

## Health and Community Care

# Patients' Rights Bill for users of the NHS in Scotland: Consultation Analysis Report

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The Scottish Government launched a public consultation in September 2008 to seek views on the possible content of a Patients' Rights Bill to be introduced in 2010. The consultation paper set out eight proposed rights and associated responsibilities in support of the aim of the Bill, which is to reinforce and strengthen the commitment to place patients at the very centre of the NHS in Scotland; to clarify the standards expected of the NHS; and to set out the rights and responsibilities of patients in a clearer way. This report presents the findings from the consultation.

## Main Findings

- The consultation included written responses from 85 individuals and 145 organisations or groups. In addition, 102 people attended national events, and 68 people participated in one of eight focus groups. Hundreds of people also attended events organised by Health Boards and Public Partnership Forums.
- The over-riding perspective from the consultation process was one of general support for the notion of a Patients' Rights Bill.
- There was also general support for the eight areas around which entitlements and responsibilities were presented in the consultation paper.
- There were, however, conflicting opinions about the Bill becoming entirely embedded in law.
- There were also concerns over: how patients who failed to comply with their responsibilities should be handled in law, how more vulnerable patients should be supported, and the potential creation of a more adversarial relationship between patients and health services.
- Opinions were expressed that proposals were biased towards acute services and did not take into account services for patients with long-term conditions. There were also questions about whether non-NHS services such as local authority community care ought to be encompassed by the Bill in order to present a more holistic view of health care.
- Questions about resources to support the implementation of the proposed Bill were raised in all elements of the consultation. These included funds to facilitate the waiting time guarantee and provide equitable access for patients across the country, translation/interpretation/communication support, advocacy and support for vulnerable patients, and financial support for independent redress.
- There were questions raised around the scope of the Bill and to what degree it would address the support needs of more vulnerable patients, as well as how the Bill would respond to any perceived conflict between privacy and confidentiality for service users while recognising that the more vulnerable service users will depend on third party support (for example, family members, paid carers, advocacy services, etc.).
- Some respondents felt the prolific use of the term 'entitlement' for patients, compared to 'responsibilities', positioned the patient in a more passive role, and was at odds with the idea of a mutual health service.

## Background

Within the *Better Health, Better Care Action Plan*, published in December 2007, the Scottish Government outlined its commitment to a public consultation on the contents of a Patients' Rights Bill.

The Scottish Government launched the public consultation to inform recommendations for a Patients' Rights Bill to be introduced in 2010. The consultation took place between 22 September 2008 and 16 January 2009. The consultation paper set out eight proposed rights in support of the aim of the Bill *"to reinforce and strengthen our commitment to place patients at the very centre of the NHS in Scotland; to clarify the standards expected of the NHS; and to set out the rights and responsibilities of patients in a clearer way."*

Rights were set out as:

- **Access:** My right to accessible NHS care and a waiting time guarantee.
- **Respect:** My right to be treated with dignity and respect.
- **Safety:** My right to safe and effective care.
- **Communication:** My right to clear, accessible and appropriate communication.
- **Information:** My right to information about the services I use and the treatment and care options available to me.
- **Participation:** My right to be involved in making decisions about my care and the services I use.
- **Privacy:** My right to privacy and confidentiality.
- **Independent support and redress:** My right to comment about my care and have my concerns addressed.

## Aims

The purpose of the consultation was to seek and investigate people's views about the possible content of a Patients' Rights Bill, including the rights and responsibilities set out in the consultation paper. Independent researchers were commissioned to assist the consultation process, and to analyse and report on the consultation responses.

## Methodology

The consultation comprised four main elements:

- The invitation to individuals and organisations to submit written responses.
- Two national consultation events.
- Eight focus groups.
- Health Board facilitated local consultation events.

The Scottish Government promoted the consultation on its web site and invited written responses from all sections of society: 230 written submissions were received, 85 from individuals and the remainder from organisations or groups<sup>1</sup>.

Two national consultation events took place, in Edinburgh on 25 November 2008 and in Inverness on 5 December 2008. The attendees included patient representatives, staff groups, professional bodies and voluntary sector organisations. In total, 102 people attended.

Eight focus groups were also undertaken as part of the consultation process. The groups were chosen to reflect the Fair for All strands (age, gender, disability, ethnicity, LGBT [Lesbian, Gay, Bisexual, Transgender], and religion/belief) and to help ensure the views of particular groups within society were represented in the consultation process.

The fourth element of the consultation involved NHS Boards conducting their own local consultation. The independent researchers produced guidelines to help NHS Boards stage and conduct local events and generate additional information valuable to the consultation process.

## Analysis of the responses

Written responses were categorised according to whether they agreed with the overall concepts outlined in the Patients' Rights Bill proposals, expressed mixed views, expressed disagreement with the overall concepts within the proposals, were unclear or gave no response.

### Overall opinion

Seventy seven percent (176) of those responding in writing agreed with the overall concepts within the Patients' Rights Bill proposals. The national events and focus group participants also supported the proposed eight rights as appropriate subjects for inclusions within a Bill. Key reasons for overall support included the ability of the Bill to bring the main ingredients together to make things clearer and less fragmented, together with enhancing the 'patient focus' of health services in Scotland and building a stronger sense of public ownership of the NHS.

However, people qualified their agreement with additional points they wished the Scottish Government to consider.

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<sup>1</sup> Please note 6 responses were received after the deadline for inclusion in this analysis but have been considered by the Scottish Government.

## **Access: My right to accessible NHS care and a waiting time guarantee**

Sixty five percent (150) of those responding in writing agreed that it was important to include the right to access to services in the Bill. Regional Health Boards were the most likely group to raise concerns about this right. Concerns raised included:

- the scope of the waiting time guarantee;
- the practicalities of making the guarantee and offering choices of appointment times equitable to all; and
- the relationship between the proposed 12 week inpatient and day case waiting time guarantee and the current 18 week referral to treatment time.

