



Making all consumers matter

Getting Access to Personal Health Records

Consumer Network Report

November 2005

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Introduction

Everyone in Scotland has a right to see or get a copy of their health records under the Data Protection Act 1998. We wanted to find out how this process works in practice. To do this we asked our Consumer Network¹ of volunteers to carry out a “mystery shopping” exercise to explore their experiences of requesting to see their own health records.

Our members were asked to:

- Contact their local surgery or health centre and tell them that they would like to see their health records.
- Keep a record of what happened when they made their request.
- Complete a questionnaire about their experiences.

The information that we were interested in included:

- How easy people found it to do this
- How long it took
- How much people were charged, if anything
- Whether people thought the information contained in their record was correct
- Whether people thought there was anything missing from their record

The information given by volunteers is divided into three parts as follows:

- The process of requesting to see their health records
- The process of examining their health records
- Their reflections on their overall experience of the whole process

¹ The Consumer Network is made up of people from all over Scotland who keep us in touch with local and national consumer concerns. As the Network is a self-selecting group it cannot be considered as representative of the whole population of Scotland.

Health Board Areas Covered

We had a total of twenty-seven responses covering the following health board areas:

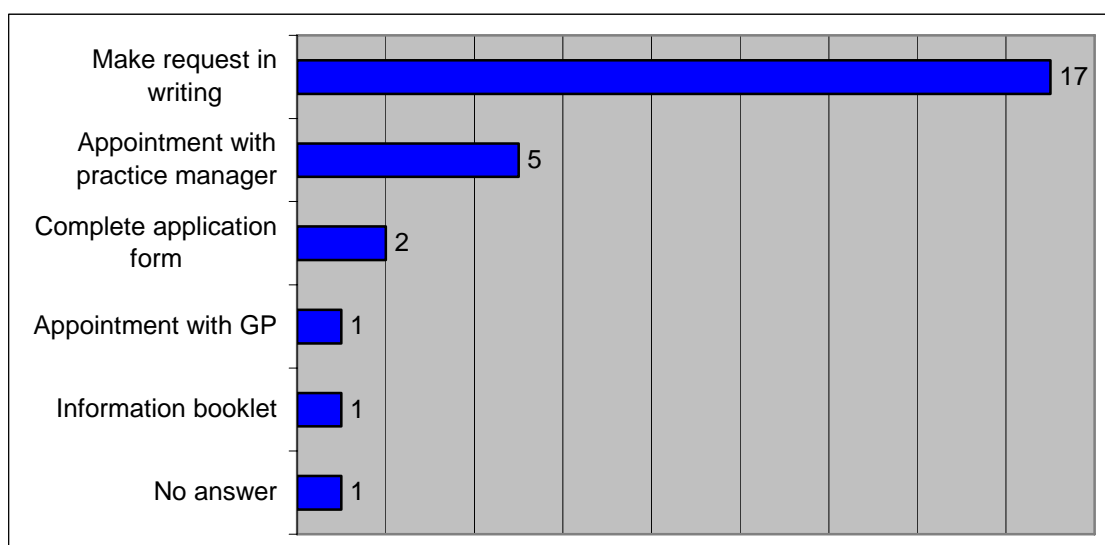
- Argyll & Clyde
- Ayrshire & Arran
- Dumfries & Galloway
- Forth Valley
- Grampian
- Greater Glasgow
- Highland
- Lanarkshire
- Lothian
- Orkney
- Tayside

Unfortunately, we did not get replies from the other four areas:

- Borders
- Fife
- Shetland
- Western Isles

Part One: Requesting to see your health records

We asked our volunteers to contact their local surgery or health centre and tell them that they would like to see their health records. We wanted to know what advice they were given at this point. Most of our respondents (17) were told to make their request in writing, five were advised to make an appointment to see the practice manager and two were asked to fill in an application form. One member was told to make an appointment with their GP, another was given an information booklet about the procedure and one volunteer did not give an answer (see table below).



Charges – is accurate information given?

Current NHS guidelines state that:

If health records are paper, or a mixture of paper and computer records, and you just want to look at them, there is no charge if they have been added to during the last 40 days. If they haven't been added to in this time, it costs up to £10.

If you want a copy of any part of your health records it can cost up to £50 depending on the size of the records and whether there are documents such as x-rays to be copied.

