

## Content

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

In general the level of detail is appropriate however it would be helpful to have a glossary of terms included e.g. not everyone will know what an optometrist is. It also would be useful to explain why the list of services on page 7 is excluded from the Treatment Time Guarantee.

With regard to the section:

*If the NHS in Scotland uses information that does identify you (for example to include it in a disease register), they must explain how and why your information will be used.*

It should be explained that this might be by means of e.g. an information leaflet or information on a website. It would be challenging to explain data flows in Scotland to each individual patient as this could add several minutes to each new patient consultation and many frontline NHS staff may have limited knowledge of these data flows.

With regard to the section:

*You have a right to say if you do not want your personal health information to be shared in particular ways, and to expect that the NHS in Scotland will not normally pass on your personal health information without your permission.*

It would be appropriate to explain some of the benefits of information sharing otherwise, the decision will not be fully informed. For example, in the context of national data collections:

- benefits for them personally – to identify them as being at risk in any future patient notification exercises. In general, as hospitals become increasingly dependent on computerised records in the interests of efficiency, it may not be possible to guarantee that a decision to “opt out” will not affect care in any way.
- benefits for their descendants – who in future may need information on their family history, for an accurate assessment of their genetic risk, and appropriate management.
- benefits for health and health services - for the purposes of planning, monitoring, and improving health and health services
- benefits for society – in the context of investigating a possible cluster of disease, or identifying a problem with health services.

## **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?

The content is generally very clear and easy to understand and the format of the document is easily read and understood, however, if it has not done been already, an equality impact assessment should be carried out in partnership with equality networks and groups as part of the consultation.

Some of the language leaves matters less than clear cut e.g. 'appropriate' and '...as far as possible'. This is perhaps simply a reflection of the complexity of balancing needs, rights and responsibilities in a busy healthcare system, but, for clarity's sake, use of such qualifications should be minimised.

## **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 design is clear and well labelled however it will need to be adapted for people with colour blindness and anyone with other communication needs to ensure equity of access. It also might be helpful to have a smaller "check card" or quick reference guide that does not run to 26 pages.

## **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) to ensure people read this and get access to this, it would need to be made available in hard copy in GP Surgeries; hospital waiting areas; libraries; clinic settings etc and online version made available through NHS24, NHS Inform and every NHS Board website including the National Boards.
- (b) Yes as long as this clearly defined and people know that alternative formats are available to them and who will be responsible for providing the alternative format, e.g. Scottish Government or the local board.

## 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 balance seems to be set out at the appropriate level.

Consideration needs to be given to how people who have less control over their own health, e.g. are dependent on a carer, might be supported to recognise this responsibility and what work should be done with carers in this regard.

In the Confidentiality section, greater clarity is required about permission to use/share information. Whilst in the opening of the section, it is clear that permission is acceptable in both express and implied form, later on it says '...right...to expect that that NHS...will not normally pass on your personal health information without your permission' without re-stating/emphasising that for many legitimate and proportionate routine, including administrative, uses and disclosures, this permission, in the absence of any objections, is implied. Without re-emphasising the link back to the fact that 'permission' means both express and implied, some patients and staff may misinterpret the right as one of express permission for every use and disclosure of personal health data. This would likely prove unworkable in practice, and conflicts with current policy.

In the Confidentiality section, consideration should be given to patients' responsibility to respect the privacy/confidentiality of others when in NHS premises. Whilst it is clearly the responsibility of NHS organisations to design and manage their workspaces in a way that minimises risks to confidentiality, patients/visitors/members of the public should be mindful of their behaviour when it can or potentially impacts the confidentiality and privacy of others e.g. ensuring that any photography/filming is only done (if at all) with the permission of the individuals affected. This is an area of increasing concern to Boards with the proliferation of mobile phone and other technologies.

The document speaks about the requirement for the health boards to consider the rights of other patients/visitors i.e. beyond the level of the individual. It may helpful for this also to be reflected in the "what does this mean for me" section. While individual patients have rights, they also have a responsibility to consider the rights of fellow individuals. This is not just a Board responsibility.

## **General**

### **Question 6**

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

### **Question 6 Answer**

It is welcome refresh of previous iterations and would be helpful if it is made clear if this fully replaces these.

In addition, it is called a charter of “patient” rights; this does not cover, for example, donors (who are not necessarily patients) or contacts with preventative or public health interventions in a healthy population. Furthermore, it may be worth considering if health and social care integration will introduce a different range of clients (other than patients) to whom this could be applicable.