

# ERDIP EHR Issues and Lessons Learned Report

notes for the national workstreams

2

**Information for Personal Health**

**FINAL Version 2.15 - 24 October 2002**

### **Purpose of the report**

This is the second report which documents the issues and lessons learned from the ERDIP Demonstrator communities, and related activities.

These findings help inform the national and local EHR development and implementation requirements.

They are important evidence in defining the future EHR implementation strategy, ensuring infrastructure and necessary supporting services are in place, identifying dependencies and resource requirements.

### **Status**

This report is in draft format until signed off by the ERDIP Evaluation Project Board. It will also be circulated for information to the ERDIP Board, and to the circulation list indicated below. It will be made public on the ERDIP website.

Author	Toto Gronlund ERDIP Evaluation Project NHS Information Authority
Further copies from	Susan Miles, Project Support NHS Information Authority ERDIP Project Office Level 3 Birmingham B5 6RQ Internet: <a href="http://www.nhsia.nhs.uk">http://www.nhsia.nhs.uk</a>
IA Reference Number	2002-IA-1106
Date of issue	24 October 2002
Version	Final 2.15
Issue to	ERDIP Demonstrators NHSIA Programme Heads of Delivery and Regional Service Coordinators ERDIP Programme Boards NHS IA ERDIP Website Regional Offices Heads of Information Health Authority LIS Leads/StHAs Contractors to the ERDIP Evaluation Project

### Contents

<b>1. INTRODUCTION</b>	<b>5</b>
Purpose of report	5
Background	5
Issues and lessons learned	5
Reporting	5
<b>2. SUMMARY OF LESSONS LEARNED</b>	<b>7</b>
Managing Implementation, benefits	7
Managing communications	7
Confidentiality	7
Developing NHS Capability and Capacity	7
HRI	8
Defining specifications for ICRS	8
Building the IT Infrastructure	8
Developing Industry Capacity	9
Managing Clinician Engagement (and other stakeholders)	9
Electronic transfer of prescriptions, e-booking	9
National patient record analysis service	10
<b>3. LESSONS LEARNED</b>	<b>11</b>
Managing implementation	11
Managing Communications	14
Confidentiality	15
Developing NHS IT Capability & Capacity	16
Health Records Infrastructure	18
Defining specifications for ICRS	18
Application services	18

## **ERDIP and the Demonstrators**

### **Local and National EHR Implementation Issues 2.15**

---

<b>Building the IT Infrastructure</b>	<b>20</b>
<b>Developing Industry Capacity and Managing procurement</b>	<b>21</b>
<b>Managing clinician engagement, also other stakeholders, patients</b>	<b>22</b>
<b>Electronic Transmission of Prescriptions</b>	<b>23</b>
<b>E-Booking</b>	<b>24</b>
<b>National Patient Record Analysis Service</b>	<b>24</b>
<b>4. MIGRATION PATH TO EHR</b>	<b>26</b>
<b>ANNEX A:</b>	<b>30</b>
<b>Themes and Top level issues</b>	<b>30</b>
<b>Engaging Stakeholders</b>	<b>31</b>
<b>Moving to mainstream</b>	<b>31</b>
<b>Delivering the benefits</b>	<b>32</b>
<b>Standards and Guidance</b>	<b>33</b>
<b>Implementation</b>	<b>35</b>
<b>Managing the environment</b>	<b>35</b>
<b>ANNEX B REFERENCES</b>	<b>37</b>

## 1. Introduction

### Purpose of report

This is the second report which documents the issues and lessons learned from the ERDIP Demonstrator communities, and related activities.

These findings help inform the national and local EHR development and implementation requirements, and more recently, the National Programme for moving the NHS into the 21<sup>st</sup> Century in information technology.

They are important evidence in defining the future EHR implementation strategy, ensuring infrastructure and necessary supporting services are in place, identifying dependencies and resource requirements.

The report is not intended to be a comprehensive review of all aspects of the demonstrator experience. It will however continue to be updated with further reports as new issues emerge, old issues are resolved, and lessons are learned.

### Background

Work on evaluation has been an ongoing aspect of the Demonstrator programme. To date, ERDIP has conducted a comprehensive set of subject specific reviews and evaluations, as well as reviews of all the deliverables of ERDIP demonstrators.

The information in this report is derived from the experience of the demonstrators, many of their reports, and the outputs from the Evaluation Work Packages. Existing ERDIP surveys and reports on demonstrator, NHS and international experience in developing and implementing EHR also provide valuable data for this document.

### Issues and lessons learned

Issues and lessons learned are documented in Access Database format. The forms in the database include descriptive details about the issues and lessons learned, potential preventative measures, actions to be taken and resolutions.

This report is based on the August 2002 version of the lessons learned database, which documents a total of 335 lessons learned.

There have been no new top level issues identified since the first report. The issues identified in the first report are updated in this report in Annex A.

The categorisation into workstreams is based on highest or most immediate relevance, but the issues and lessons are interconnected and interdependent, and many issues naturally fall into more than one workstream.

### Structure and Reporting

The issues and lessons learned documented in this report will be subject to ERDIP Evaluation Board review, which may raise actions or escalate issues as appropriate.

Issues and lessons learned will be reviewed and validated on a regular basis. Updates to this report and the items in Annex A will be provided at regular intervals, at least quarterly.

The ERDIP Evaluation Reference Group will be asked to help with the review process, and recommend actions, which the Evaluation Board will need to consider and ensure appropriate action is taken.

### **Local and National EHR Implementation Issues 2.15**

---

Section 3 of this report collates many of the key lessons learned under the headings of the workstreams for the national programme.

A summary of these is provided in Section 2.

Section 4 updates the steps on the route map to EHR. These were originally identified in the first Issues and Lesson Learned Report, but several more steps have been added in this report.

## 2. Summary of Lessons learned

Many of the issues that have been identified in the ERDIP communities have 'lessons learned' linked to them as the issue is resolved. There are other lessons learned from the ERDIP experience which do not necessarily relate to an issue. The lessons-learned and issues databases have been developed to collate these.

In this report the lessons learned clearly feature around the subject of culture change, training, implementation, engagement of stakeholders, and supplier management.

One of the key lessons continues to be the importance of recognising the central role of the patient, and the significant benefits that shared information can bring not just to the clinician and carer, but also to the patient and to care outcomes.

This report has not repeated many of the lessons learned around technical aspects of the demonstrators which have been reported in detail in other reports. These have already been shared with the National Programme ICRS and HRI workstreams.

### Managing Implementation, benefits

The lack of guaranteed funds to carry on working after the formal ERDIP project phase has created problems for a number of the communities. Future national programmes should plan better for this transition phase from project to live and continue operation.

The benefits of shared electronic health records are beginning to emerge from the demonstrator communities.

Typically all report the fact that patients enjoy this new found access to their information, and very few report adverse reactions from patients.

Automated processing of some communications elements (e.g. referrals) speeds the process up, reduces errors and frees up resources.

Some of the communities claim between 4 and 8 % time savings for different care provider groups.

### Managing communications

The communities highlight the importance of having an internal and external communications programme as part of the project. This is particularly important for those projects planning to move to mainstream, to roll out the project to the whole community.

Good communication tools allow the stakeholders most closely involved with the project to communicate with their respective colleagues.

### Confidentiality

Consent issues continued to vex the demonstrator communities. Those adopting the pragmatic approach of gaining explicit consent at the point of intervention have been able to proceed with their projects, but this approach to obtaining explicit consent may not be possible for all patient groups, or rolled out across the whole NHS.

National work on consent will soon publish a code of practice, for which the ERDIP experience has provided invaluable practical input.

