

POLICY BRIEFING – SCOTTISH GOVERNMENT CONSULTATION ON A PATIENTS’ RIGHTS BILL FOR USERS OF THE NHS IN SCOTLAND



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INTRODUCTION

The Scottish Government launched its consultation on a Patients’ Rights Bill for users of the NHS in Scotland on 22nd September 08. This is in line with the commitment made in the *Better Health, Better Care Action Plan*, and is one of the key steps that the Scottish Government is taking towards developing a mutual NHS in Scotland – “...an NHS where ownership and accountability is shared with the Scottish people and with the staff of the NHS”¹.

The consultation paper seeks views on the possible content of a Patients’ Rights Bill, and includes a number of measures designed to reinforce and strengthen the rights and responsibilities that patients have, and to create a clear framework for seeking redress when things go wrong. One of the proposed rights relates to ‘participation’ i.e. the right to participate in decisions about your healthcare and the health services that you use. The consultation is therefore of major interest to the Scottish Health Council, as we work to promote patient and public involvement in the NHS, and we will be leading in the development of a national Participation Standard, in partnership with other stakeholders.

This Policy Briefing has been written to raise awareness of the consultation and the process which will follow, and to provide some initial commentary. We hope that a wide range of organisations, groups and individuals across Scotland will take this opportunity to have their say on the content of the Bill.

OVERVIEW OF THE MAIN CONSULTATION PROPOSALS

Although patients already have a number of rights, these are not always widely understood or made use of. The intention is that the Patients Rights Bill would bring all of these rights together, with some additional rights, in a way that is easy to understand and simple to enforce. The Bill would be supplemented by a Charter of Mutual Rights, which would set out how the rights would work in practice.

¹ *Better Health, Better Care Action Plan*, The Scottish Government, 2007, section 1.1., page 5

In addition to having rights, patients have responsibilities relating to their use of the NHS. It is intended that these responsibilities would also be set out in the Bill.

The consultation paper seeks views on eight 'key patients' rights', as follows:

1. Access: Right to Accessible NHS Care and a Waiting Time Guarantee

One of the main proposals in the Bill relates to a new waiting time guarantee for treatment. This includes a maximum 12 week wait for inpatient or day case treatment from the point that treatment has been agreed as necessary, until the treatment takes place. This will operate within a maximum 18 week patient journey from initial referral to treatment. Patients will have the right to be informed about what the NHS Board will do to fulfil this guarantee – this could include accessing treatment in a neighbouring health board area or elsewhere in the UK or even, as a last resort, travelling overseas.

Other proposals relating to access include entitlements to:

- Choice of appointment times
- Support for patients to access care e.g. interpreters, patient transport services etc
- Equitable access – taking account of equality and diversity, economic and geographical factors
- Decisions about access that are transparent and clearly communicated.

The only responsibility proposed for patients in relation to access relates to attending agreed appointments.

2. Respect: Right to be treated with Dignity and Respect

This right is about ensuring that people are treated fairly and in a way that is sensitive to their individual circumstances, beliefs etc. Interestingly, it also covers an entitlement to “relief from suffering, including palliative care that is dignified, comforting and supportive.”

Patients' responsibilities relate to treating staff with dignity and respect, and not physically or verbally abusing staff.

3. Safety: Right to Safe and Effective Care

This right concerns the need: for health care staff to be appropriately trained and skilled; for the care provided to be safe and clinically appropriate; and for the healthcare environment to be of an appropriate standard.

There are two patients' responsibilities proposed in this section: first, complying with advice on medication and treatment, and second, raising legitimate concerns about safety.

4. Communication: Right to Clear, Accessible and Appropriate Communication

Breakdowns in communication are a common cause of complaints. The proposals therefore underline the importance of good communication, ensuring that patients receive information about key issues in their care, in a format that they can understand, with support to aid communication provided as necessary.

Patients' responsibilities in terms of communication relate to providing necessary information about their history, medication etc when required, telling health care providers about changes in their circumstances, and taking an active part in discussions and decisions about their care.

5. Information: Right to Information about Services and Treatment and Care Options

This right aims to ensure that people have all the information they need to stay healthy, to understand health conditions and related treatments, and to tell them about the health services provided locally. It also covers individuals' rights to see information in their own health records and to request copies of letters, emails etc written about them by NHS staff.

Patients are expected to be responsible for seeking and using information to support their own health, and to ensure that they have the information they need to make treatment decisions.

6. Participation: Right to be Involved in Making Decisions about Own Care and Health Services

This right covers a range of issues, including:

- Being involved in, and supported to make, decisions about care and treatment, including giving informed consent to, or refusal of, care and treatment
- Involving other people – family, carers, nominated support persons – in care and treatment issues
- Choosing whether to take part in the teaching or training of staff or in research
- Being supported to be involved in decisions about health services, locally and nationally
- Being informed about how well local health boards are performing against standards and expectations through receipt of an 'ownership report'.

