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 Charter is very detailed and this might be a bit off-putting for a lot of people.

Therefore, it is vital that the Summary leaflet makes the relationship between the Leaflet, the fact sheets and the Charter sufficiently clear as this is potentially confusing for people. The summary leaflet should give people a simple guide to the six areas and then only if they needed to take something further might the majority of people make the effort to scrutinise the Charter. For example if the Factsheets are intended to give specific examples of rights and responsibilities in the Charter, then it should clearly spell that out not just in the Leaflet but also in all 3 documents as people may not be consulting them together.

In terms of examples given, near the beginning of the Charter page 3, reference is made to rights and responsibilities – these should be explained and defined with simple examples as not everyone will know what they mean.

b) There is the very obvious comment which we made in our response to the consultation on the original Patients' Rights Act namely that there is no mention anywhere of Children and Young People's (CYP) Rights and Responsibilities. We feel that the specific rights and responsibilities of children and young people are not represented in a 'one size fits all' document.

Action for Sick Children (Scotland) (ASC(S)) warmly welcomes the Scottish Government's declared intention to develop information for CYP on their rights and responsibilities.

c) ASC(S) works in partnership with parents, carers, professionals and the children and young

people to access best quality healthcare provision. ASC(S) is a member of the European Association for Children in Hospital (EACH). A key focus for members is the EACH Charter and its ten Articles which explain the rights of children, young people and families when using health care services. The EACH Charter is underpinned by the United Nations Convention on the Rights of the Child (UNCRC) and members aim to have the principles of the Charter incorporated into their countries' health laws, regulations and guidelines. The Scottish Government has recommended in *Delivering a Healthy Future: An Action Framework for Children and Young Peoples' Health in Scotland*, that the EACH Charter is to be used by NHS Boards as a standard against which to assess their child health services.

In relation to the Patients' Charter, CYP's healthcare rights are already clearly set out in the 10 Articles of the EACH Charter as follows:

Access – EACH 1, 3 and 9

Communication and Participation – EACH 2, 4 and 5

Confidentiality – EACH 9

Respect – EACH 6 and 10

Safety – EACH 7 and 8

Further information on EACH Charter and ASC(S) is available at: www.ascscotland.org.uk

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?

By its very nature it cannot be easy to understand as it is so detailed and dense. Language is not always in plain English and not accessible to all sections of the public. We suggest development of alternative easy-read versions, adapted for patients with Additional Support Needs and sensory impairments.

The tone is rather legalistic in places (see above for simplified version)
The Layout could be more uniform and consistent – at present the mixture of bullets and dashes makes it too busy and thus confusing e.g. page 6. For example on page 3 – first section - Introduction - more use of bullets and bold for the title of the Charter to bring into line with section *What the Charter does*?

ASC(S) welcomes the inclusion of the picture icons to accompany the written topic areas both in terms of the concept and the colour coding i.e. amber for security, green for access and gold for confidentiality, etc.

We strongly recommend harmonising the layout of the Charter page 4 so that the topics areas are mentioned alongside their icons as per the front cover and summary leaflet. This will aid accessibility and understanding by providing visual cues to those who need it.

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

(See above and comments on the icons and topics)

ASC(S) welcomes the inclusion of visual icons to enhance understanding of topic area but would suggest that the purple icon for Communication and Participation be reconsidered as there is no obvious interaction going on here. It would be better to include the speech bubble one here or a combination of people *and* speech bubbles. This would necessitate changing the comments and complaints icon but perhaps this could be an email envelope icon as per the HRIS *Have your say* leaflet.

The safety icon is confusing as it could be confused with the Red Cross that many people associate with emergency – we suggest a safety triangle as used in cars or some other similar icon.

Colour coding with meaning is welcomed but the respect and comments and complaints icons are very similar colours and don't stand out sufficiently from each other.

We strongly recommend including icons in the Charter whenever the topic areas are mentioned particularly at the start of the Charter pages 2 and 4.

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)

The Charter is a long and weighty document and it may not be the best use of resources to send out multiple copies to everyone as not all will need or want to access it.

ASC(S) would suggest that there are print copies of the Charter available for patients to consult in health centres, GP surgeries and hospital clinics and waiting areas and other gateways to frontline services.

Patients can be provided with the summary leaflet at times of interaction with the NHS (i.e. in appointment letters and pre-admission information letters) This would then signpost interested parties to the full Charter.

The summary leaflet should be made widely available as the Emergency Care Summary was before, in public areas (health centres, GP surgeries, hospital clinics, waiting areas, Libraries, schools). Consider providing the summary leaflet in large poster format for public areas.

b)

Yes, as there is no way of gauging the uptake on alternative formats. However, the existence of these needs to be very clearly signposted on the summary leaflet and on posters in all areas so that people not only know of the existence of the Charter but also are fully facilitated access. A sample of the alternative formats need to be shown and how to obtain copies of these.

Alternative formats should include DVD, Audio, Web, simplified versions etc.

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) There is a good balance of rights and responsibilities.
b) Under Respect: Responsibilities, ASC(S) would recommend you consider wording about respect and due care for NHS property and devices used on loan by patients and property that is used while in hospital.

General

Question 6

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

Question 6 Answer

As previously stated, it is imperative that there is a clear and transparent relationship between the Charter, summary leaflet and factsheets.

Posters in all health care waiting areas in the early stages of introduction will help alert people to the existence of the new information.

ASC(S) would recommend that all healthcare staff working with children and young people have knowledge and understanding of the rights of children and young people as specified in the Charter and that they are willing to act as advocates for the child or young person in upholding these rights when necessary. This includes staff working on adult wards that admit young people under 18 years of age.