### Developing NHS Capability and Capacity

Training requirements have been underestimated in many of the communities. It has been observed that even for the IT literate clinicians, training has been a significant requirement. Training issues have not just centred on keyboard skills, but around the

need to understand importance of data quality and the wider range of information now available.

The role of the 'record' has changed, and it is no longer merely a mechanism for maintaining a static, passive history of the care given. The ability to share electronically, often in real time, means the 'record' now is also a means of communication between clinicians. Clinicians need to learn that record keeping is no longer an administrative burden, but a key to more effective communications.

The role of the Information Support Worker has also emerged as a new skill required, most likely in the primary care setting. National clinical education programmes should recognise that this new role exists, which requires a mixture of clinical and information skills. This role is there to support the patient, as needed, in understanding their record, help with clinical administration such as booking, and help the patients use the record to their own benefit, including links with knowledge bases.

The patient is seen to be a key driver in culture change in the NHS. As citizens, many patients are internet aware, and are far more aware of the availability of information through the internet and other means. This challenges conventional clinical practice, where the doctor now must be able to meet the challenges of patients regarding appropriate therapy etc.

### **Health Records Infrastructure(HRI)**

If the HRI is to provide portal services, then consideration needs to be given to what facilities are offered to patients/service users. Various infrastructure requirements have been identified:

- effective authentication standards for carers and service users
- central systems need to be more flexible, both technically and in access procedures (e.g. NHSnet & Open Exeter)
- need to support links to Social Services and other care sectors, as well as NHS organisations

### **Defining specifications for ICRS**

Review of the technical aspects of the ERDIP communities has provided information about the practical aspects of EHR architecture. A three level architecture is suggested, with local systems being integrated or interfaced at an intermediate level, typically about StHA level, with national systems providing portal, authentication and directory services, for example.

The importance of provenance of data is highlighted, including the need for existing EPRs to be able to attach provenance data to any information shared with an EHR.

The reviews have shown that physical, virtual and hybrid EHRs can be built, though a likely solution that is scalable will be based on a hybrid approach.

The technical reports include practical use of some standards, eg ENV 13606 for EHR architecture. This is already reflected in the developing specification for ICRS.

### **Building the IT Infrastructure**

NHS Net capacity and access has been the single main infrastructure issues for the communities. The main concern has been to ensure all carers involved in the EHR can gain access, which in the case of social care, has been achieved in only two of the ERDIP communities.

Patient access is also seen as important, and it is not clear how this can be provided if they cannot access their information via www.

A pragmatic approach to security has been adopted. Biometric authentication is seen as providing a way forward; smart cards have not gained favour in any of the communities. The use of a non-smart card (ie no chip or magnetic stripe) for strong authentication has been observed in Europe; this may provide a cheap and simple way forward, particularly for citizen access to the NHS.

### **Developing Industry Capacity**

The importance of good working relationships with suppliers is highlighted in this report. The communities report a new breed of supplier, the smaller and innovative solution provider has been seen to be successful.

Many of the communities have encouraged all suppliers to work together, forming groups that meet regularly to gain a joint understanding of plans and resolve issues together. This collaborative approach has been successful, reducing secrecy between suppliers, and between suppliers and the customer.

The partnership working has on the whole been successful, the unexpected withdrawal of a supplier from the partnership in response to changing commercial priorities caused significant problems for a project. This is a low risk but high impact event. The management of such risks requires genuine fall back plans to be considered.

### **Managing Clinician Engagement (and other stakeholders)**

The difficulties experienced in engaging clinicians have been overcome by taking advantage of key clinical drivers:

delivery of NSFs,

the need to provide care which is not within a single organisational boundary

improved decision making and care

Other drivers include:

Patients interested in access to their information, and wishing to contribute to this

Legal requirements, confidentiality,

Clinical Governance

Other initiatives, eg e-booking, GP-GP record transfer, e-government

There has been real benefit in getting clinicians together to map and discuss the care process. The clinicians found it very useful as it enabled them gain a better understanding of the whole process of care, clarified how the EHR could help this process, and clarified the purpose of the EHR as an information sharing tool for the care team.

A number of projects developed collaborative working groups, such as 'focus' groups and clinical consensus groups. These have proved necessary and effective.

### **Electronic transfer of prescriptions, e-booking**

Referrals could be improved with electronic links and appointment booking systems, supported by an EHR.

A complete list of medications is an important element of the EHR, to clinicians and patients. This could be obtained from electronic transfer of prescriptions recorded in an EHR.

#### **National patient record analysis service**

Many of the current systems do not hold the data sets required to support the NSFs, eg cancer or coronary heart disease.

For system performance reasons, many of the communities recommend that operational systems are interfaced to management information systems, or separate data warehouses support secondary information uses.

Data quality is still an issue in many existing systems. Coding is a particular problem, most communities seeking standardisation. Patient review of records is advocated by many communities.

### 3. Lessons learned

A number of lessons learned are reported in the table below, and have been grouped under the current national programme workstream headings.

Many of the lessons learned grouped under one section are still relevant and important in other workstreams – there is a great deal of interdependency, reflecting the interdependencies of the workstreams themselves.

**Table 1**

<b>Managing implementation</b>
<p><b>Benefits</b></p> <p>With the UK Internet penetration now at 18.8 million and projected to rise to 25 million by 2003 online Patient-Accessed health records offer several potential benefits.</p> <p>Better record keeping</p> <ul style="list-style-type: none"><li>- The ability to link data-items in the health records with useful and high-quality internet based information.</li><li>- On line health record can be kept up to date from any site, at all times.</li><li>- Data quality improved through patient access.</li><li>- Standardisation of language of care across care communities has been required.</li></ul> <p>Support of routine care, across care communities</p> <ul style="list-style-type: none"><li>- Easier access to accurate, up-to-date and personalised health information for carers and for patients</li><li>- Easier access to accurate personal health care records for third parties (e.g. Healthcare professionals, emergency workers, specialist advisors, carers).</li><li>- Better communications as well as better record keeping: faster and more secure professional-patient and professional-professional communication.</li><li>- The facility to provide better referral information to enable appropriate allocation to care.</li><li>- Problems with drug interactions and allergies can be avoided.</li><li>- Improved care outcomes, patient satisfaction, clinician confidence and staff morale</li><li>- Involving the patient as a partner in care and treatment should help reduce the workload on the carer.</li><li>- The records improve communication and health professionals found improved sharing of responsibility for continuity of care.</li><li>- Access to other sector records helps to<ul style="list-style-type: none"><li>o Reduce duplication of tests</li><li>o Reduce visits by the patient to institutions,</li><li>o Streamline any home visits by carers and clinicians.</li><li>o Improved data quality</li></ul></li><li>- The use of the NHS number across health and social services to track records:<ul style="list-style-type: none"><li>o The opportunity to give feedback to GP's from social care</li><li>o The ability to share the risk assessment with social care</li></ul></li></ul> <p>Efficiency and effectiveness</p> <ul style="list-style-type: none"><li>- Improved IT functionality as a result of integration of IT systems.</li><li>- Cost-effective IT solutions based upon Internet technology.</li><li>- The secondary effects of streamlining care result in a net decrease of use of resources</li></ul>

#### Managing implementation

inappropriately or wastefully. Increasing the transparency of the care process has been shown to reduce the amount of care being demanded.

Clinical governance, audit, planning and public health

- Generation of an accurate, up-to-date and validated health database for the whole population.
  - o More efficient and accurate public health planning stemming from this database.
  - o Easier to identify and correlate relationships between a large number of variables
- Ability to track and respond to changes in a patient's condition within hours and conduct hitherto impossible clinical trials.
- The EHR will help reduce errors, and will ensure appropriate information is available thus streamlining care process, making this more transparent and available for the patient to see as well. This reduces the likelihood of complaints or litigation.

