

**AVAILABILITY OF
HRIS LEAFLETS**

**CONSUMER NETWORK
RESEARCH PROJECT**

SPRING 2007

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Introduction

Health Rights Information Scotland (HRIS) is a project funded by the Scottish Government and based at the Scottish Consumer Council. Its aim is to improve the information that is available to patients about their rights and responsibilities in relation to the NHS. HRIS has produced the following leaflets for use by the NHS in Scotland:

- *Confidentiality - it's your right*
- *How to see your health records*
- *Making a complaint about the NHS*
- *The NHS and You*
- *Consent - it's your decision*
- *Consent – your rights* (a guide for children and young people under 16); and
- *Confidentiality – your rights*¹ (a guide for children and young people under 16).

NHS boards are responsible for printing and distributing the series of leaflets to services within their area that provide NHS care (including GP surgeries, hospitals and pharmacies) to make it as easy as possible for patients to get the information they require at a time when they need it.

We wanted to find out if health boards were making the leaflets available to the public from these places, and if NHS staff were aware of the information. In order to do this we asked our Consumer Network² volunteers to undertake some mystery shopping exercises.

Aim

The aim of the exercises was to assess:

- the availability of HRIS leaflets from NHS services within each health board area;
- the awareness of NHS staff about the leaflets' existence; and
- the quality of the information provided, in terms of format and whether it was up to date.

¹ *Confidentiality – your rights* was first issued to health boards around the time that this mystery shopping research commenced. Therefore, it was not considered appropriate to assess its availability from health boards in this research.

² Our Consumer Network was set up in 1986 to help the Scottish Consumer Council (SCC) keep in touch with consumer concerns at a local level. Over 150 volunteers from all over Scotland assist by identifying local consumer issues and investigating facilities and services for SCC research projects.

Methodology

Chief Executives at all fourteen health boards were notified in advance that the mystery shopping exercises would be carried out during April and May 2007, and were asked to inform all relevant staff.

The research was carried out in two ways.

1. To find out if health boards are making the information produced by HRIS available to members of the public directly, phone requests were made by volunteers, as follows.

General request for written information

Half of our volunteers were asked to telephone their local health board (between 9am and 5pm, Monday to Friday) and request written information (*i.e.* patient leaflets) on one or two of the following topics:

- How the NHS keeps personal information confidential
- Looking at health records
- NHS complaints procedure
- Consenting to treatment
- Rights of young people
- Patients' charter (patients' rights and responsibilities)

Twenty-one volunteers took part in this exercise covering all health board areas except Borders and Forth Valley.

Specific request for HRIS leaflet(s)

The other half of volunteers were asked to telephone their health board (between 9am and 5pm, Monday to Friday) and ask for one or two of the following HRIS leaflets (they were asked to request the leaflet by its title rather than call it an HRIS leaflet):

- *Confidentiality – it's your right*
- *How to see your health records*
- *Making a complaint about the NHS*
- *Consent – it's your decision*
- *Consent – your rights* (leaflet for young people)
- *The NHS and You*

Twenty-two volunteers took part in this exercise covering all health board areas except Borders, Fife, Highland, Lanarkshire and Shetland.

2. To find out if health boards are making HRIS information available from services providing NHS care in their area, we asked volunteers to visit their GP surgery, community pharmacy, and, if possible, a hospital waiting room. If the leaflets weren't obviously available, volunteers were asked to approach a member of staff and ask directly for one or more of the leaflets.

In total:

- 44 GP surgeries were visited;
- 45 community pharmacies were visited; and
- 31 hospital waiting rooms were visited.

After completing the mystery shopping exercises, volunteers were asked to fill in a short questionnaire, describing their experiences. We also asked volunteers to send in, or describe, the written information they received (if any), to allow us to establish its quality.

