

# **Charter of Patient Rights and Responsibilities for People who use the NHS in Scotland**

## **Consultation Report**

# CHARTER OF PATIENT RIGHTS AND RESPONSIBILITIES FOR PEOPLE WHO USE THE NHS IN SCOTLAND

## CONSULTATION REPORT

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# CHARTER OF PATIENT RIGHTS AND RESPONSIBILITIES FOR PEOPLE WHO USE THE NHS IN SCOTLAND

## CONSULTATION REPORT

### 1. Acknowledgements

The Scottish Government would like to thank everyone who considered and responded to the questions in the recent consultation on the Charter of Patient Rights and Responsibilities for people who use the NHS in Scotland.

### 2. Introduction

[The Patient Rights \(Scotland\) Act 2011](#) was passed by the Scottish Parliament on 24 February 2011, and gained Royal Assent on 31 March 2011. The aim of the Act is to improve patients' experiences of using health services and to support people to become more involved in their health and health care.

The Act requires Scottish Ministers to publish a Charter of Patient Rights and Responsibilities („the Charter’) setting out a summary of the rights and responsibilities for anyone who uses the NHS in Scotland. The Charter does not introduce any new rights rather it sets out the existing rights and responsibilities including those introduced by the Patient Rights (Scotland) Act.

The Charter is in three parts. Patient Rights and Responsibilities are set out in Part 1, which is split into six sections. This covers Access, Communication and Participation, Confidentiality, Respect, Safety, and Feedback and Complaints. Part 2 explains what to do in the event that rights have not been respected. Part 3 provides advice and signposting for further information and support.

The Charter will be laid before the Scottish Parliament prior to its launch on 1 October 2012. The Charter, a summary version and a series of seven supporting factsheets (Access, Communication and Participation, Confidentiality, Respect, Safety, Hospital Waiting Times, and Feedback and Complaints) will be available from Health Rights Information Scotland ([www.hris.org.uk](http://www.hris.org.uk)) and the Scottish Government website at <http://www.scotland.gov.uk/Publications/Recent> from October 2012. The factsheets will provide further information about what the rights and responsibilities in the Charter mean for people using the NHS. It is also a requirement to review and update the Charter at least once every five years.

On 2 April 2012 the Scottish Government launched a consultation seeking views on a draft of the Charter. The consultation sought views on six questions which focused on the content, accessibility, design, availability, the balance of rights and responsibilities and general views on the draft.

The consultation document was sent directly to 82 organisations and individuals, and was available on the [Scottish Government website](#). Of the 82 recipients,

38 responded to the consultation. The 12 week consultation period ended on 25 June 2012 but an extension to 4 July was given. A total of 63 responses were received by the 4 July. Four responses received after this date from 2 individuals and 2 organisations have been taken into account in the review of the Charter.

Consultation exercises aim to elicit the views and experiences of a wide range of stakeholders. The nature of the submissions varied with some respondents providing comment on some but not all of the questions and others provided more detailed comments on sections of the proposals that were of interest to them. In some instances comments received were relevant to more than one question.

The findings are specific to the consultation exercise and do not necessarily reflect the weight or range of views within the population as a whole. The nature of the consultation and the small number of responses does not necessarily support the presentation of the findings in a quantitative way. We have presented results in percentage form, where possible, but have sought to focus on the qualitative findings.