Emergency care

- Access to information in emergency and urgent care and out of hours situations will allow more appropriate treatment and care decisions to be made.
- Problems with drug interactions and allergies can be avoided.
- Circumstances where without information the safe procedure has been to transfer to A&E may now be avoided.

Patient satisfaction

- There is some evidence that greater access by patients to their information will help in targeting treatment, reduce number of visits required, reduce scope for errors, and improve compliance.
- Patient confidence improved in having access to own information, and knowing health professionals have access to this.

#### Funding

- Where protected funds have been provided, the project has been able to press forward and deliver against well defined targets.
- Meeting stage deliverables in order to meet financial obligations as a method of funding provides good control of project, but may restrict flexibility and detracts from long term planning. Short term funding creates problems with uncertainty and strategic plans.
- Adequate funding is essential - there is an inherent tendency not to fund the development fully. Costs include aspects like stakeholder involvement, evaluation, consultation, prototyping, communications.
- Funding should be planned for moving to mainstream – for when project is rolled out to the whole community and becomes part of the operations. Projects would probably win greater commitment if funding could be guaranteed for ongoing activities, so that the EHR development becomes part of a long-term directive.

#### Costs

- It is possible to retain many of the legacy systems, which should help contain costs, and reduce the amount of training required etc.
- Training costs will be large. There should be protected money for training (gps are fully paid and have locums whilst they attend compulsory training). Staff undergoing training will expect equivalent treatment.

#### Managing implementation

##### Feasibility

- Patients and health professionals find the Patient Held Record is acceptable, manageable and that it increases information sharing.
- The Project confirmed that patients having access to their actual primary care health record in a primary health care setting is achievable

##### Implementation

- Planning needs to be as specific as possible, including details of what and how objectives will be achieved and preparation of contingency plans where uncertainties exist.

##### Transition plan

- EHR will require adequate electronic feeds - this presumes that all clinical notes will be made electronically. For many there will be a transition period where paper and electronic records will need to co-exist without adversely impacting clinical care and resources.
- Parallel working can be costly and may involve additional time from users. Attention will need to be paid to
  - o incentives for primary care to move to a wholly electronic basis (the systems exist) with rich clinical information;
  - o secondary care will need attention in respect of workflow requirements in order to be able to move to a wholly electronic basis;
  - o mobile solutions will be needed for emergency and community care (as well as in many areas of secondary care)

##### Benefits of EHR and use of hand held devices

- More prevalent use of Integrated Care Pathways and Clinical Protocols, leading to better care.
- Much more up to date patient information for clinicians to act upon.
- Better presented and more efficiently produced discharge information to be passed on to referrers.
- More accurate information leading to better decisions and therefore, outcomes.
- More efficient scheduling of planned assessments and treatments, leading to less wasted time for both patients and staff.
- Used and liked by the majority of Health Visitors.

#### Managing Communications

##### Benefits

- Benefits of good communications during major change such as introduction of EHR:
  - o Maintains coherence, consistency across all parties concerned
  - o Supports stakeholder commitment throughout project
  - o Reduces user anxiety
  - o Encourages adoption of the system
- Communication about activities both internally and externally can help to keep staff interested in the changes and motivate them for continued progress.

##### Mechanisms

- Develop a *communications plan*, as part of the project plan, with regular updates to key stakeholders, ensuring that the communications work
- Use a *communications expert* to manage communications. This will take the pressure of other members of the team and ensure a consistent approach. Use existing communications staff from the NHS where possible.
- *Champions* who provide a communications function must have professional credibility, which usually means they must be practicing a relevant profession.
- Identify a *dedicated individual* who is responsible for all public relation and communications issues across the project.
- Use Open days, Regular meetings for different staff groups, and include EHR as agenda item in existing meetings to promote the project.

##### Meaningful communications

- The terminology used around EHRs can often cause confusion and unintentionally raise users' expectations. For example, terms such as: pilot, simulator, prototype, demonstrator and implementation are often used interchangeably and mean very different things.
- Projects should communicate to learn from each other – central support needed to put mechanisms in to place to enable this.

#### Confidentiality

Many of the lessons learned about confidentiality and consent have already actively been fed back to the relevant national working groups on the subject, and have contributed to the guidance which will be published in the Autumn 2002.

Some basic principles include:

- Allow access on a need-to-know basis.
- Gain informed consent from the service user.
- We are custodians of the service user's information.
- Service users should be provided with the opportunity to access to their information

Some practical points

- Suitable patient authentication methods need to be agreed. A pragmatic approach has been taken, ie the practice staff know the patient, or identification such as banks might require is taken as evidence of identity.
- To ensure confidentiality is preserved, patient and field blanking has provided a pragmatic short-term way forward.
- Some projects found that security is not as big a worry for patients as expected. Yet patient organisations express that such a fear exists – it may be a fear of the unknown, which is alleviated when it is clear that security arrangements are adequate to support confidentiality.
- Patient consent has been gained successfully in the practice environment with the support of an 'Information Worker', typically a health visitor or other health professional. If explicit consent is to be taken, it must be at the start of a care pathway. This will inevitably be at a visit to a GP.
- One of the projects made the decision at an early stage to obtain informed, explicit patient consent to sharing information. Consent is gained at each intervention, and has worked successfully.
- Patient consent has been gained successfully through agreement with the practice with a written 'contract' between the patient and the practice.
- Consent and access permission details need to be held so that they apply to all systems that contribute information to the EHR
- Patients must be able to see and review their consent details
- Results of a postal survey on the expectations of service users:
  - o Access is to be granted by the service user to specific categories of information for different groups of care professionals.
  - o Need to be able to distinguish between different circumstances of care (emergency and routine) when considering the access that should be permitted to records.
  - o The majority of respondents consider they should be able to decide who can use the information maintained within their electronic health records.
- Views on patient consent vary between primary and secondary care:
  - o In primary care, there is sensitivity and patients are less likely to give unconditional consent
  - o In secondary care, patients assume care professionals share information as a matter of course
  - o In Diabetes, all 2000 patients gave consent for their record to be shared
-

#### Developing NHS IT Capability & Capacity

##### Training

The term training does not fully reflect the change intended to health care provision. Education is a more appropriate, broader term that also includes the patients. I.e., we need to take an educational approach rather than learning.

The education process needs to flow from clinicians to staff to patients and actually goes beyond the use of IT.

Training may not be a priority for staff as clinical care comes first - that's what staff enjoy / need to do.

Some basic computer training such as the ECDL (module 7) may be the necessary catalyst for some users to overcome their fear (or complete lack of exposure) to computer technology.

Most junior doctors in hospital are IT literate and have used computers from school onwards. If anything this group is frustrated by the lack of facilities to use IT. Levels of IT literacy for GPs are very mixed.

Staff Appraisals should identify the training requirements of staff and they should form the basis of a staff development training plan that can be adopted as and when sufficient funding is made available.

Training support will need to be provided to patients

The change to an EHR will include agreement and implementation of new clinical protocols and care pathways. Training programmes need to support these, not just EHR.