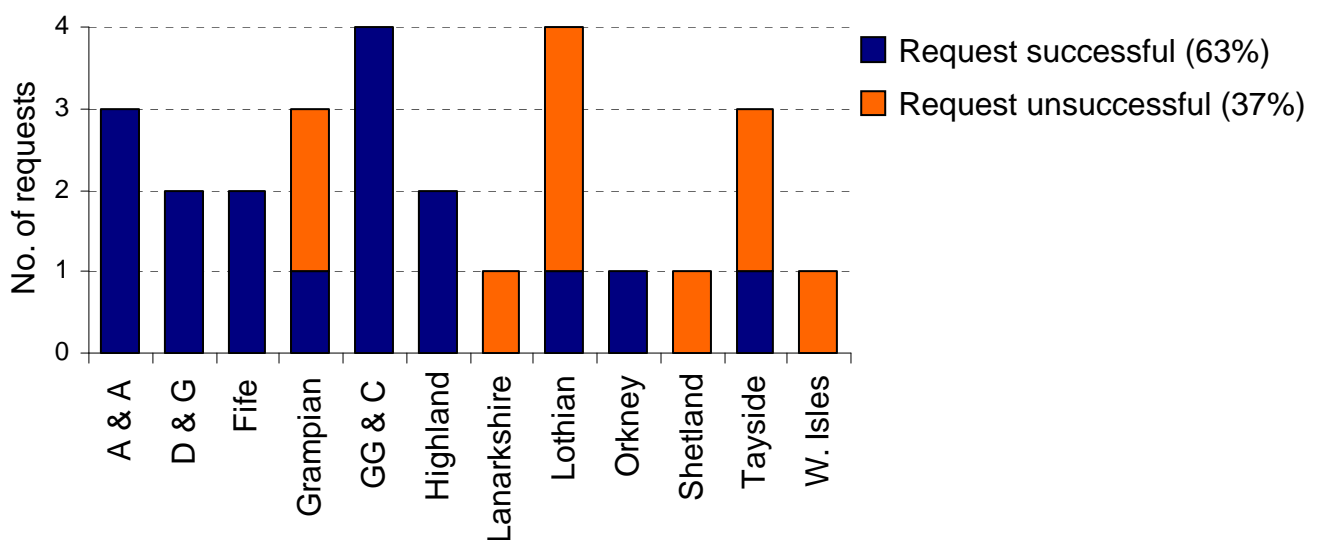
The number of volunteers taking part in each health board area was very low, so we are unable to use the findings as firm evidence for what is happening across Scotland.

Findings

General request for written information

In total, 21 volunteers made requests for one or more information leaflets. 63% of requests resulted in HRIS-produced leaflets being sent out to volunteers by NHS boards (see Graph 1).

Graph 1: Response by health board to requests for general written information



Six health boards were able to meet all requests successfully. However another six health boards were unable to meet one or more requests successfully.

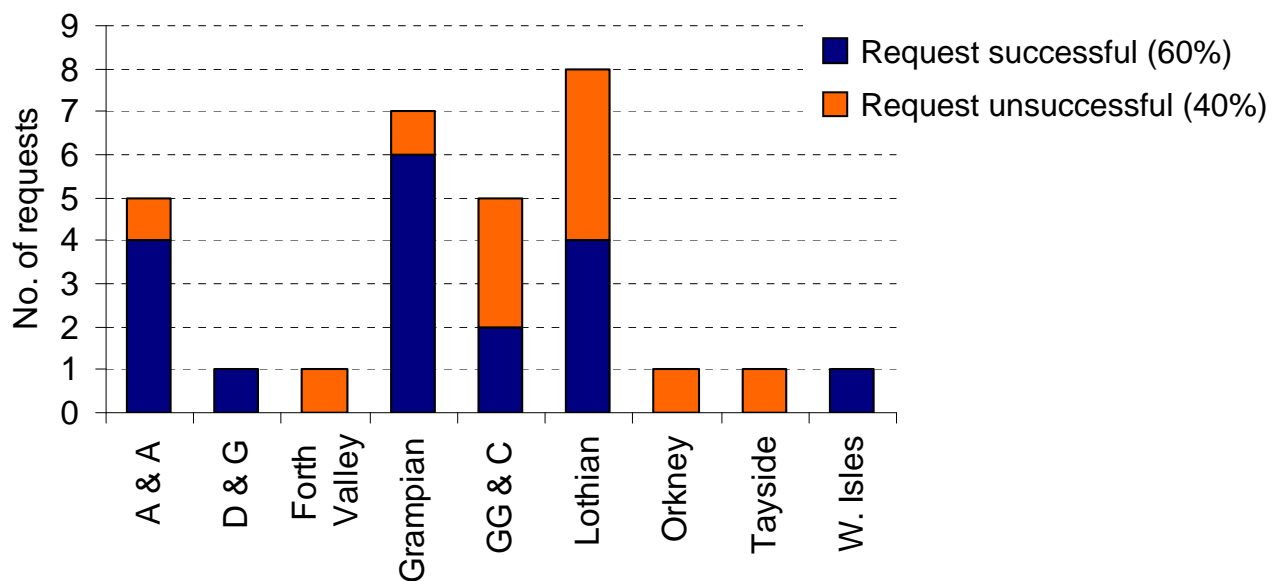
Disappointingly, for NHS Grampian, NHS Lothian and NHS Tayside where more than one request was made, the majority were not met successfully.