If health records are held totally on computer, it costs up to £10 to see or have a copy of them.

We wanted to find out what kind of information about charges was given to our volunteers. First of all, we asked whether our members were given *any* information about charges. The majority of our respondents (17) reported that they were indeed given information about possible charges for access to their health records – while in the other ten cases charges were not mentioned at all.

Charges for viewing health records

Five of our members were told that there would be a charge of £10 to view their health records. However, although NHS guidance states that “if your records are paper or a mixture of paper and computer records and you just want to look at them, there is no charge if they have been added to during the last 40 days” – two of our members who had indeed visited their GP within this period were still charged £10 to see their records anyway when this should have been free.

Charges for getting a copy of health records

Ten of our volunteers were told that there would be a charge for a copy of their health records. However, five of these respondents were not told how much this would be. The other five responses are given below:

- “up to £50”
- “£50”
- “I was told that only a lawyer or medical professional could request a copy and it would cost around £100”
- “£10 - £50”
- “40p per sheet up to £50”

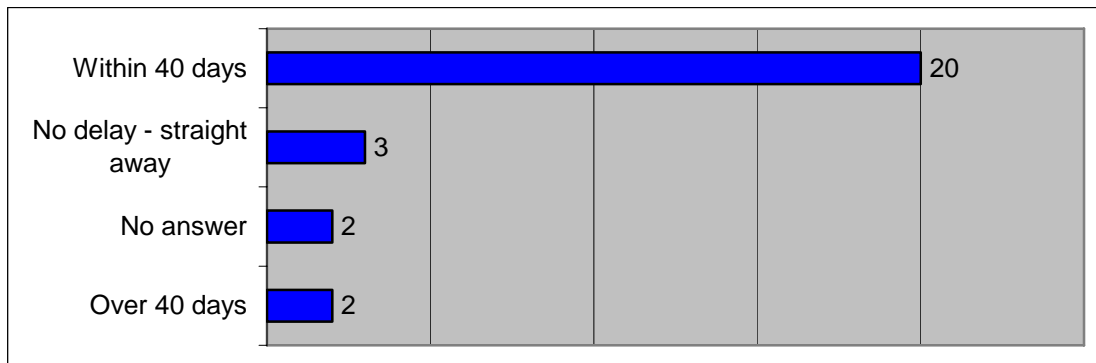
It should be noted that one of our members from the Greater Glasgow Health Board area was charged £50 for a full copy of their health records. However, this member reported that her records are held totally on computer and so

strictly speaking the charge should have been just £10, because according to NHS guidelines “if health records are held totally on computer, it costs up to £10 to see or have a copy of them”.

How long did it take?

“After you have given NHS staff enough information to identify you and your records, and paid any fee, you are entitled to get the information within 40 days”.

The majority of our volunteers (20) told us that they were able to get access to their health records within 40 days (time waited varied from 2 – 20 days). Three members were given access straight away – no waiting at all. Two members were given access straight away – no waiting at all.



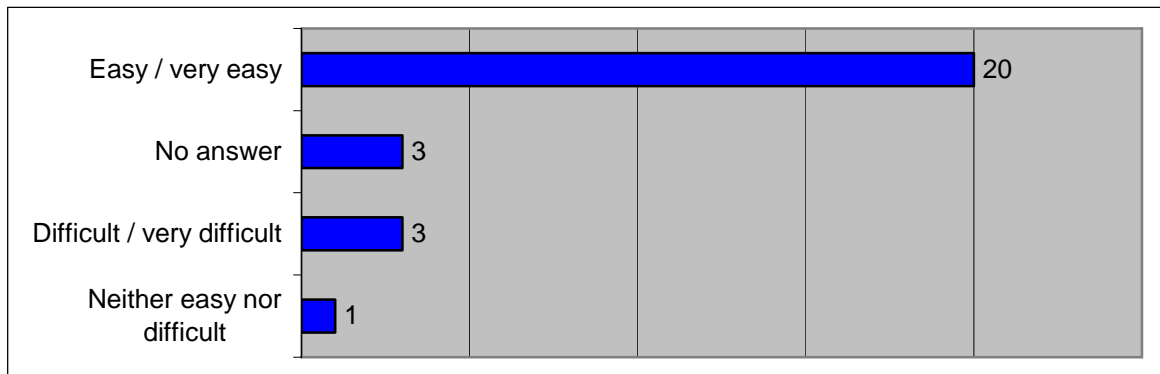
Only two people had to wait over 40 days and commented:

“the practice manager was very helpful and told me to make an appointment (on Friday 23 June, 3.00pm) for the following Tuesday (27 June). At 5.00pm (on Friday 23 June) the doctor telephoned me to say that he needed more information and that he would get back to me – I’m still waiting!”

