

# Information governance: exploring public attitudes to electronic health records

Prepared by

Linda Nicholson  
**The Research Shop**

For Consumer Focus Scotland

June 2009

Fòcas Luchd-  
Caitheimh Alba  
Comhairle Luchd-caitheimh ùr na h-Alba



**Consumer Focus  
Scotland**  
Scotland's new Consumer Council

## Contents

<b>1</b>	<b>Summary</b> .....	<b>1</b>
<b>2</b>	<b>Introduction and research objectives</b> .....	<b>8</b>
<b>3</b>	<b>Method</b> .....	<b>11</b>
<b>4</b>	<b>Public understanding about how personal health information is currently stored and shared</b> .....	<b>13</b>
4.1	Awareness of how health records are stored.....	13
4.2	Views on the merits and drawbacks of electronic record keeping.....	14
4.3	Views on the merits and drawbacks of paper records... ..	18
4.4	Views on how patients can access their records once held on computer.....	19
4.5	Summary of key points.....	19
<b>5</b>	<b>Views on whether people want to be informed about how their personal health information is stored and shared</b> .....	<b>21</b>
5.1	Summary of key points .....	22
<b>6</b>	<b>Views on whether people are content for some information storing to be done without explicit consent</b> .....	<b>23</b>
6.1	Views on the importance of being given the option to opt out of having personal health information stored electronically.....	23
6.2	Views on the benefits of a system of implied consent for electronic storage of information unless a patient specifically opts out .....	24
6.3	Views on the automatic electronic storage of test results .....	25
6.4	Summary of key points .....	26
<b>7</b>	<b>Views on models of consent appropriate for accessing and viewing information</b> .....	<b>28</b>
7.1	Views on whether it matters who can view health information .....	28
7.2	Views on NHS staff outwith the doctor's surgery having to ask for permission before they can look up health records.....	30
7.3	Views on access to medical test results without requesting explicit consent.....	33
7.4	Summary of key points .....	34
<b>8</b>	<b>Views on extending content of and access to the Emergency Care Summary</b> .....	<b>36</b>
8.1	Views on extending the ECS.....	36
8.2	Views on whether the GP should ask for explicit consent prior to adding details to the ECS.....	38
8.3	Views on extending access to the ECS.....	38
8.4	Summary of key points .....	39

<b>9</b>	<b>Views on what concerns, if any, participants have about information being stored on national databases .....</b>	<b>40</b>
9.1	Summary of key points .....	41
<b>10</b>	<b>Reflections on participants' views .....</b>	<b>42</b>
10.1	Key conclusions .....	43
<b>Annex 1:</b>	<b>Core focus group discussion schedule.....</b>	<b>44</b>

# 1 Summary

There have been significant developments in recent years in the ways personal health information is stored and viewed within the NHS using information technology. Electronic record-keeping is gradually replacing paper records, with the aim in Scotland to develop links between different health record computer systems such as the Emergency Care Summary, the Scottish Care Initiative – Diabetes Collaboration, and test results. A Palliative Care Summary is also planned for introduction throughout Scotland following successful trials in NHS Grampian.

However, whilst technical advancements have allowed for the extraction and sharing of data across different systems, the managerial and governance frameworks to support the storage, viewing and sharing of electronically held health information have not been fully developed and appear inconsistent and incomplete.

Previous research<sup>1</sup> suggested that members of the public support the move towards greater use of computers and more sharing of information between health professionals, but it also raised questions about extending access to health records, and the security of computer-held records. Clinicians have also expressed their need for simple procedures and rules about storing and accessing health information electronically, which both they and their patients find acceptable.

This research was commissioned to provide evidence of public attitudes and views on the storing, viewing and sharing of personal health information in electronic form which can be used to inform the development of a model for how this should be carried out in different clinical settings.

Eight focus groups were held to discuss aspects of electronic health information. They involved 66 participants aged from 16 – 87 years, representing a variety of patient perspectives.

Overall, participants appeared to be largely ignorant of electronic health information systems and models of consent for storage and viewing of data. Despite this lack of awareness, participants generally accepted and indeed expected that their health records would, over time, become computerised. On balance, they considered that the benefits of storing health data on computer outweighed the drawbacks, and they provided constructive suggestions for minimising risks and maximising the merits of electronic health databases.

Participants favoured the framework of separate health databases developing in NHS Scotland with different data sets housed in different locations, but with the potential to be linked by NHS clinicians.

---

<sup>1</sup> Scottish Consumer Council, *Health On-line: Public attitudes to sharing data in the NHS*, Glasgow (2005)

The Emergency Care Summary (ECS), containing summary basic information for use by medical staff when the GP practice is closed was also seen by participants to be of potential value, but they expressed some resistance to its extension and were cautious about widening access to its database.

There were mixed views on who should be able to view patient health information held on computer. Whilst participants agreed that doctors and consultants should have a right to view this information, there was little agreement on extending access to view data to other NHS personnel such as nurses, and professionals such as dieticians or physiotherapists.

Whilst many participants described how at present they were not too concerned about who stored and viewed their health records, they acknowledged that this might not always be the case. The prevailing view was a preference to be able to opt out of having personal health information inputted onto electronic records, and also to keep the requirement for explicit consent to view such data.

A cross-cutting theme was the need for patients to be better educated about ehealth. Participants wanted the public to have more information, not only on the different electronic health databases and models of consent, but also on the benefits of having their data stored on computer, so that their decisions on consent could be better informed.

**A summary of key findings** which emerged are below:

#### **Chapter 4: Public understanding about how personal health information is currently stored and shared**

Participants' knowledge of electronic health information systems was patchy and limited. In the main, previous knowledge had been gained from news reports about developments in England and from observations at participants' own GP surgery or hospital. Indeed, all but one of the participants with diabetes had no previous knowledge of the SCI-DC store dedicated to diabetics' health information.

Participants considered that neither paper nor electronic record-keeping were totally risk-free, but the benefits of electronic records outweighed the potential drawbacks. A wide range of benefits of keeping health records on computer was identified by participants with advantages perceived for patients, carers and NHS staff. The drawbacks to electronic record-keeping identified by participants focused largely around potential breaches of security.

It was commonly accepted that changes would need to be made to enable patients to view their records in different ways once their information is stored on computer, for example, on screen, or in a print-out.

## **Chapter 5: Views on whether people want to be informed about how their personal health information is stored and shared**

Views were divided on whether it is important to be kept informed about how personal health information is stored and shared. Some people wanted to know about storage and sharing because they had heard about previous breaches of data security. Others felt that people may have sensitive information on their health records which meant that knowledge of storing and sharing of these details would be important to them.

Participants identified information they wished to know about storage and sharing of information, such as how securely the data would be held, who has access and where the data is held.

Young people expressed the least amount of interest in knowing how their health information is stored and shared

## **Chapter 6: Views on whether people are content for some information sharing to be done without explicit consent (stage 1 consent issues)**

It appeared that with few exceptions, participants were largely ignorant of the different models of consent in operation at the stage of storage of health information (stage 1). None of the participants in the diabetes focus group had encountered the current model of consent for storing their details.

Participants saw both pros and cons to the model of implied consent for storage of health information electronically. A common view was that whilst there were clear benefits to having everyone's health details stored electronically, the right to opt out should be retained. A recurring argument for retaining the opt-out option was that this is a basic right which should be preserved. It was argued that hand-in-hand with retaining the right for patients to opt out of having their information stored on computer should be education about the benefits of permitting their details to be stored electronically.

Some participants recommended a partial opt-out system whereby they could specify that certain information on their health records (eg. sensitive data) could be excluded from being stored electronically.

Having health information stored electronically was seen to benefit both patients and NHS staff. Computer-based data was seen as particularly advantageous to people with long standing and complex health conditions, and people with incapacity.

People were split on whether the automatic electronic storage of test results was acceptable, with many arguing for the right to opt out of having test results stored in this way, but others regarding electronic storage of such results to have wider public benefits.

Both diabetic and non-diabetic participants did not foresee insurmountable difficulties for diabetics who opted out of having their medical information stored on the diabetic store, and who would not therefore receive automatic appointments for retinopathy screening.

## **Chapter 7: Views on models of consent appropriate for accessing and viewing information (stage 2 consent issues)**

Few clear cut and overriding views and recommendations could be drawn from the discussions on stage 2 consent issues, with opinions very much grounded in individual circumstances and perspectives.

Most participants considered it important that there are controls in place over who can view their health information outwith their GP surgery. Whilst most people expected doctors and consultants to have access to their electronic health information, there were differing views on extending access beyond these NHS personnel. Many participants suggested that nurses over a certain seniority should be able to view their health information. Hospital pharmacists appeared to be more acceptable to participants as potential viewers of electronic health data than were community pharmacists.

Overall carers were the most agreeable to widening access to patients' electronic health records, suggesting that even allied professionals such as social workers, support agencies and dieticians should be able to view information in certain circumstances.

A common view was that health service receptionists should not be able to view anything more on health records than administrative contact details. On balance, participants appeared to support dieticians and physiotherapists having access to health records in specific circumstances, where their need is clearly justified and following explicit consent from the patient.

Some participants reported feeling reassured by a system in which their explicit consent was required before NHS staff could view their electronic records. It was argued that it was important for a patient to retain the right to refuse consent as there might be circumstances in which they would not want their records to be viewed. Where electronically held data is to be *shared* rather than simply *viewed*, a general view was that the patient's explicit consent should be given first.

Some participants argued that giving explicit consent for NHS staff to view their records at the start of a period of treatment, such as a stay in hospital, should suffice for any episodes of care received during that period.

A minority view was that the requirement to seek a patient's explicit consent before NHS staff viewed their records was pedantic and largely unnecessary.

Concerns were raised that having to seek explicit consent (perhaps from a legal guardian or power of attorney) should not result in delayed treatment of patients. The notion of a GP having to seek consent to view their own patients' electronic health data was greeted largely with derision.

Participants' views were mixed on the issue of automatic access to their test results by their GP. Reassurances and more information were requested by participants before they could come to any firm views on their GP's access to their test results

### **Chapter 8: Views on extending the content of and access to the Emergency Care Summary (ECS)**

Views were split on the merits of extending the ECS to include more information. A common view was that adding more information might defeat its purpose of access to summary details in an emergency situation. Those who favoured adding more information suggested the inclusion of administrative details such as next of kin, power of attorney, and carer contact details, in addition to medical information associated with long standing illnesses and conditions. Some participants opposed the inclusion of what they regarded as sensitive information such as STD tests, and mental health diagnoses.

There was general agreement that whilst the current content of the ECS could be inputted on the basis of implied consent, it seemed appropriate to require a patient's explicit consent for any further details to be added. A two-tier system of ECS information was recommended with tier one containing standard (current) ECS data, but patients having a say in what information they wished to be added to tier two.