Specific request for HRIS leaflet(s)

In total, 22 volunteers made a specific request, by title, for one or more of the leaflets produced by HRIS. Although fewer health boards were contacted, the success rate was comparable with the general phone request exercise, with 60% of requests resulting in HRIS-produced leaflets being sent out to volunteers by NHS boards (see Graph 2).

NHS Ayrshire & Arran was able to meet four out of five requests for specific leaflets successfully. And despite performing less well in the general phone request exercise, NHS Grampian was able to meet the majority of requests received successfully. NHS Greater Glasgow & Clyde did less well in this task compared with the general phone request exercise, meeting only two out of five requests successfully. And, disappointingly, NHS Lothian was only able to meet half of all requests received successfully.

Graph 2: Response by health board to specific request for HRIS leaflets



Quality of information received

A number of volunteers sent in or described the leaflets they had received from their health board in response to their request for information. The findings below are based only on the information which we have seen or which volunteers have described.

Approximately 80% of volunteers received the most recent version of HRIS leaflets. However, some health boards did provide some out of date information. Around half of volunteers received professionally-printed colour leaflets. The other half received information as a photocopy or computer print-out, either in black and white, or in colour.

Notably, although NHS Ayrshire & Arran was able to meet the majority of phone requests successfully, a number of leaflets sent out were not the current version and were often provided as black and white photocopies. Conversely, volunteers who contacted NHS Dumfries & Galloway had received professionally-printed and up-to-date versions of HRIS leaflets.

Positive outcomes

The experience of some volunteers who took part in the telephone request exercises was encouraging.

- Some health boards met all or nearly all telephone requests successfully.

“The girl who answered the phone was very pleasant and helpful – she asked if any other leaflets were required and read me the list of titles.”

“I asked for the leaflets about how the NHS keeps information confidential and looking at health records and received the actual HRIS leaflets.”

- In some cases, the staff member receiving the call was able to re-route the volunteer’s call to an appropriate member of staff or department who was then able to send out the required information. For example, some volunteers were transferred to the patient liaison office, the complaints officer, or the resources department.

“I was transferred to Library Resources which closed at 4pm so I left a message on their answer phone. I was contacted the next day at 08.30 and they said they would contact Raigmore Hospital and have it sent out. They also said that I could source the information on www.hris.org.uk. They were very helpful.”

- There was some evidence that staff were aware of the HRIS leaflets. For example, as well as sending out the requested information, NHS Fife and NHS Highland also made efforts to inform volunteers that the information was available from HRIS’s website. And at NHS Grampian effort was made to establish which of the two consent leaflets one of the volunteers wanted.

“I asked for information about how the NHS keeps information confidential and the patients’ charter. I got a very professional response – I cannot find any fault with it. I was sent out the leaflets that I requested – an actual colour copy of *The NHS and You* and a colour photocopy of *Confidentiality*. These were sent with a covering letter explaining that I could also download the information from the HRIS website.”