“I was advised by the receptionist to put my request in writing to the practice manager. I did this but have never heard anything back at all!”

Requesting to see health records – overall experience

When asked to evaluate their overall experience of requesting to see their health records most of our members (20) found the process easy or very easy. There were only three volunteers who had difficulties. The first two problems involved our members (see page 8 – How long did it take?) who are still waiting to be contacted. The third problem involved another respondent who reported that when telephoning the surgery to enquire about seeing her health records was asked questions as to why she wanted to see them. This should not have happened because according to NHS guidelines - “you do not need to give a reason for wanting to see your health records”.



Other comments:

“It was obvious that staff thought it unusual to request to see your health records”

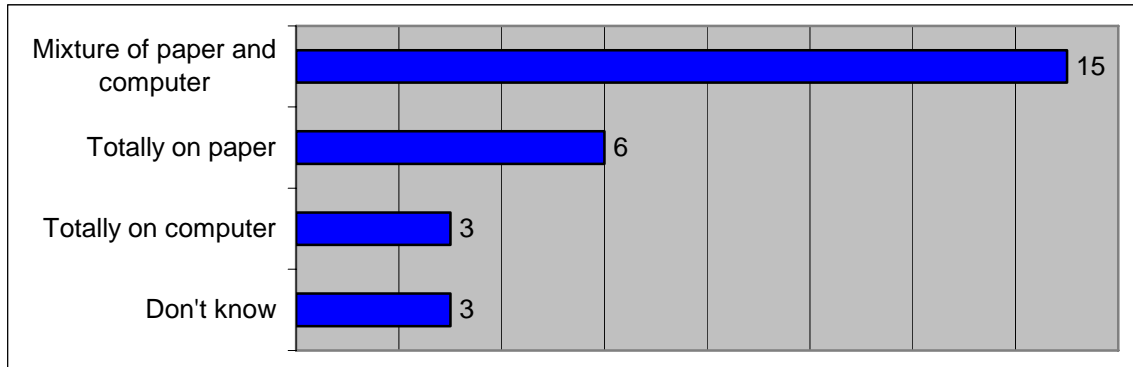
“I was told by the practice manager that no-one had asked to see their health records before”

“It was a very positive and pleasing experience – the doctor couldn’t have been more helpful”

Part Two : Examining your health records

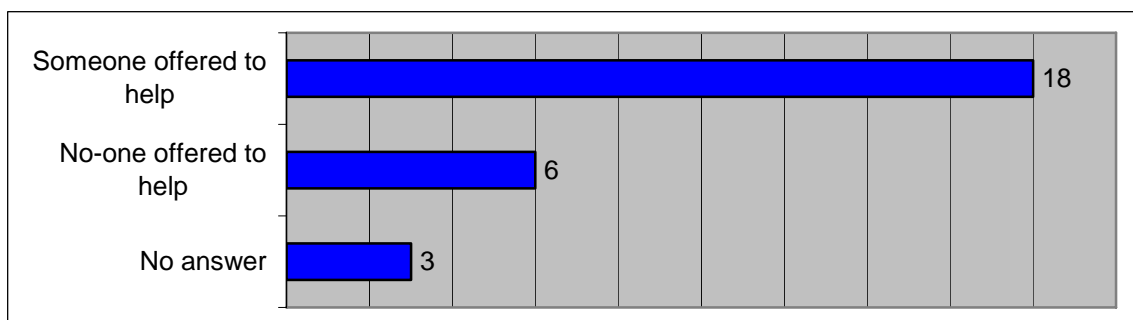
How are your records held?

We asked our volunteers to tell us whether their health records are held totally on computer, totally on paper or a mixture of computer and paper. The majority (15) reported that their records are a mixture of paper and computer records.



Was any assistance offered?