Some practical points

- liaise with practice / department managers to schedule training
- expect logistical difficulties
- provide training slots for part-timers, night staff etc within their hours
- start training sufficiently early with basic skills
- provide training close to time of going live, so users don't forget
- staff needed more training than expected
- use trainers to provide support during go live and immediately afterwards. Trainers should be physically present, not just on the end of the phone
- communicate training programmes, so staff know if and when they can expect more training
- provide mobile training facilities, train at the normal place of work
- using dummy data is OK, but the real glitches appear with real data
- ensure software is fully functional and without bugs
- be sensitive to users who are embarrassed about their lack of IT skills,
- expect to provide one-to-one training for many members of staff, not just lead clinicians or GPs
- training needs to cover use of the internet, web browsers, security protocols, confidentiality, use of email
- while IT trainers can be used for the training in general EHR capabilities, specialist practice educators are needed for the clinical applications. This was effective in providing clinically relevant IT training.

#### Developing NHS IT Capability & Capacity

- borrow experienced staff from other sites to support training
- develop a training course in conjunction with a local college and send staff there to be trained. The college benefits by receiving grants to develop and teach the course, the staff can earn an NVQ qualification out of it and get quality education that is pitched at the right level.

The characteristics making an effective practice educator include:

- A practicing clinician, credible to colleagues;
- A 'people' person, ideally well known to local users;
- An ability to grasp the IT system (without any preconceptions);
- An ability to interpret the use of the system into clinical practice;
- An ability to view the system from the perspective of someone who has never used a computer before.

#### New Roles

- Information Support Worker: Support will need to be provided to many of the patients who wish to view or hold their records. Technical, clinical, counseling support may be required. This information support worker could also help with e-booking.
- Some primary practice nurses and other clinicians are used to recording data for secondary information uses only (administration, performance management, audit) - they need to be convinced that they must record certain clinical information for the benefit of all healthcare staff and the care process.

#### Culture Change

- The change process needs careful management in order to gain the most out of staff and the new opportunities. The process will likely include the use of implementation teams, and these should be established early on, especially as the stakeholders involved are numerous and varied
- Culture change needs a methodology that will integrate the purpose of the EHR and generate "buy-in" from all stakeholders:
  - o identify stakeholders
  - o identify incentives and benefits to stakeholders
  - o identify potential barriers (including systems dynamics)
  - o identify key leverage points and influencers
  - o create incentive and communications plans
  - o monitor and review progress
- Changing attitudes of patients / public will help drive culture change within the NHS
- Money is not the only driver for the community. Current evidence points to people seeing the benefit and wanting to be involved with something that they expect will improve the services they give
- To make NHS Direct a success and beneficial component of healthcare, a strong drive to integrate NHS Direct and to "join it up" with primary care is necessary.
- Process mapping can be used as an effective way to approach culture change. Since the EHR programme should be seen more as a change event than the implementation of an IT system, we should look at the way we work and who does what. The change requires tasks to be performed differently and processes altered. A useful way to review how people work and how that will change can be found through process mapping.
- Users must overcome the loyalty to the old technology and toolsets. Often the only reason for change is to improve the common good, and individual users may bear more of the impact of change than others

#### Health Records Infrastructure

- For the EHR to inter-operate at national level there need to be designated standards - the content of the standard will depend on what is inter-operated. E.g., it is necessary to have a standard for inter-operation of demographics through Open Exeter.
- Open Exeter with minimal development work provided a simple patient portal to allow patients access to their electronic patient records and which also gave them confidence in the security of the system.
- Ideally the instructions for navigating through the patient portal need to be imbedded into the portal i.e. be the first page that you were directed to.
- Further consideration needs to be given to using the patient portal as the means by which the patient sets and controls the access rights to their own electronic record.
- Various infrastructure requirements have been identified:
  - o effective authentication standards for carers and service users
  - o central systems need to be more flexible, both technically and in access procedures (e.g. NHSnet & Open Exeter)
  - o need to support links to Social Services and other care sectors, as well as NHS organisations
- Open Exeter contains limited but useful demographic data

#### Defining specifications for ICRS

##### Application services

The majority of the feedback in this workstream is already documented in the technical reports from the ERDIP Evaluation Programme and the EHR Requirements Report.

Some specific additional points include:

- Patient access required to deliver benefits to patients: Access to information can increase patient involvement, helping to maximise the benefit of treatment and achieve the overall objective of raising the individuals' role of participation in their own healthcare.
- Requirements for patients using online access:
  - o To ask questions using their own language.
  - o To get responses from knowledgeable professionals or self-helpers, tailored to their concerns.
  - o To know the types of questions other people ask and their responses.
  - o To access the FAQ lists of online support groups.
  - o To interact: a strong preference for two-way dialogue, much of it with peers, integrated with the best professional information.
- The virtual EHR model
  - o The Virtual EHR is dependent on the synchronous and rapid retrieval of structured data from distributed clinical systems and the implementation of a consistent security and confidentiality model across systems. This has implications for performance characteristics, the need for synchronous interfaces, network accessibility, scalability and tailoring of end systems as well as the consistent security and confidentiality facilities. It may be possible

#### **Defining specifications for ICRS**

##### **Application services**

to achieve such cohesion within individual localities, but an implementation could impact upon the design and performance of operational systems, in that browser views would be required of those systems - which may be a problem for some legacy systems.

- In appraising potential EHR models:
  - o Look to technical standards where possible
  - o Ensure a minimum record structure is supported
  - o Consider scalability and interoperability to be as important as functionality
  - o Demonstrate robust performance in routine clinical use
  
- There will need to be a harmonisation of code sets, using SNOMED as a vehicle. The long term aim should be for standard record structure, but need to manage inter-operability between different structures through inter-operability standards.
  
- Systems have a habit of failing, and the more complex they are, the longer it can take to fix the problem. A contingency plan for failure is needed. Should a commercial ISP fail, or NHSnet go down, or any of the software along the chain develop trouble, then the message still has to flow in nearly the same time-frame. There must also be a capability built-in to re-send missed messages when normal service is resumed such that the expected populating of the GP record can occur.

#### **Building the IT Infrastructure**

##### **Code of connection, NHS Net and NHS Number**

- There is potential here for the NHS Tracing Service to provide a consistent minimum data set for all public bodies / care agencies and for the NHS number to be a key identifier
- Need to support links to social care organisations, private care agencies and the voluntary sector - there is a code of connection issue here (e.g. Palliative Care is provided by the Marie Curie unit)
- The NHS Net connection for social care was a major achievement, allowing a secure infrastructure that both care sectors could use.
- Some Social Care departments have not worked towards NHSNet connections, and do not have plans to do so. This has meant that workarounds have been necessary in order for social care staff to gain secured access to view the EHR and to submit or view their agreed dataset.
- All of the issues relating to the EHR infrastructure have been linked to NHS Net. The EHR is possibly the only project attempting to bring together data from many sources, systems and organisations. For this to happen on a national scale a clearly defined set of standards to facilitate the communication requirements of the EHR and other related communications need to be mandated.
- NHS Net firewalls have resulted in the need to procure additional scanning software and a further workaround to enable scanned documents to be transferred to the EHR across the nhsnet as a standard file.
- Need to have sufficient capacity and mechanism to transfer diagnostic images efficiently across the network.

##### **Implementation**

- The upgrade to the core infrastructure was a major task and the complexity and subsequent technical problems were totally underestimated.
- The technology employed was leading edge and although a test plan was agreed the technical problems did not become evident until deployed in a live environment. This caused major disruption for users.
- Use tried and tested technologies on major and / or critical projects
- Use rapid prototyping and high quality software rather than lengthy analysis to provide practical working solutions that deliver the majority of what is required
- Keep product and infrastructure separate – the 'product' supplier rolls out system up to icon on the screen.

