HEALTH AND SPORT COMMITTEE

AGENDA

23rd Meeting, 2010 (Session 3)
Wednesday 8 September 2010

The Committee will meet at 10.00 am in Committee Room 5.

1. **Decision on taking business in private:** The Committee will decide whether to take item 4 in private.

2. **Subordinate legislation:** The Committee will consider the following negative instruments—
   - The National Health Service (Discipline Committees) (Scotland) Amendment Regulations 2010 (SSI 2010/226);
   - The National Health Service (Tribunal) (Scotland) Amendment Regulations 2010 (SSI 2010/227);
   - The Scottish Dental Practice Board Amendment Regulations 2010 (SSI 2010/228);
   - The National Health Service (Vocational Training for General Dental Practice) (Scotland) Amendment Regulations 2010 (SSI 2010/229) and
   - The National Health Service (Tribunal) (Scotland) Amendment (No. 2) Regulations 2010 (SSI 2010/266).

3. **Patient Rights (Scotland) Bill:** The Committee will take evidence on the Bill at Stage 1 from—
   - Lauren Murdoch, Patient Rights Bill Team Leader, Fiona Montgomery, Head of Patient Support and Participation Division, Alastair Pringle, Head of Patient Focus and Equalities, Margaret Duncan, Waiting Times Policy Lead, and Kathleen Preston, Health and Community Care Solicitor, Legal Directorate, Scottish Government;

   and then from—

   - Christine Lang, Independent Advice and Support Service (IASS) Development Worker, and Suzanne Dyer, Independent Advice and
Support Service (IASS) case worker, Peebles CAB, Citizens Advice Scotland;

Liz Macdonald, Senior Policy Officer, Consumer Focus Scotland;

Jim Martin, Scottish Public Services Ombudsman.

4. **Draft Budget Scrutiny 2011-12 - appointment of adviser (in private):** The Committee will consider a candidate list for the post of budget adviser.

Douglas Wands
Clerk to the Health and Sport Committee
Room T3.60
The Scottish Parliament
Edinburgh
Tel: 0131 348 5210
Email: douglas.wands@scottish.parliament.uk
The papers for this meeting are as follows—

**Agenda Item 2**

Paper from the clerk

SSI/2010/226

SSI/2010/227

SSI/2010/228

SSI/2010/229

SSI/2010/266

**Agenda Item 3**

Submission from the Scottish Government on the Patient Rights (Scotland) Bill

Submission from the Scottish Government on Patient Rights and Principles

Submission from the Scottish Government on the Treatment Time Guarantee

Submission from the Scottish Government on the Patient Advice and Support Service

Submission from the Scottish Government on Patient Complaints and Feedback

Patient Rights (Scotland) Bill - Regulatory Impact Assessment

Patients Rights (Scotland) Bill - Equality Impact Assessment

Submission from Citizens Advice Scotland

Submission from Consumer Focus Scotland

Submission from the Scottish Public Services Ombudsman

SPICe briefing on the Patient Rights (Scotland) Bill

Report from the Subordinate Legislation Committee on the Patient Rights (Scotland) Bill
Agenda Item 4

PRIVATE PAPER

HS/S3/10/23/19 (P)
### Abridged Subordinate Legislation Briefing

#### Negative Instruments

<table>
<thead>
<tr>
<th>Name</th>
<th>Deadline</th>
<th>Motion to Annul</th>
<th>Purpose</th>
<th>Drawn to attention by Subordinate Legislation Committee (SLC)?</th>
</tr>
</thead>
<tbody>
<tr>
<td>The National Health Service (Discipline Committees) (Scotland) Amendment Regulations 2010 (SSI 2010/226)</td>
<td>13 Sept</td>
<td>No</td>
<td>These Regulations amend the National Health Service (Discipline Committees) (Scotland) Regulations 2006 (&quot;the principal Regulations&quot;) which make provision relating to the NHS discipline committees.</td>
<td>No comments</td>
</tr>
<tr>
<td>The National Health Service (Tribunal) (Scotland) Amendment Regulations 2010 (SSI 2010/227)</td>
<td>13 Sept</td>
<td>No</td>
<td>These Regulations amend the National Health Service (Tribunal) (Scotland) Regulations 2004 (&quot;the principal Regulations&quot;) which make provision relating to the NHS Tribunal, representations to it and its procedures. The main purpose is to extend the NHS Tribunal's jurisdiction to assistant dentists and dental bodies corporate.</td>
<td>The SLC reported a minor technical error in the instrument relating to the prescribed forms to be used by tribunals. The Scottish Government acknowledged and has brought forward SSI/2010/266 to correct this error.</td>
</tr>
<tr>
<td>The Scottish Dental Practice Board Amendment Regulations 2010 (SSI 2010/228)</td>
<td>13 Sept</td>
<td>No</td>
<td>These Regulations amend the Scottish Dental Practice Board Regulations 1997 (&quot;the principal Regulations&quot;) which make provision for the continued existence of the Scottish Dental Practice Board.</td>
<td>No comments</td>
</tr>
</tbody>
</table>
| The National Health Service (Vocational Training for General Dental Practice) (Scotland) Amendment Regulations 2010 (SSI 2010/229) | 13 Sept | No | These regulations make amendments (regulation 2(2)(a) and (b)) to the National Health Service (Vocational Training for General Dental Practice) (Scotland) Regulations 2004 to provide the necessary arrangements for NHS Education for Scotland ("NES") to exempt a dentist from the requirement to | The SLC reported that—
• it considered that regulation 2(6) fails to follow normal drafting practice; and
• regulation 2(6) contains a drafting error, in referring to the National Health Service (Vocational Training in |
<table>
<thead>
<tr>
<th>Agenda Item 2</th>
<th>8 September 2010</th>
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</thead>
<tbody>
<tr>
<td>complete one years vocational training, provided the dentist is on the General Dental Council specialist list for orthodontics, and is able to demonstrate to the satisfaction of NES they have appropriate orthodontic experience or training.</td>
<td>General Dental Practice) (Scotland) Regulations 2004 rather than to that instrument’s correct title. However, the SLC considers that it is unlikely that either of these points will affect the operation of these Regulations.</td>
</tr>
</tbody>
</table>

| The National Health Service (Tribunal) (Scotland) Amendment (No. 2) Regulations 2010 (SSI 2010/266) | 13 Sept | No | These Regulations amend the National Health Service (Tribunal) (Scotland) Regulations 2004 (SSI/2010/226) which make provision relating to the NHS Tribunal, representations to it and its procedures. | No comments |

Where instruments have been drawn to the Committee’s attention, the relevant extract from the SLC report is given as an annex to this paper. If members have any queries or points of clarification on the instrument which they wish to have raised with the Scottish Government in advance of the meeting, please could these be passed to the Clerk to the Committee as soon as possible.
Patient Rights (Scotland) Bill

Cover Note from the Scottish Government

The Patient Rights Bill is a key opportunity to place patients at the heart of the NHS in Scotland. The Bill does this by legislating for: rights for patients about the way in which healthcare is received, support through a Patient Advice and Support Service with its Patient Rights Officers, for a right for patients to raise concerns and complaints, and for a treatment time guarantee to give eligible patients surety about length of wait for agreed treatment. The Bill is about the way in which healthcare is received rather than rights to specific treatments or services.

We know that the vast majority of patient encounters are good – the Government wants this to be the case for every patient, every time and considers that the Bill contributes to this, whilst respecting the duties of Health Boards to all patients. There are also provisions to ensure that clinical judgement remains key and, because this Bill is about delivery, the Government has included provisions against the Bill being used to sue the NHS – we know from debate that Members were concerned about the potential for the Bill to create ‘a lawyer by every bedside’.

The Bill contributes to the patient focused aspect of the Quality Strategy’s person-centred work. In tune with the Strategy, the Bill is about ensuring that every individual contact between a patient and a member of NHS staff is the best that it can be.

The Bill contains provisions for healthcare principles, to which providers of healthcare should have regard. These mean that when a patient receives healthcare, it should be patient focused, it should have regard to the importance of providing the optimum benefit, it should allow for the patient’s participation in decisions, and it should provide appropriate information and support to allow them to do so. We believe that codes of conduct, governance standards and professional regulations offer avenues to deal with potential breaches of the rights and principles. The implementation planning for the Bill, including staff training, will include embedding a patient focused approach at all levels.

The technical and administrative detail of the Bill will be in secondary legislation and directions, supported with guidance and public information. Scottish Government officials are continuing to work with relevant stakeholders to consider how the Bill will be implemented in practical terms, to aid the drafting of regulations, directions and information. The Government aims to share early drafts of secondary legislation with the committee at stage 2, which would then be more fully consulted on at a later stage, but in attached information sheets we have outlined the general areas that we anticipate these will cover. These are for information only and may be subject to change.
In summary, the aim is to reinforce a mutual NHS which respects the rights of both patients and staff. This Bill gives an opportunity to give prominence, through primary legislation, to the quality of care and to patients as the centre of the NHS.

Patient Rights (Scotland) Bill Team
Scottish Government
September 2010
Patient Rights (Scotland) Bill – Directions - Health Care Principles

The Scottish Government may issue Directions on the practical application of the Health Care Principles of the Patient Rights (Scotland) Bill, in accordance with Section 5 (3) of the Patient Rights (Scotland) Bill.

It is anticipated that the Directions will cover these broad aims:

- **Awareness raising**
- **Patient focus**
- **Quality care and treatment**
- **Patient participation**

**Awareness raising** – publicising of the Principles to patients and staff.

**Patient Focus** – to arrange appropriate support in advance where possible, and to communicate this to relevant staff. The support that is available for patients and how to request it should be publicised; types of support might include advocacy or communication support.

