

Content

The Charter contains information on rights and responsibilities in six areas: Access, Communication and Participation; Confidentiality; Respect; Safety; and Comments and Complaints.

There are also sections describing what you can do if your rights have not been respected, and where you can get further information and support.

A leaflet will be produced to summarise this information further, and factsheets will provide practical examples of your rights and responsibilities in the six areas described above.

Question 1

- a) Do you think the level of detail in the Charter is useful and appropriate?
- b) Is there any information not included in the Charter that should be covered?
- c) What would make it better?

Question 1 Answer

The document is quite long and may be daunting for people to read. It would be better to cross refer to other leaflets and fact sheets rather than always try to summarise. For example, in the section on complaints.

People want to see the information they need on the topic that is currently affecting them.

Accessibility

We want the Charter to be as accessible as possible. This means that the language is easy to understand, and it is set out in a way that is easy to read.

Question 2

- a) Do you think the information in the Charter is written in a way that is easy to understand?
- b) Does the format of the Charter make it easy to find the information you need?
- c) What would make it better?

Question 2 Answer

The fact that the sentences are not too long make the Charter easy to read, and there is a refreshing lack of jargon and of acronyms.

The layout using bullet points and explanations makes it easy to find your way to the information you need – though still daunting in length.

The language switches between “you should” and “you can expect”. It would be helpful if these could be used consistently, or for it to be made

clear if there is a difference in the strength of the commitment or requirement.

In some cases it is clear where conditions or qualifications apply to the rights, or where there are other considerations. However, it is not consistent. For example, in relation to the right to request a second opinion which may be interpreted as the right to an opinion from a specific professional. In general it would be helpful to be clearer about the limitations of some rights.

Design

The Charter is presented in A4 format, with a different colour and icon for each section.

Question 3

Do you have any comments on the design of the Charter?

Question 3 Answer

The format enables significant sections to be seen on any one page.

However, there are concerns about how it will work in eg leaflet dispensers, which tend to be designed with smaller formats in mind.

Would it be possible to design a poster that includes the key headings and points and displays information about how and where to obtain the full Charter?

Availability

The Patient Rights (Scotland) Act 2011 says Health Boards must make copies of the Charter available without charge to patients, staff and members of the public.

The Charter will also be published online, and supporting information such as a summary leaflet and fact sheets will be available.

We are considering what the most appropriate alternative formats for the Charter or the supporting information is. For example, different languages, large print or audio may be produced. We would normally make available alternative formats on request.

Question 4

- a) What do you think is the most appropriate way for people to get a copy of the Charter?
- b) Do you agree that we should only make alternative formats available on request?

Question 4 Answer

The Charter and fact sheets and summaries should be available in health centres, GP practices, pharmacies, libraries, local clinics, hospitals, and through community organisations.

Having to make a specific request gives a mixed message about the universality of the Charter and the value put on diversity. Accessible formats should be available on the website and in hard copy for the most commonly used languages and formats. It need to state clearly on it where you can get the accessible formats.

Rights and Responsibilities

The Charter outlines responsibilities as well as rights. These are things that people using health services can do to help the NHS in Scotland work effectively and deliver quality care and treatment.

Question 5

- a) Do you have any comments on the balance of rights and responsibilities set out in the Charter?
- b) What would make it better?

Question 5 Answer

It would be helpful to include a statement on responsibilities in the introductory paragraphs as well as in the specific parts of each section.

People should be made more aware of their general responsibility to use the NHS with discretion and care in the context of finite resources, particularly, but not only, in the current economic circumstances. And equally, about their responsibility to consider their own health.

There needs to be more stress on mutuality and the importance of working together (as for example in the point about patients respecting staff and professionals on p 17).

It would be helpful to include more information on the responsibility to follow suggested treatment courses, take medication as advised and consider any advice on maintaining or improving health.

The responsibilities for patients in relation to discriminatory or abusive behaviour should be strengthened. The second bullet point in this section could be clearer that discriminatory language or behaviour towards staff or other patients is not acceptable (not just violent or aggressive behaviour).

General

Question 6

Do you have any additional comments to make about the Charter of Patient Rights and Responsibilities?

Question 6 Answer

P5 – Final bullet point – “informed decisions” should include reference to cost and evidence, and delete the words “share out the resources it has”.

P6 – Not everyone is eligible to register for the MAS – should this be included? Emphasis should be on fundamental and universal rights.

P7 – Second main bullet point should commence “You should make every effort to attend.....” After third main bullet point should include comment about ordering only those medicines you are using.

P9 – This section should include at least once that you can expect to be given time to reflect on information that you are given before coming to a decision.

P10 – Information on how to contact NHS24 should include what options there are for those who require communication support.

P11 – More information about how to provide feedback other than complaints would be helpful – will there be factsheets on this?

P12 – “If you need an interpreter or a sign-language interpreter, or other communication support, you can ask a member of staff to arrange help for you in advance.” Should read: “If you need an interpreter or a sign-language interpreter, or other communication support, you can ask a member of staff to arrange **this** for you in advance.”

P15 – This should include information about making sure that NHS staff, including your GP, know who is your next of kin.

P18/19 – The points about medicines safety are important and well made, and should include a point about bringing your medicine with you to hospital if asked to do so.

P20 – This seems weighted towards the negative and should include more about positive feedback. As mentioned above, this is an area that would benefit from supplementary fact sheets.

P21 – As regards expectations of patients, there needs to be more information about how to provide feedback on paper if there is no suggestions box available – not everyone wishes to use the internet.

P22 – This title is very blunt and could be reworded to “What if I think my rights have not been respected?”

Additional General Comments

The document doesn't refer to the right to ask for a staff member of a specific sex.

Feedback from some of our patient groups was that not enough consideration has been given to those who are older and infirm who may not have a family member or friend who can help them understand what is being told to them and the implications of such. Although the document refers to the ability to ask for support or independent advocacy, it is not clear how those who need help but may not be able to acknowledge or ask for it will be supported, or offered this support proactively.

The section on hospital cleanliness has a separate route for raising concerns directly with the Healthcare Environment Inspectorate (HEI). It is not clear why a separate process is set out for this category of issues. The information on how to contact the HEI also only gives a web address which will not be accessible for all.

The document refers to some very complex areas (eg on p11 re legal proxy, organ/tissue donation, under 16s). The Charter cannot cover all the issues here and should be clear about that, and not attempt to over simply or summarise complex issues.

The section on how to raise issues and complaints does not seem to be in line with complaints guidance on resolving issues as locally as possible in the first instance, and emphasises the formal complaint routes, Ombudsman and compensation. It would be helpful if the section on compensation could be clearly distinguished from the wider process of feedback and complaints; as it stands it could imply that compensation may be an outcome from a complaint, rather than being a totally separate process that has to be instigated with legal advice.

Specifically, we would note the comment on p22 "you can speak to the person in charge at the NHS organisation involved" which implies that individuals would be able to speak directly to the Board Chief Executive – this is unlikely to be feasible given the size of the organisations involved, and it would be more appropriate for this section to encourage people to speak to the person in charge of the ward or department. This section should be consistent with other complaints guidance and leaflets.