



**Health Rights
Information Scotland**

Stakeholder Evaluation Report



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1. EXECUTIVE SUMMARY

Background

Health Rights Information Scotland (HRIS) is a joint initiative of the Scottish Consumer Council and Scottish Government Health Directorates which aims to produce and raise the quality of information available for patients about their rights when using NHS Services in Scotland. In addition, HRIS provides support and advice to other organisations involved in the production of patient information.

HRIS staff work to raise and maintain the awareness of the project and its remit amongst NHS staff, particularly those involved in information production. To achieve this, the project has established an extensive network of stakeholders involved in, or interested in, producing and distributing health rights information to the public both within and outside the NHS.

George Street Research was commissioned by HRIS to conduct an independent evaluation to establish the views of these current stakeholders. HRIS were also keen to establish the views of users of the information namely, the general public.

Aims

The key aims of this study were:

1. To establish the extent to which key organisational stakeholders consider that HRIS has been able to fulfil its role in terms of:
 - (a) Producing information about patients' rights
 - (b) Providing support for other bodies that produce patient information.
2. To establish the awareness and usefulness of health rights information among the general public.

Methodology

George Street Research used a combination of qualitative and quantitative techniques comprising a number of different elements. Semi-structured telephone interviews were conducted with 120 key organisational stakeholders. Second, to access the views of the general public, a range of questions were included as part of the Scottish Opinion Survey which was administered by interviewing face to face, a sample of 1,000 adults in Scotland aged 16+. Third, to identify users of HRIS information, a link to an online recruitment survey was placed on the HRIS website as well as the websites of a range of patient support groups. Finally, a qualitative phase of research was undertaken in the form of telephone depth interviews with people recruited in this way, to explore in-depth how the information contained in the leaflets was used.

Key Findings

PUBLIC PERSPECTIVE

Awareness of sources of health rights information

The quantitative research revealed that, when looking for health rights information, the public would go to GP Surgeries / Health Centres to acquire information about their rights (54%). Nine percent would go to a Citizen's Advice Bureau and 8% refer to Health Board websites. The most frequently mentioned sources of information after prompting were GP surgery / health centre (73%), Citizen's Advice Bureaux (32%), NHS 24 (29%) and Pharmacist (28%).

Awareness of health rights information

There appears to be limited recognition of health rights information amongst the public. Seven in ten respondents (69%) did not recognise any of the leaflets, of those who did recognise a leaflet, 51% had not read any of the leaflets and 72% had not kept any leaflets for future reference. The most recognised leaflets are:

- *Your Emergency Care Summary: What does it mean for you?* (12%)
- *The NHS and you* (10%)
- *The NHS Minor Ailment Service at your community pharmacy* (9%)

Use & impact of health rights information

Of those who had read one or more leaflets, 31% felt they knew more about their rights and 23% knew where to go for more information or support. Almost all (91%) described the advice provided in the leaflets as useful to any extent.

Awareness & use of alternative formats

In terms of the provision of leaflets in other available formats and languages 48% of respondents who recognise or have read more than one leaflet were aware that leaflets are available in large print and 41% were aware of leaflets produced in other languages. Only a limited number had used the leaflets in any alternative format or language.

PROFESSIONAL PERSPECTIVE

Awareness of HRIS leaflets

Almost three in ten respondents recognised one or more of the leaflets (29%); of those 46% had read any of the leaflets and 28% had kept one or more of the leaflets for future reference.

There were high levels of awareness amongst stakeholders of all the leaflets produced by HRIS. Almost all (95%) were aware of the leaflet *'Making a Complaint about the NHS'* and 91% were aware of the leaflet *'Confidentiality – it's your right'*.

Importance of alternative formats and languages

Almost all (95%) felt the provision of leaflets in alternative formats and languages is important.

Usefulness of HRIS leaflets

Most stakeholders (85%) agreed the HRIS leaflets meet patients' needs well. Stakeholders noted the leaflets provide clear and simple information and the presentation / layout is good, attractive and colourful.

Quality of HRIS leaflets

Stakeholders were very positive in their views about the quality of the leaflets. Almost all described the leaflets as good in terms of plain language / readability (93%), accuracy and being up-to-date (91%) and layout / design (90%).

Suggested areas for improvements include the need for more graphics, pictures and images (9%) and the need for formats for those with disabilities (e.g. Braille, formats for people with dyslexia, learning difficulties) (7%).

Printing & distribution of HRIS leaflets

In general, stakeholders believe the current approach for printing and distribution of HRIS leaflets is good and works well (43%). Thirty-six percent agreed it is a good approach but could be improved. Although most stakeholders who are able to comment are happy with current approach to printing and distributing leaflets, some believe it could be improved through developing better/more specialist key contact lists, improving publicity and providing advice and support in a variety of ways. NHS stakeholders in particular also suggest some degree of centralisation. Funding seems to be at the heart of this, with significant proportions of NHS stakeholders suggesting that there should be centralised and better funding and resource for printing and distribution.

A majority of stakeholders (75%) agreed the approach to the distribution of leaflets in alternative formats and languages is good and works well. Stakeholders explained the website is easy to access, although some highlighted the fact that not everyone has internet access.

Public involvement

A majority of stakeholders (73%) considered the approach to consulting on draft versions of newly developed patient information is good and works well. Stakeholders explained this approach ensures a wide range of views are obtained. Some suggested HRIS should consult a wider range of people / groups.

Contact with HRIS

The main methods stakeholders have contact with HRIS is by accessing the web site (76%), receiving a quarterly newsletter (58%) and commenting on draft information about health rights (51%). Thirty-three percent contributed to the development of HRIS information about health rights and 20% contacted HRIS for specific information.

The website tends to be accessed infrequently by stakeholders - 55% access the website less often than monthly. Patient information is the most accessed part of the website (69%) and patient information for young people (45%).

Almost all (91%) of those who receive the HRIS newsletter found it useful to some extent. A small proportion (4%) suggested distribution should be better and 3% suggested newsletters should be available in other formats.

Understanding of HRIS's consultancy role

Around a third of stakeholders (39%) were aware of HRIS's consultancy role.

Developing patient information

Thirty percent of stakeholders said they had worked with HRIS. All felt HRIS worked well with them. According to stakeholders, HRIS are willing to listen to views and take comments on board.

Contributing to content

One third of all stakeholders (33%) said they have contributed to the development of HRIS information about health rights. Of these almost all (93%) agreed HRIS worked well with them. Stakeholders noted there is good communication with HRIS and that HRIS are willing to take comments on board. Almost all felt sufficiently involved in the process (91%) and all (100%) would work with HRIS again.

Organisational performance

Of the areas HRIS are performing well, the most frequently mentioned were providing good quality information / leaflets (39%); providing clear, understandable, accessible information (13%) and distributing information / leaflets (10%). Limited NHS funding (8%); a lack of promotion / publicity (6%) and the fact that leaflets are not printed centrally (5%) were identified as factors preventing HRIS from doing a good job.

Improvements & future development of HRIS

According to a small number of stakeholders HRIS should work more closely with Health Boards (8%); should raise awareness of information by using advertising, marketing and publicity (8%) and should produce a wider range of information / leaflets (5%).

RECOMMENDATIONS

In light of the findings of this evaluation we have developed a number of recommendations for HRIS to consider.

1. The findings suggest that after reading the HRIS leaflets people feel they know more about their health rights and where to go for more information or support. HRIS should work with its NHS contacts to ensure that leaflets are as accessible as possible, by encouraging distributors to target most the most frequently cited channels to promote leaflets to the public e.g. local GP Surgeries / Health Centres, Citizen's Advice Bureaux and Health Board websites.
2. HRIS should continue to involve the public in the development of information and should, if possible, consult earlier in the process and more widely. Young people should continue to be involved in development of information aimed at them.
3. The availability of information in alternative formats and languages is important and should be maintained for all publications. It would be worthwhile considering how to increase awareness of the availability of the alternative formats and languages amongst the general public and supporting NHS contacts to do this effectively.
4. Maintain the quality of leaflets in terms of attractive layout and design, accuracy and language. Consider using more graphics, pictures and images in the leaflets.

5. HRIS should work to improve awareness and usage of its website amongst stakeholders.
6. Most stakeholders are happy with the current approach to printing and distribution of information, but improvements are needed to make it work more effectively. HRIS should further develop its role in training, advice and support for NHS contacts, in relation to printing and distribution, and should ensure that this support is well publicised and accessible.
7. There are some suggestions that the network of key NHS board contacts could be widened and improved and some who have worked with HRIS would like improved communication. HRIS should review this network and undertake work to ensure that relevant people with appropriate specialisms are included. Further work should be done to develop an effective communication strategy for this network, perhaps beginning with a dialogue to better understand their communication needs and preferred channels.
8. NHS contacts find funding and resource for printing and distribution of leaflets difficult to identify and access. HRIS should explore mechanisms to provide central funding sources and/or additional central resource to support local contacts.
9. The findings revealed 91% of stakeholders found the HRIS newsletter useful. It should be distributed as widely as possible and used as a key channel for communication about the roles of HRIS, the website and the various advisory and support functions of the organisation. It could also be used as an ongoing mechanism to encourage feedback from stakeholders on a variety of issues.
10. Awareness of HRIS's roles varies amongst stakeholders. The majority are not aware of the consultancy role. Other communication channels, such as seminars, conferences, emails, leaflets, web alerts and so on could be usefully employed to further raise awareness of all of HRIS's roles and services.

2. BACKGROUND & OBJECTIVES

Health Rights Information Scotland (HRIS) is a joint initiative of Consumer Focus Scotland (formerly the Scottish Consumer Council) and Scottish Government Health Directorates which aims to produce and raise the quality of information available for patients about their rights when using NHS services in Scotland. In addition, HRIS provides support and advice to other organisations involved in the production of patient information.

HRIS produces information (in the form of leaflets etc.) for patients about their rights, about how to use NHS services, and about what they can expect from the NHS. This information is produced on a national basis for use throughout the NHS and NHS boards are responsible for printing and distributing information. The aim is to provide patients with a better understanding about their rights and choices and to increase confidence when making decisions about health and when interacting with NHS staff. HRIS also provides direct advice and assistance to other organisations producing patient information.

In order to ensure the information meets people's needs and is accessible in terms of format, language and style, information is produced in consultation with NHS staff, patients and members of the public. Examples of resources produced by HRIS include:

- *Making a complaint about the NHS*
- *Consent – your rights*
- *The NHS and you*

Examples of resources produced by HRIS in partnership with other organisations include:

- *The NHS Minor Ailment Service at your community Pharmacy*
- *It's okay to ask!*
- *Your Emergency Care Summary: what does it mean for you?*

HRIS produces information in a range of alternative formats including translations into nine minority languages, British sign language, audio file, large print versions in English, easy read versions with illustrations for people with learning difficulties and HTML web-based versions for people who need to use a screen reader.

HRIS staff work to raise and maintain the awareness of the project and its remit amongst NHS staff, particularly those involved in information production. To achieve this, the project has established an extensive network of stakeholders involved in, or interested in, producing and distributing health rights information to the public both within and outside the NHS. HRIS is keen to understand the views of these

stakeholders. HRIS is also keen to establish awareness of health rights information and acquire feedback from patients who have followed the advice provided in HRIS leaflets.

Aims

George Street Research was commissioned to conduct an independent and objective evaluation of the effectiveness and impact of work carried out since the HRIS project started in 2003. The two key aims of the study were:

1. To establish the extent to which key organisational stakeholders consider that HRIS has been able to fulfil its role in terms of:
 - (a) Producing information about patients' rights
 - (b) Providing support for other bodies that produce patient information.
2. To establish the awareness and usefulness of health rights information among patients.

To achieve these aims, research was conducted with the following key stakeholders:

- Representatives from 14 geographical health boards with a stake in HRIS core leaflets. This included departmental representatives from
 - Communications
 - Patient information
 - Complaints
 - Patient focus public involvement (PFPI)
 - Clinical governance
 - Information governance
- Non-NHS stakeholders: organisations with a similar remit to HRIS, for example, information providers in the voluntary sector
- HRIS Network members
- Representatives from organisations that have used HRIS's consultancy role (e.g. special NHS boards, the Scottish Government)
- the general public

3. METHODOLOGY & SAMPLE

To meet the aims of this study, a combination of quantitative and qualitative techniques were employed comprising a number of different elements. First, a semi-structured telephone interview was conducted with 120 key organisational stakeholders. Second, to access the views of the general public, a range of questions were included as part of the Scottish Opinion Survey which was administered by interviewing face to face, a sample of 1,000 adults in Scotland aged 16+ at the respondent's home. Third, to identify users of HRIS information, a link to an online recruitment survey was placed on the HRIS website as well as the websites of a range of patient support groups. Finally, a qualitative phase of research was undertaken in the form of telephone depth interviews involving 6 members of the general public to explore in-depth how the information contained in the leaflets was used

3.1 Semi-structured telephone interviews with key organisational stakeholders

In September 2008 George Street Research conducted 120 semi-structured telephone interviews with key organisational stakeholders to establish the extent to which HRIS has been able to fulfil its role in terms of a) producing information about patients' rights and b) providing support for other bodies that produce patient information. The interviews lasted up to 20 minutes in length. A copy of the questionnaire is attached as Appendix 1 and Table 3.1 provides an outline of the sample profile achieved.