**Quality Care and Treatment** – that current clinical guidelines and standards are followed when delivering medical care; that care governance standards are implemented at all levels; to take action to ensure the delivery of patient focused, safe and effective care.

**Patient Participation** – measures to take in order that patients understand the information that is given to them; that all staff receive training in communication skills and that staff are aware of how to access support services for patients to enable participation and to promote these options to patients.

Patient Rights (Scotland) Bill Team
Scottish Government
September 2010
Patient Rights (Scotland) Bill – Regulations and directions – Treatment Time Guarantee

The Scottish Government will issue regulations and direct Health Boards on the Treatment Time Guarantee, in accordance with Section 7(1) to (3) and Section 9(2) and (3) of the Patient Rights (Scotland) Bill.

As outlined in the Policy Memorandum to the Bill, it is intended that the treatment time guarantee will apply to patients receiving planned, elective treatment on an inpatient or day case basis. This will be much simpler than giving very long lists of included treatments. The Policy Memorandum also outlined proposed exclusions, and why, and the Government is continuing to consider these. A limited number of excluded treatments to the treatment time guarantee will be set out in the Regulations.

It’s likely that methods for calculation of the waiting time will be modelled on the calculations and circumstances currently used in waiting times’ targets (New Ways of Defining Waiting Times) to ensure that there is consistency of use and understanding across health boards. The method of calculation will be set out in the Regulations. These regulations will be technical and administrative in nature. The Government also proposes that Boards should make it clear to patients how their waiting time is calculated.

The Government proposes that regulations on what Boards should do to comply with the Guarantee and which Board has responsibility for individual patients should cover such issues as monitoring the treatment time guarantee, arranging for provision of treatment with appropriate alternative providers (such as the National Waiting Times Centre) and in what circumstances responsibility for the patient should transfer to another provider.

The Government may issue guidance to assist boards in the administration of the treatment time guarantee. This could include giving worked examples of situations.

The Bill also allows for Ministers to direct a Board to take specific action. These may be actions that all Boards should do or there may be circumstances where Ministers direct specific Boards to take specific actions. This would be dependent on the issues. Ministers may also direct that the treatment time guarantee should be suspended in exceptional circumstances. Currently, the Government doesn’t propose to specify what those circumstances will be since their exceptional nature means that they are difficult to predict: that includes how the NHS may be affected by them and whether it would be necessary to suspend the treatment time guarantee.

Patient Rights (Scotland) Bill Team
Scottish Government
September 2010

Regulations and directions are in the process of being drafted: this document is for information, provides only an outline of intentions, and may be subject to change; it carries no legal status.
The Patient Rights (Scotland) Bill - The Patient Advice and Support Service (PASS)

The Scottish Government may issue Regulations about the Patient Advice and Support Service, in particular about the service it is to provide, in accordance with Section 15(6) of the Patient Rights (Scotland) Bill. The Government is considering what should be set out in Regulations and what will be set out in the contract specification between the NHS’s Common Services Agency and PASS. The information below therefore sets out how it is anticipated the PASS will operate.

Who can use Patient Advice and Support Service (PASS) – that the service is available to patients, carers, users of NHS services and members of the public (including children).

Geographic coverage – that the service is to be accessible across Scotland including to those living in remote and rural areas.

Cost – that the PASS will be provided free at the point of delivery.

Function of PASS – the Patient Rights (Scotland) Bill states that PASS will help patients and members of the public raise concerns, make a complaint or raise feedback about their healthcare. PASS will also make patients and members of the public aware of their rights and responsibilities when using the NHS. The PASS will not give legal or clinical advice on healthcare issues, investigate complaints, assist with complaints about private healthcare services (except where these have been purchased by the NHS but are provided by an independent sector organisation) or support a patient/carer/relative to attend a Fatal Accident Inquiry.

Patient Rights Officers (PRO) – there must be at least one PRO per health Board and they will provide support and advice to any member of the public (see ‘Who can use PASS’) regardless of which Health Board they reside in or are receiving care in.

Staff Training – that PROs should be suitably trained in order to carry out their functions effectively, that training should take account of the needs of the service users and the support and advice they might require e.g. mental health, gender, sexual orientation, and long-term care.

Monitoring and Evaluation – that there will be monitoring and evaluation of the PASS.

Reporting to Health Boards – that the PASS will report on its activities.
Role of responsible bodies – that Health Boards and service providers will make service users aware of the PASS.

Patient Rights (Scotland) Bill Team
Scottish Government
September 2010
Patient Rights (Scotland) Bill - Complaints and Feedback

The Scottish Government may issue Regulations and Directions relating to the arrangements for dealing with complaints and feedback, in accordance with Sections 11(4) and 12(5) of the Patient Rights (Scotland) Bill. The Directions on Complaints and Patient Feedback may be combined into one document as this will avoid duplication given they are closely related.

The Government anticipates that the following issues will be covered:

- who can make a complaint and how a complaint should be acknowledged and investigated
- what’s excluded from the NHS complaints process
- the method of communication between the Health Board and the complainant
- the information which must be given to a complainant such as details of the Patient Advice and Support Service
- the time period for making a complaint and timescales for responding to complainants
- monitoring and reporting of complaints and feedback and reviewing these
- publicising the NHS Complaints Procedure
- encouraging patients to raise concerns or give feedback on healthcare they have received.
- staff training
- how Health Boards should publicise the various advice and support available to service users
- learning from complaints

Patient Rights (Scotland) Bill Team
Scottish Government
September 2010
PATIENT RIGHTS (SCOTLAND) BILL - REGULATORY IMPACT ASSESSMENT

1. Title of proposal
Patient Rights (Scotland) Bill

2. Purpose and intended effect

Objectives
1. The Bill is intended to reinforce and strengthen the Scottish Government’s commitment to place patients at the centre of the NHS in Scotland. It will facilitate a truly mutual NHS which respects the rights of both patients and staff and embeds partnership working to enable the NHS in Scotland to become a world leader in person-centred health care.

2. The Patient Rights (Scotland) Bill will provide that the health care that patients receive should meet certain criteria, according to a set of health care principles. The Bill will legislate for a patient advice and support service, for a treatment time guarantee, and will establish a right to make complaints and give feedback. The Scottish Government wants to develop a clear, shared understanding between health services and the people they serve of the expectations and entitlements of patients and of responsibilities when using health services. As we take forward implementation of the Bill, we will set out patients’ rights and responsibilities in relation to their own health care.

3. As a result of the Bill, patients will be more aware of the rights they have and they will be better able to exercise those rights. Implementation will encourage the notion that as owners of the NHS, patients have responsibilities. This will contribute to a mutual ethos for the NHS, where people are partners in their care with staff. Ultimately, this will contribute to the Government’s purpose and its strategic objectives, especially around improving health outcomes and tackling health inequalities.

4. For the purposes of this assessment the Bill has been divided into four areas:

   - Rights and Principles
   - The treatment time guarantee
   - Support
   - Right to make complaints

Rights and Principles

5. The Bill establishes that it is the right of every patient that the health care they receive is patient-focused, has regard to providing the optimum benefit to the patient’s health and wellbeing, allows for patient participation as fully as possible, allows for information and support and allows for concerns or complaints to be raised. This is underpinned by a schedule of health care principles which health care providers will have a duty to have regard to when delivering NHS services.
**The Treatment Time Guarantee**

6. This will provide eligible patients with a guarantee of treatment within 12 weeks from agreement to treatment to the start of that treatment.

7. Through Regulations and Directions we intend to set out eligibility criteria for the treatment time guarantee and the limited number of services that are excluded; these are explored in the Policy Memorandum.

**Support (Patient Advice and Support Service, Patient Rights Officers)**

8. The Bill will legislate for a Patient Advice and Support Service (PASS), with a staff of Patient Rights Officers (PROs). The intention is to place a duty on the Common Services Agency (NHS National Services Scotland) to secure this nationally.

**Right to make a complaint**

9. The Bill will establish a right to make complaints about health services. It will also revoke and restate existing legislation to strengthen the complaints process. It will also legislate for encouraging feedback.

10. People who wish to complain about a primary care issue have a choice to complain direct to the primary care provider or to the Health Board. In secondary legislation we intend to amend timescales to respond to complainants with the result of an investigation. We intend that Health Boards should ensure that primary care services they contract report in a consistent manner on complaints received.

**Background**

11. A Patients Rights Bill and a Waiting Time Guarantee were manifesto commitments. In the *Better Health, Better Care Action Plan* (December 2007) the Scottish Government committed to a public consultation on the possible content of a Patients’ Rights Bill as part of the Scottish Government’s commitment to a mutual NHS.

**Rationale for government intervention**

12. While there are currently in place existing rights for patients and expectations on them, these are articulated in disparate ways and are not always known nor well understood by patients or by staff. We want to be in a position where: patients recognise their rights and have independent support and advice available to ensure these are met; patients work in partnership with staff to support their own health rather than being passive recipients of care, where this is possible; staff fully recognise that patients have rights and feel comfortable with patients articulating them; and patients recognise and accept that they have responsibilities on them to support their own health and in their use of the health care system.
13. The treatment time guarantee will provide clarity and certainty to eligible patients about what they can expect in terms of waiting time (for planned or elective care delivered on an inpatient or day case basis) and will place a duty on Health Boards to ensure that the treatment time guarantee is met.

14. In terms of the wider strategic context, the Bill should contribute to improved health outcomes through:

- Placing patients at the centre of the NHS
- Setting out in a clearer way what patients can expect from the NHS
- Introducing a treatment time guarantee.

15. The Patient Rights Bill also contributes to the Scottish Government's Strategic Objective of a Healthier Scotland and contributes to the following National Outcomes:

- We live longer, healthier lives
- Our public services are high quality, continually improving, efficient and responsive to local people's needs.

