consumers’ knowledge of their health rights
About the Scottish Consumer Council

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.

Consumers benefit from efficient and effective services in the public and private sectors. Service-providers benefit from discriminating consumers. A balanced partnership between the two is essential and the SCC seeks to develop this partnership by:

- 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 assesses the consumer perspective in any situation by analysing the position of consumers against a set of consumer principles. These are:

**ACCESS**
Can consumers actually get the goods or services they need or want?

**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**
Are standards as high as they can reasonably be?

**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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Chairman’s preface

We are increasingly being told that members of the public must become more involved in their own health. People must take more responsibility for making healthy choices, and when they need to make use of health services, they should be partners in their own care, rather than passive recipients of what the NHS offers. They should be active and informed, and able to share in decision making. To be an active, informed patient means knowing more about one’s own health, understanding the choices which are available and having enough information to make choices.

We thought it would be interesting to explore one aspect of what is now called ‘health literacy’. We asked people in Scotland how much they felt they knew about their rights in relation to health, and we checked how much they really did know. Our findings are based on interviews with just over 1000 people from all over Scotland. This research shows that while most people know quite a lot about some aspects of their rights, they are quite uninformed about others. In particular, where a new policy is introduced by the Scottish Executive it can give rise to what can be described as ‘rights’, even if they are not enforceable in law. But unless people know about these rights, it is unlikely that they will be able to benefit from them.

We were surprised by the low level of awareness of how people’s personal health information could be used and shared, both within the NHS, and outside it. For example, almost half of those interviewed incorrectly believed that information about their health could be passed to the Benefits Agency, and almost a quarter did not know whether this was true.

It is also important that people are able to get information about their rights when they need it. The report makes recommendations about raising people’s awareness of where they can get information about their rights, and also about making sure that information is available in the kind of places where people say they are most likely to look, which at present is at GP surgeries. We also recommend that better use is made of the internet as a source of information for patients, so that it is easier for members of the public in Scotland to get access to reliable, up-to-date information about their rights.

This report uncovers concerns which we hope will be addressed constructively by the Scottish Executive and by other organisations working with the NHS in Scotland, so that patients can increasingly take more responsibility for their own health and make informed choices about their healthcare.

Graeme Millar
Chairman
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Acknowledgements

MORI Scotland carried out the face-to-face interviews on which this report is based. The data was further analysed by Andrew Pulford, SCC’s Researcher.

The research was overseen by the SCC’s Health and Social Care Committee. The members at the time were John Hanlon (chair), Liz Breckenridge, Isabelle Low, Mukami McCrum, Richard Norris, Helen Tyrrell, Graeme Millar (ex officio), Heather Brash (ex officio), and Martyn Evans (ex officio).

The report was written by Liz Macdonald, Policy Manager, and Andrew Pulford, Researcher at the SCC.
Background and aims

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 to meet their needs. 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, and how to complain when something goes wrong.

Knowledge of health rights is one aspect of health literacy, about which the NCC has recently published a report. The NCC has defined health literacy as ‘the capacity of an individual to obtain, interpret and understand basic health information and services in ways that are health-enhancing’. Health literacy is important in relation to managing one’s own health but also in connection with making choices about health services. To exercise greater control over their health, people need information, knowledge and understanding. They also need the skills to identify their information needs, and to know where to find that information.

1.1 What are health rights?

The concept of rights in relation to health services is complicated. There are some legal rights which could be enforced in a court of law, for example the right that personal health information should be kept confidential and only used and shared in accordance with the Data Protection Act, 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 a wide range of ‘rights’ which derive not from common law or from statute, but 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. Many of the things which have been described as rights in recent years are based on the Patient’s Charter of 1991. In many of these areas, patients’ rights are what patients are entitled to expect from the NHS, rather than something they can enforce in court. If the Health Minister announces that by the end of 2007, no patient should have to wait longer than 18 weeks from a GP referral for a hospital out-patient appointment, then for most people that sounds like a ‘right’ to get an appointment within 18 weeks.