Participants considered that in the event of the ECS being extended to contain more information, more stringent access procedures would need to be put in place

### **Chapter 9: Views on what concerns, if any, participants have about information being stored on national databases**

The approach in Scotland to storing data in several different electronic databases housed in different places was praised by some participants as being potentially more secure than hosting all data in one place on one database.

Most participants saw both pros and cons to storing data on national databases, with views reflecting individual personality and experiences rather than age or type of patient group. National databases were viewed as beneficial for people becoming ill away from home, or for those who moved residences frequently. National databases were also seen to be well serviced and managed and would be taken seriously.

Perceptions of the disadvantages of national databases focused largely around higher risks of security breaches and errors being made in inputting and accessing. Some participants felt instinctively that they had more control of their data if it is



housed locally and generally felt more confident about local databases rather than national stores in terms of trust and accountability.

## **Chapter 10: Reflections on participants' views**

People's attitudes to electronic health record-keeping tended to be individual, based on personal experience and beliefs rather than reflective of particular patient types.

Participants' general ignorance of how their health information is stored electronically, and the models of consent in place, suggest that an education campaign is required in order to stem any possible development of misinformation and suspicion over ehealth developments. In particular, it appeared that people needed more information about the purposes and potential benefits to patients of new information systems such as the ECS in order to bring them onside and help to maximise the advantages of ehealth systems. For example, although most people had not heard of the ECS prior to their taking part in the research, the concept of a summary health record, for emergency purposes, was readily understood and broadly welcomed.

Reassurances are also required over the security and confidentiality of health data held electronically, as these issues featured prominently in discussions as potential barriers to widening the information stored electronically, widening access to that information, and storing data in national (as opposed to local) databases

The research revealed that people are, in general, relatively cautious about professionals viewing and sharing their electronic health information. It was interesting that despite most participants acknowledging the benefits of electronic health records for their healthcare, and perceiving themselves as having "nothing to hide" and their information being relatively innocuous, they could not rule out a time in the future when they might feel differently. Being able to opt out of having their health data stored electronically, and being asked for explicit consent before their data is viewed and shared were seen as important and reassuring controls for patients to retain.

### **Summary of recommendations**

The research revealed little consensus in attitudes to electronic health records, with issues of storing, viewing and sharing data generating much debate and disagreement amongst focus group participants, depending on their individual circumstances and perspectives. Despite this, the following 6 broad recommendations could be derived from the findings:

1. Patient information is needed which outlines clearly the ehealth developments in Scotland. This should cover:

- Where data is held; who has access; how securely the data is held; how patients can access and update their records once they are held on computer (chapters 4 and 5)

- Benefits of electronic record keeping (chapter 4)
- Specific information about dedicated databases such as the diabetic store (chapters 4 and 5)
- Reassurances about the security and confidentiality of national databases (chapter 9)
- Clarity on the position regarding the viewing of test results (chapter 7)

2. The right to opt out of having health records stored electronically should be retained, but should be supported by patient information on the benefits of ehealth to encourage patients not to opt out without good reason (chapter 6).

3. Consideration should be given to a partial opt-out system whereby it is assumed that data can be held on computer (implied consent model), but patients are also able to nominate particular information which they do not wish to be stored electronically (chapter 6).

4. A transparent and simple framework or mapping of the controls over who can view electronic health records, in what circumstance and under what rules of access (e.g. passwords, authorisation, restrictions on type of data) should be constructed, particularly in the light of the possible extension of and linking of databases (chapter 7).

5. As protocols for consent and access develop, efforts should be made to keep these streamlined and simple so that these procedures in themselves do not result in delays to patients' healthcare (chapter 7).

6. Care should be taken to ensure the ECS is maintained as a summary data store, fit for purpose, and not extended to the extent that it loses its benefits in out-of-hours and emergency situations. However, consideration should be given to the development of a 2-tier ECS, with standard data held at one level (as at present), but the option for patients to identify specific information which they wish to be held at level 2. This is likely to be details of a longstanding health condition such as diabetes or epilepsy. The storing of level 1 data would be on the basis of implied consent, with level 2 data storage based on explicit consent (chapter 8).

## 2 Introduction and research objectives

The Government's eHealth Strategy 2008-2011 (June 2008) set out a vision based on the NHS Scotland goals outlined in the Better Health Better Care Action Plan (2007)<sup>2</sup>. It highlighted the need to exploit electronic information "*to help ensure patients get the right care, involving the right clinicians, at the right time*". Benefits of eHealth are envisaged for the patient in terms of "*improving patient safety and effectiveness through information*".

There have been significant developments in recent years in the ways personal information can be stored and shared by using information technology. Within the NHS information technology has enabled the gradual replacement of paper records with electronic record keeping, in addition to facilitating, for example, sending x-rays and test results electronically rather than by post; using video links to provide specialist services in remote and rural areas; storing test results on computer; providing reliable information about health conditions on the internet; and moving towards the capacity to link electronically held health records stored in different places and databases.

Within the NHS in Scotland, the approach has been to focus on developing links between different computer systems already in use rather than aim to create a single new computer system for the whole of the NHS or a single electronic record for every patient. Examples of current systems are the Emergency Care Summary, containing summary basic information for use by medical staff when the GP practice is closed; the Scottish Care Initiative – Diabetes Collaboration, involving special records containing all information about a patients' diabetes care; test results (e.g. blood or urine) which are sent electronically from the lab to a computer in each NHS board area; and electronic referrals for use by GPs when they refer patients to a hospital out-patient clinic or to a specialist. In addition, a Palliative Care Summary is planned for introduction throughout Scotland after being trialled successfully in NHS Grampian.

Whilst there have been agreed principles and rules about how paper-based health information should be stored and shared within the NHS, a variety of different practices have developed in relation to the storing and sharing of electronic databases. For example, across NHS Scotland, there is evidence of different models for seeking consent from patients, different security arrangements for protecting personal information from unjustified use, and different access protocols.

At present, many patients are unaware of the way in which information about their health is stored and protected electronically, and there is a lack of clarity about the consent models for storing and viewing such personal data in different situations. Clinicians need assurance that the way they are handling personal health information is not only in line with legal and professional guidance but also acceptable to their patients.

---

<sup>2</sup> <http://www.scotland.gov.uk/Resource/Doc/206458/0054871.pdf>

So whilst technical advancements have allowed for the routine extraction and sharing of data across different systems, the managerial and governance frameworks to support this sharing are not fully developed and appear inconsistent and incomplete.

It is important to have systems and procedures in place which ensure that patients' right to confidentiality over their health information is maintained, and that where their information is shared, this is done with their consent. However, the nature of the consent and how it needs to be expressed is at present not always clear. The 2-stage process in the handling of patient information of firstly storing data in particular ways, and then subsequently accessing the data, is common, yet no standard set of rules is in place to govern the way in which these processes take place. So differing procedures take place in different clinical settings in terms of, for example, gaining patients' consent to their data being handled in certain ways, or allowing various healthcare staff access to the records.

Other issues have also arisen in previous research. A study carried out by the Scottish Consumer Council<sup>3</sup> found that members of the public supported the move toward greater use of computers and more sharing of information between health professionals, envisaging that this can make health care quicker, safer and more effective. However, whilst participants in the focus groups conducted for this research supported wholeheartedly the notion of core health information being made available in an Emergency Care Summary, and being accessible to ambulance staff, accident and emergency departments and NHS 24, they had mixed views about extending access further to include, for example, community pharmacists. People with HIV were particularly concerned about who would have access to their information and others stressed that they would want to see what information about them had been stored and be able to check it for accuracy.

Other research supports these findings. For example, Gertz (2007)<sup>4</sup> highlights the benefits of the Electronic Health Record (EHR) as providing an open data system throughout the health service and preventing the so-called "multiple-blood-test-syndrome" due to the lack of communication between health care providers. However, whilst she argues that it offers potential advantages in terms of increased efficiency within the healthcare system, reducing the burden on patients, she also highlights potential problems with confidentiality and liability regarding, first, the question of creation and control over the EHR, and secondly, over issues of access to the EHR.

As a result of the different systems in place and the differing rules about consent and access to information, clinicians (doctors, nurses and other healthcare staff) have expressed their need for simple procedures and rules about storing and accessing health information electronically, which both they and their patients find acceptable.

---

<sup>3</sup> Scottish Consumer Council, *Health On-line: Public attitudes to sharing data in the NHS*, Glasgow (2005)

<sup>4</sup> Gertz, R (2007) "An Electronic Health Record for Scotland: Legal Problems Regarding Access and Maintenance"

This research was commissioned to provide evidence of public attitudes and views on the storing and sharing of personal health information in electronic form which can be used to inform the development of a model for how this storing and sharing should be carried out in different clinical settings.

Specific objectives were to find out:

- how much the public understands about how personal health information is currently stored and shared;
- whether people are content for some information storing or sharing to be done without explicit consent;
- what kind of conditions they might expect to be applied – eg in relation to information being available to them, or of appropriate and adequate security arrangements being in place;
- whether people want to be informed about how their personal health information is stored and shared;
- whether people would like to be asked for their explicit consent to storing and sharing in different ways;
- what concerns, if any, members of the public have about information being stored on national databases.

This report documents the research process (chapter 3) and addresses the above objectives in chapters 4 - 10.

### 3 Method

Eight focus groups were conducted during May - June 2009. They were held in locations spread across 4 different NHS health board areas: Lothian, Borders, Dumfries and Galloway and Lanarkshire. They involved a total of 66 participants with an age range from 16 to 87 years. Overall, 37 participants (56%) were female and 29 participants (44%) male.

The composition and location of the 8 focus groups were:

<b>Group</b>	<b>Features of the Group</b>	<b>Health Board</b>	<b>Age</b>
<b>1</b>	Urban recent patients	Lothian	18 – 67 years
<b>2</b>	Rural recent patients	Borders	31 – 75 years
<b>3</b>	Mental health patients	Lothian	37 – 55 years
<b>4</b>	Diabetic patients	Lanarkshire	40 – 74 years
<b>5</b>	Carers	Dumfries and Galloway	38 – 64 years
<b>6</b>	Patient representatives	Lothian	44 – 87 years
<b>7</b>	Young people	Borders	16 – 21 years
<b>8</b>	People with HIV-Aids	Lothian	40 – 59 years

Participants were invited to provide a list of any long-standing health conditions from which they suffered, to help provide some context for their views. Within the 8 groups the following conditions were mentioned by participants:

- HIV Aids
- Bipolar disorder
- Clinical depression
- Diabetes
- Arthritis
- Back pain
- High blood pressure
- Angina/heart disease
- Asthma

Several different recruitment strategies were adopted to populate the groups. The urban and rural recent patient groups were recruited via an on-street recruiter and newspaper advert respectively, with a second-stage screening questionnaire used to ensure that potential participants matched the requirements of having recent patient experience, and represented both genders and a range of socio-economic backgrounds and ages.

