e.g. press releases	500 500 200	Committee and board papers, internal emails, internal and consultancy reports, project initiation documents, press releases, and similar documents
Bolton Letters and emails Official documents Official communications	100 200 50	Project initiation document, board papers, minutes of meetings, progress reports to CFH, email exchanges,
Bury PCT Letters and emails Official documents Official communications	100 200 50	As above
South Birmingham PCT Letters and emails Official documents Official communications	50 200 50	As above
Dorset PCT Letters and emails Official documents Official communications	50 200 50	As above
Total	2500 pages	

9.1.6. To ascertain the perspective of patients and service users, 103 adults were recruited from waiting rooms in GP surgeries, Accident and Emergency departments, and walk-in centres. Potential participants were approached by someone who was not a member of the research team (e.g. a receptionist) wherever possible, and if interested were given a 'plain English' information sheet about the study. Participants were not required to give their names but were asked their age and occupation, and health literacy estimated as 'high', 'medium' or 'low'. 'Special' information sheets and consent forms were provided for those with low health literacy.

The demographic characteristics of this sample are shown in Table 6 below:

	Source of recruitment				Total
	GP surgeries	Walk-in centres	A&E departments	Out of hours centres	
Age (median / range)	45 (25-75)	28 (16-78)	50 (21-59)	36 (34-53)	35 (16-78)
Gender					
Male	22	14	7	2	45
Female	22	32	3	1	58
Ethnicity					
White	40	43	10	3	96
South Asian	4	1	0	0	5
African	0	2	0	0	2
Occupation					
Professional or managerial	2	5	5	0	12
'White collar' e.g. clerk	0	11	2	0	13
Manual	5	8	2	1	16
Unemployed	2	4	0	2	8
Housewife	16	12	0	0	28
Student	0	5	0	0	5
Missing /did not want to say	19	1	0	0	20
Estimated health literacy					
High	11	3	6	0	20
Medium	27	14	2	2	45
Low	6	29	2	1	38
Total	44	46	10	3	103

- 9.1.7. Individual interviews were intentionally brief (around 5 minutes), and were not tape-recorded, so as not to put people off participating. We asked around 8 questions, adapted flexibly to fit with the person's responses (Box 5).

Box 5. SEMI-STRUCTURED INTERVIEW SCHEDULE FOR A TYPICAL PATIENT INTERVIEW
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- | |
|---|
| <ol style="list-style-type: none">a. [Explain purpose of study and gain consent for interview.]b. Do you know anything about the electronic [computer] records?c. Did you get a letter about the SCR [explain if necessary]?d. Would you want a SCR? Why / why not?e. What would you see as the benefits of the SCR?f. What would you see as the disadvantages of the SCR?g. Any other concerns?h. Have you heard of HealthSpace? [explain if necessary]i. Would you want an advanced HS account to see your medical record? Why / why not? |
|---|

- 9.1.8. We measured health literacy (see footnote page 72) pragmatically using the following classification:

- High: articulate, finds the invitation and background information sheet easy to read and understand, rapidly grasps explanations about the SCR, makes comments or asks questions that suggest good understanding;
- Medium: able to read the information sheet without problems, appears to grasp explanations about the study and the SCR;
- Low: appears unable to read or understand the standard information sheet or to grasp basic issues about the SCR despite repeated explanations; researcher judges that the 'special' information sheet and consent form should be offered.

- 9.1.9. A total of 7 focus groups were held to explore the perspective of people with potentially stigmatising conditions and/or difficulty accessing healthcare (or people who represented such groups). The groups comprised:

- a. *Advocates of vulnerable groups.* This group was initially convened as a requirement of the Research Ethics Committee to identify key issues around vulnerable groups before such groups were approached directly. We approached public and voluntary sector organisations, and participants represented NHS patient involvement groups (two people); local council (with responsibility for homeless and refugees); gay and lesbian; people with learning difficulties; mental health; HIV / AIDS (two people); an advice centre for young people; and a charity supporting victims of domestic violence. Representatives from elderly and minority ethnic organisations were invited and showed interest, but were unable to attend because of logistical problems on the day.
- b. *Advocates of limited English speakers.* This group was convened from people interested in supporting others in their community who sought to access health care and other services. All but one were first-generation immigrants who had not learnt English before arriving in the UK. The group comprised two lay people, two Expert Patient Group facilitators, three lay interpreters (who, for example, interpreted regularly for their own family members in healthcare consultations), and three professional bilingual health advocates. They represented 7 different ethnic groups and 6 countries of origin in South Asia, Africa, and Eastern Europe. They had lived in the UK for between 4 and 30 years.

- c. *HIV positive*. This group was held in a voluntary sector support centre for those living with HIV. The centre had a large social space, a kitchen, and a playroom for children. Volunteers gave general support and advice on benefits and accessing care. Participants comprised five white men (three of whom volunteered that they were gay), five African women (two with babies), and one African man. One person was a health professional who had contracted HIV via occupational contact.
- d. *Mental health service users*. This group was convened in association with MIND and held at the local MIND offices. All participants were mental health service users; several also had a relative with a mental health condition. We did not ask what mental health problem participants suffered from but conditions volunteered included bipolar disorder, depression, “feeling suicidal”, “being sectioned”, “needing counseling”, “finding things scary”, “finding it extremely difficult to communicate with people”, “not always being rational” and “personality problem”.
- e. *Older people*. This group was convened via a lunch club for older people in a suburban area. Participants were regular attenders of the lunch club which meets once per week, as well as arranging holidays and day trips. The focus group was run prior to the regular meeting, in its usual venue, a sports and recreation club.
- f. *Young people*. This group was held at the Brook Advisory Centre, a voluntary sector sexual health advice organisation. Participants were recruited via the Brook reception and support staff; they comprised both Brook clients and social contacts of the latter.
- g. *People on a drug recovery programme*. This group was convened in association with Turning Point, West Midlands and held at one of its centers in an inner city area. All participants were attenders of a structured recovery programme. The focus group was run during a session reserved for outside speakers on the programme, and it was made clear in advance that the session would involve voluntary participation in research. No questions were asked regarding the participants’ background or patterns of drug use. However, some participants volunteered information that indicated intravenous drug use.

Table 7. DEMOGRAPHIC CHARACTERISTICS OF SAMPLE FOR FOCUS GROUPS

	Advocates of vulnerable groups	Advocates of limited English speakers	HIV positive	Mental health service users	Older people	Young people	People on drug recovery programme	Total
Age range (ages estimated where not stated)	30-55	30-60	25-50	18-60	69-84	17-21	27-45	17-84
Gender								
Male	3	0	6	2	5	4	6	26
Female	7	10	5	5	7	4	3	41
Ethnicity								
White	10	1	5	7	12	4	7	46
South Asian	0	7	0	0	0	0	1	8
African	0	2	6	0	0	0	0	8
Mixed-race	0	0	0	0	0	4	1	5
Occupation								
Professional / senior manager	10	0	1	0	0	0	0	11
'White collar' e.g. clerk	0	8	1	0	0	0	0	9
Manual	0	0	0	0	0	0	0	0
Unemployed	0	0	4	0	0	0	0	4
Housewife	0	2	3	0	0	0	0	5
Student	0	0	0	1	0	0	0	5
Missing /did not want to say	0	0	2	6	12	8	9	33
Estimated health literacy								
High	10	8	3	2	4	0	0	28
Medium	0	2	4	3	8	8	4	29
Low	0	0	4	2	0	0	5	11
Total	10	10	11	7	12	8	9	67

9.1.10. Focus groups were held at community venues with which participants were already familiar. The topic guide used in the focus groups is shown in Box 6 below. This list was adapted flexibly in each group in response to emerging themes.

