Health on-line:

public attitudes to data sharing in the NHS

Scottish Consumer Council
Making all consumers matter

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The Scottish Consumer Council (SCC) was set up by government in 1975. Our purpose is to promote the interests of consumers in Scotland, with particular regard to those people who experience disadvantage in society. While producers of goods and services are usually well-organised and articulate when protecting their own interests, individual consumers very often are not. The people whose interests we represent are consumers of all kinds: they may be patients, tenants, parents, solicitors' clients, public transport users, or simply shoppers in a supermarket.

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- carrying out research into consumer issues and concerns;
- informing key policy and decision-makers about consumer concerns and issues;
- influencing key policy and decision-making processes;
- informing and raising awareness among consumers.

The SCC is part of the National Consumer Council (NCC) and is sponsored by the Department of Trade and Industry. The SCC's Chairman and Council members are appointed by the Secretary of State for Trade and Industry in consultation with the First Minister. Martyn Evans, the SCC's Director, leads the staff team.

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CHOICE
Can consumers affect the way the goods and services are provided through their own choice?

INFORMATION
Do consumers have the information they need, presented in the way they want, to make informed choices?

REDRESS
If something goes wrong, can it be put right?

SAFETY
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FAIRNESS
Are consumers subject to arbitrary discrimination for reasons unconnected with their characteristics as consumers?

REPRESENTATION
If consumers cannot affect what is provided through their own choices, are there other effective means for their views to be represented?

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Published by the Scottish Consumer Council
October 2005

ISBN 0-9549004-6-4

Chairman's preface

Technological change has huge potential for the NHS. Making better use of information technology can transform the way services are provided, creating more efficient processes, and allowing care to be quicker, safer and more cost effective. One aspect of this is the way in which our personal health information is stored and shared. The recent Kerr report described the single electronic health record as 'the single most important development in information and communications technology' supporting new methods of health care delivery.

The idea of sensitive personal information being stored on computers is scary for many of us. How can we be sure people won't hack into the system and take advantage of what they find there? Most of us have little idea who is allowed to see our personal health information, and many people have real fears about other agencies, like the Department of Work and Pensions, having access to this information. Even worse, we may be concerned that commercial companies, including insurance companies, could exploit the information contained in central NHS registers. If information is stored centrally for the whole of Scotland, it would only take one corrupt NHS employee to pass on sensitive information to whoever he chose.

We carried out this research to find out more about what people in Scotland think about personal health information being stored on computer, and shared within the NHS. We focused on one particular development, the introduction of an Emergency Care Summary for patients in Scotland, which aims to make medical care in out-of-hours centres quicker and safer.

Our findings broadly support what other research has found: that people do not know very much about how their personal information is stored and shared; that they support the increasing use of computers; and recognise the benefits that this can bring. However, they do have concerns about security and confidentiality, and they would like to know more about what is happening and what is planned. This is, perhaps, the main message coming out of this research: that the NHS in Scotland needs to pay greater attention to informing and involving members of the public in the move toward a single electronic health record in Scotland, in order to increase public confidence, and inform people effectively about their rights in this area.

Graeme S Millar

Graeme Millar
CHAIRMAN

Acknowledgements

We would like to thank all the focus group participants who gave up their time to take part in discussions with us. Prestige Partnership recruited six focus groups with members of the public in Cults, Dunfermline, Edinburgh, Eyemouth, Falkirk and Glasgow. Thanks to Lanarkshire Links and the Waverley Trust for their support, and for recruiting people to two groups held in Edinburgh and Motherwell. Thanks to Kirsty McLeod, Scottish Executive Health Department, and other members of the Emergency Care Summaries Project Board, for advice on the topic guide.

All the focus group discussions were facilitated by Anna Ritchie, Researcher at the SCC, with support from Liz Macdonald, Policy Manager.

The SCC's Health and Social Care Committee oversaw the research. Members of the committee are John Hanlon (chair), Liz Breckenridge, Isabelle Low, Mukami McCrum, Helen Tyrrell, Graeme Millar (ex officio), Martyn Evans (ex officio) and Heather Brash (ex officio).

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1 Introduction and methods

1.1 Background

We live in an age in which personal information is increasingly collected and stored on computers. This makes it possible to share it with those who need to have access to it more easily than can be done with paper-based records systems. It also raises the possibility of information being used in ways which would not have been foreseen by the person whose information it is, and for purposes which are not necessarily related to the reasons for which the information was originally provided. Aggregated personal information can also be valuable for those planning and designing services, and for monitoring services.

However, the ability to make full use of information depends on people accepting that their personal information can be stored and used in these ways. The Scottish Consumer Council was concerned that some of the developments in this area in the NHS were being driven by technical possibilities and service needs, without fully involving patients and members of the public, whose information it is.

1.2 Aims and methods

This research report aims to explore public attitudes in Scotland towards sharing personal health information in the NHS through electronic means. It draws on the existing literature on the subject, and on the results of eight focus group discussions held in May 2005. Six of these groups were held with members of the public throughout Scotland. Two were with groups who were believed likely to have particular concerns about privacy: people living with HIV/AIDS and people using mental health services. The discussion in the focus groups concentrated on one particular development currently being introduced by the NHS in Scotland: the use of an Emergency Care Summary for patients, which is stored on computer and can be accessed by medical staff in an out-of-hours centre.

We specified that members of the groups:

- should have been in contact with the NHS within the previous six months;
- should include some with caring responsibilities; and
- should include some with a chronic condition which required a regular doctor or hospital appointment at least once every six months.

	Location	Age	Socio-economic group	Gender	Parents	
Group 1	Glasgow	20-40	Mixed	Mixed	No	
Group 2	Falkirk	Retired	C2D	Mixed	Mixed	
Group 3	Edinburgh	20-40	ABC1	Women	Yes	
Group 4	Dunfermline	45-65	Mixed	Mixed	Mixed	
Group 5	Cults	20-40	C2D	Mixed	Yes	
Group 6	Eyemouth	45-65	Mixed	Mixed	Mixed	
Group 7	Motherwell	Mixed	Mixed	Women	Mixed	Mental health Problems
Group 8	Edinburgh	Mixed	Mixed	Mixed	Mixed	Living with HIV/AIDS

The research explored:

- the attitudes of the public towards the sharing of patient information electronically in a particular context, ie between GPs and out-of-hours services through the Emergency Care Summary;
- the attitudes of the public to wider sharing of information, for example with accident and emergency departments, with the ambulance service, with providers of secondary care (hospitals or clinics), or with other agencies;
- how much information should be contained in the Emergency Care Summary, for example in relation to past medical history;
- who should have access to information held electronically;
- how and when patients would like to give consent to being included in these developments; and
- how patients would like to be informed and what they would like to know.

2 Policy context

Both the UK government and the Scottish Executive recognise the importance of data sharing in the context of improving public services, but also the need for public trust in the way personal information is shared and protected.

In April 2002 the Cabinet Office's Performance and Innovation Unit (PIU) produced a report *Privacy and Data Sharing: the way forward for public services*. The report put forward a five-point strategy for more effective data sharing, and the Lord Chancellor's Department (now the Department of Constitutional Affairs) was given responsibility for taking the work forward. It recommended that the move towards making more effective use of personal data would need to be accompanied by building public trust in the ways in which people's personal information was protected. It recommended that all public sector organisations should comply with a Public Services Trust Charter, which set out their key commitments.

2.1 Scottish Executive

The Scottish Executive is committed to promoting better, joined-up and customer-focused services in the public sector. The ministerial publication *Working Together for Scotland* includes a commitment to join up government across the public sector. In July 2004, the Scottish Executive produced legal guidance for the public sector on data sharing (Scottish Executive, 2004). In the ministerial foreword to this guidance, the Minister states:

> *Scottish public sector bodies recognise that their ability to deliver high quality services and target policies to meet people's needs depends on effective use of information - including personal data about their customers. This needs to be done within the law and with respect for individuals' rights to privacy and confidentiality. …We acknowledge the need for more effective data sharing across the public sector, not as an end in itself, but as a way of improving services.*

Under the general banner of Open Scotland, the Scottish Executive has a range of programmes and activities funded by the 21st Century Government Unit. These include work on and support for data sharing, the development of eGovernment, and electronic service delivery.

Various projects have been funded which make use of information and communications technology in innovative ways. These include the eCare programme which aims to improve the experience of the client/patient through electronic sharing of information and joint service provision between health and social care agencies. This work has been piloted in four health board areas in Scotland.

2.2 Local authorities

Customer First, a strategic framework for the Scottish Executive and Scottish local authorities, was published in November 2004. It sets out a common framework to support local authorities in their plans to deliver 'consistent and measurable improvements' in local customer services. It also sets out how local authorities can contribute to a national secure data-sharing infrastructure (Scottish Executive, 2004), and proposes the idea of a citizen's account – a single electronic record for each customer, which provides a transaction history, and a means of secure data sharing across service delivery partners.

