Consumers’ knowledge of their health rights

Summary of findings
March 2006

Background
People need a wide range of types of information about health, including information about healthy living, about conditions and illnesses, and about what local services are available. It is also important for people to know about their rights in relation to their health, and what they are entitled to expect from different parts of the NHS. For example, they are entitled to know how personal information about them is used, how to see their health records, or how to complain when something goes wrong.

The concept of rights in relation to health services is complicated. There are some legal rights which can be enforced in a court of law, for example the right that personal health information should be kept confidential, or the right to see one’s own health records. The right to consent to medical treatment derives from the fact that if there is no consent, those providing services could be prosecuted for assault.

But there are also ‘rights’ which derive either from public policy, professional codes of conduct, or standards set by bodies such as NHS Quality Improvement Scotland, where the primary aim is to improve the quality of services in the NHS. Patients’ ‘rights’ are what patients are entitled to expect from the NHS, rather than something they can enforce in court. In this research, we have used a broad definition of rights, to include ‘rights’ which derive from Scottish Executive policy as well as rights which are based in common law or legislation.

This paper summarises research carried out by the Scottish Consumer Council into people’s knowledge of their health rights in Scotland. We commissioned over 1,000 face-to-face interviews with a representative sample of the Scottish population. We also asked our Consumer Network volunteers to ask to see their own health records, to find out what it was like for them to try to exercise their right to see their own record.

Overview of findings
If awareness of rights in relation to health is seen to be a part of health literacy, then it appears that we are still some way from being literate in relation to our health in Scotland. Our research shows that while most people know quite a lot about some aspects of their rights, they are quite uninformed about others, particularly when they are created by new Scottish Executive policy. But unless people know about these rights, it is unlikely that they will be able to benefit from them.

Much of the time people do not need to have a knowledge of their rights at their fingertips. It is only in certain circumstances that this knowledge becomes important. In these kinds of situation, it is more important that people can find out easily what their rights are than that they have a detailed knowledge of them in advance.

Key Findings
Varying levels of knowledge according to age and socio-economic characteristics
In general the variation in the levels of knowledge between different groups in the population was less than the variation in people’s knowledge of different aspects of their rights. However, there are some notable variations between different groups.

Age appears to have an impact on people’s knowledge of their rights. In general, middle-aged people (the 45–64 age group) felt best informed of their rights, and had higher levels of knowledge than either younger people or retired people. They were also more confident of their ability to get the information they needed. The lower levels of knowledge amongst the younger people in the survey may partly be explained by their lower level of use of services.
Unemployed people were less confident about their knowledge of their rights compared with employed people. They were also less sure about how they would get information about their rights, with 47% thinking this would be easy compared with 65% of those in work. Unemployed people had poorer awareness of their right to see someone at their GP within 48 hours, despite being high users of NHS services. They were also less interested in having more information about things like the qualifications of doctors, or the standards in different hospitals. However, unemployed people were better informed about whether personal health information could be shared with the Benefits Agency, an area which is clearly of greater direct relevance to this group of people. Two-fifths of unemployed people (40%) got the correct answer compared with 17% of retired people.

**Variation in knowledge of different rights**

The most striking finding of this research is the extremely variable levels of knowledge in relation to different rights.

There were higher levels of knowledge about GP services. Over 90% of respondents knew about the availability of help for low income consumers, and 82% knew about the right to change your GP. 92% knew that they could refuse treatment. Around half of all respondents knew that GP surgeries should be providing advice or an appointment within two working days, but there were still two in five people who did not know this. Fewer people are aware of their rights in relation to treatment in hospital. For example only 36% knew that you can choose the hospital for your treatment.

There was a poor level of knowledge and awareness of ‘rights’ derived from policy developments, even among those who considered themselves well informed about their rights. This suggests the need for better communication about such policy initiatives so that patients can contribute to the policy being implemented in practice, for example by asking for choices as to where or by whom they are treated.

People did not know that they could not claim financial compensation through the NHS complaints procedure, with only 13% giving the correct answer. While most people will have no experience of using the procedure, or of seeking financial compensation from the NHS, complaints is an area in which it is particularly important to have clear information available. Health Rights Information Scotland, a project based at the SCC, has recently provided NHS bodies with a complaints leaflet which provides the basis for patients having consistently accurate and relevant information on their rights in this area. NHS bodies must make this information available to patients when they need it.

