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THE DEVIL'S IN THE DETAIL

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

Executive summary

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Background

1. This report summarises findings from Years 2 and 3 of a 3-year evaluation of the Summary Care Record (SCR) and HealthSpace programmes. It covers the period 1st May 2008 to 28th February 2010. It is intended for all stakeholders in these programmes, including the Department of Health (which funded the evaluation), NHS Connecting for Health (CFH), policymakers, the Information Commissioner, healthcare and ICT professionals, NHS staff, service users, citizens, academics and evaluation scholars. It should be read in conjunction with our Year 1 reports on the SCR programme (May 2008)¹ and data quality (May 2008).²
2. The SCR is an electronic summary of key health data, currently drawn from a patient's GP-held electronic record and accessible over a secure Internet connection by authorised healthcare staff. It is one of a suite of innovations being introduced as part of the National Programme for IT in the English National Health Service (NHS) and delivered via a central 'Spine'. Policy documents published in 2005-8 anticipated a number of benefits of the SCR, including:³⁻⁶
 - a. Better care (i.e. the SCR would improve clinical decision-making);
 - b. Safer care (i.e. the SCR would reduce risk of harm, especially medication errors);
 - c. More efficient care (e.g. the SCR would make consultations quicker);
 - d. More equitable care (i.e. the SCR would be particularly useful in patients unable to communicate or advocate for themselves);
 - e. Reduction in onward referral (e.g. the SCR would avoid unnecessary ambulance callouts, A&E attendances and hospital admissions);
 - f. Greater patient satisfaction (by allowing people to state care preferences, receive better care and access their record via HealthSpace).
3. HealthSpace is an internet-accessible personal organiser onto which people may enter health data (such as blood pressure) and plan health appointments. Through an advanced HealthSpace account, they can gain secure access to their SCR and email their GP using a function called Communicator. Policy documents published in 2005-8 anticipated five main benefits of HealthSpace:^{3;7-9}
 - a. Personalisation of care (by supporting choice and increasing access options, HealthSpace would allow NHS care to be adapted to individual needs);
 - b. Patient empowerment (by entering their health data onto HealthSpace, and by accessing their SCR via an advanced HealthSpace account, patients would be better able to manage their illnesses, especially long term conditions);
 - c. Accountability, quality improvement and safety (patient input, supported by high-quality, accessible information, would drive up quality in the NHS – for example, by spotting data quality errors on their SCR);
 - d. Reduced NHS costs (e.g. more self-management would potentially reduce the cost of managing long-term conditions); and
 - e. Improved health literacy (the availability of HealthSpace would improve people's ability to understand and manage their illness).
4. We were asked to highlight that the SCR and HealthSpace are evolving technologies at an early stage of implementation. Versions evaluated were not the final, definitive ones envisaged by policymakers. As the main report makes clear, numerous environmental factors influenced delivery of the programmes over the timescale covered by the evaluation. This report should be read with this caveat in mind.

The evaluation

5. The full aims and terms of reference of the evaluation are set out in Section 3.1 of our main report. The research questions were:
 - a. At the 'micro' level, what is the usability, usage, functionality, and impact of the SCR and HealthSpace in participating localities, and what explains variation in their adoption and use?
 - b. At the 'macro' level, what is the social, political, technological and economic context into which these technologies are being introduced? How does this context shape and constrain micro level usability and usage – and how, conversely, does the experience at micro level impact on the macro context?
 - c. What aspects of implementation are seen by different participants and stakeholders as important? How (if at all) might these be expressed as generic, transferable implementation standards and strategies?
 - d. What can we learn from this project about how best to evaluate large-scale healthcare IT programmes more generally?

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

7. Collection and analysis of data was informed by academic perspectives outlined in Section 3.4 of our main report. In sum, we used Patten's utilisation-focused evaluation, supplemented by theories and methods from ethnomethodology, sociology, computer-supported cooperative work and empirical philosophy.^{10,11}

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

Main findings: summary

9. When we began this phase of the evaluation in May 2008, four primary care trusts (PCTs) were actively involved in the SCR programme. About 150,000 SCRs had been created; 600,000 patients had been sent a letter informing them of the SCR programme, and 0.81% had formally opted out. About half these patients had also been informed of HealthSpace. About 200 patients had completed registration for an advanced HealthSpace account through which they could access their SCR.
10. As of 1st March 2010, 50 of 152 PCTs in England had begun to write to patients and 16 had begun to create SCRs. 8,853,358 people had been mailed about the SCR and 14,505 (0.65%) had opted out. 201 GP practices had 'gone live' (uploaded patient data to create SCRs). 1,243,911 SCRs existed and 14,266 had been accessed. 25 settings had achieved 'technical go-live' (i.e. had all technical links in place to use SCRs in clinical care). In settings using the Aadastra interface (GP out-of-hours and walk-in centres), SCRs were being accessed in approximately 4% of all encounters and 22% of those in which a SCR was available. SCR accesses varied considerably depending on the setting, type of clinician, experience of clinician, nature of encounter and time of day. According to updates supplied by CFH, fewer than 30 SCRs per week appeared to be being accessed in secondary care settings across the country. Fourteen PCTs were participating in the HealthSpace programme but activity in most of these was described as at an early stage. Approximately 110,000 people had opened a basic HealthSpace account and 2219 had activated an advanced HealthSpace account.
11. Bearing in mind the caveat in paragraph 1.4, evidence that the SCR programme had so far achieved the benefits set out in paragraph 1.2 was limited. Specifically:
 - a. There was evidence of improved quality in some consultations, particularly those which involved medication decisions;
 - b. There was no direct evidence of safer care but findings were consistent with the conclusion that the SCR may reduce rare but important medication errors;
 - c. There was no consistent association between use of the SCR and consultation length;
 - d. There was evidence that the SCR was particularly useful in patients unable to communicate or advocate for themselves;
 - e. There was no evidence that use of the SCR was associated with reduction in onward referral;
 - f. Impact of the SCR on patient satisfaction was impossible to assess.
12. Bearing in mind the caveat in paragraph 1.4, in relation to HealthSpace:
 - a. There was no evidence to date of improved personalisation of care;
 - b. There was no evidence to date of increased patient empowerment or increased ability to manage long term conditions;
 - c. We did not find any patients who had used HealthSpace to input to the data quality process, so the anticipated benefits of improved accountability, quality improvement and safety as a result of such input were impossible to assess;
 - d. We had detected no reports of reduced NHS costs, though assessing such costs was beyond the scope of our evaluation;
 - e. There was no evidence to date of improved health literacy in patients as a result of using HealthSpace;
 - f. Few practices or patients had yet used Communicator.