2.3 NHS

The final report of the Treasury Review Team led by Derek Wanless (Wanless, 2002) entitled *Securing our future health: taking a long term view* projected a doubling of spending on information and communication technology (ICT) in the NHS, and reinforced the importance of ICT applied directly in support of care professionals:

> *Without a major advance in the effective use of ICT (and this is a clear risk given the scale of such an undertaking), the health service will find it increasingly difficult to deliver the efficient, high quality service which the public will demand. This is a major priority which will have a crucial impact on the health service over future years. (Para 6.22)*

Following publication of the report, the National Programme for IT in the NHS (NPfIT) in England and Wales was launched. This has recently been renamed Connecting for Health.

There is a commitment in the NHS in Scotland to make best use of developments in information technology to provide better care for patients. Partnership for Care (Scottish Executive, 2003) states:

> *Our goal is to deliver an Integrated Care Record jointly managed by patients and professional NHS staff with in-built security of access governed by patient consent.*

Section 4 of *Our National Health: A plan for action, a plan for change* set out one of the core aims of the health plan - to improve the patient's journey. It recognised that information and communication technology had the potential to transform the patient's experience and concluded:

> *We want to see integrated patient records in GP practices and health centres, electronic transmission of prescriptions between GPs and pharmacists, all primary care staff connected to NHSnet, and electronic clinical communications (ECCI) to support booking of in-patient appointments from the GP surgery, faster test results, protocol-based referrals and timely discharge information. (NHS Scotland, 2000)*

Ultimately, the vision is for a single electronic record which can be accessed from NHS facilities in any part of the country when that is needed for patient care. This would mean that health care professionals had access to current information about factors which have a significant bearing on safe and effective health care, such as any allergies a patient has, and what medication they are taking, as well as other details about their care and treatment in different parts of the NHS. Records would be more accessible, and would be stored together, rather than, as now, in different locations.

These moves are supported by the Kerr report *Building a health service fit for the future,* published in May 2005. This report describes the present situation in the NHS in Scotland as being very far from ideal, with a high proportion of its business not being conducted on computer. The level of investment in IT in the NHS lags considerably behind other sectors. The report calls for a dramatic acceleration in information technology provision in health care, with an electronic health record system in place within three years. With this in place a range of benefits can be introduced, such as electronic prescribing, and electronic booking of appointments. Kerr argues that an electronic health record is essential:

> *The electronic health record is at the heart of the information requirements. It is central to NHS reform and will transform the way health and social care information is managed. It must give health and care professionals access to patient information where and when it is needed. It must meet the needs of patients and give them access to their own private health records.*

The advantages are seen to be improving access, quality, research, and integration of the NHS and NHS care. Personal health information is not only relevant to a patient's own care, but is very useful in aggregate form to guide the planning and design of services, to inform audit and monitoring of services, and to contribute to the understanding of patterns of health and in research into the effectiveness of treatments. However, these additional uses of personal information all need the consent of patients under the Data Protection Act.

3 Data sharing in practice

3.1 Developments in Scotland

The technical possibilities for the greater use and sharing of information electronically are increasing rapidly, and various initiatives are taking place within the NHS in Scotland. This work is now being taken forward under the broad umbrella of the National eHealth IM&T Strategy. In relation to sharing personal health information electronically, the following areas are currently being developed:

- Lab results are being transferred electronically to a central store (known as SCI store) where they can be accessed by those who need to do so, for example, GPs or hospital doctors.
- Clinical letters between GPs and consultants, including referral and discharge letters, are being communicated electronically and held in SCI store.
- The use of an Emergency Care Summary (ECS) has been piloted in two board areas, with a view to rolling it out across Scotland during 2005 and early 2006. The Emergency Care Summary will form part of the proposed single electronic health record.
- Booking of Outpatient appointments electronically
- Sharing information when patients' conditions are being managed in both primary care and secondary care sectors - for example for patients with diabetes.

The benefits are seen to be:

- releasing clinicians and administrative staff from the burden of paper information systems;
- enabling staff to spend more time directly addressing patient needs;
- patients getting results more quickly;
- less chance of information being lost;
- safer care when more staff have access to life-saving information;
- patients don't have to tell their 'story' several times;
- greater confidentiality and security of patient information is possible;
- an audit trail of who has looked at patient information can be kept.

Consumer or public input

There has been a lack of any significant input from members of the public, and those who use services, into the developments and pilot work already going on in relation to electronic information sharing. This contrasts with the approach taken, for example, in Australia, where the Consumers' Health Forum has led an extensive programme of work with consumer health organisations in parallel with developments in the health service. The success of these developments is likely to be greater if there is a strong sense of partnership between service providers and consumers.

3.2 Developments in England

The development of the NHS National Programme for IT (NPfIT) has experienced some problems and delays since it was launched in 2002. The NHS Care Records service is aiming to put 50 million records on a digital database, allowing information to be shared safely across the NHS (Cross, 2005). The Department of Health has produced a 'care record guarantee' which makes 12 commitments to patients about their electronic records. These include giving patients the right to stop any clinical data being seen by anyone outside the organisation in which it was created. Access to records by NHS staff will be strictly limited to those having a 'need to know', in order to provide effective treatment to a patient. In the future, patients will be able to block off parts of their record to stop it being shared with anyone in the NHS, except in an emergency.

There is, however, some evidence that GP support for these new systems is falling rather than increasing. Some clinicians argue that the nature of a consultation on a medical matter is not susceptible to being recorded succinctly in electronic format (Walsh, 2004). Data entry is also a barrier to the acceptance of new systems by doctors. If structured code has to be used, this does not necessarily sit comfortably with traditional ways of recording consultations in free text.

Bend (2004) has argued that despite the clear potential benefits of improving use of ICT, evidence of a positive impact in practice is still quite scarce. He assessed this impact in terms of 'public value', a concept comprising better value for money, greater satisfaction with services, improved health outcomes or greater trust in the NHS. Bend also highlights the potential for a backlash from the public if they are not kept fully involved in the process of developing the use of ICT in the NHS, particularly in relation to security and confidentiality. This view is echoed in NCC's book *The Glass Consumer.* (Lace, 2005)

Electronic health record

In England the NHS care record will consist of a basic health record, known as the 'spine record' for every patient. It will contain essential information, enable appointments to be booked by computer, and ensure that prescriptions, test results, scans and x-rays can be shared electronically. In England they have used the concept of a 'sealed envelope' for storing information which a patient wants to be kept confidential. Research by Health Which shows that patients want to be informed and involved in these developments, and to be reassured about the security of any new systems. Patients supported the improved communication which should follow, and welcomed the potential for them to be more involved in what was in their records. Key issues for patients are who would have access to their information and how the information would be kept secure.

A huge amount of work has been carried out in England in relation to the electronic record, through the Electronic Record Development and Implementation Programme. This has included a lot of work on patient attitudes and experience. (NHS IA, April 2003)

One of the early trials of electronic health records in England showed that a significant number of errors do occur (Singleton, 2005). It also appears that in England the development of the electronic record is going forward even though the 'sealed envelope' has not yet been developed.

3.3 Safeguards

The Data Protection Act 1998 gives people rights and provides them with protection from the use (processing) of their information without their consent. The Act is based on eight data protection principles which define the duties of people who collect and provide personal data. The Better Regulation Task Force recently reviewed the law on data protection on a EU-wide basis. It argued that there were some difficulties with the legislation as it was not clear how the Act should apply to the current realities of data management. There is also evidence that the European directive on which the Act is based has been interpreted differently in different EU states so that there is not necessarily a 'level playing field'. The third area of concern raised is that because of the complicated nature of the legislation it is hard for smaller companies to comply with the legislation, and it is likely that many such companies do not register with the data protection authorities. (Better Regulation Task Force, 2004)

The Human Rights Act and the European Convention on Human Rights give members of the public certain rights, including the right to respect for private and family life (Article 8). This right can only be interfered with in specific circumstances, such as to prevent crime, or to protect the rights and freedom of others.

In addition to these statutory rights, there is a duty of confidentiality in common law, covering, for instance, confidentiality between a doctor and patient. These common law duties are often spelled out in greater detail in professional codes of conduct.

In April 2003 the Department of Constitutional Affairs recommended the publication of standards which the public sector would adhere to when collecting, holding, using or deleting personal information in April 2003. As a result they have published a public service guarantee, which is described as a straightforward document that lets people know about the standards they can expect from organisations that request or hold their personal information, and what they can do if they do not think these standards are being met.[1] The guarantee seeks to educate and empower citizens by providing a clear statement of their rights. The Department produced a toolkit on data sharing in May 2004 aimed at service providers, containing legal guidance and examples of practice.