##### **Access and authentication**

- Need effective authentication for all users, including patients/service users.
- Need to consider how access can be provided via www.
- Central systems need to be more flexible, both technically and in access procedures
- Encrypted smart cards are more secure but greatly increase complexity and were not used because of this
- Simple non-smart strong authentication solution provided by European supplier. Allows citizen authentication; no need for technology, eg card readers.
- Biometric interface has worked in providing secure access and rapid authentication.
- The security firewalls, which are there to protect unauthorised access to the network, in most cases impeded the transfer of files to the central repository.
- Concerns over ID hijacking are still seen as threats to record security. Counteract this type of security breach by using telephone banking methods of caller identification .

#### **Developing Industry Capacity and Managing procurement**

##### **Strategy / Policy**

- The NHS cannot assume that there is commitment from suppliers even to a national programme such as ERDIP, or the new 'national programme'. It should not be assumed that suppliers will respond, and will be equally as enthusiastic as local/national NHS leads.
- Allow adequate time for negotiations and be prepared to seek an alternative solution.
- Suppliers have had significant problems in resourcing multiple projects, need to ensure the load can be spread
- EHR /ICRS environment means that a number of complex supplier relationships and dependencies exist
- Big projects are not an exact art - suppliers experience unforeseen difficulties, obstacles and delays.
- To the user, NHS net, NHAIS etc are also 'suppliers'. Same terms and conditions, slas should apply as to commercial partners.
- The NHS needs to take on board supplier development in defining the direction of travel for standards, such as HL7.

##### **Supplier characteristics**

- Commercial suppliers need to think how their markets will change with the advent of EHR systems.
- Suppliers may need to re-think their boundaries, and to consider partnerships, collaborations
- Smaller/medium-size suppliers may be more responsive in providing an approach fitting to NHS strategy
- Scan for new 'market entrants' who may offer significant advantages in terms of flexibility over existing suppliers
- -supplier needs experience in public sector/partnership working
- From a supplier's perspective, there are two important reasons to participate in ERDIP: cultivating new relationships and knowledge.

##### **Tactical / Operational**

- Link suppliers together as a co-operative group, a Supplier Forum [this was the most striking reward in terms of building up a team]. The Forum should be part of the project/project team.
- While solutions must first fit with NHS national strategy, it may be easier [initially] to build a solution which works with the supplier's own long-term strategy.
- Each supplier is unique and there is a need to understand their perspective, motivations to help achieve success.
- Ensure good supplier communications, both individually and collectively, and about the whole project, not just supplier issues
- Active engagement early appears to be best approach - ensure supplier has positive interest in implementation and ultimate outcome
- Ensure a fit with supplier's long-term strategy, influence it if necessary
- Contract to include :
  - o the full life span of the project,
  - o resource commitment, escalation mechanisms
  - o Intellectual Property Rights,
  - o Documentation,

- System development methodology,
  - Maintenance arrangements during and beyond the project lifespan.
  - Helpdesk services
- 
- Agree to use the same mechanisms to address interaction with suppliers as they use with the client
  - New systems should be fully tested before live operation with users
  - Supplier must have a well-established, reliable help desk, which is able to respond to critical issues speedily.
  - Suppliers / designers don't fully understand the requirements of users –more user involvement with suppliers is needed at the outset. The problems getting gp system suppliers to respond to the needs of users have been the single greatest cause of delay
  - Pragmatic, workable solution using rapid prototyping and high quality software rather than lengthy analysis.

#### **Difficulties with partnership working**

- Unexpected withdrawal of supplier from the partnership in response to changing commercial priorities caused severe difficulties for the project, and delay.
- Lack of documentation from the supplier / guarding of commercial interests causes problems for working with other suppliers.

#### **Managing clinician engagement (other stakeholders, patients)**

- Involve Stakeholders early – consult, listen and feedback. Reimburse costs. Budget for time and resource into stakeholder involvement. The process is time-consuming. Ensure there is a dedicated person on the project team to work with this.
- Create 'consensus' groups of stakeholders
- Ensure patient representation is included, eg on project board
- Terminology used in the projects can be confusing and lead to misunderstandings and expectations
- Different expectations and/or understanding in key groups such as GPs can give rise to difficulty when trying to establish a common view of an EHR and what it can deliver. Get user requirements from the stakeholders, mix the groups. Agree scope.
- While all stakeholders may agree at the outset of the project, circumstances may change, as may the project objectives or deliverables. Maintain contact with stakeholders throughout.
- It is important to involve a representative set of stakeholders, both across groups and within groups. Engaging too few within a group may lead to the aims of the project being diverted by particular interests, and then experiencing resistance by the group at large
- Users have been very willing to take part in focus groups - additional training can be obtained from National Society for Research Methods on Focus Group methodology.
- Understand the processes that will be impacted, changed or challenged. Process analysis must be done with the stakeholders. Today's processes will not be the same as tomorrows.
- Where role and status of staff may change, involve representative stakeholders who must take message back to their groups.
- Money is not the only driver for the community. The current evidence points to people seeing the benefit and wanting to be involved with something that they expect will improve the services they give.
- More emphasis should have been given to engaging senior management particularly at

#### **Managing clinician engagement (other stakeholders, patients)**

PCG/T level. Although Board members have a responsibility for engaging their own organisations and acting as 'champions', the management structure of PCG/Ts was not well enough understood to ensure that the project was lead from the top.

- No local listing at any one site encompassed the wide range of professional fora locally (or nationally) despite the commonality of health focus. Such a listing of all professional groups would be of benefit for any cross community consultation.
- Access to information can increase patient involvement, helping to maximise the benefit of treatment and achieve the overall objective of raising the individuals' role of participation in their own healthcare.
- Online patients want
  - To ask questions using their own language.
  - To get responses from knowledgeable professionals or self-helpers, tailored to their concerns.
  - To know the types of questions other people ask and their responses.
  - To access the FAQ lists of online support groups.
- Interaction - a strong preference for two-way dialogue, much of it with peers, integrated with the best professional information.

#### **Electronic Transmission of Prescriptions**

- Smart cards not a safe way of storing prescribing / medication details. As the security levels are increased, so are the complexities of accessing the information in cases of legitimate need.
- It is essential that electronic codes for prescribed drugs are uniform, and that the source data is updated frequently.
- Current GP use demonstrates differing coding systems, which may have different interpretations, and coding levels may vary.
- Medication and data about the purpose of it, or the condition being treated, should be linked
- Patients are keen to know side effects and contraindications for drugs, and how the drug works.

#### **E-Booking**

New role of an Information Support Worker has been used to support patients when accessing their records, for example at practice premises. Support will need to be provided to many of the patients who wish to view or hold their records. Technical, clinical, counseling support may be required. This information support worker could also help with e-booking.

Experience from cancer referrals indicates that the EHR can support patient requirements for:

- Knowledge of cancer symptoms
- Quick referral
- Support in accessing additional information

The use of an EHR with hand held devices provides the following benefits:

- On the spot referrals,
- Booking for appointments
- More efficient scheduling of planned assessments and treatments, leading to less wasted time for both patients and staff.

The development of the EHSCR (Electronic Health and Social Care Record) has led to a number of benefits by enabling access to shared records at health and social services.

These include:

- The facility to provide better referral information to enable appropriate allocation
- Electronic / automated reminder notification for follow-up appointments , with information about what will happen, could take some of the stress away for patients.

#### **National Patient Record Analysis Service**

It is recommended for Joint Working Teams to share a single operational system rather than attempting to create interfaces between separate systems. The creation of an interface at the management information level is preferred.