Table 3.1:
Sample Profile –organisational stakeholders

	N=120	
	%	No
CATEGORY OF STAKEHOLDER		
NHS stakeholder (e.g. representatives from 14 health boards with a stake in HRIS leaflets (e.g. communications, patient information, complaints, PFPI, clinical governance, information governance)	46	55
HRIS network member	43	51
Representatives from organisations that have used HRIS's consultancy role (e.g. special NHS boards, the Scottish Government)	13	16
Non-NHS stakeholders: organisations with a similar remit to HRIS (e.g. information providers in the voluntary sector)	6	7
ROLE IN PATIENT INFORMATION		
Develop information for patients	61	73
Give information to patients	56	67
Involvement with patient information is indirect (e.g. distribute, monitor or manage patient information provision)	77	92
None of the above	3	4
LENGTH OF TIME IN CURRENT JOB/ROLE		
More than 5 years	44	53
2-5 years	35	42
1-2 years	11	13
Less than 1 year	9	11

Source: Classification questions, Q1

As Table 3.1 shows, the sample achieved included individuals who have a strong and longstanding role in patient information and therefore can comment with some confidence on the work of HRIS.

3.2 Omnibus survey of general public

In order to establish awareness of sources of information on health rights and to establish recognition and readership of leaflets about health rights, research was conducted amongst the Scottish population, using the Scottish Opinion Survey as a means of data collection.

A sample of 1,032 adults (representative of the Scottish population in terms of age, sex, socio-economic group and ethnic origin) was interviewed face to face in 43 constituencies throughout Scotland between 24 and 30 September. All interviews were conducted at the respondent's home using CAPI (Computer Assisted Personal Interviewing) which included images of health rights information from a variety of sources that had been distributed in different ways. The questions used for this element of the research are attached as Appendix 2.

3.3 Online recruitment of leaflet users

To target users of the HRIS leaflets, a link to a George Street Research online survey was made available on the HRIS website. The survey link was also sent to 36 organisations including patient and other support groups, charities and other advice providers (e.g. Carers Scotland, Young Scot) who had agreed to put a link to the survey on their website.

The online survey contained images of six HRIS leaflets and asked respondents to indicate:

- Whether they had looked at the leaflet but not used the information in it
- Whether they had used the information in any leaflet

Only 13 responses were received and those who had indicated they had used any of the leaflets gave their permission to interview by providing their name and contact number. A copy of the online survey is attached as Appendix 3.

3.4 Telephone depth interviews with the general public

During the fieldwork period George Street Research also undertook a qualitative phase of research with six members of the general public who had indicated on their online survey that they had *used* any of the specific leaflets. The aim of this stage was to establish the circumstances in which they made use of the leaflet; how they accessed the information; the helpfulness of the information in the leaflet and how they rated the quality of the information in the leaflet etc. The topic guide for this element of the research is attached as Appendix 4.

The telephone conversations with these respondents revealed that only one of the six respondents had actually used a leaflet in the context of being a patient. Of those remaining, one had incorrectly completed the online survey and four were stakeholders i.e. who had completed the survey in their professional capacity, rather than as a patient.

3.5 Reporting

Throughout the report all quantitative and qualitative data and responses are analysed collectively. Where key differences between different sub-groups occur these are reported, though it should be noted that sub-group sizes are often small and differences not necessarily statistically significant.

In addition, appropriate verbatim comments received from stakeholders and other respondents have been selected to illustrate key themes and to provide extra detail for any specific areas of interest.

4. PUBLIC PERSPECTIVE

This chapter is based on the research conducted with the general public. The chapter explores awareness of health rights information in general. It also examines awareness of health rights information and the perceived usefulness of the leaflets amongst the general public.

4.1 Awareness of sources of health rights information

In order to ascertain levels of awareness of health rights information, at the start of the interview, all respondents were asked to spontaneously state the places they would go to acquire information about their rights (as NHS patients).

Across the sample as a whole, the source mentioned by the highest proportion of respondents at a spontaneous level was GP surgeries / health centres (54%). Across the sub-groups, a lower proportion of those aged 16-34 would go to GP surgeries / health centres to obtain information on their rights than those aged 65+. Respondents also spontaneously mentioned Citizen's Advice Bureaux (9%) and Health Board websites (8%). Eight percent also said they used internet searches to acquire information on their rights. This included a higher proportion of those aged 25-44 and those who live in the North of Scotland.

Respondents were then prompted with a list of places patients can go to obtain information on their rights.

Table 4.1
Sources of information about NHS patients' rights

	Spontaneously mentioned	Total (after prompting)
	%	%
GP surgery / health centre	<u>54</u>	73
Citizens' Advice Bureaux	<u>9</u>	<u>32</u>
Health board website	<u>8</u>	23
Internet search / Google / search engine	<u>8</u>	10
Health board (phone/in person)	7	14
NHS 24	7	<u>29</u>
NHS24.com	6	17
NHS Helpline	5	24
Family and friends	4	22
Pharmacist	3	<u>28</u>
Local library	2	17
Hospital	2	3
Dental practice	1	13
None	7	2

Source: Q1A, Q1b

Base: All respondents (1032)

As shown in Table 4.1, the most frequently mentioned sources of information after prompting were GP surgery / health centre (73%), Citizens' Advice Bureaux (32%), NHS 24 (29%) and Pharmacist (28%).

When we examine the results across sub-groups, higher proportions of those aged 25-44 and from socio-economic group AB said they would use Health Board websites. A higher proportion of those aged 35-44 would contact NHS 24 for information in comparison to those in the older age ranges and those aged 25-34 are more likely to use NHS24.com. Those aged 16-24 are more likely to go to family and friends to obtain information about their rights than those in the older age ranges. Those aged 25-34 are more likely to go to a Citizen's Advice Bureau to obtain information about their rights than those in the other age ranges.

4.2 Awareness of health rights information

One of the key aims of this study was to establish awareness of health rights information, including HRIS leaflets, amongst the public. HRIS does not aim to establish an unrealistically high level of awareness of health rights or recognition of health rights information in the general public. Their priority is that health rights information is available when people need it. However, establishing availability is outwith the scope of this evaluation as it is currently the NHS's responsibility to distribute HRIS leaflets. It is hoped that by gauging awareness levels of 6 pieces of health rights information that have been distributed in different ways, good practice in dissemination can be identified. To achieve this, all respondents were shown images of six leaflets and asked which they recognised. Respondents who recognised any leaflet were then asked to specify the leaflets they had read and the leaflets they had kept for future reference.

As shown in Table 4.2, almost three in ten respondents recognised one or more of the leaflets (29%); of those 46% had read any of the leaflets and 28% had kept one or more of the leaflets for future reference.

'Your Emergency Care Summary: What does it mean for you?', which was delivered to every home in Scotland, was the leaflet recognised by the highest proportion of respondents (12%). Eleven percent of people who recognised at least one leaflet had read this leaflet and 8% of people who recognised at least one leaflet had kept this leaflet. While this leaflet was recognised by the highest proportion of respondents, awareness of the leaflet is not very much higher than that of the others.

Ten percent of respondents recognised *'The NHS and You'* leaflet which sent to health board contacts to co-ordinate distribution. Eight percent of people who recognised at least one leaflet had read this leaflet and 7% of people who recognised at least one leaflet had kept this leaflet.

Nine percent recognised the ‘*The NHS Minor Ailment Service at your community pharmacy*’ leaflet which was sent to all GPs and community pharmacies. Fourteen percent of people who recognised at least one leaflet had actually read this leaflet and 10% of people who recognised at least one leaflet had kept this leaflet.

It does not seem that the distribution method has a great impact on the level of patients’ awareness of the leaflets.

Some respondents indicated they recognised, had read or kept a leaflet, but were uncertain as to which leaflet exactly this was.

Table 4.2
Awareness of HRIS leaflets

	Recognise leaflet	Read Leaflet	Kept for future reference
	n=1032	n=298*	n=298*
	%	%	%
One or more of the leaflets	29	46	28
<i>Your Emergency Care Summary: What does it mean for you?</i>	<u>12</u>	<u>11</u>	<u>8</u>
<i>The NHS and you</i>	<u>10</u>	<u>8</u>	<u>7</u>
<i>The NHS Minor Ailment Service at your community pharmacy</i>	<u>9</u>	<u>14</u>	<u>10</u>
<i>Making a complaint about the NHS</i>	8	9	5
<i>Consent – your rights</i>	7	10	5
<i>It’s okay to ask!</i>	7	7	3
Recognise but not sure which	3	n/a	n/a
Read but not sure which	n/a	13	n/a
Kept but not sure which	n/a	n/a	3
None	69	51	72

Source: Q2a, Q2b, Q2c

*All those who recognise one or more of the leaflets

Analysis of sub-groups reveals that females are more likely than males to recognise any of the leaflets. In comparison to those aged 55+, 16-34 year olds are more likely to recognise the leaflets. In terms of readership of leaflets, those aged 25-34 and those living in the North of Scotland are more likely to have read any of the leaflets than others.

During the qualitative phase of research, respondents discussed the HRIS leaflets in general. One respondent clearly recognised the branding and associated it with reliability and with information they can trust:

“They are a good group of leaflets... they are a co-ordinated group... There was continuity in them so that you would know that they

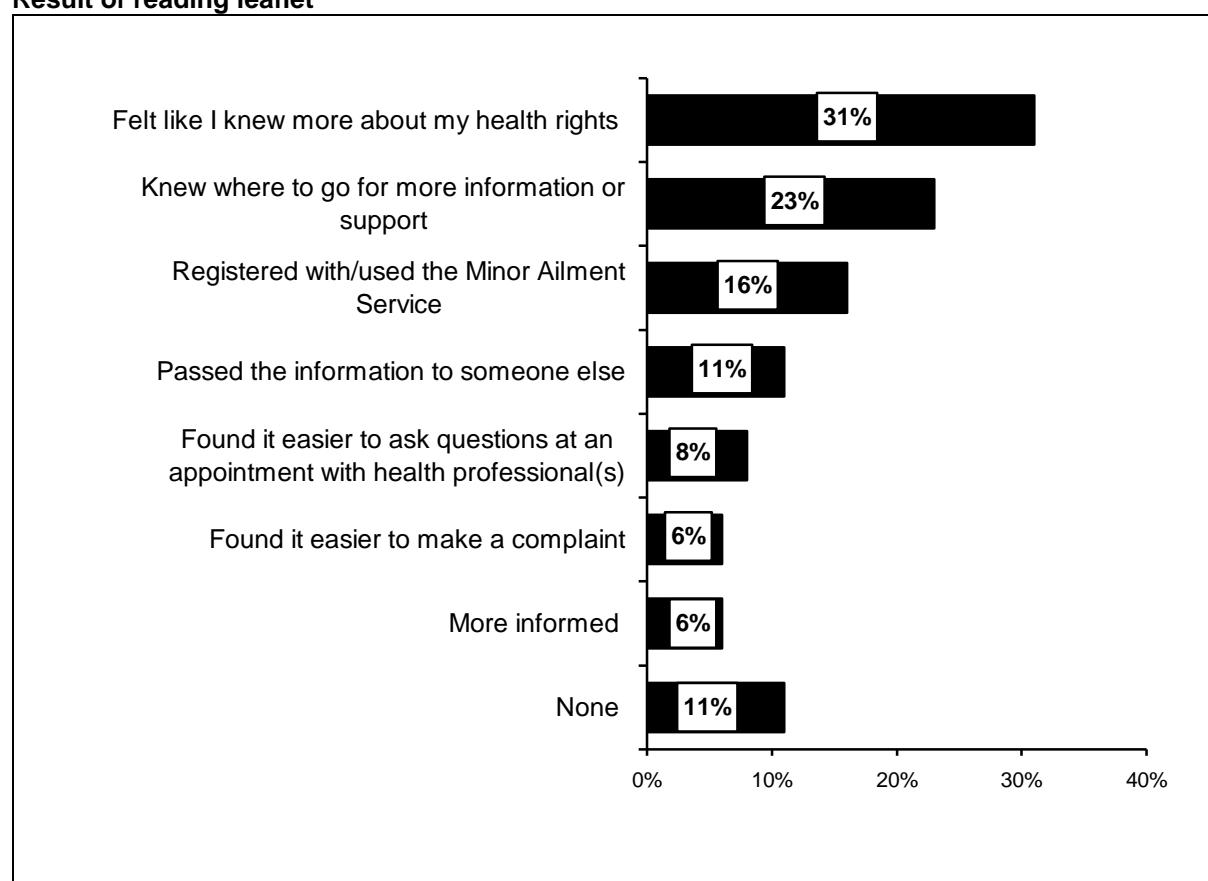
came from a recognised source and I think these days it is important that they come from a recognised and reliable source”.