The right to access was well supported at the national events, but there were concerns about what specifically this covered, for example, people questioned whether the access guarantee applied to mental health services and NHS dentistry. Participants from the focus group with disabled people felt physical access to health service premises had a bearing on people's ability to keep medical appointments.

## **Respect: My right to be treated with dignity and respect**

Seventy three percent (169) of the written responses agreed with the inclusion of the proposed entitlements and responsibilities around dignity and respect. It was the most strongly supported right of the eight with strong support from all categories of respondent. The right to respect was also universally seen as very important by people at the two national events, to the point where people saw it as a natural expectation of a public service. People also saw it closely linked with the right to privacy. One theme to emerge from the focus group discussions was the view that, in the NHS, the attention is on a person's medical problem rather than it being on the person. Participants in the socio-economic disadvantage focus group saw this as making dialogue less personal and contributing to a perceived attitude of superiority by some health professionals. Participants in the minority ethnic communities' focus group felt that training for health care staff on cultural and diversity issues would be desirable.

## **Safety: My right to safe and effective care**

Sixty six percent (152) of those responding in writing agreed with the inclusion of a right to safe and effective care. Where health boards, medical and professional bodies disagreed with the right, the reasons tended to relate to definitions (and the need for definitions) and interpretation of the term 'safe and effective care'. People at the national events saw the right to safe and effective care as being at the centre of what

health services provide. People felt it important that this right embraced a person's 'whole life' care and not just services via hospitals or of an acute nature. Focus group participants raised the issue of hospital cleanliness in the context of safe and effective care, with people expressing concerns over the perceived cleanliness of some health service premises.

## **Communication: My right to clear, accessible and appropriate communication**

Seventy three percent (167) of written responses agreed with the inclusion of the right to clear, accessible and appropriate communication in the Patients' Rights Bill. Where concerns were raised they were mainly about resource implications around strengthening communication. At the national events, the right to communication was seen as a fundamental issue, complicated by the need to communicate effectively with groups of people as well as individuals. Within the focus groups a concern was raised about the over-technical nature of translations from English into other languages, the results being too complicated to understand.

## **Information: My right to information about the services I use and the treatment and care options available to me**

Seventy one percent (163) of written responses agreed that a right to information should be included. The main concerns regarding this proposed right related to issues around access to information in health records and the ability of patients to assimilate the information they need to know about their own care. There was also a view that this right overlapped with the previous right on communication. At the national events, some people saw the inability and/or reluctance of some patients to challenge (i.e. to assimilate information and seek further insight from health professionals) as a potential barrier to the effective communication of information from the health service. People in the minority ethnic communities' focus group emphasised the value of community groups as channels for communicating information.

## **Participation: My right to be involved in making decisions about my care and the services I use**

Sixty eight percent (157) of written responses agreed that the right to participation should be included within the Bill. Where people expressed concerns, they centred around the varied ability of patients to participate in decision-making. People at the national events saw a strong link between the proposed right around participation and the above right on information. People felt the capability of the patient to

participate in decision-making was key to effective participation. Respondents highlighted the fact that often patients' conditions prevent this from being the case. Members of the socio-economic disadvantage focus group felt their ability to participate was limited as they were not medically qualified; people from this group were inclined to accept the views and opinions of health professionals, almost without question.

### **Privacy: My right to privacy and confidentiality**

Seventy percent (160) of written responses agreed with the inclusion of this right within the Patients' Rights Bill. Some respondents raised questions about how these principles varied from existing legislation in this area. People at the national events saw the right to privacy as closely linked to the right about dignity and respect. There was recognition that health services provide a level of privacy and confidentiality, but not absolute privacy. Participants in the focus groups expressed concern about the way privacy and confidentiality were handled in the NHS. Concerns included data protection/security and working practices, such as having one's name shouted out in front of a full waiting room.

### **Independent support and redress: My right to comment about my care and have my concerns addressed**

Sixty five percent (149) of written responses agreed with the inclusion of the right to independent support and redress. There were, however, concerns raised about the financial implications of introducing a no-fault compensation system and whether such a move would be detrimental to the sense of mutuality between patients and health services. Participants at the national events were concerned that giving prominence to independent support and redress in

patients' rights could raise the incidence of compensation claims. Similarly, concern was expressed about where the funding to meet compensation claims was going to come from. People were concerned about these potentially diverting funds from health care provision. Some people in the faith group felt that no-fault compensation implied some form of contract rather than a sense of joint responsibility.

## **Conclusions**

There was overall support for a Patients' Rights Bill, and a range of support expressed for the eight areas around which entitlements and responsibilities were presented. The analysis of the data can be seen to have five over-arching themes which respondents wished to be further considered in the development of the Bill. These were as follows:

- Questioning the need for legislation.
- The scope of the health services covered by the proposed Bill.
- The resource implications in implementing the Bill's proposals.
- Issues to do with patient privacy, confidentiality and capability.
- Patient responsibilities.

The consultation showed support for the proposed elements of a Patients' Rights Bill. The Scottish Government may now wish to consider: the concerns around the legal status of some of the rights, the scope of the Bill, the resource implications to help move the ideas forward, strengthening the aspects around patient responsibilities, and, ensuring the Bill addresses the particular circumstances of more vulnerable patients.

This document, along with full research report of the project, and further information about social and policy research commissioned and published on behalf of the Scottish Government, can be viewed on the Internet at: <http://www.scotland.gov.uk/socialresearch>. If you have any further queries about social research, please contact us at [socialresearch@scotland.gsi.gov.uk](mailto:socialresearch@scotland.gsi.gov.uk) or on 0131-244 7560.



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