IM&T Programme Board

Electronic Health Records

issues for discussion leading to a policy framework

1. Summary

This paper is designed to discuss and propose policy and strategic approach to development of Electronic Health Records.

Several issues arise when thinking through the policy framework. These issues are aired here along with discussion. Programme Board are asked to come to a view where possible.

In summary, the position put forward is that EHR should be more overtly patient-focussed than anything we have done thusfar.

2. Context

The thread which runs through *Our National Health* is involvement of patients in their care. The final draft of NHSScotland IM&T Strategy reflects this with a commitment to EHR …

- *Develop and consult on a specific policy for personal electronic records in the form of EHR by October 2001, with options for patient involvement, access and control.*
- *Establish with active co-operation of patients first versions of electronic health records based on GP summary information. First pilots to be in place 2002. All in place by 2005. Must be accessible by patients.*

It should be said that the concepts and proposals here may seem futuristic when compared to the state of development of the 'basics' of electronic patient records to support care. Yet some areas within NHSScotland are already wanting to get ahead with EHR. For once we have a blank slate. Without clarity about policy there is the danger of going down blind alleys with short term developments.

3. EHR – the issues

3.1 What is EHR? How does it differ from EPR?

NHS England use the term EHR to describe the concept of a longitudinal record of patient's health and health care, from cradle to grave. It combines both the information about patient contacts with primary health care as well as subsets of information associated with the outcomes of periodic care held in the EPRs.

An Australian study[1] provides a definition which goes further and defines EHR as "an electronic longitudinal collection of personal health information, usually based on the individual or family, entered or accepted by health care professionals which can be distributed over a number of sites or aggregated at a particular source including a hand-held device. The information is organised primarily to support continuing, efficient and quality health care. The record is under the control of a known party."

Boiling these definitions down to their essentials, EHR shares the same characteristic with EPR is that they are both useful to care. However where differs from EPR is that it is …

- complete (ie. not just one organisation's contribution to care)
- life long (ie. information from birth onwards)

However this definition still begs questions. These are discussed below with a view to refining the definition, and how to make it happen.

3.2 What is EHR's purpose?

The EHR is seen internationally as an important tool which can play many roles in the provision of care to individuals and to populations. Annex 1 lists benefits compiled by the Australian study[1], showing benefits ranging from care providers to planners to the patient.

And yet the confusion persists with EPR – one organisation's record. What of the theme which underpins *Our National Health*, ie. the direct involvement of patients in their care? The bulk of IM&T developments are for the patient in the sense of support for direct care. Examples of these systems include GP systems, hospital electronic records and ECCI communications.

Yet in a sense these systems are 'for' the patient's clinician rather than for the patient themselves. While IM&T is doing its bit by continuing to improve information for the patient available via SHOW and so on, there has yet to be serious development of personal condition information designed with patient involvement in mind.

Personal or patient-held records are not a new idea and are backed by a list of benefits which echo those aspired to in *Our National Health*. Hence the academic literature shows that patient-held records have been used successfully to improve communication, to allow patients to audit the quality of data, to identify gaps in their knowledge and to prompt them to attend for reviews. Patients may feel an increase in empowerment, be reassured, and most think that patient-held records is a good idea.

The proposal to Programme Board is therefore is to develop IM&T which directly promotes patient involvement in their own care through access and contribution to personal care records. This direction will be known generally as the Electronic Health Record.

If this aim is accepted then the earlier definition gets augmented to EHR being..

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[1] The benefits and difficulties of introducing a national approach to electronic health records in Australia. Report to the Electronic Health Records Taskforce, Flinders University Adelaide, Australia. April 2000

- complete (ie. not just one organisation's contribution to care)
- life long (ie. significant information from birth onwards)
- useful to care (ie. a potential life saver)
- useful to self (ie. help with understanding conditions etc)
- understandable (ie. summarised and interpreted information)
- accessible (ie. by patients and when appropriate clinicians)
- safe (ie. protected against unauthorised access).

It is proposed that these seven principles form the definition of NHSScotland's EHR.