Main findings: national level

13. The period May 2008 to February 2010 was characterised by a number of key developments at national level:
 - a. De facto responsibility for implementing the NPfIT shifted from CFH to the Strategic Health Authorities (SHAs), reflecting a statutory change in April 2007 that the NPfIT would become “locally owned and delivered”. NHS organisations were encouraged to maximise creation of SCRs from GP-held records, promote use of these records in provider organisations and document locally-relevant benefits. Tools and resources were made available and National Implementation Managers appointed to support local business process development;
 - b. As a response to findings reported in our Year 1 evaluation, a change in the consent model was introduced such that clinicians were required to ask a patient's consent to access their SCR at the point of care. Largely as a result of this, support from professional bodies (especially the British Medical Association) for the SCR increased, though some concerns remained;
 - c. Some changes to contracts with IT suppliers were necessary to incorporate requirements that had not been fully anticipated at the outset of the programme. Some informants described these changes as costly;
 - d. CFH produced an internal report on the relatively low uptake and use of the SCR, particularly in secondary care settings. This report flagged a number of factors influencing use, including low numbers of SCRs created to date, complexity of implementation plans, perceptions about data quality and the practicalities of information governance measures;
 - e. Civil liberties groups continued to question the SCR programme;
 - f. The UK economy went into recession and public-sector services came to be characterised by growing uncertainty and a perception by NHS staff that financial controls were being tightened. The work of CFH became mainstreamed within the DoH in a new Health Informatics Directorate. Resources across the health economy for supporting NPfIT-related work diminished. Political parties began to prepare for a general election.

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

- d. Small IT suppliers tended to have a close and responsive relationship with their customers and understood the 'workaday world' into which their products were being introduced. Some supplier informants felt that CFH staff did not fully understand clinical work in primary and unscheduled care and that deadlines set for delivery of technical solutions were unrealistic and politically driven.

Main findings: NHS organisations

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

Main findings: use and non-use of the SCR at the clinical front line

16. In relation to use of SCRs by clinicians in unscheduled care settings, most of which were in a primary care setting:
 - a. We observed cases in which the SCR appeared to add value in the out-of-hours consultation, especially by informing medication decisions in patients who had been prescribed multiple medications and were unsure what these were. We also observed many cases in which a patient's SCR was not available but *might* have added value had it existed and had it contained the data needed for a key clinical decision;
 - b. We observed few cases in which the presence of the SCR unequivocally made care safer, or where care was unsafe in the absence of the SCR. This seemed to be because doctors, nurses and pharmacists tended to err on the side of caution. They took additional safety measures if key data were not available and they referred many patients on to the next step in the system 'just in case' whether SCR-held data were available to them or not;
 - c. When dealing with complex cases, health professionals sometimes found it stressful and challenging to make decisions in the absence of reliable data on medication and allergies. In such circumstances, the clinician expressed more confidence in their decision and described the consultation as "easier" when the SCR was available, even when the information on it did not change that decision;
 - d. Analysis of a large quantitative dataset of clinical encounters in out-of-hours settings showed that use of the SCR was significantly more common amongst experienced regular clinicians than occasional staff, in marker conditions where a drug or allergy history was likely to be important, and in cases where the patient had more than one diagnosis. SCRs were less likely to be accessed in the elderly (a finding which we could not explain) and in the early hours of the morning. However, most variation in SCR use remained unexplained even when these and other demographic and diagnostic variables were taken into account. There was no consistent association between use of the SCR and consultation length;
 - e. Qualitative data suggested that where the information held on the SCR was poorly matched with the scope of practice of the clinician (e.g. when a complex medication list was viewed by a nurse without senior-level prescribing training), the SCR appeared to reduce rather than increase clinician confidence and increase rather than reduce consultation length;
 - f. We encountered no examples of SCR use leading to a change in onward referral within the local health community, nor of a patient without a SCR whose onward referral decision was likely to have been different had a SCR been present;
 - g. We found it impossible to assess whether patients were more satisfied as a result of their SCR being present because satisfaction was a function of the consultation as a whole, not of the presence or absence of the SCR.
17. The above points resonated with findings from other data sources set out in paragraph 1.8. Thus, in contrast to expectations expressed by many stakeholders that the SCR would bring clear, easily defined and readily measurable benefits, we found that when benefits occurred, they were subtle, hard to articulate and difficult to isolate out from other aspects of the consultation. However, because it is rare for patients to encounter serious harm (e.g. from medication errors) in the primary care setting and the SCR was little used in any other setting, our findings do not exclude a significant positive impact of the SCR on patient safety.
18. Our findings indicated that like other medical records, SCRs sometimes contained incomplete or inaccurate data. Our study was not designed to quantify the prevalence of these. In particular, we observed cases in which:

- a. The patient was taking medication which was not listed on the SCR (e.g. obtained from pharmacies, unscheduled care settings, the private sector, a relative's medication, a stockpiled supply of past drugs, or abroad);
 - b. The SCR listed 'current' medication which the patient was not taking;
 - c. The SCR indicated allergies or adverse reactions which the patient probably did not have;
 - d. The SCR failed to indicate allergies or adverse reactions which the patient probably did have.
19. Clinicians working in unscheduled care drew eclectically on multiple data sources – including the patient, electronic and paper records, and their own observations and measurements. When these data sources conflicted, they made a contextualised judgment about two things: (a) which source was most likely to be reliable and (b) the level of residual uncertainty in the case. We did not see any cases where incomplete or inaccurate data on the SCR led to harm or risk of harm to the patient – precisely because clinicians did *not* view the SCR as the sole source of reliable data.
20. When the SCR was not accessed in an unscheduled care consultation, reasons were sometimes multiple and complex, and included both social and technical factors. Examples of reasons for the SCR not being available or accessed included:
- a. Information held on the SCR was not needed (most commonly because the patient had a minor illness and/or sought something other than a clinical decision e.g. reassurance, certification), so the clinician did not check if one was available;
 - b. Information held on the SCR was reliably provided by some other source (most commonly the patient or carer);
 - c. The patient did not have a SCR (most commonly because they were registered with a GP practice which was not participating or had yet to go live);
 - d. The patient's SCR was not available for technical reasons (e.g. temporary loss of the organisation's connection to the Spine, lack of access to a computer terminal);
 - e. The patient's SCR was not available for human reasons such as patient not identified on the Personal Demographic Service of the Spine (e.g. through misspelling of name); SCR use not compatible with organisational routines and micro-practices; staff member not trained, not issued with smart card, not authorised, not motivated, not encouraged or supported by seniors or overly concerned about information governance issues (e.g. fear of triggering an 'alert').