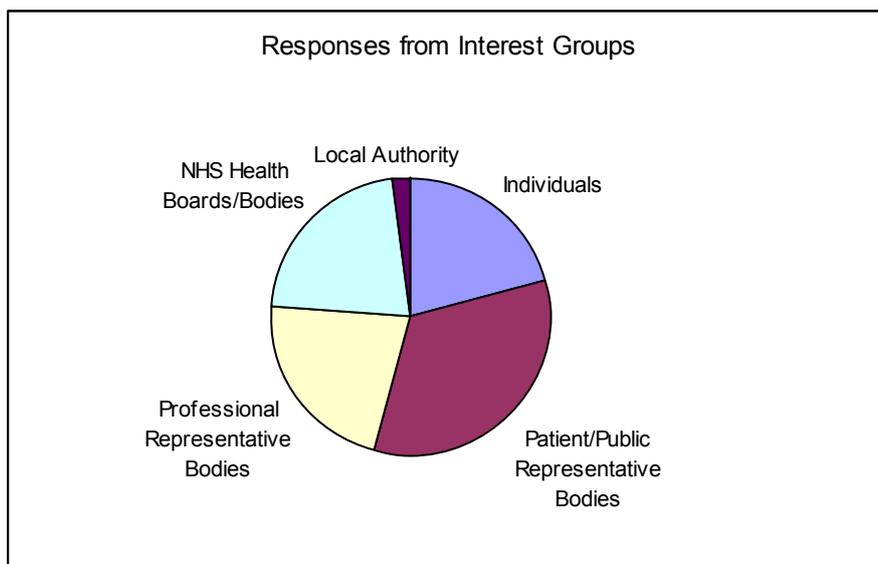
We have attempted to provide further explanation within the report about the proposals where we felt respondents needed more information or clarity around the intention.

### 3. Responses

Of the 63 responses received by the extended closing date of 4 July, 13 (21%) were from individuals and 50 (79%) were from organisations/bodies. Four responses received after this date from 2 individuals and 2 professional representative bodies have been taken into account in the review of the Charter. The late responses have not been published with the others but they have been taken into account in the review of the Charter and are reflected in this analysis and report on responses.

The [published responses](#), where respondents gave permission and their response was received before the closing date, can be viewed on the Scottish Government website at: <http://www.scotland.gov.uk/Publications/Recent>. The 63 responses received by interest group are as follows:

<b>Interest Group</b>	<b>Number of Respondents</b>	<b>% of responses</b>
Individuals	13	21
Patient/Public Representative Bodies	21	33
Professional Representative Bodies	14	22
NHS Health Boards/Bodies	14	22
Local Authority	1	2
<b>Total</b>	<b>63</b>	<b>100</b>



A list of respondents can be found at [Annex B](#).

#### 4. Approach

Each response was reviewed in full and summarised. A qualitative and thematic analysis of the responses was undertaken. Each response was reviewed by at least two people, then summarised with the respondents' comments entered onto a spreadsheet recording answers to each of the six questions. The responses to each of the questions were further reviewed by more than one person.

Quotes have been identified and have been used within this report to illustrate respondents' views.

#### 5. Findings

The consultation paper sought views on six questions which focused on the content, accessibility, design, availability, the balance of rights and responsibilities and general views on the Charter. The questions are set out below with a summary of the main points and issues raised in the consultation responses shown under each. The Scottish Government response and the actions taken or proposed are reflected at [Section 6](#) of this report.

The link to the consultation paper is given in [Annex A](#) together with the full list of questions.

##### Question 1 – Content

- 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?

A total of 56 responses were received to this question. There was a general consensus amongst most of the respondents that the detail in the Charter was well

pitched for raising public awareness of rights and responsibilities when using the NHS in Scotland.

“The Charter is a useful summary of what NHS service users should expect in Scotland, and is built on solid equality and human rights principles such as respect, safety and transparency.”

Equality and Human Rights Commission

It was felt that whilst the signposting at the end of the Charter to more detailed information was appropriate this should feature or be referred to at the beginning.

Some respondents thought the Charter was too long, a bit repetitive and the level of detail given and terms used in the various sections was not consistent.

Several respondents offered comments on specific areas and suggested detailed examples, additional or alternate wording for use in the Charter. For example, suggesting:

- that information should be given in relation to:
  - the specific pieces of legislation which gave rise to the rights
  - support and assistance available in relation to health costs, patient transport and travel expenses
  - accessing hospital health services through GPs
  - access to independent advocacy and spiritual care
  - situations where it wouldn't be possible to ask for a second opinion
  - the documents you would be charged for if you request copies of health records
  - the rights and responsibilities of children and young people
- that the terms such as „clinical judgement', „pharmacies', „obstetrics' and „optometrists' should be avoided
- further clarity, rewording or expansion was needed in some entries and in particular:
  - around the use of the words „should' and „must'
  - the Treatment Time Guarantee and its application
  - clarity on the roles of the organisations listed (e.g. the Information Commissioner and Patient Advice and Support Service).