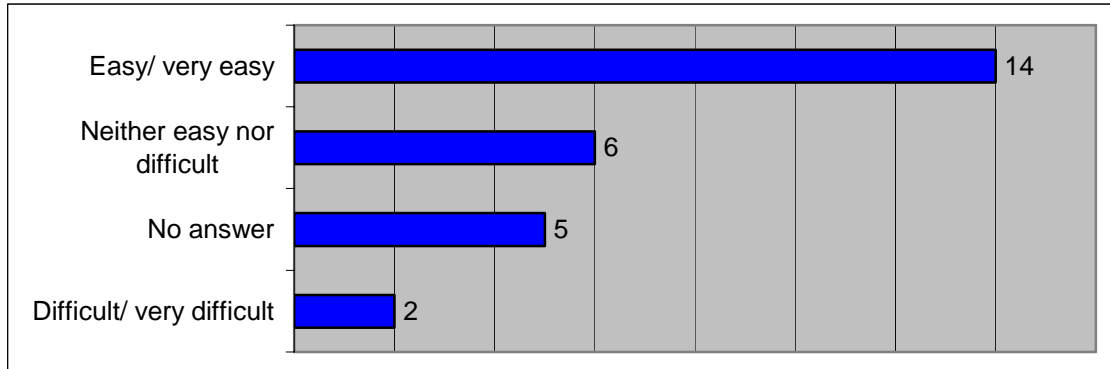
We wanted to know if anyone at the surgery offered to help our members look through their records, for example, to explain anything which might be unclear. It was good to see that the majority of our volunteers (18) reported that they were indeed offered such help, if required. Disappointingly, six people were not offered any assistance.



How easy to understand are health records?

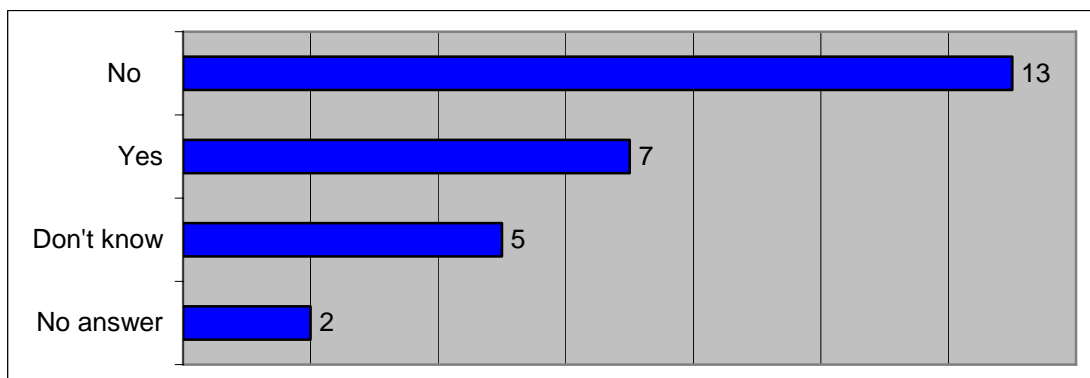
We asked our members to evaluate how easy or difficult they found it to understand their health records. The majority (14) did not seem to have any problems at all. There were two volunteers who found understanding their records difficult – one because of illegible handwriting, abbreviations and

photocopies being too faint and another who reported similar problems and in addition said that unfamiliar medical terms and jargon were used.



Was anything missing?

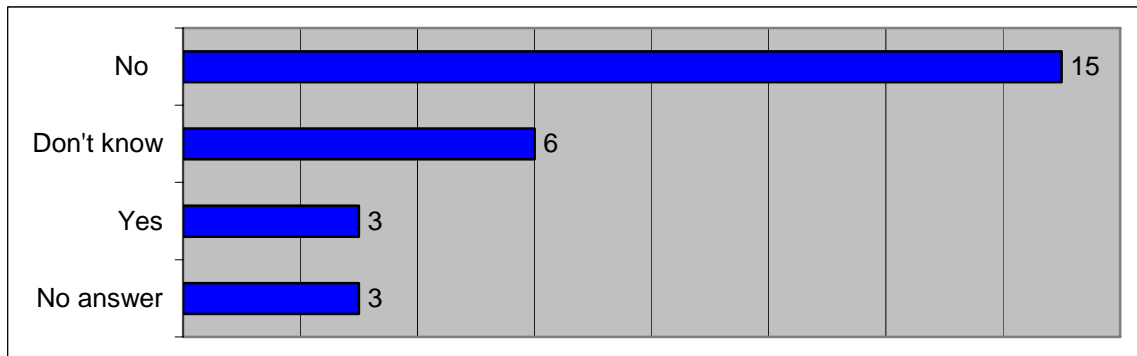
We wanted to know if our volunteers found any parts of their health records missing. For the majority there was nothing missing (13) but seven of our members did find that some things were missing.



