

CONSULTATION ON A PATIENTS' RIGHTS BILL FOR USERS OF THE NHS IN SCOTLAND

Responding to this consultation paper

We are inviting written responses to this consultation paper by 16 January 2009. **Please send your response with the completed Respondent Information Form (see "Handling your Response" below) to:**

patientrights@scotland.gsi.gov.uk

or

Patients' Rights Consultation
FREEPOST NATN542
Mailpoint 1
Healthcare Policy and Strategy Directorate
St Andrews House
Edinburgh
EH1 0BR

If you have any queries please e-mail these to patientrights@scotland.gsi.gov.uk.

We would be grateful if you would use the consultation questionnaire provided as this will aid our analysis of the responses received.

This consultation, and all other Scottish Government consultation exercises, can be viewed online on the consultation web pages of the Scottish Government website at <http://www.scotland.gov.uk/consultations>. You can telephone Freephone 0800 77 1234 to find out where your nearest public internet access point is.

The Scottish Government now has an email alert system for consultations ([SEconsult: http://www.scotland.gov.uk/consultations/seconsult.aspx](http://www.scotland.gov.uk/consultations/seconsult.aspx)). This system allows stakeholder individuals and organisations to register and receive a weekly email containing details of all new consultations (including web links). SEconsult complements, but in no way replaces SG distribution lists, and is designed to allow stakeholders to keep up to date with all SG consultation activity, and therefore be alerted at the earliest opportunity to those of most interest. We would encourage you to register.

Handling your response

We need to know how you wish your response to be handled and, in particular, whether you are happy for your response to be made public. Please complete and return the **Respondent Information Form** which forms part of the consultation questionnaire enclosed with this consultation paper and will ensure that we treat your response appropriately. (Also available at: <http://www.scotland.gov.uk/consultations/health/PatientRights.asp>.) If you ask for your response not to be published we will regard it as confidential, and we will treat it accordingly.

All respondents should be aware that the Scottish Government are subject to the provisions of the Freedom of Information (Scotland) Act 2002 and would therefore have to consider any request made to it under the Act for information relating to responses made to this consultation exercise.

Next steps in the process

Where respondents have given permission for their response to be made public and after we have checked that they contain no potentially defamatory material, responses will be made available to the public in the Scottish Government Library. These will be made available to the public in the Scottish Government Library by mid April 2009 and on the [Scottish Government consultation web pages by the end of April 2009](#). You can make arrangements to view responses by contacting the SG Library on 0131 244 4552. Responses can be copied and sent to you, but a charge may be made for this service.

What happens next ?

Following the closing date, all responses will be analysed and considered along with any other available evidence to help us reach a decision on the content of a Patients' Rights Bill. We aim to issue a report on this consultation process by mid May 2009. The Cabinet Secretary will consider all information available to her and all representation made to her before coming to a final decision on the Patients' Rights Bill and introduction of legislation in 2010.

Comments and complaints

If you have any comments about how this consultation exercise has been conducted, please send them to patientrights@scotland.gsi.gov.uk.

Patients' Rights

A Public Consultation on a Patients' Rights Bill for users of the NHS in Scotland

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Scotland

Responses to this consultation paper are invited by

Friday, 16 January 2009

Healthcare Policy and Strategy Directorate
Scottish Government

September 2008

Patients' Rights

Electronic publication and additional copies:

This consultation paper is available via the internet at:

<http://www.scotland.gov.uk/Consultations/Current>

You can use this to find out more about the consultation; ask questions; submit your views; and view submitted responses.

Or if you want additional paper copies of the consultation paper, or if you or someone you care for needs this paper in a different format or language, please contact us at:

Patients' Rights Consultation
FREEPOST NATN452
Mailpoint 1
Healthcare Policy and Strategy Directorate
St Andrew's House
Edinburgh
EH1 0BR

Or e-mail to: patientrights@scotland.gsi.gov.uk

Copies of the documents mentioned in this paper can also be obtained from these addresses.

This consultation is being conducted in line with the Scottish Government's consultation process Consultation: Good Practice Guidance¹

This consultation, and all other Scottish Government consultation exercises, can be viewed online on the consultation web pages at <http://www.scotland.gov.uk/consultations>. You can telephone Freephone 0800 77 1234 to find out where your nearest public internet access point is. There will be no charge for this call.

¹<http://www.scotland.gov.uk/Resource/Doc/1066/0006061.pdf>

Patients' Rights

This consultation is for anyone who uses the NHS in Scotland in any way.

The consultation paper is in two parts:

Part 1 - seeks views on the development of a legal framework for what individuals² can expect from the NHS in Scotland and what can be expected from them. It does so by looking at what:

- you have a right to expect including, for example, a new in-patient and day case waiting time guarantee;
- your responsibilities are;
- involvement and support you can expect in decisions about your own health and about the health services³ you use; and
- you can expect to happen if things go wrong.

Part 2 - explains how you can respond to the consultation.

² In this document the words "individual" or "patient" should be read as applying as appropriate to health service users and patients.

³ In this document the word 'services' means services provided by the NHS in Scotland locally or nationally.

Foreword

The people of Scotland are more than users of the NHS. As tax payers and as citizens, we all have a stake in how the NHS operates, and are part-owners of the NHS. That gives us rights, but also responsibilities. But some of the people I meet say that they don't feel that the NHS is working with them or for them. Rather it feels as if it is doing things to them.