Box 6. TOPIC GUIDE FOR A TYPICAL FOCUS GROUP

1. Explain purpose of study and gain verbal consent and commitment to confidentiality on tape from all participants.
2. Ask if anyone knows about electronic records and if they'd like to tell the others about them.
3. Follow up on any interesting stories raised spontaneously about electronic records (e.g. "what do others think about that story?" "has anyone had a different experience?").
4. Ask if anyone has been approached about the Summary Care Record, or if they know what it is.
5. Follow up on any stories raised by participants about the SCR. Specifically invite comment on any views (e.g. "do others agree with that? Does anyone have a different view?")
6. Ask about other experiences with large-scale IT systems e.g. "Does anyone do their shopping on the Internet or use Internet banking? What do you think of those services? Why do you (or don't you) trust them? What do you think about their security level? If you don't think about that, why not – what makes you trust them?"
7. Introduce vignette style prompt e.g. "Let me tell you about Fred. Fred is HIV positive and he also has diabetes. He goes to the hospital for some of his diabetes care but he also sees his GP. He quite likes the idea of the Summary Care Record for his diabetes care but he has concerns about his HIV status being seen by people who don't really need to know that information. What do you think is going through Fred's mind when he gets the letter about the Summary Care Record? What do you think he'll decide to do and why? Fred gets told that there is a 'virtual sealed envelope' for private information, and that he can ask to have his HIV status put in that part of the electronic record if he wants. What do you think Fred would think of the virtual sealed envelope?"
8. Ask what sort of person would NOT want to have their medical record stored electronically in the form of a Summary Care Record? What would that person's reservations be? What might change their mind?
9. Ask about HealthSpace and discuss whether people are interested in an online health organiser/record, and if so, what sort of person would use it and what for.
10. If technical facilities available, show training DVD of Summary Care Record and ask what people think of it.

9.1.11. We did a 'mystery shopper' survey of the advice given by the NHS Information Line. We made 12 targeted telephone calls to this line, using questions derived from a wider set of concerns and issues based on our emerging data (i.e. we asked questions that we knew service users wanted to know the answer to). In general, we gave our real names and said we were calling on behalf of a friend in Bolton or Bury in order to advise them. Sometimes we asked to remain anonymous. Some calls were intentionally made by researchers with strong foreign accents. The questions we asked are given in Box 7. We made detailed field notes on all the calls, writing most of the responses down verbatim, and analysed the data qualitatively.

Box 7. QUESTIONS ASKED IN MYSTERY SHOPPER CALLS TO NHS INFORMATION LINE

1. What is the opening time of the local PALS office?
2. Can my elderly relative put a living will on her Summary Care Record?
3. In relation to someone with mild learning difficulties and epilepsy, can the epilepsy be withheld from his SCR as he doesn't want his employer to know about it?
4. Will the DVLA have access to the Summary Care Record (could I lose my licence if they find out about my medical condition)?
5. Will an HIV test done at a STI clinic go on the Summary Care Record?
6. Will my mother find out (via her friends who work in the NHS) about a termination of pregnancy done while I was at college in Bolton?
7. How can my limited English speaking parents get information in Arabic?
8. I am an asylum seeker with three children. Could my ex-husband possibly access my family's details and find out where we are living via his friends who work in the NHS? I'm worried that my ex-husband plans to kidnap the children and take them out the country.
9. I have changed my mind about having a Summary Care Record and now want it deleted.
10. How can my housebound disabled relative register for HealthSpace?
11. How can I register for HealthSpace outside office hours as I work 9-5?
12. If my GP refuses to take part in the Summary Care Record upload can I override his decision and have my record uploaded anyway?

9.2. Detailed findings from patient survey

9.2.1. Table 8 summarises the findings from our patient survey in relation to awareness of the SCR and HealthSpace and the decision about whether to participate in these (see paragraph 9.1.6. for sampling frame and 9.1.7. for questions asked).

Table 8. AWARENESS OF, AND DECISIONS ABOUT, THE SCR AND HEALTHSPACE IN 103 PATIENTS AND CARERS				
	Estimated health literacy			Total
	Low (n = 38)	Medium (n = 45)	High (n = 20)	
Awareness of the SCR				
Received letter from GP and/or PCT	4	5	5	14
Saw leaflet in GP surgery	0	3	0	3
Aware via mass media (newspaper, radio)	3	1	2	6
Other (e.g. health professional)	1*	1	1	3
Did not state how became aware	0	2	1	3
TOTAL number aware of SCR	9 of 38	12 of 45	9 of 20	30 of 103
Of those (n = 30) who said they had received the letter or were otherwise aware of the SCR				
Took no action as happy to have a SCR	7	7	7	21
Did not want a SCR so actively opted out	0	1	0	1
Still considering whether to have a SCR	0	1	2	3
Put letter or leaflet aside to think about later	1	1	0	2
Binned letter as junk	1	2	0	3
Decision about the SCR				
Yes would like one	18	31	15	64
Not sure / haven't made mind up	2	3	3	8
Don't care / not bothered	8	0	0	8
No don't want one	5	3	0	8
Changed mind during interview**	2	0	0	2
Missing data	4	8	2	14
Awareness of HealthSpace				
Had previously heard of HealthSpace	0	6	2	8
Had not previously heard of HealthSpace	34	35	15	83
Missing data	4	3	3	10
Decision about HealthSpace				
Yes would like a HealthSpace account	3	11	9	23
Not sure / haven't made mind up	1	5	4	10
No, definitely don't want one	31	25	6	62
Changed mind during interview**	1	0	0	1
Missing data	2	4	1	7
Gender				
Male	11	20	11	45
Female	24	25	9	58
Age				
Median (range)	40 (16-75)	29 (16-78)	35 (24-70)	35 (16-78)

9.2.2. Table 9 summarises the perceived benefits of the SCR found in our patient survey (see paragraph 9.1.6. for sampling frame and 9.1.7. for questions asked).

Table 9. BENEFITS OF SCR PERCEIVED BY SERVICE USERS	
INDIVIDUAL INTERVIEWS (n = 103)	
SCR is a "good thing" (unspecified, or "the more information the better")	14
Having medical details safely and consistently in one place, especially in emergency situations or chronic / complex illness	13
Makes care easier / more efficient / saves time / helps you fill out other forms	13
Not having to answer questions, fill out forms, or remember what medication you are on	10
Stops people giving you the wrong medication, or medication that you are allergic to	8
Medical record available when not near own GP / can move house without changing GP*	6
Could prevent a recurrence of a previous bad experience (lost medical record, duplicate blood test, bad allergic reaction, collapse)	6
Can print off for own records or to take to another healthcare professional	3
Provides evidence about a problem that patient knows they have but which health professionals may doubt	2
Stops people lying	1
Useful for deaf people	1
There are no benefits	3
Can't think of any benefits	13
ADDITIONAL THEMES RAISED IN FOCUS GROUPS	
<ul style="list-style-type: none"> • The SCR could be printed out and taken to another clinician for a second opinion. • New immigrants may change GP frequently and often have particular problems articulating key aspects of their medical record (some of which may be traumatic). The SCR will help continuity of care in this group. • Potential research uses of aggregated data from SCR. • If someone has a SCR a GP would not be able to refuse treatment pending arrival of records. • Useful for elderly people who may be forgetful but on lots of different tablets. • "To put my side of the story". 	