A few respondents seemed concerned about the purpose of the Charter and how it might be used, with a suggestion that the language was confrontational, paternalistic and the document “...*biased in favour of the service provider*”.

### **Question 2 – Accessibility**

- 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 total of 52 responses were received to this question. Some of the comments received in response to this question related to the „content’ and have been considered as part of Question 1.

Most of the respondents felt that the Charter was written in a way that was easy to understand. There was however an acknowledgement that there was a need for alternative formats to make it accessible for all. A variety of suggestions were given on what alternative formats should be made available. This included other languages; Braille, British Sign Language (BSL) and audio versions; children’s versions; as well as a summary and Easy Read versions. The majority believed that these formats should be easily accessible through the internet, with access to non-web formats on request.

It was suggested that the inclusion of electronic hyper links within the Charter would allow easier and quicker access to the different sections when viewing online.

A few commented that it was not necessarily clear what subject area the icons used in the Charter related to.

### **Question 3 – Design**

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

A total of 43 responses were received to this question.

The general consensus was that the design and layout were clear but views were split on whether the A4 format was appropriate pointing out that A5 booklet was the norm for many for display purposes and was easier to handle. Several respondents suggested the development of a summary quick reference version as the length of Charter might be off putting for some.

“Its not the kind of document that could be mass produced and distributed in that format, but I don’t think it is designed to be used in this way, but rather for people who want to find out more.” NHS Highland

**Question 4 – Availability**

- 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?

A total of 54 responses were received to this question.

The views expressed were mixed with various suggestions on how to raise awareness to all of the Charter ranging from press and media campaigns to posting one copy of the Charter to every home in Scotland.

Some suggested that there should not be a reliance on the web for public access and the Charter or a summary version should be available in GP practices, hospital receptions, waiting areas, community services etc. Others were of the view that electronic versions should be available to view online with paper copies, and alternative formats (identified in response to Question 2) should be provided on request.

Several responses did ask that the decision be influenced by the costs involved.

**Question 5 - Rights & 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?

A total of 51 responses were received to this question.

A few respondents called for clarity around the use of terms „should’ and „must’ throughout the Charter in order to clarify the areas which reflected the legal rights of patients and which constituted good practice and were expected of staff.

The general consensus was that the balance between rights and responsibilities was appropriate but some considered that the Charter did not go far enough to ensure patients took their responsibility seriously or that they would necessarily understand or appreciate the potential implications of certain behaviours.

Several respondents felt that the Charter was useful and would serve to encourage patients to become more involved in their own health care.

“I think it is good to remind patients that they also have a responsibility to help themselves, and not just expect the NHS to do all the work.”

Individual

With a focus on their rights, the patient would not only become empowered, but would feel able to challenge the NHS when their rights had not been respected.

Those concerned about its purpose suggested the Charter would be used as a management tool to regulate patient access to services.

#### **Question 6 – General views**

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

A total of 46 responses were received to this question.

In response to this question several respondents chose to comment on previous personal experiences and perceived failures in existing practices and procedures, rather than the content of the Charter. Although outwith the scope of the consultation the underlying issues raised in the patient experience stories were taken into account in the review of the Charter.

“The patient / doctor / health professional should be approached as a partnership, each with responsibilities.” Individual

#### **6. Action taken or proposed**

- A complete review of the Content of the Charter has been undertaken and where it was considered appropriate revisions have been made to reflect the views expressed in the responses received.
- In order to maintain a balance in the level and type of detail within each section of the Charter some of the comments offered have, where appropriate, been incorporated within the respective supporting and more detailed individual factsheets developed to support the Charter.
- Appropriate signposting to the seven leaflets covering Access, Confidentiality, Communication and Participation, Respect, Safety, Feedback and Complaints and Hospital Waiting Times has been included at the beginning of the Charter.
- The language used within each section of the Charter has been reviewed and simplified and as far as possible and the areas of repetition have been removed or reduced.