That is why our action plan, *Better Health, Better Care*⁴, commits the NHS to working in partnership with you, the people it serves. A truly "mutual" NHS will be one where we all take more control of our health and become more active in deciding how **our** NHS is run.

I want you to see yourself not as a passive recipient of NHS services, but as an active partner in decisions about your health and healthcare. I know from speaking to our dedicated staff, that they want you to receive care that is respectful, compassionate and responsive to your individual needs. That was why I recently launched *Better Together*⁵, our new Patient Experience Programme, to ensure we systematically tap into the views and experiences of people who use NHS services, and to work with them to design services that better meet their needs.

If this is to be a true partnership you need to know what you can expect of the NHS and what it can expect from you in return. If you experience discrimination or disadvantage in your life, I want you to know how your NHS will help you to access your rights and, where appropriate, support you in accepting your responsibilities.

I encourage you to respond to this consultation. We need you to tell us what rights are important to you, what involvement you want in your health service and, in particular, what involvement you want in decisions about your own care and in influencing decisions about the services you use.

We've set out a new vision for a mutual NHS – now I need you to help me deliver it.

Nicola Sturgeon MSP

Deputy First Minister and Cabinet Secretary for Health and Wellbeing

⁴<http://www.scotland.gov.uk/Publications/2007/12/11103453/0>

⁵Initially *Better Together* will look at inpatient hospital care, GP services and the care we provide to people with long-term conditions.

Patients' Rights

A Public Consultation on a Patients' Rights Bill for users of the NHS in
Scotland

Part 1: The Consultation Paper

Introduction

1. Our action plan *Better Health, Better Care* committed us to ensuring that NHS Scotland is based on a mutual ethos. Delivering our vision of a mutual NHS requires us to set out what patients can expect from their NHS and what the NHS can expect from them.

2. We want to create a clear legal framework of rights for patients to support them in knowing what their rights are and to provide effective redress where they consider that their rights are not being fully delivered. In doing so we need to avoid encouraging a culture of blame or litigation. Our aim is to provide accessible, quick and effective redress through processes that work independently of patients and NHS Boards.

3. We need to strengthen the rights of patients to ensure that they are seen and treated quickly; treated as partners whose expertise is respected; and informed and supported to be involved in decisions that affect them.

The aim of a Patients' Rights Bill

4. The aim of a Patients' Rights Bill will be 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.

Purpose of consultation

5. The purpose of this consultation is therefore to seek your views on the possible content of a Patients' Rights Bill, which will deliver this approach and form the basis of a mutual NHS. In this document we set out our thoughts on:

- why patients' rights are important;
- what rights should be included in this legislation;
- what difference this will make; and
- proposals for improving the effectiveness and independence of redress – what you can do if things go wrong.

Patients' Rights in NHS Scotland

6. There are a number of existing patients' rights and entitlements⁶, although these are not always widely understood or exercised by patients. These include some legal rights as well as expectations deriving from Government policy and clinical standards, for example to:

- refuse medical treatment;
- consent to treatment;
- see personal health record;
- personal information being kept confidential;
- be treated without discrimination on grounds of e.g. race or disability;
- be treated with dignity and respect;
- be treated within maximum waiting time;
- be involved in treatment choices; and
- be treated in a safe and clean setting.

The Context of Care – what can patients expect?

7. NHS Scotland aims to deliver health services that are good quality, clinically safe and effective. The Patients' Rights Bill will strengthen patients' rights to receive this quality of service and to be involved in decisions about their health and health care and the services they use. Where patients feel that services could be improved, they will have a right to offer feedback and to know, where appropriate, this has been acted upon.

8. Access to treatment and waiting times are key issues for patients. Consequently, a central part of the Patients' Rights Bill will be a waiting time guarantee, with an easily understood way to ensure that this is met. Independent support and advice will be available to those who need it.

⁶ <http://www.hris.org.uk/index.aspx?o=1021>

Making Rights a Reality

9. To be useful to patients a Patients' Rights Bill will need to be easily understood, clearly communicated and simple to enforce. It will therefore include provision for a Charter of Mutual Rights, which will set out how these rights will be delivered in practice. It will also set out what patients' responsibilities are in relation to their use of health services.

10. This approach will raise patients' awareness of their rights and help to develop a clear, shared understanding between health services and the people they serve of the expectations and entitlements of patients.

Delivering a Patients' Rights Bill that is fair for all

11. The Patients' Rights' Bill will also acknowledge that Scotland is a socially, culturally and geographically diverse society and that patients' rights apply across that diversity. It will require health services to provide accessible and appropriate services that are responsive to the individual needs, background and circumstances of people's lives. It will also require Boards to consider the ways in which they support patients to ensure they are able to exercise their rights, for example through their Independent Advice and Support Services.

Key Patients' Rights

12. We believe that setting out the key patients' rights in legislation will help patients in knowing and taking advantage of their rights, and provide a clear framework and guidance for staff. These rights, and their associated responsibilities should apply wherever and whenever care is provided and should state patients' entitlements to:

- **Access** - equity of access to NHS care;
- **Respect** - respect, dignity and consideration for the individual;
- **Safety** - safe and effective care and treatment;
- **Communication** - which is clear and appropriate;
- **Information** - about services and care and treatment options;

- **Participation** - in decisions about health and services;
- **Privacy** - and confidentiality of personal information; and
- **Independent Support and Redress** – by commenting on care and having concerns addressed.