The remaining groups were recruited via voluntary and NHS organisations which held regular meetings with specific groups of patients of interest, or held databases of patient representatives. In the latter cases, an invitation to express interest in taking

part in the research was sent in group emails to members of the relevant databases, to allow individuals to choose whether they wished to take part.

These various recruitment strategies resulted in relatively well-attended groups ranging from 7 to 10 participants. Annex 1 provides the outline topic guide used for the focus groups. Each focus group followed a deliberative model, with the moderator explaining in stages key aspects of electronic health record systems, and answering questions, before inviting comments at each stage.

The schedule also contained 2 vignettes, designed to pose hypothetical scenarios to prompt in-depth discussion on important issues. The vignettes were deployed once participants had provided their initial views on the central issues of consent at stage 1 and stage 2. The scenarios helped participants consider the issues from different perspectives and challenge their initially held views, testing whether these stood up in different circumstances.

Most or all of the schedule was covered in each group, but where time was short due to lengthier discussion of some issues, or unavoidable disruption within a few groups (on account of various participants' health conditions), the second vignette and final few questions were not covered. The duration of each focus group was around 1 hour 25 minutes.

The discussion in each group was audio-recorded and subsequently transcribed. The transcriptions were subject to content-analysis based on the key themes of: current understanding of how personal health information is currently stored and shared; importance of having information about storing and sharing of personal health information; views on stage 1 consent issues; views on stage 2 consent issues; views on the ECS (extending and accessing); and views on storage of personal health information on national databases. Particularly succinct and/or illustrative comments made by participants were highlighted for inclusion in the report.

The following chapters address the specific objectives of the research, relating the discussion which emerged in each focus group to the key issues of interest. The final chapter provides general reflections on participants' views.

## 4 Public understanding about how personal health information is currently stored and shared

It was expected that different focus group participants would have different experiences of accessing NHS healthcare, and have varied understandings and knowledge about electronic health record keeping. To address this, the moderator adopted a deliberative approach to facilitating the discussion, with each discussion topic preceded by a short description of relevant developments in electronic health recording before opening up the topic for consideration by participants. The use of 2 vignettes also helped to challenge initial views and test how these might stand up in different circumstances. In this way all participants had an informed base upon which to provide their views.

It was clear that participants had a range of experiences and varied levels of knowledge about electronic health record systems. Their awareness of how their health records are stored, their views on the merits and drawbacks of electronic record keeping, and their preferences on, and expectations about, how they should be able to view their electronic records were explored in the groups.

### 4.1 Awareness of how health records are stored

Participants were informed about the move in Scotland from paper-based health record-keeping to electronic systems of keeping health records. The Emergency Care Summary, diabetic store of health information and the database of test results held by health boards were outlined briefly as examples of electronic health databases. Groups were asked about their level of awareness of such systems prior to attending the session.

Overall, knowledge of electronic health information systems was patchy and limited. Whereas many participants commented that they had expected the NHS to be developing electronic systems for storing health records, very few had any specific knowledge of the developments which had taken place, and if indeed their records were currently stored on paper or computer. Some participants remarked that they had assumed that computerisation of records was taking place in Scotland as they had heard or read about developments in England. Views included:

*“I would have been shocked if they weren’t planning to put things on computer” (Rural)*

*“Electronic records...you just have to accept this as the way things are going” (HIV-Aids)*

Many participants explained that their level of awareness stemmed from their recent experiences of the NHS as a patient or carer. Some GPs appeared to have moved to an electronic system of record keeping, with participants reporting their GP’s use



of a computer in their surgery rather than taking notes on paper. One participant remarked candidly:

*“Mine (GP) just uses a computer ...no notes at all...it is annoying as the doctor is looking at the screen rather than you!” (Mental health)*

Those using the NHS frequently over recent years had contrasting experiences. For example, a pregnant woman in one group reported all of her test results being stored on computer. Another recently pregnant woman recalled paper-based notes being used throughout her healthcare.

Participants who had recently used NHS 24 all confirmed that they had been asked for their permission by the operator to access their health record. For one carer amongst these, the welcome knowledge that her son’s health records could be accessed electronically out-of-hours was somewhat tempered by the subsequent arrival of the out-of-hours doctor who seemingly was not equipped with her son’s health details nor had electronic access to these.

Other ways in which participants had gleaned information about developments in electronic health record keeping were by attending health board meetings (Patient representative), through information provided by their workplace (Rural), or due to current or previous employment within the NHS (Rural).

Participants with diabetes were asked specifically about their awareness of the diabetic store of health information (SCI-DC). Only one participant (a member of a patient forum) had a clear grasp of how the details about her diabetes were stored. Participants in the focus group for people with diabetes did not appear to be aware of the SCI-DC system, yet some described the use of computer records by health professionals in their dealings with them over recent months:

*“The doctor asked me when I had had the test last, but I wasn’t sure. She said stay there, I can look it up (on computer) and I can see when you’ve been and what your results were”*

So whilst some diabetics had already experienced the benefits of having their details readily accessible on computer to healthcare professionals, they had not realised that their health records were being handled in a specific manner as part of ehealth developments. One participant commented:

*“We knew it existed (the diabetic database) but no one has made a conscious effort to explain it to us”*

#### **4.2 Views on the merits and drawbacks of electronic record keeping**

Many participants agreed that their views on the value of electronic record keeping of sensitive information were influenced by well publicised security breaches involving such data over recent years. However, in discussion most were able to weigh up the

potential merits and disadvantages of keeping health information on computer, with neither paper nor electronic record-keeping seen as free from risks, but the benefits of electronic records outweighing the potential drawbacks.

#### *4.2.1 Merits of electronic record keeping*

A wide range of merits of keeping health records on computer was identified by participants during the focus group discussions. These have been summarised below:

#### **Advantages for patients and healthcare teams in complex cases**

- Useful for those on multiple medications e.g. those with longstanding and complex conditions.
- Useful for older people who may forget what medications they are taking, or are traumatised on admission to hospital and are unable to provide information about themselves.
- For diabetics, having the entire healthcare team able to view health information is very efficient and means that the patient does not have to try to remember details about the results and timing of their tests.

#### **Advantages for carers and people with incapacity and their healthcare teams**

- Useful for carers who may make relatively more use of GPs out-of-hours for the person they care for.
- Useful for people with incapacity who may not be able to articulate the medications they are on and any allergies.

#### **Ease of access**

- Computer records lend themselves to being easily read by NHS staff and by patients, rather than their having to sift through piles of paper notes.
- Access to health information on computer is quicker than searching through paper documents and will lead to obtaining prescriptions more quickly.

#### **Practical benefits**

- Beneficial if a patient needs to use the NHS when away from home, or at other times when their usual GP is unavailable.
- Helpful if a person moves addresses a lot to have their health records readily available to new GP practices.
- Because computer records can be easily shared, this minimises patients having to fill in lengthy questionnaires at the start of episodes of care.

#### **Operational benefits**

- Electronic records are more easily updated than paper records. In addition to amendments and additional information, sensitive data which a patient wishes to be removed can more readily be taken from computer records than from paper records.
- Health records on computer can be easily corrected if errors are found.
- Electronic records can be kept up-to-date by automatic procedures and this can happen frequently.
- Electronic files can hold much larger quantities of data than paper records (although there was a debate about whether this was beneficial or not).

### **Security benefits**

- Electronic records can be backed up by automatic procedures, again at frequent intervals.
- Data held on computer can be encrypted, making the information more secure than paper records.
- Computerisation of records enables a greater control over access to records. For example, very sensitive data can be easily isolated and password protected.

#### *4.2.2 Drawbacks of electronic record keeping*

Participants also identified what they perceived to be potential drawbacks to electronic health record keeping:

### **Concerns over security and confidentiality of data**

- A third-party needs to be involved in electronic record keeping – IT companies – which introduces another tier of potential security breaches.
- Electronic databases, particularly those containing personal details, are valuable to various individuals and organisations such as insurers and criminals, so lost data is highly vulnerable to ending up in the “wrong hands”.
- Data held in computerised health records could assist criminals intent on identify theft.
- Electronic records are potential targets for computer hackers. One participant remarked: *“This happened to us when I worked at XXX, - a boy hacked into the system over a period of 2 years. He was prosecuted, but he did it again and again”* (Carer).
- Computer data is easier to “tamper” with for those intent on changing details in people’s records.
- It is easier for an unauthorised user to locate a particular record when data is held on computer, compared with having to search through paper records. One comment was: *“It happens at the bank – you are not allowed to do this without a valid reason, but there are people who are just nosy and do it anyway”*.
- Once data is on computer, this is the start of the slippery slope with more and more access being permitted and information *“dribbling out all over the place”*.

- Computer-based records are too easy to share, “*one click and they are gone to someone else*”.
- More rules are needed to govern the use of information held on computer compared with information held on paper records.

### **Concerns over technology**

- Data can be lost either in transit if held on disc or on computer if it crashes. Whilst it was acknowledged that paper records could also be lost, participants argued that if records are held on electronic databases, one incident of losing data could result in record loss on a vast scale, rather than losing only one or a few records which would be the more likely scenario with paper-based record-keeping.
- Computer systems can suddenly crash or “go down” just at times when the information is required.

### **Concerns over accuracy of data held on computer**

- Once data is inputted onto computer, patients may not know how to get inaccurate details changed. Data is more “set in stone” when on computer than on paper.
- The accuracy of computer records depends very much on the care taken by the data processor.
- It is more likely that NHS staff might make errors in looking up the wrong records for patients when their information is held on computer than when their records are on paper.

### **Concerns about impact on patient:doctor relationship**

- Holding data electronically dilutes the special contract and relationship between a patient and their GP. Your records should be part of the contract between you and your doctor in which your information is confidential, but computerisation of these provides the opportunity for “*too many fingers in the pies so that no one knows who is responsible*” for confidentiality.
- Information held on computer means that the GP is talking to the screen and to other people electronically rather than focusing on the patient – electronic records results in some diminution of the “*human touch*” of the NHS.

Some participants foresaw potential problems arising in the future regarding computerised records. One predicted that any extension of the Emergency Care Summary (ECS) might bring with it further issues regarding confidentiality, with patients increasingly concerned over the privacy of any further medical data being held on electronic databases. A contrasting view was that as people become more tolerant and understanding of certain conditions, for example, bipolar disorder or HIV-Aids, recording these on computer records would not require such sensitive handling in the future as they do now.

