### **Consultation on Charter of Patient Rights and Responsibilities**

## Patient Rights (Scotland) Act 2011

The Patient Rights (Scotland) Act 2011 was passed by the Parliament on 24 February 2011 and gained Royal Assent on 31 March 2011.

The Act aims to improve patients' experiences of using health services and to support people to become more involved in their health and health care. It will help the Scottish Government's aspiration for an NHS which respects the rights of both patients and staff. It supports the NHS Scotland Quality Strategy ambition for a person-centred NHS, with mutually beneficial partnerships between all stakeholders

## **Charter of Patient Rights and Responsibilities**

The Act places a duty on Scottish Ministers to publish a Charter of Patient Rights and Responsibilities. This document will bring together, in one place, a summary of the rights and responsibilities that patients have, when using NHS services.

The Charter will have to be updated at least once every 5 years.

The Scottish Government are now at the consultation stage looking at the format and what should be included. The Charter of Patient Rights and Responsibilities is due to be published by 1 October 2012.

All Boards were sent details of the consultation with links to the Scottish Government site for comments from staff, patients, carers etc. to be registered.

#### **The State Hospital Consultation**

The State Hospital decided the best way forward with the consultation exercise was to disseminate the documentation across the hospital, through the staff bulletin, emails, Groups etc. A comprehensive list of the consultation is below:

Who we asked for feedback / comments	Means used to receive feedback / comments
Board	Personal email from PA to Board Staff Bulletin Intranet
Executive Directors	Personal email from PFPI Co-ordinator Staff Bulletin Intranet
Heads of Departments	Personal email from PFPI Co-ordinator Staff Bulletin Intranet
Clinical Leads &Hub Management Teams	Personal email from PFPI Co-ordinator Staff Bulletin Intranet
Hospital Staff	Cascaded from Hub Management Team / Head of Department / Clinical Leads Staff Bulletin Intranet
Patients Groups	Patient Partnership Group

Patients	Ward drop ins Copies available in all wards Advocacy support
Volunteers	Volunteers Service Group
Carers	Personal email from PFPI Co-ordinator Carers Reference Group Copies left in Carers Centre Copies left in Family Centre Link placed on carers section of The State Hospital website
Spiritual & Pastoral Care Team	Personal email from PFPI Co-ordinator
Advocacy	Personal email from PFPI Co-ordinator Staff Bulletin Intranet

It was agreed that an organisational response would be given to Scottish Government. The following comments and responses provide an accurate and proportionate response to each question for each stakeholder group:

#### Staff

## Q1: Content

- a) Do you think the information in the Charter is written in a way that is easy to understand?
  - Level of detail is both useful and appropriate.
  - Yes, very appropriate and useful.
  - If anything I would say the Charter is too detailed and has too much information although the idea of leaflets and factsheets to summarise the information will offset this.
  - Yes
  - Yes, the level of detail is useful as it sets out very clearly what it means for me and what is expected.
  - Detail is appropriate and easy to understand.
- b) Is there any information not included in the Charter that should be covered?
  - No
  - Don't think so.
  - No
  - No
  - All information included adequate.
- c) What would make it better?
  - Possible different format available

## **Q2: Accessibility**

- a) Do you think the information in the Charter is written in a way that is easy to understand?
  - Yes
  - Given the level of detail I would say some patients will struggle to understand the Charter.
  - Yes
  - Yes
  - The charter is very easy to understand it sets out the information clearly and concisely.

- b) Does the format of the Charter make it easy to find information you need?
  - Yes
  - The format is good.
  - Yes
  - Yes, very clearly set out and language is appropriate making it easy to find the info needed.
- c) What would make it better?
  - Different format.
  - Ensure the information leaflets and factsheets are simplified.

## Q3: Design

Do you have any comments on the design of the Charter?

- I presently like the format and design.