Privacy enhancing technologies (PETs) can help to ensure that personal data is handled legally and securely and that privacy is respected. Some forms of PET can empower consumers and build trust by allowing them to access their own data. (NCC, 2005)

The role of the Office of the Information Commissioner is central to the process of developing respect for individual information. The NCC argues that 'a governance of privacy' has yet to take shape, whether domestically or globally. (NCC, 2005)

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[1] http://www.dca.gov.uk/foi/sharing/psguarantees/data.htm

4 Literature review – public attitudes to data sharing

4.1 Public views on data sharing in general

Research throughout the UK in 2003 showed low levels of public awareness of how personal information was used, coupled with a desire to know more about this – 64% wanted to know more. There were fairly high levels of concern about information sharing (60%), mainly focusing on the lack of control people felt. Almost three quarters (74%) didn't know how to find out what personal information was held about them; 68% didn't know how to make a complaint; and 53% didn't know what their rights were regarding their personal information.

At the same time, when presented with particular scenarios, 45-50% said they would not be at all concerned about data sharing between health and social services for after-care purposes. Middle class people appeared to be least concerned about this. Younger people seemed to be more concerned. There were fairly high levels of trust among those who had given information. There was a low awareness that data sharing might be of benefit to the individual in terms, for example, of better care. People were most likely to be concerned about the idea of a central database of information. (MORI, 2003)

These findings are broadly in line with research carried out by the National Consumer Council in 1999. This suggested that consumers were uneasy about the amount of personal information held about them and how it would be used. People were concerned that they did not know how their information was being shared. This was linked with a feeling that individuals had little control over data sharing, which in turn often led to a degree of suspicion, and even fear. At the same time, most people did not object to providing personal data when the benefits were clear.

There is concern about an increasing flow of information between the public and private sector, for example when census data is used for purposes which might not have been expected by the person returning the census form. (Lace, 2005) The NCC argues that much more needs to be done to empower consumers, so that they can begin to assert their own interests and drive change.

4.2 Public views on data sharing in the NHS

Health information is particularly personal, and often sensitive, including information which citizens would not want widely shared, or shared at all. Health status can affect employment prospects, insurance applications, a person's reputation and self-esteem, as well as personal relationships.

Research for the NHS Information Authority showed a lack of awareness about how information was stored, with a third assuming that electronic records were already in use. Nearly a quarter of those spoken to did not know what the NHS did with their patient records. People were generally happy to share their information, and had high levels of trust in both GPs and hospital doctors. The research showed that almost half the population would only feel comfortable about their medical details being held electronically if the NHS spelled out in an agreement or charter how it would look after their confidential information. Concerns were expressed about the difficulty of getting consent to the sharing of information held electronically, for example from patients with a mental disorder (Consumers Association, 2002).

Most people welcomed the possibility of keeping sensitive information in a 'sealed envelope' which could only be looked at with the patient's permission, although most patients did not think they would have anything to put in it. People recognised the benefits of being able to see their own records, and of being able to carry a copy on computer disc, for example when they were on holiday. The CA research suggested that for most people, the benefits of electronic records outweighed the risks, provided appropriate safeguards were in place.

Follow up research in 2003 focused on what people wanted to be included in their electronic record and how this should be done. There was broad support for the introduction of electronic records, but security of the information held in the record was an area of concern. When asked about who should have access to their records, respondents thought that accident and emergency departments should be able to override any protections, but more than a third did not want NHS Direct to have access. Most (68%) wanted to have access to their record via their home computer, while 58% would be happy to log on at their local GP. (Health Which?, 2003)

A small scale piece of research in Scotland suggests broadly that people were not concerned about how their personal health information was used by the NHS, and a large majority were not worried about their personal health information being held or shared electronically, though there were concerns expressed about security. The groups demonstrated a low level of awareness of how personal information was used at the time, as well as a desire to be told more about this. They had mixed feelings about whether information should be produced in leaflet form, and some argued that money was better spent on patient care. (FMR research, 2002)

4.3 Electronic record development and implementation programme in England (ERDIP)

This programme, led by the NHS Information Authority in England, has created a huge amount of evidence about all aspects of developing an electronic patient record. A large number of pilot sites focused on issues affecting patients, and the evidence from these pilots is helpful for developments in Scotland. The following themes can be identified:

- Patients expect information to be shared within the NHS, and are often surprised to find this is not already happening.
- There is a general acceptance that an electronic record is a good thing.
- There is a low level of public awareness of information issues.
- There is a high degree of trust in the NHS.
- Patients want to be in control of their records.
- Patients want to decide who has access to their records.
- Most patients think A&E staff should be able to override any restrictions on access.
- Some patients want to restrict access to named individuals.
- Over 90% of patients would share their whole record with GPs, hospital doctors and consultants.
- There was a concern about commercial exploitation of information.
- There was a fear of hackers altering or distributing information.
- Most patients would like to be able to access their records.
- A majority would like to access records at the GP surgery (61%), while 47% would like to see them at home, but would be unlikely to access them often.
- Patients would like the facility to be able to add their own comments to the record.
- It is important that patients can understand what is contained in their record if they are accessing it themselves – most patients did.
- Some doctors still see patients requesting records as a threat to their autonomy.

Consent – opt in or opt out?

The ERDIP projects in England found that when GPs asked patients on an individual basis if they would like to opt in to the use of an electronic record, it required a considerable amount of time (with some projects estimating that it took from 30 minutes to an hour), both to explain what was involved to the patient, and to ensure that the information could be shown to patients without breaching confidentiality. Some projects felt that consent would only be informed when patients had seen their record. Some of the projects felt that getting consent during a consultation both lengthened and interfered with the consultation.

The NHS is likely to use an opt-out system rather than an opt-in, because of necessity and efficiency. There need to be enough records on the system to encourage clinicians to use it. An opt-in system would be expensive and time consuming, and the evidence suggests that most people have no objection to an opt-out situation. (Singleton, 2005)

There are likely to be problems in relation to people who choose to opt out of the system, depending on how it is set up. For example, if someone is taken unconscious to A&E, the staff there may be unable to access any records. However, they will not necessarily know that the patient does not want any information stored electronically, and so will record information about the A&E episode on the electronic system. Alternatively, the central system could have a record for everyone, which contains no medical information for the patient who has opted out, saying only that the patient does not want anything recorded electronically. The only other possibility would be to have a ‘sealed envelope’ or ‘break glass’ situation, in which you put information which is not normally accessible, but could be accessed in an emergency situation or to specified members of staff.

Patients' access to their own records

The evidence from the ERDIP projects suggests that health professionals were often more in favour of patients looking at their own records than patients were themselves. Some projects reported fairly high levels of interest with up to two-thirds of patients being interested in this. Many members of the public felt that it would help them feel more involved in the management of their own healthcare, and they would welcome the chance to add information to their record if it was relevant.

One project found that when patients accessed their records for the first time they needed a facilitator to guide them through the process, and provide any additional information they might need. This is supported by research which showed that patients needed support in relation to technical aspects of accessing an electronic record, and in understanding the content of the record. (Harris and Boaden, 2004)

ERDIP projects also explored some of the barriers to people accessing their own records. These included professional attitudes, technological problems, fears about the security of the internet, and patient apathy.

Research in the USA has shown that more than half of all patients would like to be able to see their records on the internet, but that those who did not want to look at their records on the internet were likely to feel quite strongly about this. In general, GPs were less convinced of the benefits of patients looking at their own records than patients were. (Ross et al, 2005) This appears to contradict the evidence from the ERDIP studies.

4.4 Patient views on electronic records and data sharing in mental health

The Improving Mental Health Information Programme is run with the Information Services Division (ISD) of NHS National Services Scotland. The philosophy behind the programme is that better information allows better decisions to be taken and better care to be delivered. The programme has developed an Information Core for Integrated Care (ICIC), designed to support improved inter-agency, multi-disciplinary mental health care provision.

Service users in this area may have particular concerns about sharing of information in their health record which may be of a highly personal nature, including fears, phobias, addictions etc. Some service users feel that the knowledge that this information is being held and shared electronically may make them less likely to open up fully and trust the health professional they are dealing with. (IMHIP, 2004)

The Improving Mental Health Information Project has held a series of workshops on information sharing and shared care records in various parts of Scotland. At a workshop with care providers in November 2002, there was a clear view that any shared records must be considered to belong to the patient. Patients should know what it contains and who has access to it, and they should be offered some choice on these matters.