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1 S Sihota and L Lennard, *Health literacy: being able to make the most of health*, NCC, London, 2004
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.

If people know that they have these ‘rights’, they can contribute to the process of driving change and quality improvement within the NHS by asking for these rights to be respected, and made a reality for them.

### 1.2 Reasons for doing the research

The SCC considered that it would be useful to have some baseline information about how much members of the public know about their health rights, and about where they would go to get information in this area. This would provide evidence of the level of need for information, and also provide some insight into areas in which there might be a need for more information or support for members of the public.

The Health Rights Information Scotland project (HRIS), based at the Scottish Consumer Council, is involved in producing information for patients on a range of topics related to their rights in relation to healthcare. It was considered useful in relation to assessing the impact of this project if we had more information about how much people know about their rights, and about any particular areas where it appeared that they needed more or better information.

### 1.3 Aims and objectives

The aim of the research was to explore how much members of the public know about their rights in relation to health. It was also hoped that we would be able to identify:

- issues about which there was a particular need for more information;
- where people expected to find this kind of information; and
- whether there were any significant differences between different groups, for example in relation to age, social class, employment status, etc.

The areas to be explored included areas in which HRIS has been working to produce information for patients, for example:

- how to make a complaint about NHS services;
- how to see one’s health records; and
- how personal information about people’s health should be used and shared.
1.4 Methods

The Scottish Consumer Council (SCC) contracted MORI Scotland to carry out face-to-face interviews with a representative sample of the Scottish population to assess the extent of knowledge of their rights in relation to the health service. During April and May 2005, 1015 members of the general public were interviewed as part of the MORI Scotland Social Policy Monitor. The data has been weighted by local authority, age and sex using the 2001 census data.

In parallel with this survey work, we asked the SCC Consumer Network volunteers if they would ask to see their health records. They were given a short questionnaire to fill in to record their experiences. The findings provide some evidence both of how people felt about exercising their right to see their health records, and also of the barriers to their doing so, for example, if they were given incorrect information about what it would cost.
2 Respondent profile

Over three-quarters of respondents were found to have used National Health Service (NHS) services two or more times in the previous year, with 40% using NHS services between two and five times, 17% using services between six and ten times and 21% having used NHS services more than ten times in the last year. Nine per cent reported never having used NHS services in the last year, while 13% had done so on only one occasion.

The following groups were found to have been more likely to have used NHS services more than ten times in the previous year: those aged 65 and over; those not in employment, whether unemployed, unable to work or retired; and those living in rented accommodation.

Just over one-fifth of respondents felt that they knew a lot about their health rights, while slightly fewer (16%) said they knew nothing about their health rights. Thirty-six per cent felt that they knew a bit about their health rights and just under one quarter knew very little.

Only 4% of unemployed respondents felt that they knew a lot about their rights compared with 25% of those employed or unable to work and 22% of retired respondents.
Respondents aged 45–64 were more likely than older or younger respondents to feel that they knew a lot about their rights as NHS patients. Around two-thirds of this age range felt that they knew a bit or a lot about their health rights, compared with 49% of those aged 16–24.

Perhaps unsurprisingly, those who had seen their own health records were more likely to feel they knew about their health rights than those who had not. More than three-quarters (77%) of those who had seen their health records (75 people in all), felt they knew a lot or a bit about their health rights, compared with 57% of those who had not.
3 Getting information about your health rights

It is important that when consumers want to find out about their health rights that they can access this information easily and in an appropriate format. The survey asked how easy or difficult respondents thought it would be to get information about their rights as an NHS patient; where they would go to find out more about their rights; and whether it would be helpful to receive information in large print, a language other than English, or some other format.

“Sixty-two” per cent of respondents felt that, if they wanted to, it would be fairly or very easy to get information about their rights as an NHS patient. Just under one-fifth (17%) thought that it would be fairly or very hard to get this information.