Main findings: mobile SCR

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

Wicked problems

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

- a. Content and scope of the SCR. In particular, the task of defining a standard 'minimum dataset', 'enrichment dataset' and 'exclusion dataset' proved more difficult than originally anticipated;
 - b. Data quality. In particular, there was a tension between setting a high standard for a GP practice to be allowed to join the programme (hence SCRs would be more likely to be complete, accurate and trusted by clinicians) or lowering this standard so as to increase the overall number of records, thus achieving critical mass and a higher 'hit rate';
 - c. The consent model. In particular, some front-line staff were reluctant to ask consent to view the SCR at the point of care because they saw this as unworkable, inappropriate or stressful;
 - d. Information governance. In particular, fears about possible security loopholes tended to generate expensive and time-consuming technical fixes and some staff perceived the system of alerts designed to pick up rare incidents of malicious access as cumbersome, bureaucratic and intrusive;
 - e. "Technical" problems. In reality, these often had social, political and legal elements as well; and
 - f. Children. In particular, questions of consent and information governance were raised by cases of 'at risk' children whose parents may seek to opt out on their behalf and the question of whether and how the SCR might be used to support child protection work;
 - g. Training. In particular, standardised, topic-based packages delivered predominantly via methods which did not involve active, on-the-job learning had limited potential to equip staff for the complex, situated and unpredictable challenges associated with delivering the programmes.
23. Wicked problems had a number of common characteristics:
- a. They spanned the different 'worlds' of different stakeholder groups (paragraph 1.31), which brought different assumptions and values;
 - b. They involved a tension between different philosophical models of reality ('hard', rationalistic, factual versus 'soft', contextualised, interpretive);
 - c. They tended to include a claim on contested resources (i.e. not everyone agreed that money or time should be spent on them);
 - d. They were vulnerable to multiple external influences, some of which were not under the control of those charged with 'fixing' them;
 - e. They had complex interdependencies with other problems and issues in the programme; and
 - f. They produced unanticipated ramifications elsewhere in the system.

Main findings: HealthSpace

24. Fewer people registered for HealthSpace during the period of this evaluation than early strategy documents had predicted. Explanations for this included:
- a. The SCR and HealthSpace programmes, originally linked at policy level, were later uncoupled both nationally and locally. Funding for HealthSpace moved from the NPfIT to the Darzi Next Stage Review stream, and many PCTs decided to address the SCR roll-out first and then (at a later date) invite patients to register for HealthSpace to view their SCR;
 - b. The initial version of HealthSpace was seen as 'clunky' and its functionality as limited;

- c. A proposal for HealthSpace Extension with greatly increased functionality was initially rejected for funding and a scaled-down version based on a more recent survey of what potential users wanted only gained funding in January 2010; and
 - d. The registration process for HealthSpace was complex and a planned technical solution to allow online registration for advanced accounts had not yet become available.
25. In our study of the use and non-use of HealthSpace by patients, very few people who had registered for a HealthSpace account were willing to be interviewed. The main reason for declining appeared to be that they were not actively using the technology and not interested in saying why this was. HealthSpace users interviewed found the current release of the technology of limited value; some had high hopes for future enhancements in functionality. One informant described the 'sleeping gym membership' phenomenon: registering for HealthSpace, accessing it once, then losing interest. Our study was not designed to quantify this phenomenon.
26. Ethnographic observation of a sample of people with diabetes and other long term conditions revealed insights about how HealthSpace may or may not help with the lived reality of chronic illness. In particular:
- a. Some people appeared to lack the health literacy or IT literacy required to use a technology-based health organiser. Others were either not motivated to reflect on the progress of their condition or felt that this was a task for their doctor or nurse;
 - b. Some had no access to computers or saw them as serving other purposes in their lives (games, shopping, social networking);
 - c. Some were already using or exploring other ways of documenting and monitoring their condition e.g. paper (e.g. diabetes diary), bespoke software (Excel spreadsheet), or downloads for digital personal organisers (iPhone 'apps') and found these more fit for purpose than HealthSpace;
 - d. Many patients' needs were not primarily for codified data (e.g. blood glucose levels) but for practical knowledge of how to live with their condition and for emotional support. They tended to get this from other people (e.g. relatives, local diabetes support group, Facebook);
 - e. Some patients were constrained by poverty, an adverse physical environment (e.g. poor housing, overcrowding), major family stress, or serious disabilities related or unrelated to their condition (e.g. depression, stroke). Monitoring and managing their long term condition competed with these other problems for emotional and material resources and was rarely top of the priority list.
27. Attempts to introduce HealthSpace Communicator in three pilot practices produced examples of patients whose access to their GP, overall care and satisfaction appeared to be significantly enhanced by this technology, but such cases were rare. Even in these highly selected volunteer practices, and especially more widely, questions remain about the acceptability of Communicator to patients and staff and how its use could be aligned with the culture and routines of general practice.
28. Attempts in one locality to link an integrated record scheme for long term conditions (supported by an independent IT supplier and already in use between primary and secondary care) with patient access to records via HealthSpace met operational difficulties. Enthusiasm from patients, clinicians, the PCT and the supplier of 'middleware' was high and much work was undertaken by all parties. But challenges relating to information governance and complex commercial relationships had not been overcome by the time this report was submitted.