In general, the kind of concerns which people with mental health problems have in relation to shared records are slightly different from those of an average user of the NHS who does not have any mental health problems. This is partly because they may have greater contact with services, and those services may be provided by other agencies, such as local authorities or voluntary sector organisations. It is also partly the result of the stigma which still attaches to mental health problems. Some people with a mental health problem may experience a crisis, at which point access to a shared record could be beneficial. This would be particularly true when the crisis occurred out of hours. (IMHIP, July 2003)

At a workshop in Aberdeen, the view was that information about prescriptions was a key element in a shared care record. It was generally felt that out-of-hours and crisis access to the record should be through a PIN to unlock the record (IMHIP, July 2003). A similar workshop in Lanarkshire felt that the level of access which should be accorded to A&E, locum or crisis services should be pre-agreed with the service user. This would be discussed and agreed as part of a person's assessment process.

4.5 Creating an electronic record

Innes and Ward (2003) have argued that involving patients in the development of an electronic record can have considerable benefit. It can help to ensure that errors are not made in the content, and can offer useful suggestions about content. Booth (2003) has expressed concern about the creation of the record, based on English research which has shown that up to 40% of the summary information derived from current computer records was inaccurate. He argues that the only way patient information can be acceptable in a shared NHS information resource will be if summarised records have attested accuracy, agreed by patient and general practitioner together.

4.6 Australia

The Consumers' Health Forum of Australia has carried out several consultations on consumer attitudes to electronic health records, and their research suggests that many consumers recognise the benefits which electronic records will bring in terms of safe, appropriate, cost-effective health care (CHF, 2001a and c). The Forum developed a set of principles which were considered to be important for consumers in relation to electronic health records. (CHF, 2001d) These include the following:

- Consumers will be informed and consulted about an electronic health record network, including potential uses of the information it contains.
- A consumer's decision about whether to participate in an electronic health record network will be voluntary, free from coercion and based on full information.
- Consumers will decide who else can access their personal health information.
- Consumers' personal health information will be held and transferred securely.
- Consumers will be fully informed of any privacy breaches that occur in relation to their information.
- The development and operation of any electronic health record network will be independently evaluated, including its impact on consumers.

Areas of concern in relation to electronic records were found to be:

- privacy, and the need for mechanisms to protect individuals' privacy;
- consent, so that consumers understand what is involved;
- opt-in – inclusion should be on an opt-in rather than an opt-out basis;
- a unique patient identifier should be used;
- data linkage – concern about the balance between individual privacy and the advantages to the public of increased data sharing; and
- the benefits of electronic records must be open to all, including disadvantaged consumers.

4.7 Key points from the literature review

The following are the main messages to emerge from this short literature review.

- There are generally low levels of awareness of how personal information is stored and shared, by service providers in general, and also by the NHS.
- There is a desire to know more about this.
- Data sharing is supported where this is seen to contribute to better care or services, both in general and in the NHS.
- A significant percentage of people believe that health records are shared more widely than is the case.
- Most people are happy for personal information to be stored electronically, provided there is a clear agreement about rights and responsibilities.
- The most commonly expressed concerns are about security.
- There is support for the concept of a 'sealed envelope' in which particularly sensitive information could be held.
- Most people would like to be able to see their own records and have the opportunity to correct any mistakes.
- People would like to have some control over who has access to their records.
- There is a fairly high level of trust in relation to how information is used in the NHS.
- There is general acceptance of an opt-out system.
- Because there are greater sensitivities around information about mental health, it is particularly important that mental health patients are involved in deciding who sees what in their record.

5 Analysis of focus group discussion

This chapter presents the findings of the focus group research carried out in May 2005. The discussion focused on the use and content of the Emergency Care Summary (ECS) which has been piloted in Grampian and Ayrshire and Arran out-of-hours medical centres, to ensure that doctors at these centres have access to basic medical information about patients. As a warm-up exercise we asked participants how much they knew about how their records were stored, and whether they had ever had any problems because their records were not available.

5.1 General awareness of how health records are stored

Generally, participants thought that their health records were stored both on paper and on computer. Some of the participants in the rural group had only seen their files on paper. One participant did not know how his health records were held at all.

Participants' knowledge of who had access to their records was mixed. Some thought it was only doctors within their surgery, while others thought that it was all the people who worked in their surgery, including the receptionists. In each of the groups, most of the participants admitted that they did not actually know who had access to their records, although most hoped that it was just their doctors:

> *You don't really know do you? I wouldn't like to say who…I would prefer only my GP and any doctor in a hospital, I would hope that would be it…but I have no idea.* (Group 5)

> *You go in with this kind of feeling that it's like talking to a priest, you know, it has that sort of confidentiality thing that nothing goes elsewhere…but quite possibly it's not like that.* (Group1)

Some had more awareness of the fact that permission should be sought before looking at someone's record:

> *One time a doctor just started looking through my records, who I didn't know…which he shouldn't have done, he should have asked me first 'is it alright if I have a look through your records?' and I would've said yes, but to do it without asking wasn't nice.* (Group 7)

Those in the group of younger participants felt that this was something on which they needed more information:

> *Even just something on the practice wall - because there's always a notice board you're left to stare at when you're sitting there…a wee information poster [saying] these are the people who can ask to see your records.* (Group 1)

Experience of medical information not being available

Many of the participants had experienced medical information not being available when it was needed, either for them or for a family member. Some participants had experience of being kept waiting at the hospital when files were missing. Participants had also experienced missing or late test results and difficulty in accessing test results.

> *It was a lot of organisation to get there to sit and be told by a registrar who didn't have a clue about what was going on…basically the results were not there and nobody could even phone up and find out for us – a total waste of time.* (Group 4)

> *My mum will get to the hospital and be sent home because her records haven't been sent up from another hospital…the amount of times I've took my mum home is ridiculous, or sat for hours and hours waiting on a taxi to bring them up.* (Group 1)

One participant mentioned the difficulty in getting test results over the phone, although she said she was aware of confidentiality issues, but found it difficult sometimes to find the time for an appointment when there could be a quicker way for receiving test results:

> *You just can't get hold of your own information, it takes a lot longer than it should.* (Group 1)

> *You can only phone between certain times…if you can't get a hold of your results then you're stuck in limbo until you get a day off. And if you don't have access to a phone, and not everyone can use the phone from their work.* (Group 5)

There were also several concerns raised about receptionists giving out test results over the phone.

> *The experience I've had is times where maybe you've had a test done or something and the person that's done it has asked you to come back and see them for the results, and you phone up for an appointment and my receptionist will say 'An appointment for this? Well, hold on a minute…it's fine, it's all clear' and she's gone and checked it obviously and she just tells you over the phone and possibly I've wanted to discuss it with the practice nurse or the doctor and I think 'did she really check my file or is she just saying that to get me off the phone?'* (Group 1)

5.2 Response to use of the Emergency Care Summary

The purpose and content of the Emergency Care Summary (ECS) was explained to the groups. They were given a card showing what information was included in the ECS, ie name, address, date of birth, phone number, name of GP, details of current medication, and details of any allergies. All groups were, in general, either very positive or broadly in favour of the use of the ECS. Those who raised concerns either thought it contained too little information, that it was a waste of resources, or they were worried about security.

Advantages of using the ECS

The groups highlighted a number of advantages in using the ECS:

- it contains basic information which would be useful in an emergency, without being too personal;
- it would help patients with memory problems, such as older people, and those taking several different medicines;
- less chance of doctors making a mistake in the cross-reference of drugs;
- doctors will know from the medication record if the patient has a chronic condition;
- patients will not have to answer so many questions at out-of-hours; and
- it would be helpful for patients who are feeling confused or anxious.

Overall, those who had caring responsibilities were much quicker to recognise the advantages of the ECS. One participant, who had caring responsibilities for both her parents, saw the advantages in the ECS for people who are taking lots of different medication:

> *Both my parents have medical conditions and my father has to take loads of drugs for his heart, and the number of times we have been to the out-of-hours service, and my Mum's useless, she can't remember what he's taking, and they ask me and so it would be great for me. If he's ill he can't remember himself.* (Group 3)

Another participant, who cared for his fiancée, echoed these thoughts:

> *If she was rendered unconscious, who's going to tell the doctor what she's on? Not me. She's got ten, twelve different kinds of medicines, and there's a lot of stuff she can't take.* (Group 4)

Another advantage highlighted was that the ECS would save patients having to answer all the questions they are asked when using the out-of-hours service. Several participants commented on the number of times they have had to repeatedly answer questions about themselves when using the out-of-hours service:

> *If my partner's phoned up NHS 24 for me, he's had to go through all this but then I still have to go through it all as well…that's the worst thing, you don't really want to speak to someone when you've got a really bad stomach ache, you want to just give your name and your first initial.* (Group 5)

One participant, who had used the out-of-hours service while she had meningitis, had similar views:

> *We gave all this information, even though I could hardly speak. I was taken into hospital and I was sent home again and I came back again. While I was practically unconscious, I was completely unaware of what was going on, they tried to get me again to reel off all this information…and I didn't know where I was, I was just out for the count basically.* (Group 5)

Further advantages mentioned included:

- it could make it easier to get repeat prescriptions;
- it would help calm down panicky patients and act as an 'ice-breaker'; and
- information would be more open and in a more simplified format.