3.3 What should EHR contain?

The purposes above suggest information in addition to descriptions of an organisation's contribution to care of the patient. This additional information includes items such as potential/ active problems, current medication, alerts, allergies, and blood group.

Nevertheless a more direct take from the patient's perspective would emphasise the availability of key facts which were potentially life saving, hence the popularity of the various 'alert' cards carried by patients. By implication, the EHR could therefore include an **'emergency screen'**.

The concept of the Emergency Screen

This idea envisages that all patient record systems contain a single screen in universal format containing key facts pertinent to the patient's care. This screen would also be available to the patient via their EHR.

What is its purpose?

Currently emergency care is often delivered on a 'treat as seen' basis. Clinical professionals may at best be able to find limited information about the patient in their local EPR or paper notes, or at worst have no previous clinical history at all. The Emergency Screen in EHR will provide at-a-glance support for treatment decisions. The metaphor is the electronic equivalent of red cards paper-clipped to case notes folders and in every wallet and purse.

What will it contain?

To be determined, but likely to include allergies, alerts, blood group, significant conditions, current medication, organ donor and other patient preferences.

Who will use it?

Ambulance, NHS24 and A&E staff most obviously, but it would also have potential benefit in GP, dentist and Outpatients consultations and indeed in any care situation.
Health Board areas.

How does it relate to others systems and information processes?

For reasons of accuracy and currency the information in a patient's Emergency Screen would be largely a by-product of other information flows. Hence while some information would be set up once, eg. blood group, other information would be abstracted from clinical and message systems. These include GP Summary, referral and discharge letters, and electronic transmission of prescriptions. The metaphor is of doctors and patients ticking particular items of information which they believe should be present on an Emergency Screen.

In general, some of EHR's information would be static and get entered on initial set up of the record, with patient's consent. Other information would build up during the patient's health career and would include summaries of information such as contact information for the patient's clinicians.

An essential feature is active buy-in and use by patients and the public. A further level of patient buy-in can be envisaged – personalised health promotion and education. Technology now exists to offer customised web sites for individuals. The following scenario is not fanciful:

> *Patient/citizen is offered a **My Health** personal page within their EHR record. They fill in a paper or online form such as General Health Questionnaire which would cause a page to be automatically generated for them, complete with 'health information prescription' based on feedback from the form. The end result would include buttons to take them to information relevant to their specific needs and appropriate email discussion forums.*

Also possible is a form for the patient to record things like food allergies, who to contact in emergencies and organ donor preferences.

Does Programme Board accept these kind of content implications of a patient-focused perspective?

3.4 How would contributions to care be expressed?

To an extent this issue is about relationship to an organisation's EPR. What to feed into EHR?

To replicate all would seem foolish and potentially confusing. The surgeon needs to record type of cement used in a hip replacement while other clinicians need to know 'which hip and when'. Patients themselves may most appreciate access to advice on rehabilitation and the fact that their allergy to a particular anaesthetic drug would be made known to any future carers.

Similarly with primary care information, each and every encounter with GP or community nurse would not be duplicated into EHR, although there could be 'pointers' to where such information is stored within EPRs. On the other hand there are other NHSScotland record systems which could contribute or even become part of EHR. These include birth and immunisation records, screening and records for chronic condition such as diabetes. And from the patient's perspective these are core elements.

This argument suggests that EHR contains **Summaries**. Patient Summaries are not new and have existed in GP and other records for some time. In paper form they are essentially a half page of key information relevant to a patient's current health and care status – problems, medication, allergies, and so on. GPs see maintenance of Summaries within their patient records system as good practice, and hospital clinicians value receiving Summaries appended to referral letters.

Does Programme Board accept that EHR should contain summarised and as far as possible plain-English information?

3.5 Who will use it?

The direction of the analysis thusfar suggests that the main users of EHR would be:

- the patient or his relative/carer
- NHS and other agreed professionals at point of care (including NHS24, A&E, GPs)

It is proposed that NHS statisticians would also have access but only to anonymised and aggregated outputs of information. The main source of information for planners would continue to be EPRs, if only because information therein is of sufficient detail to meet requirements.