Analysis

29. The most striking overall characteristic of the SCR and HealthSpace programmes was their scale and complexity. They can be thought of as emerging from a heterogeneous socio-technical network with multiple interlocking sub-networks:
- a. The design network: professional advisers, software developers (based variously in CFH, commercial IT companies and academic institutions), and a large and complex technical infrastructure;
 - b. The implementation network: civil servants, policymakers, national and local managers, clinical leads, suppliers, trainers and front-line NHS staff, as well as those who sought to 'resist' the implementation in different sectors;
 - c. The governance network: professional, legal and regulatory bodies; technical security features and the CFH staff who designed and built them; security testing contractors; business processes, tools, and systems that supported information governance activity; and individuals such as Caldicott Guardians and privacy officers;
 - d. The front-line user network: NHS clinicians, local administrators and call handlers, 'front end' software, terminals and smart card readers, patients using HealthSpace and the staff and systems who supported registration; and
 - e. The evaluation network: different groupings who deliberated in a highly contested space on what counted as 'success' in the programmes and how this should be measured, including policymakers and business managers who constructed the 'benefits realisation' case; teams and systems involved in in-house monitoring; official bodies such as the National Audit Office; the media and lobbyists who made claims and counter-claims about the justification and progress of the programmes; communications staff and systems within CFH; patients (whose healthcare experience was intended to improve); and our own team.
30. During this evaluation period, this complex socio-technical network was dynamic and unstable. At any time point, there was a particular alignment of people who were developing and implementing the technologies, using them (or not), training and supporting others to use them (or not), monitoring the performance and security of the system with a greater or lesser degree of success, and debating whether the programmes were 'on track', ethically justified and so on. Sometimes the technologies 'worked' in particular settings, and at other times they did not 'work' – either because particular technical components of the network failed (or had never been put in place), or because people in the network *chose* to behave in particular ways (e.g. because they felt ethically compelled to do so) or were *prevented* (socially or materially) from behaving as they would have wished to. In some parts of the programme, there appeared to be an overall trend towards stability of the network, but other parts are currently characterised by continuing instability.
31. The SCR and HealthSpace programmes spanned a number of different 'worlds' – political, clinical, technical, commercial, academic – with different institutional logics, as well as the personal world of the patient.
- a. In the political world, the programmes were an exercise in modernising the NHS by delivering measurable benefits to patients and taxpayers;
 - b. In the clinical world, they were an initiative to improve the quality of care in an area (unscheduled care) where concerns had been raised about standards;
 - c. In the technical world, they were a software development project for 'use cases' characterised by unpredictability and a high degree of exceptionality;
 - d. In the commercial world, they represented (for some but not all ICT suppliers) relatively high-risk but potentially high-revenue business contracts;

- e. In the academic world, they were complex case studies which demanded critical analysis through multiple disciplinary lenses including informatics, biomedicine, psychology, sociology and political science;
 - f. In the personal world, they were a potential encroachment (for good or ill) of the system into the lifeworld of the patient.
32. Differences in norms, values, priorities and ways of working between these six worlds, and imperfect attempts to bridge these differences, accounted for much of the instability in the socio-technical network – and this in turn explained many of the challenges and frictions encountered as the complex collaborative tasks of design, implementation, governance, front-line use and evaluation were pursued.
33. The main organisations involved in the programmes each occupied one or more of these different institutional worlds. For example:
- a. CFH's activity spanned political, technical and commercial worlds. Its activities were closely aligned with the prevailing government policy of the new public management, addressed via the development, justification and implementation of robust business models for public-sector spending. CFH's core business was the procurement and deployment of IT solutions on behalf of the NHS. At the time of this evaluation CFH's work on the SCR appeared to be well resourced and the implementation team could respond to problems by allocating staff and money to address them;
 - b. NHS provider organisations operated largely in the clinical world where 'business processes' and training for anything other than direct patient care tended to be given relatively low priority. Staff interviewed in these organisations perceived that there were severe and worsening constraints on resources and staff time;
 - c. IT suppliers operated in the commercial and technical worlds and were strongly customer-oriented;
 - d. Professional organisations occupied both the clinical world (in relation to professional standards and patient care) and the political world (in relation to clinicians' workload and liabilities).
34. A prominent finding in this study was the large amount of *work* involved in the SCR and HealthSpace programmes, the difficulty and complexity of this work, and its critical dependence on the qualities and capability of particular people. The numerous individuals involved in these programmes occupied disparate worlds, brought different values and spoke different 'languages'. Those who proved most pivotal held boundary roles between different organisations and sectors and managed to align – to some extent at least – the complex and competing institutional logics which characterised the programmes. They achieved this by engaging actively in what previous authors have called 'translation', which involves four stages:
- a. Problem construction: defining a problem for which the SCR and/or HealthSpace offered a solution;
 - b. Selling the idea: getting others to accept this problem-solution link;
 - c. Enrolment: defining key roles and practices in the socio-technical network; and
 - d. Mobilisation: engaging others in fulfilling the roles, undertaking the practices and linking with others in the network.
35. A number of key boundary roles were apparent. For example:
- a. National Clinical Directors tended to be well connected across all or most of the clinical, political, commercial and technical worlds. Their translation activities included influencing national policymaking groups within and beyond the NPfIT, negotiating with suppliers, engaging and mobilising professional bodies and attempting to secure funding streams to support new workstreams;

- b. National Implementation Managers interfaced between CFH and managers in NHS organisations. They attempted to socialise the latter into the business processes and reporting structures required by CFH, and (equally importantly) conveyed the world of cash-limited, clinically-oriented NHS organisations to central CFH staff;
 - c. Local Clinical Leads' translation challenge was getting the SCR and HealthSpace on the agenda in local decision-making groups. Their efforts tended to be more effective when their connections in the political world (e.g. PCT, Local Medical Committee) were strong.
36. Towards the end of the period we were evaluating, there was evidence of a more mature and responsive relationship between CFH staff and front-line implementation staff, born of a developing understanding of one another's 'worlds'. Relationships between CFH staff and GP system suppliers also appeared to have matured for similar reasons. We note these changes with cautious optimism.
37. Implementation of the technologies depended crucially on front-line NHS staff, who brought various beliefs, values, meaning-systems and motives to their organisational roles ('normative' influences). Their actions were shaped and constrained by such things as job descriptions, access privileges and the functionality and limitations of technologies ('causal' influences). Qualitative case studies of micro-level incidents and encounters (Section 10.5) showed that relatively small differences in normative and causal influences on individuals, along with the potentialities and constraints of the technologies, sometimes explained wide variations in actions and outcomes.
38. The SCR and HealthSpace technologies contained a number of inscribed assumptions about the nature of illness and the behaviour of patients and staff. For example, inscribed in the SCR was the assumption that GP practice staff would enter all key data in coded fields on the local record. The 'permission to view' screen inscribed powerful institutional messages about autonomy, trust, surveillance and performance management. Inscribed in the HealthSpace technology was the assumption that patients would be capable and motivated to monitor and manage their long term condition using biomarkers such as weight, blood pressure and blood test results. Mismatches between these inscribed assumptions and the reality of clinical work or living with illness explained much of the non-adoption, partial adoption and abandonment of these technologies at the level of the individual user.