Of those seven people who reported that some information was missing from their records - three said that quite a lot of it was missing, three said some of it was missing and one said that only a little was missing.

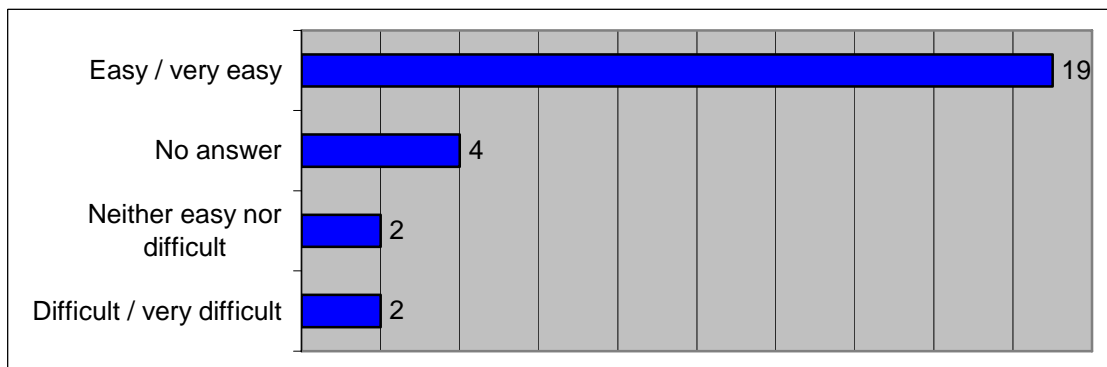
Were there any mistakes?

Our next question was whether our volunteers found any inaccurate information in their health records. Most of our respondents (15) found that there was no inaccurate information, three found some inaccuracies (1 major and 2 minor mistakes) and five didn't know if there was inaccurate information or not.



Examining health records – overall experience

Finally, we asked our members to evaluate their overall experience of examining their health records. The majority seem to have had no problems at all (19), two did not have an opinion one way or the other and two reported having difficulties.



Only two respondents reported difficulties - specifically that there was a lot of missing details, a good deal of information was illegible and that there were many abbreviations.

Other comments:

“I was surprised at how well maintained my records were – much better than I expected”

"I had never contemplated viewing my health records before and enjoyed the experience which was comparable to looking through an old photograph album"

"Although the handwriting was 'difficult' because I work in the NHS I understood all the abbreviations etc"

A number of our volunteers noticed that there was no record of their earliest years:

"No record of my life pre-1970 (I was born in 1950)"

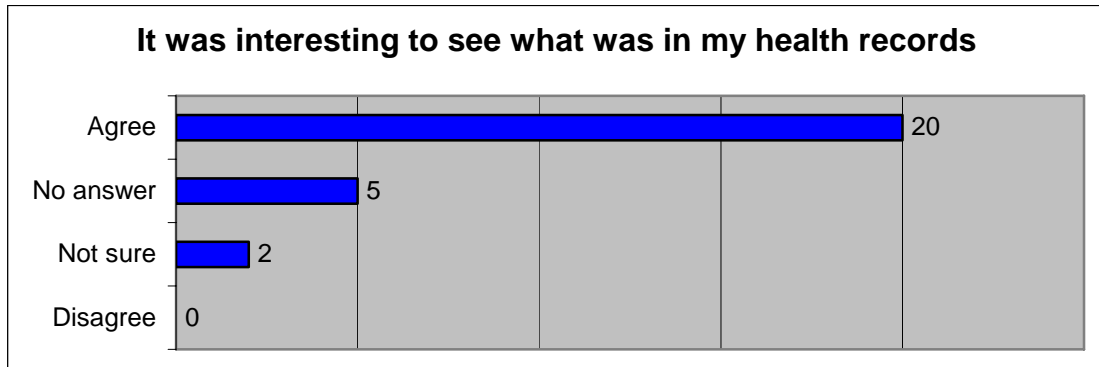
"My records went back to 1975 (born 1959)"