13. These rights have relevance to all aspects of health and healthcare, and to patients, carers, families, local communities and to NHS staff. We set out below some examples of the difference each of these rights will make to a patient's experience of treatment or care.

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

14. The NHS was established on the basis that its care would be accessible to all and free at the point of delivery. However, the public and patients also attach particular importance to waiting times. The Government is committed to give patients a legally binding waiting time guarantee appropriate for their condition.

15. We propose that this should take the form of a new in-patient and day case waiting time guarantee for treatment. The NHS in Scotland has already started work to deliver a maximum 18 week wait from referral to treatment, by 2011. Patients want to know with certainty that they can rely on swift treatment at a time that suits them. Therefore, once in-patient or day case treatment has been agreed as the most appropriate way forward between the clinician and the patient, we will guarantee that it takes place within a maximum time period of 12 weeks. This guarantee will operate within the overall referral to treatment patient journey of 18 weeks.

16. Fixing a maximum 12 week wait for the most important part of the patient pathway should help Boards to reduce overall maximum waiting times even further.

17. This guarantee applies to all patients who require hospital (elective) in-patient or day case treatment. This should be viewed as a "longstop" guarantee. Our vision is that many patients will not wait for treatment and will be seen and treated well within the overall 18 week referral to treatment standard, by 2011. Clinicians will continue

to have the flexibility and freedom to set the clinical priority that is most appropriate for their patients – particularly for those patients requiring urgent treatment and who we expect to be treated well within these maximum limits.

18. This will provide significantly increased assurance to patients that their treatment will be provided quickly, and minimise any period of waiting and anxiety. Furthermore, in the small number of cases where it is not clinically appropriate for treatment to begin within the 18 weeks referral to treatment standard, for example, where a series of tests needs to be done in sequence; where the patient and consultant have agreed that the patient should receive a second opinion; or a difficult diagnosis may require a series of interventions and a period of time to resolve, the new guarantee will ensure a firm and guaranteed end-point for the patient once a decision has been made that inpatient or day case treatment is required. The 12 weeks waiting time guarantee will remove any risk of unacceptably long waits following diagnosis.

19. The Patients' Rights Bill will set out clearly the terms of this guarantee. This will mean that a patient will have the right to receive healthcare services that have been agreed with their clinician within the stated time and this will be subject to and protected by processes designed to ensure that this maximum wait is adhered to. If things did go wrong and the guarantee, for whatever reason, can not be met, patients could seek redress through their right to Independent Support and Redress (see paragraph 60).

20. This guarantee will provide clarity and certainty to patients about what they can expect in terms of their individual waiting time for NHS services by providing clear assurances on how quickly treatment will be provided helping ensure that NHS Boards see and treat patients quickly;

21. Patients will have the right to be informed of the steps an NHS Board will take to fulfil this guarantee, for example, accessing healthcare services in a neighbouring health board area; in an existing independent (private) sector facility; elsewhere in the UK; or as a last resort overseas.

22. There are other rights relating to access that will also need to be considered. These include the right to the support necessary to enable patients to access the care offered to them, such as access to an interpreter or to patient transport. Also, access to healthcare must be equitable, appropriate, and responsive to individual need, including age, disability, ethnicity, gender, religion or belief, sexual orientation and transgender status.

23. Patients also have key responsibilities in relation to access. For example, failing to keep appointments wastes resources and the time of staff, and may lead to unnecessary delays for others.

24. In summary, a Patients' Rights Bill will ensure accessible and timely health services for all by laying out clear entitlements to:

- **in-patient and day case waiting time guarantee;**
- **a choice of appointment times;**
- **support for individual needs to enable access to care;**
- **equitable access, taking account of equality and diversity, economic and geographical issues; and**
- **a decision regarding access to care that is transparent, accountable and clearly communicated.**

Patients will be responsible for:

- **attending agreed appointments.**

Question 1

Do you agree with the inclusion of these entitlements and responsibilities? Do you agree that there should be a 12 week in-patient and day case waiting time guarantee as proposed in this paper from 2011? Is there anything you would like to add to the right to Access? What do patients and/or the NHS need to do to make this happen?

Respect: My right to be treated with dignity and respect

25. The mutual NHS described in *Better Health Better Care* is one where patients and staff value each others' experiences, knowledge and skills at all stages of care and treatment. At the heart of our vision of a mutual NHS are a set of principles including dignity, equality, respect, fairness and autonomy - principles that mirror Human Rights legislation.

26. Many people feel vulnerable when they are ill. They tell us health service bureaucracy can feel disempowering, leading to a feeling that things are being done to them, not with them. The Patients' Rights Bill will therefore ensure that patients have a right to be listened to and have their views taken on board.

27. Patients also have responsibilities to treat staff with dignity and respect. The treatment the NHS offers is possible only because of the skills, motivation and commitment of staff across a very wide range of jobs and professions. Any form of abuse or violence towards staff is an offence at common law, and under the Emergency Workers (Scotland) Act 2005, and is unacceptable. Patients need to respect the skills, expertise and compassion of the staff who treat them.

