Looking back, moving forward
Capturing lessons and building the evidence base for health informatics
The Connecting for Health Evaluation Programme
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Unfinished business: A national research programme to evaluate the effect of IT on Patient Care

Professor Richard Lilford
University of Birmingham

It was a privilege to lead the NHS Connecting for Health Evaluation Programme from 2006 until 2012. The National Programme for Information Technology (NPfIT) was an ambitious Department of Health programme that aimed to move the NHS in England towards a single, centrally-mandated electronic care record for patients and to connect 30,000 general practitioners to 300 hospitals, providing secure and audited access to these records by authorised health professionals [1]. The programme to evaluate implementation under NPfIT owes its existence to Professor Sir Muir Gray, (previously) Director of the National Knowledge Service and Chief Knowledge Officer to the National Health Service, who stressed the importance of independence in the conduct of research. This is necessary to win public confidence and there is empirical evidence that non-independent interventions are liable to bias [2]. My team and I were contracted to manage the programme under an extension to the Department of Health Patient Safety Research Programme. And what did we achieve for £5m? The outputs of the Programme are described in this supplement which contains a paper from each of the nine commissioned projects (although two of these projects have combined to produce a single paper).

The impact of eHealth on the Quality and Safety of Care (Parts 1 and 2)
Susannah McLean

Computer systems can be used for tasks ranging from providing static databases, through implementing an electronic postal service (e.g. transferring laboratory results to clinical areas) to decision support systems to assist in diagnosis and treatment [3-6]. Computer systems have also been used to obtain clinical histories from patients [7, 8], to automate certain procedures such as dispensing medicines and for bedside use to reduce the risk of patient misidentification – for example through bar coding. With this in mind a call was put out to review the entire world literature and summarise the state of the science. The team who took up this challenge constituted Aziz Sheikh, Susannah McLean and colleagues at the University of Edinburgh. The finding of their final report, based on no less than 67 systematic reviews, was published in PLoS Medicine by Ashly Black [9]. However, the team were commissioned to extend their compilation of world literature to include telemedicine and produce a publically available database. The team have now assembled a database of an astounding 162 systematic reviews. This is a valuable repository of literature and I hope that means can be found to keep it up to date in this fast moving field. This is especially important in the area of clinical decision support where most evaluations arise from a small number of sites where IT has evolved over a long period of time. Results may be quite different for commercial systems where the technical and social factors can not evolve together over a time span measured in decades.

Electronic Blood Tracking: improving blood management and patient safety
Abdul Roudsari, Jonathan Kay, Sanaa Henni, Kate Goddard, Phil Gooch, Omid Shabestari, Juan Adriano Moran and Kamran Golchin

The most important factor in ‘incorrect blood component transfused’ incidents is misidentification of the patient. The ‘weak spot’ at which this occurs most frequently is the point of the final identity check at the bedside. These errors should be avoidable through the adoption of more modern measures to improve transfusion safety [10]. The National Blood Transfusion Committee and NPSA produced recommendations for safer transfusion in 2006 and these included a specification for the Electronic Clinical Transfusion Management Systems (ECTMS).

Abdul Roudsari, Jonathan Kay and colleagues from the Centre for Health Informatics, City University, London were selected to evaluate a pilot ECTMS at Croydon University hospital. The study showed that moving to a new system requires a much more detailed project plan and more vigilant day to day managerial oversight than would intuitively be supposed. Explicit managerial/administrative time must be resourced and allocated for the purpose. In part, this need arises because the systems which new IT protocols have to interface are all different – hence there is no ‘one size fits all’ implementation method. Electronic systems to manage transfusion comprise just one example where it is easy to under-estimate the resources needed to successfully manage change. They are also an example of the need to tailor systems to local circumstances.

The Electronic Prescription Service in Primary Care: Great oaks..?
Nick Barber

The NHS CFH Evaluation Programme commissioned Nick Barber’s team to study a new electronic:
system to transfer electronic prescriptions directly from GP to pharmacy. Their paper provides yet further evidence of the complex ways that IT systems interact with existing work practices. The evaluation exposed all sorts of problems that would be very hard to predict – non-delivery of prescriptions because the wrong date had been entered at the GP end for example. Beware the systems engineer who thinks that functioning IT systems can be derived without a period of trial and error. The detailed observational work in this study also documented existing practices such as the high level of personal discretion pharmacists use to enhance the amount of information included on the medicine label. It is important that systems do not impose excessive regimentation, so that they can be adapted to suit different work practices. The authors also make a heartfelt plea to reduce the number of hoops that must be traversed to conduct research in the general interest. Readers might be interested to learn about another project concerning prescribing, funded by the Patient Safety Research Programme. Electronic prescribing has been shown to reduce prescribing errors in hospital [11] but has not been adequately evaluated in primary care. This deficiency has now been corrected by a cluster randomised controlled trial (RCT) involving 65 general practices to evaluate a combined IT and educational intervention to reduce prescribing errors in primary care [12]. The results show a statistically significant effect with a reduction in prescription errors [13].

Lessons learned from implementation of nationally shared patient records in England, Scotland, Wales and Northern Ireland
Trish Greenhalgh, Libby Morris, Jeremy Wyatt, Gwyn Thomas

Trish Greenhalgh reported on two projects [14, 15] that investigated what seems like a simple solution to a straightforward problem – making clinical information from one place available in another. Again, we find that “there is always a well-known solution to every human problem - neat, plausible, and wrong” [16]. The results suggest the importance of giving people what they need, and not what you think they want; (unless your product is truly novel in the fashion of Steve Job’s innovations). The paper offered in this supplement also provides an interesting comparison between the electronic health systems developed by different countries in the UK and implications for the future. In her application Trish Greenhalgh promised a report contextualised in the wider political environment and that is what she delivered.

Understanding the Implementation and Adoption of the NHS Care Record Service (CRS) in English Secondary Care
Zoe Morrison

The ‘NHS Care Records Service in secondary care’ was a large scale project into the adoption of electronic health in hospitals. Professor Sheikh’s research team worked with early adopter Trusts as they implemented one of three core software systems. Utilisation of a prospective case study approach allowed the team to track implementations. The ‘mixed-methods’ evaluation aimed to evaluate the organisational aspects, costs and certain aspects relating to patient safety. The results were described in the context of a politicised and changing external environment. The study revealed tension between standardisation and the perceived need to adapt systems to meet local needs. Work-loads were increased for some front-line staff and there was a redistribution of work practices when the computer system was first introduced. At least in the early stages paper and computer systems ran in parallel. This work is now being extended under a NHS programme grant held jointly between Sheikh in Edinburgh and Coleman from the NIHR CLAHR for Birmingham and the Black Country.

Should there be greater structuring and coding of the medical record?
Zoe Morrison and Bernard Fernando

The ultimate aim of structuring and coding clinical records is to retrieve information for decision making. Coded information supports algorithms for computerised decision support. The advantages and limitations of algorithms in medical practice have been studied. I have argued that formal systems are beneficial in scenarios where a problem is tractable, but there are many scenarios in medical decision making where a more intuitive, ‘emergent’ process is required [17].

Aziz Sheikh, Zoe Morrison and colleagues have now completed their mixed methods evaluation to develop best practice recommendations on the structuring and coding of clinical data. This involved a formal systematic review on structuring/coding the patient’s presenting history and an in-depth qualitative exploration of the perspectives of healthcare professionals, patients/carers, administrative staff and academics on the optimal balance between free text and coded data and how this can be achieved.

The research team have utilised four case studies – patient’s ethnicity, drug allergies and adverse drug reactions, diabetes mellitus and depression. It will be very interesting to compare these four areas given their inherent differences; but already many studies have been found which show that enhanced coding can lead to improved care. This supports the results of a MRC funded trial of enhanced coding in antenatal care [18]. Additionally, the team are taking into consideration the approach to structuring and coding clinical records in several other countries including Germany, Sweden, USA and Australia. I anticipate that this work will extend the status of the UK as a world leader in this field and that the project recommendations will inform policy and practice for years to come.

Understanding the impact of information technology on interactions between patients and healthcare professionals: the INTERACT-IT study
Fionagh Thomson, Heather Milne, James Hayward, Hilary Pinnock, Kathrin Cresswell, Bernard Fernando, Guro Huby, Robin Williams, Aziz Sheikh

The NHS has introduced a number of new functionalities into primary and secondary care such as Choose and Book (eBooking), Electronic Prescribing (ePrescribing) and Summary Care Record to name but a few. To a greater or lesser extent, computers have the capacity to affect communication between service user and clinician [19-21]. The study commissioned here aims to understand how the computer affects the interaction between patient and healthcare professional during the consultation with a focus on the introduction of new IT functions. The
research team are looking at four sector groups - GP Practices, Out of Hours, Oncology clinics (Outpatients) and A&E. The paper in the supplement is an important summary of how consultations differ according to the aforementioned context. In general, computers are acceptable in the consulting room (and will become increasingly so) and Fitter's original guidance to ensure that the patient can share a view of the screen, seems to hold. The final report will inform both IT design and computer etiquette.

Conclusions
Information technology is here to stay and the issue now is how it can best be implemented and integrated into clinical practice. The work described in this supplement will need to be extended through other NIHR programmes since the rate of IT adoption is accelerating and independent evaluations are more necessary than ever. Capacity has been generated for follow on research, and a network of committed researchers has been developed in the UK. Numerous international links have been forged and there is considerable interest from colleagues working in health policy internationally on the lessons arising from this unique evaluation. At the time of writing, one project is still ongoing and the final report of another is under review. This programme has already provided an excellent evidence base to help inform the future implementation and development of IT systems with the production of over 54 publications, eight of which have appeared in the BMJ or Lancet – a credible return on investment.

Acknowledgements
I would like to express my appreciation to Mike Pringle from the University of Nottingham for chairing the Programme Executive and Advisory Groups and for his support throughout. I also thank the Programme Advisory Group members; Justin Rioridan-Jones from the Department of Health, Jeremy Wyatt from the University of Warwick, Nick Barber from the University of London, Aziz Sheikh and Dr Claudia Pagliari from University of Edinburgh, Maureen Baker, Michael Thick, Nigel Beasley, Jana Dale from NHS CFH, Martin Waller from the SDO Programme and Paramjit Oberoi our Consumer Representative. I am also deeply grateful to Jo Foster, Lee Priest, Nathalie Maillard and Pamela Nayyar for their unstinting support in managing the programme here in Birmingham. The programme has benefited from international advisors such as David Bates and Denis Protti. Here in the UK, the programme has been supported by Kay Pattison, Sally Beck and Chris Long of the DH Research and Development Directorate, along with Mave Smith, Philip Candy, Kathy Mason, Suzanne Lea, David Jennings and Charlotte Wood from NHS CFH. I am thankful to the NHS CFH project sponsors – Maureen Baker, Ian Lowry, James Hawkins, Mark Davies and Stephen Corbett.

References
Evaluation crucial to learning from both disasters and triumphs

T he NHS’s National Programme for IT is widely and wrongly regarded as an unmitigated disaster. The default position adopted towards any government IT programme is that it will wreck its budget and fail to deliver. NPfIT was meant to be different, yet it seems to have reinforced rather than undermined that view.

The latest brickbat thrown the way of NPfIT came courtesy of the Cabinet Office which declared the programme: “has not and cannot deliver to its original intent”.

Yet the same review concluded that NPfIT had also contained notable successes, including the NHSmail email system, the Choose and Book system for patient referrals and the Picture Archiving and Communications Service.

No one with any understanding of the demands being placed on the NHS and of how they will grow and change, will believe those challenges can be meet without significant use of and investment in IT.

As House of Commons health committee chair Stephen Dorrell is famous for nearly saying, the greatest challenge facing the NHS is “efficiency, stupid”. A sage from an earlier time, Sir Derek Wanless, made it clear in his seminal 2002 report that, without significant investment in IT, the NHS would face unaffordable cost escalation.

This is what makes NHS Connecting for Health’s Evaluation Programme so important. The NHS has a tendency to rush on to the next project without learning the lessons from the successes and failures of the work they have just undertaken.

As Professor Richard Lilford, leader of the Evaluation Programme says in the foreword: “Information technology is here to stay and the issue now is how it can best be implemented and integrated into clinical practice.”

Careful evaluation of key aspects of the programme increases the chances of avoiding the mistakes and repeating the triumphs of the programme.

The full results of the evaluation programme come at very opportune time. With the ending of the National Programme, individual NHS organisations are increasingly being asked to make their own IT investment decisions. The level of expertise of those placed in that position varies hugely from leading Foundation Trusts who have always controlled their own IT destiny, to emerging clinical commissioning groups who know they need to corral a bewildering array of data to drive service change, but are wondering where and how to start.

Then there is the Department of Health’s long awaited – and much rewritten – Information strategy. Despite the fact that it no longer bears the “revolution” tag, big things are expected of it. But determining the priorities and setting out a bold vision is proving challenging. An added complication has been the need to take on board the January recommendations of the NHS Future Forum – hence the long delay.

The government’s commitment to giving the public online access to their patient records by the end of the parliament is a welcome sign of ambition. Prime minister David Cameron has said: “Information is power and, by sharing it, we can deliver modern, personalised and sustainable public services.” Without greater engagement by people in their own healthcare, even the most successful efficiency and reform programmes will deliver diminishing returns. However, the recent Cabinet Office consultation on the use of public data showed the nervousness of many in health over patient confidentiality. In short, the greater use of IT will always be a question of balancing risks and opportunities.

Robust evaluations of the kind included in this supplement will help strengthen the case for an appropriate and incremental expansion of the NHS’s use of IT.
Background

The world’s population is increasing exponentially and is expected to reach 9 billion people by 2050. This is due to increasing life expectancy and also as a result of more successful treatment of infections, such as HIV/AIDS. Such a vast increase leads to a fundamental dilemma as to how to care for all these people. In particular, there will be an increase in the proportion of elderly people in the population. The ratio of frail elderly people with one or more long-term condition to the fitter, younger and economically active, will increase. In England it is estimated that there will be 18 million people with one or more long-term condition by 2025. These people will often have complex healthcare needs, as more than one long-term condition affects their ability to live a healthy independent life.

In addition, moves by the government to introduce “choice of provider”, although rendered irrelevant by geography in much of the country outside of London, are also having an effect. People have high expectations of their healthcare provider and some may also demand further information that they then need help to interpret correctly. There is also an increasing number of expensive drug and non-drug treatments to which the public expects to have unrationed access.

The recent economic downturn has seen multiple plans to reduce public spending. In order to meet the increasing demands of an ageing and expanding population, we will have to find ways of delivering healthcare much more efficiently.

It is in this context that the government has been championing eHealth. It is hoped that eHealth will lead to increased information provision and healthcare capacity. eHealth is expected to improve efficiency, support greater patient self-management and choice, and remain within strict boundaries of cost-effectiveness. This is an optimistic wish list: can eHealth deliver? In the face of powerful pressures to “do something” the government uncritically accepts the presumed advantages of eHealth. The government’s white paper “Liberating the NHS: an Information Revolution” emphasises the benefits of eHealth but is lacking in supportive evidence.

Manufacturers of eHealth technologies sensed an opportunity. The healthcare market has been deluged with devices promising to make care easier and more efficient at both the level of the individual patient and at the level of organisations. But how many of these claims are substantiated with robust evidence?

In a nutshell, does the evidence-base support eHealth? This was the impetus underlying our extensive search for relevant published works on eHealth. Around the UK, eHealth interventions are being implemented despite the technology remaining unproven. Our aim was to review the evidence for eHealth and see if the claims made in its favour stand up to scrutiny.

Our research was conducted in two phases. Phase 1 provided a synthesis of the evidence to inform the development of NHS Connecting for Health’s (NHS CFH) strategy as it sought to deliver the National Programme for Information Technology (NPfIT). Phase 2 followed this up and concentrated on the remote delivery of care, or “telehealthcare”. There were a number of significant challenges facing the evaluation team in producing these pieces of work.

Challenges faced by the Evaluation Team:

- Vast volume of potentially relevant literature
- Large range of potentially relevant technologies
- Short timeframe in which to undertake work
- Papers not indexed by terms of interest in the academic databases
- No standardised methods for appraising such studies

The work was in the form of a literature review. A “review of reviews” as the volume of primary
literature precluded any direct assessment. We spent some time developing detailed search strategies for the academic databases and websites pertinent to this subject area. This involved conceptualisation of “What is eHealth?” and “What do we mean by quality and safety?” Once we had mapped these terms and conducted our searches the results of the overview were synthesised into the following broad categories:

- Data storage, management and retrieval
- Supporting clinical decision-making
- Supporting the remote delivery of care

The first two categories are summarised below and the third is the subject of the article covering Phase 2.

**Data storage, management and retrieval – the electronic health record (EHR)**

We found that the following themes are useful to consider when assessing the appropriateness of a particular EHR for implementation to a healthcare setting. This list is constantly evolving and will need to be updated as the numbers and types of electronic health record increase. Below we describe the most useful parameters regarding EHRs.

**EHR origin**

For example, where an EHR is home-grown in an institution, the users have a sense of ownership and have often tried different designs of EHR until they find the one with which they are most comfortable. In this way, a gradual process of customisation takes place and the record ends up highly “fit for purpose”. However, such “bottom up” EHR design evolutions will often not meet interoperability criteria and so are not portable to different settings. Alternatively, the EHRs may be “top-down”, where a central bureaucracy has taken charge of the commissioning of the software and the setting of the specifications. These EHRs may have a high degree of interoperability, so that information may be easily transferred between distant institutions, however, the users in certain institutions may find that the EHR does not cater for specific workflow functions and so their processes are not supported and they become less efficient. In some cases the users in an individual institution may resent that the EHR was specified for centrally without taking into account a particular need of theirs and this can cause major problems with implementation. The “central versus local” is a major tension in the development of EHRs and cannot easily be resolved. There is a need for good communication during the specification and commissioning process to ensure that as many needs are catered for as is possible and consideration given to the adoption of standard (evidence-based, where possible) workflows across institutions.