Discussion

39. The question of how to measure success in these programmes was contested. We documented 28 different metrics used for the SCR programme (Table 11.1) and 14 for the HealthSpace programme (Table 11.2), each of which was given different significance by different stakeholder groups.¹
40. At the outset, stakeholders from all 'worlds' appear to have shared a number of expectations of the material and technical properties of the SCR and HealthSpace technologies (e.g. many had imagined that the SCR would be near-universally accessible to staff and patients, that it would offer complete and accurate information and that it would 'work' with minimal maintenance effort). Given these unrealistic expectations, the first releases of the technologies were destined to disappoint: they

¹ In response to an earlier draft of this report, CFH pointed out that "low uptake of HealthSpace was not explained in terms of the required change of culture for patients, the need for a new clinical context, and the need to target it on those most likely to benefit once advanced accounts are widely available." See paragraph 3.3.13 of our main report for an explanation of how footnotes such as this came to be added.

were perceived as difficult to access, 'clunky' to use, offering considerably less functionality than expected and raising numerous ongoing operational challenges.

41. The PRINCE 2 model used in efforts to implement the programmes (the current government standard, in which explicit goals and milestones are systematically defined, pursued and signed off) appeared to be an efficient business tool for managing the parts of the programme that could be controlled, isolated into discrete work packages and 'managed' in the conventional sense of the word. But the sheer complexity of the socio-technical network, its embeddedness in wider institutional structures and the fact that many risks were outside CFH's control meant that this linear approach was a poor fit in many parts of the programme, particularly the 'wicked problems' listed in paragraph 1.22.
42. The huge scale of the programmes inevitably brought increased complexity as well as a tension between 'national coordination' and 'local ownership'. The tension between standardisation (which helps stabilise the socio-technical network) and contingency (which reflects and responds to local needs and priorities) can never be resolved; rather, it must be actively and creatively managed – and this gets harder as the network gets bigger. The Law of Medical Information appears to apply: *"the further information has to be able to circulate (i.e. the more diverse contexts it has to be usable in), the more work is required to disentangle the information from the context of its production. The question that then becomes pertinent is; who has to do this work, and who reaps the benefits?"*¹²
43. The scale of the SCR programme, along with the struggles of the Information Commissioner to apply data protection legislation in a way that keeps pace with technological innovation, has created new ambiguities about who now 'owns' patients' medical records, who is responsible for assuring the quality and confidentiality of the data on those records and in what circumstances consent should be asked for sharing these data.
44. Risks identified in early strategy documents had included the possibility of delays in the delivery of compliant GP systems, difficulty introducing new business processes in NHS organisations, technical problems (e.g. interoperability), inadequate administrative capacity in the NHS, "professional resistance", high public opt-out rate and low use at the clinical front line. Measures to mitigate these risks had been couched largely in terms of providing a clear scope and specification for the technologies, adjusting deployment schedules to align with delivery dates from different suppliers (commencing with the most compliant), ensuring sound business processes and "communication about the benefits and importance of the SCR".
45. Some risks in the programmes were thus identified at the outset and successfully mitigated. But a number of mission-critical risks could not be mitigated and/or were not identified or fully explored. The standard DoH approach of assessing options and risks by a highly formalised process of assigning quantitative scores to subjective perceptions about complex issues may have lent a spurious objectivity to the risk assessment process and diverted attention from systematic *qualitative* methods such as deliberation or defending one's ideas in front of an audience.
46. The fortunes of the SCR and HealthSpace programmes appeared to turn partly on the philosophical question *"Where is the wisdom we have lost in knowledge?"*. Many though not all senior stakeholders in CFH, the professions and the IT industry viewed knowledge as stable and discrete data items which could be extracted from their context, placed on the SCR and transmitted to new people and contexts while retaining meaning. An alternative perspective holds that much knowledge is tied to particular people, organisations, experiences and practices and is difficult if not impossible to extract from its context or the people who know it.

47. The extent to which context matters depends on the type of data. As data fields in the SCR expand from 'hard' (objective, relatively uncontested, relatively context-free e.g. medication) to 'soft' (subjective, contestable, context-bound e.g. some clinical diagnoses), the quality and trustworthiness of SCR-held data could be jeopardised. Furthermore, the context-bound nature of much knowledge underpins a radical and important suggestion: that very large, centrally stored record systems, though expected to bring increased clarity, transparency and trust, may actually lead to confusion, paradox, and loss of trust.¹³
48. The programmes' strong emphasis on the structured reporting and collation of quantitative, 'factual' data meant that other forms of knowledge (such as personal experience; knowledge of a particular NHS organisation, locality or individual; and intuitive or emotional knowledge) were given limited emphasis. The culture of delivering training in discrete topic-based packages focusing on standard processes, procedures and responses sometimes but not always prepared staff adequately to cope with the complex and unpredictable challenges associated with implementing and using the SCR.
49. Most criticisms of the SCR and HealthSpace programmes to date have been presented as technical ('wrong underlying design'), operational ('poor programme management') or economic ('poor value for money') issues, and solutions have tended to be couched in terms of better design, better business processes or tighter financial management. Our findings suggest that at least some of the problems encountered in the SCR and HealthSpace programmes to date are essentially philosophical. If that is the case, the urgent question for public debate is not "Why have most of the benefits of these technologies not yet been realised?" but "To what extent were these programmes built on an inadequate conceptualisation of what knowledge is, a privileging of facts over values, a failure openly to debate what is reasonable and an unrealistic expectation that a defined input would produce a predictable output in a complex system?".

Recommendations

50. As an academic team whose task was to illuminate rather than judge the SCR and HealthSpace programmes, and whose brief specifically excluded financial audit or developing and applying performance metrics, it is beyond our remit to pass definitive comment on the success of the programmes. We recommend that those who make such judgements consider the points below.
51. Some important high-level decisions have already been signed off (and others are pending) by the DoH, HM Treasury, the boards of major IT companies, professional bodies, patient organisations and lobbying groups. Questions have been asked at this macro level about the goals of the programmes; their cost in relation to anticipated or established benefits; the extent to which they are 'on track' (and the extent to which fixed milestones are appropriate or helpful); whether the contractual relationship between suppliers and the state is optimal; whether the 'database state' has encroached too far on individual privacy and who now 'owns' the medical record of an NHS patient. We hope that public debate on these questions will continue and will take account of the points raised in paragraphs 1.39 to 1.49 above.
52. There is another macro question which has so far attracted much less public debate, which relates to the role of the individual in looking after their own health and in improving health services. The HealthSpace programme was built on the assumption that a significant proportion of patients will have the motivation and capacity to 'self

manage' their long term condition using this technology; that this will reduce costs to the NHS; and that patients' access to their SCR via HealthSpace will contribute substantially to improving data quality. Notwithstanding our comment in paragraph 1.4 above, the findings of this study to date – that few people are currently interested in using HealthSpace to manage their illness or access their SCR – suggest that it may be time to revisit all these assumptions. Deliberation on the future of the HealthSpace programme should take account of the availability of low-cost technologies for supporting self-management and the rapid pace of change in the market for such technologies. It should also reconsider the logic behind the policy-level link between 'empowerment' and a state-run online records service.