28. In summary, a Patients' Rights Bill will ensure that at all stages of their care and treatment a patient is entitled to:

- **be treated with dignity and respect;**
- **care provided in a manner that is responsive to their culture, beliefs and values;**
- **care that is responsive to the individual circumstances of their life, such as their age, disability, gender, race, faith or belief, or sexual orientation; and**
- **relief from suffering, including palliative care, that is dignified, comforting and supportive.**

Patients will be responsible for:

- **treating staff with dignity and respect; and**
- **not physically or verbally abusing staff.**

Question 2

Do you agree with the inclusion of these entitlements and responsibilities? Is there anything you would like to add to the right to Respect? What do patients and/or the NHS need to do to make this happen?

Safety: My right to safe and effective care

29. Patients have a right to expect health care services to be provided with care, skill and competence in a safe environment. We know that while the care provided in NHS Scotland is already safe, but it could be even safer.

30. We have set up the *Scottish Patient Safety Alliance* to make sure that our services are as safe as possible and that we learn from errors if they do occur. The Alliance is supporting staff in improving safety wherever and whenever care or treatment is delivered. Our work on patient safety dovetails with our work on healthcare-associated infection, patient experience and on ensuring clinical practice is evidence-based. Together they will ensure a safer, more reliable, more anticipatory and more integrated NHS.

31. To guarantee a right to safe and effective care, hospitals and health services will strive to continuously improve quality and safety. Healthcare professionals have responsibility, within their scope of practice, for the safety of a healthcare intervention. The development of a national Knowledge and Skills Framework for all NHS staff is one of the ways of ensuring that they have the knowledge and skills appropriate to their responsibilities.

32. Patients will also have access to independent advice and support to raise concerns about safety, effectiveness, cleanliness or other issues that they feel may affect their right to safe and effective care.

33. Patients also need to accept a role and responsibility for their own care, for example, in following advice about medication, treatment and suggested lifestyle changes. Many treatments will not be effective if advice about taking medication and appropriate doses is not followed, and a patient's health may suffer or fail to improve as a consequence.

34. In summary, a Patients' Rights Bill will ensure that at all stages of their care and treatment a patient is entitled to:

- **safe and effective care provided by health care professionals who have the right training and skills for their job;**
- **care that is informed and clinically appropriate;**
- **effective continuity of care and appropriate referrals; and**
- **an environment where patients, staff and systems are working to ensure quality and patient safety.**

Patients will be responsible for:

- **complying with advice on medication and treatment; and**
- **raising legitimate concerns about the safety of their care.**

Question 3

Do you agree with the inclusion of these entitlements and responsibilities? Is there anything you would like to add to the right to Safe and Effective Care? What do patients and/or the NHS need to do to make this happen?

Communication: My right to clear, accessible and appropriate communication

35. We know from the reports of the Scottish Public Services Ombudsman that communication problems are a frequent issue in the complaints she receives. Although in most cases there are no problems, we know that communication can break down at any stage of the patient's journey: in the movement between primary and secondary care; at the point of sending out an appointment card; when passing on information to relatives; at discharge; or when someone is making a complaint about the care they have received.

36. A Patients' Rights Bill will underline the critical importance of communicating with patients in a clear, accessible and appropriate way. This is particularly important when plans change or if something goes wrong. Patients should be communicated with in a language or format they can understand.

37. There is also a responsibility for patients to communicate with those treating them. This could be about medication they are taking, or about changes in their condition. This is necessary to allow healthcare staff to provide the best and most appropriate treatment.

38. In summary, a Patients' Rights Bill will ensure that at all stages of their care and treatment a patient is entitled to:

- **clear, accessible and appropriate communication throughout the period of care, but particularly when plans change or if something goes wrong;**
- **be told the names of the staff responsible for their care;**
- **be told when their care is being handed over to another health care team or provider, with regard for confidentiality, wherever possible;**
- **translation or interpreting services;**
- **independent advice and support, or to an advocate or other supporter; and**

- **ask questions⁷ and obtain information about diagnosis, treatment and care from members of the healthcare team.**

Patients will be responsible for:

- **providing information about their history, current treatment medication and alternative therapies directly or through their family, carer or other nominated supporter;**
- **informing their healthcare provider of any changes in their condition; and**
- **taking part actively and constructively, where possible, in discussion and decisions about their health and health care.**

Question 4

Do you agree with the inclusion of these entitlements and responsibilities? Is there anything you would like to add to the right to Communication? What do patients and/or the NHS need to do to make this happen?

⁷ E.g. by being provided with the HRIS leaflet *Its OK to ask*: see <http://www.hris.org.uk/?o=3454>

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

39. The Patients' Rights Bill will make provision to ensure that people have clear, accessible, open and appropriate information on staying healthy; on health conditions and related treatments; and about their local health service.

40. When people become ill, they will have the right to accessible and appropriate information to enable them to actively participate in decisions on their health and the care and treatment options available to them. Our proposals will also provide for independent advice and support for those who require it, including those who have additional needs in terms of understanding information, for example people with learning difficulties, people with low literacy levels and children.

41. Patients will have the right to information about the services available to them; the standards these services are expected to meet; and to see reports of any inspections or reviews of services which take place. They will also have a right to a clear explanation of the purpose of, and to give informed consent to tests or treatment. This will include an explanation of any risks and the expected benefits of each option.