"Birth to age thirteen not available – I was advised to write to Primary Care"

"No records available at the surgery for the first twenty years of my life"

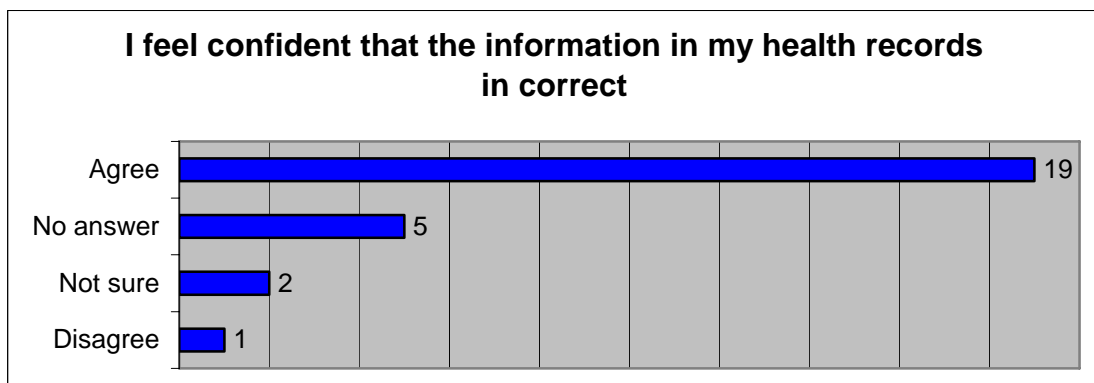
Part Three – Review of the whole process

We asked our members to tell us their views on a number of issues after viewing their health records.



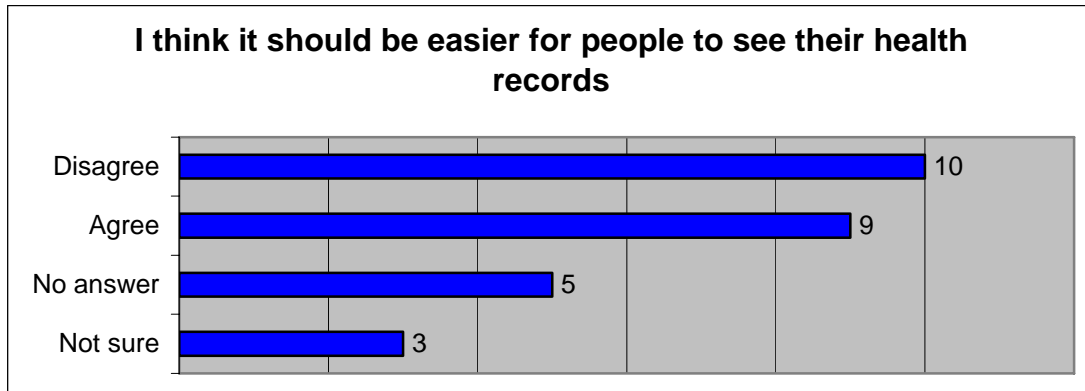
Most of our volunteers (20) agreed that it had been interesting to see what was in their health records, with only two members unsure. One member commented:

"I enjoyed reading my records especially from when I was a child – the whole of my life was there. I would like to see my hospital records now!"



Most of our members (19) agreed that the information contained in their health records is correct with only one person disagreeing (two people were unsure). The respondent who was not confident that the information in her health records is correct found large amounts missing and some parts illegible. She states:

"a lot of incomplete records – filing system very obscure – much information illegible"