16. It will also contribute to meeting the targets set by the following National Indicators and Targets:

- Improve people's perceptions of the quality of public services delivered
- Improve the quality of the healthcare experience
- Achieve annual milestones for reducing inpatient or day case waiting times, culminating in delivery of an 18 week referral to treatment time from December 2011.

**Consultation**

17. **Within government:**
There has been ongoing consultation with Scottish Government officials, particularly in the Health Directorates, on the principles, provisions and structure of the Bill. There has also been close collaboration with the Scottish Government Legal Department and the Office for the Scottish Parliamentary Counsel. This process is ongoing.

18. **Public consultation:**
A public consultation on a Patients' Rights Bill for users of the NHS in Scotland took place from September 2008 until January 2009. The Scottish Government sought to ensure that the consultation documents were widely circulated, hard copies were sent out where required, in addition to the document being available online, and there was an easier read version of the consultation document available.

19. An external company was used to set up eight focus groups as well as two national events. Funding was also offered to NHS Boards to hold local consultation events. Officials working on the Patient Rights Bill attended and spoke at a number of these local meetings, as well as the two national events. It is estimated that approximately 800 people attended meetings on the Patient Rights Bill.
20. The response to the consultation included 230 written submissions and the findings from the meetings and focus groups. These were analysed and reported on by the external company that set up the focus groups and the two national events, as well as being considered by Scottish Government officials.

21. The following documents were published on 17 June 2009:
- Research Findings: http://www.scotland.gov.uk/Publications/2009/06/10131718/0


23. **Ongoing stakeholder engagement:**
Since the consultation closed the Scottish Government has continued to engage with stakeholders on the development of the Patient Rights Bill. It has been an agenda item at a number of NHS staff/Scottish Government meetings and officials have spoken on the Bill and answered questions. Officials have also proactively arranged meetings, including with professional organisations, community health partnerships, NHS staff, and the third sector, to inform the development of the Bill. This process is ongoing.

**Options**

**Option 1 - Do nothing**

24. With this option there would be no treatment time guarantee for eligible patients (planned or elective care as an inpatient or day case). The opportunity to facilitate a mutual NHS in Scotland, where patients and NHS staff would work together in partnership and patients would be involved in decisions about their care and treatment, would be lost. Patient Rights Officers would not be available to support patients.

25. This option represents the baseline against which other options will be assessed. The costs and benefits of this option are therefore zero.

**Option 2 - Deliver a Patient Rights Bill**

26. This Bill will facilitate partnership working in NHS Scotland between patients and staff. It will facilitate improving patients’ health and health experiences by letting them know what they can expect from the NHS and, in turn, what the NHS expects from them. It will also help to reinforce and strengthen the Scottish Government’s
commitment to place patients at the centre of the NHS in Scotland and it will legislate for a treatment time guarantee.

27. The Bill will give patients the right to make complaints and will legislate for a Patient Advice and Support Service (PASS), with a staff of Patient Rights Officers to provide support and assistance to patients in finding out about and exercising their rights.

Costs and benefits

28. It should be noted that the benefits described in the following pages do not represent direct financial gains to NHS Scotland. Rather, they are an expression of the benefits of the Bill in monetary terms. The Bill also has significant social and health benefits, which are described below, but which are not easily quantifiable in monetary terms.

29. A full and detailed methodology for this Regulatory Impact Assessment can be found at Annex A.

Rights and Principles

Benefits

30. This part of the Bill sets out rights and principles in the delivery and receipt of health care. It aims to encourage a partnership between patients and staff. By increasing patients’ involvement in health care provision, confidence in the NHS, and understanding of their rights and responsibilities, broad impacts are foreseen. Some of these impacts it has been possible to assess quantitatively, while other benefits are social in nature, or are more difficult to quantify.

31. The overall monetary benefits associated with Rights and Principles are estimated at between £0.19 million and £1.9 million, as shown in the table below.

<table>
<thead>
<tr>
<th>Impact</th>
<th>Low estimate</th>
<th>High estimate</th>
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<tbody>
<tr>
<td>Reduced missed appointments</td>
<td>£0.19 million</td>
<td>£1.9 million</td>
</tr>
<tr>
<td>More efficient use of resources</td>
<td>Not assessed quantitatively</td>
<td>Not assessed quantitatively</td>
</tr>
<tr>
<td>Sub-total</td>
<td>£0.19 million</td>
<td>£1.9 million</td>
</tr>
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</table>

32. Detailed methodology and discussion behind the calculation of the costs and benefits associated with Rights and Principles (where this has been worked out quantitatively) can be found at Annex A.

33. The Scottish Government anticipates 6 broad impacts:

- A potential reduction in the number of missed appointments. This will arise through two channels. Firstly, more patient focus and greater partnership between patients and staff should ensure that the timing of appointments is more suitable to the requirements of the patients. This will make attending
appointments less costly to patients in terms of opportunity costs; secondly, a greater partnership and understanding of their responsibilities by patients should result in patients making greater effort to attend appointments. Both these effects should result in an increase in attendances.

- **A more efficient use of health resources.** Greater partnership and understanding of their responsibilities should also mean that patients are more likely to notify the appropriate health bodies when they know in advance that they will be unable to attend a scheduled appointment. Patients will also have a greater incentive to cancel appointments as they will know that the official measurement of time spent waiting could revert to zero should they miss an appointment without cancelling in advance, and so they could risk incurring longer wait times, where this applies. These factors should result in a reduction in the number of missed appointments through the formal cancellation of appointments that would otherwise have been missed. Knowing about these cancellations in advance will allow health services to reorganise their resources to provide better care to patients.

- **An improvement in the respect and dignity between staff and patients.** We anticipate that making patients feel more involved in the healthcare process, and giving them a clearer understanding of the rights of staff, may result in staff being treated with more respect by patients.

- **Greater emphasis on the patient as an individual.** We anticipate that the greater emphasis on a patient’s individual needs, combined with working in partnership with patients, will contribute over the long term to improved patient experience and increased patient satisfaction and participation in their own health care, as well as a greater sense of ownership of the NHS for everyone in Scotland.

- **Greater emphasis on appropriate communication and information.** We have developed rights and principles on areas such as communication and participation. Research tells us, for example, that tailoring information to patients’ needs and characteristics is important\(^1\). For example, this might include focusing on patient requirements from information gathered from the patient, rather than from clinician expectation of what is important.\(^2\) We anticipate that this could lead to long term gains to patients’ confidence and a better experience for those living with long term conditions.\(^3\)

**Sub-total of benefits**

34. The overall monetary benefits associated with Rights and Principles are estimated at between £0.19 million and £1.9 million (see Annex A for further detail). In

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\(^3\) For example, in patient-clinician interactions, there is evidence that the sharing of the patient’s actual experience, as well as knowledge of their social circumstances may contribute to a more successful management of illness. Coulter A, Ellins J. *Patient-focused interventions: a review of the evidence*. London: Health Foundation, 2006.p.60
addition to these monetary benefits there is also the benefit of more efficient use of resources, greater emphasis on the patient as an individual and greater emphasis on appropriate communication and information. These benefits have not been assessed quantitatively. Nevertheless, we might speculate that an underpinning through the Bill of improved patient participation and appropriate communication could lead over time to an increase in a better understanding of health care and treatment, better self-care and a reduction of complaints in this area, leading to a reduced burden on services and potential cost savings, as well as the social benefits to the patient and the NHS in Scotland.

Costs:
35. The costs for the general framework of rights and responsibilities relate to the education of staff and patients on the rights in the Bill as well as public information awareness raising. The costs for these activities are:

Table 2 - Staff education and development costs (outturn prices)

<table>
<thead>
<tr>
<th>Activity</th>
<th>2010-11 Costs</th>
<th>2011-12 Costs</th>
<th>2012 - 13 Costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Planning and specification*</td>
<td>-</td>
<td>800,000</td>
<td>800,000</td>
</tr>
<tr>
<td>Scoping study</td>
<td>60,000</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Communications and awareness raising</td>
<td>34,000</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td><strong>Sub-total</strong></td>
<td><strong>94,000</strong></td>
<td><strong>800,000</strong></td>
<td><strong>800,000</strong></td>
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</tbody>
</table>

*A cost of £25,000 for Planning and Specification is incurred in 2009-10.

Table 3 - Public awareness raising costs (outturn prices)

<table>
<thead>
<tr>
<th>Activity</th>
<th>2010-11 Costs</th>
<th>2011-12 Costs</th>
<th>2012 - 13 Costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consultation with stakeholder organisations</td>
<td>2,500</td>
<td>60,000</td>
<td>10,000</td>
</tr>
<tr>
<td>Draft &amp; test public information</td>
<td>15,500</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td><strong>Sub-total</strong></td>
<td><strong>18,000</strong></td>
<td><strong>60,000</strong></td>
<td><strong>10,000</strong></td>
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36. For staff education and development, costs are lower in the first year as this represents a lead-in period, with full costs being incurred in the following years.

Costs and benefits – Treatment Time Guarantee

Benefits
37. This part of the Bill will provide eligible patients with a 12 weeks treatment time guarantee (TTG) from agreement to treatment to the start of treatment. It is intended that eligibility and exclusions will be dealt with in secondary legislation. We expect the TTG to cover approximately half a million patients a year. Detailed methodology and discussion behind the calculation of the costs and benefits of the impacts (where this has been worked out quantitatively) can be found at Annex A. Two main impacts expected are:

- **Reduced waiting times.** Eligible patients currently waiting more than 12 weeks will directly benefit from receiving treatment within the new guaranteed timescale; and
- **Reduced uncertainty.** Patients will have greater certainty regarding how long they will need to wait to receive treatment.

