Summary Care Record Early Adopter programme
An independent evaluation by University College London
Trisha Greenhalgh, Katja Stramer, Tanja Bratan, Emma Byrne, Jill Russell, Yara Mohammad, Gary Wood, Susan Hinder

Executive summary

Background and context

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.

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).

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.

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).

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.

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

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.

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.

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.

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.

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.

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.

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**

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.

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.

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.

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.

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.

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.

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

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.

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.

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.

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.

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.

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.

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.

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’).
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.

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.

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.

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.

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.

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.

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.

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.

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.

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.

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.

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

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?
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.

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.

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.

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.

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.

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.

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.

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.

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.

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.

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.

University College London
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