“I was passed on to three different extensions – no-one could help until I eventually got through to the Resource Department. The person there knew exactly which leaflets I was talking about. He even confirmed whether I wanted *Consent* for under 16s or adults.”

Less positive outcomes

However, there were a number of issues that arose from the experiences of many volunteers taking part in the telephone request exercises.

- On the whole, NHS staff were not aware that the HRIS leaflets were available. In one extreme case, a volunteer was questioned about the existence of the leaflet *Making a complaint about the NHS*. The volunteer was informed they were wrong to think there was one. Unfortunately this was not simply a case of one staff member being misinformed, as her supervisor also verified what the volunteer had been told.
- Many volunteers were referred to seemingly inappropriate departments or organisations, such as their local Scottish Health Council office, the press officer, public health department, or told to contact their GP. In other cases, the person answering the phone was unable to offer any help or transfer the call appropriately.

“The person who answered the telephone sounded puzzled at my request and asked if I needed the press officer. I didn’t know who I needed to speak to. However, I was able to speak to a press officer quickly. She promised to send out the information and asked for my name and address. I have not received anything.”

“The switchboard operator had no idea about the leaflets and put me through to Human Resources. They assumed that I was employed by the health board (and they didn’t know about the leaflets either!). They put me back to the switchboard who then transferred me to the Chief Executive’s office!”

“The phone rang for quite a while and when it was answered (eventually) I asked for information about the patients’ charter. I was told it would be better if I phoned another number. However this number proved to be a ‘jobline’ answer phone for people wanting jobs. I then gave up – no time!”

“My first call was not answered but the second time I got through to someone. I asked for the HRIS leaflet *Making a complaint about the NHS* but they could not help me any further.”

- A number of volunteers were told that they should download the information themselves from the internet, and others were asked why they needed the information.

“None of the leaflets were in stock and they wouldn’t allow me to order anything over the phone – must order via email. They told me to check the website to download the information – but when I looked I couldn’t find anything.”

“I was given the internet address to view information online.”

- In one health board, on requesting the *How to see your health records* leaflet, two volunteers were told by the medical records department that they only had one copy of the leaflet and they need to keep it for their own reference.

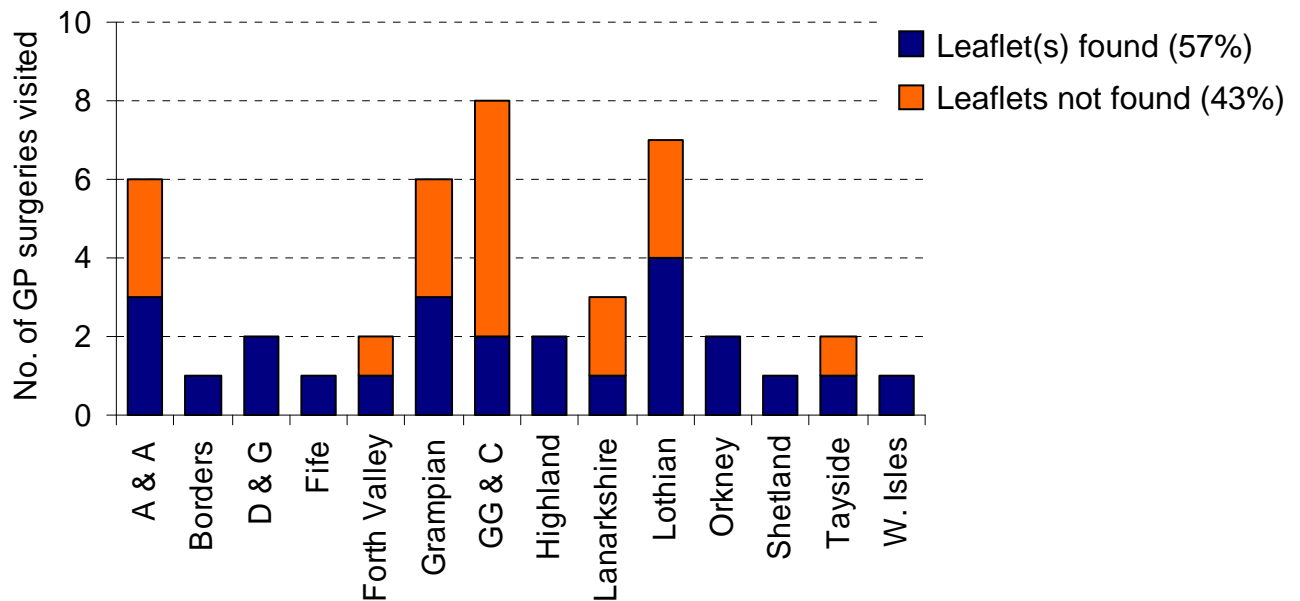
“The phone rang out for a very long time and was eventually answered and I asked for leaflet about how to see your health records. I was transferred to Medical Records. The staff member said they only have one copy for themselves but would give me the address and telephone number of the [local] Scottish Health Council.”