As an example of data collection tool, MIQUEST has the following benefits:

- Facility to express requests for aggregated information or for data downloads for central analysis
- A common technical interface (removes dependence on bespoke software and/or manual data collection)
- Individual schemes can choose the data collected and share queries with other schemes to collect comparable data
- Data set collected can be amended to meet changing requirements without reference to system suppliers
- Ad-hoc enquiries can be written to complement regularly collected data
- Overall costs of data extraction are low with MIQUEST

The data mapping work at one site proved that the data held electronically in existing systems does not provide the data set needed for the cancer network.

In trying to decide what data is collected, the British Association of Surgical Oncology

#### **National Patient Record Analysis Service**

(BASO) was a good source for collection of many breast cancer MDS items.

Use of NHS Number essential for minimum data sets for public bodies, for information sharing for disease registers

The long term indicator will be population health statistics. This may be illustrated by the ability to act more quickly and accurately as a result of diagnosis (earlier intervention), impact of faster referrals (higher rates of successful treatment), and the ability to provide more appropriate care based on fuller information (fewer errors / more effective treatment). Data quality can be a key limiter on EHR projects

Data quality: records have been reviewed by patients themselves, which has resulted in corrections of matters of fact, up to date information on contact details etc. Patients can be a very useful resource, thus reducing the amount of time clinicians need to spend reviewing the record for accuracy, especially concerning data in the record about which the patient knows best.

There will need to be a harmonisation of code sets, using SNOMED as a vehicle. The long term aim should be for standard record structure, but need to manage inter-operability between different structures through inter-operability standards.

#### 4. Migration Path to EHR

From the experience of the demonstrators to date, as documented in a number of reports produced by the communities and the ERDIP Evaluation project, it is possible to identify some of the essential steps and activities that health communities should be undertaking in their preparation and planning for shared electronic health records, which form an important part of the National Programme.

These activities are sufficiently fundamental to be relevant and necessary whichever approach and priority is taken to achieve the various targets. The table below has been updated to reflect the current status at the time of writing.

**Table 2**

<b>Migration path, next steps</b>	<b>Status</b>	<b>Recommendations</b>
Health Informatics Service (HIS)	Some of the communities had already established single community wide HIS to support IT issues community wide. This ensure consistent strategy, training / education support, network and procurement support.	Continue to support the development and maintenance of HIS. This is probably best provided at StHA level.
Network	Many of the ERDIP communities had already implemented community wide virtual private networks. This provides enhanced connectivity within the primary care community. Some communities had not completed full code of connections for all of their primary care which caused delays to their projects.	All communities should ensure that they have adequate network capacity, that all primary care is connected with full code of connection.
Single Patient index	<p>Many of the communities had already implemented a single community wide patient index.</p> <p>This has helped to integrate multiple GP/Trust and other indices.</p> <p>Local index has advantages with improved data quality.</p> <p>Local index link to national index essential to provide NHS Number, national EHR access, patient access.</p>	<p>All communities to consider their indices (GP systems, secondary care, community etc), and how they can be linked or merged, and how data quality can be improved to avoid duplication of entries etc.</p> <p>Check NHS number availability on systems. Mandate use of NHS Number.</p> <p>Current national options include:</p> <p>Development of a Health Record Infrastructure, using Open Exeter; use of NSTS (steps to permit use of NHS Number by social care.)</p>

## ERDIP and the Demonstrators

### Local and National EHR Implementation Issues 2.15

<p>Business Process Redesign</p>	<p>Many communities completed process analysis of working practices and information flows, and considered how these could be improved. This has helped in generating user requirements, and to target their efforts, and to provide baselines with which to compare their outcomes.</p> <p>Testing requirements has been successfully conducted by developing use-case scenarios and simulations (eg Devon, Durham, Tees)</p>	<p>Process and information flow analysis should be conducted to help define the scope for each project. It is invaluable in helping to develop user requirements (though users must be consulted as well) and to design systems to work better, rather than reproduce current working practices.</p> <p>Another technique that can be tried is to develop use case scenarios / simulations.</p>
<p>Stakeholder consultation</p>	<p>Engaging all user communities is an important early step in the project. A consensus groups have helped develop practical user requirements. Taking account of user requirements and their objectives has helped commitment to the project. Each community has considered it a good investment despite time and resource it takes.</p>	<p>Stakeholder engagement is essential to develop consensus, meaningful and achievable requirements and objectives.</p> <p>Ideally develop overall joint working arrangements (ie not just project related) with organisations who will be involved in the project.</p>
<p>Supplier relations</p>	<p>Many communities formed supplier for a, ensuring all suppliers where kept closely informed of each others efforts and the project as whole. This was seen as an essential step in what is a complex project</p>	<p>Establish who are the key (current) suppliers and involve them, ensuring they have a commitment to successful project outcome.</p>
<p>Data quality</p>	<p>GP systems remain a major problem in terms of extracting high quality data</p> <p>Patients have been provided access to their GP records at two pilots. This is an essential step to assure patients the content of their record is accurate, and provides opportunity for patient input to indicate disagreement if necessary.</p>	<p>Need to establish how GP systems can be updated with patient corrections/additions as necessary.</p> <p>All NHS communities to consider data quality, not just in coding terms. Allow patient access - patients will check data relevant to them (eg address, demographics, contact details), and can query events, times, dates etc.</p>
<p>Data sources</p>	<p>Current data feeds into EHR are mainly GP systems, for reasons of practicality (ie data available) and user requirements.</p>	<p>Need to consider a model of picking up any existing / emerging transactions, e.g. prescriptions, e-booking, pathology and radiology messages, referral and discharge messages, as further</p>

## ERDIP and the Demonstrators

### Local and National EHR Implementation Issues 2.15

		EHR feeders.
Data extraction / integration	Most communities had problems with data extraction from their GP and other systems.	If value from legacy systems is to be maintained, data extraction / integration options should be considered at an early stage in the project.
Data Provenance	EHR systems require source of data to be indicated, as it could be from one of multiple feeder systems from several organisations.  S Staffs pilot organises data within source folders; the author if the data is also indicated	Extracts from feeder systems need to consider how to attribute source to data extracts (whether actual or virtual). EHR to support metadata, EPR systems to be able to supply the information.
EPRs	Many communities prioritised sources of information (or requirements for the shared record) eg Computerised data from Trust, Community, ambulance and other systems to interact with EHR  Some EPRs are being used to form the basis for the full EHR (Cornwall, SW Devon, Bradford)  A phased approach to implementing community wide integration has been taken, based on for example: Disease groups, care sectors, PCTs.	StHA's to review EPR requirements: need to assess suitability of EPR to provide wider cross community functionality or to act as a feeder into a shared record.  EPRs to be able to provide provenance information.
Certification , Authentication, Encryption	Encryption at present provided by off-the-shelf software  Intermediate encryption guidance has been provided.  Simple non-smart strong authentication is used by other countries to provide access – cheap, and no technology required.	National directory and authentication services to be provided.  National guidance on encryption requirements to be updated.  Registration issues to be resolved, eg royal colleges to act as registering authorities.  Registration of the citizen is still to be resolved.
Consent	Consent work package (evaluation) has reported all demonstrator experience to date (March 2002)  Many of the projects ensured explicit consent was obtained (for the purposes of the project) so that the project could go ahead.  Many of the projects have	Code of practice to be published in the Autumn (DoH). Information governance to be supported by NHSIA. A sharing model for information established. Two of the ERDIP communities have satisfied GMC/LMC requirements for consent and confidentiality.  Review of some of the

## ERDIP and the Demonstrators

### Local and National EHR Implementation Issues 2.15

---

	<p>provided direct patient access to their records, some as read only, others also enabling input to the record.</p>	<p>provisions under the Data Protection Act by a DoH working Group.</p> <p>Consent issues will become less contentious once service users know they can access their record and review it. This practice should be commenced, and facilitated wherever possible.</p>
--	----------------------------------------------------------------------------------------------------------------------	----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

#### Annex A:

#### Themes and Top level issues

A brief description of the themes for the issues is provided in the table below. These are reproduced from the first Local and National EHR Implementation Issues report. There have been no new issues reported, but the original set of issues is updated as appropriate.