53. In relation to NHS organisations, this study has shown unequivocally that the SCR is not a plug-in technology and its implementation should not be left to the IT department. Like many other components of the NPfIT, the SCR requires fundamental changes to systems, protocols, budget allocation and existing hardware and software – and also to organisational culture and ways of working. Adjustments will be required to the roles of health professionals and support staff; the competences and attitudes they need to fulfil those roles effectively; what staff are performance-managed on and how; the way they relate to patients; the way they handle information; and the way they share information with others both within and across organisations. We recommend that organisations who are contemplating becoming part of the SCR programme ensure early and active involvement of staff at all levels in discussions on these issues.
54. The SCR and HealthSpace programmes raise questions for individual clinicians who seek to behave ethically and in accordance with the core values of their profession. Until recently, the goals of high-quality personal care, accurate record-keeping and patient confidentiality were straightforward, uncontested and commensurable. The introduction of national electronic shared records and the patient's acknowledged right to choose what data (if any) are entered on those records and who may view them means that the values and principles which have guided the health professions for centuries now come with inherent tensions and paradoxes. We are impressed that professional bodies appear to have recognised that good clinical practice in the technological age is a complex and situated achievement which is informed but not determined by lists of frequently asked questions, and that their role is more to keep debate open than to produce final answers. We hope they continue to take this stance.
55. The NHS and professional bodies should consider the implications of this study for training and support of front-line staff. Our empirical data highlight the lack of predictability or universal solutions at the level of the fine-grained detail of the patient encounter. We have shown that front-line staff must take account of the emergent detail of *particular* situations when considering such things as how the consent model should be operationalised, how and with whom patient data should be shared and whether data can be trusted. These findings raise questions about the extent to which standard operating procedures can or should substitute for reflection, situational judgement and real-time consultation with colleagues. To the extent that these latter skills and approaches are considered important, it must also be recognised that there is a limit to how far they can be standardised.
56. The SCR is a rapidly evolving technology. The version we evaluated was 'Release 1', which comprised three relatively hard data fields uploaded from a single source for which the guardian of the source data was readily identifiable, the consent model clear (implicit consent to upload; explicit consent to view) and the main use case relatively well-defined, though we still found variability in how staff operationalised these concepts in practice. The SCR has already begun to include an 'enriched' dataset which covers much broader and softer data fields and for which both content and consent to upload are differently interpreted by different staff in different settings. On the horizon is

'Release 2' – a plan for various staff in various NHS and non-NHS organisations to enter various types of data onto the SCR for viewing by various other staff in various other contexts, for which consent will be sought and applied in various ways. Healthcare organisations from Strategic Health Authorities to singlehanded GP practices should take note that the many uncertainties implicit in the previous sentence do not lend themselves to resolution by high-level committees, no matter how exalted and/or inclusive their membership. There is much further debate to be had at local level with attention to the detail of what the proposed extensions to the technology mean for *our organisation, our staff, these patients, taking account of these particular priorities, constraints and contingencies.*

57. The SCR and HealthSpace have important implications for each of us as citizens. We must all make (or live with the consequences of not making) a number of personal decisions – whether to 'opt in' or 'opt out' of the SCR; whether to seek a discussion about how our own SCR should be 'enriched'; whether to modify these decisions as the technology evolves (see previous paragraph); whether to seek access to our SCR through HealthSpace and whether and how to challenge entries we do not consider accurate. The findings of this study suggest that for most people, engaging with these questions is a better option than not engaging with them.
58. Advocates of those who lack full understanding or capacity must attempt to achieve the difficult tasks set out in the previous paragraph on someone else's behalf, sometimes in tragic and emotionally-charged circumstances. The advent of nationally shared records suggests a new and/or extended role for public-sector and third-sector advocacy organisations in supporting such individuals and informing policy. This role appears to be one that must evolve with careful attention to what happens to real people in real situations.
59. Finally, all those who care about and/or seek to influence these programmes should note that dialogue (or lack of it) occurs in the context of multiple conflicting worlds (political, clinical, technical, commercial, academic and personal – and probably others as well). Strong feelings, misunderstandings, conflicting values and competing priorities are to be expected – and we offer no magic recipe for resolving them. But we do offer an observation from three years' involvement with these complex programmes: greatest progress appeared to be made when key stakeholders came together in uneasy dialogue, speaking each other's languages imperfectly and trying to understand where others were coming from (a state which has been termed 'accommodation'¹⁴), even when the hoped-for consensus never materialised. As the NHS reflects on an uncertain future, we believe that the fortunes of these programmes will continue to depend on (among other things) efforts to bridge the deep cultural and institutional divides which have so far characterised the NPfIT.

TABLE 11.1: MEASURES AND METRICS OF SUCCESS IN THE SCR PROGRAMME (as of 1st March 2010)