4.3 Use & Impact of the Leaflets

Those respondents who said they had read one or more of the leaflets were then asked the question ‘*What was the result of reading the information?*’. As Chart 4.1 reveals almost one in three respondents (31%) felt they knew more about their health rights; 23% knew where to go for more information or support; 11% had passed the information to someone else and 6% were more informed.

With reference to the specific leaflets, 16% stated they had registered with / used the Minor Ailment Service; 8% found it easier to ask questions at an appointment with a health professional(s) and 6% found it easier to make a complaint.

Chart 4.1
Result of reading leaflet



Source: Q4a

Base: All those who have read a leaflet or leaflets (98)

During the qualitative phase of research two respondents discussed the leaflet – ‘Making a complaint about the NHS’. One respondent was particularly impressed with the content and the advice the leaflet provided:

“It gave me the information to help me decide whether I wanted to pursue a complaint or not and it was clearly marked who to contact if I wanted to make a complaint in our area. It was quite good and clear... it made it quite easy to take the step of how to go about complaining.”

“It makes it easier for people like me who hadn’t decided what we were going to do but the leaflet was there and gave the steps so we could actually go ahead”.

This respondent also described this leaflet as: eye-catching, user-friendly, of a good size. Another respondent said:

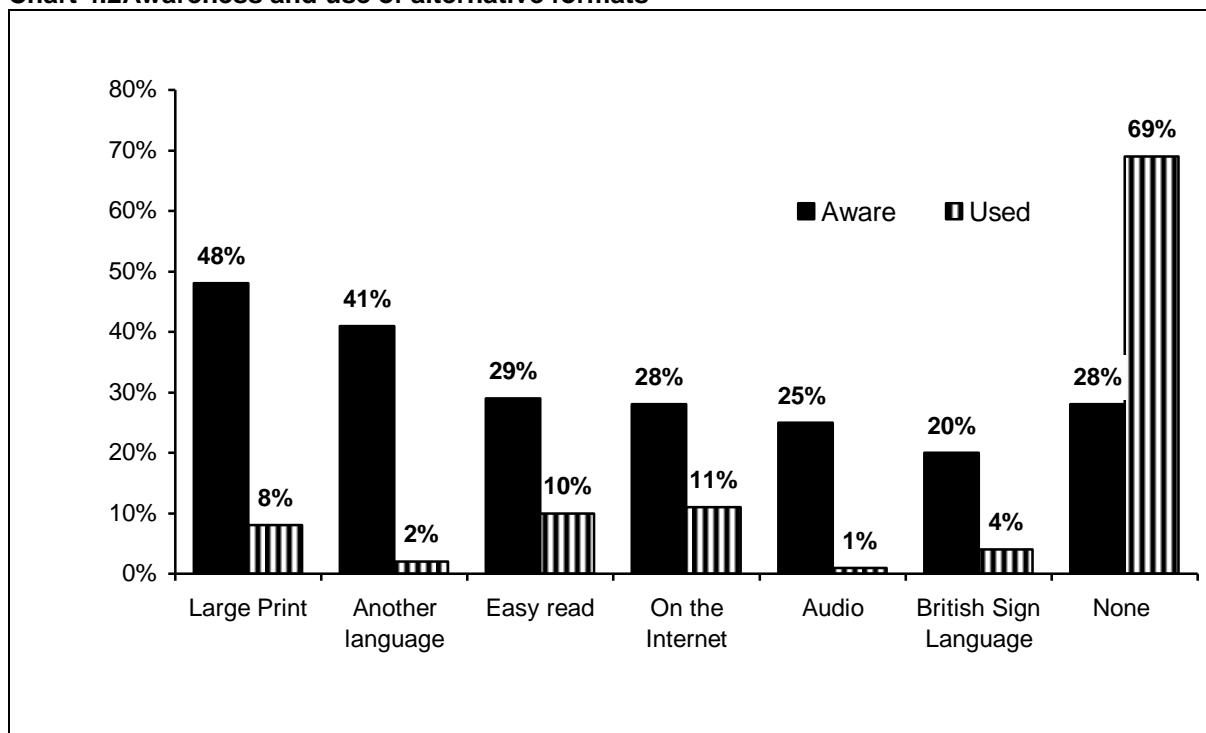
“Yeah, I think its fine. It gives plenty of information and tries to cover a lot of areas. I think the design and everything is easy enough to read and you can see it well enough.”

Another key aim of this study was to establish the usefulness of HRIS information amongst patients. Those respondents who had read one or more of the leaflets were asked to rate how useful they found the advice provided. In response to this question respondents provided very positive feedback with 91% stating the advice is useful including 46% who said it is very useful). Seven percent said the advice provided in the leaflet(s) is not very useful and 2% said not at all useful.

4.4 Awareness & use of alternative formats

As outlined in the Background chapter HRIS produces information in a range of alternative formats and languages. All those respondents who recognised at least one leaflet were asked about the type or types of alternative formats they were aware of (see Chart 4.2). Almost half of these respondents (48%) were aware of leaflets in large print and 41% were aware of leaflets in another language. Around three in ten were aware of easy read (29%) and 28% were aware of different formats on the internet. In relation to usage of alternative formats, the highest proportion of respondents (69%) had not used any. Of those that had used alternative formats, 11% had accessed these on the internet; 10% had used the easy read format and 8% had used large print versions of the leaflets.

Chart 4.2 Awareness and use of alternative formats



Aware - Source Q3a, Base all who recognise one or more HRIS leaflet (269)

Used – Source Q3b, Base all aware of one or more alternative format (195)

A higher proportion of males, those aged 25-34, 65+ and those in the socio-economic grouping C2 said they had used leaflets in alternative formats.

4.5 HRIS website / distribution of HRIS leaflets

During the telephone conversations with respondents, one praised the HRIS website:

“The website was very good, there was a lot of information there; it was quite easy to navigate.”

In addition, when speaking about the availability of HRIS leaflets the same respondent suggested:

“I don’t know what the availability is but it would be a good idea for those leaflets to be available within the local community centres, because there are quite a few people who come in... I think there would be a better uptake.”

5. PROFESSIONAL PERSPECTIVE

A key aim of this study was to establish the extent to which key organisational stakeholders (referred to as stakeholders from this point onwards) consider that HRIS has been able to fulfil its role. The following sections discuss HRIS's performance in producing information about patients' rights as well as providing support for other bodies that produce patient information. This chapter is based on the results obtained from the semi-structured telephone interviews conducted with stakeholders.

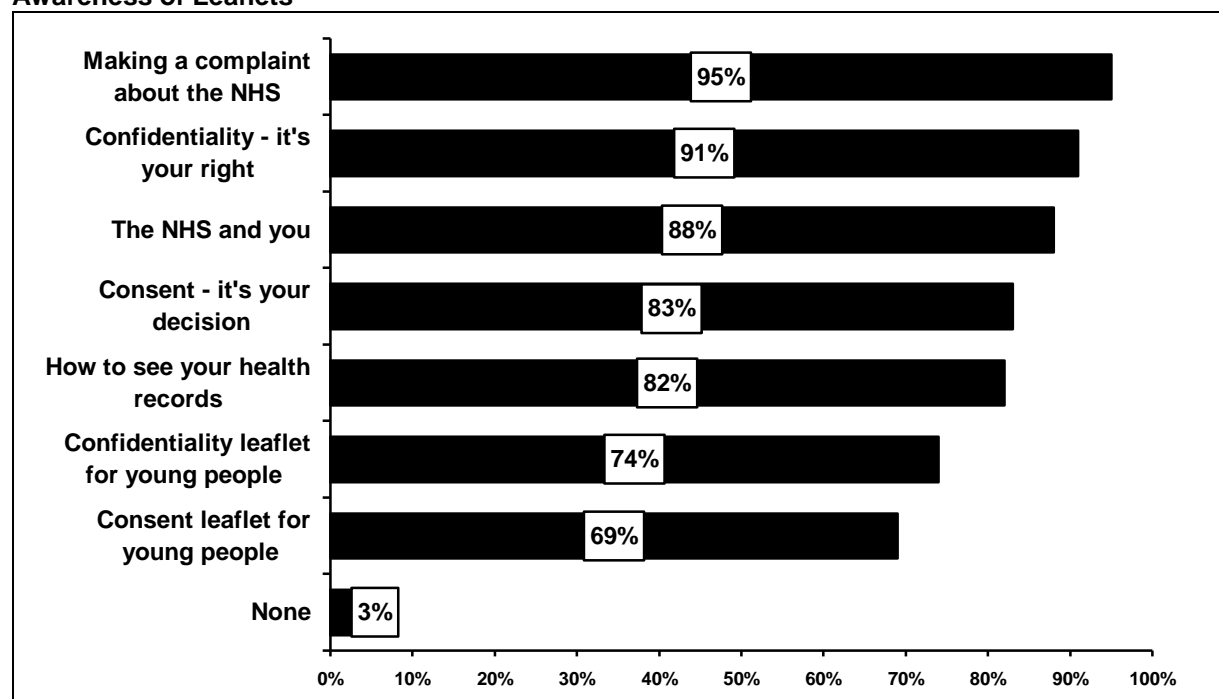
5.1 HRIS leaflets

This section examines the extent to which stakeholders are aware of the 5 core HRIS leaflets and the alternative formats and languages these are available in. This chapter also discusses how well the leaflets are meeting patients' needs and how these needs are being met. Views on the printing and distribution of leaflets are presented and perceptions of the leaflets are discussed.

5.1.1 Awareness of HRIS leaflets

At the start of the telephone interview all stakeholders were asked to state the HRIS leaflets they were aware of. As Chart 5.1 shows, there was a high level of awareness of all leaflets produced by HRIS, with between 69% and 95% of stakeholders aware of each. Almost all (95%) were aware of the leaflet *'Making a Complaint about the NHS'* and 91% were aware of the *'Confidentiality – it's your right'* leaflet. When we examine the data excluding the HRIS network members who receive regular updates by newsletter, the data mirrors that of the overall sample with between 67% and 94% of stakeholders aware of each leaflet.

Chart 5.1
Awareness of Leaflets



Source: Q2

Base: All respondents (120)

5.1.2 Importance of alternative formats and languages

All stakeholders were asked how important it is that leaflets are available in a range of alternative formats and languages. Almost all (95%) were of the view that this service is important, including 75% who thought it is very important. One in five (20%) said it is quite important. Five percent of all stakeholders said it is not important, this included 2% who stated it is *'not at all important'*.

Across the different sub-groups, a higher proportion of representatives from organisations that have used HRIS's consultancy role felt it is very important that leaflets are available in a range of alternative formats and languages (88%). The data revealed there are no differences between the views of NHS department representatives and the sample as a whole.

5.1.3 Usefulness of HRIS leaflets

Those stakeholders who said they were aware of one or more of the HRIS leaflets were asked to rate how well the leaflets meet patients' needs. Encouragingly 85% of stakeholders agreed the leaflets meet patients' needs well. This includes 47% who

said 'very well' and 38% who said 'quite well'. Only 3% felt the leaflets do not meet patients' needs very well. Twelve percent said they did not know.

When we examine the data in terms of sub-groups, a higher proportion of representatives from organisations that have used HRIS's consultancy role said very well (69%) and a higher proportion of HRIS network members said quite well (49%). The data revealed there are no differences between the views of NHS department representatives and the sample as a whole (46% very well, 39% quite well, 2% not very well).