**Recommendation 1**

Where policy gives patients ‘rights’, the Scottish Executive must ensure that people know about these rights, and have the information needed to make meaningful use of those rights.

**Recommendation 2**

In assessing how effectively NHS boards are meeting their requirements to provide a patient-focused service and to involve the public in their work, the Scottish Health Council should monitor how effectively information about the NHS complaints procedure is being provided to patients.

A question about dental services was poorly answered, which confirms the SCC’s belief that many consumers in Scotland are confused about dentistry, not being sure what they are entitled to, or what to do if they cannot find a dentist to treat them on the NHS. The research suggests the need for some generic information for patients about their rights in relation to dental services.

**Recommendation 3**

The Scottish Executive should provide clear information for patients on their rights to NHS dental services in Scotland.

**Access to health records**

Our research shows that a high percentage of the population, particularly those aged between 25 and 65, know that they have a right to see their health records, but most have never seen their records and have never wanted to. There are much lower levels of knowledge about how the NHS can use and share the information in health records.
There were extremely low levels of knowledge of what people could be charged for looking at their health records. At the same time, our research with our Consumer Network shows that staff may be giving incorrect information about what this costs. If we are to move to a situation in which people are more involved in their own health and healthcare, people need to be encouraged and enabled to look at their own record, if they want to do this.

**Recommendation 4**
Those responsible for training front line staff in GP surgeries, health centres and hospitals must ensure that staff are properly trained to provide accurate information and advice to patients who want to look at their own health record.

**Recommendation 5**
The Scottish Executive Health Department should ensure that in the move towards a single electronic health record, patients are encouraged to check what is contained in their record. They should ensure that access to their records by patients is made easy by the design and structure of the new system.

**Sources of information about patients’ rights**
The research shows that around two-thirds of the public would seek information about their rights as a patient from their GP surgery. No other source of information was anywhere near as popular. The internet came second, with 27% of respondents, although among the younger respondents this figure increased to 40%. Health boards and the NHS Helpline would be used by 18%, and NHS 24 trailed, with only 3% of respondents.

To design a system in which there is confidence that people can get the information they need when they need it, it is important either to improve people’s awareness of where they can find information, or to make use of the places where people currently say they would seek information.

While many people stated that they would go to their GP surgery, it is unlikely that most surgeries would be able to respond to people’s information needs in the area of patients’ rights. Providing information about people’s rights is unlikely to be seen as a key part of the work of a GP surgery. Nonetheless, if this can be
Recommendation 7
The Scottish Executive Health Department should consider how GP surgeries could be encouraged to play a part in ensuring that patients in Scotland are able to access the information they need.

For those who said they would use the internet, there is a problem about knowing whether they will be able to find appropriate, relevant, quality assured information. A search on the internet for information about people’s rights is as likely to produce sites in other parts of the world, sites which are out of date, or sites which contain false or misleading information.

It is for these kind of reasons that some people within the NHS in Scotland have been promoting the concept of a single electronic gateway to quality assured patient information. NHS 24 already has information about self care and medical conditions on its web site, but does not have any information about health rights at present.

The Health Rights Information Scotland (HRIS) website provides access to information on patients’ rights produced by HRIS. If this was well publicised in GP surgeries, many people’s needs for information in this area would be met.

Recommendation 8
The Scottish Executive should take forward the proposals to develop and promote a single gateway to patient information on the internet, but bearing in mind the need to ensure that this information can also be accessed in other ways.

Alternative formats
The research does not allow us to make any clear recommendations about people’s need for information in other languages or alternative formats, although there was a significant percentage of older respondents who would like information in larger print. As a matter of good practice it is important that people who need information in another format or language are able to get this when they need it.

More Information
The full report Consumers’ knowledge of their health rights (ISBN 0-9551942-1-0 (10 digit) 978-0-9551942-1-4 (13 digit)) is available from the Scottish Consumer Council (SCC), price £10.

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 web site at http://www.scotconsumer.org.uk. The web site 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. March 2006.