Availability of HRIS leaflets

a) At local GP surgery

Volunteers visited 44 GP surgeries in total, and over half of these had at least one of the HRIS leaflets available (see Graph 3). In some GP surgeries the full series of leaflets was found; however, this was an infrequent occurrence. In a number of cases, volunteers were not able to find the leaflets in the waiting area, and had to ask a member of staff directly – in the majority of these cases, volunteers were not successful in acquiring the information requested.

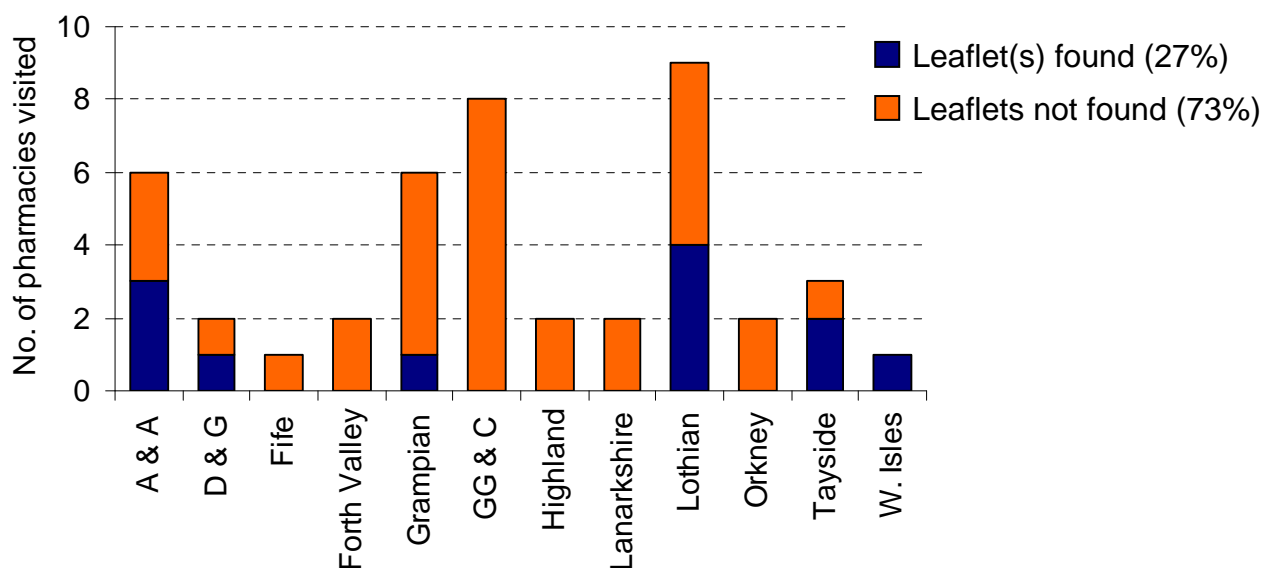
Graph 3: Availability of one or more HRIS leaflets from GP surgeries



b) At local community pharmacy

Volunteers visited 44 community pharmacies in total, but only one-quarter of these had at least one of the HRIS leaflets available (see Graph 4). This was limited to pharmacies within only six health board areas. In some pharmacies the full series of