	Measure or metric	Stakeholder(s) using this metric	Extent of 'success' according to this metric	Comment
BENEFITS REALISATION				
1	Better care (i.e. improved clinical decisions)	CFH, NHS organisations, professions, press, patients, official auditors	Our qualitative findings confirmed an impact of the SCR on clinical decision making for the minority of patients who have complex needs and/or taking multiple medication	Overall, there is very limited evidence that benefits identified in early policy documents have yet been realised. See paragraph 11.1.2 for comment on initial expectations for the SCR
2	Safer care (i.e. reduced risk of harm, especially medication errors)		Our qualitative findings were consistent with, but did not actually demonstrate, a positive impact of the SCR on patient safety.	Serious harm is a rare event, hence a much larger dataset than the one we collected would be needed to exclude a significant reduction in harm.
3	More efficient care (shorter consultations)		There was no consistent effect on consultation length, but in 2 of 3 sites SCR use was associated with significantly longer nurse consultations	These findings should be interpreted with caution because of risk of confounders (encounters in which SCR is used differ in unmeasured ways from those in which it is not)
4	More equitable care (for patients unable to communicate or advocate for themselves)		Our qualitative findings were consistent with the conclusion that the SCR adds particular value when the patient has communication difficulties or has multiple illnesses or medications	The ability of the SCR to add value in such situations is crucially dependent on data quality, discussed in Section 8.3.
5	Reduction in onward referral (ambulance callouts, A&E attendances, admissions)		Our qualitative findings showed no impact of the SCR on onward referral	NHS staff tended to err strongly on the side of caution and refer on to the next stage in the system when there was the slightest doubt.
6	Greater patient satisfaction		We found the impact of the SCR on patient satisfaction impossible to measure	The impact of the SCR on satisfaction was impossible to isolate out from other contributory variables. To do this would need a large, randomised study
7	Improved clinician experience (consultations easier and less stressful, especially in patients with complex needs)	Front-line clinicians, professional bodies	Our qualitative findings were consistent with significant added value from the SCR on clinician confidence and reduction in the perceived stress of seeing patients without full records	This benefit of the SCR is particularly hard to measure, especially using quantitative metrics
8	Value for money	Official auditors	Beyond the scope of this evaluation	See Terms of Reference paragraph 3.1.7

BUSINESS MILESTONES				
9	Sign-off of business case and/or allocation of interim resource	CFH, DoH	Business case signed off by DoH Capital Investment Board and Minister of Health but not by HM Treasury	Non-approval of business case is seen as biggest risk to programme by CFH
10	'Proof of concept' (demonstration of the technology in a non-live setting)	CFH, technical designers	Technical demonstration in non-live environment seen as successful	A recurring complaint from NHS staff was trainers' focus on 'proof of concept' rather than use of live system
11	Number of PCTs who have begun some activity on SCR programme	CFH, SHAs, PCTs	50 PCTs have commenced public information programme	Many PCTs were keen to take advantage of a one-off offer of central funding to undertake the public mailout before end March 2010.
12	Mailshots (absolute or relative number of people sent a letter)	CFH	8,853,358 people have been sent a letter about the SCR	
13	'Opt out rate' (proportion of people who actively state that they do not want a SCR)	CFH, civil liberties lobby, critical press	% of opt-outs has remained below 1% throughout the programme	High opt-out rate was identified as a risk to the programme but this has not materialised. New releases of the SCR change the nature of what people are opting into or out of
14	Number of PCTs / GP practices who have begun to create SCRs	CFH, SHAs, PCTs	16 PCTs have at least one GP practice which has gone live with SCRs. 201 out of 8390 GP practices have gone live.	Several PCTs have sent letters to take advantage of funding offers but have no current plans to commence SCR creation
15	Proportion of GP practices using local record systems that are compliant with the SCR	CFH, GPSoC suppliers	80% of GP practices use systems that are SCR-compliant in theory but half these use a system (EMIS LV) which at the time of writing had yet to support an unproblematic automated 'go-live'	EMIS LV is the GPSoC system with the largest market share. The question of compliance 'in practice' as opposed to 'in theory' is a recurring issue in at the operational front line. As Section 5.5 showed, GP system suppliers have limited incentive and capacity to prioritise SCR compliance over other development work.
16	Achievement of go-live in a 'First of Type' (FoT) GPSoC system	CFH, technical staff, GPSoC suppliers	Four GPSoC systems (INPS, TPP, iSoft Synergy and EMIS LV) have had FoT uploads to the Spine. EMIS LV required manual correction of technical glitches	
17	Proportion of GP practices using a particular GPSoC system who have gone live	CFH, GPSoC suppliers	Proportion of practices supplied by GPSoC systems which have gone live: TPP (7.1% of supplier estate), INPS (4.5%), iSoft (4.5%) and EMIS LV (0.6%)	Go-lives with TPP, INPS and iSoft are now occurring in a largely automated way. There is concern about supplier capacity to support go-lives if programme expands rapidly
18	Proportion of GP practices in a participating PCT who have signed up to the programme in principle	CFH, BMA, RCGP, press	% of GP practices committed to participating in principle in SCR programme rose from approximately 50% to 85% in early adopter sites since 2008	Change in consent model was probably the single most significant factor explaining this shift

19	Proportion of GP practices in a particular PCT who have gone live	CFH, BMA, RCGP	% of 'gone live' GP practices rose from 18% to 44% in the first early adopter site and from 50% to 76% in the second between April 2008 and February 2010.	Change in consent model was probably the single most significant factor explaining this shift
20	Number of SCRs created	CFH, press, official auditors	1,243,911 SCRs have been created	CFH's internal target of 'one million SCRs' was reached on 12 th January 2010
21	Number of unscheduled care sites achieving 'hard' (technical) go-live	CFH, SHAs, PCTs	25 sites are now technically live for viewing SCRs	There is a big difference between 'hard' and 'soft' go-live (see footnote to paragraph 6.6.2). Technical go-live alone does not result in any SCRs being accessed. See Section 6 for examples of disconnect between 'hard' and 'soft' go-lives.
22	Number of unscheduled care sites achieving 'soft' go-live (regular use of the SCR)	CFH, SHAs, PCTs	National data not available. 5 of 13 viewing sites in the early adopter PCTs we visited were technically live but not accessing SCRs	
23	Absolute number of hits (e.g. total number of SCRs accessed)	CFH, press, official auditors	14,266 SCRs have been accessed. Expressed as a proportion of all encounters, access rate varies from 2 to 20% in GP out-of-hours and walk-in centres and is below 0.1% in secondary care settings	In some but not all GP out-of-hours centres access rate for the SCR is rising steadily over time. See Section 6 for detailed qualitative analysis of this finding.
24	'Hit rate' (proportion of patients for whom a SCR is found when the clinician looks for it)	NHS organisations, front-line staff	'Hit rate' in early adopter sites has risen from around 10% in 2008 to 50-75% now, depending on the particular site and setting	Some NHS organisations in early adopter sites perceive a hit rate that is lower than the actual hit rate (i.e. believe hit rate <i>would be</i> low so are "not pushing" the SCR)
25	'Slippage rate' (i.e. pace of progress in any given indicator compared to original predictions)	CFH, government, press, public	Policy documents in 2000 predicted an integrated NHS record system with patient access to own record by 2004/5. ¹⁵ In 2002 the milestone shifted to 2007 ¹⁶ and in 2007 to 2010. ¹⁷	Whilst 'slippage' has negative connotations, managers and front-line staff were critical of what they viewed as its flip side: ruthless pursuit of 'political' targets which was perceived as hindering socio-technical change efforts
COMMUNICATION SUCCESS				
26	Opinion leader endorsement (senior clinicians recommend SCR)	CFH	Communication material produced by CFH cited senior clinicians claiming that the SCR was in use and associated with benefits	Claims were typically made in vague terms and focused more on future, hoped-for benefits than established ones
27	'Good news stories' (anecdotes of patients helped by SCR)	CFH	Communication material produced by CFH described patients who benefited from SCR being accessed	Very few such stories were produced despite several requests to front-line staff and PCT managers
28	Lack of 'bad news stories' (no examples of SCR linked to poor care, harm or security breaches)	CFH	We encountered examples of the SCR containing incomplete or inaccurate data but no harm resulted. No stories of serious security breaches emerged	The SCR programme remains politically sensitive and vulnerable to 'bad news stories'