Concerns about the ECS

There were three main areas of concern raised in most of the groups:

- security and confidentiality;
- accuracy; and
- resources.

There were concerns about security, even among those who were in favour of the ECS. These focused on who would have access to the ECS, and about the possibility of non-medical staff accessing the information. This issue was discussed in the group of people living with HIV, some of whom had particular concerns about confidentiality. One participant was particularly worried that the diagnosis of HIV might be on the ECS and that this information could then 'fall into the wrong hands'.

Another worry was that the use of the ECS could lead to fraud and identity theft:

> *I think there's fraud issues as well. It's a perfect way in to know where you live, what your phone number is, your date of birth, go and get a credit card in your name.* (Group 1)

There was some misunderstanding in one of the groups about the way the information contained within the ECS could be used. A few participants thought that drug addicts might be able to get access to the database, find out that a patient was taking a particular type of drug, obtain their address and then break into their house to steal the drugs.

There was a concern about who would be inputting the information and the information not being correct because of, for example, an inability to read the doctor's handwriting. Some participants felt that creating this information would be a lot of work for relatively little benefit. These participants usually felt that most people would be able to provide this information in person at an out-of-hours centre.

> *That's ok if you're unconscious but everybody here could answer all that in two seconds.* (Group 4)

> *Anybody that's taken ill, nine times out of ten, they're not going to go in on their own are they? Somebody's going to go with them who can answer these questions.* (Group 4)

It was also pointed out that the system would require frequent updating, which could be a large task and would depend on having a good system in place.

A few participants questioned the motives behind the ECS. One participant wondered if this was part of a trend towards cutbacks in the NHS and whether it was a move away from personal service.

The group of participants with mental health problems did not see any disadvantages in the ECS, and were all quite happy with it.

5.3 Extension of the content of the ECS

Groups were asked how they would feel about other information being included in the ECS and discussed what types of information would be useful. Just over half of participants felt that the ECS already contained enough information, while just under half felt that there should be more information included.

A number of participants thought the ECS would be more useful if it had more information on it:

> *There's nothing there to tell you if I've got any heart trouble or liver problems or anything…there's not enough on it for it be of any value.* (Group 4)

> *It's almost like the doctor who is looking at that is being given half a story.* (Group 4)

Medical history and family history were considered by some participants to be important information that should be included in the ECS. Others were strongly of the view that as the ECS was only for emergency use it should contain only basic information.

> *Even when you go to your own doctor, they don't need to access your whole medical file, depending on what you're there for. At the end of the day, this is for an emergency. It's like people who train as first-aiders, they're just there to get you to the next stage.* (Group 6)

Some participants thought that next of kin should be included in the ECS. Some participants in the group of people living with HIV raised concerns about this as they felt it could lead to the next of kin finding out about their HIV status. Others in this group, however, suggested that HIV diagnosis did not have to be on the ECS and that next of kin could be an option and patients would not have to provide that information if they did not want to.

Those who were in favour of more information being included mentioned the following as being things which might be useful:

- blood group;
- organ donation status;
- contact details for carers;
- disabilities; and
- translation and interpretation needs.

The group of people living with HIV agreed that having the name of their consultant on the ECS would be an important inclusion. This group generally considered that their consultants were the people who really understood their condition and treatment, whereas their GPs had less knowledge.

There was some discussion in several of the groups about whether a doctor could tell what a patient was being treated for by what medication they were taking. Many participants felt that a doctor in an out-of-hours centre could tell quite a lot from the ECS, for example about any chronic conditions. The participants in the HIV group felt that it was not always the case that medication would reveal that a patient was living with HIV. They thought that GPs would not necessarily recognise their medication, while others were not taking any medication for HIV. By the same token, a doctor in an out-of-hours centre would not necessarily know about possible side effects from prescribing drugs in combination with medication being taken for HIV.

> *They don't know anything about the treatments. They don't know anything about the virus. They don't know anything that's going on and it can be very frustrating.* (Group 8)

Other suggestions for inclusion made by participants included:

- other people in the household or carers;
- last few visits to the hospital/GP; and
- previous major surgery.

Information that should definitely not be included

The groups were asked if there was any information which they thought should definitely not be included in the ECS. Opinion was divided in all the groups, with some not wanting certain information included, while others did not mind what was included. Some participants felt that the more information was on the ECS, the higher the security risk:

> *The biggest problem is the more information that goes on the computer, the more people have access to that information and that is where the big fear lies, it's who can get hold of that information eg insurance companies and everything.* (Group 4)

Some participants also felt that there might be certain parts of a patient's past history that need not be on the ECS as they are no longer relevant:

> *Someone who had depression or schizophrenia 20 years ago, that's going to make no difference to the treatment you're given there and then, so there's no need for that to be on.* (Group 5)

Some also felt that if a person had a drug or alcohol problem, or mental health problems, then they might not want that included. As in the other groups, opinion was divided in the mental health group, with some wanting all information on the ECS, including any mental health problems, while others felt that only relevant information that is vital in an emergency situation should be included. Overall, there did not appear to be much difference between the opinions of those in the mental health group, who might be expected to have greater concerns about confidentiality, and those in the other groups.

The group of participants living with HIV were divided with regard to whether HIV status should be included on the ECS. Most of the participants agreed that there was a propensity for GPs to automatically relate any medical complaints to the HIV:

> *I don't like HIV being on the form because if anything goes wrong the first thing the GP does is link it to the HIV.* (Group 8)

> *There's still a lot of ignorance out there and a lot of people say 'it's HIV', 'it's this virus that you've got that's causing it', because most people don't know the information about the viruses…there's misconception, so it's not something I'd want on because they're prejudiced the way they treat you.* (Group 8)

Some participants felt that as long as the Data Protection Act was applied and only medical professionals were accessing information then there was nothing to worry about if more information was included.

5.4 Making the ECS available to other parts of the NHS

Participants were asked how they would feel about their ECS being made available to other people in the NHS, but only looked at when they needed care or treatment. Generally, participants were happy about services such as NHS 24, the ambulance service and A&E departments having access to the ECS, but would worry if non-medical staff had access. Several felt that it was more important to have access to the ECS in an A&E department than in an out-of-hours centre, as patients would be less likely to be able to provide information themselves. Several participants thought that staff throughout the NHS already had access to their health records.

Generally, participants were in favour of NHS 24 having access to the ECS, although some were happy as long as it was only nurses who were accessing the information, as opposed to call handlers. One participant, a carer for her parents, who had children with a lot of health needs, thought it would be particularly useful for her if NHS 24 could get access to this information. Another participant thought that it might not be necessary for NHS 24 to have that information if someone was only phoning up for advice.

The majority thought that it would be useful for A&E and the ambulance service to have access to the ECS as it would save time. There were a few who thought that such a move would be unnecessary:

> *I think you're going to overload the system if you do that, because you only go to A&E if you need to…and if they're as stressed as they supposedly are, putting all that onto a data system…* (Group 7)

There was a strong feeling among the participants that non-medical staff should not have access to their ECS, whether in NHS 24, the GP practice or in community pharmacies, although at a later stage in the groups some people appeared to have changed their minds on this, and could recognise that sometimes it would be useful if non-medical staff were able to access and pass on the ECS.

Community pharmacists and opticians

Most of the participants were opposed to community pharmacists having access to the ECS. The groups did not discuss hospital-based pharmacists having access to the ECS. Confidentiality and privacy were big issues in this respect and community pharmacists were viewed as businesses there to make money. In addition, participants had particular concerns about shop assistants in pharmacies having such access. One participant did not think that it was ethical that such people have access to health information:

> *I don't think it's ethical that they should have that information. I mean, doctors swear the Hippocratic Oath, anyone working in the NHS like a nurse all have written or whatever confidentiality and I think you could have anyone working in an opticians or a pharmacy and ok, maybe not dispensing but they could still get access to that information.* (Group 4)

A few participants, however, had no concerns about pharmacists having this access. Groups indicated some awareness that pharmacists might already hold some information on them:

> *They've already got your name, address and your date of birth, it's only another few details so it won't make any difference.* (Group 5)

> *I think the pharmacists one is grey because there's a lot of people who use pharmacists as GPs.* (Group 1)

One of the participants with mental health problems expressed a clear view that pharmacists should have more information. She reported a bad experience when she urgently needed medication and the pharmacist did not have the correct information and would not phone the doctor.

> *But in an emergency, yes, so they could look up and see that you've always had these tablets.* (Group 7)

Almost all participants felt that they would not want opticians to have access to the ECS. One participant thought that it might be useful for opticians to have limited information. Others in that group thought that that this would not be necessary, unless a person had a medical condition concerning their eyes, but even then, opticians should have their own records. It was also suggested that people did not often have emergency eye appointments.