**Setting**

Setting is a major consideration in the design and implementation of EHRs to improve quality and safety in healthcare.

**Level of functionality**

This is a very variable aspect of EHRs. EHRs may be very simple with only one or two entry fields. Or increase in complexity up to the model of a kind of portal which opens up numerous different EHRs (one for radiology, one for biochemistry, one for general practice, one for each medical speciality) each populated from a different database and allowing ordering of tests or prescribing of medications as ancillary functions. There are reasons to keep some functionality outwith a complex EHR: for example the ITU ventilator settings should not become confused and should only be adjusted by a suitably qualified member of staff.

**Access**

Collated EHRs, such as that described above which is accessed via a portal, may be convenient because a large cross-section of information is available to whoever has access. However, limiting access for certain sensitive areas, e.g. records of psychological consultations or with child protection significance, may be more consistent with patient desires for confidentiality. There is a major public debate to be had as to what level of access patients should have to their own records, and what contributions and changes they can make to it. Web-based records represent a potential minefield in terms of data-security against data-intruders and cyber attackers. Then there are questions regarding the ethics of patients choosing to sell their own data, either for research or to marketing companies to inform targeted product placement.

**EHR effectiveness**

But the bottom line is whether EHRs have any effect on the quality and safety of healthcare? Our literature search generated only anecdotal evidence of such desired improvements. There was some research that indicated that factors such as the legibility and completeness of EHRs were improved and consequently time was saved for some healthcare professionals and administrators. There was no research into difficulties such as risks generated by having an inflexible record or increased time for data inputting. The one area of exception to this was that of the Picture Archiving and Communication System (PACS) where there was...
Looking back, moving forward

Recent announcements from the department

- Interoperability – in September 2011 the Department stated that “The exchange of information between patients and clinicians and across the NHS is a fundamental part of how we are centring care on patients and making sure innovation and choice are fully supported” and the Future Forum interim report in November 2011 stated “data about a patient or service user should – with their consent and with the right safeguards – be shared between all the organisations involved in caring for that person”
- Data Standards – in August 2011 the Information Standards Board for Health and Social Care, approved SNOMED CT as a fundamental standard and notified all NHS organisations, independent providers and information system suppliers of the need to use SNOMED CT when providing care
- Clinical buy-in and end use – support from Ministers and Officials for the eHealth Insider Chief Clinical Information Officer campaign.

NHS CFH sponsor comment

I would like to thank Prof Sheikh and his team for this very thorough piece of work. They have added to the formal knowledge in the area of eHealth by creating a strategy for identifying high quality primary and secondary literature in this field, a tool for critically appraising the literature based on internationally agreed approaches and a framework with which to consider the planned implementation of eHealth innovations into complex health service organisations. They have also created a database of research in this field which will aid many decision-makers across the health and care system when considering investment in eHealth.

Their conclusions as outlined in the accompanying article are soundly based on this research and, while in places they make sobering reading, are timely as the Department considers policy and strategy in this area.

Some of the key headline conclusions including a focus on interoperability and data standards, attention to data recording by healthcare professionals and the need for greater focus on clinical involvement in eHealth applications have already been publically accepted by the Department in statements from Ministers and this report has been extensively consulted as we build the evidence that will support the forthcoming Information Strategy.

Kathy Mason, Director – Policy Planning and Information Governance, DH Informatics Directorate

reasonably good evidence of an improvement in work efficiency and increased productivity for radiology services.

Supporting clinical decision-making - Clinical decision support systems (CDSSs)

There are a variety of forms of technology that support clinical decision-making. However, we are concentrating on computerised decision support systems. There are two main parameters that need to be described in considering CDSSs.

Processing

This refers to the level of sophistication of the decision-making of the computer programme. Does it simply match a result with something in a database or does it apply a logic process, such as a multi-level perceptron or other such model? How many variables can be input and how long a differential diagnosis or how many decision outputs will it make?

Integration

This refers to whether the CDSS stands alone, e.g. to help doctors reach a diagnosis, or is integrated into an EHR. When integrated, the role of CDSS may be to assist smooth, timely and efficient (non-wasteful) ordering of laboratory tests. Similarly, a specific style of integrated CDSS assists the safe prescribing of medicines. These latter two type of CDSS often produce warnings or alerts if the system disagrees with any of the user’s actions. In some cases these warnings are trivial and may be over-ruled. If this is happening repeatedly then this can lead to “alert fatigue” where the user no longer reads the warnings as they always expect them to be trivial. This risks the user missing a significant warning. This situation of “alert fatigue” can be avoided by careful design involving discussions between users and IT specialists.

What is the evidence?

So again, what did we find in terms of evidence regarding these systems? There is only weak evidence of any behaviour change at all and it did not inevitably lead to higher quality of patient care. However there was evidence of increased provision of preventive care measures, disease-specific examinations and monitoring of side effects. Surrogate outcomes did improve in some cases, however, the evidence was variable.

Conclusions

Overall, there is a rush to introduce these eHealth measures and it appears that the evidence is not strong in substantiating the claims made regarding them. In particular there is no evidence regarding cost-effectiveness.
In theory, the main benefits of telehealthcare include that travel time and costs are avoided so that one professional may see more patients in a shorter time.
managers are keen to see if telehealthcare will enable patients to take greater responsibility for their illness themselves and “self-manage”

Some professionals are also concerned that this process risks “medicalisation” of some aspects of patient care. Where in the case of minor complaints or illnesses, where the patients might have self-managed their problem previously, or waited a few days to see if it would resolve before making an appointment, they contact the doctor directly for advice, because the access has improved with telehealthcare. Therefore, medical complaints that would not traditionally come to a doctor’s attention, would receive a full medical opinion. This would result in unnecessary consumption of valuable resources and has the exact opposite effect to the intended aim of telehealthcare – i.e. to increase “self-management”. There is some empirical evidence from patient qualitative studies that patients are aware that this would happen. A focus group study found that patients were concerned that, rather than supporting self-management and greater independence for patients, telehealthcare would re-enforce traditional professional power hierarchies [8]. The passive patient would consult frequently: double-checking their illness-related decisions, and would be more inclined to trust a monitoring system to tell them whether they were ill or well regardless of how they felt in themselves [9]. In this way, a passive patient would become trapped in the “sick role” with little authority over their daily life in terms of health related decisions, such as:

- When/whether to take medications
- Varying of dosage (e.g. insulin in diabetes)
- What to eat
- What to drink (especially in the case of alcoholic beverages)
- When to go to bed/get up
- How much exercise to undertake

Also to be found in the evidence reviewed, were multiple short surveys [10-14] that assessed the patients’ level of satisfaction with telehealthcare as they encountered it in studies. These consistently found that patients were broadly very satisfied with telehealthcare. But it is very important to note that the majority of patients wanted to keep the option of a face-to-face consultation in addition to the telehealthcare. This shows that patients would prefer to have the choice of seeing a clinician face-to-face, rather than the blanket introduction of telehealthcare across all types of consultation.

In theory, by using telehealthcare, a patient who would often previously have been admitted to hospital, would be managed at home.
This effectively reduces the frequency and intensity of care, consequently reducing costs, as long as the set-up and running costs of the technology are not too great. However, there is the risk that a patient with an exacerbation of a chronic illness may suffer a rapid unpredictable decline in their home setting - far from comprehensive emergency care. A result of this might be an increased death rate among patients managed by telehealthcare. So far, there is little evidence to consider regarding death rates in telehealthcare, because most of the relevant studies are too small or too short to have a significant number of patients die in either the intervention group or the control group. One study which did find an increase death rate among patients using telehealthcare for chronic obstructive pulmonary disease, was the Polisena [15] meta-analysis. Unfortunately, it appears that there was a transposition in the data extraction from one of the contributing trials [16]. We have made the authors aware of this, when the data are entered correctly there is no significant difference in death rates for telehealthcare compared to normal care. Patients are no worse off but no better off either.

We also wish to sound a note of caution regarding other hoped-for benefits of telehealthcare. There is a hope that increased access to healthcare would improve morbidity measures, however, there is little evidence of this. Some studies have measured small improvements in surrogate markers of morbidity such as glycaemic control, blood pressure and lipid profiles in a telehealthcare-treated group in comparison to a usual care group, but whether such small changes will translate into improved rates of heart attacks, stroke and other important morbidities cannot yet be known, as studies are neither large nor long enough to demonstrate any such changes.

With regards to hospital admissions the evidence was of moderate quality. However, there is a natural principle that needs to be taken account of in this context – see box.

Unfortunately the literature that addresses these types of rationing and cost-effectiveness questions was of poor quality. There were 55 studies summarised by one systematic review [17] and our broader investigations supported their findings. Important health economics measures were absent from the literature, such as opportunity cost (the financial value of foregone benefit – see box below).

### Cost–effectiveness Glossary:

#### Opportunity Cost

If a hospital decides to invest in a new gym for its staff, for example. Then the opportunity cost of this decision is the value of benefits (i.e. interest) it would have achieved if the next best alternative use for the money was to deposit it in a bank to earn interest.

#### QALY – Quality Adjusted Life Years

A health outcome that takes into account the combined benefit to quality of life and to life expectancy of a specific healthcare intervention. If a person has a high QALY they have more to gain than someone with a low QALY for the same intervention. If different interventions worth the same in QALYs are to be compared for the same person, they may have to choose between living for a long time with a low quality of life, or living a shorter time with high quality of life.

It is difficult to measure quality of life, as results vary between individuals.

#### Cost Utility Analysis

This allows comparison of two or more health interventions in terms of the cost of the “utility” or quality of life/patient satisfaction gained. There may be multiple effects of the health intervention and these are summarised into QALYs gained. Cost utility analysis then involves calculation of the cost per QALY gained thus giving an idea which intervention is more cost-effective.

In addition, benefits were only ever calculated from the healthcare provider’s perspective, whereas most treatments give the greatest benefit to the patient, in terms of improved quality of life and reduction of disability, and benefits to society, in terms of resulting in fewer disabled patients requiring resources to care for them and also allowing patients to continue economic activity in society, rather than, for example, retire early on grounds of ill health. It is important that these perspectives are taken into account, as may be done by the calculation of QALYs and cost-utility analysis, see box above.

There are examples in the literature of telehealthcare improving access to care although this may have unforeseen consequences. Telehealthcare is also capable of reducing admissions to hospital, especially among patients who are more severely ill and as a result at a higher risk of admission. Overall the evidence regarding telehealthcare is only low to moderate quality and the evidence on cost-effectiveness is particularly poor. In the future, research needs to be designed to address these areas and focus on meaningful clinical endpoints. In conclusion, we have significant reservations as to whether telehealthcare will deliver to meet the high expectations that policymakers and manufacturers have of it.

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http://www.birmingham.ac.uk/cfhep
This is an impressive and very thorough piece of work, Professor Sheikh and his team have examined the baseline of published research about the impact of IT on the quality and safety of care, providing a status report of current scientific evidence to inform future investment in systems; and have added over 20 systematic reviews to the formal body of international research on eHealth.

This latest report, which focuses on telehealthcare, highlights that there is still a significant gap in good quality evidence. This flags the need for those of us engaged in the development and delivery of eHealth to be rigorous about collecting the evidence about the extent to which theoretical assumptions about benefits and outcomes are realised and about unanticipated and unintended consequences; and, most importantly, are shared in order to shape and improve progress.

Kathy Mason, Director – Policy Planning and Information Governance, DH Informatics Directorate
Electronic blood tracking: improving blood management and patient safety

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“The World Health Organization (WHO) defines eHealth as the cost-effective and secure use of information and communications technologies in support of health and health-related fields, including health-care services, health surveillance, health literature, and health education, knowledge and research.”

The UK’s public health care system is complex and many-sided with the key question continuing to be asked: as costs keep rising, how can healthcare services provide the best care for patients? The mantra of “safety, effectiveness and efficiency” is fundamental in driving research into finding innovative ways to improve the healthcare process for healthcare providers and patients. Evaluation of these proposed advances and how they are implemented is crucial to understanding the strengths, weaknesses and lessons learned in designing and applying such novel systems.

Blood transfusion

Transfusion of the incorrect blood type - ‘ABO incompatibility’ - is the most serious blood-type related error, primarily resulting from failure to carry out final identity checks. Reports published by Serious Hazards of Transfusion (SHOT) have shown that, between 1996 and 2004, five patients died directly as a result of being given incompatible blood. Furthermore, ABO incompatibility was a contributing factor in the deaths of nine patients and caused major illness in 54 patients. In 2005 the Medicines and Healthcare products Regulatory Agency (MHRA) produced the Blood Safety and Quality Regulations to maintain a complete traceability record for all blood components and products from donor to recipient for 30 years. In 2006, the National Blood Transfusion Committee (NBTC) along with the National Patient Safety Agency (NPSA) and SHOT issued the ‘Right Patient, Right Blood’ Safer Practice Notice [1] which provides recommendations for improving the safety of blood transfusions, including an IT specification, the Electronic Clinical Transfusion Management System (ECTMS) guide.

With this in mind, an evaluation of a new blood tracking system being implemented was carried out at The Croydon University Hospital (formerly Mayday) NHS Healthcare Trust. The NHS Connecting for Health (NHS CFH) funded the work and, after considering a high number of applications, selected Croydon University Hospital as the most appropriate Trust to carry out the pilot of a new electronic blood tracking system according to ECTMS guidance. The NPSA worked closely with NHS CFH on the pilot and was represented on the steering group. The guidance provides a ‘gold standard’ for the automation of the blood transfusion process from identifying a patient and ordering of blood transfusion, through to the taking of blood samples for crossmatching, to final transfusion of the blood product. The expected benefits gained by the deployment of an electronic blood tracking system ranged from reducing inpatient safety incidents, reducing the number of samples rejected by the lab, and improved traceability of blood.
System (PLIMS), Radio Frequency Identification (RFID), wireless fidelity (WiFi) and barcodes (linear and 2D) could be used to support adherence to the ECTMS guidance and reduce human error. The new blood tracking system was implemented within the Croydon University Hospital in selected pilot wards, CCU/ICU units, maternity unit, theatres and LifeBlood suite, and included all stages of the blood transfusion process from phlebotomy to final transfusion and fusing of blood. This included the introduction of an electronic kiosk at the blood bank, and computers on wheels (COWs) with barcode and RFID scanners on the wards.

A systematic review of the literature looking at electronic interventions in the blood transfusion process confirmed that, globally, barcode and RFID systems are the main technologies used in electronic blood tracking, and appropriate software, use of barcodes and RFID tags can prevent identification matching errors. These studies also provided preliminary recommendations for the automation of the blood tracking process, as shown in Box 1.

**Box 1.**

**Recommendations from the systematic review of studies of electronic interventions in blood transfusion**

1. Patients should wear appropriate identification at every step of blood transfusion procedure.
2. Bedside handheld scanners and printers should be used because, even with automated transfusion systems, human error occurs during patient identification at the bedside.
3. New procedures, both technical and non-technical, should be investigated and adopted to reduce the risk of error. For example, the risk of patient identification errors can be reduced by using accurate verbal identification.
4. Training and communication should be improved. Staff training is needed when new technology such as a barcode system is introduced. Feedback and discussion among health professionals can be used to develop a quality assurance plan for monitoring and correcting transfusion procedures.
5. Automation should be employed to reduce the incidence of error at each stage of the transfusion procedure. However, it is important to note that unreliable equipment/equipment failure can be a “show stopping” problem. The resilience of the network is crucial to the successful usage of electronic systems.

**Blood tracking project evaluation**

The Centre for Health Informatics at City University, London was commissioned by NHS CFH to undertake a full independent, multi-method evaluation of the Croydon University Hospital pilot to ensure that the process is recorded, user views are accounted for, and recommendations about the implementation and effectiveness are useful to share with other NHS Trusts looking to use the IT specification. The evaluation was collaborative with the Croydon University Hospital and CFH, and incorporated formative, summative and comparative elements using both qualitative and quantitative methodologies.

The findings of the quantitative analysis of system usage, user expectations, satisfaction and perceived effectiveness have been triangulated against the results of the qualitative stakeholder analysis and usability evaluations.

**Benefits of electronic blood tracking system**

During the course of the evaluation the main benefits of this ECTMS implementation were found to be improved blood unit management and improved patient identification – the trade-off being a slower process that requires changes to clinical workflow. The evaluation suggested that the system provided a useful audit trail, although workarounds were required to remove duplicate and redundant data (see Recommendations below), and did enforce a strict, although linear, workflow, to ensure procedures are followed, assuming the system is used end-to-end as intended.

A number of factors in the electronic blood tracking system were evaluated in terms of the importance placed on them by healthcare providers and the final satisfaction that they reported for the same factors. This was carried out to compare user satisfaction with stated importance with various elements of the system.

Certain system characteristics were identified in which a moderate increase in their level of end-user satisfaction increased the perceived effectiveness of these features, leading to improved perceived effectiveness of the system overall. These system factors were:

- Reducing the number of blood samples rejected by the lab
- Time savings for staff involved in blood transfusions via the automation of processes
- Having guided steps in any given process involved with blood transfusion
- Improving access to patient transfusion history and any special requirements
- Patient information is accurate and complete at the time of enquiry due to quick and easy information updating
- Providing early alerts to blood labs for product requests and special product requirements
- The system is reliable and does not experience substantial “down time”
- Removing paper-based processes and providing information electronically
- Improving the wristband technology to assist the checking process.
System compliance

The ECTMS sets out the steps by which an electronic blood transfusion system should satisfy a number of end-user scenarios or ‘use cases’. These specify a fully integrated, end-to-end system, complete with e-prescribing and ideally decision support. The Trust did not have an e-prescribing system in place, so a workaround had to be found that involved use of the Trust’s existing OCS used for all blood requests. However, there were a number of potential risks associated with this, acknowledged in the Trust’s final report:

1) Use of OCS involved printing off the prescription for blood components and placing it in the patient’s paper record. As this would be separate from the main prescription chart, it could be accidentally overlooked, so the required transfusion may not be administered.

2) The OCS allows duplicate records for the same patient, which may increase the risk of user error as an extra search step is required by the blood laboratory to ensure that information stored against a duplicate record is not overlooked.