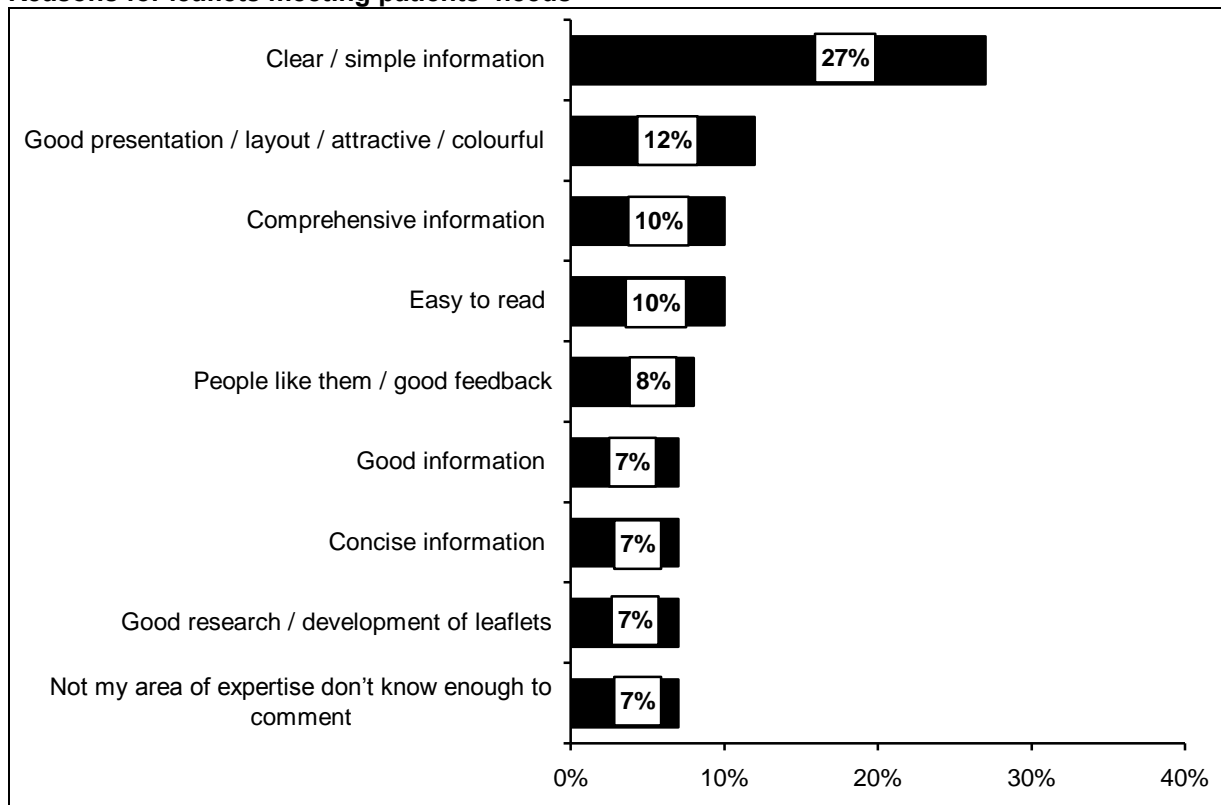
All those stakeholders who said the leaflets meet patients' needs 'very' or 'quite' well were asked to state the reasons for their view. The responses to this question are illustrated in Chart 5.2. The chart shows, the highest proportion of stakeholders said the leaflets provide clear and simple information (27%). Twelve percent maintained the presentation and layout of the leaflets is good, attractive and colourful. A number of stakeholders also described the information in the leaflets as comprehensive (10%) and easy to read (10%). The following quotes represent typical responses by stakeholders:

"All the 'need to know' information is there in an easily understood format."

"They are easy to read, in plain English, and accessible."

"Good style, format and layout."

Chart 5.2
Reasons for leaflets meeting patients' needs



*Values under 7% not presented

Source: Q3b

Base: All those who described leaflets as meeting patients' needs very or quite well (100)

Only three stakeholders felt the leaflets do not meet patients' needs well. When asked to give their reasons for this all three said the leaflets should be simpler referring to the language and jargon used in their response.

Stakeholders were invited to comment on specific HRIS leaflets. The following table provides a summary of the comments made by two or more stakeholders:

Table 5.1
Comments about specific leaflets

	<i>The NHS and you</i>	<i>Making a complaint about the NHS</i>	<i>Confidentiality leaflet for young people</i>	<i>Consent leaflet for young people</i>	<i>Consent - It's your decision</i>	<i>Confidentiality – It's your right</i>	<i>How to see your health records</i>
	n=6	n=12	n=11	n=10	n=1	n=4	n=3
Should be written in simpler English (e.g. too much jargon)	3	3	2	-	1	2	-
Leaflet stakeholder most familiar with	2	4	2	2	-	2	-
Useful/ helpful / meets patients' needs	-	3	-	-	-	2	2
They are good	-	-	4	4	-	-	-
Easy to read / well written	-	-	2	2	-	-	-

*One stakeholder made one comment the *Consent – It's your decision* leaflet (the leaflet should be written in simpler English)

Source: Q3c

5.1.4 Quality of HRIS leaflets

The quality of leaflets in terms of language, accuracy and presentation is essential to their purpose. It was therefore important to access the views of stakeholders in respect of this.

During the course of the telephone interviews, those stakeholders who were aware of one or more of the seven HRIS leaflets were asked to rate the leaflets in terms of the following attributes:

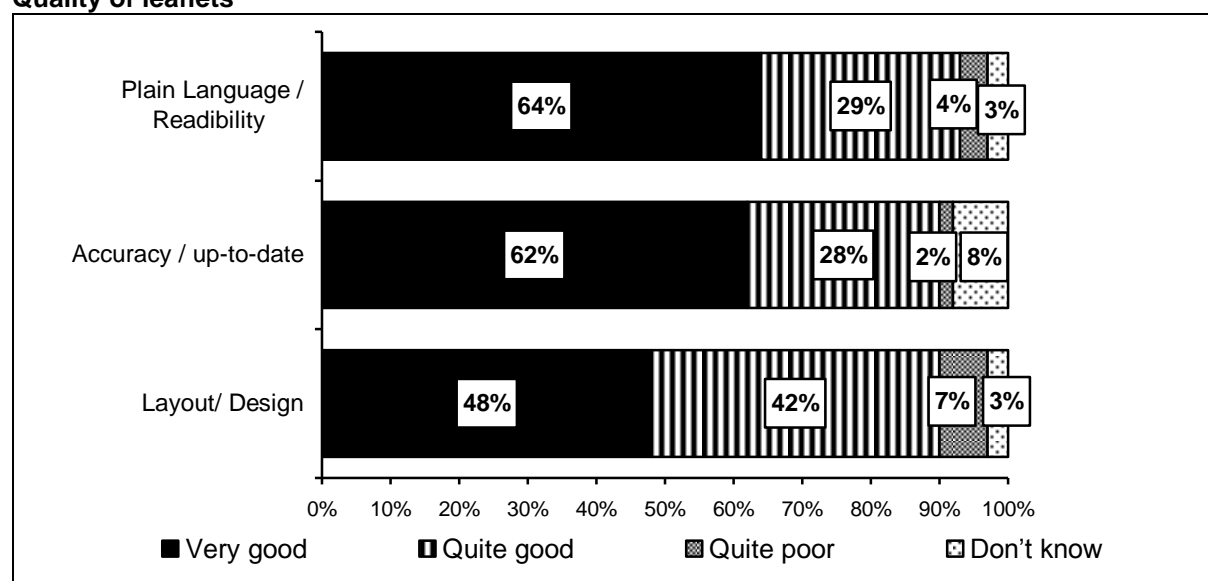
- Layout / Design
- Accuracy / Up-to-date
- Plain Language / Readability

As Chart 5.3 shows, stakeholders were very positive in their views about the quality of the leaflets. Almost all (93%) described the leaflets as good in terms of plain language / readability and this included 64% who said the leaflets were 'very good'. In contrast four stakeholders described the leaflets as 'quite poor' and 3% did not know.

A similar proportion (91%) said the leaflets were good in terms of accuracy and being up-to-date, 62% said ‘very good’. Only a few (2%) described the leaflets as ‘quite poor’ in terms of quality. Of the remaining stakeholders, 8% said they did not know. When we examine the data in terms of sub-groups, a higher number of representatives from organisations that have used HRIS’s consultancy role described this element as very good.

Stakeholders were also positive about the quality of the layout / design of the leaflets. A total of 90% described the leaflets as good to any extent (48% said ‘very good’). Seven percent of stakeholders however disagreed describing the leaflets as ‘quite poor’ and 3% did not know.

Chart 5.3
Quality of leaflets



Source: Q4ai, Q4aii, Q4aiii

Base: Those aware of one or more leaflets (117)

Stakeholders were invited to comment further on the quality of any specific leaflets. The following table provides a summary of the positive and negative comments received by two or more stakeholders:

Table 5.2
Quality of specific leaflets

	<i>The NHS and you</i>	<i>Making a complaint about the NHS</i>	<i>Confidentiality leaflet for young people</i>	<i>Consent leaflet for young people</i>	<i>Consent - It's your decision</i>	<i>Confidentiality – It's your right</i>	<i>How to see your health records</i>
	n=16	n=17	n=11	n=9	n=11	n=13	n=12
Good / excellent quality	2	3	3	2	2	3	4
User-friendly / accessible / easy to read	2	2	-	-	-	-	-
Good content / information	-	2	-	-	2	2	-
Down to earth 'does what it says on the tin'	-	-	2	-	-	-	-
Negative comments about presentation / physical format (e.g. too glossy, colours too bold, too many colours)	4	2	-	2	2	2	-
Needs to be updated / revised	3	-	-	-	-	-	-
Difficult to understand / confusing	2	-	-	-	2	2	2
Poor design (e.g. too complicated, dated, institutional appearance)	-	2	-	-	-	-	-
Graphics don't appeal to young people (e.g. replace cartoons with photographs)	-	-	2	2	-	-	-

Source: Q4b

With specific reference to leaflets for young people, one stakeholder noted the leaflets were well laid out, whilst a different stakeholder made comments about the illustrations:

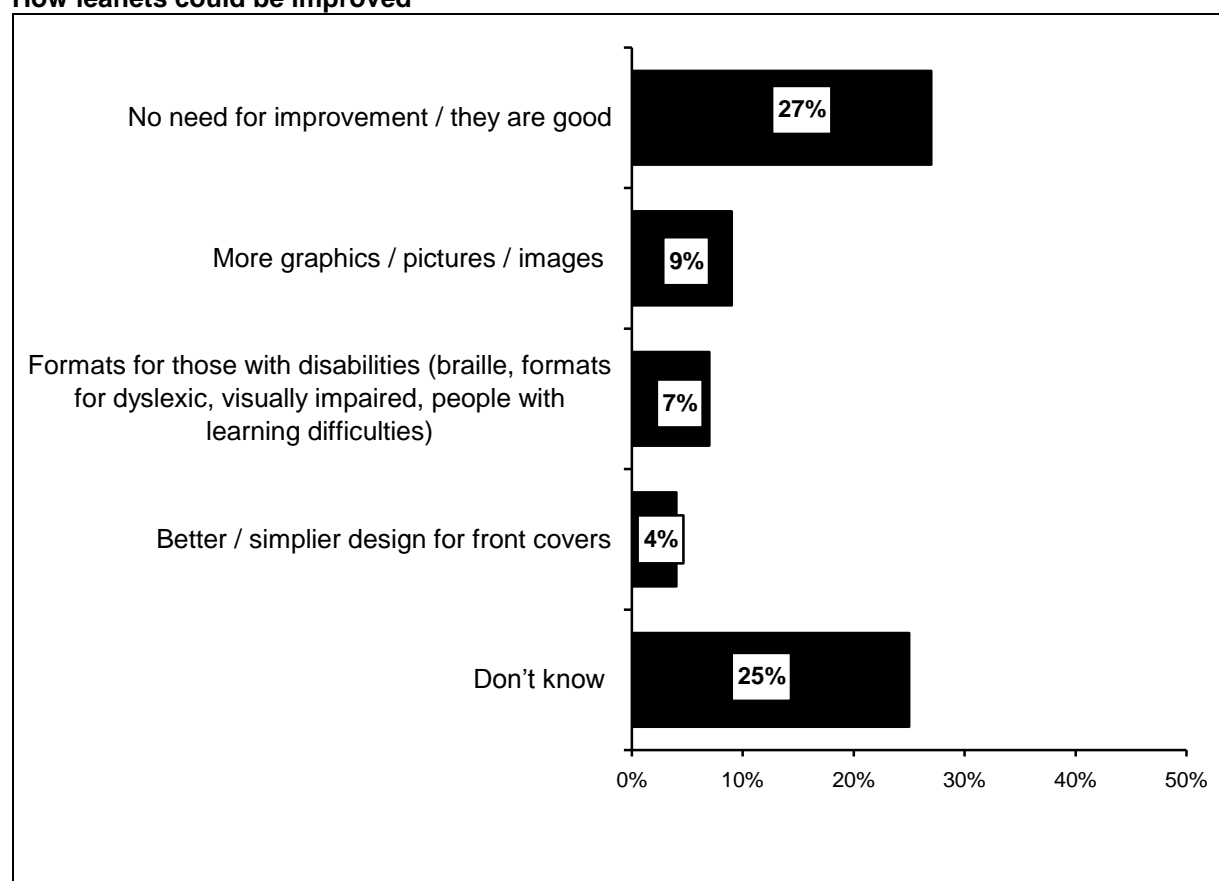
“The young people’s leaflets are particularly well laid out for their target audience, making them more widely available to the people who need them and the people they will hold relevance to.”

“The youth leaflet cartoons should be replaced with photographs.”

One other stakeholder said the leaflets were of *“Very high quality and do what it says on the tin”*.