### Sub-total of benefits

The overall benefits associated with the treatment time guarantee in the Bill are therefore estimated at between £1.01 million and £5.345 million, as shown in the table below. It should be noted that these do not represent financial gains to NHS Scotland. Rather, they are an expression of the benefits to patients of the treatment time guarantee in monetary terms.

<table>
<thead>
<tr>
<th>Impact</th>
<th>Low estimate</th>
<th>High estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reduced waiting times</td>
<td>£0.01 million</td>
<td>£0.045 million</td>
</tr>
<tr>
<td>Reduced uncertainty</td>
<td>£1.0 million</td>
<td>£5.3 million</td>
</tr>
<tr>
<td><strong>Sub-total</strong></td>
<td><strong>£1.01 million</strong></td>
<td><strong>£5.345 million</strong></td>
</tr>
</tbody>
</table>

### Costs

38. The introduction of the treatment time guarantee will not introduce an additional financial cost on Scottish Government budgets, as it is to be funded by NHS boards through existing monies.

39. It is difficult to directly assess the costs to NHS Boards of earlier treatment. In an attempt to approximate for these costs, an assumption has been made that bringing forward treatment will increase the costs to the boards of treating patients waiting in excess of the 12 weeks by between 10%-20%. Due to the small number of patients waiting more than this period, the costs involved are small, with the high cost estimate at less than £150,000 per year across Scotland. The costs are shown in the table below, on the basis that there are approximately 325 patients currently waiting longer than 12 weeks affected by the treatment time guarantee at an average cost of £2,000 each.

<table>
<thead>
<tr>
<th>Activity</th>
<th>Low estimate</th>
<th>High estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bringing forward</td>
<td>£71,500</td>
<td>£143,000</td>
</tr>
<tr>
<td>treatments</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Sub-total</strong></td>
<td><strong>£71,500</strong></td>
<td><strong>£143,000</strong></td>
</tr>
</tbody>
</table>
Costs and benefits – Support and Right to make Complaints

Benefits

40. This section of the Bill covers the Patient Advice and Support Service and Patient Rights Officers.

41. The Bill will legislate for a Patient Advice and Support Service (PASS), to be staffed by Patient Rights Officers (PROs). Health Boards will also be obliged to inform patients about the support they can receive from the Patient Advice and Support Service, and PROs will have a duty to signpost patients to further sources of support where appropriate, such as advocacy services, to ensure that those who need it have the appropriate support to access their rights.

42. We anticipate that there will be social benefits to legislating for an advice and support service, and we can speculate that over time, there may also be some cost savings and reduction in administrative burden on health services involved, if, for example, an effective advice and support service leads to a reduction in complaints.

Table 6 - Benefits associated with Support

<table>
<thead>
<tr>
<th>Impact</th>
<th>Low estimate</th>
<th>High estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Improved healthcare experience and public satisfaction with the NHS.</td>
<td>Not assessed quantitatively</td>
<td>Not assessed quantitatively</td>
</tr>
<tr>
<td><strong>Sub-total</strong></td>
<td><strong>N/A</strong></td>
<td><strong>N/A</strong></td>
</tr>
</tbody>
</table>

Costs:

43. Support for patients will be provided through improvements to a number of means of patient support, which support the principles in the Bill. Costs are shown below.

Table 7 - Costs associated with Support (outturn prices)

<table>
<thead>
<tr>
<th>Activity</th>
<th>Costs</th>
<th>Activity</th>
<th>Costs</th>
<th>Activity</th>
<th>Costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>National procurement of Patient Advice and Support Service</td>
<td>-</td>
<td>Patient Advice and Support Service</td>
<td>1,116,000 (New SG funding)</td>
<td>Patient Advice and Support Service</td>
<td>1,116,000 (New SG funding)</td>
</tr>
<tr>
<td>Investment in development of Translation, Interpreting and Communication Support Services</td>
<td>250,000</td>
<td>Investment in development of Translation, Interpreting and Communication Support Services</td>
<td>250,000</td>
<td>Investment in development of Translation, Interpreting and Communication Support Services</td>
<td>250,000</td>
</tr>
<tr>
<td>Investment in development of advocacy services</td>
<td>500,000</td>
<td>Investment in provision of advocacy services</td>
<td>500,000</td>
<td>Investment in provision of advocacy services</td>
<td>500,000</td>
</tr>
<tr>
<td><strong>Sub-total</strong></td>
<td><strong>750,000</strong></td>
<td><strong>Sub-total</strong></td>
<td><strong>1,866,000</strong></td>
<td><strong>Sub-total</strong></td>
<td><strong>1,866,000</strong></td>
</tr>
</tbody>
</table>
44. Further details on the costs associated with the Patient Advice and Support Service and Translating, Interpreting and Communication Support Services are provided in Annex A.

45. The Bill will establish a right to make complaints. It will revoke and restate existing legislation to strengthen the complaints processes. It will legislate for a principle of feedback. Through secondary legislation and directions, we aim to amend the collection, quality and overview of information to address concerns raised elsewhere about patient complaints/feedback and the use of that information.

46. Establishing greater understanding of a patient’s right to complain may increase the number of complaints; however, a greater patient focus and involvement in the health care process could increase patient satisfaction and reduce the number of complaints.

**Small/Micro Firms Impact Test**

47. It is not expected that the proposals in the Patient Rights Bill will have a direct or immediate impact on small or micro businesses. However, in the long-term, the proposed treatment time guarantee may result in some positive impact on all businesses, as employees who are absent from work due to illness may be treated earlier as a result of the treatment time guarantee and will therefore be able to return to the workplace earlier.

48. Although the use of private sector health care will be an option available to Health Boards to ensure the treatment time guarantee is met, its use is expected to be minimal. There may also be some members of the public in Scotland who currently make use of health care in the private sector for inpatient and day case treatments, who choose to use the NHS instead because of the treatment time guarantee and other measures within the Bill which are intended to improve the services provided by the NHS. However, it is expected that this will be minimal since most people who use private sector health care in Scotland do so because medical insurance is provided as part of their employment package.

**Legal Aid Impact Test**

49. We sought to look into whether there would be some impact on legal aid if, as a result of an improved complaints system and better support, more people complain which could lead to an increase in the absolute number that are then taken forward as medical negligence cases. It is important to note, however, that medical negligence cases are usually separate from complaints and an increase in pressure on the legal aid budget would be largely dependent on an increase in medical negligence itself.

**“Test Run” of business forms**

50. Currently there is no intention to introduce new forms as a direct result of the Patient Rights Bill.

**Competition Assessment**

51. It is unlikely that the Patient Rights Bill will have an impact on competition. See Annex B.
Enforcement, sanctions and monitoring

52. The aim is to introduce legislation in 2010. Delivery will be undertaken by NHS Boards, although certain aspects will be taken forward by the Scottish Government and third party organisations.

53. Compliance with patient rights legislation will be monitored through a number of existing or soon to be established measures outwith the Bill. These include the Participation Standard, which NHS Boards in Scotland will have to meet from April 2010 to show that they are involving the people who use their services. This Standard focuses on three key areas: Patient Focus; Public Involvement; and Corporate Governance of Participation.

54. Better Together: Scotland’s Patient Experience Programme will provide a measure of progress against the delivery of patient focussed services by Health Boards, which reflect the principles raised in the Bill. Results from the patient experience surveys will be published by different equality strands where it is statistically valid to do so.

55. As part of the Scottish Government’s work developing the Quality Strategy for NHS Scotland, a range of measures are being explored that will demonstrate improvements in the delivery of patient focused care; these include the possibility of using a Patient-reported outcome measures (PROMS)-based approach.

56. It is intended that the contract specification for the Patient Advice and Support Service, which will be drawn up by the Common Services Agency, will include details of how the service will be monitored and the statistical information that NHS Boards should receive from the service, which will include equality monitoring. Currently, the Scottish Health Council has a role to monitor the existing Independent Advice and Support Service and it is envisaged that this role will continue for PASS.

57. It will be the responsibility of Health Boards to ensure and monitor the delivery of the 12 weeks treatment time guarantee. There is no financial penalty should a breach of the treatment time guarantee occur, rather the emphasis is on how the situation will be rectified. Health Boards are obliged to ensure that the patient is provided with an explanation for the delay, information about the Patient Advice and Support Service and the complaints process and confirmation that they will begin treatment at the next available opportunity. The Scottish Government also monitors Boards’ delivery of waiting times standards and targets. This will also apply to the treatment time guarantee.

Implementation and delivery plan

Implementation

58. The intention is that Scottish Ministers will issue guidance to Health Boards setting out the details of implementation of the Bill. The Bill will provide that Health Boards have a duty to follow this guidance.

59. An implementation plan is being developed for the Bill as introduced to Parliament.; the plan will cover staff training, patient and public awareness, the advice
and support service and Patient Rights Officers, advocacy funding and funding for translation, interpreting and communication to support patients.

**Post-implementation review**

60. The effects that the Bill has on patients’ experiences of the NHS will be monitored, for example through *Better Together*: Scotland’s Patient Experience Programme.

61. The effects of the Bill will also be monitored through the “Participation Standard”, which NHS Boards in Scotland will have to meet from April 2011 to show that they are involving the people who use their services.

62. Waiting times will be monitored to ensure that NHS Boards are complying with the treatment time guarantee for inpatients and day cases, see the Enforcement section, above.

**Summary and recommendation**

63. The results of the Patient Rights Bill Cost-Benefit appraisal are summarised below. The high and low ‘net benefits’ figures have been calculated using the high benefits against the low costs, and the low benefits against the high costs respectively; they therefore represent ‘best case’ and ‘worst case’ scenarios respectively. The ‘benefits: costs ratio’ shows the return on each £1 spent. For more detailed analysis and methodology behind these conclusions, please see Annex A.