- Reference in relation to access to support services such as advocacy, the patient transport service, spiritual care and help with health and travel costs have been included.
- Explanations to provide clarity around terms used and the roles of organisations signposted within the Charter have also been added.
- The icons used within each section have been added to the contents page at the beginning of the Charter and also at the beginning of Part 1.
- Electronic hyper links have been included to allow easier and quicker access to the different sections when viewing on line.
- Arrangements will be made for the following to be available to download from Health Rights Information Scotland ([www.hris.org.uk](http://www.hris.org.uk)) and the Scottish Government (<http://www.scotland.gov.uk/Publications/Recent>) from October 2012:
  - an A4 version of the Charter
  - associated supporting (A4) factsheets
  - an A5 summary version of the Charter

This will allow Health Boards and others to make copies of these documents available to patients, staff and members of the public on request.

- Alternative formats including appropriate other languages; Braille, BSL and audio versions; children's versions; an A5 summary and an Easy Read version of the Charter will be made available as soon as possible and will be easily accessible from Health Rights Information Scotland ([www.hris.org.uk](http://www.hris.org.uk)). Access to non-web formats will be available on request.

## **Link to consultation and list of consultation questions**

The consultation paper is available at:

<http://www.scotland.gov.uk/Publications/2012/04/6273>

## **Consultation questions**

### **Question 1 – Content**

- 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 2 – Accessibility**

- 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 3 – Design**

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

### **Question 4 – Availability**

- 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 5 - Rights & 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?

### **Question 6 – General**

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

**List of Respondents by interest group****NHS Health Board/Body**

NHS24	NHS National Services Scotland
Lothian Sexual and Reproductive Health Service	NHS Highland
NHS Lanarkshire	NHS Health Scotland
State Hospital	NHS Education for Scotland
NHS Ayrshire & Arran	NHS Shetland
NHS Tayside	NHS Dumfries & Galloway
Scottish Health Council	NHS Greater Glasgow & Clyde

**Individuals**

Jack Graham Ferris	Jack Ferguson
Kathleen Butlin	Jeannie Erskine
Colin Angus	Anne Lindsay
7 x anonymous	

**Local Authority**

Stirling Council

**Patient/Public Representative Group**

North Lanarkshire Disability Forum	Citizens Advice Scotland
Scottish Women's Convention	Action for Sick Children (Scotland)
Scottish Independent Advocacy Alliance	Inclusion Scotland
NHS Tayside Public Partners	Scottish Consortium for Learning Disability
East Dunbartonshire Public Partnership Forum	South Edinburgh Health Forum
Information Commissioner's Office	PAMIS
Sense Scotland	Froghall Community Council
North Lanarkshire Public Partnership Forum	Genetic Alliance UK
Scottish Council on Deafness	Borders Public Partnership Forum
Scottish Disability Equality Forum (SDEF),	Long Term Conditions Alliance Scotland
Independent Living in Scotland (ILiS), and	(LTCAS)
Inclusion Scotland ( <i>Joint Response</i> )	
1 x anonymous	

**Professional Representative Body**

Equality & Human Rights Commission	Royal College of Surgeons, Edinburgh
Royal College of Radiologists	Royal College of Midwives
Royal College of Nursing	British Medical Association (Scotland)
Royal College of Physicians of Edinburgh	Scottish Public Services Ombudsman
British Dental Association	General Dental Council
Scottish Medical & Scientific Advisory Committee (SMASAC)	Academy of Medical Royal Colleges and Faculties in Scotland
Law Society of Scotland's Mental Health and Disability Sub-Committee	Scottish Independent Hospitals Association (SIHA)



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