3) The pathology laboratory information system (PLIMS) was not fully integrated with the OCS, requiring some duplicate data input to be done at the lab.

At the point of evaluation, the system was unable to record the end-time of transfusion, which has implications for the ability to audit outcomes. Also, PLIMS was not fully integrated with the blood tracking application, again requiring information to be entered twice at the end of transfusion and for fating of blood products.

Workarounds to overcome these integration issues required a change management process and updates to laboratory standard operating procedures (SOPs), the impact of which was perhaps underestimated.

Training, user acceptance and technology uptake

A survey was carried out to assess system user expectations and the importance placed on different aspects of the system, in terms of the system itself (e.g. system use and speed), the implementation (e.g. training), the support in place (e.g. availability of online help), and the outcomes (for example, the improved ability to track blood products, and reducing the number of blood products rejected by the laboratory). The survey found that of 126 staff respondents, the majority (76.2%) indicated that the need for adequate training was very important, and 63.7% of staff also attached this level of importance to the need for a formalised change management and training plan.

The cost of installation, training and project management for the system applications used by clinical staff was estimated at £2000, which was 2% of the estimated cost of the system installation (excluding consumables). The deployment plan allocated four months for key user training, with one month for end-to-end testing and end user training ready for ‘go live’ the following month.

It has been shown that software acquisition projects tend to focus on the technical resources required for implementation, and underestimate the ‘hidden costs’ incurred by the organisation, such as user and management time, testing, user training, and access to domain experts. In terms of the cost of staff time, these hidden costs may exceed the total project costs initially estimated for the project, and that the impact of underestimating these costs is predominantly borne by the end users [2].

These concerns over training and staff time, and of the need for more consideration of human factors in relation to the attention devoted to technical effort, were echoed in staff interviews.

The Croydon University Hospital final report on this ECTMS implementation also confirms this, noting that the impact of testing and validation of software changes placed a huge additional workload burden on staff, and that the blood transfusion process remains heavily reliant on training.

The final report also noted that the lack of separate test/training environment made evaluation difficult. In an analysis of the underlying database to the blood tracking system, it was noted that live and training data coexisted in the same database tables, which poses challenges for data analysis and true auditability of the system.

User errors resulting from system usability faults, identified in the training sessions, tended to persist in the live environment. These errors often resulted from a lack of familiarity with the scanning sequence and with the touch-screen interface. There were suggestions that staff who had initial training could have benefitted from further training with the bedside client application, although this may have been reduced by the software providing online help and being more able to recover from user error. At the time of evaluation, the software did not have these features. However, the lack of such features, with the resulting increase in manual steps (for example, by having to repeat steps performed incorrectly through lack of help or prompting in the application), were a major source of staff dissatisfaction with the system.

Usability problems in clinical information systems can impose unwanted changes on clinical workflow, such as inflexible serialisation of task sequences previously done in parallel, leading to increased cognitive load and user error [3]. During evaluation, of the system alerts that were recorded resolved, user error was the third most common cause.

The usability faults, and staff dissatisfaction with them, may have been a factor in the low uptake of the pilot system as recorded in the database logs. During the evaluation period, less that 2% of all blood transfusions were recorded as a complete, end-to-end process in the system, i.e. starting and ending at the bedside using the client application. However, for the majority of the evaluation period, the bedside system was used only in working hours. Transfusions performed outside this time interval were a considerable percentage of the overall transfusions performed. Transfusions performed across work shifts tended not to be both started and completed with the bedside client application; those that were started with it were frequently cleared via the system management software following an overdue alert.

The Croydon University Hospital Project Initiation Document identified that limited training resources made available during the project, and pressures on staff time and resources, would pose risks of medium likelihood and severity to the success of the project. Staff resistance to process change and new ways of working were also recognised as being of medium likelihood and medium severity.

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Looking back, moving forward
The Trust’s report suggests a number of reasons for the low uptake of the bedside transfusion management technology, in addition to those already identified:

- Delays in finding a suitable mobile device for use on the wards by clinical staff. The tablet PC was felt to be too heavy by some staff.
- The requirement to log into another system (i.e. bedside client). Although this was performed by the swipe of an ID card, users still had to manually ‘OK’ this in the user interface, and logging in was required for each patient visited.
- Lack of staff confidence in the reliability of the wireless technology, such as lost connectivity and network card failure, leading to reluctance to use the device.
- Software change requests and the subsequent validation and testing required.
- The bedside client application introduced additional steps in the clinical workflow of phlebotomists and nursing staff, which resulted in a perceived slower process. For example, in the new system blood units needed to be fate at the end of the transfusion, whereas the preferred workflow was previously to fate the unit just after hanging the bag at the start of the transfusion.
- Lack of confidence in using a new system in environments in which transfusions are carried out infrequently.

However, as can be seen in Figure 1, once the system went from use during working hours only to round-the-clock usage, uptake rose rapidly over the final two months of data collection, from a very low base (0.5%) to 14% of all transfusions ordered electronically.

In a previous evaluation of a system for end-to-end electronic management of transfusion [4], there was a similar, initial low uptake (5%) that rose to 14% over four months, rapidly increasing to 91% over the following 12 months before full usage (99%) was achieved five years from system rollout. Given a longer period for implementation and evaluation, it may be that the Croydon University Hospital pilot will show a similar increase to full usage over time.

**Recommendations**

Semi structured interviews were carried out with the local implementation project team to assess their expectations, their concerns and their recommendations for future implementations. The main emergent themes as a result of the interviews were:

1. **Timeframe**
2. **Staff resource**
3. **Communication**
4. **Change and Change management (access and training)**
5. **The technical system (reliability, flexibility)**
6. **External guidance and legislation.**

These factors were perceived to be core to the successful implementation of the electronic blood tracking system. Box 2 lists recommendations from the Croydon University Hospital implementers to carry out a successful, timely implementation:
Box 2. Croydon University Hospital implementation team recommendations for the implementation of an electronic blood tracking system

- Ensure project management is in place and formalised from the outset.
- Ensure there is adequate supplier representation at board meetings from as early on in the project timeline as possible.
- Have adequate BMS cover, to cover routine BMS staff and transfusion nurses, for example, a full-time trainer.
- Have more regular (but shorter) board meetings, especially post-implementation, with focus on driving through deadlines.
- Ideally, there would be more dedicated resources specifically for carrying through the implementation. In relation, designated/protected time would mean people have adequate time to absorb changes.
- Include a more formal preparation period looking at outstanding validation issues, steps and the development required for each of the Use Cases required for meeting each step of the ECTMS guide.
- Have explicit consultation with appropriate clinical staff with regards to suitable timescales and deadlines.
- Have a clearer idea of the precise hardware requirements from the outset of the project.
- Have more formal input from junior and registrar-level doctors. The difficulties with this are, however, recognised due to changing rota.
- Make substantial visits to other Trusts implementing at least parts of the system to help illustrate how the end system will look; for example, this will be an aid to training in that it will help develop clearer aims.
- Training plan and guidance from the outset: it was predicted in the questionnaires that there would be a serious under-estimation of the time and resource required for training. Respondents indicated that clinical staff could have been involved sooner and the training programme could have started earlier.

In summary, the evaluation team identified the following ‘lessons learned’ and made a number of general recommendations. We hope that these prove useful for those planning future implementations.

- Future ECTMS implementations should not underestimate the impact on staff time and workload resulting from the testing, validation and roll-out of a new system. Implementations in which blood tracking software is being integrated with existing laboratory systems should consider and prepare for the impact on laboratory staff workload in terms of validating software updates and changes to SOPs. However, the ECTMS requirements do not address integration with legacy systems. To accommodate this, a sub-set of essential requirements could be produced for partial or staged implementations where, for example, e-prescribing, decision support, or interfaces to the systems of 3rd party suppliers is not initially available. Technical challenges in integrating blood tracking software with existing, legacy systems, in order to comply with ECTMS, should not be underestimated.
- Project management should be in place right at the start, to assist with project initiation, resource planning, and change management. Protected staff time or a dedicated team should be available in the initial stages of implementation and evaluation.
- Future implementations should also provide more realistic estimates for the time needed for user training. Training should be staggered and should be ongoing so that, if the ‘go-live’ date is delayed, there is not a large delay between using the system in a training environment and in the live environment, during which time users may forget the training received.
- ECTMS implementations should have separate, end-to-end, test and training environments for all aspects of the system. It is essential for data accuracy, reporting and audit purposes that live clinical data remains separate from non-clinical, dummy data. The MHRA “orange guide” mandates that system data must be accurate and up to date.
- ECTMS implementations should be fully evaluated for compliance to user interface standards and usability metrics during testing and validation. Serious usability faults should be resolved before the system ‘goes live’. As such faults can impede clinical workflow and lead to user error. It may be desirable for future implementations to be initially trialled on a small scale (for example, on a single ward), to allow inevitable live-system usage problems to be identified and resolved prior to gradual roll-out on a larger scale, round the clock. Analyses of cost-benefit and effects on clinical practice in terms of error reduction and improvements to patient safety, can then be performed once the system has bedded down and usage data becomes available.

Reference List


http://www.birmingham.ac.uk/cfhep
Benefits

The pilot shows that implementing a blood tracking system based on the national standard (the Electronic Clinical Transfusion Management System - ECTMS) makes patient care safer by:

- Ensuring better processes for accurate patient identification
- Reducing patient safety incidents
- Reducing the number of blood samples rejected by the laboratory
- Improving the traceability of blood
- Automating information checking
- Enhancing accountability and audit trail
- Making time savings for staff involved in blood transfusions via the automation of processes
- Introducing innovative use of mobile technologies.

NHS CFH sponsor comment

The pilot at the Croydon University Hospital was to test the national standard (the Electronic Clinical Transfusion Management System - ECTMS) on blood tracking which was developed jointly by the National Patient Safety Agency, the National Blood Transfusion Committee and the Serious Hazards of Transfusion. NHS Connecting for Health (NHS CFH) wanted to gain maximum learning for the NHS by testing whether the standard, based on work in one of the largest NHS teaching trusts in the UK, could be implemented in a district general hospital setting. NHS CFH and the Trust were also keen to explore the use of Radiofrequency Identification (RFID) - a relatively new technology in healthcare – and what other clinical benefits could be derived from the technological investment necessary to improve blood transfusion safety.

As might be expected from a pilot, the outputs have been both positive and negative, but overall the learning will be invaluable for others in the NHS who are putting in blood tracking systems. The key clinical safety outputs of the pilot are, the achievement of much better and safer patient identification processes; reduction in the number of blood samples that are rejected by the laboratory; improving the traceability of blood; using automated information checking; time savings for staff involved in blood transfusions via the automation of processes; and, enhanced accountability and audit trail. The Trust are now using the technology purchased for the blood tracking system for other purposes, for example the introduction of the Learning Clinic’s VitalPac clinical system which the Trust say is having huge benefits for improving patient safety and reducing length of stay.

Chris Ranger, Clinical Safety Project and Standards Lead
The Electronic Prescription Service in Primary Care: Great oaks...?
Nick Barber

What could be simpler? Businesses transmit orders electronically all the time – we even do it ourselves when buying goods online or dealing with our bank. Why not do it with prescriptions, which are after all just orders to supply something, with a bit of additional information on how it should be used? Today a prescription sits in the computer of a prescriber as electronic information. It is then printed out and carried to the pharmacy. The pharmacist types in the data to his or her computer, dispenses it and keeps a computer record. Pharmacists then endorse the paper prescription with additional information and send the paper to the NHS Prescription Services, which converts the information again to electronic data by scanning the form, involving quite a lot of human interventions to get the data right, so as to allow reimbursement of the pharmacist.

At each stage information sits in computers, but is communicated by paper, only to be rekeyed by a person with all the associated costs and errors. Why not transmit this information electronically throughout the chain that leads from prescriber to patient, pharmacist and on to reimbursement rather than on paper? The changes required were essentially just upgrades to software in GP practices, pharmacies and the reimbursement authorities. The scheme was originally called the Electronic Transmission of Prescriptions, and now is called the Electronic Prescription Service (EPS). What could be simpler or a more obvious and straightforward case for harnessing computers and networks to make the NHS more efficient?

Well, quite a lot of things, as it turns out. The evaluation of the Electronic Prescription Service Release 2 (EPSR2) has proved to be anything but simple. In this article we outline the EPS service and its complexity, we discuss the challenges of evaluating the service as it continues to be implemented, and we share some initial thoughts on the experience so far.

It will not be too many years before a billion prescription items will be prescribed and dispensed in England each year and for which the pharmacist will be reimbursed. The continued growth of prescription items was anticipated in the 1990’s; because of the concerns about the associated problems and costs when dealing with such large volumes of paper, pilots of ways to move from paper to electronic messages were initiated. The aim was essentially simple – to replace the paper prescription with an electronic version which worked in almost the same way as the paper. Eventually in 2003 the Electronic Prescription Service was announced to be delivered in two releases (EPSR1 and EPSR2 respectively, illustrated in Figure 1); the first pilot of EPSR1 was in February 2005 and currently 8,126 GP practices and 9,225 community pharmacies are enabled with Release 1.

EPSR1 involves the printing of a bar code on the paper-prescription, manually signed by the doctor, which the pharmacist can scan to bring up details of the patient and the prescription. EPSR2, currently in use in few areas of England, can be completely paperless and allows the patient to nominate a pharmacy from which they wish to collect their dispensed items; the electronic prescription is created and signed electronically before being sent to a central repository (the “Spine”), from which the pharmacy can download it. Over 184,000 patients have nominated a pharmacy so far. If the patient does not want to nominate a specific pharmacy in advance they will be able to take a bar coded token (a piece of paper akin to the current prescription) to any high street pharmacy, which the pharmacists can use to identify and download the electronic prescription from the Spine. An additional benefit is that EPSR2 allows for repeat dispensing; there is currently a paper based system which is little used – the electronic system has the potential to improve the system and reduce GP practice workload. For EPSR2 to go live the Secretary of State needs to authorise the use of digital signatures by doctors in a Primary Care Trust.

Achieving the delivery of EPSR2 requires making changes, and adding specific new functionality, to the prescribing and dispensing software already in use across England. It is essentially an upgrade, and thus software suppliers implementing the EPSR2 compliant functionalities, would need to have the software accredited by NHS Connecting for Health (CFH), after a thorough process of testing, especially focused on safety (the Common Assurance Process).
Figure 1: A comparison of releases 1 and 2 of EPS

**Release 1**

Electronic Prescription Service

- Reimbursement Agency
- Electronic messaging
  - Electronic copy of prescription
  - Scanned barcode
  - Electronic copy of prescription
  - Confirm what has been dispensed

**Prescriber**

- Prescription with barcode

**Patient**

**Dispenser**

- Medication dispensed

**Release 2**

Electronic Prescription Service

- Reimbursement Agency
- Electronic messaging
  - Electronic prescription
  - Scanned barcode non-nominated prescriptions
  - Electronic prescription
  - Confirm what has been dispensed
  - Electronic Prescription & endorsement message

**Prescriber**

- Prescription token

**Patient**

**Dispenser**

- Dispensing token

**NHS UK**

Search for EPS Release 2 enabled dispensing contractors

Overview of Operation of EPS Release 2

Source: NHS CFH
Our Evaluation

In 2007 we were commissioned to conduct an independent evaluation of EPSR2. In response to the call, and our understanding of the context of pharmacy and primary care, we framed our research around four broad areas:

- Safety
- Changes to working practices in pharmacies and GP practices
- The patients’ perspectives
- Future changes in the organisation of healthcare and the professions.

It is still early days in the roll out of EPSR2, and our evaluation is still underway, with our final report to be delivered at the end of this year. However our studies have already identified findings potentially useful in informing the continuing roll-out of EPSR2. In the following sections, after describing our research activities and methodological challenges, we introduce some initial themes and share some thoughts on our experiences so far.

The evaluation story so far...

When we responded to the call for bids of interest for undertaking an evaluation of EPSR2, it was clear that EPSR2 was expected to be ready for roll-out within the next few months, and plans were made to gain access to sites (GP practices and pharmacies) in a small number of pilot PCTs in England. By the start of the evaluation, about six months later, we faced quite a different picture. The programme had encountered delays for a variety of reasons. EPSR2 compliant software packages, both at dispenser and prescriber sites, were not ready for roll-out until well after the beginning of our research. We were uncertain where in the country the first sites would be, which caused logistical challenges and was one factor that made research governance particularly challenging (see below).

Our sampling strategy had to be flexible while at the same time embrace some risk-averse measures

Given the uncertainty about which of the software packages would obtain first NHS CFH approval, identifying which sites to target across England for our study was akin to playing the lottery. Our sampling strategy had to be flexible while at the same time embrace some risk-averse measures (such as for instance, obtaining Research governance approval from a larger number of PCTs than necessary, to avoid the risk of missing access, should a GP practice or pharmacy in the area adopt EPSR2 before others in other areas). Given the distributed nature of the Programme, with software deployed in a variety of independent GP and pharmacy sites, and the need for a range of local approvals, the research governance process was extremely complex.

As the research has progressed, we have been able to engage with all the early implementing sites until recently, when we have had to focus on those we have already recruited. We are studying 4 EPSR2 GP practices and the 13 associated pharmacies. In addition we are measuring various factors in a range of pharmacies that can act as controls. The extent of EPSR2 prescribing in each practice varies markedly, from around 50% of repeats in one pharmacy, to one or two prescriptions a day in others.

Safety

In most areas of IT implementation in health care, such as electronic prescribing in the USA, there have been worries about new procedures and practices creating new opportunities for error, as well as limiting other errors. We therefore wished to know whether the new system was any less safe than the current system, and whether it could improve safety. There has been little research on dispensing errors in community pharmacy (or, indeed, prescribing errors, or many other areas of primary care, as will be seen later). The definitive study, by one of our team, had suggested an error rate of 3.3%, using a definition of error devised with practicing health care professionals (Franklin et al 2007). The vast majority of these errors were unlikely to affect health, but some could have. Around half the errors were labelling errors and half content errors (which included, for example, supplying more tablets than specified on the prescription). It is hard to see how EPSR2 would affect prescribing errors or content errors, since the added EPSR2 functionality of transmission of the prescription, should not change the existing functionalities used in prescribing in GP practices. However it was envisaged that EPSR2 could affect labelling errors at the pharmacy.