## Q4: Availability

- a) What do you think is the most appropriate way for people to get a coy of the Charter?
  - Hard copy, online, audio, on demand.
  - Inpatients have copy posted.
  - In addition to what is detailed above; the Charter should be available on request at any / all Health Care establishments.
  - Have paper copies in Reception by request, on the internet, given to patients upon admission.
  - Patients laminated nominated areas throughout hospital wards. Copy to each carer. All visitors. Hospital waiting areas. Equality Diversity and Rights induction and training.
  - Public areas in hospitals also through Patient Focus: Public Involvement groups.
     Ward bulletin boards, nursing staff and Occupational Therapy.
- b) Do you agree that we should only make alternate formats available on request?
  - Alternative formats should be readily available to encourage inclusion.
  - Yes, this will save money.
  - Yes
  - Yes
  - Yes

### Q5: Rights and Responsibilities

- a) Do you have any comments on the balance of rights and responsibilities set out in the Charter?
  - Balance is fine.
  - No
  - I think the balance is about right; it is essential that patients are informed of their responsibilities.
  - No
  - Yes
  - I think that it is appropriate to highlight the responsibilities of the individual to NHS Scotland in return for access to appropriate services. The balance is equal - it is important that individuals are aware of their responsibility aspect as well as what services they can access.
- b) What would make it better?
  - Enforcing both.
  - Nothing

Q6: Comments

- Hope the principles outlined are achievable.
- As stated already, the document is very detailed and some patients may struggle to understand what it means to them. It is essential that the more vulnerable, more dependent etc. patients receive this information.

#### **General Comments**

Generally I don't think there is much to disagree with in this document. The only 2 things that I can see as potentially being different / problematic for The State Hospital are:

- a) The right to refuse treatment, the Mental Health Act doesn't seem to be mentioned although Adults with Incapacity is.
- b) Whilst the statement on treating staff with dignity and respect is very welcome I don't see how it is achievable. Actually none of the patient requirements are really enforceable in the same way as the staff / organisational requirements are, but maybe it will act as a reminder / discussion point.

#### **Patients**

#### Q1: Content

- a) Do you think the information in the Charter is written in a way that is easy to understand?
  - Very much so, its useful and appropriate.
  - Generally appropriate; clarification on the definition of 'treatment'.
  - Yes
  - About half of detail is useful and appropriate (some of it). Access issue section is useful. Confidentiality. Waiting time's section is useful.
- b) Is there any information not included in the Charter that should be covered?
  - Good feedback, all areas appear to be covered.
  - Patients should have free and open access to all their reports. Reports should be specific to the individual and not a generic 'catch-all' comment.
  - Information on how to rectify inaccurate medical records.
  - Media issues should be covered in more depth. NHS should take responsibility to 'blanket' media stores etc. Powers to investigate the source of media 'leaks' is a big issue for high security patients.
- c) What would make it better?
  - Available in large print and different languages.
  - Early regular access and sharing of medical records as (a) Large number of errors noted and (b) Handwritten notes unreadable.
  - It is very lengthy, dry and overwhelms. It is not presented in a way that all people can understand. Language too complicated and lots duplicated. Perhaps a separate document for patients and staff would be beneficial. Should be shorter and succinct.

## Q2: Accessibility

- a) Do you think the information in the Charter is written in a way that is easy to understand?
  - Yes easily understood
  - Some words could be broken down into more easily understood language e.g. 'summarise'.
  - Yes
  - No, it is too overwhelming and people will 'switch off' and get bored with it. Words are quite difficult to understand.
- b) Does the format of the Charter make it easy to find information you need?
  - Yes, look at headings and more in-depth views.
  - Yes. overall it is readable.
  - Yes
  - Contents page should be on first page upon opening in order to make it easier to locate information. Not spread out enough, too much on one page.
- c) What would make it better?
  - Single summary sheet available in all wards with reference to where the main document is located.

# Q3: Design

Do you have any comments on the design of the Charter?

- Well understood, format is good.
- Bigger print for those that require it.
- The pages / words are too cramped and should have less on the page. Colour code is good, but presented in a folder with side locators may be easier.

#### Q4: Availability

- a) What do you think is the most appropriate way for people to get a copy of the Charter?
  - Sent to patient by address.