Unemployed respondents appeared to be less confident about obtaining information about their rights as NHS patients. Forty-seven per cent felt that it would be easy compared with 59% of retired respondents, 57% of those unable to work and 65% of those currently in employment. Almost one-quarter of unemployed respondents did not know whether it would be easy or difficult to get information about their health rights.

Respondents who felt more knowledgeable about their health rights were also more likely to feel that it would be easy to obtain information about their rights as an NHS patient. 75% of those who reported knowing a lot or a bit about their health rights felt that it would be easy to get this kind of information compared with 44% of respondents who knew little or nothing.
The survey then asked respondents where they would go to find out more information on their rights as NHS patients. They were shown the following options:

- CAB or other advice agency
- Dental practice
- Friends and family
- GP surgery
- Health board
- Healthy living centre or community health project
- Internet
- Local library
- NHS helpline
- NHS 24
- Pharmacist
- Other
- None/Nowhere
- Don’t know

The most common answer given was GP surgery, with almost two-thirds of respondents choosing this option. This is in line with recent research by the Welsh Consumer Council which showed that a large majority would like to get health information from their GP surgery.³

Just over one-quarter (27%) reported that they would use the internet. This option was more popular among younger respondents – 40% of those aged 18-24 would consider using the internet compared with just 4% of those aged 65 or over. Less deprived respondents were also more likely to consider the internet as a source for finding out more about their rights as NHS patients. Twenty-six per cent of the least deprived selected the internet, while only 20% of the most deprived did so. Just under one-fifth would go to their health board or the NHS Helpline (both 18%) to find out more about their health rights.

Ten per cent of respondents indicated that they would go to a Citizens’ Advice Bureau or another advice agency. The same percentage regarded friends and family as a potential source for obtaining more information about their rights as NHS patients. Only 3% said they would go to NHS 24 for information.

These figures suggest that NHS 24 has some way to go before it can be regarded as the first port of call for people seeking health information. Recognition of the NHS Helpline is relatively high in contrast, and six times higher than NHS 24. This may be partly due to the title ‘helpline’ more clearly describing its purpose, and shows the importance of choosing appropriate titles for such services.

³ S Richards, In Sickness and in Health: consumer access to health information, Welsh Consumer Council, Cardiff, 2005
A small number of respondents were found to want information about their rights as an NHS patient in alternative formats. Eight per cent would have liked to receive the information in large print and 1% in a language other than English. Almost one-fifth of retired respondents indicated that they would like to receive information in large print. Respondents who felt they knew a bit or a lot about their health rights were found to be less likely to want to receive information in alternative formats. Ninety-one per cent of those who felt they knew a bit or a lot about their health rights did not wish information in an alternative format, compared with 83% of those who knew little or nothing about their health rights.
4 Knowledge of rights as an NHS patient

To test people’s knowledge of their rights, we presented them with a list of statements and asked them to indicate whether they believed them to be true or false. We also asked how quickly they believed they should get advice or an appointment from a GP surgery.

<table>
<thead>
<tr>
<th>Statement</th>
<th>True or false</th>
<th>Correct</th>
<th>Incorrect</th>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>People on a low income can get help with NHS costs, for example the cost of prescriptions</td>
<td>True</td>
<td>93%</td>
<td>2%</td>
<td>5%</td>
</tr>
<tr>
<td>You can refuse treatment even if recommended by your doctor</td>
<td>True</td>
<td>92%</td>
<td>4%</td>
<td>4%</td>
</tr>
<tr>
<td>You can change your GP at any time</td>
<td>True</td>
<td>82%</td>
<td>11%</td>
<td>7%</td>
</tr>
<tr>
<td>The NHS will provide an interpreter, if you need one</td>
<td>True</td>
<td>78%</td>
<td>3%</td>
<td>18%</td>
</tr>
<tr>
<td>If you are registered with a dentist, you can insist on getting treatment on the NHS</td>
<td>False</td>
<td>47%</td>
<td>33%</td>
<td>20%</td>
</tr>
<tr>
<td>You can choose your hospital for treatment on the NHS</td>
<td>True</td>
<td>36%</td>
<td>49%</td>
<td>15%</td>
</tr>
<tr>
<td>You can choose the consultant who treats you in an NHS hospital</td>
<td>True</td>
<td>21%</td>
<td>59%</td>
<td>20%</td>
</tr>
<tr>
<td>You can receive financial compensation through the NHS complaints procedure</td>
<td>False</td>
<td>13%</td>
<td>51%</td>
<td>36%</td>
</tr>
</tbody>
</table>

In some areas there were found to be high levels of knowledge. However, there were also some clear gaps in people’s knowledge.