	Title	Description
1	Engaging Stakeholders HUMAN	This covers areas from: establishing links to relevant parties, assessing user requirements, anticipating barriers or resistances to change, understanding motivations, identifying requirements on other stakeholders for change, gaining commitment to change, maintaining communications and commitment during implementation, etc. Would include culture change
2	Moving to mainstream STRATEGIC	ERDIP has been mainly local projects – how can these scale to regional or national systems, what national infrastructure is required to support this, what additional areas may need to be explored to establish a national solution, to what degree are local problems or issues applicable to a national solution, and what modifications may be needed; what additional resources may be needed at both national and local levels; what levels of local autonomy or choice should be supported
3	Delivering the benefits FINANCIAL	Covers areas of programme and project management, maintaining focus on real benefits to be delivered; includes aspects of funding and cost-justification, control and planning
4	Standards and guidance OPERATIONAL	Identification of areas needing policy standards for consistent working and interoperability; national resolution of key issues such as security and confidentiality, architecture and data-sets, and messaging. Covers procedural and technical issues.
5	Implementation TECHNICAL	More detailed experiences born out of practical implementation, includes aspects of data quality, coding standards, linking with existing infrastructures. May include practical assessments of technologies, including user (stakeholder?) acceptability.
6	Managing the environment STRATEGIC	Not eco-friendly(!), but ensuring EHR initiatives link into other NHS national initiatives, wider government initiatives, and possibly international implications (EEC, GEHR). Key is to ensure that by addressing immediate requirements we do not lose sight of the 'big picture', or fail to gain synergies with other changes in process.

#### **Engaging Stakeholders**

##### **Engaging Suppliers (00318)**

There are many different suppliers involved in NHS computers systems. EHR cuts across many existing boundaries, opening new issues for all parties. When dealing with an individual site, or Health Authority, suppliers may not assign sufficient resources or priorities to what is effectively a national programme.

Some projects are being delayed through issues with suppliers. Some of these delays may result from poor planning or optimistic assumptions about supplier responsiveness.

Most of the projects have achieved good relationships and co-operation with their suppliers. Holding joint supplier workshops / meetings has proved very successful.

Most issues relate to data transfer, this should be started earlier in the project plan on a trial basis, even if there is no receiving system to test the data.

##### **Engaging Patients (00483)**

Patients have right to see and request details to be corrected and enter disagreement and enter information themselves. It will be necessary to involve patients so they are given an opportunity to review their record.

Patients also provide an important source for the user requirement, as in the future they too will be users of the record. Most communities were inexperienced in involving patients. It is also resource intensive.

##### **Engaging User communities (00485)**

Though the involvement of a number of different stakeholders may appear to be time and resource consuming, this investment has been proven worthwhile by the demonstrators.

User requirements have to be sought from the users, though it is necessary to manage their expectations by indicating what is feasible to deliver.

##### **Culture change (00493)**

It is important to be able to identify those stakeholders who are in a position to enable the necessary culture change and decision making. Those in positions of influence and authority need to be involved so they understand the issues and help things move forward, rather than block them

#### **Moving to mainstream**

##### **Follow through of funding (00319)**

Most communities identify lack of funding as a major barrier to progress.

Many sites are now discovering lack of commitment and funding from within the LIS process or its replacement as Strategic Health Authorities are being formed, and PCTs control the funding. The opportunities for EHR to be rolled out, for the project to move from project mode to operational across the community, are now being compromised by competing priorities

##### **Interoperability and Legacy systems (00353)**

Interfaces and data extracts from legacy systems need further assessment. It is not clear whether they can all be linked to a national solution.

#### **National vs local (00354)**

The boundary between the national parts of EHR and what will be part of the local domain need to be defined. This will impact procurement for example.

The perception is that it is preferable to minimise new national procurement, build on current infrastructure.

#### **Communications (00488)**

There will be a need for national communications about EHR, which addresses consent, confidentiality and security, in the context of why the EHR is important to the patient, and why the EHR is important to the NHS.

Further work around the national elements and infrastructure for the EHR must be linked to lessons learned from ERDIP, and must not appear to be yet another separate initiative, whether this is being done by NHS Direct, the NHSIA or a new consortium. However, ERDIP is not the brandname for EHR, ERDIP is a life limited project.

Communications will need to be made with NHS staff and other carer organisations / people first, before public communications are commenced.

### **Delivering the benefits**

#### **Personnel and resources (00323)**

Lack of sufficient skilled resource is a problem.

The requirement for a new role is emerging - that of a clinical information support worker. At one community a health visitor has been available to help patients view their records, and assisted with terminology etc. The same role could help support patients in understanding consent issues, and in providing consent. A similar role may be required by other initiatives, eg e-booking, where patients may need help to understand new information and new ways of working.

#### **Project management issues (00335)**

While some projects are very well run, there seem to be a number of problems around project management, either with staff poorly trained or inappropriate for role. Issues include: lack of resources, lack of organisational skills, staff turnover, inadequate issue management, poor reporting, ineffective or absent communication. The NHS may have a harder time than most retaining good project management staff. The role should be recognised as a demanding one, requiring competence in planning, organising and management, but also insight into the NHS and its priorities, and the constraints and advantages of the NHS environment.

#### **Interworking (00482)**

The ERDIP communities were intended to engage in significant interworking/joint working throughout the programme. Most communities welcomed this, and have tried to do so. However there appears to be have been far less interworking than might have been desired, partly due to lack of national co-ordination of such effort, and partly due to local priorities and time commitments preventing significant time away on workshops and meetings. Consideration should be given to building in even more time into resource

plans than the ERDIP programme estimated (a nominal estimate of 32 days) , to structure workshops to provide more opportunity for interaction, and to hold smaller group events involving only some of the demonstrators.

#### **Evaluation (00492)**

How and when it should be done, and how best to learn and share lessons. Most communities find it difficult to engage in evaluation, despite provision of guidance eg PROBE. Many are welcoming the provision of support and facilitation.

### **Standards and Guidance**

#### **Security: standards and procedures (00341)**

As identified in technical sections, the lack of precise guidance or agreement on sufficient security arrangements in the development period for EHR has delayed projects. Guidance on technical aspects of security is now available in the form of the product selector guide for encryption, and BS 1799.

#### Standards for Access controls

Current demonstrators, about to go live, are utilising relatively few levels of access control, eg to demarcate demographics from clinical data.

The Tees Security Model is being tested to see if the approach is feasible to implement: this is based on access controlled by role type, individual type, organisation type etc.

The HL7 and ENV 13606 EHR architecture standards will also ultimately include role types etc. It is essential to include patient and carer roles into this model.

Policies and procedures to ensure the security of data are equally as important as encryption.

#### Authentication of patients:

Initially patient access is seen as being mainly through GP practices.

Ultimately patients want access at home, and at other care centres, for example.

Successful authentication has been conducted using biometric interfaces, smartcard/PIN, and by provision of access with GP/health care staff.

#### **Consent and confidentiality: Standards and procedures (00342)**

To provide informed consent, patient has to be offered the opportunity of reviewing the information to be shared, and to comment on it (eg identify any points of disagreement).

There are two main approaches to gaining consent to information being shared: Opt-in vs Opt-out.