- Copies should be lodged with staff and available on request. Audio version of Charter would be beneficial. Pictorial versions e.g. DVD which may aid a better understanding for those unable to read or comprehend it in writing.
- Large print.
- Posters, billboards laminated and in wards, presenting most important points. Easy access in an area which access is granted for everyone. Training sessions for staff could be beneficial on equality, diversity, rights training. For new staff as part of induction. For public copy to every carer (post). In hospital waiting areas. Give to visitors / lawyers.
- b) Do you agree that we should only make alternate formats available on request?
  - Yes, alternative format on request only.
  - Alternative formats should be available at all times.
  - Perhaps a tape / CD could be made available in each hospital.
  - Yes, as it would be expensive to produce lots of copies and they may not be used.

# Q5: Rights and Responsibilities

- a) Do you have any comments on the balance of rights and responsibilities set out in the Charter?
  - Well balanced document.
  - Charter is balanced between rights and responsibilities.
  - Balance appears ok.
  - It seemed equal, and patients should have responsibilities as well as staff. Staff should support and encourage too and not just leave the patients - relying on patient responsibility - it should be partnership.
- b) What would make it better?
  - No, nothing would make it better.
  - Support on understanding the Rights and Responsibilities.
  - Difficult to challenge staff who are in wrong unless witnesses exist. More independent access to wards by volunteers. More supervision of staff to ensure good level of care.

#### Q6: Comments

- Very helpful to make standards that governing bodies comply with. But standards must be met or it will just be a paper exercise.
- Advertise on television and radio.
- Welcome long overdue document as a form of reference.
- Format of feedback should be in survey checklist style as many people cannot write or have the patience to write lengthy comments. Tick boxes in the actual charter to flag up areas that are poorly understood, and to keep the place for those with low concentration. Tick to understand sort of thing.

#### **Volunteers**

#### Q1: Content

- a) Do you think the information in the Charter is written in a way that is easy to understand?
  - Yes, but should offer information on how to achieve certain things like accessing files.
  - Yes, very clearly laid out point by point with appropriate advice. Each point stands well on its own making information easy to access.
- b) Is there any information not included in the Charter that should be covered?
  - No
- c) What would make it better?

## **Q2: Accessibility**

- a) Do you think the information in the Charter is written in a way that is easy to understand?
  - For people who have knowledge, average intelligence yes, but people who have low attention span, disabilities or low education - no.
  - Yes, the point by point layout with sub divisions and wide spacing clarifies different subtopics.
- b) Does the format of the Charter make it easy to find information you need?
  - Not really, contents page on page 1 would be better.
  - Yes contents list is clear and succinct. Headings for subdivisions coloured. Important points in bold highlights.
- c) What would make it better?
  - Presented in file form with new sections starting on independent pages rather than having overlaps.

#### Q3: Design

Do you have any comments on the design of the Charter?

- File format would be better. Separate info for staff, public, patients etc. would be better. Colour coding scheme is not apparent from contents page or within text.
- A4 size allows for the fairly large print giving clarity. Separation of sections again allows for differentiation of aspects and topics allowing a clear focus on specific areas, points. Spacing between each point helps clarity.

### Q4: Availability

- a) What do you think is the most appropriate way for people to get a coy of the Charter?
  - Televise that the info is available. Give it out with peoples prescriptions e.g. public available in waiting rooms. Give to all carers and staff in induction packs etc.
  - I would suggest for many people the paper version is appropriate as many are not so computer literate. The paper version also allows for browsing. Online version saves paper and is easy for internet users to access - no need to store paper version.
- b) Do you agree that we should only make alternate formats available on request?
  - Yes
  - Yes I agree to save energy, that alternative formats be available only on request.

## Q5: Rights and Responsibilities

- a) Do you have any comments on the balance of rights and responsibilities set out in the Charter?
  - I think it relies on patients being independent and this may not be possible e.g. it's
    patients responsibility for own health but this isn't always the case they still need
    appropriate support and encouragement in the case of severely disabled, mental and
    physical. A lot of people are vulnerable and may not be aware of all of their rights and
    can get advantage taken shoddy treatment etc.
  - I think that it is important that responsibilities are outlined as well as rights. That it is pointed out that service users should play a part complementary to staff contribution.

The balance set out seems to me about satisfactory, more space being devoted to rights but each section having a clear outline also.

# b) What would make it better?

- Educating vulnerable groups and staff at all levels.

# **Q6: Comments**

- It appears to be produced in an appropriate and satisfactory form.