Over 90% of respondents were aware that people on a low income can get help with NHS costs and that you can refuse treatment even if recommended by your doctor. Surprisingly, older people (over 65) were more likely to answer ‘don’t know’ to the first statement (12%, compared with 1% of those aged 45-54). With both these questions the highest percentages of correct answers came from the 45-64 age group.

The next most correctly answered statements were that you can change your GP at any time and that the NHS will provide an interpreter, if you need one. Around four-fifths correctly identified these statements as true. There were more people over the age of 65 (26%) and people in rented housing (24%) who answered ‘don’t know’ to the question about whether interpreters should be provided.
Some of the questions involve ‘rights’ which derive from policies which are in their early stages, and which people are less likely to know about. For example, with the creation of the National Waiting Times Database, it is now possible for patients, in discussion with their GPs, to make choices about which consultant treats them. This can be in any hospital, and does not even need to be in their own health board area. It is probably not surprising that only 21% of respondents were aware of this, with slightly more (36%) being aware that they could choose the hospital. As most people’s contact with the NHS is at primary care level (for example, with a GP or dentist), it is also to be expected that there would be a lower level of knowledge about patients’ rights in relation to hospital care. Even among those who claimed to know a lot or a little about their health rights, only 24% thought that you could choose the consultant who treated you.

It is important to be aware that in this area (rights derived from policy developments), there is probably an additional source of confusion for some Scottish citizens: whether the situation is the same in Scotland as in England and Wales. News report in the mass media, or public advertising, often do not distinguish between whether they are referring to the UK as a whole or only to England and Wales.

Almost half knew that if you are registered with a dentist, you cannot insist on getting treatment on the NHS (47%). Overall, one-third of respondents thought that you could insist on NHS treatment, which seems a surprisingly high percentage. A large minority (20%) did not know, with higher levels of don’t knows among lower socio-economic groups. Older and younger groups were less likely to answer this statement correctly (16-24 and 65+). Only 38% of retired respondents answered this statement correctly compared with 58% of those in employment.

The general policy in relation to NHS complaints has been that financial compensation is not available, and information about NHS complaints has usually stated that if you want financial compensation you should seek legal advice. Only 13% of respondents were aware that the NHS complaints procedure cannot award financial compensation. Again, slightly higher percentages of those in the 35-44 and 45-54 age brackets got this right (17% and 18% respectively). This was the only statement that was not identified by a higher percentage of respondents who felt they were very/quite well informed about their rights as NHS patients, compared with those who felt they knew little or nothing. This low lack of awareness may reflect a lack of use of the NHS complaints procedure.

4.1 Getting advice or an appointment at GP surgeries

GP surgeries are obliged to provide advice or an appointment within 48 hours (two working days) of a patient contacting them. We asked respondents how quickly they believed their GP surgery was required to provide them with either advice or an appointment.
Just under half the respondents (48%) were able to correctly identify 48 hours as the time scale that GP surgeries are required to provide either advice or an appointment. Seven per cent thought that an appointment or advice must be given within 24 hours/the same day. Almost one-fifth (16%) thought that the correct timescale was a week, while 4% thought that it was two weeks. A fifth (20%) did not know what the timescale was. Another 5% gave an answer which did not fit any of our options.

Unemployed respondents were less likely to answer correctly, with only 32% doing so. Since the policy was only introduced in April 2004 we would expect that those who make more frequent use of services are likely to be more aware of it than infrequent users. This would help explain the low levels of awareness among younger respondents, but appears to be contradicted by the higher percentage of wrong answers among unemployed people, who are quite high users of the service.