* two people independently described the SCR as a "fantastic" idea because (in their view) it allowed them to remain registered with a GP in a different part of the country after moving house

9.2.3. Table 10 summarises the perceived disbenefits of the SCR found in our patient survey (see paragraph 9.1.6. for sampling frame and 9.1.7. for questions asked).

Table 10. DISBENEFITS OF SCR PERCEIVED BY SERVICE USERS	
INDIVIDUAL INTERVIEWS (n = 103)	
Malicious or inappropriate access (total number mentioning this)	18
Hackers/fraudsters	6
Benefits Agency	4
Employers / insurance companies / credit control agencies	3
Local NHS colleagues (unauthorised access to records of NHS staff)	3
Parents (in relation to pregnancy test or termination of pregnancy)	2
"The general public"	2
Receptionists	1
"Foreigners"	1
Security breaches	
Technical error (includes power cuts, system breakdown)	14
Human error or not enough people to run the system	3
SCR a "bad thing" (unspecified or all computers are bad)	8
Stigma / labelling (e.g. depression, counselling, sexual infections, child with ADHD)	6
Waste of money	3
People won't understand their choices / too complicated	3
NHS would need to provide more computers e.g. in operating theatres	2
Mistaken identity (e.g. similar name)	1
If inaccurate, could cause more harm than good	1
There are no disadvantages	3
Can't think of any disadvantages	3
ADDITIONAL THEMES RAISED IN FOCUS GROUPS	
<ul style="list-style-type: none"> • Allows GPs to turn away expensive-to-treat patients who seek to register with them. • Government would sell data to private companies. • Staff "incompetence" is likely to exacerbate problems if the SCR is introduced, since more can go wrong. • An accurate and complete SCR is dependent on data quality standards & practices. • People with sexually transmitted infections may be open to blackmail as information indicating an affair could be passed to a spouse. • Discriminates against those who have chosen not to register with a GP. • Family members may find out about drug addiction. 	

9.2.3. Table 10 summarises the attitudes of service users to HealthSpace (see paragraph 9.1.6. for sampling frame and 9.1.7. for questions asked).

Table 11. ATTITUDES OF SERVICE USERS TO HEALTHSPACE	
INDIVIDUAL INTERVIEWS (n = 103)	
Would not want any kind of HealthSpace account (total)	62
Not interested, wouldn't want to see own record	44
Worried about security	9
Prefer to discuss my health with my GP or other practice staff	8
Don't use the Internet for anything / haven't got a computer / "I'm old fashioned"	7
Pointless, wouldn't tell me anything I don't already know	6
Registration process too much hassle	4
Worried about a family member or partner seeing	3
A printout of my GP record would give all the information needed	3
"No time to mess around"	1
Yes, would like some sort of HealthSpace account (total)	23
Sounds like a good idea / sign of progress in the NHS	5
Would like HS to keep track of child or elderly parent's illnesses	5
Would like to see HS once, just to have a look at what is there	4
Have a lot of health problems myself, would like to keep track of them	4
Enjoy using computers / interested in playing with the technology	2
See my [child's] X-rays	1
Undecided (total)	10
Haven't thought about it, but haven't ruled it out	6
Might want it but it's not a priority	4
Ambivalent (because of security worries)	2
Unable to understand explanation of what HS is	2
ADDITIONAL THEMES RAISED IN FOCUS GROUPS	
<ul style="list-style-type: none"> • Creates a route for hackers to access the SCR. • Not fit for purpose – could just as easily write personal health data down in a book or keep a file on a personal computer. • A person's medical record could be accessed by a partner without their full consent if in a coercive domestic relationship. • Registration process is complex and requires very high IT literacy; this will discriminate against people with low literacy and those who are dyslexic. • Registration process requires a consistent date of birth, consistently spelt surname, and three pieces of identification e.g. utility bill, driving licence; refugees and asylum seekers may not have these documents and may use different spellings of their surname. 	

9.2.4. Findings from our 'mystery shopper' survey of the NHS Information Line, undertaken in Nov-Dec 2007, which were fed back to CFH for immediate action, are shown in Table 12 (see paragraph 9.1.11. for details of questions asked).

Table 12. FINDINGS AND RECOMMENDATIONS FROM MYSTERY SHOPPER SURVEY	
Finding	Recommendation
Callers were routinely asked name, date of birth, full address, and ethnicity. We suspected that this approach (presumably undertaken with a view to producing usage statistics) breached the Data Protection Act. ^{II}	We suggested that a review of the number and intrusiveness of personal questions asked of callers to the Information Line was urgently undertaken.
All calls were answered promptly and dealt with politely and efficiently. However, replies were bland and homogeneous, and not adapted to an estimated ability of the caller to understand.	We acknowledged the trade-off between consistency of replies and adaptation to estimated caller needs. We suggested that Information Line staff may benefit from training in how to assess understanding and/or health literacy of the caller and 'customise' response.
In this small and atypical sample, callers with foreign accents were more likely to be asked their ethnicity, to be pressed for personal information even when reluctant to give it, and to be asked to complete a satisfaction survey. In a single example, there was lack of awareness of the high personal risk that some immigrants face in relation to security of personal data.	We suggested that Information Line staff may have unmet training needs in cultural awareness and the handling of calls from vulnerable immigrants.
Information Line staff appeared to equate the security of the system with its <i>technical</i> security, and not to take seriously the risks of <i>operational</i> security or possibility of human error or malice.	We recommended that training should be given in the operational aspects of security. NHS staff may forget their smart cards and/or let others use them; they are very occasionally put under pressure (or given corrupt incentives) to access records illegally. The risk of a security breach is real, though small, but in situations where even a small risk is unacceptable, callers should be warned accordingly.
The advice given on role based access controls aligned well with what technical developers have assumed and what information governance advisers would recommend, but it was somewhat at odds with actual plans for accessing the SCR in unscheduled care settings, in which (for example) an extended healthcare assistant role is being developed.	We recommended that training on who will access the SCR should take account of the reality of NHS work rather than reproducing the 'clean' world of the designers. We suggested that a form of words should be developed that conveys a sense of general professionalism in the use of the SCR without offering false reassurance.
NHS Information Line staff were helpful in answering questions about local services but inevitably they found this 'bespoke' information somewhat difficult to access. Staff in other local agencies (e.g. PALS) were friendly and sympathetic but (in this small preliminary survey) were unable to provide the relevant information.	We questioned whether it was an efficient use of Information Line staff time to pursue questions about local operational issues, and suggested that in the future, callers might be directed more promptly to local information sources. However, local agencies did not seem able (at this early stage) to address <i>general</i> questions about the SCR and HealthSpace.
Only two of 12 callers in this survey were asked to complete the satisfaction survey.	We suggested a review of the sampling procedure by which callers are selected to complete the satisfaction survey to confirm no systematic bias.