Stakeholders were asked ‘*How could these leaflets be improved?*’ As shown in Chart 5.4 the highest proportion of stakeholders (27%) said there was no need for improvement / the leaflets are good. Additionally, one in four stakeholders (25%) said “*don’t know*”. Of those stakeholders who did provide comments, 9% suggested the leaflets should contain more graphics, pictures and images and 7% were of the opinion that the leaflets should be in other formats for those with disabilities (e.g. Braille, formats for people with dyslexia, visually impaired, learning difficulties etc.). The remaining stakeholders suggested improvements to the design of the front covers of the leaflets (4%).

Chart 5.4
How leaflets could be improved



*Values under 4% not presented

Source: Q4c

Base: Those aware of one or more leaflets (117)

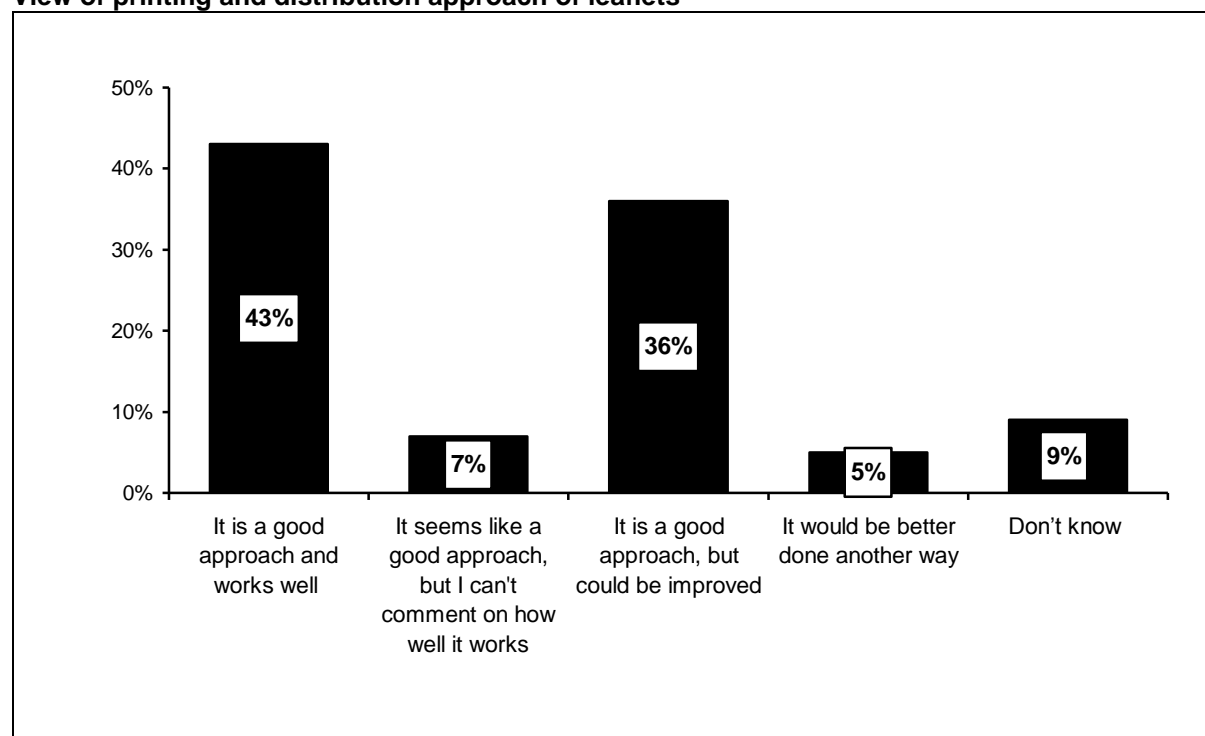
5.1.5 Printing & distribution of HRIS leaflets

HRIS produces patient information centrally and there is a key contact in each of the Health Boards who is responsible for printing and distributing the information in their area. All stakeholders were asked their view on this approach. Chart 5.5 presents the findings in relation to this question.

Views on current approach

In general, stakeholders think this is a good approach. The highest proportion of stakeholders (43%) agreed it is a good approach and works well. While agreeing it is a good approach, 7% could not comment on how well the approach works and just over one third of stakeholders (36%) said the approach is good but could be improved, rising to 40% amongst NHS stakeholders. In contrast, 5% (11% of NHS stakeholders) said it would be better done another way and one in ten stakeholders (9%) did not know.

Chart 5.5
View of printing and distribution approach of leaflets



Source: Q5a

Base: All respondents excluding network members (69)

All stakeholders were asked the reasons for their views on the approach and the following are the most common responses (it should be noted that smaller proportions of those who were positive about the approach provided specific reasons than did those who think it could be improved):

- No problems / happy with approach (22 mentions, 11 of which are HRIS network members)
- Printing should be centrally funded / have to pay for printing / difficult to afford cost (13 mentions, 10 of which are NHS stakeholders)
- Leaflets should be printed centrally / should not have to print ourselves (12 mentions, 8 of which are NHS stakeholders)
- Good to have key / regional contact (e.g. has local knowledge, knows how to distribute) (11 mentions, 6 from NHS stakeholders)
- Distribution could be better / not enough distribution routes (10 mentions, 7 from HRIS network members)
- Distribution difficulties / cost of distribution (9 mentions, 5 from NHS stakeholders)
- Problems with key contact (e.g. not responsible for printing) (5 mentions)
- Quality of locally printed / produced leaflets is poor (4 mentions, all NHS stakeholders)
- Communication and administration difficulties (4 mentions)
- Allows Health Boards to add local information for distribution (3 mentions)
- Local areas receive the leaflets when they need them (3 mentions)
- High level of awareness of the leaflets (3 mentions)
- Approach works better in some areas more than others (3 mentions)
- Quick / easy distribution (3 mentions)

To summarise, although stakeholders are generally happy that the current approach is good, just over a third think it could be improved. HRIS network members are most likely to specifically say that they are happy with the approach and NHS stakeholders are most likely to mention specific problems. These are most often suggestions that printing should be centrally funded (10 of the 28 NHS stakeholders who commented said this) or that the leaflets should be centrally printed (8 said this). Five NHS stakeholders mentioned difficulties with the cost or resourcing for distribution and 4 have concerns about the quality of locally printed leaflets.

Suggestions for improvements

All stakeholders were specifically asked for their suggestions on how to improve the approach to printing and distribution. Around one third (36%) of stakeholders did not know. Fifteen percent (and 24% of NHS stakeholders) referred to central government funding / centralised printing and/or distribution; 13% said there is no need for improvement as this is a good approach; 7% felt there should be better distribution of leaflets; 5% said there should be more publicity and advertising and

4% noted there should be better communication with Health Boards and improved contact lists.

Of the 61 stakeholders who made improvement suggestions, almost a third (18 people) made suggestions relating to centralised printing, funding or distribution and 13 of these were NHS stakeholders. Four respondents also mentioned that the printer and distributor being different organisations causes a problem and 2 want budgets/resources for distribution.

Other suggestions relate to improvements to the current approach:

- 8 suggested better or wider distribution points distribution
- 6 mentioned more publicity/advertising
- 5 want better communication with health boards and other key contacts
- 5 mentioned improvements to contact lists
- a variety of suggestions relating to central support, training and advice were also made

Alternative formats

HRIS also produce a range of alternative formats and languages which are made available to health board contacts through the HRIS website. All stakeholders were asked their opinion on this approach. Three in four stakeholders (75%) agreed it is good and works well. When we assess this data across the different sub-groups, a higher proportion of representatives from organisations that have used HRIS's consultancy role agreed it is good and works well compared with a lower proportion of HRIS Network members. While agreeing it is a good approach 3% could not comment on how well the approach works. Fifteen percent noted the approach could be improved. Only 1% said it could be done better another way. Seven percent did not know.

Those stakeholders who agreed it is a good approach and works well (75%) or that it seems like a good approach but couldn't comment on how well it works (3%) were asked why they held this view. The majority of responses received relate to the availability of alternative formats and languages on the HRIS website:

- Easy to access website (24 mentions)
- No problems / it works well (18 mentions)
- Most people have internet access these days e.g. good source of information for those with computers (8 mentions)
- Web version saves printing (7 mentions)
- Need to make sure people are aware of this information (7 mentions)
- Good links to HRIS website (6 mentions)
- Didn't know HRIS did this (5 mentions)
- Website is useful (4 mentions)

Those stakeholders who agreed it is a good approach but think it could be improved (15%) or that this would be better done another way (1%) were asked to state the reasons why they were of this view. Responses related to accessing, promoting and the distribution of alternative formats and languages:

- Not everyone has internet access (7 mentions)
- Not sure if the community groups who help foreign people receive all the information (3 mentions)
- No point having options unless it's promoted e.g. by Health Boards (3 mentions)

5.1.6 Public involvement

HRIS tries to improve the quality of its information by consulting on draft versions of newly developed patient information. It does this through focus groups with patients and members of the public and by seeking comments from patient representative organisations.

All stakeholders were asked for their views on these approaches. Encouragingly, around three in four stakeholders (73%) agreed it is a good approach and works well. Five percent agreed it is a good approach but could not comment on how well it works. While 13% agreed it is a good approach, they also suggested the approach could be improved. Only 1% said it would be better done another way. Eight percent did not know.

Those stakeholders who agreed it is a good approach and works well (73%) or that it seems like a good approach but couldn't comment on how well it works (5%) were asked why they think this. The majority of responses revealed stakeholders like this approach because it obtains the views of a range of people; ensures patients' needs are being met and improves the quality of leaflets:

- Obtains a wide range of views / consults a wide range of people / inclusive (26 mentions)
- Good / no problems / works well (23 mentions)
- Obtains patients' / end-users' views which is essential to ensuring they meet patients' needs (23 mentions)
- HRIS are good at organising consultations (7 mentions)
- Have been involved in consultations (7 mentions)
- Get the professionals' views (4 mentions)
- Improves quality of leaflets e.g. more readable, simpler (4 mentions)

Those stakeholders who agreed it is a good approach but could be improved (13%) or thought this would be better done another way (1%) were asked why they were of this view. The following comments were noted:

- HRIS need to consult with more people / groups (5 mentions)
- HRIS will never be able to get everybody's opinion (3 mentions)
- HRIS need to conduct more consultation with young people / on children's issues e.g. in schools (2 mentions)

During the telephone conversations stakeholders discussed the consultation process in terms of involving different types of people. One stakeholder suggested that HRIS should *"Make consultations more widely known among the general public"* a different stakeholder also noted:

"[HRIS] don't really get to the real patients, just people who volunteer or have vested interests."

All stakeholders were asked *'How, if at all, could consultation on new leaflets be done better?'* In response to this question the highest proportion of stakeholders (39%) stated they did not know and one in five (20%) said there is no need for improvement. Twelve percent of stakeholders suggested HRIS should consult a wider range of people / groups and 7% suggested consulting the public / organisations at an earlier stage in the development of leaflets.

5.2 COMMUNICATION & INFORMATION PROVISION

This section of the report examines communication and information provision and assesses the usefulness of different communication methods.

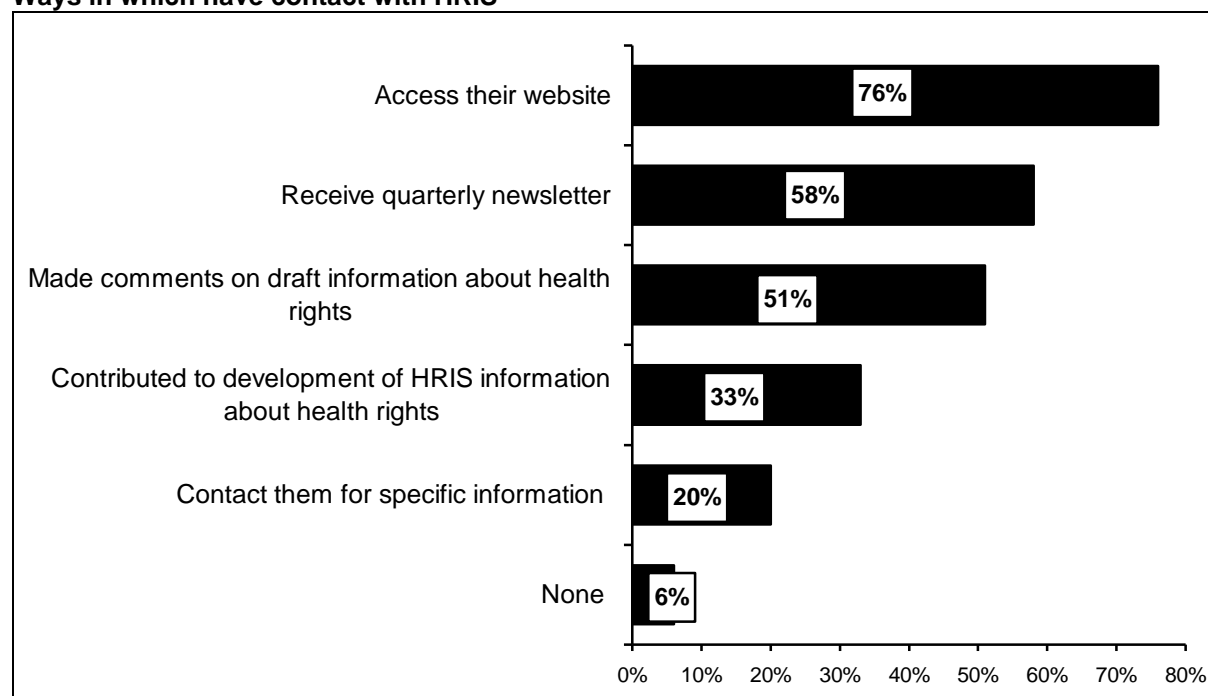
5.2.1 Methods of contact with HRIS

All stakeholders were asked to cite the ways in which they have contact with HRIS. As Chart 5.7 reveals, the highest proportion of stakeholders have contact with HRIS by accessing the web site (76%). Around three in five (58%) said they receive a quarterly newsletter and just over half (51%) have made comments on draft information about health rights. One third (33%) have contributed to the development of HRIS information about health rights and 20% have contacted HRIS for specific information.