A few participants within the diabetic and patient representative groups expressed their concern that the CHI number recorded on the ECS might in future be used to link their medical records to other non-medical databases such as social work records. Members of the HIV-Aids group argued that whilst confidentiality of individual patients underpinned electronic record-keeping now, in the future it would be possible to reveal individual identities if Government or other powerful bodies thought this justified:

*“The Government will know more about you (if your health details are on computer). They can go from saying ‘so many people have Gonorrhoea’, to saying ‘so many named people along with their addresses have Gonorrhoea’”*

#### **4.3 Views on the merits and drawbacks of paper records**

Whilst most discussion focused on the use of electronic records, some views were expressed by participants regarding the pros and cons of paper record-keeping. These factors can also be considered, indirectly, to reflect views on the merits and drawbacks of electronic records.

One of the key benefits of paper records over computer records was identified by a few participants (largely those with mental health problems, but also representatives from the urban group), as being the facility offered by pen and paper for doctors' annotations to the formal information they recorded. So rather than shoe-horn descriptive health information into a system of computer codes and categories as might be the case with electronic databases, paper record-keeping enabled less clear-cut, yet potentially very valuable information to be stored.

One participant in the HIV-Aids group argued that paper records could be stored more securely than computer based information, “*safely under lock and key*”. A member of the rural group considered that data entry onto records might be more accurate using pen and paper than typing on a keyboard:

*“There is the advantage that if you are inputting on paper, you tend to be more concentrated on what you are doing when you are inputting. When you input on computer, you could quite easily put information onto the wrong record”*

Some participants raised concerns over paper-based records. A recurring view was that handwriting could be difficult to decipher and this could lead to errors. Another common view was that most people, whether authorised or not, could easily read through paper records if they came across them inadvertently, whereas accessing computer-held data would always require some degree of expertise and knowledge as to how to log on, what password to enter, and so on. A few participants considered that paper records could more easily be misplaced than electronic records. Finally, one participant (Urban) remarked that it was far easier to back up computer-held data than to provide back up copies of paper files.

#### **4.4 Views on how patients can access their records once held on computer**

An emerging theme within several of the groups was the implication for patients wishing to take up their right to view their health records once they are held electronically. When participants queried the practicalities of this, they were asked how they expected this to be conducted, and what their preferences for viewing their own records would be.

It was commonly accepted that moving to an electronic system of record-keeping would not necessitate restrictions on patients' right to see their own records, rather, systems would need to be developed to enable patients to view their details in a manner appropriate for them.

Most of those who commented envisaged a system of viewing whereby patients gave notice of their wish to see their details, and these were then printed off for patients to take away and study at home. One group considered that a charge might be levied for this facility. A query arising in the urban group was how patients would be able to view their full records, when their details were split across several different databases at local, regional and national level.

Some participants expressed their preference for viewing their records on computer screen. A few of the members of the mental health group anticipated viewing their details on screen at their doctor's surgery. Members of other groups (Young people, Urban) recommended that patients be given a password to enable them to view their own records from their home computer system. There was some debate amongst those in the mental health group as to whether this would compromise the security of the data, however one participant argued strongly that this system would be no different from accessing bank details using a password, stating:

*"It's more important that someone doesn't run off with my £10,000 on internet banking than worry about them seeing how many tablets I'm taking for my bipolar!"*

A common view was that records should not be emailed to patients wishing to look at them, as email attachments were vulnerable to interception. Also, participants in the carers group did not favour providing patients with a disc containing their information, as recent stories in the news had shown to them how easy it was to lose these.

#### **4.5 Summary of key points**

- Participants' knowledge of electronic health information systems was patchy and limited.
- Previous knowledge was gleaned in the main from news reports about developments in England and from observations at participants' own GP surgery or hospital.

- All but one of the participants with diabetes had little previous knowledge of the SCI-DC store for diabetics' health information.
- Participants considered that neither paper nor electronic record-keeping were risk-free, but the benefits of electronic records outweighed the potential drawbacks.
- A wide range of benefits of keeping health records on computer was identified by participants with advantages perceived for patients, carers and NHS staff.
- The drawbacks to electronic record-keeping identified by participants focused largely around potential breaches of security.
- It was commonly accepted that changes would need to be made to enable patients to view their records in different ways once their information is stored on computer, for example, on screen, or in a print-out.

## 5 Views on whether people want to be informed about how their personal health information is stored and shared

Participants were divided on whether it was important to them to be kept informed about how their personal health information is stored and shared. Whilst most of those who commented argued in favour of having this information, a vocal minority felt that it was not a priority for them to be kept informed.

Those wishing to have information about how their personal health information is stored and shared provided several arguments to support their view. A common rationale was that the recent well-publicised breaches of security of personal information by the Government and others meant that people now needed to be made more aware of how their data was being handled. Some participants commented that although they themselves may at present have nothing which they considered sensitive on their health records, other people did, and they might be in this situation in the future. It was argued that data which might not be considered sensitive in one context, for example, in an urban area, might acquire a greater degree of sensitivity in a more rural location:

*“(knowing how my information is stored) doesn’t bother me so much in Edinburgh as I don’t know that many people...where I was brought up I know people I went to school with” (HIV-Aids)*

Others considered that people should be informed about the storage and sharing of their personal health information simply because they had a right to this (Urban) and they are entitled to know (Patient representative).

Participants were asked to identify what they wanted to know about the storage and sharing of their information. Their responses are summarised below:

- How secure is the information?  
*“As long as you know it is secure then that is all that matters” (Urban)*
- Who has access to the data?
- Reassurance that access is controlled and that rules are in place to prevent breaches of access
- Where is the data held?
- Who is inputting the data?
- How up-to-date is the information?
- What is on the records?
- Is every word from the GP notes entered, or is the information coded and categorised?
- What is the process for viewing your records?
- What is the procedure for requesting that information be added/removed?
- What happens to health information stored in private clinics –will this be transferred to the NHS record?



A minority of participants considered that they did not need to know how their health information was stored and shared. Young people expressed little interest in being informed about this. Others (within the urban group) felt that so long as they trusted that appropriate rules and protocols were in place to govern the storage and sharing of their data, this was enough for them. One comment from the rural group was that the precedent of having personal banking details already held on computer data largely successfully, meant that the storage and sharing of health information on electronic systems should be taken for granted, without the need to know further details about these systems.

### **5.1 Summary of key points**

- Views were divided on whether it is important to be kept informed about how personal health information is stored and shared.
- Some people wanted to know about storage and sharing because they had heard about previous breaches of data security. Some felt that people may have sensitive information on their health records which meant that knowledge of storing and sharing of these details was important to them.
- Participants identified information they wished to know about storage and sharing of information such as how securely the data would be held, who has access and where the data is held.
- Young people expressed the least amount of interest in knowing how their health information is stored and shared.

## 6 Views on whether people are content for some information storing to be done without explicit consent (stage 1 consent issues)

The example of the ECS was used in focus groups to stimulate discussion on views on appropriate types of consent for storing health information on computer. The model of “implied consent” used at the stage of storing information electronically onto the ECS was described by the moderator, with participants informed that they can opt out of having part of their GP record stored in this way, and if they do so, none of their information will leave their GP practice and any information already up-loaded onto the ECS system will be deleted. The system of storing test results was contrasted with that of the ECS, so that participants were clear that in the case of the electronic storing of their test results, they were not given the choice of opting out, so neither was explicit consent requested, nor could consent necessarily be implied to holding their information in this way. A third system of storage was outlined, that of the SCI-DC for diabetic record keeping, in which patients give explicit consent before their health information is stored.

Overall it appeared that, with few exceptions, participants were ignorant of these different models of consent. Indeed, most of the participants with diabetes had not even encountered the model of consent established for storing their details on the SCI-DC, with none of them recalling providing explicit consent for their details to be stored. Participants in the carers group argued that people needed to be made more aware of the different types of consent associated with different databases.

### **6.1 Views on the importance of being given the option to opt out of having personal health information stored electronically (outwith the GP surgery)**

Participants were asked whether, at the stage of storing their health information electronically (outwith the routine storage at the GP surgery) it mattered to them to be able to opt out of the system.

It was apparent in several groups that many participants saw both pros and cons to being given this option, with some people changing their mind on the issues during more detailed discussion. A common view was that whilst there were clear benefits to having everyone’s health details stored electronically, the right to opt out should be retained. Several participants commented that although they did not feel strongly about having the option to opt out, they could recognise that others may feel that this is very important. It was suggested that people in rural settings might feel more keenly that the opt-out option should remain, compared to people living in urban areas where they could remain relatively anonymous if they so chose. Interestingly, several participants in the rural group described how they had become used to others knowing their business, and considered that retention of the opt-out option was of more significance to patients with certain illnesses, e.g. those to which stigma was attached.

One recurring argument for retaining the option to opt out of having personal health information stored electronically was that this is a basic right which should be preserved. Typical comments were:

*“You should have the choice to opt out. Because that’s how life is. It’s your health, it’s your information, it should be up to you”* (Diabetic)

*“We are human and we have rights and if we don’t want it it shouldn’t be done”* (Patient representative)

Some people argued that the opt-out option should remain only if patients are better educated about the benefits of allowing their details to be stored electronically. It was recommended that the implications and potential consequences of opting-out should be explained, in order to minimise the number of people choosing not to have their details stored electronically.

Several participants emphasised their view that at the stage of storing patients’ data, a system of opting out was better than one of opting in, in order to ensure that consent could be implied in most cases. However, a small minority of participants (from the mental health and from the young people’s groups) recommended a system of explicit consent before information is held electronically, as being “safer” for patients. It was argued that some people had good reasons for not wanting their details to be stored electronically, with the potential this gave for wider viewing and sharing of their information.

Participants in the patient representative group argued for the retention of a partial opt-out option for requesting that specific aspects of health records be excluded from the computer system. Some members of the young people’s group agreed, with one stating:

*“It’s important to have the option to ask for details to be taken off. When I saw my records there was a lot of stuff which I really, really disagreed with and didn’t want on my records. There should be a way of taking stuff off your records”*

## **6.2 Views on the benefits of a system of implied consent for electronic storage of information unless a patient specifically opts out**

Participants were asked if they envisaged any benefits to a system in which it is assumed that patients are happy for their information to be stored electronically unless they specifically opt out.

Many people identified benefits to patients of such a system which was seen to be “to their advantage” (Diabetic) with the information readily available for NHS staff who are there to help you. One view was:

*“..if anyone opted out they would be a wee bit foolish I would think”*  
(Diabetic)

It was considered that a system of implied consent would speed up healthcare, making the storage of records more streamlined and comprehensive. One view from the young persons’ group was that trying to operate a system of explicit consent could waste the time of healthcare professionals. One comment was

*“...if you had to ask everyone if it was OK, and edit everything people wanted (on their records), well.....!”*

Another participant (Rural) remarked that as patients did not give consent for their information to be held on paper records, then it should be assumed that people are happy for their records to be stored electronically. A view from the carers group was that there should be no opt out at all in relation to the ECS which was very important to them in their caring role.

Other participants commented that the automatic storage of information electronically was particularly beneficial to doctors, was important in an emergency situation, and could be crucial for patients with complex, long-standing conditions. It was argued that instituting a system which made it easy for people to opt out might lead to difficulties for NHS staff to carry out their jobs.