^{II} Anyone who processes personal information must comply with eight principles, which include that the information should be processed for limited purposes; relevant and not excessive; and not kept for longer than necessary.

9.3. Examples of forms, letters, and posters

9.3.1. The NHS Care Records Service Confidentiality Leaflet states:

“Anyone who has access to your clinical care records:

- must be involved in your care;*
- must have an NHS smartcard, with a chip and a passcode;*
- will only see information appropriate to the job they are doing (for example, a receptionist will only see the relevant information needed to process your appointment, and will not need to see your full clinical records); and*
- will automatically have **their** details recorded - who they are and what they did (you can ask to see this).”*

9.3.2. Example of a patient information leaflet (developed when stage 2 information began to be added to SCRs):

HealthSpace

You are now able to see your Summary Care Record using a secure website called HealthSpace. This will allow you to check the accuracy of the information being held about you, which could be especially useful if you are managing a long term illness or chronic disease. You will need to register for access to HealthSpace first. A leaflet on how to do this is available from your GP practice, or you can visit www.bolton.nhs.uk/healthspace to find out more.

Can I change my mind at any time?

Yes. Tell your GP or a member of the practice team if you change your mind about having a Summary Care Record or about sharing the information it contains.

What happens next?

If you are happy for this information to be added to your Summary Care Record now, and for the types of information described in this leaflet to be added in the future, please sign a consent form (available in the practice) and give it to a member of staff. **You do not need to see your doctor for this.**

If you would like to see an example of the type of information that would be added to your Summary Care Record before making your decision please ask a member of staff.

For more information about Summary Care Records visit www.bolton.nhs.uk/carerecords or call the NHS Care Records Service Information Line on 0845 603 8510.

You may also contact the PCT's Patient Advice and Liaison Service on 01204 462700 during office hours or by e-mailing PALS@bolton.nhs.uk

Bolton NHS Primary Care Trust

Developing Your Summary Care Record

A Guide for Patients

Figure 3a: Patient information leaflet (Bolton)



What is my Summary Care Record?

Your Summary Care Record is an electronic record of important information about your health. It will be available to NHS staff providing you with healthcare, first locally here in Bolton and later anywhere in England.

This means that if you have an accident or fall ill the people treating you will have immediate access to important information about you, helping them to provide you with safer, better care. A letter was sent to you earlier this year telling you about this.

How will it be developed?

At the moment your Summary Care Record only contains details of allergies, current prescriptions and previous bad reactions to medicines. We would now like to offer you the opportunity to have more information about your health added to your Summary Care Record, and we need your agreement to do this.

You may request an example of the sort of information that would help improve your care by asking a member of staff.

What type of information can be added?

To start with, important information will be added such as:

- Significant illnesses and health problems from the past, such as a heart attack
- Illnesses that you take regular medication for, such as asthma, diabetes or multiple sclerosis

Further types of information that may be added later are:

- Important test results
- Immunisations

How will this benefit me?

- Information you might have given your GP about how you want to be treated in an emergency, such as not wanting a blood transfusion
- Items of information that emergency clinicians need to know to protect your health and safety, such as the name and contact details of a Community Nurse who is involved in your care

Hospitals are not currently able to add information to your Summary Care Record. In the future, though, they will be able to add information such as:

- Outpatient treatment you may have received
- Discharge information about episodes of inpatient hospital care


Hospitals will let you know when they start to add information to the Summary Care Record.

There might be additional information that you would like included in your Summary Care Record and you will be able to ask your GP to add such information.

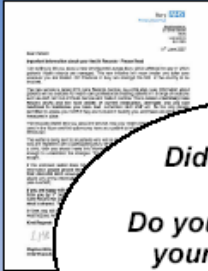
If there is any information that you do NOT want to be included in your Summary Care Record you must let your GP know.

Figure 3b: Patient information leaflet (Bolton)

9.3.3. Example of a poster used in the public information programme:

Bury 
Primary Care Trust


NHS Summary Care Record Roadshow



*Did you get your letter?
Do you wish to record your preferences?
Do you wish to find out further information?*

Bury is the 2nd PCT in the country to enable patient information to be shared electronically between health professionals in different health organisations.

As part of the public consultation process for this pilot scheme, all Patients are invited to attend our roadshow, the dates and times of which are shown opposite; where you can register your consent/dissent and speak to our helpful staff in order to find out further information.



Date: Monday 23 July 2007

**Times: 12.00 - 2.30pm
5.00 - 7.30pm**

Place: Car park, behind Co-op, Market Street, Tottington.




Figure 4: Poster used in public information programme (Bury)

9.3.4. Example of a letter used in the public information programme:

Bury 
Primary Care Trust

Headquarters:
21 Silver Street
Bury
Lancashire
BL9 0EN

11th June 2007

Dear Patient

Important Information about your Health Records - Please Read

I am writing to tell you about a new development across Bury, which affects the way in which patients' health records are managed. This new initiative will mean better and safer care wherever you are treated. GP Practices in Bury are amongst the first in the country to be involved.

The new service is called NHS Care Records Service. As a first step, key information about patients will be available for health care professionals treating patients in a range of locations such as A&E, GP Out of Hours Service and Walk-in Centres This is called a **Summary Care Record (SCR) and will hold details of current medication, allergies and any bad reactions to medicines you have had.** Authorised NHS staff will be the only people permitted to access your SCR if they are involved in treating you, and there are strict security measures in place.

The enclosed leaflet tells you about the service; how your health information would be stored, used in the future and the options you have as a patient to influence this before and after it is introduced.

This leaflet is being sent to all patients who will be aged 16 and over by 1st October 2007 and who are registered with a participating Bury GP Practice. If you are the parent or guardian of a child, then you should make this information available to them if you feel they are old enough to understand the changes. The leaflet also sets out where more advice can be sought.

If the enclosed leaflet does not answer all of your questions or you would like more information **please phone the dedicated NHS Care Records Service Information Line first: 0845 603 8510.** However, if you would like to discuss your options face-to-face you can attend any of the information centres or road shows which are being held in the Bury area (see overleaf).

If you are happy with these changes there is no need to do anything. If we do not hear from you by 1st October 2007, your GP surgery will automatically create a Summary Care Record for you. You can choose not to have a Summary Care Record, or to limit what is shared. You can change your mind at any time.

In time, you will be able to access your Summary Care Record via a secure website called HealthSpace. An enclosed leaflet tells you more about the service and how you can register.

Kind Regards



**Stephen Mills,
Chief Executive Bury PCT**

Figure 5a: Patient letter (Bury)

Where can you get more information?

Contact us by phone

NHS Care Records Service Information Line: 0845 603 8510.

Information Centres

- **114 The Rock, Bury Town Centre**

Weekdays Monday 11th June – Friday 6th July, 9am – 5pm

Saturdays 10am – 2pm

Weekdays from Monday 9th July – Friday 28th September. Two drop in centres per week.

Watch out for dates and times in the Bury Times Newspaper

HealthSpace registration available on the above dates and times.