To investigate the effect of EPSR2 on dispensing errors we designed a trial in which we would collect data in pharmacies that were expected to adopt EPSR2, before its implementation, and measure them every three months for the duration of the trial. We used an experimental design that allowed us to group all the results and compare those done under EPSR2 with control data. Given the information we were told at the time – the expected rollout sites and that rollout would be expected to be rapid within sites (i.e. most repeat prescriptions would soon be delivered electronically) – this design was very powerful. As mentioned above, the reality has been that it has been hard to know which sites would go live and when. Additionally, the number of EPSR2 prescriptions handled in each pharmacy has been small in some sites, making it hard to capture their activity.

Our approach has been to go to each of our trial pharmacies every three months and spend one or two days checking bags of dispensed items for errors; these are the bags of medicines the pharmacy has ready to hand out to patients. In some sites items had to be checked live immediately before being handed out. In studying these items to detect dispensing errors, we gained unexpected insight into the extent of one aspect of the working life of pharmacists. As so often when research is given a fairly wide brief, we have found something previously not documented, which is the surprisingly large amount of work the pharmacies put into enhancing the label over and above the information given on the prescription.

Changes to working practices in pharmacies and GP practices

It was 2004 when the National Prescribing Centre pointed out that: “There is, however, only limited, robust, published research into repeat prescribing. The research has tended to be tightly focused and involve relatively small numbers of practices...” (National Prescribing Centre, 2004, p.6). Very little has changed since then. There is little documentation about the ways in which GP practices manage repeat prescribing. We have found, and GPs have...
subsequently confirmed, that there is a seemingly infinite number of ways in which a repeat prescription can be received, organised, approved and returned to the patient or their representative. Each has emerged locally reflecting the working patterns of those involved – such as including the desire of doctors to fit signing the prescription into their coffee-breaks. Even the first step in the process – a patient’s request of a repeat may vary greatly between practices, as illustrated by the variety of request forms in use which range from the minimal to the complex.

As only a small number of GP practices are currently using EPSR2, our data is limited, however we can see we need to study how it could affect the three stages of the process: reception and sorting of the prescription requests, the checking of some prescriptions and authorisation (signing) by the doctor, and issuing. A simple example is that authorisation will need to be done at a computer (with smartcard, most likely in a GP office) rather than, as is possible with a paper prescription, in a range of venues. We can also see signs that the handling of prescriptions before they are authorised may be simplified with positive overall effects on the time spent in a GP practice around repeat prescriptions.

The problem in trying to study repeat prescribing in general practice is that very often the activity is interspersed with other activities. Examples include: for administrative staff, sorting the paper prescriptions for doctors’ authorisation while also receiving patients at the front desk, or for GPs, signing a prescription while also calling the patient. Calculating exactly how much time would be saved (or not) by the elimination of paper is more complex than a simple modelling of individual tasks would suggest. Two researchers have been spending time in several GP practices to capture with stop-watches the exact time spent by administrative staff on processing prescriptions and to observe the process of repeat prescribing in its entirety and its range of activities. We now do have some robust data on an aspect of medicines use that has so far been rather opaque.

Similarly, the dispensing of prescriptions is a major part of a pharmacy’s, and a pharmacist’s, time. However, we still know relatively little, in research terms, about how this time unfolds. What is the range of activities that pharmacists do? How do pharmacies differ? We have approached this in two ways. The first is to just observe, using an ethnographer, the activities of pharmacy staff. This fresh pair of eyes can reveal everyday features of work that pharmacy staff take for granted, and relate these and other observations to changes that result from EPS. We wished to supplement this with quantitative measure of how people spend their time. We faced two problems here, first, how to measure for a long period of time across a geographically spread series of locations; second, that, contrary to expectations, EPSR2 prescriptions were generally a minority of prescriptions which would be processed in the study period. Their effect would be watered down in the daily flow of paper prescriptions. We have developed a novel system of capturing the activities of pharmacist and dispenser by giving them a mobile phone each and a coded list of activities. An automated system texts them at random intervals and they text back the code for the activity they are engaged in at that time.

The patients’ perspective

Towards the end of our evaluation we will be asking patients what their experiences are of the system, and their thoughts on it. Given the limited current state of implementation we are waiting as long as possible in order to get a good cross section of patients who have experienced the system. However some interesting observations have come from the piloting of the interview schedule. Many pharmacies offer a repeat prescription service. They keep a database of patients and the dates when their prescription is due, order and collect the repeat from the surgery and, particularly if the patient has difficulties with mobility, they deliver the prescription to the patient’s home. These patients are unlikely to notice any difference in that service, although we will still check whether the new way of delivering the service concerns them.

Future changes in the organisation of healthcare and the professions

Like the rest of the NHS, perhaps more so, primary care in England is currently experiencing a transformation that will significantly reshape its organisational arrangements, business processes and professional practices. How, in such a great sea of change, will we be able to pin-point the effects due to the introduction of EPSR2? We have been investigating the organisational and business consequences EPSR2 will bring to the wider context, with interviews with a variety of stakeholders, which includes dispensing doctors, appliance contractors and software companies.

Computerisation of previously paper-based processes may lead to potentially significant transformations in healthcare structures and business models

It is not only the EPSR2 messaging system and the electronic transmission of previously paper prescriptions that will bring change in the wider context, but the whole infrastructure put in place for EPSR2 to work – the secure N3 network, the central repository of the Spine, the mandated use of smartcards both on GP and pharmacy sides. To use EPSR2, pharmacists too will be using smartcards and can more easily (and securely) communicate with other NHS service providers. Although this brings community pharmacies further into the NHS IT family it is still only a partial involvement – for example they are not allowed access to the NHS intranet (NHS Wide Web) and so are not informed when the Spine is down, leaving them in a fog of uncertainty as to whether a day-to-day operational problem sits in their system, the spine or the GP’s system.

Computerisation of previously paper-based processes may lead to potentially significant transformations in healthcare structures and business models, in professions and in organisational practices and business processes. Some of these changes are expected to be going in the same direction to the stream of changes introduced by the new pharmacy contract – more involvement of pharmacy in the care of the patients, whereas other may pave the way to more automation and standardization of pharmacists’ work and delivery of care.

Why has it taken so long?

EPSR2 has taken a long time to come to life for a variety of reasons, which are important to understand. Among them, the business critical nature of the intervention for pharmacies, the distributed nature of the initiative, with originally 11 GP systems and nine community pharmacy systems which were challenged with
Issues of Research governance in primary care

We have wasted, and we think wasted is the appropriate word, an incredible amount of time and resource in satisfying an inchoate group of research related governance requirements. Indeed, had EPSR2 rolled out to schedule we would not have been able to evaluate it in a timely manner as we would have been bogged down in governance issues. It has probably taken a year of staff time, and public money, to negotiate our way through these processes. There have been several problems. First, our research was classed as ‘systems evaluation’ when we submitted it to a research ethics committee (REC), and hence not something they would consider. We are sure this was meant to be helpful, however the research did involve patient contact, research questions and included a powered quantitative trial. This threw people into a spin.

Letters of Access had to be obtained in order to protect patients and our staff, which we had to ask Research Governance Offices to issue. However, Research Governance Offices in some PCTs were unsure as to whether they should be considering service evaluations, and were unwilling to consider the study. We are sure this was meant to be helpful, however the research did involve patient contact, research questions and included a powered quantitative trial. This threw people into a spin.

Research passports were not routinely accepted and further information was often required - one ‘helpful’ person said ‘You do have a passport but now you need a visa’. The Primary Care Research Network could have added resource to the project, however they did not recognise the project until it was too late to be of use – first, again, because we had not been approved by a REC and hence it was believed it was

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**Figure 2**

Design Requirements (“Compliance Baseline”) and programme-specific “CAP Approach” formally published by responsible programme eg. CAB, EPS, etc.

Scope Defined
- ATP
- DevMAC
- CATR
- CATD
- Volume Rollout

Initial Design
- ATP
- DevMAC
- CATR
- CATD
- Volume Rollout

Detailed Design
- ATP
- DevMAC
- CATR
- CATD
- Volume Rollout

Module Test
- ATP
- DevMAC
- CATR
- CATD
- Volume Rollout

System Test
- ATP
- DevMAC
- CATR
- CATD
- Volume Rollout

Integration Test
- ATP
- DevMAC
- CATR
- CATD
- Volume Rollout

Ready for Operations Test
- ATP
- DevMAC
- CATR
- CATD
- Volume Rollout

Initiation Complete
- ATP
- DevMAC
- CATR
- CATD
- Volume Rollout

GoLive Preparation
- ATP
- DevMAC
- CATR
- CATD
- Volume Rollout

Deployment Verification
- ATP
- DevMAC
- CATR
- CATD
- Volume Rollout

Deployment
- ATP
- DevMAC
- CATR
- CATD
- Volume Rollout

Development
- ATP
- DevMAC
- CATR
- CATD
- Volume Rollout

Clinical Safety

Service Introduction

Source: NHS CFH slide
not research, and later because the whole NHS CFH evaluation programme was not recognised by the PCRN until too late. There is a need to review research governance in primary care for national projects such as this. The current systems can be a significant barrier to generating timely evidence in real world, nationwide initiatives such as this.

Conclusions
This is probably the most low profile change within NPfIT and yet it has the potential to be one of the most transformative as it offers doctors and pharmacists new ways of working, and can offer patients new experiences of care. It is a relatively low cost intervention that could benefit the public purse as well as safety. Its potential contributions to Quality, Innovation, Productivity and Prevention (QIPP) are described in Box 1.

Box 1

**EPSR2 and QIPP**
Will EPSR2 contribute to QIPP? It is early days to pass judgement, however the potential is certainly there. In this box we focus on the potential, the text gives more information about some of the issues which will decide whether the potential is reached. It is hard to see the effect on Prevention, however the other areas are:

**Quality**
If we take Darzi’s three criteria of quality as being related to safety, effectiveness and patient experience then we can see the potential for success. Safety could be improved by direct transmission of information from the GPs screen to that of the dispenser. If this were to be linked to a robotic dispensing machine, as at one of our sites, there is also potential to reduce errors in picking the right product. Effectiveness may not be affected, but efficiency could be improved in several ways within the GP practice, the pharmacy, and the NHS Prescription Services (NHSPS). For some patients the experience of ordering and collection of repeats could be simpler and more convenient, however for those patients for whom the pharmacy already operate a repeat prescription service (in which the repeat is ordered and collected by the pharmacy and in some cases delivered to the patient’s home) it is hard to see how things will improve.

**Innovation**
This service is certainly innovative – in world terms as well as in the UK. It could reduce the workload in GP practices (particularly if repeat dispensing is used) and has the potential to change the way in which medicines (and appliances) are delivered. The patient no longer needs to be close to the pharmacy, and the potential for internet pharmacy is enhanced. The reduction in checking done by community pharmacists, and the smoothing of their workload, could allow them enhanced professionalization, building on their already increasing clinical involvement.

**Productivity**
There is potential to be more efficient in three areas. To reduce the work of organising repeat prescriptions in GP practices – if EPSR2 brings a wider use of repeat dispensing, the effect could be much greater. There could also be a very significant effect on the NHSPS, automating many of the payments. Workload is more easily planned and dispensing workload smoothed through the day instead of being in peaks, and improving stock management and reducing ‘owings’. Dispensing could become quicker and simpler, particularly if linked to robotics. There is also the potential for the DH to pay the community pharmacies more rapidly than currently.

In our evaluation so far we have been surprised how little evidence exists about the repeat prescribing/dispensing process and the work in GP practices and community pharmacy. These organisations deal with billions of pounds of medicines and over 100,000 staff – we need to understand them better. We have also been surprised by the substantial barriers to national research in primary care that result from the current research governance structures and their enactment in practice.

Our report will be delivered in January 2013. Looking forward from the imminent wider roll-out of EPSR2, and the substantial changes it seems to prefigure, the findings of this study will be of great significance as substantial decisions come to be made about the country wide processes of medication supply, systems of reimbursement, and most of all patient involvement in the main element of their care. The ‘simple’ process of transmitting prescribing messages electronically instead of by paper – a little ‘acorn’ of a change – could lead to substantial changes in the organisation, delivery and experience of primary healthcare – the ‘Great oaks’ of the title of this article.

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References


**Lessons learned**

Many lessons were identified by the EPS team as sites began to use EPS Release 2. Four early ones were:

1. Pharmacies should to talk to their system supplier so they can include EPS within their existing business continuity plan. The pharmacy should log an issue with the supplier as soon as it is identified
2. Block out 15 minute slots in prescribers’ appointments in the go live week as a catch up on the system and to help iron out any usability issues
3. During system setup and training get the supplier to check the system is configured in line with the user’s business processes
4. Prescribers and surgery staff should synchronise patients medication wherever possible in advance of go live as this helps the EPS Release 2 process, including repeat dispensing.

See www.cfh.nhs.uk/eps for more information.

**NHS CFH sponsor comment**

Nick Barber eloquently describes the nonsense of the current prescription process flow repeatedly involving converting computer information to paper and back again and how the case for harnessing the power of IT in the NHS is nowhere more obvious. With the number of prescription items up by 68% since 2000 it is no wonder that the Government is committed to EPS. However, it is not just the efficiencies in processing that EPS can deliver. There are patient benefits, business change opportunities and the chance to reinvest clinical time in providing better, more joined up patient care.

EPS is clearly a business change project not just an IT upgrade.

There was surprisingly little data on the prescribing, dispensing and reimbursement process before this research began and it was important to establish this baseline so that the full benefits and impact can be measured and assessed. EPS is complex, with so many different suppliers and because clinical safety is paramount it is understandable why Release 2 of the service was not more widely available before now, and that has made the evaluation task more difficult. As more GPs and pharmacies upgrade to EPS Release 2, more patients nominate dispensers and more prescriptions complete their whole journey electronically we are beginning to see and hear of significant benefits; I am looking forward to the final evaluation report to see how much the oak has grown.

it is no secret that attempts to implement nationally shared summary records in practice have rarely gone as planned
The Summary Care Record (SCR) was introduced as part of the former National Programme for IT via a Programme Board within Connecting for Health (the IT arm of the Department of Health), with a detailed national implementation plan and central monitoring scheme. SCRs were introduced in two early adopter sites (Bolton and Bury) from 2007; a national roll-out began in 2009. A public information programme to inform people about the SCR and their ability to opt out comprising individual letters, local mass media and talks to third sector groups was locally led but had input and ‘branding’ from Connecting for Health. Participating primary care trusts were required to produce a Project Initiation Document with milestones, named staff allocated to key tasks and a ‘benefits realisation plan’. Individual general practices worked with one of several software suppliers to upload selected data fields from their own system to the central Spine. England has numerous different suppliers of general practice software, only some of whom were able or willing to develop functionality to create SCRs. Some general practitioners considered the programme unethical because personal medical data were to be shared without the patient’s explicit consent, hence refused to participate, though resistance appeared to lessen as more practices joined the scheme.

Clinicians’ use of SCRs was low in most though not all emergency and unscheduled care settings for numerous reasons, including technical glitches (e.g. ‘bugs’, slowdowns, temporary loss of access to the Spine), non-availability of records (“low hit rate”), low levels of training and motivation, information governance issues (lost clinician identity Smartcards, forgotten passwords) and fear of surveillance. Negative press coverage and resistance from civil liberties groups added to the political sensitivity of the programme, which was associated in the minds of many citizens with a wider ‘surveillance state’ (e.g. it was linked to the contemporaneous but separate policy of universal ID cards). An independent evaluation report in June 2010 raised a number of concerns (which did not necessarily reflect the views of other stakeholders), including the high complexity of the programme, greater than anticipated workload for front-line staff, scope creep, persistent technical challenges, whether the ambitious information governance plans were workable and sustainable, and the slow overall pace of progress. As of October 2011, over 33 million of England’s 50 million population had been sent a letter about the SCR and just over 9 million SCRs had been created. While this was significantly slower than the projected pace of progress, the programme appears to have become less politically contentious over time and the opt-out rate is low (0.03%).
Box 3: Wales

The Individual Health Record (IHR) in Wales was developed with a ‘hybrid’ vision in mind (a mixed economy of the best of the NHS with the best that commercial systems can provide). There were (deliberately) no large procurements and the £4.7 million initial budget for the project (again, deliberately) was found from existing funding streams within healthcare infrastructure.

The IHR was conceptualised from the outset as one component of a wider programme of work, which comprised both new technologies and new clinical and business processes. The main technological elements were:

[a] a public sector broadband network aimed at connecting organisations to share information securely;
[b] email and a unique identifier for all NHS staff (later extended to local government);
[c] a Clinical Communications Gateway for (“any to any”) referrals and discharges;
[d] the Individual Health Record, and;
[e] a patient portal (My Health Online) for appointment booking, prescription requests and self-management.

The main clinical and business processes are ultimately being brought together through the Welsh Clinical Portal. They are:

[a] a master patient index (to identify the right patient at every contact via systematic cleaning of databases);
[b] e-booking using a home-grown PAS (the service infrastructure to support electronic booking);
[c] scheduling and ordering (the service infrastructure to support electronic ordering of tests and procedures
[d] information management for pathology laboratories;
[e] medicines management (the infrastructure to allow GPs and pharmacists to maintain accurate lists of patient medication on the Welsh Clinical Portal);
[f] documentation service (to enable health professionals to view and create clinical documents and records) which is particularly relevant for community and social care staff.

The complex challenge of a shared summary record

Implementation of a nationally shared electronic summary record requires a number of overlapping tasks:

1. Scoping and set-up:
   a. Naming and framing the programme
   b. Defining the scope and purpose of the shared record
   c. Assigning leadership roles and domains of responsibility
   d. Setting strategic direction.