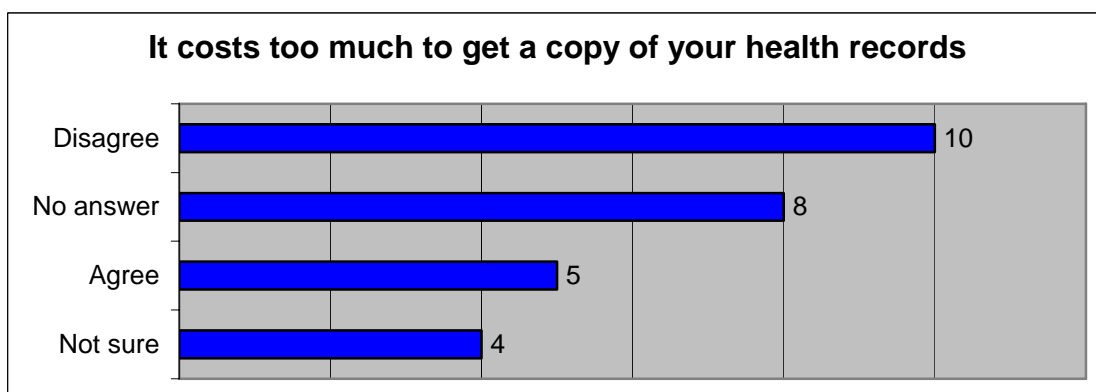


Our members were more divided over this issue. Ten people thought that it should not be easier to get access to personal health records - most of these gave the explanation that it is already quite straightforward. However, one person made the following comment:

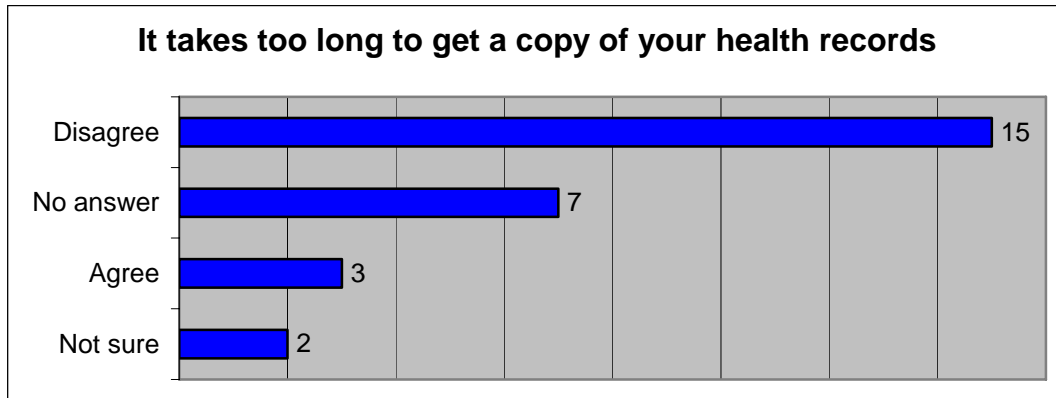
“although I agree that a person should have access to their records if necessary I don’t think it should be made any easier – it could become disruptive to health centre work”

Nine respondents agreed that it should be easier for people to see their health records with one person stating:

“I would recommend that people look at their health records. I found data from 1960 which has affected me all my life but which I didn’t know about”



Of the nineteen people who answered this question only five members think that it costs too much to get a copy of your health records. The majority (10) disagree that it costs too much and four people remain undecided.



Only three volunteers think that it does take too long to get a copy of your health records. The majority (15) of respondents disagree that it takes too long, while two people are unsure.

Conclusion

The process of requesting to see health records seems to have been quite a positive experience for most of our volunteers with twenty reporting that they found the procedure easy or very easy. Most of the respondents (17) were told about possible charges, although the information given was not always accurate. The majority of people (20) were successful in getting access to their records within the specified time limit of 40 days.

One area of concern is the incorrect information which some volunteers were given about charges and about their rights. Two volunteers were wrongly charged for seeing their record, when it had been added to within the previous 40 days. Some volunteers were given incorrect information about how much charges would be, and even whether they could ask for a copy of their record. Surgery staff need to be more knowledgeable and clear about what charges may apply and what patients' rights are in this area.

The process of examining health records was viewed positively by most of our members (19). The majority (18) were offered assistance (if required) whilst looking through their records. Only seven respondents reported that any information was missing from their records. Some of these commented that information from their early years was missing from the record. The majority of our volunteers (15) found that their records were accurate with just three members finding any mistakes. However, only just over half found it easy or very easy to understand what was in their record.

When asked to reflect on the whole experience the majority of our volunteers (20) agreed that it had been interesting to see what was in their health records. Encouragingly, most of our members (19) are confident that the information contained in their records is accurate. However, opinion is divided on the question of whether it should be made easier to see health records with ten volunteers saying that it *should not be* made easier, whilst nine think that it *should be* made easier.

When it comes to charges - only five of our respondents agree that it costs too much to get a copy of health records while ten people think that the charges are appropriate. Finally, most of our volunteers (15) think that it does not take too long to get a copy of your health records – only three people disagreed with this and two members are unsure.