64. It is clear that there are significant benefits associated with the Bill. However, in the ‘worst case’ scenario, the monetized net benefits are negative. This must be weighed against the significant positive social benefits associated with the Bill, which cannot be estimated in monetary terms. These provisions will not only improve patient experience of the NHS in Scotland, but will contribute to improved health in Scotland overall, as well as lead to more efficient use of resources and the improved quality of the health care experience and better support for patients.

65. Furthermore, a relatively conservative ten year period has been used for the appraisal. As costs are incurred upfront whilst benefits accrue over time, if a longer time period were to be used for the appraisal, the scale of net benefits would become increasingly large.

66. Table 8 shows the total costs and benefits over a ten year period. Again, it should be noted that these are not primarily financial impacts to NHS Scotland but overall social costs and benefits expressed in monetary terms. These have been adjusted over time using the methodology set out in Annex A. As is consistent with HM Treasury’s *The Green Book*, more importance has been attached to costs and benefits occurred in the short term.
Table 8 - Summary of costs and benefits over the appraisal period of ten years (discounted 2008-09 prices)

<table>
<thead>
<tr>
<th></th>
<th>Low estimate</th>
<th>High estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Rights and Principles</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Benefits</td>
<td>£1,225,000</td>
<td>£12,254,000</td>
</tr>
<tr>
<td>Costs</td>
<td>£1,691,000</td>
<td>£1,691,000</td>
</tr>
<tr>
<td><strong>The Treatment Time Guarantee</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Benefits</td>
<td>£10,129,000</td>
<td>£50,643,000</td>
</tr>
<tr>
<td>Costs</td>
<td>£479,000</td>
<td>£958,000</td>
</tr>
<tr>
<td><strong>Support</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Benefits</td>
<td>Not assessed quantitatively</td>
<td>Not assessed quantitatively</td>
</tr>
<tr>
<td>Costs</td>
<td>£12,737,000</td>
<td>£12,737,000</td>
</tr>
<tr>
<td><strong>Overall</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Benefits</td>
<td>£11,354,000</td>
<td>£62,896,000</td>
</tr>
<tr>
<td>Costs</td>
<td>£14,907,000</td>
<td>£15,386,000</td>
</tr>
<tr>
<td>Net Benefits</td>
<td>-£4,032,000</td>
<td>£47,989,000</td>
</tr>
<tr>
<td>Benefits: costs ratio</td>
<td>0.7</td>
<td>4.2</td>
</tr>
</tbody>
</table>

67. As has been discussed in this assessment, the impacts of the Patient Rights Bill (Scotland) remain uncertain. This is natural given the innovative nature of the Bill, which makes drawing lessons from other health services, either in the UK or the rest of the world, difficult.

68. The approach to assessing benefits has, therefore, erred on the side of caution. Nonetheless, despite this cautious approach, the benefits assessed for the Bill are significant, at up to £7.3 million per year (see table 12, Annex A), and a present value of £62,896,000 over the ten year appraisal period. In addition to these monetary benefits, there are equally significant non-monetary benefits such as the improved health care experience for patients. These benefits need to be viewed in the context of the numbers benefitting, with more than 400,000 patients covered by the treatment time guarantee and all patients benefitting from the rights set out in the Bill. It should be noted that these do not represent financial gains to NHS Scotland; rather, they are an expression of the benefits to patients of the Bill in monetary terms.

69. The costs of the Bill will take several years to be fully incurred, as new staff are trained and support services such as the Patient Advice and Support Service further bedded in. They are expected to amount to a present value of £15,386,000 over the appraisal period. This figure needs to be viewed in the context of the health budget, approximately £11.3 billion per year.

70. Overall, the net impact of the Bill is uncertain. The analysis indicates that the monetized elements of the Bill provide net benefits with a range of -£4,032,000 to £47,989,000. Given this range, it is highly likely that the Bill will deliver significant positive benefits, particularly when the non-monetized benefits, such as the improved patient experience, are considered. In order for the overall impact of the Bill to be
positive in the worst case scenario, the social and health benefits to the people of Scotland would have to be valued at approximately 10 pence per year by each person in Scotland, which is again highly likely.

71. It is therefore recommended that a Patient Rights Bill, as set out in option 2, be delivered in Scotland.

Declaration and publication
72. I have read the Regulatory Impact Assessment and I am satisfied that the benefits justify the costs.
ANNEX A
COST AND BENEFITS ANALYSIS - DETAILED METHODOLOGY

1. This annex sets out in detail the methodology behind the calculation of the costs and benefits of the impacts, both direct and indirect, of the Patient Rights (Scotland) Bill.

2. It is important to note that the Patient Rights (Scotland) Bill introduces a significant change to the NHS in Scotland reinforcing and strengthening the Scottish Government’s commitment to place patients at the centre of the NHS in Scotland as part of facilitating a truly mutual NHS. It represents a new concept in the delivery of health services, not just in the UK, but to a degree in the world as a whole. Very few countries have introduced such an approach, although many are now considering it. Due to differences in the rights covered by those countries that have introduced Patient Rights legislation and the Scottish Bill it is difficult to infer from elsewhere the potential impacts that may occur in Scotland. It must therefore be recognised that any discussion of the benefits, and indeed costs, of the Patient Rights (Scotland) Bill takes place in an environment of uncertainty. It is inappropriate to attempt to produce spuriously accurate predictions of any future costs and benefits, and the figures presented here reflect this inherent uncertainty.

3. All monetary figures presented below are in 2008-09 prices unless otherwise stated. Where costs and benefits have been converted between years, HM Treasury’s GDP deflator has been used to adjust for differences in prices between years. Benefits relating to health or which are income-contingent have been grown by 2% per year in real terms, in line with standard practice in health appraisal4. Healthcare costs have been grown in real terms in line with the Personal Social Services Research Unit (PSSRU) hospital and community services pay and price index5.

Benefits

Option 1 – Do Nothing

4. This option represents the baseline against which other options will be assessed. The benefits of this option are therefore zero.

Option 2 – Introduction of the Patient Rights (Scotland) Bill

5. For the purposes of this assessment the Bill has been divided into four areas:

- Rights and Principles
- The Treatment Time Guarantee
- Support
- Right to make complaints

The benefits of each part are assessed below.

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4 Department of Health (2004), Policy Appraisal and Health
5 PSSRU (2008), Unit costs of health and social care 2008.
Rights and Principles

- A potential reduction in the number of missed appointments.
- A more efficient use of health resources.
- Improvements in the respect and dignity between staff and patients.

Reduction in the number of missed appointments

6. Currently there is no central collection of data on the number of missed appointments in NHS Scotland as a whole. The area for which official data is available relates to outpatients. Outpatient data is reported in SMR00\(^6\), and has recently been summarised in a useful form in a Scottish Parliamentary Question\(^7\). This gives a figure of 162,285 missed first patient appointments in the financial year 2008-09. Other unofficial data sources come from surveys undertaken by other bodies; for example, a survey by the BBC\(^8\) in 2005 suggested that approximately one million GP appointments and half a million nurses appointments were missed in Scotland in that year. According the BBC article, the British Medical Council estimated this to have a cost of £21 million. Since the level of missed appointments in the outpatients data has remained broadly constant over this time, it may be reasonable to assume that the level of missed GP and nurse appointments has also been maintained, although there is no evidence to inform this issue.

7. Due to difficulties in establishing any change in missed GP and nurse appointments since 2005, in establishing whether there is any double counting between the missed nurse appointments and the missed outpatient appointments, and in verifying the costs assigned by the British Medical Council, only the figures relating to the outpatients have been used in the estimate produced below. The figures presented below are therefore a relatively conservative estimate of the overall benefit to NHS Scotland as a whole.

8. The average cost of an outpatient appointment in 2008/09 was £112\(^9\). Assuming that there is no relationship between the type of appointments which are missed and the cost of the appointment, this suggests that a 1% reduction in the number of missed outpatient appointments would deliver benefits of £180,000 per year; a 10% reduction would deliver benefits of £1.8 million per year. Although a 10% reduction may be viewed as somewhat optimistic, given that data limitations have resulted in the exclusion of considering missed appointments in other healthcare services such as GP practices and inpatients appoints, the figure of £1.8 million is likely a reasonable estimate of the benefit of fewer missed appointments in NHS Scotland as a whole.

9. Consideration also needs to be given to the potential benefits in future years. Although the percentage rate of missed outpatient appointments has declined slightly over the past decade, the numbers of missed appointments has been increasing as the overall number of cases increases. It is reasonable to assume that the overall number of missed appointments will continue to increase. For the purposes of the

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\(^6\) Scottish Morbidity Record 00
\(^7\) Scottish Parliament written answer, 14 September 2009, S3W-26533
\(^8\) http://news.bbc.co.uk/1/hi/scotland/4178590.stm, accessed 10\(^\text{th}\) November 2009
\(^9\) Scottish Health Services Costs (Cost Book) 2008-09 – Executive Summary
assessment, the number of missed appointments has been assumed to increase in line with patient numbers. Activity data for the past five years suggest that patient numbers have been increasing in total by approximately 0.8% a year. Adjusting for expected patient numbers and costs in 2010/11, the expected benefits from fewer missed appointments have been estimated at £0.19 million and £1.9 million per year. The cost of each missed appointment is assumed to remain constant in real terms, which is a conservative assumption as potential cost savings are being measured.