42. Patients will have a right to this information in a way that they can understand, for example, in Braille or in a language other than English. They will have a right to the support of a family member, interpreter, advocate or other independent supporter to help them understand the implications of the options available to them or help them express their views.

43. Patients have a responsibility, where possible, to seek and use information in an appropriate way, for example to enable self-care for minor conditions.

44. To support this right we will, by April 2009, introduce a National Health Information and Support Service. This will bring together quality assured local and national information from the NHS, the

voluntary and other sectors, which patients and their families will be able to access online, by telephone or in their local high street.

45. In summary, a Patients' Rights Bill will ensure that at all stages of their care and treatment a patient is entitled to:

- **information communicated in a language or format that they can understand;**
- **information about their health and wellbeing, care and treatment;**
- **information about their maximum waiting time guarantee;**
- **information that satisfies them about the treatment and medication options open to them, including the possible risks and benefits;**
- **information about continuing health care arrangements when in hospital and discharge, including medication, care planning, timely and appropriate referrals, convalescence, rehabilitation, self care and end of life care;**
- **see information in their health records; and**
- **request that they be copied any letters, faxes or emails written by NHS staff about their care and treatment.**

Patients will be responsible for:

- **seeking and using information appropriately to support their own health, for example to enable self-care for minor conditions; and**
- **ensuring that they have the information to understand what they need to know about their care, and to provide consent to treatment.**

Question 5

Do you agree with the inclusion of these entitlements and responsibilities? Is there anything you would like to add to the right to Information? What do patients and/or the NHS need to do to make this happen?

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

46. The Patients' Rights Bill will give people a right to participate in decisions about their health care and the health services provided for them.

47. In a mutual NHS all patients will have the right to understand the options open to them and participate as fully as possible in decisions about their care and treatment. Their views will be given the same level of consideration as clinical opinion when coming to decisions about their care and treatment. Independent advice and support, and advocacy services, will be available to help those that need it.

48. We recognise that health services are more effective when the people and communities they serve are involved in their design, development and delivery. NHS Boards are therefore required to demonstrate how the views of the people they serve, including potentially excluded or disadvantaged individuals and communities, have been taken into account in their decisions about the development of the services they provide.

49. Patients are responsible for ensuring that they have the information to understand what they need to know about their care, and to provide consent to treatment. Patients may wish different levels of information and participation in decisions. However, there is a responsibility to take part actively and constructively in discussion and decisions about their health.

A participation standard

50. We will work with NHS Quality Improvement Scotland, the Scottish Health Council, Public Partnership Forums and other groups, including patient and staff representatives, to agree a participation standard for all NHS Boards. This will cover a patient's right to participate, as well as the involvement of patients, staff and the public more generally. This standard will build on existing guidance on

community engagement^{8 9} and reflect the needs of Scotland's diverse population.

51. NHS Boards will be asked to conduct an audit against the participation standard in order to collect systematic, comparable information on good practice and inform the future development of their approach to participation. We will include a target for performance against this standard amongst the key measures for NHS Boards by 2009.

An Ownership Report

52. Patients will also have a right to information about how well the NHS in Scotland is being run. Every household in Scotland will receive a report to strengthen their ownership of the local NHS. We think this ownership report will be a good way to tell patients about their rights and responsibilities, what services are available to them and how well their health board is doing against the participation standard.

53. In summary, a Patients' Rights Bill will ensure that at all stages of their care and treatment a patient is entitled to:

- **be involved in, and supported to make, informed decisions about treatment and care to the degree and extent that they choose;**
- **involve family, carers or other nominated support people in their health care treatment, decision-making, participation and communication;**
- **be involved in decisions about who will treat them and where;**
- **give informed consent prior to any procedure, with discussion of options available, expected outcomes for each option, and success rates and incidence of side-effects for each option;**

⁸Community Scotland's *National Standards for Community Engagement* see http://www.comunitiesscotland.gov.uk/stellent/groups/public/documents/webpages/otcs_008411.pdf

⁹*Informing, engaging and consulting the public in developing health and community care services* see Annex 3 of <http://www.scotland.gov.uk/Publications/2007/10/26111633/0>

- **withdraw consent or refuse further treatment, even if previous consent has been given to the treatment or procedure;**
- **choose whether to participate in the teaching or training of clinicians or research activities;**
- **be supported to be involved in decisions about their health services – locally and nationally; and**
- **information about how well their health board is performing against standards and expectations.**

Patients will be responsible for:

- **asking for further information if there is any uncertainty about their care;**
- **giving informed consent or not; and**
- **participating constructively in decisions about healthcare and services where they wish to do so.**

Question 6

Do you agree with the inclusion of these entitlements and responsibilities? Is there anything you would like to add to the right to Participation? What do patients and/or the NHS need to do to make this happen?

Privacy: My right to privacy and confidentiality

54. The Data Protection Act¹⁰ gives every patient a right to know what information the NHS holds about them, and sets out rules to make sure that this information is handled properly.

55. Patients have a right to know that the information the NHS holds on them will be kept accurate and up-to-date and, whether written on paper, held on computer, or both, will be stored securely. Patients also have a right to know how the NHS uses, shares and protects their personal health information and to see, or have a copy of their health records¹¹.