Graph 4: Availability of one or more HRIS leaflets from community pharmacies

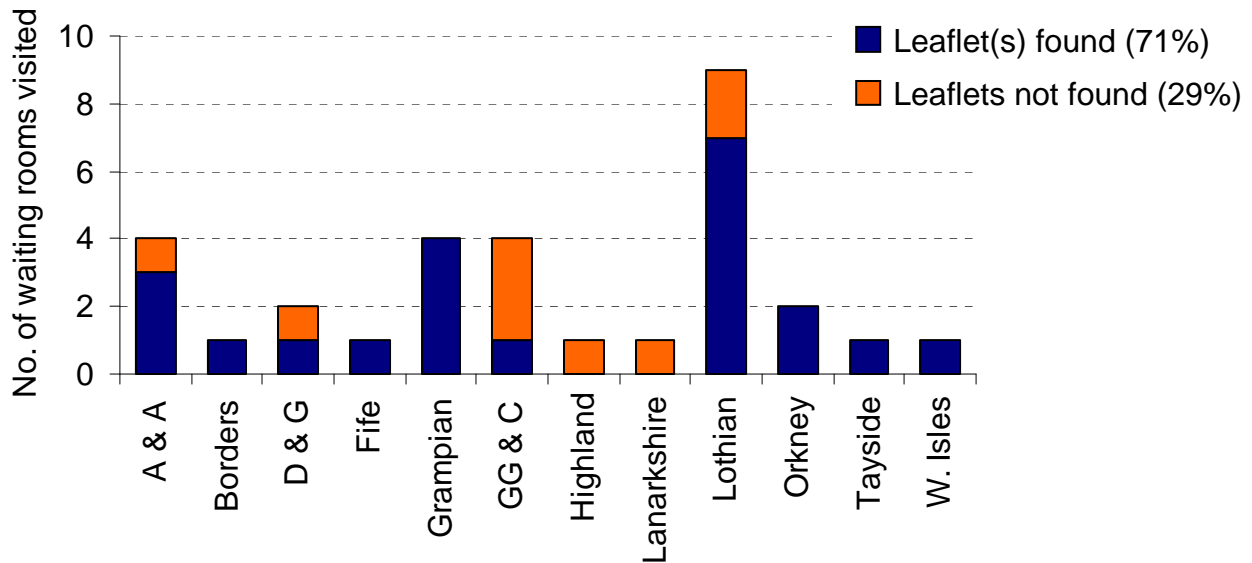


leaflets was found; however, as was the case for GP surgeries, this was a very infrequent occurrence. The majority of volunteers found that the leaflets were not available and, when approached, staff were generally unaware of their existence.

c) In hospital waiting rooms

Volunteers visited 31 hospital waiting rooms in total, and the majority of these had at least one of the HRIS leaflets available (see Graph 5). The full series of HRIS leaflets was found in very few waiting rooms.

Graph 5: Availability of one or more HRIS leaflets from hospital waiting rooms



Positive outcomes

As for the telephone request exercises, the experience of some volunteers was encouraging.

- A number of volunteers who found one or more of the leaflets reported that they were often easy to see, and could be reached, for example, by someone using a wheelchair.

“All of the leaflets were available and easy to see and reach . . . I am a wheelchair user.”

“I was able to find the leaflets pretty much straight away in the Out Patients (Department 2) . . . I identified them straight away as I feel they are nice – brightly coloured to catch your eye.”

- In a number of places where the leaflets were not available (or obviously available), volunteers reported that staff made efforts to get the information they were looking for, or advised them of other places they could try.

“The pharmacist was very helpful and did usually have some of the leaflets but had run out. He told me where to get them locally and said if I had any problems to come back in and if he hadn’t got more in he would order some.”

“The receptionist [at GP surgery] did not know about the leaflet I asked for but spoke with someone else who immediately brought me one. She also had the other leaflets and said they should be out and put them in the display stand.”

- One volunteer was told that her GP surgery was planning to include reference to the leaflets on their website, which is accessible to patients.

Less positive outcomes

Unfortunately, there do appear to be a number of issues of concern, and these seem to outweigh the positive reports.