### 4.2 Information about doctors and hospitals

Respondents were asked whether they would like more information on the quality of different hospitals, and also the experience or track record of particular doctors or surgeons. Just over one-third displayed an interest in receiving more information on the quality of different hospitals, while 45% indicated that they would like more information on the experience or track record of particular doctors or surgeons.
Unemployed respondents were found to be less interested in receiving more information on the quality of service provided in different hospitals, just 21% compared with 38% of employed respondents. Thirty-nine per cent of respondents were not interested in receiving more information about either aspect of the NHS. This figure was higher among those who did not know much about their health rights (44%), respondents aged 16-24 (44%) and those aged 65+ (48%).

If patients are given more choice over where they are treated and who is responsible for their treatment, this is the kind of information which might be considered useful. But since our findings show that people are unaware of this choice, it is perhaps not surprising that they do not show much interest in information which would support such choices.
One particular area of interest to SCC was patients’ knowledge of their rights in relation to their health records. Again, respondents were asked to indicate whether they thought a series of statements were true. They were also asked whether they had seen, or tried to see, their health records; and how much they thought they could be charged to access their health records.

5.1 Knowledge of rights in relation to health records

The table below shows the statements shown to respondents ranked by the level of correct response. Again, there were high levels of knowledge relating to some issues relating to health records, while the level of knowledge in other areas was found to be worryingly low.

<table>
<thead>
<tr>
<th>Statement</th>
<th>True or false</th>
<th>Correct</th>
<th>Incorrect</th>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information about you can only be used for research if you have agreed</td>
<td>True</td>
<td>86%</td>
<td>6%</td>
<td>8%</td>
</tr>
<tr>
<td>You have no right to see your health records</td>
<td>False</td>
<td>85%</td>
<td>8%</td>
<td>7%</td>
</tr>
<tr>
<td>Only NHS staff caring for you can look at your health records without your permission</td>
<td>True</td>
<td>57%</td>
<td>26%</td>
<td>17%</td>
</tr>
<tr>
<td>There are no age restrictions on when you can see your health records*</td>
<td>True</td>
<td>46%</td>
<td>35%</td>
<td>20%</td>
</tr>
<tr>
<td>Information about your health can be passed on to the Benefits Agency</td>
<td>False</td>
<td>30%</td>
<td>46%</td>
<td>24%</td>
</tr>
<tr>
<td>Your doctor can refuse to show you part of your health records*</td>
<td>True</td>
<td>17%</td>
<td>66%</td>
<td>16%</td>
</tr>
<tr>
<td>If you go to an Accident and Emergency department (casualty), staff there will be able to look at information about your health on computer</td>
<td>False</td>
<td>17%</td>
<td>68%</td>
<td>16%</td>
</tr>
</tbody>
</table>

* These statements were only shown to those who correctly identified ‘You have no right to see your health records’ as false.

Respondents were found to be most knowledgeable regarding whether information about them could only be used for research if they had agreed (86%) and whether they had the right to see their health records (85%). There was a higher percentage getting the latter question right from respondents aged between 25 and 64.
Almost 60% knew that only NHS staff caring for them could look at their health records without asking their permission, though this dropped to 51% of those unable to work and 52% of those aged 16-24.

Data sharing with other agencies
Under one third of respondents (30%) correctly identified the statement ‘Information about your health can be passed on to the Benefits Agency’ as false. Unemployed respondents were more likely to know this than respondents from other economic groups, with 40% identifying this statement as false. The figure was lowest among the retired (17%). Almost half of respondents thought this statement was true (47%) which seems surprisingly high. Almost a quarter (24%) did not know, with lower numbers of don’t knows among those aged 35-54.

Accident and emergency
The final statement was ‘If you go to an Accident and Emergency department (casualty), staff there will be able to look at information about your health on computer’. The answers to this question tell us something about the perception of members of the public about the way the NHS currently stores and shares the information held in health records. At present, GPs and hospitals have their own computerised systems, which are generally not accessible to anyone outside that particular organisation. Although there are moves afoot to develop a single electronic health record which could be accessed from any location where a patient is receiving care, we are still far from the reality of this.