2. Designing the system:
   a. Deciding who will do what (including who will set the standards, build the technology etc)
   b. Defining the use case(s) and core clinical content – including what the record will be used for, what data it will contain, where it will be available, and who may access it under what circumstances
   c. Designing the underlying record architecture (e.g. coding structure) including security features and access controls
   d. Developing and testing software
   e. Designing the consent model.

3. ‘Hard’ aspects of implementation, including:
   a. Project management, which involves liaising across different organisations and sectors and managing and prioritising numerous interacting tasks and sub-projects
   b. Mobilising funding streams for particular sub-projects
   c. Assuring data quality in the records from which the summary will be drawn
   d. Accommodating the competing interests, priorities, values and practical constraints (e.g. budgets) of different stakeholders.

4. ‘Soft’ aspects of implementation (promoting acceptance and use), including:
   a. Informing patients and answering queries from the public
   b. Engaging clinicians and encouraging active use of the record
   c. Managing concerns about privacy and data protection
   e.g. civil liberties lobby, professional groups.

5. Evaluating, monitoring and learning
   a. Defining and measuring “success”
   b. Monitoring uptake and use
   c. Demonstrating clinical and other benefits
   d. Maintaining an over-arching narrative of coherence and progress (and in some cases, countering narratives of “failure” generated by the press or other stakeholders)
   e. Generating and incorporating organisational and system learning.

Whilst these implementation challenges were common to all four programmes, they played out very differently because of substantial differences in contextual variables. Key features of the programmes are summarised in Table 1. We consider key contextual issues and tasks below.

Scoping and set-up

‘Naming and framing’ is a somewhat nebulous concept but key to implementing any technology programme which has (or may have) social or political significance [12]. People make sense of such programmes by telling and re-telling stories about them, and it is through these stories that the technology acquires a shared social meaning (or, in some cases, how a truce about its contested social meaning is negotiated) [13,14]. In Scotland, a small number of enthusiastic clinicians led the programme from the outset with minimal input from government. Early and ongoing consultation with patient groups created a prevailing narrative of ‘improving clinical care and assuring quality and safety’ with which the name “Emergency Care Summary” was quickly associated, and within which additions to the programme (notably the recently introduced Palliative Care Summary) were interpreted and pursued. Technical and management expertise was supplied by key organisations holding national contracts. Whilst the Northern Ireland implementation of the ECS is in its early stages, a similar approach seems to be being taken there too.

In England, the idea of the Summary Care Record was announced by the newly-elected Prime Minister in 1998 with the now infamous words, “If I live in Bradford and fall ill in Birmingham then I want the doctor treating me to have access to the information he needs to treat..."
me. [15]. This seemingly laudable policy vision led to the Summary Care Record emerging as a component of an ambitious, government-led IT programme of unprecedented scale, involving financially costly and relatively inflexible contracts with a handful of IT suppliers, and associated in the minds of press and citizens with other aspects of the ‘Database state’ (notably the Blair government’s contemporaneous attempt to introduce a national ID card) [16]. Perhaps for this reason, civil liberties protests were particularly vocal in England. The focus on IT by New Labour was perceived by many commentators as a mechanism to bring about public sector reform, partly due to its ability to destabilise organisations and prompt transformational change. The Choose and Book programme was an example of this, whose introduction was said to be about to make the booking of hospital appointments “as easy as booking an aeroplane”.

In Wales, the ‘Informing Healthcare’ strategy had been written in 2002 by a combination of NHS Wales clinicians and managers and had been launched by the then Minister for Health so there was a high degree of local ownership and national political commitment. The introduction of the Individual Health Record (IHR) was the first important step in its implementation. The leaders were highly experienced clinicians and managers who also had extensive technical knowledge, leadership experience and political connections (some had previously worked on the English NPfIT) and had chosen to move to devote their energies to delivering a national strategy for electronic patient records that had taken on board the lessons of previous initiatives. They saw inherent risks in a strongly top-down and milestone-driven approach which was entirely procurement driven. However, they were also very committed to the principle of clinical information being available wherever an NHS patient was being treated and of ensuring national-level interoperability and integration as far as technically possible. To this end, a broad-based partnership (under the banner of ‘Informing Healthcare’) was established which included Welsh Government, national and local-level NHS, local authority, and the IT industry. The main strengths and distinguishing features of the Informing Healthcare Programme are [a] strong national leadership; [b] technical governance (via the National Architecture Design Board, NADB); [c] explicit acknowledgement of the tension between technical design and clinical need (e.g. NADB is chaired by a clinician and has equal membership of technical and clinical staff); [d] extensive stakeholder involvement and engagement; [e] a mixed economy of systems; [f] incremental development and deployment; and [g] the need to be user led and benefits driven to provide clinicians with something better than they already had. These aspects of the Welsh system are described in more detail in other sections below.

System design

A striking difference between the four programmes was the overall approach to system design. As Table 1 shows, the Scottish team viewed the programme primarily in social terms and a key preliminary task as “getting everyone on board”. The programme’s leaders did little else in the first year except build dialogue and negotiate with patient and clinician groups and consult with formal bodies such as the defence societies and the Information Commissioner. Issues such as privacy and security were extensively discussed and qualitative research commissioned, but the solutions which emerged were pragmatic and relatively light-touch (with scope for individual judgements implicitly accommodated and based on clinical need).

Whilst early discussions with patients, clinicians and professional bodies were also held as part of the Summary Care Record programme in England, the overall emphasis here was on building an infrastructure within the civil service in which a series of committees and working groups were allocated particular tasks and charged with ‘fixing’ the programme’s numerous problems and challenges. Perhaps because of this, issues such as privacy and security were constructed in absolute and somewhat legalistic terms, and solutions were correspondingly technology-focused and perceived by many as bureaucratic. Under the Labour administration 1997-2010, there was a strong belief in the positive benefits of management consultancy. The civil service sought to commission management consultants to help implement change, and the English NPfIT aligned this strategy with the procurement of short term consultancy to help develop the SCR programme. Such individuals typically brought generic project management skills but limited or no previous experience in the NHS.

civil liberties protests were particularly vocal in England. The focus on IT by New Labour was perceived by many commentators as a mechanism to bring about public sector reform

In Wales, the idea of a centrally stored summary (Spine) was rejected at an early stage on design grounds. The IHR technology therefore differs from other shared electronic record systems in the UK in that it is not a summary but a full extract from the GP record with certain “sensitive” fields (notably sexual health and some mental health) obscured. The core design principle was to create a mixed economy of ICT systems which made the best use of existing NHS systems and staff skills while also combining this with ‘best of breed’ commercial offerings. Interoperability would be managed through the compliance with the national architecture and standards. Another important difference was in the development of the patient consent model for access to the record. It was based on the following principles: [a] Solving real world problems in a specific care setting and not rooted in a philosophical debate about governance. [b] That clinicians are professional people who, if they can be trusted to provide patient care, can be trusted to share information responsibly. [c] That all of the management policies that were needed already existed to deal with professional conduct around information sharing. [d] That there was no need to create a complicated technological rule-based access and control model. [e] That strict audit processes would be put in place to identify those who had accessed patient records and to provide this information to patients if requested.[f] That the principles of the consent model would be owned and developed by the professional bodies (BMA,RCN, practising clinicians, patient representatives (CHGs) and the Information Commissioner and not by technologists and managers.

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Looking back, moving forward 31
Table 1: Comparison of the implementation of four national shared electronic record schemes in UK

<table>
<thead>
<tr>
<th>Broad aspect</th>
<th>Specific factor</th>
<th>Scotland Emergency Care Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>National context</strong></td>
<td>Population ONS 2007 figures (proportion of UK)</td>
<td>5.1 million (8%)</td>
</tr>
<tr>
<td></td>
<td>Key geographic and demographic features</td>
<td>Some geographically remote areas. Very large public sector. High public trust in clinicians and the NHS</td>
</tr>
<tr>
<td><strong>Scoping and set-up</strong></td>
<td>Scheme initiated by</td>
<td>Clinicians</td>
</tr>
<tr>
<td></td>
<td>Designated leader</td>
<td>General practitioner</td>
</tr>
<tr>
<td></td>
<td>Programme philosophy</td>
<td>Thrifty and restrained approach, maximising use of existing systems and materials. Emphasis on simplicity and fitness for purpose</td>
</tr>
<tr>
<td></td>
<td>Set-up budget</td>
<td>£0.5 million</td>
</tr>
<tr>
<td></td>
<td>Scope and purpose of shared record</td>
<td>Tightly defined and non-negotiable clinical use case: emergency care</td>
</tr>
<tr>
<td><strong>System design issues</strong></td>
<td>Approach to requirements definition</td>
<td>Predominantly social: wide consultation defined as “getting everyone on board”, including early patient consultation</td>
</tr>
<tr>
<td></td>
<td>Key design principles</td>
<td>Emergent and intuitive: “keep it simple and practical”. Ambiguity tolerated and/or addressed in a pragmatic, common sense way</td>
</tr>
<tr>
<td></td>
<td>Approach to privacy and consent</td>
<td>Seen as a pragmatic trade-off against access to data</td>
</tr>
<tr>
<td></td>
<td>Approach to software development</td>
<td>Recycle and extend: Use an existing government-built infrastructure and add minimal new components to extend its function</td>
</tr>
<tr>
<td><strong>Implementation process</strong></td>
<td>Stakeholder alignment</td>
<td>Co-evolved from the outset</td>
</tr>
<tr>
<td></td>
<td>Change model / intended pace of progress</td>
<td>Organic, with strong emphasis on going at the pace at which stakeholders were comfortable</td>
</tr>
<tr>
<td></td>
<td>Approach to ensuring baseline data quality of GP record</td>
<td>Data quality of practice records was high but technical and operational challenges were encountered when practices went live with the ECS. Practices are encouraged to add medications prescribed ‘elsewhere’ but this aspect remains a challenge</td>
</tr>
<tr>
<td></td>
<td>Actual pace of progress</td>
<td>Steady</td>
</tr>
<tr>
<td><strong>Promoting acceptance and use</strong></td>
<td>Approach to patient and public engagement</td>
<td>Clinicians wrote letters and led information campaigns</td>
</tr>
<tr>
<td></td>
<td>Approach to clinical engagement</td>
<td>Clinicians seen as central driver</td>
</tr>
<tr>
<td></td>
<td>Approach to ensuring ongoing data quality of the summary record</td>
<td>Feedback to practices to encourage them to add medications prescribed ‘elsewhere’ to the ECS but this remains a challenge</td>
</tr>
<tr>
<td><strong>Evaluating, monitoring and learning</strong></td>
<td>Success” defined in terms of</td>
<td>Everyone on board; accessing shared records is part of business-as-usual of unscheduled care</td>
</tr>
<tr>
<td></td>
<td>Official evaluation by</td>
<td>In-house team</td>
</tr>
<tr>
<td></td>
<td>Approach to organisational / team learning</td>
<td>Much learning was tacit, often shared informally amongst key players</td>
</tr>
<tr>
<td></td>
<td>Approach to evaluation</td>
<td>Identify clinical success stories and critical incidents; produce pragmatic audits which gave an overview of key indicators</td>
</tr>
<tr>
<td>England Summary Care Record</td>
<td>Wales Individual Health Record</td>
<td>Northern Ireland Emergency Care Summary</td>
</tr>
<tr>
<td>-----------------------------</td>
<td>-------------------------------</td>
<td>----------------------------------------</td>
</tr>
<tr>
<td>£1.1 million (84%)</td>
<td>3.0 million (5%)</td>
<td>1.8 million (3%)</td>
</tr>
<tr>
<td>High population mobility. Mixed health-economy with complex local arrangements. Low levels of public trust in government. Strong civil liberties lobby</td>
<td>Small population; strong professional networks. Some geographically remote areas. High public trust in clinicians and the NHS</td>
<td>Small and geographically contained area covered by (e.g.) only 5 GP out of hours centres and 11 A&amp;E departments</td>
</tr>
<tr>
<td>Government and IT industry</td>
<td>Consortium (“Team Wales”)</td>
<td>Scheme initiated collaboratively</td>
</tr>
<tr>
<td>Senior civil servant</td>
<td>General Practitioner/Professional Information</td>
<td>Predominantly clinically led</td>
</tr>
<tr>
<td>Large, up-front investment to create an integrated national IT system. Emphasis on due process, formal contracts, highest security standards</td>
<td>Humility in the Face of the User, Follow Simple Rules to Manage a Complex Healthcare System. Solve real world problems and support people. Listen and Learn from others’ mistakes. Build and maintain collective confidence, credibility and commitment Adopt a tried and tested low-tech solution from Scotland</td>
<td></td>
</tr>
<tr>
<td>£200 million</td>
<td>£4.7 million</td>
<td>£240,000</td>
</tr>
<tr>
<td>Initially, emergency and unscheduled care. Later, broadened to include community based services and end of life care</td>
<td>Improve quality, safety and convenience of emergency and out of hours care</td>
<td>As Scotland</td>
</tr>
<tr>
<td>Technical: expert-led ‘engineering’ model, includes seeking ideas and feedback from defined stakeholder groups</td>
<td>Socio-technical. Technology design should, first and foremost, enable and support front-line clinical work</td>
<td>Win support for Scotland application</td>
</tr>
<tr>
<td>Centrally modelled based on assumption that all problems should be ‘fixed’ (hence multiple committees working on solutions and producing guidance)</td>
<td>Grow a locally relevant system within a national architecture. Create the potential for any NHS clinician to see the medical record wherever the patient is seen</td>
<td>Use what is already working and supported in Scotland</td>
</tr>
<tr>
<td>Seen in absolute, technical and legal terms hence initial model was complex and confusing</td>
<td>National database rejected because of patient, clinician and public concerns about security and privacy. Pragmatic consent model similar to Scotland</td>
<td>As Scotland</td>
</tr>
<tr>
<td>“Waterfall”: contract the IT industry to produce a state-of-the-art new system</td>
<td>Eclectic: buy some, build some</td>
<td>Use Scotland’s product and deploy on existing infrastructure</td>
</tr>
<tr>
<td>Multiple interest groups with different goals, norms and values. Began to co-evolve relatively late in the programme</td>
<td>Co-evolved from outset</td>
<td>As Scotland</td>
</tr>
<tr>
<td>Managerial, civil service driven (“PRINCE 2”: tightly managed via Gantt charts with a view to ‘realising benefits’)</td>
<td>Socio-technical and responsive to contingencies e.g. procurement model was changed when one IT supplier went into administration</td>
<td>As Scotland</td>
</tr>
<tr>
<td>Baseline data quality was variable. Initially LES (‘locally enhanced service’ – financial incentives and facilitation) but funding for this was withdrawn in mid 2009. Smart card requirement (but low actual use of smart cards) led to inaccuracies in data quality</td>
<td>Data quality of GP records was variable but improving, driven by QOF and professional pressure. A Data Quality System (DQS, similar to LES in England) was introduced in 2007 with the aim of improving quality for electronic record initiatives including GP2GP, electronic prescribing and the BMR</td>
<td>Demographic data on GP systems was good following data quality initiative 2004-6</td>
</tr>
<tr>
<td>Variable (slow in some areas but rapid in areas where stakeholder alignment strong)</td>
<td>Steady to begin with then static following a setback in 2008; more recently steady progress resumed</td>
<td>Slow during pilot and early rollout, on target for completion in 2012</td>
</tr>
<tr>
<td>Communications Department of Connecting for Health set ‘house style’ and supported information campaign</td>
<td>Widespread clinical and public consultation. Website and leaflet give information and FAQs</td>
<td>Clinically led communications group with patient representation</td>
</tr>
<tr>
<td>Clinicians seen as a hurdle to overcome</td>
<td>Clinicians were a key stakeholder group in a wider partnership</td>
<td>As Scotland</td>
</tr>
<tr>
<td>Technical solution: whenever someone uses a smart card, all data in relevant fields added to the record since previous upload would be added to SCR</td>
<td>Audit incentives plus training programme and engagement of clinical and professional leaders to prioritise issue of data quality</td>
<td>Some issues with accuracy of medications led to review and changes to clinical system</td>
</tr>
<tr>
<td>Records created; records accessed; benefits realised</td>
<td>Effective, efficient and safe system; widespread confidence in the IT; high staff morale and productivity</td>
<td>As Scotland</td>
</tr>
<tr>
<td>Academics under contract</td>
<td>Local teams as part of ongoing audit</td>
<td>In-house team</td>
</tr>
<tr>
<td>Knowledge seen as codified facts; documented on ‘lessons learnt’ spread sheets</td>
<td>Explicit focus on a learning community and “progress through partnership” from the outset</td>
<td>As Scotland</td>
</tr>
<tr>
<td>Internal: implement a “benefits realisation strategy” and collect examples of benefits. External: commission an independent academic team to produce a report to demonstrate transparency</td>
<td>External international advisory group undertook public peer review on annual basis. Benefits Realisation strategy and compilation of a benefits register</td>
<td>As per HSC programme governance arrangements</td>
</tr>
</tbody>
</table>

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'Hard' aspects of implementation

National-scale electronic records have multiple stakeholders (including patients, policymakers, clinicians, commercial IT companies, potential users of secondary data and civil liberties groups). Many different interests, goals and values are brought to the negotiating table, and people often feel strongly about particular issues. Hence, ‘implementation’ is rarely a politically neutral project management exercise and acquires the contested narratives of power and control. One way of conceptualising the complexities of such programmes is to consider the extent to which the various human stakeholders and also the different technologies involved (nationally shared record, local record, supporting infrastructure, availability of local terminals and so on) are aligned in a more-or-less stable socio-technical network [17]. The network may be destabilised if, for example, a supplier pulls out of a contract, a security breach story hits the press or a new regulatory ruling is made (e.g. by the Information Commissioner), since these events have knock-on effects on the wider network.

