

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

It is not clear how people with limited literacy, assisted communication needs or limited access to computers will access the information.

In terms of access, the first page refers to 2 sources of web information, but it's unclear which is the main source. All of the information sources could be rationalised on the NHS Inform site (although a view was expressed that there should be direct hyperlinks to each leaflet or factsheet without having to go through NHS Inform and then search for the appropriate leaflet). Simplicity of navigation should be the main aim.

Under 'Communication', it would be helpful to make reference to the 'teach-back' methodology which checks patients' understanding of the information they have been given. Postcards are available to NHS staff describing this approach.

It would be helpful if the opening section could be set in the context of the goals of the Scottish Parliament and the health system, for example by:

- Describing the goals as: protecting and improving the health of the population; tackling health inequalities; and providing equitable services;
- Recognising health as a fundamental human right; and
- Broadening the focus on interpretation to a right to be heard, to understand and be understood.

It might also be helpful to set out the unique context in which health services are provided in Scotland. The NHS represents a choice by the citizens of Scotland to support each other during illness. The values of collectivism, fairness and respect are fundamental and should be emphasised in the document.

The limits to NHSScotland as a universal health system need to be set out

more clearly. There is a lack of understanding of the need to seek funding for some procedures before travelling to another European country. Some administrative staff fail to understand that there is a requirement to provide public health interventions free of charge.

It would be helpful to highlight where information can be found on how to access primary care, and on the broader workings of the health service.

A section on information sharing would be helpful, to spare people the need to recount traumatic stories more than once.

In the discussion on confidentiality, it might be better to say that information that is required to manage your condition will be shared. Sensitive information such as termination of pregnancy should not be shared, as it may not be relevant to medical management of the medical problem. Information in an individual's notes may also be relevant to other family members, and consideration needs to be given to how it would be shared, since the individual concerned may have consented to the information being shared, but other family members to whom the information is relevant have not.

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?

Specify in the introduction the new rights introduced by the Act.

The document should perhaps refer to the rights people from other EEA areas have to treatment here.

It is not clear whether the document is intended for the public to use themselves, or whether it is a guide for health professionals, advocates and trusted third parties. It would be a good opportunity to introduce a requirement for health services to provide only easy-to-read materials.

On page 6, it would be difficult, on the basis of the information given, for patients to decide whether they had a clinical need for transport.

It is not clear how the systematic and structural barriers to accessing services will be addressed so that people on low incomes, with low levels of education or who have additional needs or protected characteristics can be assured of receiving equitable care.

Some sections, such as that on access, are too busy and not clearly enough set out. 'Rights vs responsibilities' risks oversimplifying the situation, especially as some rights belong to groups who may not all agree about what they want. Some further editing is needed to make this clearer.

A brief version, perhaps in poster format suitable for display in waiting rooms, might be useful.

It would be better if there was a direct link to a downloadable copy of the HCS2 document. It would also be helpful to include a direct link to the Patient Access and Support Service from the online patients' charter.

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 formatting is different in the 'access' section, where sub-bullet points are more indented. This is easier on the eye as well as making the main bullet points stick out.

The rights can get lost in the mass of text, so it might be helpful to list them under the headings in the table of contents.

The design isn't clear. There are large blocks of text and in places the extensive use of bullet points makes it harder to read.

A4 is good for downloads, but not for display or carrying. A smaller size might be more pocket or bag friendly.

The icons that are used for each specific area make them easy to identify, but the meaning of the first green icon with the arrow is not clear. A square with a road sign and a question mark on it might be preferable.

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

(a):

Alternative formats should be made available in consultation with key stakeholders.

Having paper and on-line versions would make it easily accessible. Copies could also be made available in libraries and health centres.

(b):

Yes, for paper copies, but it should be made clear in the document how long it would take to produce it in an alternative format.

All possible formats should be available online by clicking links.

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

The tone of the document still appears pejorative and focused on transaction, rather than on a requirement that all relationships reflect those of the best.

To fulfil its aims, the NHS requires patient participation in teaching, research, quality improvements and service design and delivery to be at the heart of its responsibilities.

It is not clear how people are expected to overcome the structural and procedural barriers to using services 'responsibly'. The current steep socio-economic gradient in emergency admissions is not reflected in planned admissions.

It would be helpful to endorse the document from the Academy of Royal Colleges on the role of health professionals in tackling health inequalities. A similar document has been prepared by nursing and midwifery bodies.

There should be a specific statement about the right to freedom from discrimination and not being stigmatised when seeking care.

It is helpful to have the rights first and then the responsibilities.

General

Question 6

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

Question 6 Answer

The document should include a statement that patients or service users have the right to a smoke-free environment. There should also be a responsibility not to smoke when on health service premises.