Over two-thirds of respondents (68%) thought that staff in A&E would be able to look at information about patients who presented at an A&E department. Respondents aged 16-24 and 65+ were found to be less likely to answer this statement correctly. Most people only attend A&E departments on a very occasional basis, if at all, and so it is unlikely that the hospital would hold any information about the vast majority of patients. Only 17% of respondents indicated that they thought this statement was false, with a further 16% saying that they did not know. This does suggest that there might not be huge public resistance to the idea of a single electronic health record, if people think that this is happening already. Respondents who considered themselves knowledgeable about their health rights were slightly more likely to answer correctly than those who did not.

Age limit
Whether you are able to see your health records depends on whether you are considered to be able to understand them. There is no age limit as such. With children under the age of 12 there is a presumption that they will not be able to understand them, while for young people of 12 or over there is a presumption that they can understand them. In each case, it depends on the ability of the particular child or young person, rather than on their age. We asked whether respondents believed
that there were age restrictions on when you could see your health records. Of those who believed that they had a right to see their health records, under half (46%) were aware that there are no age restrictions on when you can see your health records.

There was a low awareness of the fact that a doctor can decide that there are some parts of your health records which you should not see. This is the case where it might cause harm to your own or someone else’s health, or where the record would reveal the identity of someone else. Less than one-fifth of our respondents (17%) knew that their doctor could refuse to show them part of their health records.

For all the statements relating to access to health records, a higher percentage of respondents who felt that they were very/quite well informed about their rights as an NHS patient answered correctly, compared with those who felt that they knew little or nothing.

### 5.2 Accessing health records

The majority of respondents had never seen their health records and had not wanted to (69%). Only 7% of respondents had seen their health records, while a further 11% would like to see their health records but had not requested them. One per cent had requested access to their health records but had not seen them. Eleven per cent said that none of the possible answers applied to them. Of those who had seen their records, there were slightly higher numbers among 35–44 year olds (13%), and those unable to work (12%).
**Fees and charges**
To see their health records, consumers have to pay a fee, unless the record has been added to in the preceding 40 days, and they only want to look at it. Otherwise, the fee to look at health records can be up to £10. If patients want a copy of any part, this can cost up to £50 in total, unless the records are held on computer, in which case it costs up to £10 to get a printout. We were interested to find out whether consumers in Scotland were aware of this. There appeared to be extremely low levels of knowledge in relation to charges for accessing health records.

The majority of respondents (56%) thought that there would be no charge for accessing health records, while 28% indicated that they had ‘no idea’ what they could expect to be charged by their GP or hospital. The cost identified by those who thought there would be a charge varied from £1 to £500, with a mean of £24.

<table>
<thead>
<tr>
<th>Nothing, it would be free</th>
<th>56%</th>
</tr>
</thead>
<tbody>
<tr>
<td>£1-5</td>
<td>2%</td>
</tr>
<tr>
<td>£6-10</td>
<td>5%</td>
</tr>
<tr>
<td>£11-20</td>
<td>3%</td>
</tr>
<tr>
<td>£21-30</td>
<td>2%</td>
</tr>
<tr>
<td>£31+</td>
<td>2%</td>
</tr>
<tr>
<td>No idea</td>
<td>28%</td>
</tr>
</tbody>
</table>

It is increasingly recognised that it can be beneficial for patients to see their health records. Patients can ensure that the information in their record is correct and up to date, which will become more important as the record begins to be held electronically, and is accessible to staff in other parts of the NHS, such as out-of-hours centres or A&E departments. There can also be health benefits for patients who may be more likely to see themselves as partners in their own health, rather than passive recipients of care. Once there is a single electronic health record, patients are likely to have easier access to their records, which ultimately could be accessed on the internet in the same way as bank accounts. There appear to be significant barriers to people accessing their health records at present, including lack of knowledge about how to do so, and about costs.