In Scotland, one of the major system suppliers at the start of the ECS project was part-owned by the Scottish Government and the system was deployed in 80% of practices. This meant that development for this system was prioritised and proceeded rapidly. Other suppliers working in Scotland had to conform to the requirements for Scottish Enhanced Functionality and include the ability to work with Emergency Care Summary. The informatics community at the time had strong links with the Scottish General Practitioners Committee of the BMA and Royal College of General Practitioners as well as nursing networks and patient groups. The atmosphere was one of cooperation and improvements to patient care, particularly following the introduction of the new GP contract and devolved responsibility for out of hours care specifically to Health Boards and away from individual GP practices.

In Wales, an early strategic decision was made by the national agency Informing Healthcare to build the single electronic record incrementally – a “national programme for local implementation”. The strategy was to work with the NHS region by region, avoiding disruptive, unaffordable and (they felt) unnecessary ‘rip and replace’ approaches and learning lessons at each stage. The strategy was deliberately introduced with what its chief executive described as “no arbitrarily dictated timescales” so that progress could follow the pace of clinical and public engagement and technical development. There was a strong emphasis on the fact that ‘incremental’ meant ‘small’ not ‘slow’ and the aim was to take tightly scoped rapid steps, with the initial IHR prototype being delivered locally in 6 months at a cost of less than £1 per patient.

‘Soft’ aspects of implementation

Uptake of any technology-based innovation partly depends on its attributes – such as whether potential adopters perceive it as useful and easy to use; whether benefits are rapidly seen; whether it can be implemented with minimal infrastructure; whether it can be tried out with minimum investment; whether the mechanism that generates benefits is clear to users; and whether it is customisable to local circumstances (‘potential for reinvention’) [18,19]. Even the simplest nationally shared electronic record is technically complex, the more so if multiple functions and security features are offered. Such records inevitably come with or presuppose complex supporting infrastructure – not least the ‘locked down’ computing environments of the typical NHS organisation. Their impacts are typically distant in time and location from the individuals undertaking the initial implementation work [20,21]. In relation to IT programmes, one computer scientist has observed that “One can (with difficulty) achieve any two of (a) high security, (b) sophisticated functionality, and (c) great scale – but achieving all three is currently (and may well remain) beyond the state of the art.” [page 230[22]]. The Scottish experience with the limited functionality of ECS suggests that clinicians may be prepared to compromise on these competing ideals if there is substantial benefit to patient care, efficiency or better use of time.

The sheer scale of the English programme created multiple interdependencies and logistical challenges; some stakeholders perceived significant ‘scope creep’ as additional functionality and potential use cases were added, partly in an effort to increase use of the SCR and realise its benefits more widely. The initial plans for the SCR consent model were complicated and unwieldy and the British Medical Association strongly opposed implied consent. In contrast, the Emergency Care Summary team in Scotland adopted an explicit philosophy of “keep it simple” and resisted efforts by stakeholders to extend content and scope; there was agreement amongst all stakeholders (clinicians, patients, technical designers, policymakers) what the record was for, what it would contain and who would use it. A novel two stage consent model was proposed and supported. Initial implied consent for data upload was supplemented by explicit consent to view: This consent to view has been perceived by staff as simple and easy to administer and has been incorporated seamlessly into their workflow. Initial concerns from secondary care that it would be a barrier have proved to be unfounded and the simple question ‘are you happy to give permission to all clinicians looking after you to have access to your GP records’ appears to have driven a change in culture by encouraging clinicians to involve patients in access decisions. This change in culture has begun to permeate
secondary care settings and driven improvements in the way that patient records are respected.

In Wales, the programme’s leaders recognised that the complexities of implementing ICT at scale cannot be managed centrally and that creating the “social architecture” at local as well as national level was just as important as developing the technical one. For example, the difficulties in gaining and maintaining the trust of patients, the public and clinical professionals led to the rejection of the idea of a single large database (the Spine then being developed by NPfIT) containing all patient records. The development of a consent model was seen as a societal problem and not a technological one; it had a high degree of professional and patient involvement and ownership and also benefitted from the learning gained in Scotland.

Data quality

One central feature of any shared electronic record is the quality and completeness of data it holds. This is important both in absolute terms (an absent penicillin allergy or outdated medication list could have life-threatening implications) but also because, if the data in the shared record are widely perceived to be inaccurate or unreliable, clinicians will not access the record or act on its contents. In Scotland, medication data are automatically uploaded from the GP system twice daily. There is a tendency for greater reliance to be placed on data such as a medication list that is generated by a computer rather than a handwritten letter or a plastic bag full of drugs, particularly by junior staff who may not be experienced in questioning the provenance and accuracy of medical records [23]. A warning screen on the first page of the Emergency Care Summary advises caution when looking at the list of medications taken from the primary care systems, as these may not include prescriptions which have been handwritten on home visits or prescribed elsewhere such as hospitals, drug clinics or mental health clinics. Feedback from users identified this as a significant gap and so practices were advised to add these extra medications whenever possible. Primary Care systems are all able to record ‘medications prescribed elsewhere’ but this is time consuming and can be significant, particularly when patients are discharged from hospital on multiple medications. Recent evaluations of the Emergency Care Summary show that this is still a significant issue that needs to be addressed (Morris L, submitted). In England, upload of prescribing information is dependent on using a smart card which means that significant medication can sometimes fail to be uploaded to the Summary Care Record, for example prescribing by locums who do not have a smart card, or by clinicians who have one but choose not to use it (or are prevented from doing so when the card fails to “work”). In the Welsh system, data quality of GP records was variable but improving, driven by the Quality and Outcomes Framework (QOF) and professional pressure. A Data Quality System (DQS, similar to the locally enhanced service LES in England) was introduced in 2007 with the aim of improving quality for electronic record initiatives, referral and discharge, medicines management and the IHR.

Evaluating, monitoring and learning

The four projects took very different approaches to evaluation and monitoring. In England there was a lot of pressure (much of it political) on Primary Care Trusts and Strategic Health Authorities to demonstrate “benefits realisation”. When this did not prove as easy as policymakers had anticipated, enthusiasm waned palpably. Perhaps this was inevitable since when any system implementation is linked to a required “benefits realisation” strategy on the assumption that the technology is the source of the benefits, participants may tend to look for these benefits once the technology ‘goes live’ rather than taking active steps to achieve these benefits (e.g. through efforts to promote and support use of the technology). This is not to deny the need for an evaluation plan to ensure that the system is accepted, actually used and that usage has the desired impact [24].

Primary Care systems are all able to record ‘medications prescribed elsewhere’ but this is time consuming

A largely (though not entirely) negative press portrayed the NPfIT as a whole as inefficient and monolithic, and the SCR programme as ill-conceived and unethical (because the opt-out consent model was contested). Connecting for Health had a Communications Department which managed press releases about the NPfIT and monitored and responded to all press coverage. A formal, independent evaluation of the SCR programme was commissioned by competitive tender at a cost of almost £1 million; the 235-page academic report was “welcomed” by Connecting for Health but its key message (that the SCR programme was characterised by unwieldy political and technical complexities which stacked the odds against its smooth implementation) was not easily actioned. The report was submitted just before the 2010 general election; the new Conservative government quickly commissioned two smaller inquiries (into the opt-out process and the clinical content of the SCR), and on the basis of these stipulated a more limited clinical content (similar to the ECS in Scotland) and a modified consent procedure. This has resulted in a more acceptable technology with a simplified content and appears to have reduced the controversies surrounding it sufficiently to promote slow but steady uptake.

In Scotland, feedback from users of the ECS was gathered as part of a small-scale in-house evaluation with no allocated budget; it soon became apparent that the system had quickly become part of ‘business as usual’ and a proposal to carry out a formal randomised controlled trial was deemed unethical. Ongoing collection of staff reports has produced many stories of improvements to patient care and perceived timesaving, but because of the pragmatic study design it is difficult to attribute these perceived improvements solely to the use of the ECS. One consultant working in A&E said “I hardly ever look at ECS but when I do it is because the information is critical”. Many pharmacists gave positive feedback and Forth Valley were amongst those using ECS for medicines reconciliation in unscheduled admissions and felt that it had been highly successful in providing more accurate information about patients’ medications (Morris L, submitted). Press coverage of the successful introduction of the ECS was limited but one incident involving a hospital doctor who looked at records of celebrities and colleagues (which was rapidly picked up via routine audit procedures) was widely reported in national news. No formal response to the press stories was given, on the grounds that

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there was no control over the factual content of what would be printed and as it turned out, the publicity from the incident raised awareness in a positive way (e.g. highlighting how rapidly the breach was detected) and appeared to encourage more practices to join.

In Wales, much emphasis was placed on recognising and responding to the inherent conflicts that exist between professionals, organisations, priorities and the political reality for delivery in a constrained financial environment. Intensive and consistent attention was paid to communication and stakeholder engagement through regular meetings with local leaders and presentations to CEOs and their Boards and the appointment of nationally funded but locally based Informing Healthcare (IHC) project managers. The Informing Healthcare Programme achieved much of its stakeholder commitment through running problem solving, topic based events (the first and longest lasting five days) which involved a range of stakeholders including clinicians, ICT professionals, CEOs, Ministers, government officials, patient representatives, in making real decisions about requirements and technical design that the Programme would commit to acting upon.

It would be a big mistake to conceptualise a national EPR programme as merely technology implementation

This created a sense of common purpose, credibility and trust that the national ICT Programme was genuinely owned and driven by those who would ultimately benefit. An important part of this was the creation of the Informing Healthcare International Advisory Group with members from USA, Canada, New Zealand, Denmark, Finland, Netherlands, Republic of Ireland, Scotland and England who met annually to carry out a public peer review of the Programme. ICT Suppliers and the national and local press and TV media were also invited to participate. This had a number of benefits [a] providing independent external benchmarking of IHC progress, [b] identifying areas where Wales was at the forefront, [c] lessons that Wales could learn from the experience of others and implement through agreed action plans which were publicly reported and reviewed by subsequent IAG conferences. It also placed the Welsh ICT Programme in an international context rather than simply a comparison with the English equivalent. This helped considerably to counter the bad press about the incident raised awareness in a positive way (e.g. highlighting how rapidly the breach was detected) and appeared to encourage more practices to join.

Summary and conclusions

There is an urgent need to reflect collectively on both the successes and the disappointments of the shared electronic record programmes in the four UK countries, in order to improve the existing implementation approach and before planning further large scale roll out of national electronic summary records. We believe that the lessons described above will also resonate outside the UK to countries such as the USA, who are just beginning to implement regional and national electronic records [24].

The fortunes of these projects to date illustrate the principle that when designing and implementing such pervasive interventions, policymakers must consider not only technical issues but also social and organisational impacts [12]. It would be a big mistake to conceptualise a national EPR programme as merely technology implementation, as it would be to plan a high speed rail line without considering the conflicting views of local communities, its impact on the environment or collateral impacts on existing transport routes. In the case of the HS2 rail line, for example, government started a widespread media and local consultation process to discuss the pros and cons 13 years before planned implementation [11].

We believe that much can be learned about the implementation of other technology-based innovations in the public sector by studying the experiences of the four UK countries in setting up a nationally accessible shared patient record. We therefore recommend that evaluations of each of these ongoing programmes continue from technical, clinical, social and organisational perspectives, to ensure that the important lessons are learned and can contribute to the advancement of implementation science.

Reference List

NHS CFH sponsor comment

Simon Burns, as new Health Minister aware of conflicting opinions about the Summary Care Record, commissioned a review in 2010 into its scope, use, and legitimacy. The consensus that subsequently emerged from patient groups, nurses and doctors, was that an accessible record of key medication and allergy information could prevent wrong or even dangerous treatment decisions. The right of anyone to opt out at any time of having such a record was to be reinforced by including an opt-out form in the letter informing citizens about creating the record.

The review concluded that any further information should only be added with explicit consent from the patient. As numbers of records created and their use in out of hours and acute settings have grown, patient groups representing people with long term conditions such as muscular dystrophy, asthma and heart or lung disease, have seized on the SCR as a way of making sure the NHS knows important things about them. Neil Churchill, Chief Executive of Asthma UK, has pointed out: “You may need to go into an A&E…people will be asking you to tell them your medical history and if you’re having an asthma attack, you’re by definition breathless, it’s a very hard thing for people to do. What patients have been doing is writing their information down on their wash bags or on scraps of paper in order to have to describe verbally their medical history… So I think the Summary Care Record is going to be extremely important.”

The problems discussed in the evaluation, including the cultural change required for the Summary Care Record to be useful to patients and clinicians, have in the main been addressed. There are now a number of places across the country where more than 60 per cent of patients have a Summary Care Record and endorsements by clinicians and patients of its usefulness continue to grow.

Dr Charles Gutteridge, National Clinical Director for Informatics
Electronic health records (EHRs) are now being implemented across the globe. They offer significant potential for improving the quality of clinical care and patient safety. They also hold potential benefits for enhancing the efficiency of care delivery processes and improved resource management. However, their implementation can, given the complexities of the processes involved and the necessary disruption for staff and patients, present significant change management challenges. The National Health Service Care Records Service (NHS CRS) represented the central deliverable of the former National Programme for Information Technology (NPfIT). It was intended to allow patient information to be exchanged between sites and service providers, facilitating provision of care and, through the secondary uses of digital data, support audit, commissioning, planning and research. Given the plans to introduce EHR systems throughout the NHS, this endeavour needed business change on a national scale.

Our study involved the undertaking of real-time evaluative research into the introduction in secondary care settings in England. We utilised a mixed-methods approach, which was organised into six complementary work-packages (see Figure 1). Work commenced in September 2008 and we collected a broad range of qualitative and quantitative data between February 2009 and January 2011. We worked with “early adopter” Trusts committed to using one of the three core software systems: Lorenzo Regional Care, RiO and Cerner Millennium. Each participating Trust was treated as an individual case study site to reflect the importance of local contingencies. Data were also gathered from a range of stakeholders including policy makers, NHS Connecting for Health (NHS CFH), Strategic Health Authorities (SHAs) Local Service Providers (LSPs), systems developers and other independent sector representatives. We also consulted with academic colleagues and, involved patients and public representatives in our data collection and in the overseeing of the project.

Towards the end of our evaluation we shared our findings in an international conference we convened on the implementation and adoption of EHRs.

The former NPfIT was launched in 2002 to reform the use of information in the NHS, improving services and quality of patient care. Since its launch the Programme went through many modifications. With changes in organisational structures, contractual arrangements and business partners. Meanwhile, the provision of care continues to evolve as indeed does professional practice. The NHS itself has moved on significantly, as has the economic and political landscape. The large scale delivery of EHRs was conceived and planned under a Labour Government in a time of relative growth. We were however during the latter stages of our project evaluating system implementations during global economic recession. The formation of the Coalition Government has also led to a new strategic direction and debate over the structure of the NHS. The case study-based approach we pursued allowed us to consider and factor in the effects of these important wider developments on the local implementations in different trusts.

The highly centralised procurement and contracting arrangements surrounding the wider delivery of EHRs formed a cornerstone of the economic case for the former National Programme based upon economies of scale in procurement. However, all stakeholders interviewed found the current contractual situation unsatisfactory. We found that the opaque nature of the contracting together with the resulting practical difficulties presented significant barriers to implementation and adoption. Whilst staff from different organisations tried to work together, it was felt that they had little insight into what contracts contained and the resultant roles and responsibilities.

Another issue associated with contracting was the payment arrangements. Contracts were structured so that local payments were made some time after the deployment of local systems. This caused problems with local
finances as money was outstanding for significant periods despite implementation. This created local uncertainty and impacted adversely on LSPs.

The contracting process was also impacted upon by ambitious deployment schedules that were seen to be politically and contractually driven. Many interviewees described project timelines as unrealistic from the outset. There was concern that longer-term criteria for benefits realisation and outcome measures did not sufficiently incentivise short-term benefits for individual users and local organisations.

A key finding from our study was the sheer organisational burden associated with moving from paper-based to electronic patient records. Most interviewees were in a general sense strongly supportive of the move to EHRs despite frustrations with the practical difficulties and delays experienced during implementation. There was a noticeable difference between the imagined benefits of an ideal EHR and the reality of actually using the centrally procured EHRs. Not surprisingly, clinicians were primarily concerned with the local benefits of the systems for patients and their care rather than any concern for national objectives regarding, for example, the sharing of patient data.

Indeed, the sharing of patient data was frequently considered as a concern. The guardianship of paper-based records is an important consideration for all staff. EHRs were felt to introduce far more complex issues to do with confidentiality and data security. Some of these concerns reflected interviewee knowledge of comparative examples of data getting lost, being stolen on laptops or being hacked into in comparable sectors such as defence and local government.

Staff were also worried that patients might not be sufficiently informed about how their data were being used and shared, and about how patients might opt-out of certain types of data sharing. During our study central guidelines for storing and retrieving detailed clinical data electronically were in their infancy. As a result, local arrangements were having to be devised, requiring detailed consideration of business processes and stakeholders.

clinicians were primarily concerned with the local benefits of the systems for patients and their care rather than any concern for national objectives

Figure 1

Work Package 1 (qualitative, longitudinal)
Implementation, deployment and organisational learning
LSP roll-out teams software suppliers, members of the NHS Trust implementation team and trainers/support staff. Relevant documents

Work Package 2 (qualitative, longitudinal)
Attitudes, expectations and experiences of NHS stakeholders
Interviews with patients, carers, healthcare professionals, managers, IT service providers, IT support personnel, administrative staff

Work Package 3 (mixed methods, longitudinal)
Organisational consequences: organisational workflow, professional roles and data quality
Record review; interviews with healthcare professionals and administrative staff involved in patient pathways; relevant documents; survey

Work Package 4 (mixed methods)
Assessment of costs of wider EHR systems implementation
Estimating local implementation costs; centrally procured system cost categories. Relevant documents; interviews

Work Package 5 (quantitative, pre-post)
Assessing error, safety and quality of care
Quantitative measures of missing information in outpatient clinic records

Work Package 6
Organisational consequences and implications for future IT deployment and evaluations
Integration and summary of case study findings/conclusions; interviews with additional stakeholders; conclusions and recommendations for NHS policy and practice and future evaluations
England has in many ways pioneered the national implementation of EHRs

Local health community-based systems were advocated by a number of interviewees as an interesting alternative to the choice between local and standardised systems. These communities would not necessarily be determined by geography, but would consist of a collection of services working together to serve a particular population. The potential for local collaboration to deliver systems that could deliver immediate benefits through local data sharing seemed to many more feasible on this small scale basis.