Social inclusion and patient access is important. EHR cannot depend upon patients having their own home computer with Internet connection or cyber cafe. Hence access via Digital TVs and telephoning NHS24 call nurses must also be considered.

Does Programme Board accept the logic of this primary focus for use of EHR?

3.6 Should EHR be national or local?

Several local EHRs or a single national one? The essence of shared care and emergency access to information is that organisational and geographical boundaries mean little. Patients move between boundaries on a daily basis. Modern electronic networks make distance even less of an issue.

On the one hand the setting up of large patient specific databases poses difficult issues of confidentiality and linkage between databases. However a single system simplifies ownership, maintenance and control. Finland with a population of 5 million is setting up a single system, and the proposal is that Scotland should do likewise.

A consideration of the key other systems which relate to EHR offers further support for a national system. Hence our main systems for identifying patients and staff, CHI and NHSScotland Directory, are already national system. Moreover the vision for our key piece of communications infrastructure, SCI Gateway, is that it should be national to ensure consistency and avoid duplication. Since this system could potentially feed key items such as referral/ discharge letters into EHR this is further support for a national EHR.

Usefully, a recent report from NHS England[2] analysed various options and came to similar conclusions as this policy paper. The preferred option was: *Provide national access to an emergency care EHR by A&E, Ambulance, GP, NHS Direct, Out of Hours and Walk-In Services, Pharmacists, Dentists, Mental Health Services and Social Care, through procuring a service based on an existing system such as NHS Direct CAS, permitting patients to enter data by 2004*. Reasons given included:

- It will achieve the strategic target.
- It offers flexibility for future national development and local interim development.
- It is demonstrably feasible through using a tested solution.
- It offers good value for money through increasing return on existing investments.
- It is as affordable as other feasible options.

[2] Strategic Outline Case for a First Generation Emergency/Urgent Care Electronic Health Record, NHS Information Policy Unit, March 2001

Does Programme Board accept the argument that EHR should be a national system?

3.7 Who would own and manage EHR?

Ownership and management would normally be separated, with the latter acting on behalf of the former. It is contended that the principle of patient involvement requires that ownership is the patient's, with voluntary take-up of the offer of a record and consent over control over access.

Candidates for management on the patient's behalf include the GP and a senior medical figure, either national or local. Resolving this depends o whether EHR is national or local. Following the recommendation above, it is proposed that the system would be run by NHSScotland under the stewardship of the Chief Medical Officer heading a Steering Board with strong patient representation.

Is this basis the right basis to ownership and management?

Security is clearly a key consideration. The Finnish experience with a similar system may be relevant: participating citizens are issued with a personal digital signature on a smart card. All clinicians are similarly being issued with a digital signature (i.e. an encryption key). Access to patient's records is only possible when the two keys are used together, although there are override facilities for situations such as patient unconsciousness.

