

## 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

- a) The level of detail is about right, but however widely available it is, we believe it is unlikely to be referred to by many patients who are satisfied with the service – the information relating to comments and complaints is therefore an important element of the content in holding providers of care and treatment to account.
- b) The place for more detail to be provided is in the guides and factsheets referred to at the end of the document.
- c) We believe that the Charter is about right, as far as it goes. However, of far greater importance is what actions will be taken to promote a positive culture within the Health Service, and to ensure high quality, timely preventative and responsive care and treatment is available. We say a little more about this under question 6.

## 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?

- a) The language used is easy to understand.
- b) Yes, although the detail within factsheets is likely to be of more practical use than the Charter, for people who wish to check up on an issue.
- c) Nothing to add here.

## **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**

It is a clean, clear layout. It will be important that it is checked for accessibility with regard to screen readers.

## 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) In the interests of cost efficiency and reducing the use of paper, it would seem most appropriate to offer it at a routine contact with health services, rather than provide everyone with a copy. If a key aim of the Charter is to make sure that everyone is aware of their responsibilities for their own health, then it may be that the Charter needs to be introduced at an early age – possibly linked to citizenship-type learning.
- b) The Charter should be made available in a number of standard formats such as Easy Read; large print; braille; BSL and audio versions. Electronic and other appropriate versions of these should be available from the same launch date as the standard print version for production by local services. Health Boards should be able to produce these formats immediately they are requested, given the size of populations they serve. It is reasonable that more individualised versions for people with complex communication support needs would be made available on request, but these need to be provided within a timescale that is meaningful to the person and the level of health service involvement they are engaged in.

## **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**

- a) The balance looks about right, but our concern is that the content of the Charter can be interpreted in ways which do not serve people with complex communication support needs well. It is not enough to simply say what their rights and responsibilities are – health staff need to be supported to be pro-active in finding out whether the person is receiving a good service; to feel comfortable working with people who may be providing communication support on a daily basis to the person, and to acknowledge that these non-health professionals can contribute to a better and less frightening experience for the person in receipt of the health service.
- b) It is concerning that reference is made within the Charter to the available resources, and whilst this is understandable in the current financial climate, there is a danger this could result in compromising someone's human rights – for example through failing to fully recognise their needs for individualised communication support.

## General

### Question 6

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

### Question 6 Answer

Sense Scotland works with children and adults who have communication support needs because of deafblindness, sensory impairment, learning or physical disability. One of our key areas of expertise is communication. Working closely with people, often on a one-to-one basis, we aim to find out what their aspirations are and how we can support them to live their lives.

It is essential that people with communication support needs – often using very individual communication methods – have their needs acknowledged and responded to. We therefore welcome the section on Communication and Participation within the Charter. However, to make this applicable to the people we support, its interpretation will need creative responses from Healthcare staff, such as:

- Working together with social work departments to recognise and respond to the fact that health interventions can be very frightening for people who don't learn about the world, or communicate, in standard ways. For too many people with complex communication support needs, their paid support stops if they enter hospital. This can be the very time they (and the health staff) need it most – to help with communication; assist with personal care and eating, and to pass the time without getting both distressed and disruptive – issues which, if not addressed, can result in upset for other patients. Given the timing of this consultation, which overlaps with that on the integration of health and social care, it may have been more helpful to await the outcome of the latter and incorporate shared responsibilities within the Charter. This would not need to compromise the rights that naturally follow from The Patient Rights (Scotland) Act 2011
- Recognising that people do not all use standard communication methods which can be met by interpreting services, and responding accordingly.
- Recognising that people with communication support needs will often need more time for appointments and discussion – whether at the surgery or at the bedside, and that arrangements will need to be made to ensure that communication support is available to them for all interactions.
- Recognising that communication support is required for anyone to interact with the world around them – so providing it just for appointments may well not be enough. The person may need to take medication or have an injection without knowing why – and if they do

person they trust. They may need to co-operate or deal with any number of incidental actions during a hospital stay – for example nurses changing the sheets; cleaners they don't know mopping under their bed; staff closing the curtains between them and their neighbour; lights going on and off in the middle of the night.

The examples we have provided here relate primarily to hospital stays, although the principles can be applied to any health intervention. We appreciate the opportunity to comment, and would be happy to engage further on health issues as they apply to people with complex communication support needs.