- Very few volunteers came across the full series of leaflets at their GP surgery, community pharmacy, or hospital waiting room. Many volunteers commented on the difficulty in finding the leaflets because the leaflet racks were in such disarray.

“Both leaflet racks were untidy and if notices are still up from December 2006 it’s unlikely that anyone will sort and re-stock leaflets.”

“The leaflet stand was at a good height but had too many things stuffed into it making it difficult to see what was there.”

- There appears to be a general unawareness among NHS staff about the existence of the HRIS leaflets. This seems to be most apparent in community pharmacies.

“The staff member [at community pharmacy] looked confused and didn’t seem too bothered. She looked at some other leaflets, shrugged her shoulders and said, “Sorry – can’t help.””

“I spoke to the receptionist [at GP surgery], who didn’t have a clue what I was talking about.”

- In a number of cases, out-of-date information was given to volunteers. This was not simply a case of getting an old version of one of the HRIS leaflets.
 - One volunteer was given a series of information leaflets produced by Lothian’s Local Health Council (LHC) which are very out of date (LHCs have not existed since April 2005).
 - Another volunteer was given a leaflet produced by the Scottish Executive about the NHS complaints procedure. However, this leaflet describes the old NHS complaints system which has not been in place since April 2005. The HRIS leaflet *Making a complaint about the NHS* describes the new complaints procedure and should be being used instead of the Scottish Executive’s document.
 - Another volunteer was given a leaflet on confidentiality that had been produced by “NHS Argyll & Clyde Acute Hospitals NHS Trust”. This is a health board that ceased to exist from April 2006. Additionally, the HRIS leaflet *Confidentiality – it’s your right* should be being used by all health boards to describe a patient’s right to confidentiality of personal health information in place of any locally-produced information.

- In some cases, copies of leaflets were kept out of public reach, and so had to be asked for. One GP surgery kept leaflets in a filing cabinet, another kept them on

a shelf behind the receptionists, and another GP receptionist had her own “private” folder. When the volunteer asked about a particular leaflet, the receptionist referred to her folder, and proceeded to read out the main points from the leaflet to the volunteer.

“Some of the leaflets were available. You had to ask for them as they were kept in a filing cabinet behind the counter.”

“The receptionist was very obliging and nice and gave me a black and white photocopy of *How to see your health records* from a store shelf in the back of the reception area.”

- Seemingly inappropriate remarks were made to some volunteers who asked for the information leaflets.

“When I asked for the leaflet on consent, a staff nurse said she didn’t think they had them so asked a ward sister to see me. The sister said that they didn’t need these and that I should look at finding them in Kirkcaldy or Dunfermline.”

“The receptionist had no idea but said she would ask a senior nurse. Someone appeared and didn’t know anything about booklets but said that confidentiality would be discussed upstairs before any treatment.”

Conclusion

It is difficult to use the results of this research exercise as firm evidence for what is happening across Scotland because the number of volunteers taking part was relatively small. However, the findings do suggest that there is room for improvement by all health boards in some areas.

There appears to be a great deal of variability in the availability of HRIS leaflets from NHS services in Scotland. For some volunteers, the process of obtaining information was quite straightforward; however the majority appeared to have some difficulty. This was most apparent in community pharmacies, a finding which was reflected across all health board areas in Scotland. This is disappointing given that the developing role of community pharmacies may result in them being the first point of contact for many patients.

Staff awareness about the existence of information describing patients’ rights generally appears to be lacking, and this must contribute to the difficulties many volunteers faced in acquiring HRIS leaflets. The HRIS team need to work with health boards to help to improve public and staff awareness of the information they have produced for use within the NHS. The team should also find out from the health boards that performed well in some aspects of the research exercise how they have worked to inform staff and make the leaflets more widely available. This should be shared with the poorer-performing health boards.

A copy of this report will be sent to the NHS Chief Executives at each local health board, and to the Scottish Government Health Directorates. HRIS will also be contacting each local health board separately to discuss in more detail the findings from their area.

Acknowledgements

Thank you to all Consumer Network volunteers who took part in this research project.