- **The Elms, Unit 2, Elms Shopping Centre**

Weekdays from Monday 11th June to Friday 28th September, 9am – 5pm

No Saturday opening

HealthSpace registration available throughout

After the 28th September all Health Space registration will be taken at The Elms.

Road shows coming near you...

Venue	Dates	Times
Kay Gardens, Bury Town Centre	Saturday 7 th July 2007	11am till 2.30pm
ASDA Superstore, Radcliffe	Monday 9 th July 2007	12pm till 2.30pm 5pm till 7.30pm
Opposite Prestwich Walk in Centre, Fairfax Road, Prestwich	Monday 16 th July 2007	12pm till 2.30pm 5pm till 7.30pm
CO-OP, Tottington	Monday 23 rd July 2007	12pm till 2.30pm 5pm till 7.30pm
Somerfield, Ramsbottom	Monday 30 th July 2007	12pm till 2.30pm 5pm till 7.30pm
ASDA Superstore, Bury	Monday 6 th August 2007	12pm till 2.30pm 5pm till 7.30pm

Please note: Health Space registration will not be available at the road shows.

Online

Further information about the Summary Care Record can be found at www.nhscarerecords.nhs.uk or more about NHS Connecting for Health projects at www.connectingforhealth.nhs.uk

Figure 5b: Patient letter (Bury)

9.3.5. Example of a poster about HealthSpace:

Bury **NHS**
Primary Care Trust

HealthSpace – find out how you can see your Summary Care Record at

www.healthspace.nhs.uk

HealthSpace

Further information is available from:
Bury PCT
Patient Advice and Liaison Service
Elms Square Unit 2, Bury New Road, Whitefield, M45 7TA

Monday to Friday 9am to 5pm
Tel: 0800 328 3166

Figure 6: HealthSpace poster (Bury)

9.3.6. The opt-out consent form (known as '93C3):



Request for all clinical data to be withheld from the Summary Care Record.

Part A: to be completed by the individual (data subject) making the request.
Please complete in BLOCK CAPITALS

Title _____ Surname/family name _____

Forename(s) _____

Address _____

Postcode _____ Tel no _____ Date of birth _____

New NHS No (If known) _____

UNDER SECTION 10 OF THE DATA PROTECTION ACT I REQUEST THAT MY PERSONAL DATA ARE NOT ADDED TO THE NEW NHS SUMMARY CARE RECORD SERVICE DATABASE. I understand the consequences of taking this action and have carefully considered the implications of this for my health care. I understand that I may change my mind at a future date and can have a summary record created for me if I do. I have been offered the opportunity to discuss this with my GP.

Signature _____ Date _____

Part B: Confirmation of consent (to be completed by a health professional or suitably trained person on behalf of the GP Practice where the individual identified above is registered)

I have discussed with the patient the implications of the above action. I have confirmed that he/she has no further questions and wishes the above action to go ahead.*

The patient does not wish to discuss the implications of the above action. I have given him/her a written explanation of the implications.*

* Delete as appropriate

Signature _____ Date _____

Name _____

Job Title _____

Actioned by practice: _____	Date: _____
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Please return this form to the GP Practice where you are registered. If you register with a different Practice prior to the new Practice having gone through the process of creating Summary Care Records you will need to complete a new form for the new Practice.

Figure 7: Opt-out consent form

9.3.7. Example of 'mouse mat' giving main choice options for the SCR:

NHS Care Records
Your Choice
What do I need to do if...

South Birmingham **NHS**
Primary Care Trust

I want a Summary Care Record.

What will I need to do next?

Do nothing.
In 16 Weeks your record will be created for you.

I want a Summary Care Record but **do not** want it to be shared.

What will I need to do next?


[Access further information](#)
Call the local South Birmingham PCT Patient Advice and Liaison Service (PALS) on 0800 389 8391.

[If you do not wish to have a Summary Care Record](#)
Drop-in to meet our Summary Care Record Adviser at your practice and complete an opt out form.

I **do not** want a Summary Care Record.

What will I need to do next?

Further Information

 www.nhscarerecords.nhs.uk
www.southbirminghampct.nhs.uk/scr
info@sbpct.nhs.uk


 Text mobile: 07966 228 697
Minicom: 0121 449 8352
NHS Care Records Service Information Line on 0845 603 8510

Figure 8: 'Choices' mouse mat (South Birmingham)

9.4. Comparative examples from other programmes and countries

9.4.1. The Electronic Development and Implementation Programme (ERDIP).

- a. ERDIP was a two year project set up in the spring of 2000 under the auspices of the National Health Information Authority (NHSIA) in order to pilot different aspects of the development of EHRs in accordance with the DOH's information strategy for the NHS, Information for Health.¹⁹
- b. The programme consisted of 19 pilots, divided into two main workstreams; four 'pan community' projects, demonstrating the sharing of patient information across both health and social care communities, and 15 'focus group demonstrators', aimed at demonstrating specific areas or concepts of EHR functionality such as linking primary and acute care, support for National Service Frameworks, OOH care, telemedicine, standards, and coding and classification.
- c. An extensive programme of local and national evaluation and dissemination of the lessons learnt from each of the pilots was carried out alongside ERDIP. Local evaluations all conformed to the structured PROBE (Project Review and Objective Evaluation) methodology.⁶⁷ The five main themes used in the individual project evaluations were strategy, operational, human/organisational, financial and technical. The main purpose of the national evaluation was to [i] inform the definition and identification of EHR options, based on demonstrator experience and secondary literature review; [ii] ensure good practice in the use or development of electronic records is identified and disseminated for the benefit of the NHS; and [iii] demonstrate value for money from the Demonstrator Programme.
- d. The final report examined 21 pre-defined hypotheses about aspects of the EHR and its implementation.⁶⁸ Conclusions were reached according to the verification or non-verification of the prior hypotheses, based on evaluation reports submitted by the project teams together with responses and comments from a structured interview questionnaire. In addition to the final report and summary of findings, a separate report and academic publications on consent and confidentiality were also produced.^{76;77}
- e. Four findings from ERDIP have implications for the SCR evaluation. First is the overall picture of "success" of the various pilots (*"integrated electronic records that ERDIP sites have developed can be used as the means of promoting joined up care"* – official ERDIP evaluation report⁶⁸) despite the fact that many questions were left unresolved and one or two projects were aborted early. The general feeling of "success" appears to have been generated not by the fact that shared electronic records were actually up and running by the end of the project period (only three sites – Bradford, Walsall and the Wirral – were live by the end of 2003 and the projects had not run for long enough to demonstrate material benefits) but that it was widely perceived that key lessons had been learnt and much essential work had been done to prepare the ground for a 'definitive' electronic record programme. Many pilot sites (including, significantly, Dorset and Isle of Wight) felt they had only just got going when the funding period ended, and fought (usually unsuccessfully) for further funding to continue the work they had begun.
- f. Secondly, the ERDIP evaluation concluded that success is more likely when the users, purpose and scope of the EHR have been clearly defined. One of the report's most forceful conclusions was that *"Clarity of definition of users, purpose, scope and performance is crucial in order to engage the stakeholders and ensure agreement across different care groups before commencing development."*⁷⁶

- g. Thirdly, the ERDIP pilots showed that the EHR is more likely to be used when people trust its content. This is likely to occur only when [i] all source data are complete, accurate and timely (in practice this means updated with new/amended information at least daily), and [ii] the provenance of the data must be evident.
- h. The fourth key finding from ERDIP in relation to the SCR programme is the specific study on consent and confidentiality. Whilst much of the detail of these projects is now obsolete, the conclusion – that ‘opt-in’ is preferable ethico-legally but hard to achieve in practice – is still highly relevant. *“The ‘implied consent’ sites (e.g. South Staffordshire) have found it harder to gain the necessary ‘buy in’ from GPs to get started, both because of their larger ambitions, and also because of the greater uncertainty surrounding this approach (almost everyone is happy with express consent in principle – the practice is rather harder.”*⁷⁶ (p 12) The recommendations for policy from the ERDIP consent and confidentiality pilot are shown in Box 8.