#### **Non Executive Directors**

#### Q1: Content

- a) Do you think the information in the Charter is written in a way that is easy to understand?
  - Yes
  - Yes, clear and areas covered.
- b) Is there any information not included in the Charter that should be covered?
  - Information about exceptions to Treatment Time guarantee.
  - In comments and complaints section mention of the right not to be victimised / penalised if complaint made.
- c) What would make it better?
  - Information in each section for people who live and work in residential accommodation. (NHS, Voluntary Organisation, Local Authority and Private).

## **Q2: Accessibility**

- a) Do you think the information in the Charter is written in a way that is easy to understand?
  - Yes for people who live in the community.
  - Yes found it easy to follow.
- b) Does the format of the Charter make it easy to find information you need?
  - Not really an index and glossary would help.
  - Yes, however are the symbols at the top of page easy to see with people with visual difficulties?
- c) What would make it better?

#### Q3: Design

Do you have any comments on the design of the Charter?

- It would be better if online readers could access each section by clicking on the icon.
- Although A4 is the standard business paper size, it is not easy to slip into a pocket or bag!

#### Q4: Availability

- a) What do you think is the most appropriate way for people to get a copy of the Charter?
  - At surgeries, when being a patient or supporter of a patient is uppermost in their thinking. Staff there should encourage take-up. Usual public info channels.
  - From GPs surgeries. Fliers giving a link to online info.
- b) Do you agree that we should only make alternate formats available on request?
  - No people requiring alternative formats are less likely to access information they require.
  - Yes, as long as it is clear that alternative formats are available and where these can be accessed.

# Q5: Rights and Responsibilities

- a) Do you have any comments on the balance of rights and responsibilities set out in the Charter?
  - Glad to see it there. Good balance.
  - Yes, for those with an understanding of service etc. need to ensure that hard to reach groups are involved to check out their understanding.
- b) What would make it better?

#### **Q6: Comments**

 As a long term user of the Patients' Charter, particularly in relation to waiting times at surgeries and clinics, I welcome the document's intentions.

#### **General Comments**

It is good to see that the focus is on both rights and responsibilities. All too often public services are structured and provided in the interest of the provider rather than the user. This was significantly the case in the NHS until recent years, and in some areas still is. However, a free service is often open to abuse, hence the need to build in responsibilities for the users of these services. This aspect could be strengthened further. For instance, if people were healthier, and took more responsibility for their health, then there would be a significant reduction in demand. The responsibility for maintaining / achieving better health should therefore be strongly emphasised. Don't beat around the bushes on this. As a related issue, but significance in achieving what is both implicit and explicit in the charter, leadership style of service providers can be adopted further to enable the public and patients to assume their responsibilities. The work of Heifetz and Linsky around adoptive leadership is worth bringing into the equation. The benefit of this charter is in the implementation, as we have found in our own one for The State Hospital.

### **Spiritual and Pastoral Care**

#### Q1: Content

- a) Do you think the information in the Charter is written in a way that is easy to understand?
  - Yes
- b) Is there any information not included in the Charter that should be covered?
  - No mention of a right to Spiritual, Pastoral or Religious care. Does the NHS have an obligation to provide Spiritual / Pastoral / Religious care for patients? Although it mentions the right to respect and no discrimination because of religion, it says nothing about providing the holistic care that is Spiritual / Pastoral / Religious.
- c) What would make it better?

### **Q2: Accessibility**

- a) Do you think the information in the Charter is written in a way that is easy to understand?
  - Yes
- b) Does the format of the Charter make it easy to find information you need?
  - Yes
- c) What would make it better?

## Q3: Design

Do you have any comments on the design of the Charter?

#### Q4: Availability

- a) What do you think is the most appropriate way for people to get a copy of the Charter?
  - In print and online. Provision is made for special needs.
- b) Do you agree that we should only make alternate formats available on request?
  - Yes

## Q5: Rights and Responsibilities

- a) Do you have any comments on the balance of rights and responsibilities set out in the Charter?
- b) What would make it better?

#### **Q6: Comments**

Just to mention once again the complete lack of mention of a patients' right to Spiritual
 / Pastoral / Religious care. This can be as important as physical or mental care.