Several people favoured a system of automatic electronic storage of data only if certain conditions were met:

- The data is held securely
- The data is not shared with anyone outwith the NHS
- Patients are given clear information on how to access and view their own records as an added check on its accuracy

Finally, carers argued that assuming patients are happy with electronic storage was important in the case of people who, due to their incapacity, may not understand the issues of consent, and the consequences of dissent, and if required to give explicit consent may refuse due to failing to understand the implications.

### **6.3 Views on the automatic electronic storage of test results**

Participants were informed that they could not have a test done without the result being sent to an electronic store held at their health board, and asked for their views on this.

People were split on whether the automatic electronic storage of test results was acceptable or not. Some found this “*extreme*” (Urban) or “*disgraceful*” (Patient representative), and many argued for the right to have tests undertaken but still be able to opt out of having the results electronically stored. It was envisaged that many people might not wish it to be known that they had even had the test, never mind let

people access to the test result. Young people raised the issue of having tests for sexually transmitted diseases in this context, and members of the HIV-Aids group agreed that tests and their results can be so sensitive that information should not be stored electronically unless explicit consent has been given by the patient. They suggested that automatic computerisation of test results might lead to some patients travelling outwith their health board to get tests done.

In contrast, some participants felt that automatic electronic storage of test results was important in the public interest. For example, some conditions might pose a public health risk, and others might endanger the health of NHS staff if they are unaware of them. One young person who held this view argued that:

*“That’s wrong if you don’t have test results on your record. You are putting doctors and dentists lives at risk and they could have kids and a family life and that, and you should let them know (test results of current conditions)”*

Members of the mental health focus group agreed that test results should be computerised automatically on condition that access to them was restricted only to those NHS staff who really needed to know about them. It was suggested that organisations outwith the NHS would be willing to pay for such information and it was vital that assurances were in place that wider access to test results stored automatically would not be allowed in the future.

The case of diabetics who would not be automatically recalled for regular retinopathy screening if they did not consent to their test results being stored on the SCI-DC was discussed in several of the focus groups. Most of those who commented identified significant benefits to diabetics of having test results and other details about their care stored on computer. The issue of being omitted from notification of retinopathy screening for those not giving consent for their details to be stored was not seen as a big problem. It was argued (by both diabetics and non-diabetics) that diabetics could just as readily make a note in their diary to arrange their next screening, without having to rely on being called up automatically.

#### **6.4 Summary of key points**

- It appeared that with few exceptions, participants were largely ignorant of the different models of consent to store health information (stage 1) in operation.
- None of the participants in the diabetes focus group had encountered the model of consent established for storing their details.
- Participants saw both pros and cons to the model of implied consent for storage of health information electronically.
- A common view was that whilst there were clear benefits to having everyone’s health details stored electronically, the right to opt out should be retained.
- A recurring argument for retaining the opt out option was that this is a basic right which should be preserved.

- It was argued that hand-in-hand with retaining the right for patients to opt out of having their information stored on computer should be education about the benefits of permitting their details to be stored electronically.
- Some participants recommended a partial opt-out system whereby they could specify that certain information on their health records (eg. sensitive data) could be excluded from being stored electronically.
- Having health information stored electronically was seen to benefit both patients and NHS staff.
- Computer-based data was seen as particularly advantageous to people with long standing and complex health conditions, and people with incapacity.
- People were split on whether the automatic electronic storage of test results was acceptable, with many arguing for the right to opt out of having test results stored in this way, but others regarding electronic storage of such results to have wider public benefits.
- Participants did not foresee difficulties for diabetics who opted out of having their medical information stored on the diabetic store, and would not therefore receive automatic appointments for retinopathy screening.

## 7 Views on models of consent appropriate for accessing and viewing information (stage 2 consent issues)

It was explained to participants that at present, any staff treating patients in out-of-hours or emergency situations need to have the patient's explicit agreement (consent) to allow them to view their health records on computer (unless in a life and death situation). Participants were asked whether it mattered to them who could view their health information on computer and whether they thought that NHS staff should have to ask them before viewing their information. Issues associated with stage 2 consent were probed further through the 2 vignettes, prompting discussion on challenges which might emerge over confidentiality and handling of sensitive data.

Overall, few clear cut and overriding views and recommendations could be drawn from the discussions, with opinions very much grounded in individual circumstances and perspectives.

### 7.1 Views on whether it matters who can view health information (outwith the GP surgery)

#### 7.1.1 Views on who should be permitted to view health information

For most participants, it was important that there were controls in place over who could view their health information. However, whilst it was expected that doctors and consultants should have access to electronic health data, there were differing views on extending access further than these NHS personnel.

There was considerable debate, (prompted in particular by the issues raised in the first vignette), over whether nurses should be able to view health information, with many participants suggesting that access should depend on seniority, with only those above a certain level being able to view data. Likewise, the vignette prompted discussion over pharmacists having access to electronic health records. On balance, participants appeared to be more accepting of a hospital pharmacist having access to their health records than a community pharmacist, although many people considered that restricting the latter's access to the ECS only might be permissible. Differences between groups emerged, with carers, for example, more agreeable to the broadening of access to patients' electronic records (*"as people need to see the full picture"*), in contrast to participants in the mental health and HIV-Aids groups who urged more caution over access. One participant with a mental health condition was typical of some of those who argued that access should not extend to the local chemist:

*"...as it's not just the chemist that's looking up your notes, it's the four lassies in the chemist that help put the tablets in the bottles"*

Participants in the patient representative group also urged that care be taken over permitting wider access to electronic records. They, along with people from the mental health group, argued that it was important that people viewing health

information had the capacity to interpret sensitive information, as labels attached to patients, and recorded in their records, could disadvantage them in their treatment if not interpreted and handled appropriately.

Some of the diabetic participants stated that they expected that emergency services would be able to view their ECS automatically. People in the urban and rural groups thought that IT staff would see everyone's health records during input to the databases. There was no agreement amongst participants (in the rural and patient representative groups where this was discussed) over whether next of kin should be able to view their health records, with opinion split between commentators.

Overall carers were most likely to find wider access to electronic health records acceptable, suggesting that in certain circumstances allied professionals such as social workers, support agencies and dieticians should also be able to view information. Vignette 2, based around a hypothetical case of a man with dementia having complex healthcare needs, prompted an appreciation of the benefits of health professionals being able to share electronic health information, and provided a focus for participants in their attempts to devise broad "rules" of access.

A common theme was that rules on levels of access should be established so that different NHS staff have access to different sections of electronic databases depending on their seniority. So, for example, nurses could view restricted data such as information on prescriptions, whereas doctors would be permitted to access a much wider information base. There was one suggestion (Patient representative) that patients should be able to identify particular data they wished to be stored in a designated "sensitive data" area of their record, with very restricted access permitted amongst NHS staff.

#### *7.1.2 Views on who should not be permitted to view health information*

The most common view to emerge across the groups was that health service receptionists should not be able to view anything more on health records than administrative details such as name, address and contact information. Other personnel recommended for exclusion from permission to view records were:

- Unsupervised health service trainees
- Employers
- Third parties such as drug companies who might want to sell you their products
- Insurers
- Members of the public
- Your partner
- Specific named people whom the patient could stipulate
- People who know you personally
- People outwith the NHS who have access to your CHI number

As with the case of pharmacists, there were differing views on professionals such as dieticians and physiotherapists having access to people's electronic health records



(ECS and other electronic data stores). On balance, participants appeared to support their having access in specific circumstances, where their need to view is justified on that occasion, and they have asked for explicit consent from the patient to view. One suggestion from members of the urban group was that such professionals should be given automatic rights to input data to parts of electronic records, and permission to view only these parts of patients' records. In general, participants were more inclined to favour widening access to professionals such as dieticians and physiotherapists in the case of the ECS rather than any fuller information database.

## **7.2 Views on NHS staff outwith the doctor's surgery having to ask for permission before they look up health records**

Some participants (notably in the HIV-Aids, urban and diabetic groups) reported that they would be reassured by a system in which their explicit consent was required before NHS staff could view their records. However, there was some scepticism that what seemed to be an acceptable system in theory might not operate as intended in practice. People in the mental health group remarked that even if a patient refused to give explicit consent, health professionals might override this and view their records in any case. Other sceptical comments included:

*"It sounds like a damned good idea but I don't think they will bother asking you – they will just look them up"* (Diabetic)

*"Reassuring – but how realistic is another matter"* (HIV-Aids)

There were a few cynical suggestions (amongst carers and some young people) that by withholding consent a patient might actually spark more interest in their records, leading to unscrupulous NHS staff viewing their records without consent.

Others described how they considered a system of explicit consent for viewing to be respectful and polite, particularly for older patients, who might also find that being asked for their permission to view their records would help them to understand and follow where they were up to in the healthcare process. One comment was:

*"Getting asked is pretty good, that's respect"* (Urban)

A conflicting view was that being asked for consent over the phone might be confusing for an older person in distress:

*"If you are elderly and it is 2 o'clock in the morning and you are in your 80s or 90s and you are phoning the NHS 24, you are not best pleased to be asked for consent first"* (Patient representative)

Some participants argued that it was important for a patient to retain the right to refuse consent as there might be circumstances in which they would not wish their records to be viewed. Patient representatives envisaged this situation arising where particularly sensitive health information was recorded on a patient's records. Young

people and diabetics thought that they might want to refuse access to view where they knew the member of NHS staff (urban participants thought that this situation might be more problematic in a rural area). Members of the HIV-Aids group wanted to be able to weigh up the pros and cons of permitting access at each episode of care:

*“It depends on whether the advantages to your health outweigh the disadvantages of their finding out we are HIV positive. If we were seriously ill – you wouldn’t give 2 hoots about them viewing. But if it’s a minor problem, in our situation, you might want to say no”*

In the case of information being *shared* rather than simply *viewed*, then a general view was that it was important to request the patient’s explicit consent first, particularly if the information might be shared with personnel outwith the NHS.

One diabetic suggested tightening the consent requirements further, and stipulating that even if a patient has given explicit consent, the potential viewer of the information should also need authorisation from another member of NHS staff prior to accessing electronic records.

Some participants considered that whilst it seemed appropriate to be asked for explicit consent at the first episode of care, repeated requests for consent during subsequent episodes of care for the bout of ill-health might be overkill. Participants in both the young people’s and the urban groups recommended some form of tick-box consent form administered say, on admission to hospital, which indicated a patient’s consent for viewing their records by authorised staff during the whole period of their stay. One comment was:

*“Instead of all these levels of bureaucracy and wasting time, just say right at the start, right tick the box to say I’m quite happy for anyone to look at my records” (Urban)*

However, one contrasting view was that the process of requesting consent by NHS members of the healthcare team protected staff from any subsequent accusations of unauthorised access should these arise.