56. Patients have a responsibility for ensuring that the information they provide to health professionals is accurate and relevant, and helps in the diagnosis and treatment of their condition. They may consent to the use of this information for different purposes if they wish to do so, on the basis of an explanation and understanding of what this would mean.

57. When patients are using health services they will have the right to expect facilities which ensure privacy, particularly when healthcare staff are offering them personal care or carrying out examinations and treatment. Patients' personal privacy must be respected in the course of treatments which must take place in an appropriate environment and in the presence of only those who need to be there, unless the patient has explicitly given consent, or made a request for others to be present.

58. In summary, a Patients' Rights Bill will ensure that at all stages of their care and treatment a patient is entitled to:

- **expect that the collection, use, disclosure and storage of their personal health and other information will be undertaken in accordance with the needs of privacy and confidentiality, and remain confidential, unless legislation requires disclosure or they direct otherwise;**

¹⁰ http://www.ico.gov.uk/what_we_cover/data_protection/your_rights.aspx

¹¹ <http://www.hris.org.uk/index.aspx?o=1026>

- **health services that respect their privacy and confidentiality; and**
- **access to their health records.**

Patients will be responsible for:

- **providing the information that is appropriate and relevant to treatment of their condition.**

Question 7

Do you agree with the inclusion of these entitlements and responsibilities? Is there anything you would like to add to the right to Privacy? What do patients and/or the NHS need to do to make this happen?

Independent Support and Redress: My right to comment about my care and have my concerns addressed

59. Patients must have access to information and advice that will enable them to exercise the rights set out in this consultation document. Where patients feel that their rights have not been met they should have clear and simple means for redress.

60. In a mutual NHS, feedback will be actively encouraged. This will be used to explore the best approach to quick and effective means to resolve any problems patients may encounter when using health services, and to ensure effective redress where patient rights are not met. The feedback will also be used to make changes and improvements in the way services are delivered.

61. Research¹²¹³ shows that many patients who have concerns about NHS care choose not to provide feedback because of the barriers they perceive to complaining. They fear complaining will have an impact on their care or; they feel resigned 'to expecting these things' or; are daunted by what they perceive as bureaucratic processes. These barriers are particularly difficult for those patients who, for various reasons, may find our normal channels of communication difficult to access and use (e.g. individuals with visual or hearing impairments, literacy or language difficulties).

62. To achieve a culture of feedback and learning, rather than one of complaints and blame, we need to ensure that our systems for feedback and redress are easy to use, understand, accessible and appropriate to all patients and effective in supporting patients' rights.

63. Patients who want to feedback or complain if difficulties arise, can currently do so:

- at local level through staff or the NHS Board;
- with the support of the Independent Advice and Support Service;
- with access to the Scottish Public Sector Ombudsman; and

¹² <http://www.spso.org.uk/search.php?q=research+NHS+complaintsh>

¹³ <http://www.scotconsumer.org.uk/publications/reports/documents/CFIwithcover.pdf>

- where there is negligence, or other breach of a legal duty, through legal processes.

64. We need to be proactive to ensure that a patient's right to redress is met and that they have the support they need to navigate this system and get the quality care and treatment they have a right to.

65. Work is underway to improve feedback and our response to the needs of patients within the NHS, for example, through the introduction of the *Better Together* patient experience programme and an evaluation of the NHS Complaints Procedure, but more is required. Support and advice to exercise patients' rights should be easily available where healthcare is delivered. Patients should not have to seek this out for themselves.

66. Boards need to consider the ways in which they proactively support patients to ensure they are able to exercise their rights. They are already required to deliver an Independent Advice and Support Service to support patients and their families use health services effectively and address health-related issues such as access to benefits and making a complaint.

67. So that patients are fully aware of and able to exercise their rights, we will ensure that each NHS Board designates independent Patients' Rights Officers who will be a point of contact for patients and will be widely publicised to patients. We will also examine other new approaches to make sure that: patients are aware of their rights; local resolution happens as difficulties arise; feedback is provided to ensure the health service routinely learns from patients' experiences and, if things go wrong, patients or their families are supported to obtain appropriate redress. One possible approach may be to expand Boards' current Independent Advice and Support Service to provide Patients' Rights outreach within local health services.

68. The evidence is that in most cases what people are looking for when they seek redress is an explanation or apology, and an assurance that lessons have been learned, but in some cases financial redress will be appropriate. At present patients can

generally only receive financial compensation where they are able to establish negligence through a legal process.

69. It is possible that there may be cases in which financial compensation should be paid without the need to go through such a legal process. A no-fault compensation scheme could be simpler than existing processes, and could support the development of the concept of a mutual NHS, and a positive feedback and learning culture. We therefore favour no-fault compensation as the way forward for the NHS in Scotland, but there is a need for further work on the practical implications and potential costs of a change in compensation arrangements, which we propose to take forward before any firm decision on future arrangements is made.

70. Patients have a responsibility to raise any issues which concern them with the staff caring for them as they arise and to do so in a positive and constructive way. Where there are issues which require further investigation within an NHS Board, or by the Scottish Public Services Ombudsman, we will ensure that patients have the independent support they need to allow them to put forward and express their concerns as clearly and effectively as possible.