A Participation Standard is to be developed which will cover a patient's right to participate, as well as the involvement of patients, staff and the public more generally.

Patients' responsibilities are about seeking further information if they are uncertain, deciding whether to give consent, and "participating constructively in decisions about healthcare and services where they wish to do so".

7. Privacy: Right to Privacy and Confidentiality

This right includes ensuring that people know their rights to see their health records, and that personal information is recorded accurately and kept securely, and that confidentiality is respected.

Patients are to be responsible for providing information that is appropriate and relevant for treatment of their condition.

8. Independent Support and Redress: Right to Comment about Care and have Concerns Addressed

This right is about ensuring that there are appropriate systems, that are easy to use, understand and access, in place to enable people to give feedback or seek redress. The aim is to achieve a culture of feedback and learning, rather than complaints and blame.

The consultation paper outlines: work that is ongoing to evaluate the existing complaints system; the need for Boards to provide Independent Advice and Support Services which can assist people to make complaints; and other rights for patient to contact the Scottish Public Sector Ombudsman or take legal action. It proposes strengthening these by requiring NHS Boards to have independent Patients' Rights Officers who would promote understanding and use by patients of their rights. The possibility of expanding the existing Independent Advice and Support Services to provide patients' rights outreach in local health services is also mentioned.

Further work will be carried out to investigate the costs and practicalities of introducing a 'no fault compensation' system, which would mean that financial compensation could be paid to patients in certain cases without the need for them to take legal action.

Patients would be responsible for "offering feedback on their health services in a positive and constructive way as far as possible."

NEXT STEPS

The deadline for submitting responses to the consultation is **Friday 16th January 2009**. The consultation responses will then be analysed and a summary report will be published. The Cabinet Secretary for Health and Wellbeing will consider the responses received before making a decision on an appropriate way forward.

SCOTTISH HEALTH COUNCIL VIEW

The Scottish Health Council welcomes the commitment by the Scottish Government to strengthen and enhance patients' rights and to clarify their responsibilities. We will be encouraging people across Scotland to have their say on the issues raised in the consultation. Whilst we will be responding to the consultation in due course, we would offer some general initial comments and observations as follows.

1. Much of the proposed content of the Bill relates to rights that are already in existence. For example, Data Protection legislation already covers the rights relating to privacy and confidentiality. However, it should be helpful to have all of the existing rights, and new rights, brought together in the Bill/Charter. It should make it easier for people to have a single source of information, rather than a number of different sources relating to individual rights.
2. The Bill should help to make it clearer what redress is available to patients where they feel that their rights have not been respected. It is less clear what, if anything, will happen if patients do not fulfil their responsibilities. So far as the responsibility to refrain from assaulting NHS staff is concerned, assault is clearly an offence and would be dealt with through the criminal process. With other responsibilities, whether there would be any consequences for failing to meet these are less clear e.g. the responsibility to attend agreed appointments.
3. It appears that there may be some conflict between the right to refuse to consent to treatment and the responsibility to comply with advice on medication and treatment. This requires clarification. It should also be acknowledged that some people are unable to exercise their rights to consent to or refuse treatment, where for example, they are being treated under the Mental Health (Care and Treatment) (Scotland) Act 2003 or the Adults with Incapacity (Scotland) Act 2000. For people whose rights are restricted in this way, it is important that they are clear about which rights in the Bill they are able to exercise depending on their particular circumstances.
4. A consultation on a proposed NHS Constitution for England is currently taking place and is due to close on 17th October 2008. This sets out a number of legal rights and 'pledges', and also includes patients' responsibilities. The

range of issues covered is very similar to those covered in the Patients' Rights Bill consultation but there are some notable differences. There is no equivalent of the Scottish 'waiting times guarantee' in the English paper, although there is a 'pledge' to provide access to services within waiting times set out in the Handbook to the Constitution. However, the English paper includes a right in relation to treatment that appears to go beyond what is covered in the Scottish paper i.e. "the right to drugs and treatments that have been recommended by NICE² for use in the NHS, if your doctor says that they are clinically appropriate for you"³.

One of the main benefits of public consultation is that it enables people to say what they like, or don't like, about proposals and to raise questions about any issues that are unclear. We look forward to finding out how people feel about the proposals and will be monitoring future developments.

FURTHER INFORMATION

The consultation paper is available on the Scottish Government's website at www.scotland.gov.uk/consultations . To find out where your nearest public internet access point is, telephone 0800 77 1234.

To find out more about the Scottish Health Council, visit www.scottishhealthcouncil.org . If you have any queries regarding this briefing, please contact Elaine Anderson at elaine.anderson@scottishhealthcouncil.org or telephone 0141 241 6308.

² NICE (National Institute for Clinical Excellence) is an independent organisation that produces guidance on drugs and treatments. The Scottish Medicines Consortium has a similar role in relation to medicines in Scotland.

³ *The National Health Service Constitution. A draft for consultation. July 2008.* Section 2a, page 2.