3.8 How does it relate to others systems and information processes?

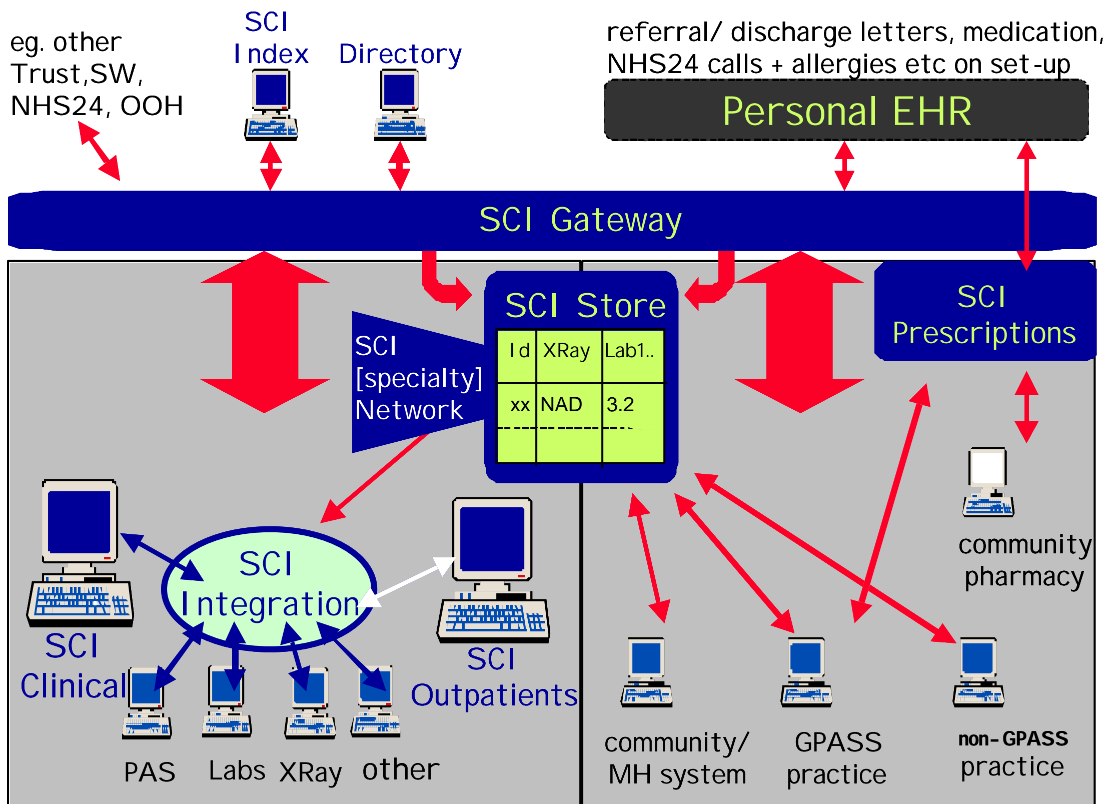
A key point in maintaining an accurate and relevant EHR is to consider how its information content could be the by-product of existing information. Obvious candidates include prescriptions and referral/ discharge letters. It is interesting that a policy commitment in NHS England is to copy all such letters to the patients.

The key systems and processes which are relevant include:

- patient identification and authorisation (CHI system, becoming SCI Index)
- staff identification and authorisation (NHSScotland Directory)
- clinical communication systems (SCI Gateway)
- organisational electronic patient general records (SCI Store), GP records and specialty records (eg. Diabetes, Scottish Birth Record).

The relevance and role of these systems is outlined in the diagram below and discussed in more detail in section 4.

Illustration of key systems inter-relating with EHR



4. Where does EHR fit with other strategic IM&T initiatives?

4.1 Patient identification: CHI (SCI Index)

The CHI system and its planned successor SCI Index will be a record of identification details of all individuals who are receiving or have received care from any NHSScotland organisation. The purpose of this record is to supply unique identifiers to NHSScotland systems which hold patient records with consequent benefit to patient-related communication.

SCI Index will relate to EHR by providing not only the identifying keys to EHR records but would also hold details of consent and access rights which would in turn govern usage of EHR.

An option still to be explored is the extent to which patient-held smart cards could provide the secure access infrastructure for EHR.

4.2 Staff identification and authorisation: NHSScotland Directory Service

This system is akin to an online 'address book' of key NHSScotland staff identification details for the purpose helping electronic communication between individuals and locations. It is planned to include unique encryption keys for individuals involved in clinical communication.

NHSScotland Directory will relate to EHR by governing access by staff to records within EHR.

4.3 Communication: SCI Gateway

Originally described in the programme of work known as SCI Lite, this will be the national infrastructural service which handles clinical communication between all NHSScotland clinicians. It can be likened to a highly secure web site on which messages are left for people or through which access to other systems can be governed.

SCI Gateway along with SCI Store could form the major 'feed' to EHR in that key clinical information from referral and discharge letters passing through can be copied into the patient's EHR record.