A prevailing minority view across several groups was that the requirement to ask for explicit consent before NHS staff viewed patients’ records was pedantic and largely unnecessary. Following discussion in the urban group about the pros and cons of requesting such consent and the potential sensitivities associated with some patients’ records, one participant became exasperated:

*“Should we be bothered just for the small minority of people who may have something on their records which they don’t want some people to see? Once you satisfy one per cent, there will be another one per cent you have to satisfy - we are going to have more and more bureaucracy, and more and more data and ....who cares (about accessing health data)?? That is*

*what people are going to end up saying, 'who cares?' So 99% of people are happy, and 1% - I'm sorry but we'll try our best for you but we have to move on"*

Interestingly, such a view was mirrored by a few of the participants with HIV-Aids who appeared to have become resigned to their health needs overriding any concerns about potential stigma attached to the HIV-Aids label (although this view was not shared by all participants in this group).

Members of the carers group recommended that gaining explicit consent for viewing should not be a requirement in the case of patients with serious illnesses, and a view from the urban group was that seeking such consent might actually slow down access to necessary healthcare. Some participants within the rural group agreed that they would not want their care to be delayed whilst formalities over requesting their consent took place. Their comments included:

*"There's nothing worse than sitting waiting when they check things with you – the waiting game..."*

*"You're obviously there (in hospital) for a health reason, so it would be stupid wouldn't it for them not to check your records?"*

Others were concerned that delays in treatment could occur in the case of people with degrees of incapacity where proxy decision-makers would need to be identified, located and their agreement sought.

Several participants from across a variety of groups argued that for the purposes of viewing ECS information only, explicit consent should not be requested. As one participant commented, this contained *"just the basics"* and in their view should not require specific consent to view. A perspective from the carers group was in the case of the ECS, if a patient has not opted out of having their information stored in this way, then viewing of the ECS should also be implied:

*"It doesn't make sense – once I have given stage 1 consent, I assume that stage 2 consent is taken as read. I have said, I want you to have this information, I need you to have this information, I want you to help me, it is to my advantage. The consent should be to anyone in the NHS working on my case"*

When participants were asked whether their own GP should need to ask for their permission to access their health records on computer this was greeted largely with derision. Some argued that as doctors had always had direct access to paper records, why should the system be changed just because data was now stored on computer? One view (Diabetic) was that by making an appointment to see a GP, consent to view the patient's records should be implied from this.

### 7.3 Views on access to medical test results without requesting explicit consent

It was explained to participants that in the case of their medical test results stored electronically outwith their doctor's surgery, their own GP is allowed to access their own patients' data and hospital doctors can view the results of all of the patients in their health board area, on the basis that patients will agree to this. It was emphasised that GPs and hospital doctors do not need to ask patients for permission before viewing their test results, but will need a password before they can access these. Participants were asked for their views on this system.

Whilst some participants perceived the arrangements for viewing of their test results by their GP and hospital doctors to be acceptable, others queried whether their own GP should have what seemed to them to be an automatic right to view their test results. There was much debate in the urban group of the merits and drawbacks of this, with a prevailing view that this required the patient to place trust in their GP, particularly if a test result carried with it some degree of stigma:

*"They may think less of you but they will still give you the same level of treatment"*

However, a contrasting view was that situations could arise where a patient may not want their GP to know about a test result:

*"I can see the situation of a rural area, where someone has a test for HIV-Aids which is positive, and they are the teacher of your doctor's child....."*

Several participants challenged the assumption that only their GP within their doctor's practice would have sight of their test results. Questions were raised about whether other GPs in the practice, or those GPs "*just passing through*" would also have a password to access patients' test results, and whether practice managers and receptionists would be informed of the results even if they did not have direct viewing rights to the information on computer. One participant (Diabetic) remarked that the interpretation and application of any rules on viewing depended to a great extent on how an individual practice was being run, and commented on the tendency for the receptionists in her practice to inform patients of test results over the phone. Another expressed concern that assuming consent for GPs to *access* their test results could lead to assuming consent for GPs to *share* the results of these tests, for example with practice managers, which this participant did not find acceptable:

*"We should be asked (for explicit consent) as there are a lot of practice managers that go tittle, tattle, tittle, tattle, and I found in my own practice that 95% of the staff knew everything about everyone"* (Patient representative)

One participant (Carer) recommended that where passwords are used to view data, these should be changed frequently to help minimise risk of unauthorised access to information.

## 7.4 Summary of key points

### General points

- Few clear cut and overriding views and recommendations could be drawn from the discussions on stage 2 consent issues, with opinions very much grounded in individual circumstances and perspectives.
- Most participants considered it important that there are controls in place over who can view their health information.

### Views on who should/should not be permitted to view electronic health records (outwith the GP surgery)

- Whilst most people expected doctors and consultants to have access to their electronic health information, there were differing views on extending access beyond these NHS personnel.
- Many participants suggested that nurses over a certain seniority should be able to view their health information. Hospital pharmacists appeared to more acceptable as potential viewers of electronic health data than community pharmacists.
- Overall carers were the most agreeable to widening access to patients electronic health records, suggesting that even allied professionals such as social workers, support agencies and dieticians should be able to view information in certain circumstances.
- A common view was that health service receptionists should not be able to view anything more on health records than administrative contact details.
- On balance, participants appeared to support dieticians and physiotherapists having access to health records in specific circumstances, where their need is clearly justified and following explicit consent from the patient.

### Attitudes to consent

- Some participants reported feeling reassured by a system whereby their explicit consent was required before NHS staff could view their electronic records.
- It was argued that it was important for a patient to retain the right to refuse consent as there might be circumstances in which they would not want their records to be viewed.
- Where electronically held data is to be *shared* rather than simply *viewed*, a general view was that the patient's explicit consent should be given first.
- Some participants argued that giving explicit consent for NHS staff to view their records at the start of a period of treatment, such as a stay in hospital, should suffice for any episodes of care received during that period.
- A minority view was that the requirement to seek a patient's explicit consent before NHS staff viewed their records was pedantic and largely unnecessary.

- Concerns were raised that having to seek explicit consent (perhaps from a legal guardian or power of attorney) should not result in delayed treatment of patients.
- The notion of a GP having to seek consent to view their own patients' electronic health data was greeted largely with derision.

### **Views on the specific case of test results**

- Participants' views were mixed on the issue of automatic access to their test results by their GP.
- Reassurances and more information were requested by participants before they could come to any firm views on their GP's access to their test results.

## 8 Views on extending the content of and access to the Emergency Care Summary (ECS)

The ECS as an electronic database was described to participants by the moderator, and showcards deployed in each group to remind members what the ECS currently contained. The ECS was also used as an example to explain the concepts of implied consent for storing health information in a particular way, and explicit consent for viewing health data.

As reported previously, participants appeared to welcome this database as providing important information about their health at times of out-of-hours care and emergency situations. There were mixed views on whether NHS staff should always need to ask for explicit consent before viewing this summary information.

### 8.1 Views on extending the ECS

Participants were asked for their views on whether in the future they could see benefits to extending the information contained on the ECS and if so, what further content might be useful.

Views were split between those who considered the ECS fit for purpose at present, with additional information risking defeating the benefits of quick provision of summary data, and those who identified further data which they felt could maximise the potential of the database.

A common remark by those who did not see benefits in extending the ECS was, “*where do you draw the line?*”. It was considered that additions to the ECS would make it too long for those wanting patient information quickly. One participant summed up the views of many:

*“But where to you stop? This (adding more information) would just start to overwhelm the system for something that’s supposed to be quick. For an emergency it should just be this” (Diabetic)*

Participants in the young persons’ group argued that what seemed important additions to one person may be different to those priority additions for another, so that blanket recommendations on extending the ECS would be inappropriate. A view from the rural group was to caution that any additional information would increase the risks associated with storing data electronically. Others (rural and young people) commented that adding administrative data would require patients to be responsible for reporting any revisions and updates (whereas medical information would be updated automatically).

Those participants who did see benefits in additions to the ECS identified the following data as appropriate:

- Next of kin details
- Power of attorney details
- Spouse/partner
- Carers' contact details

*"My son is at a day care today but if anything happens I would like my name to be on the ECS. He won't be able to tell anyone (how to contact me)"* (Carer)

- Emergency contact
- Medications which are longer term but may not show up on the current ECS such as steroids which people take for 6 months on and 6 months off
- Inoculations (tetanus was mentioned most frequently)

*"I haven't a clue what I've had!"* (Rural)

- Epilepsy
- Diabetes
- Other long-standing health conditions such as heart disease or strokes
- Alzheimer's (as this could affect a patient's ability to give consent) (Rural)
- HIV-Aids (for the protection of NHS staff) (Diabetic)
- Date of last hospital visit
- Religious beliefs where these impact on potential healthcare
- The requirement for the person to have priority access to a psychiatrist if they express this need

A few participants highlighted information which they objected to being added to the ECS:

- STD results

*"STD tests can be very sensitive. They're not like a flu jag which could go on (the ECS) automatically. There are issues (connected with STD tests) which affect an individual's life"* (HIV-Aids)

- X-rays (these were considered not to be associated with emergency treatment) (Young people)
- Employers' details
- Bipolar label

*"Definitely not. If you're admitted to hospital with a broken leg, I have seen the reaction of some medical professionals to someone with bipolar. No matter what is physically wrong with them, they automatically make a judgement that this is a mad person. They are talking to you like you're a 2 year old"* (mental health)

Some participants claimed that the ECS had already been extended: one believed that her ECS already had details of her mental illness added; another argued that as the ECS contained a CHI number, this opened up the potential for adding data from other databases with CHI numbers, thus extending the overall database.



## **8.2 Views on whether the GP should ask for explicit consent prior to adding details to the ECS**

There was general agreement that whilst the current content of the ECS could be inputted on the basis of implied consent, it seemed appropriate to require a patient's *explicit consent* for any further details to be added. Participants recommended clarity on these 2 tiers of ECS information, so that patients knew precisely what would be stored on the ECS and kept up-to-date automatically, and what data would require their explicit permission, and possibly rely on them to keep the information up-to-date.

Several participants argued that it should be up to the patient to request the specific details they wished to be inputted to the second tier of their ECS information. Young people remarked that different people considered different aspects of their health to be important to disclose in an emergency situation and so individual preferences should be accommodated. Some carers suggested what they envisaged as a simple review process, whereby a GP could ask their patients every 6 months or so whether they were happy with the content of their ECS and whether they wanted any amendments to be made. However, others within this group argued that this would entail too much extra work for GPs.

## **8.3 Views on extending access to the ECS**

Participants' views on who should be able to access their electronic records have already been documented (see chapter 7). In general, participants were more inclined to favour widening access from doctors and consultants to allied professionals such as dieticians and physiotherapists in the case of the ECS rather than any fuller information database. Following considerable debate about the merits and drawbacks of including pharmacists amongst those permitted to view electronic records, many people considered that allowing their community pharmacist to view their ECS only might be beneficial in some circumstances, such as double-checking any allergies before providing them with prescriptions.