71. In summary, a Patients' Rights Bill will ensure that at all stages of their care and treatment a patient is entitled to:

- **access to, and independent support for, processes to comment on the care they receive;**
- **receive information and support on how to provide; feedback, lodge a complaint or seek independent advice and support;**
- **have their concerns dealt with properly and promptly;**
- **be informed of what has changed as a result of their feedback or complaint;**
- **have access to the independent public sector ombudsman; and**
- **have access to independent advice and support to support their patients' rights.**

Patients will be responsible for:

- **offering feedback on their health services in a positive and constructive way as far as possible.**

Question 8

Do you agree with the inclusion of these entitlements and responsibilities? Is there anything you would like to add to this right to Independent Support & Redress? What do patients and/or the NHS need to do to make this happen?

Any Other Rights

Question 9

Are there any other key rights, which you think should be included in the Patients' Rights Bill? What do patients and/or the NHS need to do to make this happen?

What happens next?

72. You can submit your response to these questions online using the form at:

<http://www.scotland.gov.uk/consultations/health/PatientRights.asp>

can use the form in part 2 of this paper.

Will my comments be made public?

73. Copies of the written response received to a consultation exercise, where permission is given by the respondent, will be placed on the Scottish Government website and in the Scottish Government Library at:

K Spur
Saughton House
Broomhouse Drive
Edinburgh
EH11 3XD

74. If you do not wish your response to be made public, please ensure that you indicate clearly that all or part of your response is to be treated as confidential, and we will treat your response appropriately. Confidential responses will still count in any analysis and your views will of course be taken into account in the same way as for non-confidential responses.

75. All respondents should be aware that the Scottish Government is subject to the provisions of the Freedom of Information (Scotland) Act 2002 and would therefore have to consider any request made to it under the Act for information relating to responses made to this consultation exercise.

76. When this consultation is concluded, the responses will be analysed and the views expressed will be summarised. Direct quotes from individual respondents will only be used where respondents have given their permission for publication of their response.

77. A report will be published and the Cabinet Secretary will consider the views expressed and the issues raised before coming to an informed decision on the appropriate way forward. The Cabinet Secretary will consider all other information available to her and all representations made to her before coming to a final view.

How will I know what the Cabinet Secretary decides?

78. The Cabinet Secretary's decision and a report on the consultation will be published on www.scotland.gov.uk/Publications/Recent. A copy will also be sent to the address provided by each respondent.

Comments

79. If you have any comments about how this consultation exercise has been conducted, please send these to:

Patients' Rights Consultation
FREEPOST NATN452
Mailpoint 1
Healthcare Policy and Strategy Directorate
St Andrew's House
Edinburgh
EH1 0BR

Patients' Rights

A Public Consultation on a Patients' Rights Bill for NHS Scotland

Part 2: How you can respond to the consultation

Responses are invited by Friday, 16 January 2009

Patients' Rights

Please complete your response online using the form at:

<http://www.scotland.gov.uk/consultations/health/PatientRights.asp>

or use the forms on pages 37 to 46 which should be sent to:

Patients' Rights Consultation
FREEPOST NATN452
Healthcare Policy and Strategy Directorate
Mailpoint 1
Edinburgh
EH1 0BR

by Friday, 16 January 2009

Confidentiality

Copies of responses received are normally made available to the public. The views expressed by respondents may also be quoted or referred to in any future review of responses.

If you ask for your response not to be published, we will regard it as confidential and treat it accordingly. Please complete the form overleaf to indicate how you wish your response to be handled. Confidential responses will still count in any analysis and your views will of course be taken into account in the same way as for non-confidential responses.

All respondents should be aware that the Scottish Government is subject to the provisions of the Freedom of Information (Scotland) Act 2002 and would therefore have to consider any request made to it under the Act for information relating to responses made to this consultation exercise.

Patients' Rights

Please write your response here (please continue on a separate sheet of paper, if necessary.)

Question 1: The right to Access

A Patients' Rights Bill will ensure accessible and timely health services for all by laying out clear entitlements to:

- in-patient and day case waiting time guarantee;
- a choice of appointment times;
- support for individual needs to enable access to care;
- equitable access, taking account of equality and diversity, economic and geographical issues; and
- a decision regarding access to care that is transparent, accountable and clearly communicated.

Patients will be responsible for:

- attending agreed appointments.

Do you agree with the inclusion of these entitlements and responsibilities? Do you agree that there should be a 12 week in-patient and day case waiting time guarantee as proposed in this paper from 2011? Is there anything you would like to add to the right to Access? What do patients and/or the NHS need to do to make this happen?

Question 2: The right to Respect

A Patients' Rights Bill will ensure that at all stages of their care and treatment a patient is entitled to:

- be treated with dignity and respect;
- care provided in a manner that is responsive to their culture, beliefs and values;
- care that is responsive to the individual circumstances of their life, such as their age, disability, gender, race, faith or belief, or sexual orientation; and
- relief from suffering, including palliative care, that is dignified, comforting and supportive.

Patients will be responsible for:

- treating staff with dignity and respect; and
- not physically or verbally abusing staff.

Do you agree with the inclusion of these entitlements and responsibilities? Is there anything you would like to add to the right to Respect? What do patients and/or the NHS need to do to make this happen?