4.4 GP systems

GP systems are a key component since they hold the nearest equivalent we currently have to a life long record and of course current medication details. Moreover a feature of GP systems is that key information is held as a Patient Summary.

GP systems offer the potential to be a major contributor to EHR through mechanisms such as copying Summaries up to EHR on for example an overnight basis. In turn, there would be look-up access to EHR records from within GP system records.

4.5 NHS24 and Out of Hours GP services

There are two possibilities for how NHS24 can relate to EHR. Firstly by accessing a caller's record to help with advice or treatment and secondly by contributing records of such contacts.

An important point for social inclusion is that NHS24 offers a 'human route' for patients to consult their EHR record.

4.6 Ambulance Services

Principal relationship with EHR will be radio access to Emergency Screens, with a longer term possibility of contributing contact information back to EHR.

4.7 Electronic Patient Records

This is a broad title to encompass the range of 'partial' patient record systems across NHSScotland. These systems are necessarily more detailed than EHR, and it is not part of current proposals to somehow mirror all these records in EHR.

In particular the focus is on SCI Store given the goal of making this system ubiquitous across NHSScotland.

SCI Store will relate to EHR in the following ways ..

- copying agreed pieces of information such as Discharge Letters and current prescriptions to EHR,

- the provision of secure access from within EPRs to the patient's EHR, particularly to Emergency Screens.

For investigation, it should be possible from within clinical systems to 'mark for emergency screen'. This would involve clinicians in their own systems being able to 'tick' an item of information and for that item to then be transmitted to the appropriate patient's EHR record.

A special category of EPRs are those systems which contain information such as the patient's immunisation and screening history. It may be appropriate that in time these records form part of EHR, leaving call/ recall to be a function which operates off the back of EHR.

4.8 SHOW and HEBSWEB

These are our major sources of online knowledge for both patients and staff. The relationship to EHR is to develop ways of linking personal health information to appropriate knowledge. Hence the patient will be able to click on a diagnosis or drug name and be taken straight to explanatory and education information.

5. Final issues

Issues for further consideration outside this high level policy paper include …

- analysis of options for phasing delivery into do-able steps
- scale of dependency on other infrastructure developments
- definition of preliminary tasks
- extent to which EHR content and use includes social care
- analysis of delivery options, ie. NHSScotland-led development, procured commercial system, PFI etc
- definition of benefits with evaluation plan

Finally, what's in a name? A fair amount. The conclusion from the foregoing is that Electronic Health Records will have to strike a chord with both the public and NHSScotland staff if this initiative is to take off. Given the arguments, a more appropriate conceptual term might be Personal Electronic Health Records. This however doesn't trip off the tongue for a day-to-day name. A good operational public-friendly name will be required in the same vein as MediAlert, the card scheme for patients with chronic conditions.

Annex 1 **Benefits of EHR** (according to Australian study)

Supports consumer involvement	♦ Protects personal privacy and reinforces confidentiality ♦ Provides a consumer view of information ♦ Accommodates consumer decision support and self care ♦ Ensures accountability of health professionals ♦ Accesses information for the consumer
Supports consumer health care	♦ Forms the basis of a historical account ♦ Anticipates future health problems and actions. ♦ Describes preventative measures ♦ Identifies deviations from expected trends ♦ Accommodates decision support
Supports communication	♦ Supports continuing, collaborative care and case management ♦ Accesses medical knowledge bases ♦ Allows automatic reports ♦ Supports email generation and electronic data interchange (EDI) ♦ Enables record transfer ♦ Enables record access when and where required ♦ Supports selective retrieval of information
Supports management and quality improvement	♦ Enhances the efficiency of health care professionals. ♦ Supports continuing professional assessment ♦ Facilitates management tasks and reduces routine reporting ♦ Demonstrates and improves cost-effective practice ♦ Accommodates future developments ♦ Provides a legal account of events ♦ Provides justification for actions and diagnoses
Supports population health care	♦ Supports policy development ♦ Provides evidence for development and evaluation of programs
Supports enquiry and learning	♦ Supports clinical research ♦ Assists with clinical audit ♦ Supports medical education