Access to people outside the NHS

When groups were asked how they would feel about the ECS being made available to people outside the NHS, for example social services, participants were, on the whole, against the idea. Most felt that it should be limited to a medical professional within the NHS in a hospital or their GP surgery, otherwise:

> *It could just go on and on until the barman knew…* (Group 1)

Most of the participants felt that it should be on a 'need to know' basis, and in the context of the ECS this was perceived to extend only to emergency situations, and so was not relevant to social services or other settings such as private hospitals, nursing homes, or voluntary organisations.

Some participants said that they would not mind others having the information if it was going to help them. Examples given included a child's teacher, or someone in the workplace for health and safety reasons.

5.5 Attitudes to Emergency Care Summary being held electronically

There were mixed responses when participants were asked how they felt generally about the Emergency Care Summary being stored electronically. Some participants saw it as the inevitable result of progress and were comfortable with it, while others were concerned about security and who had access to this information. Interestingly, while there were a few comments about the difficulties of ensuring security in the present paper-based system, only a few people recognised that computer-based systems could actually offer better security.

Many participants recognised that storing information electronically was inevitable.

> *It's going to happen more and more. We'd probably be horrified if we knew just how much information is held about us anyway.* (Group 6)

Younger participants were more comfortable with technological change and the storing of information electronically. They also identified the advantages: for example, it is quicker to access a file on computer than on paper and it minimises paperwork.

> *I've gone into my surgery and seen walls of notes and I think to myself, if I was really ill, how long would it take them to find my notes? But if they've got a computer there…it'll come up right away.* (Group 5)

There was also a view that while they did not favour electronic storing, participants had accepted that it was happening.

> *In general, I don't like anything held electronically, I have a real problem, with the whole thing, but that's technology now so we have to get on with it.* (Group 8)

The main concern about the storing of health information electronically was security and the possibility of people hacking into the system.

> *[I think it's] bad because of hackers and things…it's probably stupid, it's probably not going to happen, but it's always possible because there's a lot of personal information in there, a lot.* (Group 5)

There was some inconsistency in participants' views on the storing of electronic data. When asked, many said they used internet banking, yet did not have any worries about their financial information being stored in such a way.

There were other concerns that related to the reliability of storing information on computers:

> *I'm rubbish with computers so I would worry that they lost all my information, that it went wrong and crashed and you couldn't get your own information.* (Group 1)

A number of participants preferred their records to be stored on paper as they saw that as the more reliable method.

> *If you put them on computer, how do you know the computer's not going to crash?* (Group 5)

> *Everything should be backed up with paper. I know it takes up space and all the rest of it, but at least it's there. Electronic stuff can be lost just like that.* (Group 6)

A few of the participants thought that patients should be able to choose the way their health records were stored, and that electronic storage should be optional. A number of participants thought that health records should be stored both electronically and on paper, so that in case one set went missing the other was there as a back-up.

There was a lack of awareness among many of the participants of electronic back-up systems and also of how electronic storage could be more secure than using a paper system.

In addition to the general issue of security, some participants were worried about who would have access to their information.

> *I have no problem with it being stored electronically, but who is going to have access to that information? To me that is so important…today you get all sorts of mail and you're thinking 'where did they get my name?* (Group 8)

> *There's a fear attached to your information being stored electronically that the entire planet will have access to it.* (Group 7)

At the same time, some participants did feel that the information contained in the ECS was not sufficiently interesting for anyone really to want to hack into it.

Scotland-wide or board-wide?

Almost all participants thought that it would be a good idea if their ECS were available anywhere in Scotland. Only some had concerns about this, which were, again, mostly about security. A few participants thought that it should be available more widely, for example, throughout the UK. A few thought that this was already done on a national basis.

The advantages were seen to be that it would:

- be available when you were on holiday, either in an emergency situation or if you had forgotten to take your medication with you;
- be accessible if you were visiting family or friends in other parts of Scotland; and
- save time, and provide quicker access to help.

Participants who had caring responsibilities saw this as a particularly good idea. One patient, who cared for his wife, described how she had taken ill while in Bournemouth and they could not get medication from the hospital, as they did not have her records. He had to get a police escort to find a chemist and thought that if they had access to the ECS, that would not have been necessary.

Another participant, whose daughter was disabled, had experience of taking her to hospital while on holiday:

> *We've had to explain all her conditions…just for someone to give her a medication. It would've been so much easier if at the touch of a button, all of her details would've been there.* (Group 4)

A few participants were not comfortable with having the ECS available throughout Scotland. It was felt that the wider the access to the ECS, the more opportunities there were for it be abused.

> *Phoning from wherever you are to your GP could do that…so your GP can access it without it being available to all and sundry.* (Group 2)

This person would be happier if the information was available only within the NHS board in which the patient lived.

One participant also thought funding was an issue, wondering who would pay for this centralised system, when NHS boards tended to operate separately.

In general, it was felt that the advantages would outweigh the disadvantages, for example, if your life was saved.

> *I think if you had a heart attack you wouldn't care who had access to it.*
> (Group 4)

Some participants thought it should be available all over Britain or even abroad:

> *As far as I'm concerned, the NHS is Britain, not England, Scotland or Northern Ireland.* (Group 5)

> *We live in a global society. I can foresee if the proper safeguards are in place then it could be a world-wide system…because we do go on holiday.*
> (Group 8)

5.6 Attitudes to opting out

Groups were given a summary of how participation in the ECS might work. Participants were given three colour-coded options and asked which they would be more likely to choose:

- opt out of the system completely so no Emergency Care Summary is available for them (the red option);
- their details would be held in an ECS and could be accessed any time (green); or
- their details would be held in an ECS but could only be accessed under certain circumstances, for example if they were unconscious (the 'break-glass' option)(blue). In this situation, patients would be informed every time the glass was broken.

None of the participants would choose to opt out of the ECS system completely, but most felt that they should have this choice. The majority would be happy for their ECS to be held and looked at in emergency situations, while a minority preferred the 'break-glass' option whereby their ECS would only be looked at in certain circumstances, for example if they were unconscious. If there was more information added to the ECS, participants would still not opt out, although some would change to the 'break-glass' option.

> *Being a red just doesn't make sense.* (Group 5)

> *It's your health. If you've got something that the doctor should know but you're not willing to disclose it then it's your responsibility…it's your loss if they can't help you.* (Group 1)

It was considered to be particularly helpful for older people who might not remember some of their information and for people who were seriously hurt and could not speak for themselves.

> *If something happened to me, I don't think my wife could think straight and remember things that had happened to me and what I'm allergic to, but if that information's there, the doctor doesn't need to go and ask her.* (Group 5)

> *I could go out and take ill and they'd know nothing about me…I prefer it so that they know what to do with me.* (Group 2)

The main concern was security, and this may have encouraged some to prefer the 'break-glass' option.

> *It's the same with all computerised systems, big brother's always watching … It's my information - why should it be available north, south, east and west? If I'm unconscious, then yes, access it by all means because I'm unable to tell you anything about myself, but other than that, no.* (Group 2)

Some of the participants thought that the 'break-glass' option would produce a lot of work, particularly for staff who were already struggling with workloads, and it would also be a drain on resources:

> *It's a great idea but who's going to pay for it?* (Group 1)

> *I like the 'break-glass' one but doesn't it create a whole load of paperwork for someone to do?* (Group 4)

One view was that it would be simple enough to set up a system which automatically notified patients when their record was looked at. Another participant suggested that she would like to see a 'sealed envelope' with specific types of her information in it, which would only be opened under certain circumstances.

One participant had an unusual perspective, and felt that the more information there was on the ECS, the more likely the doctor was not to listen properly to what you were saying was wrong with you.

5.7 Asking for consent

Groups were asked whether they thought medical staff should ask for their consent before looking at their ECS. The majority of participants did not mind whether they were asked or not, while a few definitely preferred to be asked.

One view was that in an emergency situation it was better that medical staff just got the information quickly. Another pointed out that patients are not normally asked for consent by a GP to look at their records, so it would seem odd to ask for this in out-of-hours.

Some participants did feel that consent was important:

> *I think it's important they mention it because I'd probably want them to be reading it back to me to make sure it was up to date.* (Group 6)
>
> *I think it's nicer if it's a strange doctor.* (Group 7)

5.8 How do people want to be informed?

Almost all participants wanted to be informed if the ECS were to be introduced. A few participants did not mind whether or not they were told about it. The participants who already thought that there was access to this kind of information would not expect to be told. Although the majority of participants wanted to be informed before a system was put in place, not all believed that they would be told:

> *It's something that I thought we would never get told about, it would just happen behind the scenes anyway.* (Group 1)

A few participants said that they would not mind if they were not informed and that the NHS should be left to 'get on with it':

> *At the end of the day are you going to have any choice in the matter?* (Group 6)

Various methods were suggested as to how people should be informed, including a letter from their GP; an advert on television or radio; and posters and leaflets in GPs' surgeries.