When we examine the data across the different sub-groups we note a higher proportion of people who have used HRIS's consultancy role access the HRIS

website. This group of stakeholders is also less likely to receive the newsletter than others.

Chart 5.7
Ways in which have contact with HRIS



Source: Q10

Base: All respondents (120)

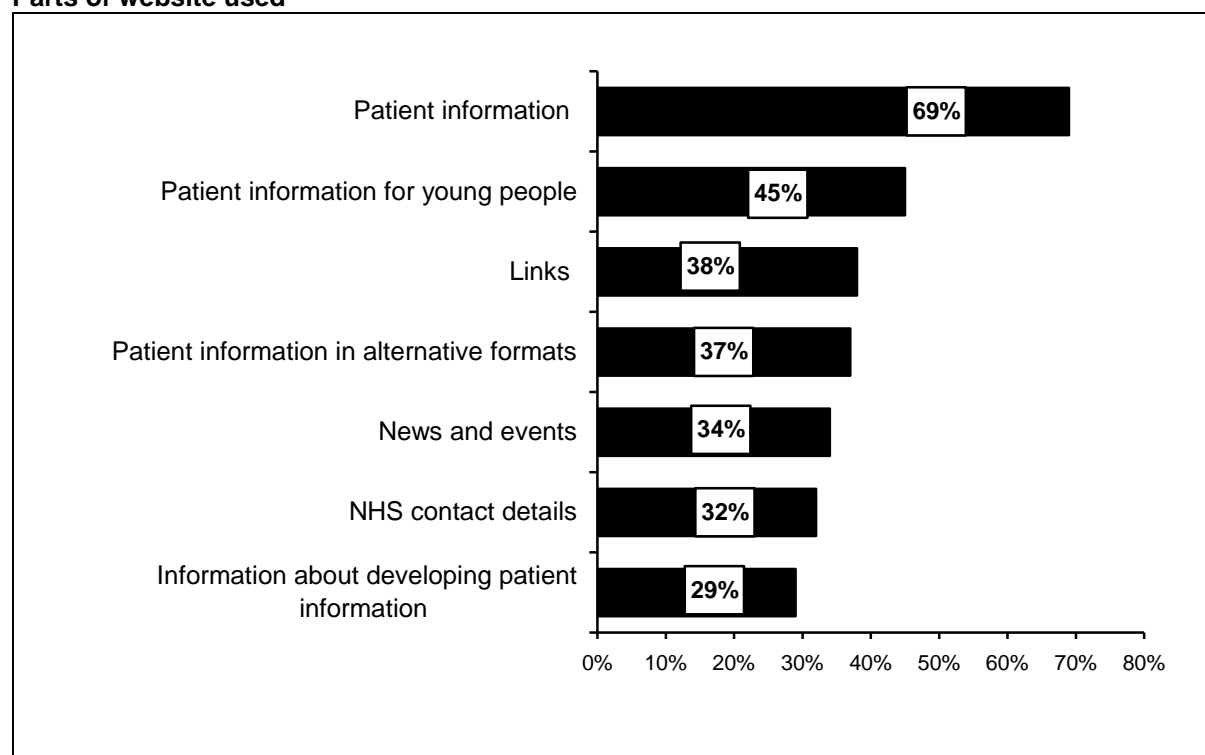
5.2.2 HRIS website

Those stakeholders who had accessed the HRIS web site were asked how often they do this and most access the web site on an infrequent basis. Only 1% access the web site daily; 2% several times a week and 3% weekly. Fifteen percent access the site several times a month and around one in four (23%) monthly. Fifty-five percent of stakeholders access the website less often than monthly.

The same stakeholders were asked about the parts of the website they have used. Around two thirds (69%) said they accessed patient information; 45% viewed patient information for young people and 37% patient information in alternative formats. Around three in ten (29%) had accessed information about developing patient information. Analysis across the sub-groups reveals a higher proportion of representatives from organisations that have used HRIS's consultancy role (e.g. Special NHS Boards) have accessed patient information, patient information for young people and information for developing patient information.

In addition, 38% of stakeholders said they have used the links on the website. Around one third of stakeholders used the website to acquire information on news and events (34%) and 32% obtain NHS contact details.

Chart 5.8
Parts of website used



Source: Q11b

Base: All those who have accessed the HRIS website (91)

5.2.3 HRIS newsletter

Those stakeholders who said they had received the quarterly HRIS newsletter (58%) were asked about the usefulness of the newsletter. Encouragingly, almost all (91%) found the newsletter useful, including 33% who said the newsletter is 'very useful'. In contrast 6% of stakeholders did not believe the newsletter is useful.

Very few stakeholders provided comments in answer to the question '*What would make the newsletter more useful?*' A small proportion (4%) suggested there should be better distribution (wider) and 3% suggested the newsletters should be available in other formats. One stakeholder acknowledged that the newsletter had recently been revamped and said "*It is much better now*". A different stakeholder suggested the newsletter "*Needs to come out more often to make it more relevant*" and other stakeholder suggested it should include "*Some snippets of good practice from local experts.*"

5.2.4 Telephone / Email Requests for Specific Information

Stakeholders who had contacted HRIS for specific information (20%) were asked how useful the specific information provided by HRIS was.

Encouragingly, almost all of these stakeholders (96%) said the information provided is useful; including 67% who stated the information is '*very useful*'. Only 4% said the specific information is '*not very useful*'. One stakeholder said there is "*not always a team member around when you need them*".

5.3 WORKING WITH HRIS

This chapter examines HRIS's approach to working with its key stakeholders and focuses specifically on the development of patient information.

5.3.1 Understanding of HRIS's consultancy role

All stakeholders were asked whether or not they were aware that HRIS is funded to act as a resource for other information providers by providing direct advice and assistance. This can take the form of commenting on the quality of existing patient information, advising on good practice for resource development, being commissioned to develop patient information that addresses an established need and working in partnership with others to produce information. In response to this question 33% of stakeholders (excluding representatives from organisations that have used HRIS's consultancy role) said 'Yes' and 67% said 'No'. The data including representatives from organisations that have used HRIS's consultancy role presented a similar result with 36% stating 'Yes' and 64% stating 'No'.

5.3.2 Developing patient information

Those stakeholders who were aware that HRIS is funded to act as a resource for other information providers were then asked if they had ever worked with HRIS to develop patient information or asked HRIS to develop information on their behalf. The data reveals that 30% of these stakeholders had worked with HRIS. Of these, all (100%) agreed HRIS had worked well with them this included 77% who said HRIS had worked very well with them.

The same stakeholders were asked the reasons why they believe HRIS worked well with them. The following positive remarks were made:

- HRIS are willing to listen to views / take comments on board (5 mentions)

- HRIS are helpful with queries (4 mentions)
- Had lots of contact with HRIS (3 mentions)

Eighty-five percent of these stakeholders also thought HRIS's involvement was beneficial to the process of information development and all of these stakeholders (100%) would work in partnership again with HRIS to develop patient information.

5.3.3 Contributing to content

One third (33%) of all stakeholders said they have contributed to the development of HRIS information about health rights. Of these stakeholders almost all (93%) agreed HRIS worked well with them including 63% who said HRIS worked *'very well'* with them. Of the various sub-groups, a higher proportion of representatives from organisations that have used HRIS's consultancy role said very well. Four stakeholders noted HRIS had not worked well with them.

Those stakeholders who said HRIS had worked well with them were asked to state the reasons why. The following positive points were noted:

- There was good communication / HRIS are willing to listen (15 mentions)
- HRIS take our comments on board (14 mentions)
- HRIS are responsive / adapted to request (12 mentions)
- No problems / HRIS were good (11 mentions)
- HRIS provided required feedback / reports (7 mentions)
- HRIS were easy to work with / approachable (6 mentions)
- HRIS appreciate your response (5 mentions)

The following quotes illustrate these positive points:

"They have recognised that we have a specialism and have taken it on board."

"They know what they are talking about and gave people time to get their views across."

"They targeted the right audience, listened very well to the forum."

Those stakeholders who thought HRIS had not worked well with them (5%) said the reason for this was because they had not had any proper or one-to-one contact with HRIS.

Stakeholders were asked to confirm whether or not they had felt sufficiently involved in the process. In response to this question 91% stated *'Yes'* and 8% stated *'No'*.

Four percent said they had not received any feedback from HRIS and 3% noted it was just an indirect contact. All of these stakeholders (100%) agreed they would work with HRIS again.

When asked for suggestions on how HRIS could improve its performance in this area, 72% had no suggestions to make. Those stakeholders who did make suggestions said:

- HRIS should listen to stakeholders / listen to new ideas (4 mentions)
- HRIS should provide more feedback e.g. let stakeholders know the outcome of the consultation (3 mentions)
- HRIS should consult stakeholders earlier in the information development process (2 mentions)
- HRIS should keep stakeholders up-to-date with new information (2 mentions)

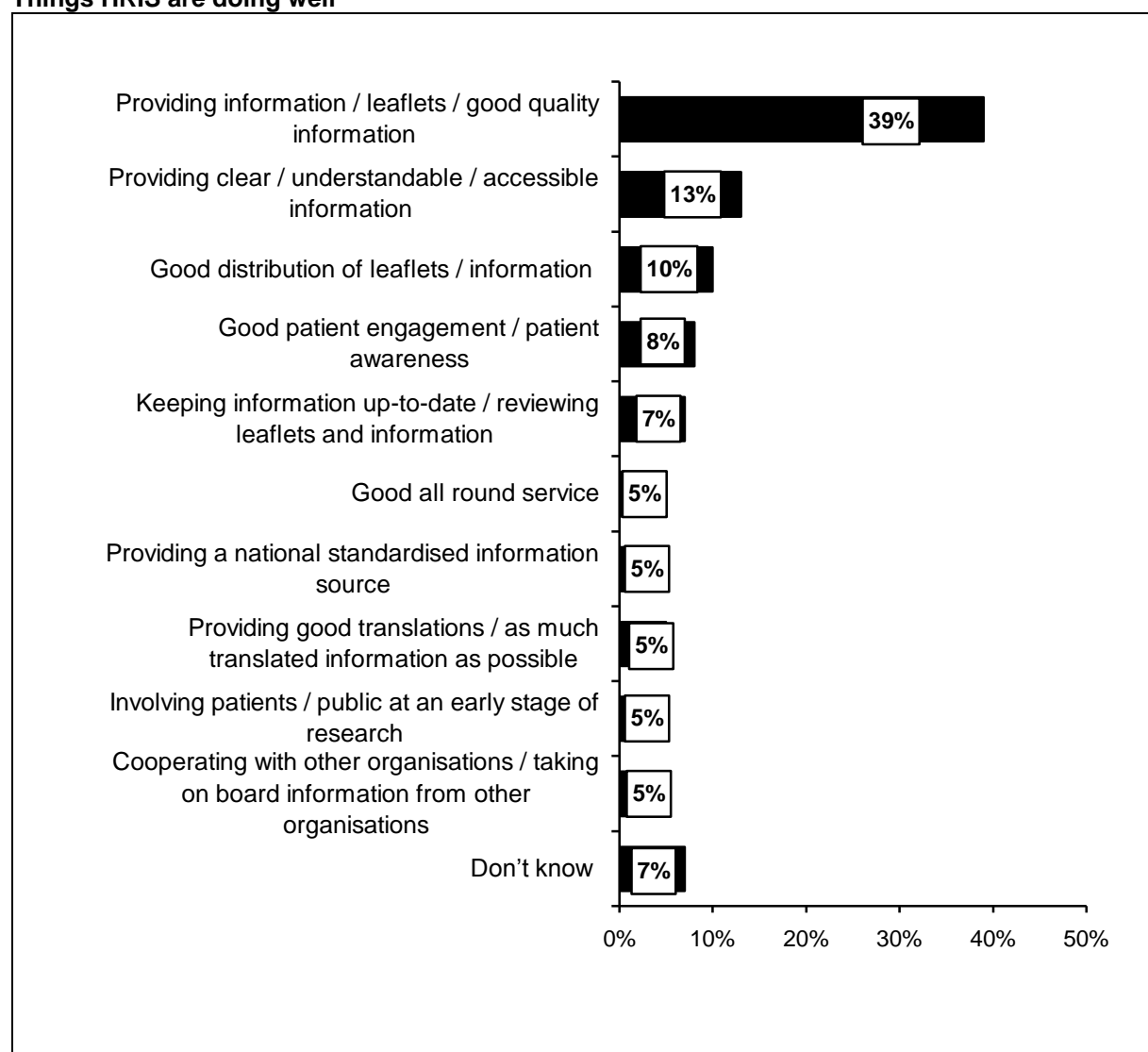
5.4 CURRENT PERFORMANCE & FUTURE DEVELOPMENT

This final chapter examines HRIS's organisational performance in terms of where the organisation is succeeding and where improvements can be made. This chapter also discusses the areas where HRIS might develop in the future.