More efficient use of resources
10. Calculation of the benefits of the more efficient use of resources due to advanced knowledge of cancellations is challenging as it is difficult to predict what each individual hospital or care provider would choose to divert these resources to, which will be determined by the clinical needs of the current patients. It will also depend on how much notice is given and therefore the impact on other patients. One possible approach would be to assume that the alternative tasks undertaken would be at least as valuable as the cancelled appointment, otherwise the resources would have been devoted to this alternative to begin with. There are several drawbacks with this approach. Firstly, it assumes that healthcare resources are perfectly substitutable between different specialities, which is unlikely to be the case; secondly, it assumes that resources are allocated purely on a clinical basis, which again is unlikely to be the case as other constraints, such as the availability of staff or facilities, performance targets, and financial concerns will all be considerations; finally, the approach risks double counting the benefits associated with reduced numbers of missed appointments, as it is again based on the cost of the appointment which was missed.

11. As no satisfactory method could be derived for valuing these benefits, they have not been included in the assessment of monetary costs and benefits; however, they are still relevant to the assessment of the Bill’s overall worth.

Improvements in the respect and dignity between staff and patients
12. We consider that an increased awareness of patients’ rights and responsibilities will bring an improvement in the respect and dignity afforded by both patients and staff. At the extreme end of lack of respect, assaults on staff can occur.

13. Records on the number of NHS Scotland staff who are assaulted are not held centrally, but are maintained by the local NHS Board. UNISON Scotland performs an annual survey of the Boards as part of their annual report on violent assaults on public sector staff. The most recent report provides data for 2008-09. Only eleven of the fourteen territorial NHS Boards submitted data, so it therefore contains a conservative estimate of the total number of assaults, especially since not all assaults on public sector staff are reported to the police it is unlikely that they would be formally recorded.

14. The Home Office has produced a measure of the economic and social costs of crime, which assigns costs to fifteen different categories of crime. The UNISON report does not disaggregate the assaults into these categories, and since not all assaults on public sector staff are reported to the police it is unlikely that they would be

10 Costs Book 2008/09, and estimated patient contacts from Practice Team Information, ISD Scotland.
12 Home Office (2005), The economic and social costs of crime against individuals and households, Home Office Online Report 30/05.
recorded in a manner which allows them to be easily compared to the Home Office categories. As such, a degree of judgement has had to be applied in converting the number of assaults to a usable format. The average values for broad categories of assaults have been taken from the Home Office report, ‘violence against the person’ at £10,407 per crime and ‘common assault’ at £1,440; these figures are in 2003-04 values and prices. It has been assumed that 50% of assaults fall into each category; although the evidence base is weak in this area this is supported by some evidence from (the then) Greater Glasgow board which suggested that the two were of equal proportion. This implies an average cost per assault of £5,924. These costs cover the fear of crime, physical and emotional costs resulting from the crime itself, and health and justice costs. Individual elements of each of these components could be criticized when it comes to applying them in a health care setting; for example, as stated above, many staff assaults are not reported to the police, so police costs may not be a relevant concern; also, since the assaults occur within a health care environment, overall health care costs may be lower, as costs such as ambulance callouts may be avoided. In counter to these criticism, it can be argued that although not all staff assaults are reported to the police, they are still formally reported within the NHS, and so there are administration costs associated with such assaults; furthermore, if only a proportion of assaults are being reported to the police, it may well be that these assaults are the more serious ones, and so the police costs for dealing with them may be higher than average; as regards health care costs of crime, it is arguably unethical for society to assign a lower cost of crimes to assaults against health care workers than against other members of society merely because they may occur within a health care environment; finally, due to the incidence of assaults on frontline hospital staff, it may be that healthcare workers suffer from a greater anticipatory fear of crime. Taking these arguments collectively, the values from the Home Office report have been left unadjusted.

15. The Home Office report gives values for 2003-04. These have been converted to 2008-09 prices using the GDP deflator series published by HM Treasury; the values have been further uplifted to 2008-09 values by 2% a year under an assumption that the costs will increase in line with real income, which is a standard assumption in the valuation of road accidents and health benefits.

16. Again, due to uncertainty over the impact of the Bill, a range of potential benefits is used. Here, the uncertainty reflects not only the impact of the Bill but also the valuation of the impact. The benefits of reducing assaults by between 1% and 10% are estimated at £1 million to £5 million per year. Although the 10% figure may appear high, it needs to be remembered that it is applied to an incomplete measure of the total number of assaults.

17. The values shown here use the number of assaults that occurred in 2008-09 as the basis for calculations. The relevant measure for the assessment is the expected number of assaults that would occur in the years once the Bill has been introduced. This can be estimated by looking at the recent trends in assaults on public sector staff.

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13 NSH Greater Glasgow (2005), Staff News, Issue 16
14 GDP deflator as published 29th September 2009.
15 See Department for Transport, WebTAG, Unit 3.4.
16 Department of Health (2004), op cit.
The UNISON data\textsuperscript{17} indicates that overall assaults in health have remained unchanged over the last seven years, but this masks significant variations, with a sharp increase up to a peak of 2006-07 followed by a sharp decrease to the latest figures. This recent decline is supported by the latest NHS Scotland Staff Survey\textsuperscript{18}, which indicates that the number of staff experiencing a violent or aggressive incident had declined by 10\% since 2006. A decline in the number of assaults by 2010-11, when the Bill comes into force, might therefore be expected.

18. Given the recent evidence of a downward trend in the number of assaults, a 5\% a year reduction has been assumed as the baseline for the analysis. This is slightly lower than the 10\% a year decline in the two years since 2006-07, for the following reasons. Firstly, although health assaults have been declining, this is from a very high level, and such dramatic reductions may well not be maintained. Secondly, the decline in assaults on health staff goes against the general trend suggested by the UNISON data of increasing assaults on public sector staff. Since the drivers of the numbers of assaults are not well understood, it is difficult to be sure that the numbers of assaults in health will continue to go against this trend. Finally, some of the decline in assaults may have been caused by legislation and campaigns to reduce assaults on staff; since the Patient Rights Bill will support these campaigns by improving patients’ understanding of their responsibilities toward staff, it would be inappropriate to include these impacts in the baseline, as it would underestimate the benefits associated with the Bill.

19. Adjusting for the expected decline in the numbers of assaults, therefore, the benefits from reduced assaults in 2010-11 has been calculated at between £1.0 million and £4.8 million. It should be noted that these are socio-economic welfare impacts and do not represent potential financial costs borne by the NHS.

20. Due to the difficulty in establishing a baseline for assaults in NHS Scotland, and in establishing a direct causal link between the Bill and numbers of assaults, these figures are not included in the overall benefits of the Bill. They should therefore be viewed as illustrative of the potential benefits should the Bill in fact result in such a reduction.

\textbf{Sub-total of benefits}

21. The overall monetary benefits associated with Rights and Principles are therefore estimated at between £0.19 million and £1.9 million, as shown in the table below. In addition to these monetary benefits there is also the benefit of more efficient use of resources, which has not been assessed quantitatively.

\textsuperscript{17} See UNISON (2006), Violence survey report 2006; and follow up surveys in 2007 and 2008.

\textsuperscript{18} NHSScotland (2008), \textit{Staff opinion survey 2008}
Table 9 – Benefits associated with Rights and Principles (in 2010-11)

<table>
<thead>
<tr>
<th>Impact</th>
<th>Low estimate</th>
<th>High estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reduced missed appointments</td>
<td>£0.19 million</td>
<td>£1.9 million</td>
</tr>
<tr>
<td>More efficient use of resources</td>
<td>Not assessed quantitatively</td>
<td>Not assessed quantitatively</td>
</tr>
<tr>
<td>Reduced number of assaults</td>
<td>Not included</td>
<td>Not included</td>
</tr>
<tr>
<td>Sub-total</td>
<td>£0.19 million</td>
<td>£1.9 million</td>
</tr>
</tbody>
</table>

**Treatment Time Guarantee**

22. This part of the Bill will provide eligible patients with the right to a 12 week treatment time guarantee from agreement to treatment to the start of treatment. Although there will be exclusions, it is still expected to benefit around half a million patients a year. Two main impacts are expected:

- **Reduced waiting times.** Patients currently waiting more than 12 weeks will directly benefit from receiving treatment within the new guaranteed timescale; and
- **Reduced uncertainty.** Patients, regardless of the amount of time they may have spent waiting, will have greater certainty regarding how long they will need to wait to receive treatment.

**Reduced waiting times**

23. Current waiting times for inpatients and day cases are published by the Information Services Division (ISD) of NHS Scotland, on a quarterly basis. This provides overall waiting times for all specialities (excluding obstetrics and mental health); waiting times for specific specialities are not available. The most recent data\(^{19}\) indicate that only 1% of inpatients and day cases were waiting more than 12 weeks, and only 0.1% waits longer than 15 weeks. The data suggest that there are in the region of 18,000 patient days spent waiting longer than the 12 weeks target per quarter; however, this covers total inpatients and day cases, whilst only 400,000 of the approximately 1.5 million of these patients will be affected; the 18,000 number can therefore be scaled down, leaving approximately 5,000 patient days.

24. One approach to the valuation of reduced waiting times would be to argue that reducing waiting times represents a bringing forward of future consumption to the present. This is a concept typically dealt with in economics using a discount rate. The standard discount rate applied in UK government appraisals is 3.5% per year, which equates to approximately 0.1% per week. This suggests that a treatment received after 12 weeks is approximately 0.2% more valuable than one received after 15 weeks. Using an average value of an inpatient and day case treatment of approximately £2,000\(^{20}\) as the shadow price to measure the value of the treatment to

\(^{19}\) Quarter ending September 2009

\(^{20}\) Costs Book 2008-09, R042X, R040X, and R040LSX. Long stay inpatient costs have been excluded from the analysis as they are typically mental health services the majority of which are unlikely to be covered by the eligibility criteria of the TTG in the Bill and secondary legislation. Average costs data in the Costs Book is not easily broken down to eliminate particular specialities, therefore the average cost for inpatients and day cases used include some specialities such as obstetrics which will be excluded in secondary legislation. Inspection of the data, however, indicates that these specialities have costs
the patient, this suggests an annual benefit of approximately £15,000 per year. If a higher discount rate were used, under the assumption that people are willing to pay more to bring forward medical treatment than consumption of an average good, then a higher estimate could be derived, for example £30,000.