Most would prefer to receive a letter from their GP, or perhaps from elsewhere in the NHS, as opposed to posters and leaflets in GP surgeries, as patients may not see these, either because they do not regularly attend the surgery or because they do not read them.

> *I think you need to draw people's attention to what's going on and just putting a poster up doesn't do that.* (Group 7)

Most participants would like the letter to be personally addressed to them, as people would be more likely to read it. They would also be more likely to read it if there was an official stamp on it, for example, an NHS stamp or logo, showing that it was something to do with their health. It was noted, however, that this would be very expensive. One way of keeping the cost down would be sending a letter to every household rather than to each person. One opposing view was that some people might panic if they got a letter through the door from the NHS. A few participants also suggested that there should be alternative formats of the letter, for example for those people with visual impairments.

Some participants also suggested a television or radio campaign although it was recognised that this would be dependent on people watching the television or listening to the radio. Other participants thought that information would be more effective on a one-to-one basis.

Another suggestion was a leaflet campaign, with leaflets delivered to patients' homes. It was however recognised that leaflets might be seen as junk mail and not be read.

Another view was that a helpline might have to be set up to deal with people's queries about the changes, following the information campaign.

Interestingly, none of the group in Grampian had been informed of or heard about the ECS pilot that was currently underway there. Posters and leaflets had been distributed to GP surgeries to inform patients but none of the participants in the group had seen any information about it.

> *I've been going to the doctor's for a while because my wife's pregnant and I read all the posters because I'm bored, and there was nothing about this there.*
> (Group 5)

5.9 Do people want to see their own ECS?

Participants were asked whether they would like to be able to see their own ECS. About half said they would, and half said that they would not really be interested.

Those who said they would like to see their ECS thought it would be a good way to check their information was correct and see whether it required updating. It was also suggested that having permanent access to the ECS would be useful if it could be used for recording test results.

Those who did not want to see their ECS said that they already knew the basic information on the ECS. A few participants agreed that it would be pointless and a bit boring. Some participants said that they would like to have the option to see their ECS if they wanted, but probably would not actually take any steps to see it unless there was something bothering them.

How would people like to access their ECS?

Participants were asked how they would like to access their ECS. The vast majority of participants would like to access it through their GP, with most preferring to have a print-out, while others would be happy looking at it on a screen in the surgery. Only a few would be happy accessing it on the internet.

Those who wanted to see their ECS on a print-out from their GP thought that this would be more private:

> *I'd like to take it home instead of looking at it with people hanging around you.* (Group 4)

It was suggested that the print-out should be signed for so that security was ensured.

Most participants felt that having it accessible on the internet would be a step too far, and they would have concerns about security and identity fraud.

> *Confidentiality and GPs go hand in hand and as soon as you start talking about the internet, it totally undermines that whole relationship.* (Group 1)
>
> *It leaves it totally wide open to abuse.* (Group 1)

A few participants, however, were comfortable with the idea of accessing their ECS on the internet.

Several participants thought that patients should not be able to change details on their ECS because that would mean that anyone who had access could alter it as well.

5.10 Protection and security

Participants wanted to see a variety of security measures to protect their personal information, including tiered access to different medical staff; passwords and authorisation codes; and spot-checking.

All participants wanted to see their information, at the very minimum, be password-protected. There were still some concerns about how secure a password-protected system could be:

> *GPs should have their own passwords so that you could see which GP was accessing which record.* (Group 3)
>
> *How many passwords would you have to have? If it's just one, then someone might see you typing it in…maybe highly unlikely but…* (Group 5)

The majority of the participants also favoured tiered levels of access. Almost all participants agreed that full access should be limited to medical professionals. It was also suggested that some receptionists, for example, those working in A&E, should have access to speed up the procedure. Similarly, it was suggested in one group that the NHS 24 call-handlers should have access to the ECS so that they can direct the call to a specialist, if appropriate.

Other participants took a less wary view:

> *I think at some point you have to trust the system. Even if there's a chance of information being misused, relevant parties are always working towards that not happening.* (Group 6)

A system of 'spot-checking' was also suggested as protection, so that an audit body could check on particular cases of access to an ECS.

However, a few thought that the security systems could become too complicated and, therefore, ineffectual in an emergency setting.

> *Thinking about emergency situations, you sound like you're adding a lot of bureaucracy…you might be lying there with a drip in you and suddenly some doctor's got to then go to someone to get authorisation and that guy could be on his lunch at that point…. I think what you want is a system where the person who's taking care of you makes that decision with your best interest at heart, if you can't make it.* (Group 1)

Breach of privacy

Generally, participants thought that any breach of privacy should be dealt with severely. Most participants felt that criminal charges should be brought against anyone committing a breach of privacy. This could be done under the Data Protection Act. It was noted by a few, however, that the Data Protection Act is frequently breached and charges are not brought against the perpetrators. Most participants also favoured dismissal for any employees who unlawfully accessed someone else's ECS.

> *They should get the jail.* (Group 2)

> *Take them out and shoot them!* (Group 7)

It was felt by some participants that when someone had accessed details unlawfully and used those details for some purpose other than medical care, then that should be treated more severely. Some took a more lenient view and said that it would depend on the circumstances under which the record was accessed.

> *It depends on what they've done and why they've done it.* (Group 1)

5.11 Attitudes to a single electronic health record

The groups were asked what their attitude was towards having a single electronic health record which could be accessed in different settings within the NHS. The general view was that such a system would be a good idea, although there were some concerns, mainly concerning security. There were also a few participants who thought that a single electronic record would be one move too far.

Participants thought that a single electronic health record would be faster to access, simpler and more efficient. Some also felt that it was inevitable. Several participants thought that a single electronic health record was already in use in Scotland.

> *If it's going to speed up getting treatment, I can't see any problem.* (Group 6)

> *I think when you're ill, you want help and if somebody somewhere has all the information on the computer and can access it, then I would say yeah, go for it. It's your health.* (Group 6)

> *It makes sense doesn't it…all those things are lying wide open that anybody and his dog could look at it if they wanted to, so it makes sense that it's on a computer as it's probably less accessible.* (Group 1)

> *As long as the computer doesn't crash, I'm quite happy…that's always a possibility.* (Group 1)

A number of participants in all of the groups felt that having one single health record would be more useful than the ECS. Many patients see a different GP every time they go to the surgery, and so the situation was not that different from attending an out-of-hours centre. Another participant felt that if the time and resources were going to set up a system with the information on the ECS, it may as well have a patient's whole record on it. It would also be useful when patients moved house, or changed their GP.

One participant suggested that the NHS should operate more like a bank: whatever branch a patient goes into, their details are there.

Those in the group of people living with HIV were positive about such a system, as many of them had experienced problems through seeing different consultants and all their information being held in different places. A single record would make it much simpler.

A number of participants thought that there would be practical problems and complications in setting up such a huge system. The majority of participants were also still concerned about security.

> *Your medical file – there's all sorts of information in there, it's not always that objective. You might not like the take they've put on certain things, which is what I'd be nervous about.* (Group 6)

> *A lot of systems aren't foolproof and when you consider the degree of sensitivity of information, somebody could easily hack into that system… because if somebody gets a hold of your medical records, they can basically find out a lot about you…* (Group 1)

One participant said she would want a say in what was on the record, favouring the 'sealed envelope' approach whereby the patient decides what information is inside the 'sealed envelope'.

Very little comment was made on what input patients might have to their own records, although this may be because it was not explicitly included in the topic guide.

5.12 Key findings from the focus groups

- Participants were generally supportive of the use of the Emergency Care Summary, with none saying that they would opt out of this.
- The main area of concern about the development of the ECS was in relation to security and who would have access to it.
- People living with HIV were concerned about who would have access to their information, particularly if it revealed their HIV status, though some were very supportive of the idea.
- Participants would like to be informed about changes to the way their health records are stored and shared, and to have the choice to opt out, even if few would do this.
- Information should be directed to everyone, and not just those attending their GP surgery or other NHS premises.
- There was general acceptance of the move towards electronic storage of information as both inevitable, and as offering possible benefits.
- There was a desire for serious penalties to be in place for any breach of security.
- There was support for the ECS to be available to staff in the ambulance service, in A&E departments and NHS 24, but more mixed views about community pharmacists.
- Some could see the benefits of including more information in the ECS, for example blood group, or name of main carer, while others preferred the information to continue to be limited to basic emergency information.
- People were generally supportive of ECS being available throughout Scotland.
- While no participants said they would opt out of the system, some might prefer some restrictions on who could access this information and in what situations.
- Some would like to see their ECS to check its accuracy, and most thought that people should have the right to see it.
- There was a recognition of the advantages of a single electronic health record, with similar concerns about confidentiality as expressed in relation to the ECS.
- People living with HIV were particularly supportive of the idea of a single electronic health record.
- There were no major differences between the attitudes of people with a mental health problem and others, though some could clearly see the advantages of the ECS, particularly in relation to their medication record.