Question 3: The right to Safe and Effective Care

A Patients' Rights Bill will ensure that at all stages of their care and treatment a patient is entitled to:

- safe and effective care provided by health care professionals who have the right training and skills for their job;
- care that is informed and clinically appropriate;
- effective continuity of care and appropriate referrals; and
- an environment where patients, staff and systems are working to ensure quality and patient safety.

Patients will be responsible for:

- complying with advice on medication and treatment; and
- raising legitimate concerns about the safety of their care.

Do you agree with the inclusion of these entitlements and responsibilities? Is there anything you would like to add to the right to Safe and Effective Care? What do patients and/or the NHS need to do to make this happen?

Question 4: The right to Communication

A Patients' Rights Bill will ensure that at all stages of their care and treatment a patient is entitled to:

- clear, accessible and appropriate communication throughout the period of care, but particularly when plans change or if something goes wrong;
- be told the names of the staff responsible for their care and how to contact them;
- be told when their care is being handed over to the another health care team or provider, with regard for confidentiality, wherever possible;
- translation or interpreting services;
- independent advice and support, or to an advocate or other supporter; and
- to ask questions¹⁴ and obtain information about diagnosis, treatment and care from members of the healthcare team.

Patients will be responsible for:

- providing information about their history, current treatment medication and alternative therapies directly or through their family, carer or other nominated supporter;
- informing their healthcare provider of any changes in their condition; and
- taking part actively and constructively in discussion and decisions about their health and health care.

Do you agree with the inclusion of these entitlements and responsibilities? Is there anything you would like to add to the right to Communication? What do patients and/or the NHS need to do to make this happen?

¹⁴ E.g. by being provided with the HRIS leaflet *Its OK to ask*: see <http://www.hris.org.uk/?o=3454>

Question 5: The right to Information

A Patients' Rights Bill will ensure that at all stages of their care and treatment a patient is entitled to:

- information communicated in a language or format that they can understand;
- information about their health and wellbeing, care and treatment;
- information about their maximum waiting time;
- information that satisfies them about the treatment and medication options open to them, including the possible risks and benefits;
- information about discharge and continuing health care arrangements when in hospital, including medication, care planning, timely and appropriate referrals, convalescence, rehabilitation, self care and end of life care;
- see information in their health records; and
- request that they be copied any letters, faxes or emails written by NHS staff about their care and treatment.

Patients will be responsible for:

- seeking and using information appropriately to support their own health, for example to enable self-care for minor conditions; and
- ensuring that they have the information to understand what they need to know about their care, and to provide consent to treatment.

Do you agree with the inclusion of these entitlements and responsibilities? Is there anything you would like to add to the right to Information? What do patients and/or the NHS need to do to make this happen?

Question 6: The right to Participation

A Patients' Rights Bill will ensure that at all stages of their care and treatment a patient is entitled to:

- be involved in, and supported to make, informed decisions about treatment and care to the degree and extent that they choose;
- involve family, carers or other nominated support people in their health care treatment, decision-making, participation and communication;
- be involved in decisions about who will treat them and where;
- give informed consent prior to any procedure, with discussion of options available, expected outcomes for each option, and success rates and incidence of side-effects for each option;
- withdraw consent or refuse further treatment, even if previous consent has been given to the treatment or procedure;
- choose whether to participate in the teaching or training of clinicians or research activities;
- be supported to be involved in decisions about their health services – locally and nationally; and
- information about how well their health board is performing against standards and expectations.

Patients will be responsible for:

- asking for further information if there is any uncertainty about their care;
- giving informed consent or not; and
- participating constructively in decisions about healthcare and service where they wish to do so.

Do you agree with the inclusion of these entitlements and responsibilities? Is there anything you would like to add to the right to Participation? What do patients and/or the NHS need to do to make this happen?

Question 7: The right to Privacy

A Patients' Rights Bill will ensure that at all stages of their care and treatment a patient is entitled to:

- expect that the collection, use, disclosure and storage of their personal health and other information will be undertaken in accordance with the needs of privacy and confidentiality, and remain confidential, unless legislation requires disclosure or they direct otherwise;
- health services that respect their privacy and confidentiality; and
- access to their health records.

Patients will be responsible for

- providing the information that is appropriate and relevant to treatment of their condition.

Do you agree with the inclusion of these entitlements and responsibilities? Is there anything you would like to add to the right to Privacy? What do patients and/or the NHS need to do to make this happen?

Question 8: The right to Independent Support and Redress

A Patients' Rights Bill will ensure that at all stages of their care and treatment a patient is entitled to:

- have access to, and independent support for, processes to comment on the care they receive;
- receive information and support on how to provide feedback, lodge a complaint or seek independent advice and support;
- have their concerns dealt with properly and promptly;
- be informed of what has changed as a result of their feedback or complaint;
- have access to the independent public sector ombudsman; and
- have access to independent advice and support to support their patients' rights.

Patients will be responsible for:

- offering feedback on their health services in a positive and constructive way as far as possible.

Do you agree with the inclusion of these entitlements and responsibilities? Is there anything you would like to add to this right to Independent Support and Redress? What do patients and/or the NHS need to do to make this happen?

Question 9: Other Rights

Are there any other key rights which you think should be included in the Patients' Rights Bill? What do patients and/or the NHS need to do to make this happen?

Thank you for taking the time to participate in this consultation. We will acknowledge receipt of your response



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