Views were canvassed on whether participants might feel differently if the ECS were to be extended to host additional health information. With few exceptions participants favoured more stringent access procedures in this event, with access restricted to those NHS staff who had a clear need to know about this information. For example, although some participants with HIV-Aids had supported having more information added to their ECS, they recommended that access to these details be carefully controlled:

*“You really don't need to tell every Tom, Dick or Harry that you are HIV positive”*

These participants also called for very firm sanctions, for example, sacking, for those breaching access protocol.

## **8.4 Summary of key points**

### **Views on extending the content of the ECS**

- Views were split on the merits of extending the ECS to include more information.
- A common view was that adding more information might defeat the purpose of access to summary details in an emergency situation.
- Those who favoured adding more information suggested the inclusion of administrative details such as next of kin, power of attorney, and carer contact details, in addition to medical information associated with long standing illnesses and conditions.
- Some participants opposed the inclusion of what they regarded as sensitive information such as STD tests, and mental health diagnoses.

### **Views on consent and controls required in the case of additions to the ECS**

- There was general agreement that whilst the current content of the ECS could be inputted on the basis of implied consent, it seemed appropriate to require a patient's explicit consent for any further details to be added.
- A 2-tier system of ECS information was recommended with tier one containing standard (current) ECS data but patients having a say in what information they wished to be added to tier 2.
- From chapter 7 it emerged that participants were more inclined to favour widening access to professionals (including for some, the community pharmacist) in the case of their ECS rather than any fuller information databases.
- Participants considered that in the event of the ECS being extended to contain more information, more stringent access procedures would need to be put in place.

## 9 Views on what concerns, if any, participants have about information being stored on national databases

The current arrangements for the storage of electronic health information, whether at the GP surgery, health board or at national level were outlined briefly to participants. They were then asked whether it made any difference to them whether their health information is stored at the place it was made, or if it is stored on a larger, regional or national store.

Some participants across several groups commented that security of information and access issues were more important than whether their information is stored locally or nationally. A few remarked that they liked the idea of the Scottish approach of establishing several databases held in different places to hold different sets of information, with a view to being able to link them as appropriate.

Most participants appeared to see both pros and cons to national databases:

### **Comments in favour of national databases** were:

- Patients move around the country and a national database would ensure that their details could be accessed wherever they may fall ill.
- A national database is relatively impersonal in that data inputters are not likely to know the patients associated with the data.
- National databases tend to be serviced more effectively than local databases.
- National databases tend to be taken more seriously than local databases.
- It is important for emergency data to be held nationally.

### **Comments against national databases** and in favour of locally held stores were:

- There is more chance of mistakes being made with national databases which may contain many people with the same name, and/or date of birth.
- The bigger and more remote a database the more risk of large-scale abuse and breaches.
- The bigger a database the more people are required to manage it, posing greater risks of breaches of security.
- There are recent examples of breaches of security associated with large databases.
- The smaller the database the less data will be lost if the system crashes.
- Patients have more trust in a database held at their local GP level.
- Once information is held nationally, this opens the floodgates for unauthorised sharing and possible selling of the data.
- Patients feel more in control of their data if held locally.
- Patients feel they can access their information more readily if held locally.
- Patients feel instinctively more comfortable with a locally held database.

- National databases are not accountable.

Participants views on where their data should be held did not appear to be determined by the group they were in, or their age, but by individual personality and trust in electronic systems of record-keeping.

### **9.1 Summary of key points**

- The approach in Scotland to storing data in several different electronic databases housed in different places was praised by some participants as being potentially more secure than hosting all data in one place on one database.
- Most participants saw both pros and cons to storing data on national databases, with views reflecting individual personality and experiences rather than age or type of patient group.
- National databases were viewed as beneficial for people becoming ill away from home, or for those who moved residences frequently.
- National databases were seen to be well serviced and taken seriously.
- Perceptions of the disadvantages of national databases focused largely around higher risks of security breaches and errors being made in inputting and accessing data.
- Participants felt instinctively more in control of their data when it is housed locally with perceptions that access to their details is easier than when data is held nationally.
- Participants felt more confident about local databases rather than national stores in terms of trust and accountability.

## 10 Reflections on participants' views

The research involved a wide range of participants of different ages with a variety of patient perspectives. However, with few exceptions, notably amongst participants with HIV-aids and those with mental health conditions, views tended to be based on individual experiences and beliefs rather than reflective of grouped patient types. This resulted in mixed views emerging from groups on most topics, rather than consistent, prevailing viewpoints.

It was clear that participants were largely ignorant of electronic health information systems and models of consent for storage and viewing of data. Even diabetics were, on the whole, unaware of the dedicated SCI-DC store and its associated consent model. Most people expressed their interest in knowing more about how their records are stored and accessed.

Despite this lack of awareness, participants generally accepted and indeed expected, that their health records would, over time, become computerised. Recent, widely publicised incidents of breaches of security of personal information held on computer clouded perspectives to some extent, increasing concerns amongst some participants about the security of their electronic health data. However, on balance, the advantages of storing health data on computer were seen as outweighing the drawbacks, with constructive suggestions made for minimising risks and maximising the benefits of electronic health databases.

The notion of a framework of separate databases, housing different sets of health information, hosted in different locations was attractive to many who saw this set-up as limiting the damage which might result from future breaches of security, or computer failure. Interestingly, many participants reported their gut feeling that locally stored data would be more secure than nationally held information, with the perception that they would have more control over access to local data, and would be better able to keep it up-to-date and accurate.

With few exceptions, participants were previously unaware of the ECS, but this particular database was viewed favourably in terms of being fit for purpose, giving speedy access to key patient data in out-of-hours and/or emergency situations. However, there was some resistance to the idea of extending its content and widening access to its database.

One issue which provoked much discussion in the groups was that of who should be permitted to view patient health records held electronically. Although it was generally expected that doctors and consultants should be able to view such data, no clear cut agreement on viewing rights of wider tiers of NHS personnel, and those on the fringes of the healthcare team (e.g. dieticians) was reached.

Although many participants felt that they, personally, were not too concerned about their own health information being stored and viewed by NHS staff without their consent, most acknowledged that this might not always be the case, and they

recommended retaining their right to opt out at stage 1 (input of data), and be asked for explicit consent at stage 2 (viewing of data). A minority of participants advocated a system of explicit consent for the input of their health information onto computer, but most were keen to avoid this, viewing it as creating an added burden for busy NHS staff.

One key cross-cutting theme was the need for patients to be better educated about ehealth. Participants wanted more information, for example, on electronic health databases, on models of consent, on how to access their own data once electronically held, and for the general public to understand the benefits of having their data stored on computer. It was of note that the ehealth information sheet (compiled by Consumer Focus Scotland) which was provided to participants at the end of each focus group was enthusiastically welcomed by most, with many people remarking that they intended to find out more about the subject.

### **10.1 Key conclusions**

- Overall, people's attitudes to electronic health record-keeping were individual, based on personal experience and beliefs rather than reflective of patient type.
- Participants' general ignorance of how their health information is stored electronically, and the models of consent in place, suggest that an education campaign is required in order to stem the development of misinformation and suspicion over ehealth developments.
- In particular, people need more information about the purposes and potential benefits to patients of new information systems such as the ECS in order to bring them onside and help to maximise the advantages of ehealth systems. For example, although most people had not heard of the ECS prior to their taking part in the research, the concept of a summary health record, for emergency purposes, was readily understood and broadly welcomed.
- Reassurances are also required over the security and confidentiality of health data held electronically, as these issues featured prominently in discussions as potential barriers to widening the information stored electronically, widening access to that information, and storing data in national (as opposed to local) databases.
- The research revealed that people are, in general, relatively cautious about professionals viewing and sharing their electronic health information. It was interesting that despite most participants acknowledging the benefits of electronic health records for their healthcare, and perceiving themselves as having "nothing to hide" and their information being relatively innocuous, they could not rule out a time in the future when they might feel differently. Being able to opt out of having their health data stored electronically, and being asked for explicit consent before their data is viewed and shared were seen as important and reassuring controls for patients to retain.

## Annex 1: Core focus group discussion schedule

### WELCOME

#### INTRODUCTION TO THE TOPIC

Each time someone like you visits the doctor or hospital or some form of NHS clinic, notes are taken about your health and these are then stored for future reference. At one time, all health records would be kept on paper in files, and to see your records a doctor would need to access this paper-based system.

Over recent years there has been a lot of work done to try to move from paper-based record keeping to electronic systems of keeping health records. You may have heard quite a bit in the press about early attempts in England and Wales to set up electronic health records with varying degrees of success.

In Scotland, the approach has been to develop electronic health records on a step by step basis. In different parts of the NHS, they store information in different ways. One of the things they have done is to create an electronic summary from people's health records which holds only:

- Name and address
- Date of birth
- Name of GP Surgery
- Identifying number called a CHI
- Information about prescriptions
- Any bad reactions to previous medications

*<Place showcards on table with these bullets listed>*

This summary record has a name which you might have heard of:

The Emergency Care Summary

The main aim of this is to provide summary information about your health which might be important if you need urgent care, say when your GP surgery is closed, or if you have to go to the Accident and Emergency department at hospital.

So across Scotland almost everyone now has one of these summaries which stores their basic health information electronically. Emergency Care Summaries come from your GPs computer system, and twice every day they are copied automatically to a national electronic store ready for access by others if needed.

There are also other electronic databases in existence, such as an electronic store of health test results within each health board, and a national database of health information about people with diabetes.

For paper-based record keeping there have been agreed principles and rules about how personal information should be stored and shared within the NHS. However, for these more recent developments in electronic record keeping the way in which information has been stored and shared varies more across the NHS in Scotland.

People working in the NHS want clearer rules on the way in which they are allowed to handle personal health information which is kept electronically. For example:

- who has permission to look at the information
- how they are given that permission
- and how the information can be kept secure

and they want these rules to be acceptable to their patients.

So what is being debated at the moment are what rules there should be for who can look at your records, in what circumstances, and what sort of agreement or permission is needed (if any) for this..

You can see that the use of computers to store and share personal health information raises a lot of issues about keeping personal information safe and confidential and I have been asked to explore the attitudes of the public to these issues. To do this I am conducting 8 focus groups for my client, Consumer Focus Scotland, to find out people's views. I'm going to pose key questions and topics which I'd like your views on and then if you feel you still have things you want to comment on, you'll get a chance to air these.

Any questions so far?