### 5.3 Consumer Network experience of accessing health records

Members of the SCC’s Consumer Network asked to look at their health records, and recorded their experience of doing this. A full report of their experience of doing this is available. A relatively small number of volunteers took part (27), and the results should not be taken as being representative. However, they do provide some insight into what happens when people ask to see their health record, and what some of the barriers to that may be.

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4 Consumer Network, *Getting access to personal health records*, SCC, Glasgow, 2005
The majority of network volunteers who took part in this exercise found it relatively easy to ask to see their health records. Most people were given information about what it would cost, which was usually accurate, and most got access to their health records within the time limits.

Only small numbers experienced any difficulty in accessing their record, or found mistakes or omissions. One person commented that s/he had read something in the file which had happened in 1960, and which explained a great deal about how s/he had been subsequently treated, but which s/he had never known about. This demonstrates that even if the number of people finding mistakes or uncovering information they had not known about is very small, it can still be quite significant for those people.

Perhaps the greatest concern is that staff gave patients incorrect information about the cost of accessing their record, and even in one case about whether they could access their health record at all. Two volunteers were wrongly charged for seeing their record, when it had been added to within the previous 40 days. Some volunteers were given incorrect information about how much charges would be, and even whether they could ask for a copy of their record. If people are told that it will cost considerably more than it ought to, it will not be surprising if they are deterred from looking at their records.

As we move towards a single electronic record, and one which, in all likelihood will be accessible through a web link, it is important that people are encouraged to see the advantages of being able to access their health records. Staff must begin to move from a culture which has traditionally been protective of patient records, to one which is open to the idea of patients checking their records, and increasingly taking a share in managing them.
6 Conclusions and recommendations

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. There are large areas covered in this work where people’s knowledge of their rights is very low. While the Health Rights Information Scotland project, working with NHS boards and the Scottish Executive, is likely to play a key role in improving people’s knowledge of their rights, attention also needs to be given to how people access this kind of information and how to make the most effective use of the structures and systems which already exist.

Having said this, 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.

6.1 Varying levels of knowledge according to age and socio-economic characteristics

In general the amount of variation in the levels of knowledge between different groups in the population was less than the amount of 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) were the 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 among 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 less sure about how they would get information about their rights, with under half believing this would be easy, compared with 59% of retired people, and 65% of those in employment. 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.
Finally, there appeared to be higher percentages of ‘don’t knows’ among the more deprived groups, and in lower socio-economic groups.

6.2 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.

In Chapter 4, people’s knowledge of their rights as NHS patients was quite high in four areas, quite poor in two areas (with less than half getting the answer correct), and very poor in the final two. Similarly, in Chapter 5 which focuses on health records, there was quite high awareness in two areas of people’s rights, moderate awareness in three (with between 30% and 57% getting the answer right), and very poor levels in the final two (with 17% giving correct answers).

Levels of knowledge of people’s rights as NHS patients

There were higher levels of knowledge about GP services, perhaps because this is the area in which there is most patient contact with the NHS. The highest levels of awareness were about the availability of help for low income consumers, the right to change your GP, and the right to 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 either got the answer wrong, or did not know the answer. This policy was introduced in April 2004 and so had been in place for just over a year at the time of the survey. This could be regarded as a reasonably encouraging response rate, although there are clearly still considerable numbers of people unaware of the policy.

It is probably not surprising that fewer people are aware of their rights in relation to treatment in hospital, as fewer people have personal experience of this. One of the areas covered looked at ‘rights’ derived from recent policy developments, for example in relation to increasing the role of choice in the NHS. There was a poor level of knowledge and awareness in these areas, even among those who considered themselves the most informed of our respondents. This suggests the need for policy initiatives to be more effectively communicated to patients if they are to contribute to the policy being implemented in practice, for example by asking for choices as to where or by whom they are treated. Another example is the right to see someone at the GP surgery within 48 hours, which has already been discussed.