5.4.1 Organisational performance

All stakeholders were asked the question *'From what you know of HRIS and their role, what would you say they are doing well?'* (see Chart 5.9). In response to this question the highest proportion of respondents (39%) agreed HRIS are doing well at providing information, leaflets and good quality information; 13% said they are doing well at providing clear, understandable and accessible information and 10% noted there is good distribution of leaflets and information. Seven percent said HRIS are good at keeping information up-to-date / reviewing leaflets and information.

Chart 5.9
Things HRIS are doing well



Source: Q13

Base: All stakeholders (120)

The following quotes illustrate some of these points:

“They are raising their profile, making sure information is available and identifying key areas to work on.”

“They are exploring ideas to get information out to people, exploiting health service networks promoting different formats.”

All stakeholders were asked to identify anything that gets in the way of HRIS doing a good job. The highest proportion (30%) said there is nothing that stands in the way

of HRIS doing a good job. In addition one in four (25%) said they did not know. The following comments were noted by the remaining stakeholders and focus on funding, promotion, printing and distribution of leaflets:

- Not enough funding / funding for printing (9 mentions)
- Not enough promotion / publicity / lack of public awareness (7 mentions)
- Leaflets are not printed centrally e.g. having to print own leaflets (6 mentions)
- Leaflets are not distributed centrally e.g. having to do own distribution (5 mentions)
- Leaflets are not distributed widely enough e.g. not sure if patients are picking them up (4 mentions)
- HRIS's lack of understanding of other organisations e.g. the way they work (4 mentions)

In relation to the distribution of HRIS leaflets two stakeholders suggested HRIS needs to make a bigger impact. One stakeholder was also concerned about the dissemination of leaflets at surgeries:

"[HRIS] have to think more about their dissemination strategy, how to make a bigger impact, to get information out to the public, and not just GP surgeries."

"[HRIS] could put internet details in public places, GPs, shopping centres, to get more average patients."

"Sometimes leaflets are not getting to waiting rooms at surgeries and staying in boxes in store rooms."

5.4.2 Improvements & future development of HRIS

All stakeholders were invited to make suggestions as to how HRIS could do better. In response to this question, over half (58%) had no suggestions to make. The following suggestions were made:

- HRIS should work more closely with Health Boards / better local communication (9 mentions)
- HRIS should raise awareness of information by advertising campaigns (media, newspapers, posters), marketing and publicity (9 mentions)
- HRIS should produce a wider range of information / leaflets (6 mentions)
- More funding support should be available e.g. for printing / centralised funding e.g. for provision of local information (5 mentions)

In terms of working more closely with Health Boards, stakeholders noted there needs to be more *“personal contact”* and *“development work”* with Health Boards and that HRIS should *“Help the health boards publicise what they [HRIS] do.”*

In relation to the future development of HRIS, 60% of all stakeholders did not provide any suggestions. Suggestions which were provided largely mirror what was said in terms of how HRIS could do better:

- HRIS should raise their profile e.g. by more publicity / (9 mentions)
- HRIS should have more communication with local Health Boards (8 mentions)
- HRIS should provide information / leaflets on other specified issues e.g. mental health, Patients' Rights Bill (5 mentions)

In terms of communication with Health Boards, one stakeholder suggested HRIS should:

“Have closer contact with Health Boards because so many information organisations out there can be confusing for the general public.”

In terms of HRIS addressing specified issues, one stakeholder suggested HRIS should *“look at the needs of people with learning difficulties and link up with the Long Term Conditions Alliance”*.

6. CONCLUSIONS & RECOMMENDATIONS

This chapter of the report draws together the key findings and the suggested recommendations. The conclusions are linked to the evaluation objectives and the findings show that views of HRIS are generally positive.

Public perspective

There appears to be limited recognition of health rights information amongst the general public. Of those who recognised one or more leaflets, half had read any and a relatively low proportion kept any for future reference. The most recognised, read and kept leaflets are *'Your Emergency Care Summary: What does it mean for you?'*, *'The NHS and you'* and *'The NHS Minor Ailment Service at your community pharmacy'*. Those aged 25-34 and those living in the North of Scotland are more likely to have read any of the leaflets.

There was some awareness of the alternative formats that leaflets are available in. The highest proportion of respondents was aware of leaflets produced in large print and in another language.

As a result of reading the leaflets, members of the public felt they had a better understanding of their rights and knew where to obtain further information or support. The vast majority of these respondents found the advice provided in the leaflets useful.

Professional perspective

Amongst stakeholders, there were high levels of awareness of each of the leaflets produced by HRIS. Almost all were aware of the leaflets *'Making a Complaint about the NHS'* and *'Confidentiality – it's your right'*. There was also a high level of awareness of leaflets in alternative formats and languages and an overwhelming majority classified this service as very important.

Stakeholders were evidently supportive of the purpose of the leaflets, with most considering the leaflets to be useful in terms of meeting patients' needs. According to stakeholders, the leaflets provide clear and simple information; the presentation and the layout are good, attractive and colourful and the information is comprehensive and easy to read. Stakeholders were very positive in their views on the quality of the leaflets.

Although most stakeholders who are able to comment, are happy with current approach to printing and distributing leaflets, some believe it could be improved through developing better/more specialist key contact lists, improving publicity and providing advice and support in a variety of ways. NHS stakeholders in particular

also suggest some degree of centralisation. Funding seems to be at the heart of this, with significant proportions of NHS stakeholders suggesting that there should be centralised and better funding and resource for printing and distribution.

A majority of stakeholders were unaware that HRIS is funded to act as a resource for other information providers. Those who were aware of this and who had actually worked with HRIS to develop information were extremely positive about how HRIS had worked with them with most agreeing HRIS's involvement was beneficial to the process of information development and all stating they would work in partnership again with HRIS to develop patient information.

In light of the findings of this evaluation we have developed a number of recommendations for HRIS to consider.

1. The findings suggest that after reading the HRIS leaflets people feel they know more about their health rights and where to go for more information or support. HRIS should work with its NHS contacts to ensure that leaflets are as accessible as possible, by encouraging distributors to target most the most frequently cited channels to promote leaflets to the public e.g. local GP Surgeries / Health Centres, Citizen's Advice Bureaux and Health Board websites.
2. HRIS should continue to involve the public in the development of information and should, if possible, consult earlier in the process and more widely. Young people should continue to be involved in development of information aimed at them.
3. The availability of information in alternative formats and languages is important and should be maintained for all publications. It would be worthwhile considering how to increase awareness of the availability of the alternative formats and languages amongst the general public and supporting NHS contacts to do this effectively.
4. Maintain the quality of leaflets in terms of attractive layout and design, accuracy and language. Consider using more graphics, pictures and images in the leaflets.
5. HRIS should work to improve awareness and usage of its website amongst stakeholders.

6. Most stakeholders are happy with the current approach to printing and distribution of information, but improvements are needed to make it work more effectively. HRIS should further develop its role in training, advice and support for NHS contacts, in relation to printing and distribution, and should ensure that this support is well publicised and accessible.
7. There are some suggestions that the network of key NHS board contacts could be widened and improved and some who have worked with HRIS would like improved communication. HRIS should review this network and undertake work to ensure that relevant people with appropriate specialisms are included. Further work should be done to develop an effective communication strategy for this network, perhaps beginning with a dialogue to better understand their communication needs and preferred channels.
8. NHS contacts find funding and resource for printing and distribution of leaflets difficult to identify and access. HRIS should explore mechanisms to provide central funding sources and/or additional central resource to support local contacts.
9. The findings revealed 91% of stakeholders found the HRIS newsletter useful. It should be distributed as widely as possible and used as a key channel for communication about the roles of HRIS, the website and the various advisory and support functions of the organisation. It could also be used as an ongoing mechanism to encourage feedback from stakeholders on a variety of issues.
10. Awareness of HRIS's roles varies amongst stakeholders. The majority are not aware of the consultancy role. Other communication channels, such as seminars, conferences, emails, leaflets, web alerts and so on could be usefully employed to further raise awareness of all of HRIS's roles and services.

APPENDICES

Appendix 1

Health Rights Information Scotland

Stakeholder Questionnaire

STRICTLY PRIVATE AND CONFIDENTIAL

This questionnaire is the property of George Street Research Limited, 24 Broughton Street, Edinburgh, EH1 3RH. Telephone 0131 478 7520.

Respondent's Name

Job Title

Company Name

Address

.....

Postcode Telephone Number

Interviewer Name Interviewer Number

Date of Interview Respondent ID Number

CLASSIFICATION

Category – as defined by HRIS

NHS stakeholder	1
Non-NHS stakeholder	2
HRIS network member	3
Partner	4

Length of time in current job/role

Less than 1 year	1
1-2 years	2
2-5 years	3
More than 5 years	4

Length of Interview: mins

Job Number: 5915

SECTION 1: INTRODUCTION

Good morning/afternoon. My name is and I am calling from George Street Research, a market research agency based in Edinburgh. We are currently conducting an evaluation of the work of Health Rights Information Scotland. You received an email a couple of weeks ago telling you about it. HRIS want to get the views of their stakeholders and we would like to conduct an interview with you as part of this research.

The interview will take 15 to 20 minutes. Would you be willing to participate in the research and could you spare the time now to go through the questionnaire?

Yes	1	CONTINUE
Yes willing but inconvenient now	2	ARRANGE ANOTHER TIME AND RECORD OR THANK AND CLOSE
No – Refusal	3	THANK AND CLOSE

- Q1 Firstly can you tell me whether your role involves patient information in any of the following ways?

READ OUT, MULTI CODE

You develop information for patients	1
You give information to patients	2
Your involvement with patient information is indirect (e.g. you distribute, monitor or manage patient information provision)	3
None of the above	4

SECTION 2: HRIS INFORMATION

- Q2 HRIS is responsible for producing the following information leaflets for patients. Which of these are you aware of?

READ OUT. MULTI CODE

The NHS and you	1	GO TO 3a
Making a complaint about the NHS	2	GO TO 3a
Confidentiality – it's your right	3	GO TO 3a
Confidentiality leaflet for young people	4	GO TO 3a
Consent – it's your decision	5	GO TO 3a
Consent leaflet for young people	6	GO TO 3a
How to see your health records	7	GO TO 3a
None	8	GO TO 5a
Don't know	9	GO TO 5a
All mentioned at Q2	10	

Q3a In general, how well would you say these leaflets meet patients' needs?

READ OUT AND SINGLE CODE

Very well	1
Quite well	2
Not very well	3
Not at all well	4
Don't know	5

Q3b In general, why do you say that?

ASK ALL CODED 1,2,3,4 AT 3a

PROBE FULLY

Q3c Are there any of these specific leaflets you would like to comment on?

PROBE FULLY, NOTING WHICH LEAFLET(S) COMMENTS RELATE TO. USE CODES FROM Q2

Q4a And how would you rate the quality of these specific leaflets in terms of

i) plain language and readability?

ii) being accurate and up to date?

iii) layout/design?

READ OUT AND SINGLE CODE EACH BELOW

	i) Plain language/readability	ii) Accuracy/up-to-date	iii) Layout/design
Very good	1	1	1
Quite good	2	2	2
Quite poor	3	3	3
Very poor	4	4	4
Don't know	5	5	5

Q4b Would you like to comment more on the quality of any of these specific leaflets?

PROBE FULLY, NOTING WHICH LEAFLET(S) COMMENTS RELATE TO. USE CODES FROM Q2

Q4c How could these leaflets be improved?