25. This discount rate, however, contains various elements which are arguably not relevant over such short timescales. As well as pure time preference, the discount rate also includes catastrophe risk (the risk that a catastrophic event may occur, such as death, that means that there would be no opportunity or benefit from receiving the treatment in the future), and an adjustment to take into account the fact that society will be wealthier in the future. Neither of these is likely to be as important over a very short timescale, which would suggest that a lower discount rate, perhaps 1%-2%, would be more appropriate. These rates would produce a range of benefits between £4,000 and £8,000 per year.

26. An alternative approach would be to directly elicit patients’ willingness to pay for reductions in waiting time. This can be done primarily through two methods, either revealed preferences, where patients’ willingness to pay for reduced waiting time is observed in a market, or through stated preferences, where preferences are elicited directly through questionnaires or similar techniques.

27. Revealed preference techniques are difficult to employ within a healthcare setting, as in most western countries healthcare is not provided in a market but is instead provided by the state. A notable exception is America, where there is a sizeable private market; however, there is little research specifically into how waiting times may affect insurance premiums. An alternative approach, similar to that adopted by the Department of Health for the valuation of providing personal care at home, might be to view waiting times as a form of uncertainty, and therefore use insurance premia themselves as a measurement of willingness to pay to reduce this uncertainty. The total payment for certainty is approximately 20% of overall health insurance costs; health care costs themselves represent the remaining 80%, and therefore the payment for certainty is approximately 25% of total healthcare costs. This approach has its drawbacks, however, as it covers all forms of uncertainty rather than those relating specifically to waiting times; the 25% figure would therefore very much represent an upper bound on the potential benefits. By focussing on uncertainty as a proxy, it also risks double-counting the benefits associated with reducing uncertainty itself.

28. Stated preference techniques also have drawbacks, as they are dependant upon the quality of the sample and measurement technique, and within a field such as health, which is relatively complicated and emotive, respondents may have difficulty in providing useful responses. The results of such studies need to be treated with a degree of caution, therefore, but still are useful. A study of Canadian, Danish, and Spanish patients suggests that total wait costs can be between 10%-25% of overall

which are similar to or below the average cost, and therefore their inclusion will not affect the conclusions of the analysis.

21 Department of Health, (November 2009), *Impact Assessment of Personal Care at Home Bill*.

treatment costs. This is for costs presented in 1991 US prices. Converting to current prices, adjusting for real income growth and differences in waiting times, and using the latest Scottish costs, this would be between 3% to 11%. An earlier study by Propper\textsuperscript{23} suggested a value at the lower end of this range, at 5%, whilst another study by Johanessen \textit{et al.}\textsuperscript{24} suggested a higher value, at between 19% and 22%.

29. Due to the wide range of results presented above, and a desire to take a cautious approach to the estimation of benefits, a range of 3% to 15% of healthcare costs has been taken as a proxy for the total cost of waiting. This suggests a cost per day of waiting of between approximately £1.90 and £9.50, which, applied to the total number of days waiting in excess of 12 weeks, suggests a benefit of approximately £10,000 to £45,000 per year. Due to the theoretical shortcomings of the discounting approach discussed above, and to maintain consistency with the calculation of benefits associated with reduced uncertainty, these figures are the preferred measure of the benefits associated with reduced waiting time.

30. One possible consequence of introducing the treatment time guarantee is that some patients with a low clinical need may experience an increase in waiting times if patients who would otherwise have been waiting more than 12 weeks are prioritised ahead of them. This impact is difficult to assess quantitatively. Firstly, it may be that no patients suffer in this manner, as depending on how health services adjust their treatment provision it may be possible that the cost is borne solely by healthcare providers rather than shared with patients; secondly, it is increasingly accepted that the context in which people receive information is extremely important\textsuperscript{25}. Therefore it is possible that, for example, a patient who would have received an offer of an eight week waiting time before the Bill would still consider themselves better off after the Bill even if their waiting time were increased to nine weeks. This is because previously they would have had no frame of reference for their waiting time, whilst after the introduction of the 12 week treatment time guarantee, patients will inevitably judge their offer of a wait time against this guarantee to some degree. Since these relativities affect people’s assessment of benefit, it may be that the knowledge that the offer of the nine week waiting time is three weeks less than the maximum they could have waited will confer a benefit great enough to offset the disutility associated with having their wait time increased from eight to nine weeks. Due to the uncertainty of this impact, therefore, it has not been quantitatively assessed.

\textbf{Reduced uncertainty}

31. It is generally accepted that people prefer certain outcomes to uncertain ones, particularly where stakes are high. Providing greater certainty in the provision of health care can therefore be expected to provide benefits in the form of a better patient experience. These benefits will accrue to all patients affected by the 12 weeks treatment time guarantee.


\textsuperscript{25} This is known as the ‘framing effect’, which was first set out in Tversky, A. & Kahneman, D., (1981), \textit{The framing of decisions and the psychology of choice}, \textit{Science}, 211, pp. 453-458.
32. The reduction in uncertainty can be viewed as resulting from the narrowing of the variability of a patient’s expected wait time. This can be proxied in a simple sense by assuming that all patients that currently wait more than 12 weeks for their treatment now wait between 9 and 12 weeks (wait time statistics are collected on the basis of three week bands). This results in a narrowing of the distribution of wait times and a reduction in the variance of wait times by approximately 4%. If the wait time of patients currently waiting fewer than 12 weeks is also affected, then depending on whether they are currently waiting more or less than the mean wait, this figure could either be increased or decreased. Due to the level of uncertainty of this impact, it has been assumed to be neutral.

33. The simplest way to value this 4% reduction in wait variability is to treat it as if it were a reduction in mean wait time. Very little evidence exists within the health field as to the relative valuation of variability and mean wait times. In other fields,\textsuperscript{26} evidence suggests that in some circumstances reductions in the variability of time can be more important than mean time reductions, with a ratio of the value of variability to mean of up to three. The only health paper which has been found to address this area is that of Propper\textsuperscript{27}, which suggests a value for this ratio close to or slightly below one. Due to the lack of a better evidence base a value of one has been assumed. As such, the two have been treated as the same with uncertainty captured through the range applied in the valuation of wait time.

34. Applying the same ranges as discussed above for the valuation of reductions in wait time to the 4% reduction in the variability of wait time suggest benefits of between £1 million and £5.3 million.

Sub-total of benefits
The overall benefits associated with the treatment time guarantee are therefore estimated at between £1.01 million and £5.345 million, as shown in the table below.

<table>
<thead>
<tr>
<th>Impact</th>
<th>Low estimate</th>
<th>High estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reduced waiting times</td>
<td>£0.01 million</td>
<td>£0.045 million</td>
</tr>
<tr>
<td>Reduced uncertainty</td>
<td>£1.0 million</td>
<td>£5.3 million</td>
</tr>
<tr>
<td><strong>Sub-total</strong></td>
<td><strong>£1.01 million</strong></td>
<td><strong>£5.345 million</strong></td>
</tr>
</tbody>
</table>

Support and the Right to make complaints

35. This covers Patient Advice and Support Service, Patient Rights Officers, and the right to make complaints.

36. The Bill will establish for the first time a right to make complaints. It will also revoke and restate existing legislation to strengthen the complaints processes. It will also legislate for encouraging feedback. It will signal to Health Boards the importance of this right to make a complaint and how information gathered through the complaints and feedback processes can aid in a continuous loop of improvement.

\textsuperscript{26}See, for example, Department for Transport, WebTAG Unit 3.5.7.

\textsuperscript{27}Op. cit
37. In terms of the wider strategic context, the Bill should contribute to improved health outcomes through placing patients at the centre of the NHS supporting the delivery of safe, high quality health care and setting out in a clearer way what patients can expect from the NHS and what their responsibilities are. This should improve the quality of the healthcare experience and the public’s perception of it. Due to difficulties in measuring these factors, they have not been assessed quantitatively.

Sub-total of benefits

<table>
<thead>
<tr>
<th>Impact</th>
<th>Low estimate</th>
<th>High estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Improved healthcare experience and public satisfaction with the NHS.</td>
<td>Not assessed quantitatively</td>
<td>Not assessed quantitatively</td>
</tr>
</tbody>
</table>

Sub-total

<table>
<thead>
<tr>
<th>Impact</th>
<th>Low estimate</th>
<th>High estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>N/A</td>
<td>N/A</td>
<td></td>
</tr>
</tbody>
</table>

Overall benefits

38. The overall benefits associated with the Bill are shown in the table below. Due to the uncertainty associated with each of these impacts, a central estimate is not presented, as this would attach spurious accuracy to a particular point estimate. The monetary benefits of the Bill are therefore estimated at between £1.2 million and £7.3 million per year, with additional non-monetary benefits relating to the more efficient use of resources and the improved quality of the healthcare experience.

