The Scottish Consumer Council carried out a study into public attitudes towards electronic sharing of personal health information in the NHS. The research report reviews the literature, and reports the results of focus group discussions held in May 2005. 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 extracted from GP records, stored on computer and can be accessed by medical staff in an out-of-hours centre.

Overview of findings
The focus group research supports what has been found in the literature. 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 changes in the way their information is held. The enduring concerns centre on security and how the confidentiality of 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 (about medication, and allergies) being available to medical staff in out-of-hours centres, to make 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 treated.

Many of those who took part in this research supported 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.

Key findings

Literature review
A small scale literature review was carried out, focusing on public attitudes to data sharing, both in general and in the context of the NHS. The following are the key findings from the literature review:

- There are low levels of awareness of how personal information is stored and shared.
- 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 or guarantee about rights and responsibilities.
- The most commonly expressed concerns are about security.
- There is support for the concept of a ‘sealed envelope’ for particularly sensitive information.
- Most people would like to be able to see their own records and have the chance 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 of greater sensitivities in relation to mental health, mental health patients should be involved in deciding who sees their record.

Focus groups
Eight focus group discussions were held in different parts of Scotland. Six were with members of the public. Two were with groups believed likely to have particular concerns about privacy: people living with HIV/AIDS and people using mental health services. Discussion focused on the Emergency Care Summary (ECS), but also discussed more general attitudes to sharing information electronically, and the development of a single electronic health record. The main findings of the focus groups were as follows:
Participants were generally supportive of the use of the ECS, with none saying that they would opt out of this.

The main area of concern was in relation to security and who would have access to the ECS.

People living with HIV were particularly 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 being 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 it to contain only basic emergency information.

People were generally supportive of the ECS being available throughout Scotland.

While no participants would opt out of the system, some preferred restrictions on who could access this information.

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.

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.

Raising public awareness and confidence

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.

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.

Information should be presented on a regular basis. With the introduction of the Emergency Care Summary throughout Scotland, it should be a priority to ensure that clear information in plain English is available for all patients. People would like this information to come into their homes. Information about the Emergency Care Summary should be presented alongside more general information about the increasing use of information technology in the NHS.

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.

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 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;
- make it clear that if patients do not opt out, that this information will increasingly be stored electronically; and
- make it clear who members of the public can complain to if they are unhappy about the way their information has been used.
If the NHS wants to be able to infer implicit consent to the use of the ECS, people must be properly informed of their right to opt out, and the process of opting out must not be made unnecessarily complicated or difficult.

**Recommendation 4**
The NHS must ensure that the process of opting out is not unduly difficult.

While it was not discussed in the focus groups, it is clear from the literature review 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, which sets out the rights and responsibilities of patients and the NHS in relation to how personal health information is stored and shared.

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, members of the public must be properly informed and consulted. In particular, the focus groups raised concerns about making information available in community pharmacies, where there were fears that too many people might have access.

**Recommendation 6**
The public must be kept informed and involved before any significant extension of sharing personal health information.

Involving patients and members of the public

There needs to be more involvement of patients and members of the public in this area. This would contribute to greater public awareness and public confidence, and help to highlight areas of concern which could create a backlash of public opinion if not tackled.

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.

**Recommendation 7**
NHS bodies 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 useful forums 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 need to be aware of the concerns of patients whose health records contain information which is likely to be particularly sensitive.

**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 have particular concerns about the confidentiality of their personal health information, they are given choices about who has access to that information.

Patient access to their health records

The development of electronic health records is likely to make it much easier for patients to access their health record. When patients see their record they can ask for errors to be corrected, and feel more involved in their own health. NHS staff will need to spend time providing access to the record and sometimes explaining what it means. Allowing patients to check and correct their information may be an essential part of people being willing to share their information 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 trained staff available to support patients who want to see their health records.
Ensuring security

Members of the public want breaches of security to be taken seriously, with significant penalties for breach of confidentiality. New developments in protecting information, such as privacy enhancing technologies, should be explored. Such systems must also be easy for health professionals to follow and use.

Recommendation 12
NHS Scotland must ensure that patients are able to correct errors on their health records.

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.

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.

More Information

The full report Health on-line (ISBN 0-9549004-6-4) is available from the Scottish Consumer Council (SCC), price £12.00.

All SCC reports are also published on our website www.scotconsumer.org.uk

The Scottish Consumer Council

The purpose of the Scottish Consumer Council is to make all consumers matter. For more information on what we are doing visit our website at www.scotconsumer.org.uk. The website gives free access to all our reports, campaigns and policy work in progress. SCC reports in printed formats are available from our office at the address below. We are often able to make our publications available in alternative formats.

Please contact us for details
Scottish Consumer Council, Royal Exchange House, 100 Queen Street, Glasgow G1 3DN.
Telephone: 0141 226 5261 Fax: 0141 221 0731 E-mail: scc@scotconsumer.org.uk

Published by the Scottish Consumer Council, October 2005.