PROBE FULLY

ASK ALL

- Q5a HRIS produces this patient information centrally, and has a key contact in each of the health boards who is responsible for printing and distributing the information in their area. What is your view on this approach?

PROMPT IF NECESSARY

It seems like a good approach, but I can't comment on how well it works	1
It is a good approach and works well	2
It is a good approach, but could be improved	3
It would be better done another way	4
Don't know	5

- Q5b Why do you say that?

ASK ALL CODED 1,2,3 OR 4 AT 5a PROBE FULLY

- Q5c How could it be done better?

PROBE FULLY

ASK ALL

- Q6a All of these leaflets are available in a range of alternative formats and languages. How important would you say this is?

READ OUT AND SINGLE CODE

Very important	1
Quite important	2
Not very important	3
Not at all important	4
Don't know	5

- Q6b HRIS provides their key contacts at the health boards with copies of the alternative formats and languages. They also make the information available from the HRIS website. What is your view on this approach?

PROMPT IF NECESSARY

It seems like a good approach, but I can't comment on how well it works	1
It is a good approach and works well	2
It is a good approach, but could be improved	3
It would be better done another way	4
Don't know	5

Q6c Why do you say that?

ASK ALL CODED 1,2,3,4 AT 6b

PROBE FULLY

Q7a HRIS tries to improve the quality of its information by consulting on draft versions of newly developed patient information. It does this through focus groups amongst patients and members of the public and by seeking comments from patient representative organisations. What is your view on these approaches?

PROMPT IF NECESSARY

It seems like a good approach, but I can't comment on how well it works	1
It is a good approach and works well	2
It is a good approach, but could be improved	3
It would be better done another way	4
Don't know	5

Q7b Why do you say that?

PROBE FULLY

Q7c How, if at all, could consultation on new leaflets be done better?

PROBE FULLY

SECTION 3 HRIS ROLES AND RESOURCES

ASK ALL

Q8 Did you know that HRIS is funded to act as a resource for other information providers by providing direct advice and assistance?

Yes	1	GO TO 9a
No	2	GO TO 10

Q9a Have you ever worked with HRIS to develop patient information, or asked them to develop information on your behalf?

Yes	1	GO TO 9b
No	2	GO TO 10

Q9b When you worked with HRIS like this, how well would you say they have worked with you?

Very well	1
Quite well	2
Not very well	3
Not at all well	4

Q9c Why do you say that?

PROBE

PROMPT

i Was HRIS involvement beneficial to the process of information development? Yes 1 No 2

ii Would you use them again? Yes 1 No 2

iii Do you have any suggestions for how HRIS could improve its performance in this area, if so what?

ASK ALL

Q10 In which of these ways do you have contact with Health Rights Information Scotland?

READ OUT MULTI CODE, THEN FOLLOW EACH GO TO IN TURN

Access their website	1	GO TO 11a
Receive quarterly newsletter	2	GO TO 12a
Contact them for specific information	3	GO TO 12b
Made comments on draft information about health rights	4	GO TO 12c
Contributed to development of HRIS information about health rights	5	GO TO 12c
Other WRITE IN _____	8	GO TO 13 if only code
None	9	GO TO 13 if only code
Don't know	10	GO TO 13 if only code

ASK ALL CODED 1 AT Q10

Q11a How often do you access the HRIS website?

Daily	1
Several times a week	2
Weekly	3
Several times a month	4
Monthly	5
Less often	6

Q11b Which parts of the website have you used?

READ OUT MULTI CODE

Patient information	1
Patient information in alternative formats	2
Patient information for young people	3
NHS contact details	4
Information about developing patient information	5
News and events	6
Links	7

CHECK Q10 AGAIN AND ASK ALL CODED 2 at Q10

12a How useful is the HRIS newsletter?

i)	Very useful	1
	Quite useful	2
	Not very useful	3
	Not at all useful	4

ii) What would make the newsletter more useful?

PROBE

CHECK Q10 AGAIN AND ASK ALL CODED 3 at Q10

Q12 b When you contact HRIS for specific information, how useful is the information they provide?

i)	Very useful	1
	Quite useful	2
	Not very useful	3
	Not at all useful	4

ii) How could they do this better?

PROBE

CHECK Q10 AGAIN AND ASK ALL CODED 4 or 5 at Q10

Q12c

When you've had contact with HRIS to comment on or contribute to developing patient information about health rights, how well would you say they have worked with you?

i)	Very well	1
	Quite well	2
	Not very well	3
	Not at all well	4

ii) Why do you say that?

PROBE FULLY

PROMPT:

ii a Did you feel sufficiently involved in the process? Yes 1 No 2

ii b Would you work with them again? Yes 1 No 2

ii c Do you have any suggestions for how HRIS could improve its performance in this area, if so what?

CHECK Q10 AGAIN AND MAKE SURE ALL RELEVANT GO TOs DONE

SECTION 4: FUTURE DEVELOPMENT

ASK ALL

Q13 From what you know of HRIS and their role, what would you say they are doing well?

Q14 And can you identify anything that gets in the way of them doing a good job?

Q15 Do you have any suggestions as to how HRIS could do better?

Q16 Do you have any suggestions for the future development of HRIS?

Q17 Any other comments?

READ OUT: If you have any queries about this survey please contact Joseph Kerr on 0131 478 7543 and quote Job Number 5915. Alternatively, for confirmation that we are a legitimate market research agency, please call the MRS Free-phone 0500 396999.

CHECK CLASSIFICATION
THANK AND CLOSE

Declaration

I declare that this interview was conducted by me with the above named respondent in accordance with survey instructions and MRS code of conduct.

Signed Date

.....

Appendix 2

Omnibus Survey of General Public

Q1a Where would you go for information about NHS patients' rights? **DO NOT READ OUT AND CODE BELOW.**

Q1b And would you consider going to any of these other places? **READ OUT AND CODE BELOW.**

	1a - Spontaneous	1b - Prompted
Health board (phone/in person)	1	1
Health board website	2	2
NHS 24	3	3
NHS 24.com	4	4
NHS Helpline	5	5
GP surgery/health centre	6	6
Dental practice	7	7
Pharmacist	8	8
Local library	9	9
Family and friends	10	10
Citizen's Advice Bureaux	11	11
Other website*	12	12
Other	13	13
None	14	14

Q2a Of the following leaflets, which ones do you recognise? **READ OUT AND CODE BELOW.**

Q2b And which leaflets have you read? **READ OUT AND CODE BELOW.**

Q2c Of the leaflets which you have read, which ones have you kept for future reference? **READ OUT AND CODE BELOW.**

	Q2a Recognise	Q2b Read	Q2b Kept
Making a complaint about the NHS	1	1	1
The NHS Minor Ailment Service at your community pharmacy	2	2	2
Consent – your rights	3	3	3
It's okay to ask!	4	4	4
The NHS and you	5	5	5
Your Emergency Care Summary: What does it mean for you?	6	6	6
None	END SURVEY	7	7

ASK IF CODED AT Q2A, Q2B, Q2C

Q3a These leaflets are produced in a variety of different formats and languages, which type or types of alternative formats are you aware of?

Q3b And which of these alternative formats have you used? **READ OUT AND CODE BELOW.**

	Q3a Aware of	Q3b Used
Large print	1	1
Audio	2	2
On the internet	3	3
Easy read	4	4
British Sign Language	5	5
Another language	6	6
None of the above	7	7

THANK AND CLOSE EVERYONE NOT CODED AT Q2B

ASK FOR ANY CODED AT Q2B

Q4a What was the **result** of reading the information?

Found it easier to make a complaint	1
Registered with/used the Minor Ailment Service	2
Found it easier to ask questions at an appointment with health professional(s)	3
Knew where to go for more information or support	4
Felt like I knew more about my health rights	5
Passed the information to someone else	6
Other	7
None	8

Q4b How useful did you find the advice provided in the leaflet or leaflets?

<input type="checkbox"/> Very useful	<input type="checkbox"/> 1
<input type="checkbox"/> Quite useful	<input type="checkbox"/> 2
<input type="checkbox"/> Not very useful	<input type="checkbox"/> 3
<input type="checkbox"/> Not at all useful	<input type="checkbox"/> 4

Appendix 3

HRIS Evaluation

Online Survey

Thank you for following this link.

Please look at the pictures of leaflets below and click the boxes to show if you have looked at a leaflet or used the information in it.



The NHS and You

I have looked at this leaflet but not used the information in it

☐

I have used the information in this leaflet

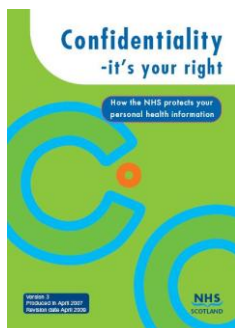
☐

Making a complaint about the NHS

I have looked at this leaflet but not used the information in it

☐

I have used the information in this leaflet

☐

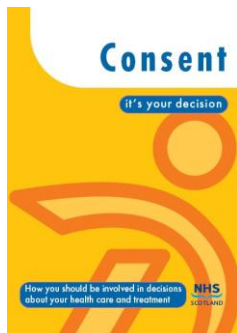
I have looked at this leaflet but not used the information in it

☐

I have used the information in this leaflet

☐

Confidentiality - it's your right



I have looked at this leaflet but not used the information in it

☐

I have used the information in this leaflet

☐

Consent - it's your decision



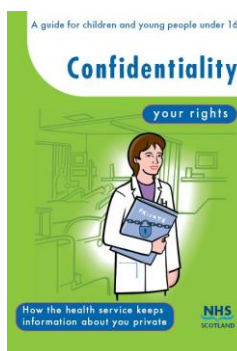
I have looked at this leaflet but not used the information in it

☐

I have used the information in this leaflet

☐

How to see your health records



I have looked at this leaflet but not used the information in it

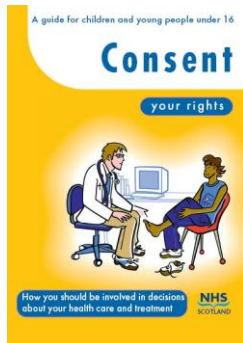
☐

I have used the information in this leaflet

☐

Confidentiality - a guide for children and

young people



I have looked at
this leaflet but not
used the
information in it

☐

I have used the
information in this
leaflet

☐

Consent - a guide for children and young people

If you have looked at or used any of these leaflets, we are interested in your views. Please tell us your name and phone number and we will call you.

Name:

Contact
number:

This is a secure website operated by George Street Research and your answers will be treated in confidence.

Your contact details will not be used for any other purpose or disclosed to anyone else. George Street Research is an independent research company, conducting this survey on behalf of the Scottish Consumer Council's Health Rights Information Project. If you want more information please contact us on 0131 478 7517. For confirmation that we are a legitimate market research agency, please call the Market Research Society Free-phone 0500 396999.

Thank you very much for your time. Now please send your answers by pressing the 'submit' button below.

Appendix 4

HRIS Evaluation

Topic Guide for Telephone Depths

The following topic areas have been developed to provide a framework for discussion. All relevant topic areas should be discussed and covered at some stage during the session, but should be addressed in such a way that facilitates a relaxed and natural flow of conversation.

Introduction

Firstly thank respondent for agreeing to interview and check still OK to speak now.

Explain confidentiality and confirm OK to record.

Introduce and remind purpose of interview.

Remind which leaflet(s) they said they've used and confirm correct – provide reminder of content if needed.

FOR EACH LEAFLET USED

Context

What were the circumstances in which they made use of the leaflet?

When did this all happen?

Where did they get the leaflet from?

If on-line:

1. What website?
2. Did you use the information on-line only?
3. Download it?
4. Print it?

Was the information easy to find?

Using the leaflet

How exactly did they use the information?

How helpful was it?

Did it impact on the way they went about their task? Did they do anything different as a result of the information?

Was there anything missing/any other info that would have been helpful?

Go through each section of leaflet asking about use, usefulness, and so on.

Did they contact any of the organisations listed at the back of the booklet? Why?/why not? Was this list helpful?

What have they done with the leaflet? Do they still have it?/anticipate using it again?

Did they tell anyone else about it? Pass it on to someone else to use?

Quality of the leaflet

How do they rate the quality of the information in the leaflet?

PROBE/PROMPT re

1. Ease of understanding (plain English, not too technical, too simple, too complicated Etc.)?
2. Order/structure?
3. Well presented (is an A5 booklet an appropriate format, good use of bullet points, illustrations etc.),?
4. Easy to use?
5. Explained in the right way (not too official, not too patronising)?
6. Accurate and reliable? (Was the information in the leaflet true for this instance/health board area) PROBE FOR DETAILS IF NOT. *NB the leaflets generally describe what a health board **should** do – need to probe carefully here to find out if any inaccuracies identified **are** in the information, or simply a matter of a health board not delivering on expected service levels!*

How does it compare to any other similar leaflets they've made use of?

Would they look for other leaflets in the series if you needed health rights information in the future?