Box 8.	LESSONS FROM THE ERDIP CONSENT AND CONFIDENTIALITY PILOT
<p>Before the introduction of shared electronic records, run an information campaign to increase transparency and patient involvement</p> <p>Seek opt-out mechanisms to provide choice</p> <p>Identify data flows where no opt-out is possible or desirable at present</p> <p>Work to ‘implied consent’ for direct healthcare, supported by ‘consent at point of access’</p> <p>Use (where practicable) anonymisation for all other uses</p>	

9.4.2. The Emergency Care Summary (ECS) in Scotland:

- a. The ECS is created from the patient’s GP record and consists of key demographic information, including any telephone numbers which are stored on the practice system, plus medication and adverse reactions to medications. It is stored centrally and updated twice a day. An ECS is created for all patients permanently registered with a GP (i.e. those who have a Scottish Community Health Index number, the equivalent of the NHS number).
- b. A pilot of the ECS started in two Health Board areas in 2004 and national rollout was completed in September 2006. The workload for GPs associated with the creation of the ECS was described as *“negligible”*. At the time of writing, 97% of Scotland’s 1030 GP practices are participating and 5.1 million records have been created (for a population of 5.5 million).
- c. The ECS is fully integrated into the emergency call centres (NHS24, the Scottish equivalent of NHS Direct), and OOH clinics (where it is fully integrated with the Adastra system and takes up to five seconds to call up). ECS is also used as a standalone system in A&E departments. There is national access control across all 14 Health Boards in Scotland via the local system administration. Over one million instances of ECS access with full patient consent have been logged to date. Users perceive the greatest benefit to be associated with situations such as *“confused elderly people on a lot of medication”*.
- d. Access to the ECS is limited to those with a legitimate clinical relationship to the patient. Administrators, receptionists and call handlers only have access to the demographic data on ECS, if appropriate to do so.
- e. The consent model in Scotland is based on implied consent to create the record plus explicit consent to view at every encounter. A total of 1040 people (0.02% of the population) have actively opted out of having a ECS and approximately one

- in 25 patients opt to withhold consent for the clinician to view their record at the point of care. A patient may change their mind at any time (e.g. may opt out when had previously opted in, and vice versa; this is easily changed by a toggle button on the screen at the GP practice).
- f. Senior managers and clinicians on the ECS programme describe it as being “*clinically led and patient focused*”; the project had the backing of the BMA, RCGP and GMC from the outset. The key driver for the programme was the new GP contract for out-of-hours provision, which motivated all parties to improve information flow from GP records to the out-of-hours organisations, A&E departments, and NHS24. The emphasis from the outset was on emergency care and patient safety, especially in relation to medications and allergies.
 - g. The limited content of the ECS was agreed amongst stakeholders from the start, and did not change despite pressure from some parties to ‘enhance’ the record. Recently, a Palliative Care Summary (PCS) for terminally ill patients, also populated from the GP record and containing additional clinical data, has been developed and is about to be piloted in one health board during 2008. This PCS will only be created with explicit consent from the patient.
 - h. At an early stage in the programme, there was a patient consultation phase which was carried out independently by the Scottish Consumer Council. This included focus groups on ordinary patients, as well as ‘sensitive information’ with HIV positive and mental health service users. Whilst concerns were raised (about security, access, and consent), most people were happy with the proposal and there was widespread public support for the ECS from the outset. A leaflet was developed with the help of the Scottish Consumer council, and a copy was delivered to every household. The strict limitation of use to emergency care seemed to reassure (for example that “*the Saturday girl at the chemist*” would not have access to the ECS).
 - i. All accesses to the ECS are audited, and it must be recorded that the patient has consented. Accesses without consent trigger a local information governance alert. If the patient is unconscious or if it is considered to be in the patient’s best interest, the clinician is permitted to ‘break glass’ (i.e. look at the ECS without explicit consent). Both the clinical report and the access log is sent back to the patient’s GP, and the Health Board is also alerted. The patient can ask to see the audit trail of accesses by asking their practice.
 - j. Information is only added to the ECS by the person’s GP, who is seen as responsible for its content and accuracy. In order for an item of data to be added to the ECS, it must first be added to the GP record.
 - k. No special data quality measures were required of GP practices for participation in the ECS programme, though data quality improvement initiatives were occurring in parallel. GPs are encouraged but not required to ensure that medication prescribed outside the practice (e.g. in hospital) is added to the GP record, from which it will automatically be added to the ECS.
 - l. Whilst patient access to the ECS was actively encouraged (e.g. via leaflets suggesting that patients ask for a printout of the record and point out inaccuracies, thereby driving up data quality), interest from patients has been very low.
 - m. The relatively smooth roll-out of the ECS in Scotland and very low opt-out rate is attributed by senior staff to [i] patient and community support for the programme; [ii] clinical leadership and the support of all professional groups; [iii] a single clearly defined use case (emergency care) and simple, clear content (medication and allergies); [iv] relatively good data quality in most Scottish GP practices; [v] a single ‘originator’ of the information for the ECS (the GP) who took responsibility for creating and maintaining it; and [vi] lack of any defined or expected timescales, which allowed roll-out to follow the pace of clinical engagement and technological readiness.

