

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) In general our group thought the level of detail was satisfactory and the information pretty comprehensive. However, it would perhaps be useful to present a summary on each topic followed by the detail, although we recognise that the intention is to provide a smaller leaflet in due course.

There is however a contradiction on page 5 of the document. It says: Your health board is committed to **taking account of your needs** when providing health services, but lower down it says that the local health board will . . . provide the **services it considers necessary**. This is a clear case of *petitio principii*, i.e., begging the question. A current example is the lack of provision of drop-in facilities for mental health patients who need community and peer support, which has now been cut (e.g. Ballendon House and Cambridge Street House). The needs of the patients are not in fact being taken account of.

(b) Please note there is no mention of research, either (a) your rights to take part in research, or not, as you wish, and (b) if you do, your rights to be fully informed about the risks as well as the possible benefits. While it is said that 'health boards must involve people in the planning and development of services' (p. 12) it does not say that research committees must also involve people in the planning and development of research. This is a crucial issue: much research would be vastly improved by consultation with competent patients at the design stage, both to check basic issues of suitability for the purpose and also to take into account the views of patients on the acceptability of the project from the consumer's point of view. Research steering committees should always have lay representatives (preferably two) with experience of the disease or condition being studied.

(c) "You have the right to request support to access NHS services etc" (p6). It may be helpful here to mention that where a Power of Attorney is

held for a patient, who may have impaired decision making, then that person must be consulted. Also, when Power of Attorney has not yet been granted (or requested), next of kin or competent proxy must be consulted in such cases, e.g. when cognition is impaired after a stroke, or when brain tumours are present.

It was thought that the “right that your local health board will assess the local community’s health needs” (p5) was a strange way of setting it out and the use of language. The way the sentence is framed at the moment suggests that the health board has the right and their decisions will outweigh any request/need for a specialised treatment and that the patient in fact has no rights. So to describe it as a right for the patient seems misleading. The wording needs some careful thought.

In describing the right to receive inpatient or day case treatment within 12 weeks (p6) it would be helpful to make it clear **exactly** when the clock starts ticking – is it in the GP surgery, or when the hospital receives a letter of referral, for example? We believe that there are exceptions to the 12 week treatment promise, for example in cancer treatment, which should be made clear explicitly for patients.

We think it important that all this information is available in GP surgeries, pharmacies, hospitals etc.

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

(a) The language is generally acceptable.

(b) Because the document in full is so long, there will be patients who find it difficult to find what they are looking for.

(c) It will be helpful to have the document available in various formats, paper, large print, alternative languages etc. A previous Patients Charter was summarised into an A3 poster which was in almost every medical facility. We think this is a good idea and should be repeated.

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 icons seem to have a gradation of colour. Some of our members thought that the colour should be full blocked and the icons have a black border. The blue colour used for some of the bullet points does not seem dark enough. We suggest checking this out for accessibility with your equal opps team.

It may be helpful to have the Charter in an A5, rather than A4 format.

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 must be published in paper form as well as online: many elderly patients do not have access to the internet. It should be available in all doctors' surgeries, and **proactively** given out to patients whenever they need to consult their doctor (i.e. on the first visit after publication). Special formats can be requested, but GPs should make a point of offering these to vulnerable patients with special needs on their first visit after publication.

(b) Not entirely. It should be possible to estimate the needs for at least some alternative formats, and for those not covered to request it. However, for something that affects all patients it is important that the Charter receives a very wide distribution.

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) We think the balance is about right.

(b) Responsibilities could include involvement in (e.g.) focus groups set up in GP surgeries to give feedback about services; volunteering to help with research projects; mentoring medical students; involving local Patient Partnership Forums , etc. etc.

General

Question 6

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

Question 6 Answer

Other points

p. 10: 'You can normally expect to see and get a copy of any letters, faxes or emails written by NHS staff about your care and treatment, if you ask for them. . . you may have to pay for this.'

You should expect to see such correspondence as a matter of course, without having to ask for it. If it is by email, it is simple enough to copy in the patient at no extra cost. If by snail mail the patient should also be sent a copy of the letter. Patients should NOT have to pay for this.

Moreover, if they see the correspondence they may wish to query details that they have not understood or indeed are wrong. This gives everyone the opportunity to be informed, to reconsider if necessary, and to work in partnership.

p. 13: Confidentiality

strongly of the opinion that information that identifies you should always be removed – it is difficult to understand why “wherever possible” is in the sentence. If it is essential for the purposes of the research that identifying details are retained, then informed consent must be sought.

p. 18 Hygiene

middle of page: ‘NHS staff should always wash their hands before they examine you.’

Doctors are by far the worst in this respect, but it is quite difficult, if you are a vulnerable patient, to say to the doctor: ‘Excuse me, would you mind washing your hands?’ However, patients should be encouraged to do this.

p. 19 Cleanliness

We would advocate a clear line of reporting dirty premises etc and a time in which this must be rectified. A phone number to call would be helpful. Sadly, the experience of one of our group on drawing the attention of the nurse to poor cleaning in a ward in the RIE, was to be told: ‘We can’t do anything about it, you’ll have to write in’. The timescale “by writing in” is simply NOT acceptable.