The extent of change going on and the commitment to the improvement in quality of care were defining features of the NHS throughout our research. Interviewees did express concerns as we have outlined here, but they also described how they were working to bring the EHR systems into being as part of their on-going service improvement. There is much written on resistance to change, but this was not in itself a feature encountered here. Rather, staff were actively taking on new processes and working practices to improve care and deliver organisational objectives around systems implementation. This was more difficult with some systems than others, principally due to poor functionality, which staff worked hard to accommodate.

The other striking feature of the wider delivery of EHR systems is its ambition. The idea of interoperable health records that can be shared to maximise the provision of care, the planning of care and research into the outcomes of care is undoubtedly an inspiring vision. England has in many ways pioneered the national implementation of EHRs and continues to progress in this area. Other nations are fast developing their own systems and approaches to implementation. Much learning can be shared across national boundaries not only regarding implementation, but importantly in maximising the benefits of these significant investments. More international discussion and collaboration can only accelerate progress.

This national study has proved interesting and not without considerable challenges. We acknowledge that it will be many years yet before we can draw firm, evidence-based conclusions about anticipated and unanticipated consequences of the implementation of EHR systems within the NHS. That said, there is great value in the preliminary lessons that may be inferred from early experiences of implementing EHR systems on such an ambitious scale. We sought to make general inferences about the implementation of EHRs to facilitate organisational learning. Sharing such lessons and considering the experiences of other international developments is vital given the stakes associated with moving towards computer-based health records.

Key Points

• The National Health Service Care Records Service (NHS CRS) represented the central deliverable of the former National Programme for Information Technology (NPfIT).
• This research involved real-time evaluative research into the introduction of the EHR systems in secondary care settings in England.
• Centralised procurement and contracting arrangements offered advantages in principal, but were found to present barriers to implementation and adoption in practice.
• The move from paper-based to electronic health records presents a huge organisational challenge that should not be under-estimated.
• Local health community-based systems offer potential for more local collaboration and data sharing arrangements.

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Looking back, moving forward

NHS CFH sponsor comment

This study reflects evidence gathered directly by the NPfIT programmes themselves in a similar timeframe, in relation to the centralised approach of NPfIT. As we know, this approach is now being replaced by a more locally driven and owned approach.

The studies in this report also highlight the challenge of ensuring an effective balance between greater access and control of health and social care records, greater transparency and sharing along care pathways versus maintaining and protecting individuals’ confidentiality and security. This evidence is highly relevant to the current work to develop an Information Strategy for Health and Social Care and the review of information governance announced as part of the latest Future Forum Report.

They also remind us of the fact that we must not underestimate the size of the cultural and organisation effort that is required to implement such fundamental change, and provide some important preliminary findings to guide future work.

Kathy Mason, Director – Policy Planning and Information Governance, DH Informatics Directorate


Should there be greater structuring and coding of the medical record?

Zoe Morrison and Bernard Fernando

The National Health Service (NHS) is committed to an ambitious programme of modernisation, which includes the richer and more strategic use of a range of information and communication technologies (eHealth). One of the key goals of this modernisation agenda is to enhance the quality and safety of clinical care. Another important anticipated outcome is the availability of good quality detailed clinical information to underpin health service quality assurance, planning, public health and to support clinical and biomedical research. These policy components are clearly outlined in the Information Revolution consultation document. This is all however crucially dependent on ready access to high quality data that can potentially be distributed and reused to support a number of ends.

At present, healthcare information (that is, personal health, health care and wellness information about an individual citizen or patient) is scattered across multiple records in both paper and electronic formats. These multiple records are now often termed silos because there is limited or sometimes no easy way for information to be combined to provide either a longitudinal whole-person record of care or to enable cross-population analyses. The potential benefits of computerised interoperable Electronic Health Records (EHRs) very much include this integration of patient data to support the delivery of care across geographical, organisational and professional boundaries.

It is undoubtedly now feasible to encourage the more complete migration from paper to EHRs, and to integrate clinical data repositories using new-generation health informatics standards, such as ISO/EN 13606, openEHR, SNOMED-CT and HL7 Clinical Document Architecture. What is more difficult is to establish which elements of a health record can be captured in a form that can be exploited by computers. A consistent approach to the structured representation of clinical data is required in order for clinical computer systems to be able to utilise the information. This requires significant changes to working practices and a major step in the evolution of medical records, not something to be undertaken lightly. What are the marginal gains of structuring or codifying increasing amounts of information? This is the fundamental question of our evaluative research; the drivers, incentives, successes, benefits realised and lessons learned world wide, in designing, implementing and adopting consistent structured approaches to the capture, representation, communication and exploitation of clinical records.

To address this question we are considering several aspects of current practice including relevant previous work, stakeholder viewpoints, case studies of particular information sets and international developments (see Figure 1). First, however, we need to clarify what is meant by ‘structuring’. We all use structures to organise and discuss our everyday thoughts and practice. The rules of grammar are in themselves a general structure for language. More specifically within patient records, medical coding systems such as ICD-10 and SNOMED-CT offer very detailed structures for classifying and representing knowledge into computable formats. How data is structured depends what computation is able to be performed. Whilst computable data offers a range of benefits for health service commissioning, provision and research it also offers significant challenges given the diversity of the information collected and used everyday within the NHS.

Clinical records have developed as part of professional practice (see Table 1) to provide information to support decision making, but they are first created by healthcare professionals whose main objective is the delivery of clinical care. Coding can be seen as a task irrelevant to this objective and some clinicians may be reluctant to code either during or after practice. This reluctance may in part be because of time constraints, poor designs of application/browser technology, skills’ gaps or simply that the value of coding is not well appreciated. We also know that GPs achieve high levels of coding when they are appropriately incentivised, if the scope of coding is well-defined and if well-designed tools such as templates are provided to them. This is the case in the General Practice Quality and Outcome Framework (GP QOF), which has produced accurate, coded information well suited to computer retrieval and analyses.

Whilst computable data offers a range of benefits for health service commissioning, provision and research it also offers significant challenges given the diversity of the information collected and used everyday within the NHS.
Information retrieval from clinical records by searching databases is undertaken by many stakeholders within, and in partnership with, the NHS. Structured and coded information can be searched easily by using computers. However, research indicates that structuring and coding patient information may not be suitable in certain clinical settings, for example whilst structured note taking has helped in decision making in infertility and antenatal clinics it did not in general medical and gynaecology clinics. This presents significant challenges for the design of electronic health records. Although clinical narrative is important as a source of information for decision making, current computer systems are unable to easily process the free-text narrative and retrieve information from it.

In clinical practice not all decisions are made on the basis of explicit knowledge. Important tacit knowledge and undocumented signals are used in formulating a clinical management strategy. There will always be clinical judgement applied in decision making and the use of codes is only one source of information. Clinicians may be reluctant to code information during clinical practice and there are many barriers to ‘real-time’ clinical coding. These include: (a) limitations of coding systems and terminologies, (b) skill gap of the users, (c) time and distraction when coding, (d) level of motivation, and (e) the priority of coding within the organisation. On the other hand, when the coding of clinical records is undertaken retrospectively by clinical coders off-line (as is the case in relation to diagnoses in most NHS hospitals) the task may be prone to inaccuracies due to poor handwriting, incomplete records and abstraction problems.

To meet this challenge software engineers engaged in designing systems need help from healthcare professionals, managers and administrators who use them and understand the context. To this end NHS CFH is engaged in developing Logical Records Architecture for Health and Social Care (LRA) to provide best practice recommendations for the meaning and structure of care records data. Another development intended to address issues relating to inaccurate data and incorrect codes is the introduction of SNOMED-CT as a terminology that is structured according to a model familiar to clinicians. The Systematized Nomenclature of Medicine (SNOMED) is a terminology of medical concepts arranged in a set of axes (i.e. Disease, Drug, Social Context, Modifiers etc.). Terms are arranged according to certain domain rules. Coding of patient information is accomplished by a process called post-coordination of terms in SNOMED-CT. That is, new terms can be constructed by combing existing terms, for example:

- Acute appendicitis $\rightarrow$ “acute” [a modifier code] + “appendicitis” [a disease code]
- Acute appendicitis $\rightarrow$ “acute” [a modifier code] + “inflammation” [a morphology term] + “vermiform appendix” [a topography term]

SNOMED is designed to be expressive and the same concepts can be coded differently by different clinicians. SNOMED-RT is the “reference terminology” that is designed to encourage consistent use of terms by defining these rules explicitly. It was an attempt to make terminology fit for computer technology. Read Codes and SNOMED-RT were combined to produce SNOMED-CT in 2002. In June 2011 the Department of Health announced that SNOMED-CT will be the sole supported terminology for the NHS from April 2015. Now it is managed by the International Health Terminology Standards Development Organisation (IHTSDO).

Terminologies can be inaccurate in themselves and quality assurance is expensive and difficult. The causes of error include (a) human, (b) evolving rules, (c) novel transactions, (d) hardware and software problems and (e) concurrency and version control. To investigate more fully the issues surrounding the use of terminologies we are conducting a collective case study to understand approaches to, and the impacts of, differing practices in data collection. A case study is an in depth investigation of an area of interest and is the preferred strategy when “how” or “why” questions are being posed, when the investigator has little control over events, and when the focus is on a current real-life phenomenon. A collective case study comprises a collection of individual studies of interest that will lead to better understanding and theorising regarding a common characteristic.

The four cases within our collection relate to structuring and coding of information within the clinical record relating to:
- Patient’s ethnicity;
- Drug allergies and adverse drug reactions;
- Diabetes mellitus;
- Depression.

These four examples have been chosen as exemplar areas that will help shed light on a spectrum of issues relating to tensions between use of narrative-based records and more structured/coded records. The relative value of structured and unstructured information is expected to be different across these case studies. The recording of ethnicity and drug allergy and adverse drug reactions related data can reasonably be expected to be stable, requiring little or no updating. Conversely, the recording of clinical information for the management of long-term conditions such as depression and diabetes is likely to be more fluid and subject to frequent updates and amendments. We anticipate that the involvement of patients in providing this information, and the potential benefits to patients will for each be very different.

We are also considering approaches to the structuring and coding of medical records in other countries. We have chosen to study nine countries from around the world: Germany, the Netherlands, Sweden, Norway, the USA, Canada, Australia, Japan and Brazil. In addition to examining policy documents and other publications, we will conduct telephone interviews with recognised experts able to comment on related developments. Whilst the UK is generally acknowledged as an international leader in this field, we hope to develop recommendations that will inform both policy and practice in this important area.

No silver bullet is anticipated from this research: no single use case or proven benefit is expected to surface as the magic answer to why clinical communities across the NHS should move to greater coding of the clinical record. Rather, we are working to determine the potential benefits and risks associated with different forms of information capture. Our aim is to identify areas where increased use of structured and/ or coded information within the clinical record will bring useful and relevant benefits which outweigh any loss of context and data richness available from current forms of data collection and retrieval. In pinpointing areas of benefit we will also consider the ease of implementation of potential changes to the clinical record, identifying some immediate areas for improved practice and some longer term aims for best practice.

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A further complexity of the anticipated picture from the research is that the benefits will often not be realised by the parties who need to make the most effort to structure the information. We aim to indicate possible incentives and benefits to strengthen the engagement and commitment of those on whom the effort largely falls.

Acknowledgements
Our thanks to Aziz Sheikh for his comments on earlier drafts of this manuscript. Our research team included: Aziz Sheikh, Emma Byrne, Kathrin Cresswell, Bernard Fernando, Akiko Hemmi, Dipak Kalra, Zoe Morrison and Ann Robertson. We are also very grateful to the participating academic colleagues, hospitals and GP practices for supporting this work and to all interviewees who kindly gave their time. Throughout the process of undertaking this work we have had helpful support from colleagues at the NHS Connecting for Health Evaluation Programme led by Professor Richard Lilford and supported by Lee Priest, Nathalie Maillard and Jo Foster. We gratefully acknowledge the advice on this research, which has been provided by members of the Independent Project Steering Committee overseeing our programme of work into the structuring and coding of the clinical record. Chaired by Professor Simon de Lusignan, this group also comprised Dr Nick Booth, Dr Stephen Kay, Peter Short, Lee Priest and Joanna Foster. We acknowledge the support of the National Institute for Health Research, through the Comprehensive Clinical Research Network.

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Suggested further reading

Table 1: The evolution of the medical record

<table>
<thead>
<tr>
<th>Year</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1907</td>
<td>The first single-unit patient record with an assigned number was created at the Mayo Clinic in the USA, replacing the practice of keeping patients’ records in a single bound volume (or a ledger book).</td>
</tr>
<tr>
<td>1968</td>
<td>Problem Oriented Medical Record (POMR) structuring introduced, based upon the ‘current active problems’ model.</td>
</tr>
<tr>
<td>1996</td>
<td>The clinical narrative model of the medical record proposed, incorporating context, structure and process within a single framework, intended to be readily understood by those in both lay and technical healthcare professions.</td>
</tr>
<tr>
<td>2003</td>
<td>The Royal College of Physicians Health Informatics Unit (RCP HIU) released draft standards for record keeping.</td>
</tr>
<tr>
<td>Today</td>
<td>NHS CFH is working with professional bodies to develop standardised structures and layouts for the medical records (both paper and electronic).</td>
</tr>
</tbody>
</table>

Key Points
- Good quality, detailed clinical information is essential to the quality and safety of clinical care, service planning, public health and clinical and biomedical research.
- The potential benefits of computerised interoperable electronic health records (EHRs) include the integration of patient data to provide this information across geographical, organisational and professional boundaries within pre-determined structures for information capture.
- This study considers the drivers, incentives, successes, benefits realised and lessons learned world wide, in designing, implementing and adopting consistent structured approaches to the capture, representation, communication and exploitation of clinical records.
- NHS CFH is engaged in developing Logical Records Architecture for Health and Social Care (LRA) to provide best practice recommendations for the meaning and structure of care records data. Another development intended to address issues relating to inaccurate data and incorrect codes is the introduction of SNOMED-CT.
- The relative value of structured and unstructured information is expected to be different across different types of patient information.
- Our aim is to identify areas where increased use of structured and/or coded information within the clinical record will bring useful and relevant benefits which outweigh any loss of context and data richness available from current forms of data collection and retrieval.

Useful definitions
A clinical document or its equivalent may be
- narrative:
  - sentences and/or informally grouped lines of text;
  - optionally using indentation or bullets;
  - in a format that is determined by the author;
  - numeric values, dates and times occur within sentences or phrases.
- organised:
  - a list or tree of clinical headings, each of which contains narrative.
- structured:
  - a set of entries, each of which has an explicitly stated or implied context label (i.e. name);
  - its values may be:
    - narrative;
    - coded: representing a term taken from a terminology or controlled vocabulary;
    - a quantity;
    - dates and/or times;
    - Boolean;
    - graphical, multimedia or a reference to such data
  - values may optionally be clustered into lists, tables or trees.

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Lessons learned

• The fundamental importance of standards in building structured records.
• The need to identify the ‘real world’ benefits and barriers to effective coding in clinical records.
• The role of incentives to improve the quality of coding in clinical records.
• The limitations of ‘off line’ retrospective coding – and its tendency to produce poorer quality structured records.
• The need to achieve a balance between coding and natural language that will need to be established for different clinical settings.

NHS CFH sponsor comment

This paper sets out to address one of the significant challenges in health information. The need to move towards more structured methods of communicating is being increasingly recognised and the shift to electronic records provides an opportunity for the profession to discuss what this structure should be. The introduction of structured records and terminology like SNOMED CT will help drive out some of the uncertainty of our clinical language but there will always be a place for free text and this will need to exist within its own structure.

The NHS relies on effective communication to coordinate care from one professional to another for example referral letters, handover forms, reports or discharge letters. If the health service adopted a standard way of constructing these communications, it could make these hand-overs more efficient and safer. That is not to say that we should lose the richness of natural language but structure would make what we are trying to say much clearer.

A balance will need to be achieved and a debate about what standards we apply to our communications in a clinical environment. Too much structure and we risk losing subtlety and may stifle the natural flow of language, too little and we leave unacceptable room for ambiguity. This paper takes this debate forwards in a significant way.

Mark Davies, Medical Director, The NHS Information Centre for Health and Social Care
Understanding the impact of information technology on interactions between patients and healthcare professionals: the INTERACT-IT study

Dr Fionagh Thomson¹, Dr Heather Milne¹, Dr James Hayward¹
Dr Hilary Pinnock¹, Ms Kathrin Cresswell¹, Dr Bernard Fernando¹
Dr Guro Huby², Professor Robin Williams³, Professor Aziz Sheikh¹

Abstract

The interactions between healthcare professionals and patients during consultations lie at the heart of the delivery of health services. These interactions play a key role in determining, for instance, the accuracy of diagnosis, patients’ commitment to medication regimes and lifestyle changes, and the extent to which patients are satisfied with the service they receive.

This paper outlines a project funded by the NHS Connecting for Health (NHS CFH) Evaluation Programme that is exploring the impact of information technology (IT) on i) the quality of clinical interactions, ii) the length of the consultation and iii) patient involvement. We video-recorded consultations and undertook non-participant observation in primary care, breast cancer clinics, out-of-hours services, and emergency departments. We present an overview of existing research and highlight where our preliminary findings support current understanding, and raise some questions about a number of the premises on which these research studies are built, in particular the definition of IT/the computer within the consultation as an artefact or tool. Participants suggested a more nuanced concept of the ‘computer/IT’ that extends beyond the Electronic Healthcare Record (EHR) or a material box that sits on a doctor’s desk, is attached to the end of a hospital bed or is placed on a moveable trolley in an emergency department. To inform our on-going analysis we have explored the literature relating to four emerging themes:

i) The dynamic interaction between patient, healthcare professional and the computer
ii) Attention, eye contact and ‘being listened to’
iii) Levels of trust in sources of information
iv) Space, place and mobility.