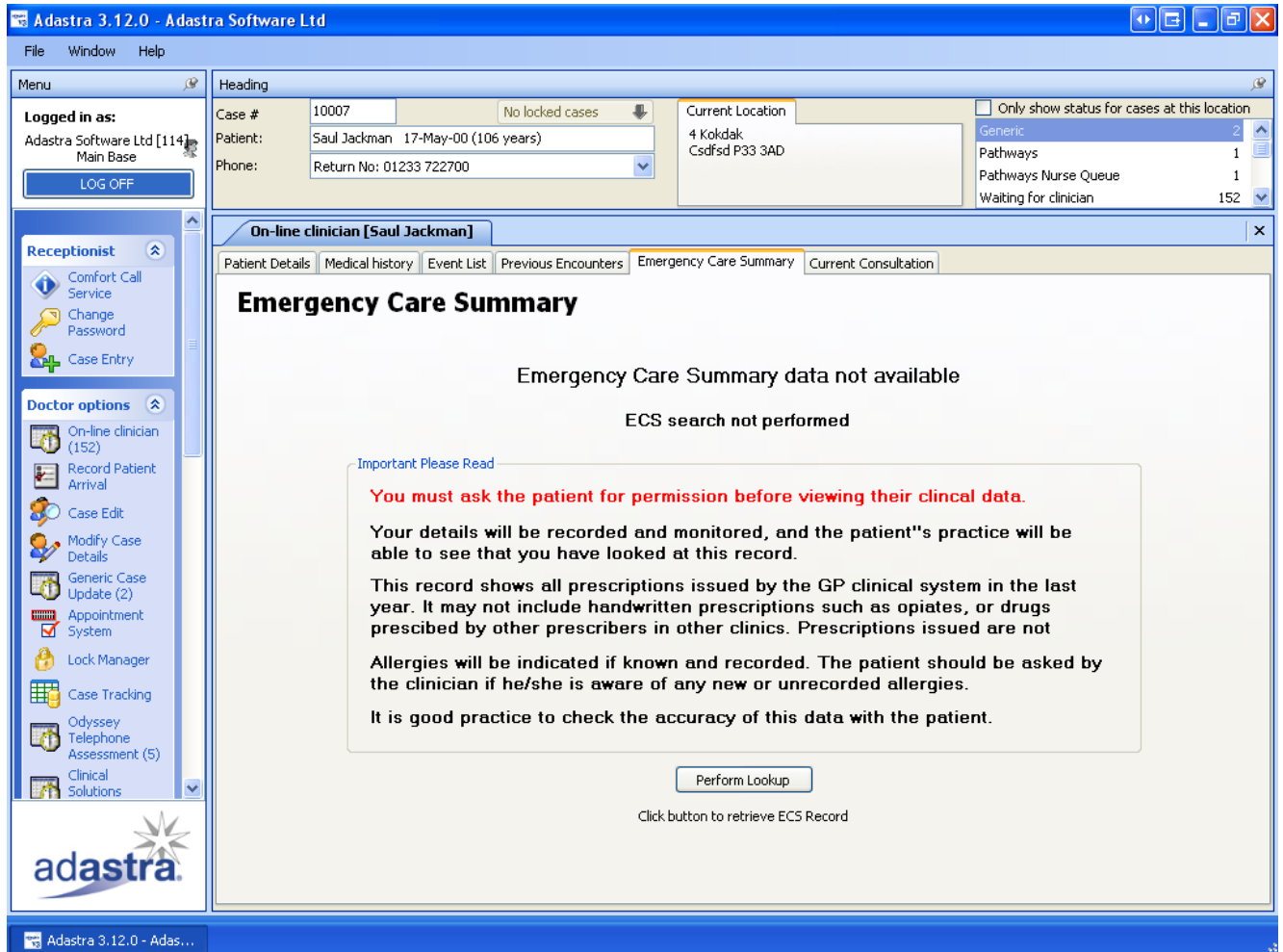


Figure 9: Screen shot of access page in Scottish Emergency Care Summary

9.4.3. The Individual Health Record (IHR) in Wales.

- a. The full name of the IHR is the 'Individual Health Record in Out-of-Hours care'. It is currently available in Gwent, and is being introduced incrementally across Wales. It is created from the GP held record, sections of which are sent to update a centrally held data store once daily. Records of people who have opted out of the system are not transferred, nor are 'sensitive codes' (such as sexually transmitted infections, abortion, or infertility) on any patient.
- b. The information visible to clinical staff (and to administrative staff whose work includes a clinical care element) include demographic details, summary of current and past diagnoses, dates of GP encounters, current and repeat medication, allergies, selected clinical data (e.g. blood pressure), and test results (e.g. ECG, blood tests). Some of the information transferred (for example, contraception, obstetric history, alcohol intake, religion) is currently blocked from view as this was not considered to be relevant to most urgent clinical encounters.
- c. A personal health record (My Health Online) has begun a pilot phase, in which patients can order repeat prescriptions and book appointments via an Internet based system. This uses the GP record and does not require a new separate

- record to be created. Access to the GP held record via My Health Online has begun in one or two practices but no data are yet available on this.
- d. The IHR began its first pilot in Gwent in 2006 and at the time of writing, 460,000 records had been uploaded (at an estimated cost of £200,000). People may opt out of having an IHR but only 90 people (0.02% of those mailed) have done so. As in Scotland, there is explicit consent to view at the point of access.
 - e. The programme is described by its architects as *“a change programme, not an IT programme”*, and is known as ‘Informing Health Care’ (IHC). IHC was conducted using a participatory, ‘bottom up’ approach in each region. The IHR sub-programme had a clear and simple aim – *“to make the important information on an individual from the GP record available in the OOH service”*, linked to an explicit business driver *“to improve the quality of the OOH service”*.
 - f. The Director of IHC describes a series of conferences and visits to agree *“what needed to be done”* (i.e. what service problems needed to be addressed, and who needed to join forces to address them). Common objectives were discovered – for example, there were already a number of service improvement initiatives around quality in the OOH service, and making the GP record available in OOH aligned closely with these existing business goals of other stakeholders. This consultation process resulted in *“the deconstruction of single record concept into a series of manageable steps”*, the first of which was tightly focused on OOH availability of records.
 - g. The principles guiding the introduction of the IHR in Gwent (and it is anticipated, elsewhere in Wales) were thus [i] early involvement of all stakeholders, including the public, and particularly local clinicians and the OOH service; [ii] locally based information governance development (e.g. the content of the record and access controls were set locally, not nationally); [iii] a focus on building trust (particularly by listening to, and responding to, the concerns of the public and professions) and maintaining it through dialogue; and [iv] ensuring that data remain under local control.
 - h. IHC has been built on ‘locally delivered’ solutions but uses a standard clinical content and technical solutions across Wales. The Welsh experience suggests that if the SCR programme were to move to a more locally-based and incremental model of development, significant changes to the information governance approach and security system would be required.

9.4.4. The Defence Medical Information Capability Programme (DMICP) in the UK Defence Medical Services.

- a. DMICP is described as *“an IT-enabled, business change programme for the Defence Medical Services”*.⁷⁸ It was introduced in 2006 with the goal of improving the coordination and integration of medical care for 250,000 service personnel (and their families when based overseas); maximising fitness for duty and appropriate deployment of personnel; improving the transfer and care of casualties; and supporting secondary uses of data (epidemiology, health surveillance, research). The main use of DMICP is UK-based primary health care but the extension to overseas operational theatres is expected to bring further significant benefits.
- b. DMICP uses an intranet-accessible detailed medical record that is held centrally and accessed remotely by primary health care, allied professions (e.g. physiotherapy), secondary care, and medical units on operations (including, where possible, temporary medical facilities in battle). It contains full GP and dental records (including scanned letters), a summary of secondary and tertiary care, and detailed data from events that occur on deployed operations.
- c. The core clinical application of DMICP is EMIS PCS, which includes decision support and interfaces with a separate Defence system for personnel

administration. The system was originally installed on existing networks to reduce infrastructure costs, but will increasingly be carried by the new Defence Information Infrastructure (DII), a high capacity broadband network equivalent to N3 in the NHS.