TABLE 11.2: MEASURES AND METRICS OF SUCCESS IN THE HEALTHSPACE PROGRAMME (as of 1st March 2010)

	Measure or metric	Stakeholder(s) using this metric	Extent of 'success' according to this metric	Comment
BENEFITS REALISATION				
1	Personalisation of care (by supporting choice and improving access)	CFH, SHAs, PCTs, patient organisations, official auditors	Some patients use HealthSpace to access Choose and Book to arrange an appointment at a convenient time. No data are available on SCR accesses via HealthSpace. Fewer than 100 patients in 3 pilot practices emailed their GP via Communicator. Those who have done so greatly value the facility	Choose and Book is accessible online via HealthSpace but it is possible to use Choose and Book by telephoning an access line. Low numbers of patients taking up the offer to use Communicator, and limited interest of many GPs in offering this service, may be explained by changes to the GP-patient relationship afforded by the technology.
2	Patient empowerment and improved health literacy (by improving the person's ability to manage their illness)		There is currently no evidence to support this claim. Our ethnographic studies suggest that patients with low health and/or IT literacy and low ability to manage their illness do not use <i>or wish to use</i> HealthSpace and that most of those with high health and IT literacy choose alternative products such as iPhone apps. Findings suggest that empowerment may be <i>reduced</i> in Communicator users	The use of personal health organisers appears to <i>require</i> but does not appear to <i>produce</i> high health literacy and IT literacy. Our findings do not exclude an untapped market of individuals with long term conditions who <i>would</i> use HealthSpace if its functionality changed, nor do they exclude an increase in self-management motivation and skill that might come with regular use of such technologies. Our limited sample of patients using Communicator included several who seemed to email their GP rather than seeking other information sources or making a decision
3	Accountability, quality improvement and safety (via patient input to the data quality improvement cycle)		There is currently no evidence to support this claim. We identified a patient who viewed a local shared diabetes record via a middleware solution and considered that the record was inaccurate, but a more likely explanation was the person's limited understanding of medical jargon	Whilst our findings do not exclude a potential impact of patient input to improving data quality, they do raise the possibility of an unintended consequence of significant numbers of patients being alarmed by, and seeking to contest, entries which were not expressed in lay language
4	Reduced NHS costs (self-management would reduce cost of managing long-term conditions)		There is currently no evidence to support the claim that self-management via HealthSpace reduces or has the potential to reduce NHS costs	See previous row. It is possible (but speculative) that efforts to promote self management by HealthSpace could <i>increase</i> the burden to the NHS
5	Value for money	Official auditors	Beyond the scope of this evaluation	See Terms of Reference paragraph 3.1.7

BUSINESS MILESTONES				
6	Sign-off of business case and/or allocation of interim resource	CFH, DoH	Original business case not approved; interim funding given from Darzi Next Stage Review	Funding has been allocated for one year from January 2010 to link with long term conditions work in DoH
7	'Proof of concept' (non-live demonstration of technology)	CFH, technical designers	Technical demonstration in non-live environment seen as successful	The technology 'works' but potential users appear disinterested in it
8	Number of PCTs who have begun activity on HealthSpace	CFH, SHAs, PCTs	14 PCTs have included HealthSpace in their public information programme for the SCR	Many PCTs were keen to take advantage of a one-off offer of central funding to undertake the public mailout before end March 2010; 14 of 33 chose to include information about HealthSpace in this.
9	Mailshots (absolute or relative number of people sent a letter)	CFH	Exact figures not available but estimated 500,000	
10	Number / proportion of people in the country who have registered for a basic HealthSpace account	CFH, SHAs, PCTs, patient organisations	110,000 people have registered for a basic account. Very few people were willing to talk about their experiences with HealthSpace. Of those who were, all were disappointed with its current functionality.	Registration for a basic HealthSpace account may be done online. There is almost no data on whether or how people who have registered for HealthSpace are using their account.
11	Number / proportion of people in participating PCTs who have completed paperwork to register for an advanced account		No direct data available on how many people have started to create an advanced account. Indirect data suggest that around 9000 people have begun the paperwork and 3100 have brought it in for sign-off.	This step cannot currently be done online; it requires sign-off by the person's GP or a PCT front office. Paperwork is processed in a national back office. The forthcoming online registration may possibly lift a significant barrier to uptake
12	Number / proportion of people who have activated their advanced HealthSpace account		2219 people have activated their advanced HealthSpace account and are technically 'live' for accessing their SCR from home	Once Exeter back office has approved application, patient has to activate the account online. Attrition rate between starting an application and activating one is about 75%
13	Number / proportion of people who have used their HealthSpace account to access their SCR		No data available. We did not identify a single person who used HealthSpace to access their SCR.	We tried to obtain quantitative and qualitative data on this but had limited success. However a lag might be expected between creating SCRs and patients seeking to view their SCR, hence findings do not exclude a future rise in interest
COMMUNICATION SUCCESS				
14	Opinion leader endorsement (service users and/or clinicians recommending HealthSpace in communication materials)	CFH	Communication material produced by CFH cited patients with long term conditions and their clinicians who describe how HealthSpace has helped manage the condition and empowered the user	Whilst patient 'ambassadors' for HealthSpace have been identified by CFH, they appear to be unrepresentative of the wider population of people with long term conditions

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