Information about the quality of hospitals or particular doctors

There was not a huge demand for more information about the quality of hospitals or of particular doctors. This is probably because not many people are aware that they have any choices in this area.
If the Scottish Executive wishes to promote the concept of greater patient choice, there will be a knock-on effect on the kind of information which patients will be seeking. More thought will need to be given to how patients can be supported to make meaningful choices, in a way which will contribute to services being provided more efficiently. For example, information about the standards of different services may be needed.

**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 them.

**Complaints**

The statement in the research about the right to financial compensation through the NHS complaints procedure was poorly answered, but this is probably not surprising, as most people will have no experience of using the procedure, or of seeking financial compensation from the NHS. Complaints, however, is an area in which it is particularly important to have clear information available at the point when patients need it. Health Rights Information Scotland, a project based at the SCC, has recently provided NHS bodies with a complaints leaflet which has been extensively consulted on, and should provide the basis for patients having consistently accurate and relevant information on their rights in this area across Scotland. The important thing is that NHS bodies make this information available to patients when they need it.

**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.

**Information about dental services**

The 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.
6.3 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, with almost half believing that the NHS can share information with the Benefits Agency.

There were extremely low levels of knowledge of how much 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 records.

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 records.

Recommendation 5

The Scottish Executive Health Department should ensure that in the move towards a single electronic health record, patients should be encouraged to check what is contained in their records. They should ensure that access to their records by patients is facilitated by the design and structure of the new system.
6.4 Awareness of information sharing

The research suggests that many think that there is much more information sharing going on both within the NHS and between the NHS and other agencies than is the case. This would suggest that a huge public backlash to the idea of single electronic health records, which could be accessed in different parts of the NHS, may be unlikely. Caution should be exercised in relying on the survey as providing this evidence, as the question was not presented in these terms.

A surprising number of people (almost half of those surveyed) also appeared to believe, incorrectly, that information about people’s health could be passed to the Benefits Agency. There was also a particularly high percentage of people who said that they did not know, in answer to this question (24%). This is a particularly serious finding for the NHS, as it is a requirement of fair processing of data under the Data Protection Act that people should be informed about how their personal information will be used and shared. Indeed, the Scottish Executive Health Department has been putting considerable effort into ensuring that patients are properly informed of this.

There are various possible explanations for the low levels of knowledge in this area. One is that people have not been in contact with the NHS recently, in circumstances in which they would be given such information. Information should now be provided in GP practice leaflets, but these are generally only given to the patient at the point of joining the practice as a patient. Similarly people who attend an appointment at a hospital should be given information about how their information will be held and shared, but only a minority are likely to fall into this category.

Another explanation is that the information is not being read by patients, or is not clear enough about this topic. It is beyond the scope of this research to provide an answer to why people’s awareness of their rights in this area are so poor, but given the requirements of the Data Protection Act that people do have this information, it is clearly an area in which it is important to monitor the effectiveness of information provision.

Recommendation 6

The Scottish Health Council should monitor how effectively patients are being informed of how their personal health information is being held and shared.
6.5 Sources of information about patients’ rights

The research shows that a significant majority (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, with the internet coming second, but with only 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.

The challenge of ensuring that people can find the information they need is considerably greater than the challenge of creating good information which meets people’s needs. 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 achieved, the Scottish Executive should consider how GP surgeries could be used to provide information for patients more effectively. This might involve changes to the GP contract, or encouraging links with local citizens advice bureaux.

**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 kinds 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 in Scotland.\(^5\) NHS 24 would seem the obvious organisation to develop such a single point of access, in a similar way to NHS Direct in England and Wales. There is some information about patients’ rights on NHS Direct, for example information about the NHS complaints procedure, and information about how to access health records, although the site does not bring this information together under a general category of information about people’s rights.

\(^5\) http://www.ehealth.scot.nhs.uk/WordDocs/Practice/Info%20for%20patients%20Report%20for%20Minister%20v0.3.doc
At present, the Health Rights Information Scotland (HRIS) web site 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.

### 6.6 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.