6 Conclusions and recommendations

The findings of our work in focus groups support much of what has been found in the literature on people's attitudes to the increasing use of electronic means to store and share personal information, both in health services, and in public services more generally. People recognise the advantages of wider sharing of information using information technology, and the inevitability of change in this area. At the same time, they want to retain choice over what happens and how they are involved, and they want to be fully informed about developments. The enduring concerns centre on security and how the confidentiality of their health information will be ensured.

In relation to the Emergency Care Summary, our research shows overwhelming support for the idea of core information about patients being available to medical staff in out-of-hours centres, on the grounds of making care quicker, safer and more effective. Even in this area, where only very basic information is being shared, there is still a desire to be properly told by the NHS that this is happening, to have the choice to opt out if the patient has concerns, and to have assurances about the levels of security in place and the seriousness with which a breach of security is taken.

Many of those who took part in this research were supportive of proposals to develop a single electronic health record for patients in Scotland. There was greater concern about this than about the Emergency Care Summary, but many participants could see the advantages of having all their health information in one place, easily accessible by NHS staff who needed it.

6.1 Raising public awareness and confidence

The importance of public confidence is likely to be central in relation to how the public responds to the increasing use of information technology in the NHS. Up till now the NHS in Scotland has not devoted much attention to this important aspect of what is happening, concentrating on the logistics of how to make systems work, and putting some effort into persuading NHS staff of the advantages of these developments.

To raise public confidence, the NHS needs to raise public awareness of what it is doing, the reasons for it, the benefits for patients, and the safeguards in place to protect against abuse of personal information and breaches of privacy. To be a successful initiative, the move towards a single electronic health record, of which the ECS can be seen to be a first step, must involve the public as equal partners, at least in terms of its informed awareness of what is going on, and increasingly through the involvement of members of the public and of individual patients in the design and functioning of the system.

Recommendation 1

NHS Scotland should adopt a strategic plan for informing members of the public of its plans for electronic storing and sharing of personal health information.

This information should be presented on a regular basis, with a view to keeping the information broadly in line with the state of developments in practice. With the introduction of the Emergency Care Summary throughout Scotland in 2005 and early 2006, it should be a priority to ensure that clear information in plain English is available for all patients. Our work with focus groups suggests that people would like this information to come into their homes, as too many people would not see it if it was only available in GP practices.

Information about the Emergency Care Summary can either be presented separately, or alongside more general information about the increasing use of information technology in the NHS. The SCC would prefer the latter option. However, depending on timing it is important that members of the public are informed of the introduction of the Emergency Care Summary in their area, and this may need to be done separately.

Recommendation 2

NHS Scotland should ensure that every home in Scotland receives information describing the introduction of the Emergency Care Summary, preferably in the context of general developments in the field of electronic sharing of personal health information, including test results and clinical letters.

Our research showed that while most people would be happy for the Emergency Care Summary to be used, they did think it was important to be informed and to have the choice to opt out of the system.

Recommendation 3

Information produced should:

- set out clearly the way in which personal information will be used and shared;
- include clear statements about the rights of members of the public to opt out of the sharing of their health information in ways which they are not happy about, including the electronic storing of personal health information with a view to this information being accessed in a range of healthcare settings, such as out of hours centres or accident and emergency departments;
- make it clear that if patients do not opt out, that this information will increasingly be stored electronically, starting with the Emergency Care Summary; and
- make it clear who members of the public can complain to if they are unhappy about the way their information has been used.

Participants in the focus groups recognised that an opt-out system was more practicable. However, if the NHS wants to be able to infer implicit consent, it will be important not only that people are properly informed of their right to opt out, but also that the process of opting out is not made unnecessarily complicated or difficult.

Recommendation 4

The NHS must ensure that the process of opting out is not difficult, or it will be less easy to imply consent to information being processed in this new way.

While it was not discussed in the focus groups, it is a clear message from the literature in this area that members of the public support the idea of a guarantee made by the NHS as to how it will treat personal health information and stating the rights and responsibilities of patients.

Recommendation 5

The NHS in Scotland should consider adopting a care record guarantee, similar to that being developed in England, which sets out clearly the rights and responsibilities of patients and the NHS in relation to how their personal health information is stored and shared.

Our research has shown that people become increasingly concerned about the confidentiality of their personal information as the scope or accessibility of that information is extended. Before the NHS moves to wider sharing of personal health information than will take place in the Emergency Care Summary, it is important that members of the public are properly informed and consulted about this. In particular, the focus groups raised concerns about making such information available in community pharmacies, where there were fears that too many people might have access to that information.

Recommendation 6

The public must be kept informed and involved before any significant extension of the availability of personal health information.

6.2 Involving patients and members of the public

There needs to be a greater level of involvement of patients and members of the public in the development of electronic means of information sharing in the NHS, and between the NHS and other agencies. This is partly as it contributes to greater public awareness and public confidence, but also as it will help to highlight areas which may be of concern to members of the public, and which would have the potential to create a backlash of public opinion if not tackled early on. The public backlash against GM food can be seen in retrospect to have been partly as a result of scientific developments having got ahead of public opinion.

Policy documents in the NHS have spoken of electronic records which are 'jointly managed by patients and professional NHS staff'. This implies a significant level of input from patients which will not happen without some effort on the part of those who currently manage patient records.

In Australia, as described in this report, consumer representatives have been involved at every stage in the development of electronic health records.

Recommendation 7

NHS bodies at all levels must ensure that patients and members of the public are informed about and involved in the development of electronic means of information sharing. The newly established Public Partnership Forums would be a useful forum in which to provide information and seek input into developments at local level. Other consultative forums or patient involvement approaches should also be used.

NHS staff also need to be aware of the particular concerns of patients whose health records contain information which is likely to be particularly sensitive, for example in relation to mental health problems or HIV status. Our focus groups showed that these groups did have particular concerns about what information was included in their records and who would have access to it.

Recommendation 8

NHS Scotland should explore the possibility of using a 'sealed envelope' to protect particularly sensitive information which may be part of a patient's electronic health record.

Recommendation 9

NHS staff must ensure that where patients are likely to have particular concerns about the confidentiality of their personal health information, they are given choices about who has access to that information.

6.3 Patient access to their health records

People who want to see their health records at present face considerable barriers. They may have to approach a receptionist, fill in a form, arrange an appointment to discuss the matter with someone like a practice manager, pay an unpredictable fee, and then wait to see what results. Many people have records in different places, such as hospitals and clinics. If they want to see something approaching their entire health record, they will have to approach several different places. It is possible that there is information in the record which they will not be shown, but they do not need to be told this.

In addition, there appears to be an enduring paternalistic attitude in relation to health records, which are often still seen as being the property of the health professional rather than the patient.

The development of electronic health records has the potential to change this, with very much easier access to the entire health record. The ability of patients to see their own record is generally seen to be a positive thing, encouraging the correction of errors (which will become increasingly important if there is a single record) and giving people a greater sense of involvement with their own health. Encouraging patients to look at their records will involve NHS staff in spending time providing the information and sometimes explaining what it means. However, it is likely to become increasingly important to patients that their information is checked and corrected if necessary, and may well be an integral part of people being willing to let their information be shared more widely.

Recommendation 10

NHS Scotland must ensure that new IT systems are able to provide suitable access for patients to see their records.

Recommendation 11

NHS Scotland should ensure that there are staff available who are trained to support patients who want to see their health records.

Recommendation 12

NHS Scotland must ensure that patients are able to correct errors on their health records.

6.4 Ensuring security

Members of the public want breaches of security to be taken very seriously, with significant penalties for breach of confidentiality. It is easy to be complacent about security systems. For example, password systems may be in place which are not used or are routinely abused. New developments in protecting information, such as privacy enhancing technologies, should be explored to ensure that best practice is being followed. Such systems must also be easy for health professionals to follow and use.

Recommendation 13

NHS Scotland should ensure that it has effective systems in place to protect personal health information from unauthorised access and use.

Recommendation 14

NHS Scotland should ensure consistency in its response to cases where data protection principles have been violated, and where personal information has been abused.

Storing information electronically makes it easier to audit who has had access to personal health information, and to identify cases where unauthorised access has taken place. To raise public confidence in the system, NHS bodies should ensure that there is a system of regular internal audit in place, and also that external audits are carried out as appropriate.

Recommendation 15

NHS Scotland should ensure that access to electronic health information is routinely audited both internally, and externally by an independent body, to check that access to health information is only obtained in line with the legal requirements of the Data Protection Act.

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