The *Opt-out* or *implied consent* approach would involve ensuring patients are informed through targeted leaflets, general publicity, etc that information is to be shared, and the rules that apply to such sharing, and must be offered the opportunity to Opt-out. The implications of Opting-out would need to be made clear. This is seen as an 'inclusive' approach.

To *Opt-in* or provide *express consent* patients/citizens would be required to complete a physical or electronic consent form defining the access rules to their information. This form could be attached to an electronic record, or it could be flagged, or filed in paper form with other notes.

In either case, the patient/citizen must be informed that they can change their mind, and be offered the facility to do so.

### Local and National EHR Implementation Issues 2.15

---

If part of the data has not been consented to share, Incomplete records may cause problems. The impact of this needs to be assessed.

Family history: many demonstrators feel elements of this need to be included. However, any third party information is subject to relevant consent requirements before it can be shared.

Caldicott guidance may need to be reviewed to ensure it incorporates EHR linked issues, eg on who is allowed to amend information in EHR

The concept of who is the Caldicott Guardian for EHR, needs to be tested, especially if EHR is virtual.

Feeder systems to an EHR have their own Caldicott Guardian, but the national or community instances of the EHR may require a national and/or community based Caldicott Guardian. There will be specific responsibilities for integrity, storage, archiving, accessibility etc of EHR.

#### **EHR Architecture and standards (00484)**

Agreed architecture required. The perception is that the process for agreeing this is not clear. It should be based on demonstrator experience. There is concern it might be designed to support a particular option

Provenance: Information displayed by the EHR must contain enough context to allow interpretation of the information. In particular it must include the origin of any information shown, ie the author, the organisation, the source system etc. Source systems must be able to support the provision of such meta-data, EHR systems must be able to retain and display it appropriately.

Speed and clarity of standards-agreement process is an issue. This is a problem for suppliers and NHS

Use of headings, coding: most sites are at data level, and use agreed standards for data items as per data manual, where they exist.

Terms and language are not consistently used across all care sectors. Coding systems are not consistent. EHR must therefore contain sufficient information about the provenance of the information to make it clear how it should be interpreted, or how information about its interpretation can be obtained.

A summary EHR only designed to meet the needs of emergency care is likely to be of limited benefit in the context of the areas of care considered in many of the demonstrators. The emergency EHR should be considered a 'view' of the full EHR.

The information required to support routine care is likely to require potential access to a significant proportion of the data held in organisational EPRs.

Alerts are accepted as an important user requirement. In practice these have to be provided at several different levels: behaviour or situation risks (to carer) risks (to patient), dates of validity and expiry, clinically confirmed allergies, suspected allergies, alerts about permanent medications and potential interactions, physical or other capacity problems, patient wishes,

Printouts typically still required; this may cause problems if EHR is real time, and paper versions which become out of date are used in a clinical situation.

Patients may wish to have paper or disk copies of information to take with them while travelling, for example.

#### **Private sector / independent sector (00491)**

Many of the sites have a practical requirement to communicate with the private and independent or voluntary sectors, eg for nursing care, hospice care. Policy guidance is required to establish use of NHS Number, compatible coding systems, compatible data sets and terminology, messages, etc by these sectors.

### **Implementation**

#### **Data Extraction (00349)**

Extracting data and interfacing systems is proving to be difficult, or expensive.

There have been technical, organisational and financial problems in extracting data from existing systems, to be made available to a shared EHR. This also links to other top level issues, including security, confidentiality, standards, and engaging clinicians to participate.

Main problems have been transferring data from legacy systems (particularly GP systems), or gaining interconnection through NHSnet This has caused project delays, additional expenditure on data conversion, possible limitations on data depth and quality. A common data interchange standards for all systems (e.g. XML) is required.

#### **National infrastructure (00357) - NHS Net, NHS number, NHS Direct**

NHSnet based around old communications technology & less flexible than Internet; internal systems in most practices and hospitals under-powered for current systems (though perfectly adequate for existing legacy systems); poor support to frontline organisations from centre (mainly over efficiencies and economies of scale) - IT staff spread thinly across frontline organisations.

NHS Number is still not used by social services, and is in many instances not accurately recorded or in common use.

Development of NHS Direct systems / messages has taken longer than expected.

#### **Data Quality (00486)**

The quality of information in the EHR is totally dependent on the quality of the underlying feeder systems / EPRs. To share the EHR, users must have confidence in the quality of data in the record, or it will not be trusted and used. To gain consent to sharing the EHR, the patient must be satisfied the information is of good quality.

An aspect of data quality is the meaningfulness of the information; whether it can be understood by the users.

The record, terms and language are not meaningful to all who access the EHR, especially not carers and patients. Some of the users of the EHR will need to be supported in understanding the record. This may be due to medical terminology, cultural or language differences, or due to disability. This will require additional staff support at the point of contact.

### **Managing the environment**

#### **Conflicting priorities with other initiatives (00336)**

### Local and National EHR Implementation Issues 2.15

---

There is a need to show how the national building blocks fit together to meet the requirements of all emerging applications – e.g. e-booking, EHR, e-comms.

There is a need for a technical design authority that is clearly business driven, with improved 'early warning' systems' that identify overlaps, feasibility of implementation, clash of priorities.

The restructuring of the NHS is proving to complicate the formation of a natural community for EHR, and has also added competing priorities to most communities.

It is essential the development of national infrastructure elements, eg community wide population indices or national indices or the HRI is done with the expertise and experience of ERDIP communities contributing. This will help streamline development and thinking.

#### **Lack of whole systems thinking (00340)**

Projects have been determined based on local issues and aspirations of principals (even though funding given based on national criteria).

Many of the projects have not tended to 'surface' knowledge for wider sharing or to inform wider EHR initiative; the 'bigger picture' questions (e.g. security and confidentiality, the relative merits of different EHR models) have generally not been addressed or have been side-stepped. Similarly, the ERDIP programme and communities have not been targeted by other national initiatives to engage in joint effort, excepting the booked admissions programme.

#### **Re-Organisation (00487)**

Implementing new systems will benefit most if new ways of working are considered, which may require new organisational structures. EHR crosses existing organisational boundaries. There are issues about different standards and ways of working in the different organisations, which are now expected to work with each other.

#### **NSFs and care pathways (00489)**

Concern has been raised by demonstrators at the suggestion of disease specific EHRs. EHR should always be perceived as patient centric.

Many demonstrators report that the data sets required by some of the NSFs cannot be delivered through current operational systems. New integrating systems that support care pathways, workflow, are being utilised alongside existing EPR type systems.

#### **Impact on EPR (00490)**

Need to manage impact on EPRs. Particular areas of concern include: coding systems used in EPRs; data architecture/standards; access levels and controls; ability to update and amend data; audit trails. A specific question is about how feeder systems are to be updated where EHR is accessed and found to be out of date or inaccurate.

This should be noted in current EPR procurements. EPR systems will continue to be used, as they supply specific functionality useful to the organisation or individual.

#### Annex B References

Lessons Learned Database 16 August 2002, CHIL  
Issues Database 30 May 2002, CHIL  
[N6/P2] ERDIP Technical Architecture Review 11 August 2002, PA Consulting  
[N6/P3] Technical standards review of the ERDIP sites , 9 August 2002, PA Consulting  
[N6/P4] "Route-maps" of development approaches taken by ERDIP sites, 1 August 2002, PA Consulting  
Electronic Health Record Requirements, ERDIP Demonstrator Experience v 2.2, June 2002, NHSIA ERDIP.  
Consent ERDIP Site  
ERDIP Evaluation Project, Patient Consent & Confidentiality, Study Report, March 2002, CHIL.