## **AWARENESS OF, AND GENERAL VIEWS ON, CURRENT ARRANGEMENTS FOR STORING AND VIEWING HEALTH INFORMATION**

1. Were you aware of how your health records were stored before you came here today? Where did you get this information from? Has anything I have explained come as a surprise?
2. I've been outlining so far how your health records are currently **stored**. First of all does it matter to you to know how your details are stored?
  - Why/Why not?
  - Would others think differently? Why?
3. How much information do you need/want to know about how your records are stored?
4. Does it make any difference to you whether your health information is stored at the place it was made, or if it is stored in a large national information store (on a computer)?



5. Does it matter to you to know who can view your health information? Why? Why not?

## **COMPARING PAPER-BASED AND ELECTRONIC RECORD KEEPING**

Most doctors and others in the NHS now store information about you on computer rather than on paper. Except in special circumstances, you won't be told about this, because this is just another way of doing something which doctors must do anyway – ie keep up to date information about your health and healthcare.

6. If you think about the 2 ways of keeping health records: on paper in files, or on computer electronically, what would you see as:

- The advantages and opportunities which electronic record keeping could bring?
- Do you think that there are any disadvantages and/or threats associated with keeping electronic health records? Explain.

## **STAGE 1 CONSENT ISSUES (regarding storing your information electronically)**

One benefit of keeping records on computer is that NHS staff who work outwith your own doctor's surgery can view parts of your health record. In fact the Emergency Care Summary which I described before has developed so that when your doctor's surgery is closed, if you need out of hours treatment or you need to go to A&E, electronic information is at hand for NHS staff to see what medicines you are taking, and to see if you have any allergies to particular medicines.

In the case of the Emergency Care Summary, the NHS tried to let people know that they are storing their health information in this way and they sent a leaflet out to people's homes explaining this. They also informed people that they had the right to opt out of this system in which their summary health information is stored on computer.

In contrast to that, in the case of storing people's medical test results (like blood tests, urine tests, pregnancy tests, HIV tests and so on) on a database in each health board, the NHS approach so far has been to assume people will be happy to have their test results stored on a database – so people aren't given the option of opting out.

7. Does it matter to you whether or not you are given the option to opt out of having your health information stored electronically outwith your own doctor's surgery?

- In what circumstances does it/does it not matter? *<e.g. depending on type of information; what the system is linked to; what will happen to the data next, etc>*

8. Are there benefits to a system in which it is assumed that you are happy for your health information to be stored electronically ready for viewing by staff in the NHS, unless you specifically opt out?

9. Do you foresee any drawbacks to this approach?

10. If you were told that you couldn't have a test done without your result being sent to an electronic store, what would you feel about that?

*<If not happy – is there anything that would make a difference to your view? For example, if only certain people had access to patients' test results with others denied access?>*

## **STAGE 2 CONSENT ISSUES (regarding viewing your information)**

I explained before that the ECS is intended for out of hours and emergency situations. So if you need to attend an out of hours medical centre when your GP surgery is closed, or if you suddenly need to go to A&E and receive emergency treatment, important details about you can be viewed readily by the healthcare staff who treat you. Although your details were stored electronically on the basis that unless you stated otherwise, you agreed to this, the situation changes when NHS staff need to actually view your Electronic Care Summary. Any staff who treat you in an out of hours or emergency situation **need to have your agreement** before they are allowed to look at your health records on computer (this is unless you are at serious risk of harm or death in which they will access your details without your consent). This means they must ask you before they look at your records and they will not view your details unless you give them permission to do so.

11. What do you think of the idea that NHS staff outwith your own doctor's surgery should have to ask you before they look up your health record?

- Might it matter in some situations more than others?
- Is it reassuring that your permission is usually required?
- Do you think that it is unnecessary (or impossible) in some circumstances? Which ones?

12. Do you think that your own doctor should need your permission before accessing your health information on computer? Explain.

13. In the case of medical test results which are already stored electronically outwith your own doctor's surgery, your own doctor is allowed by law to access to their own patients' data, and hospital doctors can view the results of all the patients in their health board area, on the basis that the patient will agree. In other words, without asking for your permission first, so long as they have a password and need to look at your results in order to treat you appropriately.

- What do you think about your own GP being able to view your test results on computer without needing to ask for your permission first?

- What do you think about hospital doctors being able to view your test results on computer without needing to ask for your permission first?
- Might this matter in some situations more than others?

## VIGNETTE ONE

We've started to talk about when you are specifically asked to give your permission for your health information to be stored electronically and viewed, and when your permission is assumed, and also the potential benefits and drawbacks which electronic health record keeping might bring. To help you to think about these issues in more depth I'm going to ask you to do a little bit of role playing and imagine yourself in a specific situation which I'm going to describe. I want you to think about how you would feel and how you might respond in this situation. Remember, everyone has their own views and yours may be very different from others in this group but equally valid.

You have been very stressed recently. You've been over-working, trying to impress at work because of threats of redundancy. One Sunday evening you feel unwell at home, become dizzy and fall whilst on the stairs. Your partner calls NHS24 who send an ambulance. Whilst you are waiting for the ambulance, the NHS24 representative asks for your permission for staff to look at your emergency care summary ready for the healthcare team in hospital.

- ❖ Do you give your permission for the healthcare team to look up your emergency care summary? Why? Why not? Benefits/any drawbacks? Do you think it should be necessary to ask for your permission to look at your record?

The staff treating you in hospital want to keep you in for a few days whilst tests are done to investigate the cause of your dizziness. You have also hurt your ankle in your fall and the hospital pharmacist wants to prescribe a painkiller for you. Before doing this she needs to check your Emergency Care Summary to find out if you have any allergies to particular painkillers.

- ❖ The hospital pharmacist has now become part of your healthcare team. Are you content for her to access your emergency care summary?
- ❖ Do you think you should be asked for your permission before she views your records or should this be assumed if you have already agreed to staff looking at your records when you were admitted?
- ❖ Are there situations/circumstances when this might matter more than other times?

At your first meeting with the pharmacist you find out that you know her – she is the wife of one of your managers at your work.

- ❖ Does this affect in any way how you feel about giving your permission for her to view your emergency care summary? In what way? Do you think a

pharmacist should have the same degree of access to your computerised health records as another member of your healthcare team? Where do you draw the line? What makes a difference?

There is one aspect of your healthcare which you have so far kept within the family for several years. You are recovering from a drug addiction and you have a longstanding methadone prescription which will be recorded in your summary.

- ❖ Does this alter the views you have already expressed about giving your permission for the healthcare team which now includes the pharmacist to view your records? In what way? Explain.

## **EXTENDING THE EMERGENCY CARE SUMMARY**

So far we have talked about the ECS which is already in use in Scotland.

*<Remind participants of what it contains using showcard.>*

On balance most of you are happy for this to be used by healthcare staff under certain conditions *<this will probably be the case>*.

14. What do you feel about the idea of extending this summary to include more details from your health records, for example, including any long term conditions you have, your previous illnesses, any x-rays and photos, previous referral letters?

- What sort of health information do you think could add benefit to the summary?
- Are there certain details which you think that you or others may not wish to be included in the summary? Why? Where do you draw the line? Does it concern you at all about what health information is held electronically?
- *<If appropriate...>* How could a future electronic system deal with the issues you raise, e.g. the inclusion of some your details and not others? How would it operate?
- If more information was added to your ECS would you want your doctor to ask your permission each time details were added?
- Would you wish to be asked in some circumstances but not others? Explain.

## **EXTENDING ACCESS TO YOUR EMERGENCY CARE SUMMARY**

15. At present, the only NHS staff members who can look at your ECS are people working in out of hours centres, at NHS 24 or in A&E departments. Would you mind if other people were able to look at it? For example, would you be happy for your local pharmacist to look at it to check that there were no problems with your prescriptions?

16. Would it make a difference if more information was added to your ECS – would you only want certain people to be able to see this information?

## TEST RESULTS

We have already talked a little bit about how medical test results such as blood or urine tests are stored electronically and viewed. At present test results are kept on an electronic store in each health board area. GPs can look at the results for their own patients. NHS staff working in hospitals can look at any results in the store, although their professional rules about confidentiality say that they should only look at information they need to see to care for a patient properly.

- Who would you expect to have access to patients' test results?
- Who would you expect to be denied access?

It may be possible in the future to have a national store for all test results rather than hold them on local health board stores.

17. Would it make a difference if results were stored in a national store rather than a health board store?

- What do you see as the benefits? To you? To healthcare staff? To the system as a whole? To the Scottish population?
- Do you foresee any challenges? Any drawbacks?

## VIGNETTE TWO

To think about this in more depth I want you to imagine the following scenario and provide your views on the issues raised:

A 56 year old man is admitted into A&E with a suspected heart attack. He has recently moved into the health board area to be nearer to his family as he is in the early stages of dementia and suffers intermittent memory loss. On the way to hospital he is given morphine and aspirin and in hospital he is subjected to a series of blood tests, an ECG, given pain relief and beta-blockers.

- ❖ In this situation, what do you see as the potential role of a system of electronic health records? (*Not just ECS here*)
- ❖ What are the advantages to the NHS healthcare team?
- ❖ What are the advantages to the patient and his family?
- ❖ Are there any barriers/challenges which electronic records might present in a situation like this?

The man is kept in hospital for a few days during which his regular drugs are changed and more blood tests are taken. However, he is clearly confused about his treatment and is then discharged into the care of a close family member. A follow up appointment with his doctor is made to discuss after care.

- ❖ Do you foresee advantages to having electronic health record keeping in this scenario – for the GP? For the patient? For his family?
- ❖ Any barriers/challenges?

The man's test results are added to the test result database where his previous test results are stored, including those for sexually transmitted diseases which none of his family, nor his new doctor know about.

- ❖ Does this affect the views you have just given on the advantages and challenges which electronic health records generate?

The doctor refers the patient to a dietician and an exercise specialist.

- ❖ Would you expect either/both of these professionals to have access to the patient's electronic health records?
- ❖ What benefits might this bring?
- ❖ What disadvantages might this bring?
- ❖ What sort of rules should be put in place regarding their access to these health records?

## **LONG TERM CONDITIONS**

This scenario provides an example of someone with a long term health condition who requires healthcare delivered by a broad range of healthcare professionals. Many people have long term health conditions such as diabetes, heart disease or MS which requires ongoing healthcare treatment and tests. As people get older they are more likely to have complex health needs, and may be taking medication for various different conditions. You may have such a condition yourself, or you may know of someone close to you who requires regular or ongoing treatment.

18. Do you think that someone in this position may hold different views to others on the issue of electronic health record keeping? For example on:

- The benefits of electronic health record keeping?
- The drawbacks?
- Who is allowed access to their records?
- Whether they must give permission for their records to be accessed?
- Holding their test results on a national rather than local database?
- For how long health records are kept before being removed from the electronic database?

## **ANY OTHER COMMENTS?**

19. Are there any comments you wish to make, or any issues which we haven't covered which you feel are relevant?