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Research Briefing

Access to health records

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Background

This briefing reports on the findings of a Consumer Network project looking at consumers' experiences of getting access to their health records. Our Consumer Network is a group of over 350 volunteers from all over Scotland who regularly assist Consumer Focus Scotland by investigating local services and facilities for small research projects. We all have a right to see the information in our health records, but the cost and difficulties of looking at them may be a real barrier to our doing this. We decided to explore these issues in more detail and so we asked our Consumer Network volunteers to contact their GP practices and ask some questions about seeing or getting a copy of their health records. 56 people responded to this request and reported back to us on their experiences.

Key findings

Although our sample size is limited (and therefore cannot be considered as representative of all GP practices), this research exercise suggests that some of the front-line staff contacted by our volunteers did not know much about the rules and regulations regarding patients' access to their health records. This is probably what we would have expected, as few patients do ask to see their health records. At the same time, many of our members found that the staff were keen to help. However, the results are disappointing overall. This is a relatively simple area, and there is clear information available for patients which receptionists should be aware of. There was little evidence that the receptionists contacted were aware of patients' rights in this area, or that they were aware of the HRIS leaflet on this subject.

Consumer Focus Scotland recommends that the Scottish Government explores how to make it easier for people to see the information in their health records. This is important both in relation to ensuring that people are able to make a reality of their legal rights, and as a way of checking that the information held in health records is correct. With health records being increasingly held electronically, with the potential to be shared more widely, it is even more important that they are accurate. Making it easier for people to see their own record is one of the most effective ways of checking this. Consumer Focus Scotland also believes that once health records are held electronically, it should be a priority to enable people to view their own records online, and our wider research in this field¹ suggests that this is what many people want.

1. Findings from the research

Our volunteers were asked to contact their own GP surgery and ask the questions set out below:

- How much does it cost to view your health records in the surgery?
- How much does it cost to get a copy of your health records?
- How long does it take to arrange to see your health records?



1.1 How much does it cost to view your health records in the surgery?

According to data protection legislation² there are two possible answers to this question:

- No charge if the record has been added to in the previous 40 days; or
- Up to £10 charge if the record has not been added to in the previous 40 days.

Surgeries do not have to charge even when the record has not been added to in the previous 40 days.

When people asked what it would cost to simply look at their records (without getting a copy to take away) almost half (25 out of 56) were told that this would not cost anything. Only five people were told that it would depend on whether the record had been added to in the last 40 days, and one person was told that it would depend on whether the record had been added to in the last 30 days.

“I was told that if you have had an appointment in the last 30 days it is free.”

Others were simply told there would not be a charge. This is quite encouraging, as it suggests that some GP practices may have a policy of not charging to look at records.

“No charge unless there is photocopying involved.”

Sixteen volunteers were told that it would cost £10 without any mention of the 40-day rule. Others were given advice that was clearly wrong, indicating a varying range of charges, with seven people being quoted figures of more than £10. It is possible that the receptionists did not understand that our volunteers only wanted to look at their records, but it is not possible to tell this from the findings. Thirteen people found that the person answering the question was not sure how much it would cost which means that almost one in four people were not even able to get an answer to this simple question.

“Not sure – apparently no-one had asked the reception team for this information previously.”

1.2 How much does it cost to get a copy of your health records?

According to data protection legislation³ the costs involved in getting a copy of a patient's health records are:

- Records held totally on computer – up to a maximum of £10.
- Records held in part on computer and in part on paper – up to a maximum of £50.
- Records held totally on paper – up to a maximum of £50.

However, when it came to asking how much it would cost to get a copy of their health records, a large majority (47 of our 56 respondents) were not told that it would depend whether the records were held on paper or on computer. This means that only nine people were correctly told that it would depend whether the information was held on computer or in paper files.

“Depends on the number of sheets – paper up to £50, computerised up to £10.”

Five of these reported a maximum charge of £50, two stated £10 and two did not specify an amount. The most common response was that the cost would depend on the size of the records with 22 people reporting that they were given costs per sheet, ranging from 5p to 50p per sheet. This could be a misleading response as it would be quite easy for the overall cost to exceed £50, which is not allowed according to the legislation.

“£10 administration fee plus 15p per page – could be more if there are X-rays.”

Eleven surgeries were unsure of what costs might be. When it comes to information about maximum costs five volunteers were told that this would be £50, five were told £10, two were told copies were free, one person was told £20 and one person £30.