- d. The idea for DMICP was first developed in 2002 and was from the outset seen as a broad-based programme of change supported (but not driven) by major changes in ICT. Following a lengthy consultation phase with all key stakeholders, and with senior clinical input, the technology was first introduced in 2007. Early Operating Capability was achieved in late 2007. It is hoped that DMICP will be fully operational in all Defence fixed sites (including overseas) by early 2009 and in deployed sites by late 2009.
- e. The integrated health records of all patients stored in DMICP are located in a single database with only users who have legitimate access to those specific records being able to access a single version of the record. The advantage of the 'single version concept' is that the record is always up to date and physical transfer of electronic records (e.g. on a memory stick) when patients are 'posted' between fixed sites is unnecessary. It also allows greater control over, and documentation of, who accesses the record and for what purpose. The disadvantage is that loss of connection to the Data Centre prevents access to all health records and requires the activation of a Local Resilience Solution (LRS), which at present is simply the capture of data on paper and subsequent entry onto the electronic record.
- f. The consent model used is implied consent (both to create the record and for a clinician to view it). It is not possible for service personnel to opt out of having an electronic health record on DMICP, but they may restrict access to selected staff at their 'parent' medical centre.
- g. The 'legitimate relationship' concept is applied in DMICP in much the same way as it is in the SCR. Access by staff without a legitimate relationship, or by those 'self claiming' such a relationship, triggers an information governance alert which is passed to the relevant Caldicott Guardian and permanently archived.
- h. Interoperability with the NPfIT (e.g. with Choose and Book, GP2GP and the Care Record Service expected 2010) will allow referral and discharge letters to be exchanged, the NHS CRS to be updated with summary data from DMICP records, and GPs' detailed records of new recruits to be imported into DMICP using GP2GP. When someone retires from service in the Armed Forces, or a family returns to NHS care, their DMICP record can be exported back to their receiving new GP. For security reasons, data identifying the individual as military will be removed from all transfers to the NPfIT, other than point to point referrals.
- i. Staff involved with strategic development of DMICP pointed out that its introduction had not been without major challenges, but that its relative success to date had been due to [i] strong leadership and efficient operations management; [ii] clear benefits of the system in the eyes of potential adopters (e.g. records accessible anywhere across the Armed Forces; an immediate comprehensive view of treatment history more efficient transfer of casualties when on operations); [iii] a culture where once a strategic decision is approved and ratified, it is rarely challenged by the rank and file; and [iv] a long and well-resourced consultation phase with front-line users prior to the introduction of the system. The main lessons learnt from DMICP are shown in Box 8.

Box 9. LESSONS FROM THE UK DEFENCE MEDICAL INFORMATION CAPACITY PROGRAMME

LESSONS ABOUT MANAGING CHANGE

Change is inevitable and essential – so be honest about it.

Wide consultation is essential but it is impossible, and probably unwise, to speak to every potential user. So at least speak to several representatives at every level and early on. This helps to achieve buy-in and wide ownership of the solution.

By involving future users, one has the best chance of getting the solution as right as possible first time.

Regular briefs gradually build up knowledge amongst the future user community – but don't try to pass on too much information too soon. As soon as possible, use members of the user community to cascade briefs 'down the line': this engenders confidence far better than only receiving briefs from apparently remote senior management.

Start business change work as soon as the outline business case is agreed, and then refine it as solutions appear. This is a business change programme after all. This should avoid the pitfall of the IT driving the business, which is so often a recipe for disaster and non-acceptance of the end product.

Emphasise benefits and when doing so focus them on the user level that is being addressed. People want to know "what's in it for me?" This helps to gain their support and enthusiasm.

LESSONS ABOUT PRACTICALITIES OF IMPLEMENTATION

Role based access controls are essential; they must be widely understood and facilitated by developing and disseminating the concept of Legitimate Relationships, together with the robust governance structure required to support this.

Clarification is needed (e.g. from legal advisers and the GMC) over how and when consents may be required from patients to import their clinical data into DMICP and how we may then subsequently process and share such data.

Locum access is a particular challenge and a 'slick' process will be required to enable locums to safely use the system at short notice. Issues need to be resolved around suitable access controls and training.

A paperless system is envisaged for DMICP and therefore policy and processes are required to enable those areas of practice where paper may still be required (e.g. for recording and storing consent).

A clear understanding is needed of how anonymised data will be managed and utilised to ensure that relevant laws and regulations are complied with.

Although all policies were developed before implementation began, the resource burden of completing all processes in the same timeframe was prohibitively high. Consequently local processes are being developed and some of these will have to be changed as global processes are published. The burden of business change should not be underestimated.

Operational aspects of a wide range of deployed environments overseas (including extreme environmental conditions and at sea) must be addressed by the adaptation of policies and processes

9.4.5. The characteristics of the ECS in Scotland, IHR in Wales, and DMICP in the Defence Medical Services are summarised in Table 13 overleaf.

Table 13. SUMMARY OF CHARACTERISTICS OF DIFFERENT EXAMPLES OF SHARED ELECTRONIC PATIENT RECORDS

	Summary Care Record (NHS, England)	Emergency Care Summary (NHS, Scotland)	Individual Health Record (NHS, Wales)	DMICP (UK Defence Medical Services)
Nature of database	Single, large	Single, medium	Federated	Single, small
What clinical information goes on the record?	Drugs / allergies / adverse reactions plus 'minimum data set' (content still being decided)	Drugs / allergies / adverse reactions	Coded information from GP record (though not all is accessible) + free text allergy qualifiers	Full GP record and additional data (full dental record; summary of secondary and tertiary care)
Change model	Conventional (i.e. goal-oriented and timetabled) with consultation and attention to 'engagement'	Emergent and incremental	Emergent and incremental	Conventional with consultation and attention to 'engagement'
Clarity / specificity of use cases	Low	High (emergency care)	High (OOH care)	Medium (all military contacts)
Level of public trust	Low	High	High	High
Where is the record populated from?	GP detailed record (plus future plans for other sources)	GP detailed record (plus palliative care in future)	GP detailed record (strictly)	All users (e.g. physio) may enter data
Where is the record deployed?	Multiple unscheduled settings	OOH, A&E, NHS24 call centres	OOH	All military contacts outside hospital (and in 6 MOD Hospital Units in NHS England)
Consent model	Opt out for initial upload, opt in for 'enriched' record	Opt out for initial upload, consent to view at point of care	Opt out for initial upload, consent to view at point of care	All military personnel must have a DMICP record; individual may restrict access to certain staff
Opt-out rate to date	0.81%	0.02%.	0.02%	Opt-out not an option
Patient access?	Via advanced HealthSpace account	Patients can request a printout free of charge in GP Practices	My Health Online, accesses GP record not IHR	No
Staff access	Any NHS staff with a legitimate relationship to the patient.	Clinicians with legitimate relationship only. Receptionists, call handlers have access to demographics only.	4 levels of legitimate relationship access – System administrator, clinician, clinical support worker, secretarial	Any Defence Medical Service staff with a legitimate relationship to the patient.

10. Glossary

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
CRS	Care Records Service
CSA	Clinical Spine Application
DCR	Detailed Care Record
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
InPS	InPractice System
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
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
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
QOF	Quality and Outcomes Framework
RCN	Royal College of Nursing
SCR	Summary Care Record
SHA	Strategic Health Authority
SUS	Secondary user service
WiC	Walk-in Centre

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