We conclude by emphasising the potential relevance of our study to the training of healthcare professionals and to the design of future IT systems. Our findings will inform the ongoing ‘feedback’ discussions between IT designers, NHS managers and those commissioning IT systems that ‘fit’ with current healthcare practices and/or seek to create new healthcare practices appropriately supported by IT systems.

Background – Defining the primary care consultation

The broadest definition of a consultation is “the meeting of persons to discuss or decide upon an issue” [1]. Within healthcare, a consultation may be the meeting of a patient with a health professional (or professionals) and/or between health professionals to discuss a healthcare problem and to decide a suitable course of action. The nature of the consultation will depend upon the healthcare setting, the type of health professional and the nature of the healthcare problem. All health professionals are taught about communication skills, though it is the postgraduate training of general practitioners (GPs) which has formalised the understanding of the consultation as a defining feature of general practice.

Although the consultation is arguably as old as the medical profession, contemporary understanding of the interaction between a patient and a healthcare advisor dates back to the 1950s, when Balint highlighted the role of the doctor during the consultation process [2]. Widely cited concepts, such as “the drug called ‘doctor’” emphasised that the feelings and attitudes of the doctor had a pivotal role in the consultation process, and that
clinicians could be trained to recognise these feelings and adapt their behaviour to become more sensitive towards the patients. ‘Balint groups’ became a feature of general practice in the 1960 and 70s before moving on to the consultation.

In the years preceding statutory training for GPs, the Royal College of General Practitioners (RCGP) developed the thinking about the nature of the consultation, and developed concepts which remain a pivotal aspect of the summative assessment for GP registrars. The ‘triaxial model’ which stated that consultations encompassed three key important aspects (physical, psychological and social) [3], was extended by the work of Stott and Davis who described the ‘exceptional potential’ of the primary care consultation in four domains [4]. The management of the presenting problem was clearly central, but needed to be seen in the context of continuing health issues (though it was recognised that extending the consultation in this way might be considered ‘irksome’ in the five minute consultations that were the norm for the 1970s). In a farsighted observation, the computer - at that time a novelty in general practice - was suggested as having a role in ‘guaranteeing continuity of care’ for people with long-term conditions.

Understanding of the construction of a consultation was significantly advanced by Byrne and Long who reported an analysis of 200 audio-recorded consultations [5]. The six key phases of the interaction (establishing a relationship, discovering the reason for the patient’s attendance, conducting a verbal/physical examination, considering the condition, determining management, and closing the consultation) remain salient 30 years later, and reflect the gradual move from paternalistic to partnership working.

Pendleton nearly ten years later [6, 7], described seven tasks which remain relevant in his updated discussion of the consultation [7]. These tasks reinforce the previous emphasis on defining the reason(s) for patient’s attendance but extend the concept of ‘sharing the understanding of the problem’ and ‘involving the patient in the management of his condition and encouraging him to accept appropriate responsibility’. Neighbour a few years later added the importance of ‘safety-netting’ the consultation, and the need for the clinician to disengage from one consultation before moving in to the next [8].

The Calgary-Cambridge model

The Calgary-Cambridge model of the consultation builds on this early work, and remains an important resource for GP registrars [9,10]. The recently updated framework translates the process of a consultation into a series of five tasks (see Figure 1) and encompasses 71 skills that clinicians may acquire and use in order to achieve effective communication within consultations [11].

The only specific mention of the computer in the list of 71 skills within these core tasks is in the context of using appropriate non-verbal behaviour and ensuring that the computer (or paper record) is used ‘in a manner that does not interfere with dialogue or rapport’ [12].

Figure 1. Calgary-Cambridge framework: flow of medical tasks in clinical consultation [11]

<table>
<thead>
<tr>
<th>Initiating the Session</th>
<th>Building the Relationship</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gathering Information</td>
<td></td>
</tr>
<tr>
<td>Physical Examination</td>
<td></td>
</tr>
<tr>
<td>Explanation and Planning</td>
<td></td>
</tr>
<tr>
<td>Closing the Session</td>
<td></td>
</tr>
</tbody>
</table>

IT and the interaction between patient and clinicians in the consultation

Several studies have indicated that the doctor-patient relationship changes with the introduction of IT during the consultation, and have raised concerns about increased time spent on computer use, and the detriment to human interactions [13-15]. Computers have been observed to interrupt communication-flow when clinicians turn to the screen to record information, losing verbal and eye contact, [16] and leaving patients unsure as to why the computer is being used [17]. Concerns that this might damage the doctor-patient relationship, however, have not been substantiated in patient surveys [18,19].
‘Computer etiquette’ and consultation styles

With increasing use of the computer in primary care consultations, a detailed discussion of ‘computer etiquette’ has been developed within the Calgary-Cambridge model [20]. This starts from the premise that the computer is potentially disruptive and reiterates the importance of ensuring that the computer is ‘not allowed to interfere’ with dialogue or rapport. Some functions (such as prescribing or checking details of past history) are identified as having equivalents in paper-based consultations whilst others (such as accessing information or decision support) require additional skills. ‘Computer etiquette’ advises that it is not possible simultaneously to pay full attention to the screen and the patient, and recommends signposting sequential use rather than multi-tasking. A number of strategies for creating breaks in the conversation in order to use the computer are suggested, including breaking eye contact.

Fitter and Cruikshank classified clinicians into three types according to how they use the computer [21]:

- ‘Minimal users’ who record information at the end of the consultation either from memory or transcribing hand written notes
- ‘Conversational users’ who multitask and record information throughout the consultation
- ‘Block users’ who interrupt the consultation to use the computer.

The design of the consulting room and positioning of the screen is important for determining how it is used [22], (see Table 1) and the computer etiquette suggests strategies to ensure that rapport is maintained [20].

Table 1: Advantages and disadvantages of different positioning of the computer relative to the doctor and patient. [20]

<table>
<thead>
<tr>
<th>Layout</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Screen and patient at opposite ends of desk</td>
<td>The patient can see the screen making it a ‘shared resource’ – though that may not always be appropriate. Turning to the screen visibly ‘signposts’ computer use.</td>
<td>The clinician has to turn away from the patient to use the computer. Eye contact is lost, ‘cutting off’ the patient. Rapport will have to be re-established after each usage of the screen.</td>
</tr>
<tr>
<td>Screen and patient at same end of desk</td>
<td>Clinician can glance from patient to screen without turning body. The patient is never out of view so non-verbal clues will not be missed.</td>
<td>The patient cannot see the screen unless it is deliberately turned towards them.</td>
</tr>
<tr>
<td>Screen in middle of desk</td>
<td>Both clinician and patient can see the screen without losing sight of each other. The ‘triangle’ arrangement ‘aids rapport and communication’.</td>
<td>The computer is implicitly a ‘full participant in the consultation’ which ‘may not be welcomed’ by some patients and clinicians.</td>
</tr>
</tbody>
</table>
IT and the attitudes of healthcare workers and patients

It is well recognised that users’ attitudes towards technological innovations influence their adoption behaviour and may sometimes ‘sabotage’ use (an expression derived from a disruptive action by saboteurs who threw their shoes (sabots) into ‘new-fangled’ weaving machines to halt industrial production in the 18th century). Studies investigating the attitudes of healthcare professionals have identified some resistance towards technological innovation in general, with specific concerns voiced about disruption of doctor-patient rapport with the introduction of electronic medical records [23]. Design considerations, interactions between healthcare professionals and organisational factors (e.g. ease of use, flexibility, intrusiveness of the system) may all influence the attitudes of health professionals to IT and e-healthcare [24]. Although most clinicians acknowledge the benefits of the specific functionalities, there is often a critical attitude among healthcare professionals towards the implementation process of centrally driven IT programmes such as the National Programme for IT [25]. Some studies investigating patients’ attitudes towards the introduction of computers in the consulting room have shown that they generally feel computers can help to improve access to information, and support the doctor-patient relationship and care, without compromising satisfaction with the service [18].

IT and time spent on tasks

Systematic reviews of computer use within primary care indicate that despite timesavings in performing specific activities (such as prescribing), overall the use of a computer increases the length of consultations [13,26,27]. There is a need to consider a ‘whole systems approach’ to using computers in health care delivery, encompassing the skills of the user, the design of the interface, and speed of the computer, as well as interruptions due to hardware or software problems [28,29].

In order to understand how computers may affect the use of time within primary care consultations we are studying the time spent on five generic computer based activities, namely: (i) reviewing, (ii) ordering tests, (iii) making referrals, (iv) prescribing, and (v) updating records. These categories are over-simplifications, but are constructs that designers and users can use to interpret tasks in different kinds of consultation and across health sectors [30-32].

The INTERACT-IT study

In order to investigate how using computer-based services affect interactions between patients and healthcare professionals, we used two techniques to observe medical and nursing consultations both before and, where possible, after introduction of new IT services in a range of settings including both rural and urban areas in north and south England. We video-recorded consultations in primary care surgeries, out-of-hours services and oncology clinics. For ethical reasons, in acute situations such as an emergency department or out-of-hours home visits where the patient cannot be given advance warning of the recording session and there is insufficient time to obtain patients’ consent to video, we carried out non-participant observation.

• Multichannel video recordings. We used three video cameras and screen capture to record a consultation [33]. One video camera recorded the clinicians’ head and upper body (to capture the direction of gaze and body language), the second recorded the patients’ upper body (to interpret the body language); the third recorded a wide-angle view of the consultation. A video output recorder captured the computer screen and data entered in real-time. (See Figure 2).

Figure 2. Multi-channel video setup – three camera angles and the screen capture software.[33]
Non-participant observation. The researcher followed the activities of a healthcare professional throughout a working shift, with a focus on collecting data surrounding the nature of patient-professional interactions and the use of IT. At a mutually convenient time shortly after each completed observation, we interviewed the participating health professional to review and discuss fieldwork notes.

Videoing consultations: hearing the participants’ voice
Despite the importance of interaction between healthcare professionals and patients in healthcare services, it is a challenging aspect of health care to study and measure. Although video recording has become established as a useful technique [17,33,34], there is a danger of misinterpreting what participants are thinking or doing. We therefore included participants’ voices by inviting the health professional and patient (independently) to watch the video with a researcher and provide a commentary, including their reflections on the use of the computer [35]. As a result of this approach, during analysis we have been able to include both patient and healthcare professionals’ perspectives on the same consultation. For example, a patient may be staring into space, apparently bored and disengaged from the consultation, while the GP types into the computer. The patients’ commentary however may reveal that they were aware why the GP was using the computer and were entirely happy to look round the room while the task was completed.

Study sites and participants
We chose four different healthcare settings for our investigation:

- Primary care. We recruited four practices, and videoed the surgeries of nine GPs and three practice nurses. Two of the practices used Vision software and the other two used EMIS. During the course of our study, the Summary Care Record was rolled out in one of the study areas and Map of Medicine was actively promoted. One of the practices in another area was seeking to integrate Choose & Book into the consultation.
- Out of hours services. We recorded the consultations of three doctors and two nurses in an out-of-hours service operating on two sites in the area where the Summary Care Record was being introduced. We also observed the use of portable laptops in doctors’ home visits, and a hand held device used by the community nursing team.
- Breast cancer clinics. We recorded consultations with a clinical oncologist, a radiographer and a breast cancer nurse in two settings one of which was computerised (Cerner Millennium) and one of which was largely paper-based with a ‘home-grown’ IT system for referrals.
- Accident and Emergency department. We observed a number of health professionals (charge nurse, registrar, and consultant) on a range of shifts, both day and night, weekday and weekend.

Redefining the computer: “what do you mean by IT?”
In order to design and develop effective and ethical technologies which support good healthcare practices, there is a need to understand how health professionals and patients understand and interact with these technologies within the ‘reality’ of everyday consultations. This seemingly simple question frames an age-old debate that has been at the centre of discussions around human’s relationship with technologies since Ancient Greece. More recent research on the relationship between humans and technologies has revolved around three main themes:

1. **technology as an artifact or tool;**
2. **technology as a social and technical entity and;**
3. **technology as a phenomenon through which humans make meaning of the world.**

**IT as an artifact or object.** A common approach towards IT is to consider it as an artefact or tool that is used by a healthcare professional or a patient, as an extension of human capacities [36]. For example, the EHR can be viewed as a system for storing relevant information on a patient, enabling professionals and patients to retrieve information on past medical history and future planned treatments. As an object/artifact the EHR is perceived as operating in a more or less uniform manner regardless of the setting or the type of healthcare professionals or patient using it.

**IT as part of a socio-technical network system.** A number of researchers propose that the artifact/tool-impact approach does not provide an adequate account of the ‘messy’ relationship between humans and IT that exists in a network of things, people, policies and knowledge [37]. For example, the EHR is a product of existing complex and subtle interactions between NHS policy, budgets, legal auditing requirements and the medical and technical know-how available.

**IT as a way of interpreting the world around.** For phenomenologists, although these two approaches are valid, they are not adequate to explain the complexity of human computer interactions. Instead, they propose that technology and social relationships coexist since humans are in essence technological beings (from fashioning a flint to make fire to inventing cloud computing that contracts time and distance) [38]. In order for humans to make sense of what is happening around them (the foreground) they draw upon their existing knowledge, memories, skills and attitudes (the background) to make sense of (interpret) what they encounter.

Our initial findings indicate that adopting phenomenological approach to human-computer interaction will create a more practical framework for understanding ‘what is happening’ within consultations. As a result, our research presents two different perceptions of the same consultation (that of the health professional and patient) as each bring their individual ‘background’ to interpret the same scenario.

**Framing four emerging themes: dynamism, listening, trust and mobility**
While our analysis is not yet complete and our findings are thus tentative, the following four themes are emerging from our preliminary analysis: i) the dynamic interaction between patient, health professional and the computer, ii) attention, eye contact and ‘being listened to’, iii) differing levels of trust in different sources of information and iv) space, place and mobility.

**A dynamic interaction.** The consultation process is often presented as involving two sets of interactions: i) the dyadic interaction between patient and health professional or ii) a triadic interaction between patient-clinician-computer [39], where the computer is held to be a ‘third person’ in the consultation. This view presents the computer as a uniform, and at times static, presence within the consultation. During our analysis, it has become increasingly evident that the nature of the interaction is more complex and more dynamic than currently presented when viewed from the different perspectives of the health professional and the patient.
• **Eye contact and being ‘listened to’: always a symbiotic relationship?** Fitter and Cruikshank propose that health professionals use the computer in three different ways during the consultation: ‘conversational’, ‘block’ or ‘minimal users’ (see above for a description of these styles) [21]. These studies present the computer as an ‘artefact’, and therefore consider that when conversational and block users turn to face the computer during the consultation, losing eye contact and at times verbal contact with the patient, rapport is lost. In contrast, our research is based upon a phenomenological approach towards technology enabling more nuanced patterns of interactions and rapport to emerge.

• **Differing levels of trust in different sources of information.** While patients’ trust in their healthcare provider has been widely researched, there has been little attention paid to clinicians’ trust in electronic sources of information during the consultation. Some studies have suggested that clinicians may invest “excessive” trust in electronically based information, such as on-line decision support systems. Others have found that locally developed EHR systems are trusted more than national systems. [40] Our initial findings suggest that professionals’ trust in information sources was complex reflecting, for example, the importance of understanding the provenance of the information in order to assess trustworthiness.

• **Mobility, Spatiality and Technology.** How people move within different healthcare settings is a core topic for researchers interested in human computer interaction (HCI) [41]. Spatial terms pervade new technological innovations. For example, one of the main aims of NHS CFH was to develop new lines of communication between dispersed healthcare settings and locations and, through contracting space, bring health professionals closer together. However, identifying health professionals’ movements and translating these observations into effective designs remains an ongoing challenge for IT designers. Our initial analysis highlights the importance of identifying patterns of mobility within health professional-patient interactions during the consultation.

**Implications for policy, design and training**

The nature of the consultation differs within the four healthcare settings as a consultation in a rural GP practice located in a close-knit community is significantly different from a consultation in a busy emergency department on a Saturday night. However, identifiable patterns of computer use for different health professionals and healthcare settings are emerging that will inform both IT design and the training of health professionals.

**Ethics approval:**

Ethic approval was provided by the Multicentre Research Ethics Committee for Leeds (East) and governance approval was obtained from all participating NHS Trusts. All participants gave informed consent prior to taking part.

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**Conflicts of interest:**

FT, HM, JH and HP have no financial or non-financial interests that may be relevant to the submitted work.

**Contributorship:**

HP led the development of the protocol, securing of funding, and supervision of the project. FT, HM and JH undertook all the data collection and analysis for the project. FT led the writing of the paper assisted by HP, HM and JH.

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NHS CFH sponsor comment

Observing people at work is an essential step in creating innovative and user friendly software and is a core ingredient used by many successful software companies. However, observing how people “actually” work in the healthcare industry is difficult. Not only are there many bureaucratic barriers to overcome but the work domain can be complex. Such factors partially explain the proliferation of “clunky” healthcare software.

That is why I am pleased to be sponsor of NHS CFHEP 010 - “Understanding the impact of information technology on interactions between patients and healthcare professionals”. The Edinburgh team has spent a considerable amount of time analysing different health IT systems scattered over England. They have observed IT used in GP clinics, out of hours services, hospital settings and mobile settings. They have video-recorded patient interactions and they have used ethnographical methods to study the effects of IT on patient clinician interactions. These techniques have been used by the Ergonomics and Human Computer Interaction (HCI) communities for many years and are a good omen for the future direction of healthcare software.

The CFHEP010 team has collected an impressive amount of data and their results will be useful to software vendors and NHS organisations. I also invite the reader to dig deeper into their main report and look at the detailed descriptions of how IT is currently being used in the different work domains. On reading you may gain new insights into working practices and ideas for future software products.

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NHS CFHEP001 Systematic Review


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Looking back, moving forward

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NHS CFHEP003 Pilot of IT specification for blood tracking system

NHS CFHEP005 Electronic Health Record
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