1.3 How long does it take to arrange to see your personal health records?

NHS guidance (based on data protection legislation⁴) states that “after you have given staff enough information to identify you and your records, and paid any fee, you are entitled to get the information within 40 days”. However, our volunteers reported that the replies they received to this question were quite vague with many people saying that the receptionists were not sure (23 out of 56). Ten volunteers were told that ‘it would not take long’, twelve were told ‘a week or two’, and four said ‘one or two days’. Only one person was told correctly that they would be able to see their records within 40 days. However, five people mentioned a specific time period of within 21 days.

“I was told it would take up to 21 days. The doctor checks the records for references to third parties. Viewing of records requires supervision by the doctor.”

It is possible that some GP practices don't mention the 40 day period as they have their own targets to do this within a shorter time, which would be encouraging. It is difficult to know from our respondents whether this is the case, or whether staff are just not sure what they should be doing.

A number of volunteers commented on the fact that receptionists were in general friendly and helpful, but were unable to answer the questions without referring to someone else, like a practice manager.

“The receptionist declined to answer the questions and advised me to speak to the practice manager.”

It is understandable that receptionists may not be well informed in this area, as they are currently not receiving many queries. Well over a third of our volunteers (23 out of 56) were told to make their request in writing, fifteen were told to make an appointment and four were asked to complete a form.

“I phoned on Friday, handed in a written application on Monday and got access on the following Friday.”

Eleven volunteers commented on the fact that they were told that when they went into the surgery to view their record, a member of staff would be with them – a practice manager, doctor or nurse. Some people expressed some resistance to this, feeling that they should be able to sit and read their own record privately.

“When looking at notes one would be supervised the whole time by a member of staff – I think this is wrong; people should be able to look at their files without supervision.”

Five members reported that they were told that the doctor would have to check their records before they would be allowed to view them.

2. Conclusions

Although our sample size is limited (and therefore cannot be considered as representative of all GP practices), this research exercise suggests that some of the front-line staff contacted by our volunteers did not know much about the rules and regulations regarding patients' access to their health records. This is what we would have expected, as few patients do ask to see their health records. At the same time, many of our members found that the staff were keen to help. However, the results are disappointing overall. This is a relatively simple area, and there is clear information available for patients which receptionists should be aware of. There was little evidence that the receptionists contacted were aware of patients' rights in this area, or that they were aware of the HRIS leaflet on this topic.

Consumer Focus Scotland recommends that the Scottish Government explores how to make it easier for people to see the information in their health records. This is important both in relation to ensuring that people are able to make a reality of their legal rights, and as a way of checking that the information held in health records is correct. With health records being increasingly held electronically, with the potential to be shared more widely, it is even more important that they are accurate. Making it easier for people to see their own record is one of the most effective ways of checking this. Consumer Focus Scotland also believes that once health records are held electronically, it should be a priority to enable people to view their own records online, and our wider research in this field suggests that this is what many people want.

About Consumer Focus Scotland

Consumer Focus Scotland started work on 1 October 2008. Consumer Focus Scotland was formed through the merger of three organisations – the Scottish Consumer Council, energywatch Scotland, and Postwatch Scotland.

Consumer Focus Scotland works to secure a fair deal for consumers in both private markets and public services, by promoting fairer markets, greater value for money, and improved customer service. While producers of goods and services are usually well-organised and articulate when protecting their own interests, individual consumers very often are not. The people whose interests we represent are consumers of all kinds: they may be patients, tenants, parents, solicitors' clients, public transport users, or shoppers in a supermarket.

We have a commitment to work on behalf of vulnerable consumers, particularly in the energy and post sectors, and a duty to work on issues of sustainable development.

References:

¹ Consumer Focus Scotland research (forthcoming)

² Statutory Instrument 2000 No. 191 The Data Protection (Subject Access) (Fees and Miscellaneous Provisions) Regulations 2000 Section 6 (3) a and Section 3

³ Statutory Instrument 2000 No. 191 The Data Protection (Subject Access) (Fees and Miscellaneous Provisions) Regulations 2000 Section 6 (2) and Subject Access and Health records DPA 1998 Compliance advice Information Commissioners Office Nov 01 v.2.1

⁴ Data protection Act 1998 Ch29 Part 2 Section 7 (8) & 7 (10) Right of Access to personal data