Table 12 - Summary of benefits associated with the Bill

<table>
<thead>
<tr>
<th>Impact</th>
<th>Low estimate</th>
<th>High estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Rights and Principles</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reduced missed appointments</td>
<td>£0.19 million</td>
<td>£1.9 million</td>
</tr>
<tr>
<td>More efficient use of resources</td>
<td>Not assessed quantitatively</td>
<td>Not assessed quantitatively</td>
</tr>
<tr>
<td>Reduced number of assaults</td>
<td>Not included</td>
<td>Not included</td>
</tr>
<tr>
<td><strong>The Treatment Time Guarantee</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reduced waiting times</td>
<td>£0.01 million</td>
<td>£0.045 million</td>
</tr>
<tr>
<td>Reduced uncertainty</td>
<td>£1.0 million</td>
<td>£5.3 million</td>
</tr>
<tr>
<td><strong>Support</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Improved healthcare experience and public satisfaction with the NHS</td>
<td>Not assessed quantitatively</td>
<td>Not assessed quantitatively</td>
</tr>
</tbody>
</table>

Total

<table>
<thead>
<tr>
<th>Impact</th>
<th>Low estimate</th>
<th>High estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>£1.2 million</td>
<td>£7.3 million</td>
<td></td>
</tr>
</tbody>
</table>

39. For consistency with the Financial Memorandum, all figures below are given in outturn prices unless otherwise stated.
Costs

Option 1 – Do Nothing

40. This option represents the baseline against which other options will be assessed. The costs of this option are therefore zero. Failure to adopt change would, however, result in a lack of integration between the strategic vision for NHS Scotland and the delivery of healthcare services.

Option 2 – Introduction of the Patient Right (Scotland) Bill

Rights and Principles

41. This part of the Bill sets out the rights and responsibilities of both NHS staff and patients. The costs will therefore relate to the education of staff and patients as well as public information awareness raising. The costs for these activities are shown below.

<table>
<thead>
<tr>
<th>Table 13 - Staff education and development costs (outturn prices)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Activity</strong></td>
</tr>
<tr>
<td>Planning and specification*</td>
</tr>
<tr>
<td>Scoping study</td>
</tr>
<tr>
<td>Communications and awareness raising</td>
</tr>
<tr>
<td><strong>Sub-total</strong></td>
</tr>
</tbody>
</table>

*A cost of £25,000 for Planning and Specification is incurred in 2009-10.

<table>
<thead>
<tr>
<th>Table 14 - Public awareness raising costs (outturn prices)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Activity</strong></td>
</tr>
<tr>
<td>Consultation with stakeholder organisations</td>
</tr>
<tr>
<td>Draft &amp; test public information</td>
</tr>
<tr>
<td><strong>Sub-total</strong></td>
</tr>
</tbody>
</table>
The Treatment Time Guarantee

42. The introduction of the treatment time guarantee will not introduce an additional financial cost on Scottish Government budgets, as it is to be funded by NHS boards through existing monies for the 18 weeks Referral to Treatment Target.

43. It is difficult to directly assess the costs to NHS Boards of earlier treatment. In an attempt to approximate for these costs, an assumption has been made that bringing forward treatment will increase the costs to the boards of treating patients waiting in excess of the 12 weeks by between 10%-20%. Due to the small number of patients waiting more than this period, the costs involved are small, with the high cost estimate at less than £150,000 per year. The costs are shown in the table below, on the basis that there are approximately 325 patients currently waiting longer than 12 weeks affected by the waiting time guarantee at an average cost of £2,000 each.

Table 15 - Costs associated with the treatment time guarantee

<table>
<thead>
<tr>
<th>Activity</th>
<th>Low estimate</th>
<th>High estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bringing forward treatments</td>
<td>£71,500</td>
<td>£143,000</td>
</tr>
<tr>
<td>Sub-total</td>
<td>£71,500</td>
<td>£143,000</td>
</tr>
</tbody>
</table>

Support

44. Support for patients will be provided through the Patient Advice and Support Service, which will build on the current Independent Advice and Support Service. This will be supported with additional staff and other resources, and funding to other forms of support, the costs of which are shown below.

Table 16 - Costs associated with Support (outturn prices)

<table>
<thead>
<tr>
<th>Activity</th>
<th>2010-11</th>
<th>2011-12</th>
<th>Costs</th>
<th>Activity</th>
<th>2012 - 13</th>
<th>Costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>National procurement of Patient Advice and Support Service</td>
<td>-</td>
<td>Patient Advice and Support Service</td>
<td>1,116,000 (New SG funding)</td>
<td>Patient Advice and Support Service</td>
<td>1,116,000 (New SG funding)</td>
<td></td>
</tr>
<tr>
<td>Investment in development of Translation, Interpreting and Communication Support Services</td>
<td>250,000</td>
<td>Investment in development of Translation, Interpreting and Communication Support Services</td>
<td>250,000</td>
<td>Investment in development of Translation, Interpreting and Communication Support Services</td>
<td>250,000</td>
<td></td>
</tr>
<tr>
<td>Investment in development of advocacy services</td>
<td>500,000</td>
<td>Investment in provision of advocacy services</td>
<td>500,000</td>
<td>Investment in provision of advocacy services</td>
<td>500,000</td>
<td></td>
</tr>
<tr>
<td>Sub-total</td>
<td>750,000</td>
<td>Sub-total</td>
<td>1,866,000</td>
<td>Sub-total</td>
<td>1,866,000</td>
<td></td>
</tr>
</tbody>
</table>
45. It is anticipated that the Patient Rights Bill will lead to an increased demand for translation, interpreting and communication support (TICS). In light of this, the Scottish Government will provide funding of £750,000 over 3 years 2010 to 2013 to support the development of TICS services. This will be provided to NHS Health Scotland to provide support, resources and guidance materials; research on needs, procurement and service standard work; community engagement and marketing; communication events, and extended partnership work across NHSScotland.

46. Note that the £1,116,000 funding for the Patient Advice and Support Service includes £116,000 redirected from the Healthcare Policy and Strategy Directorate budget; however, it excludes funds which are already spent on patient advice and support, either by NHS Boards or the Scottish Government, as these do not represent additional expenditure in the area.

Cost-Benefit Appraisal

47. The benefits and costs outlined above can be expected to accrue over time. They therefore need to be analysed over a number of years to come to a complete assessment of the net benefits to society. This appraisal has been carried out in line with HM Treasury’s The Green Book, which sets out the procedures to be followed in government appraisals. The primary feature is that costs and benefits in the future should be discounted to represent society’s preference for receiving goods and services now rather than later.

48. The total net benefits of the Bill are therefore calculated as:

\[
\text{Net Present Value (NPV)} = \sum_{t} \frac{Benefits_{t} - Costs_{t}}{(1+r)^{t}}
\]

That is, the net benefits and costs of year \( t \), adjusted by the discount rate for year \( t \), \((1+r)^{t}\), summed over all years in the appraisal period. The standard discount rate of 3.5% has been used, with 2010/11 taken as the base year. A 10 year period has been used to measure costs and benefits.

Profile of costs and benefits

49. It is reasonable to assume that not all of the benefits associated with the Bill will be realised immediately. The following assumptions have been used to profile the benefits over time:

Costs and benefits associated with Rights and Principles and Support

50. The benefits associated with Rights and Principles and Support will rely upon support infrastructure that will take time to achieve complete penetration of public awareness. The expected profile of the benefits is set out below:
Table 17 - Profile of benefits associated with Rights and Principles and Support

<table>
<thead>
<tr>
<th>Year</th>
<th>Impact</th>
</tr>
</thead>
<tbody>
<tr>
<td>2010-11</td>
<td>Zero benefits – this year sees investment in support infrastructure in preparation for delivery;</td>
</tr>
<tr>
<td>2011-12</td>
<td>25% of expected benefits</td>
</tr>
<tr>
<td>2012-13</td>
<td>50% of expected benefits</td>
</tr>
<tr>
<td>2013-14</td>
<td>75% of expected benefits</td>
</tr>
<tr>
<td>2014-15 and onwards</td>
<td>100% of expected benefits</td>
</tr>
</tbody>
</table>

51. Once the delivery of these elements has begun therefore, in 2011/12, it is expected that benefits will be fully realised within four years.

52. The costs for these sections of the Bill follow the profiles set out in the Costs section above. They are assumed to remain constant in real terms beyond 2012/13.

Costs and benefits associated with the treatment time guarantee
53. The 12 week waiting time target is expected to be achieved by 31st March 2010; therefore, the costs and benefits for this part of the Bill are expected to accrue immediately in 2010/11. It is expected that as waiting lists are brought down, the long term costs of meeting the target will decline, as more efficient systems are developed and put in place.

Table 18 - Profile of costs and benefits associated with the treatment time guarantee

<table>
<thead>
<tr>
<th>Year</th>
<th>Impact</th>
</tr>
</thead>
<tbody>
<tr>
<td>2010-11</td>
<td>100% expected benefits – 100% expected initial costs</td>
</tr>
<tr>
<td>2011-12</td>
<td>100% expected benefits – 90% expected initial costs</td>
</tr>
<tr>
<td>2012-13</td>
<td>100% expected benefits – 80% expected initial costs</td>
</tr>
<tr>
<td>2013-14</td>
<td>100% expected benefits – 70% expected initial costs</td>
</tr>
<tr>
<td>2014-15</td>
<td>100% expected benefits – 60% expected initial costs</td>
</tr>
<tr>
<td>2015-16 and onwards:</td>
<td>100% expected benefits – 50% expected initial costs</td>
</tr>
</tbody>
</table>

Benefits have been grown in line with real incomes and costs have been grown in line with real medical service costs and patient numbers.

Appraisal results
54. The appraisal results are summarised below. The high and low ‘net benefits’ figures have been calculated using the high benefits against the low costs, and the low benefits against the high costs respectively; they therefore represent ‘best case’ and ‘worst case’ scenarios respectively. The ‘benefits: costs ratio’ shows the return on each £1 spent.

55. It is clear that there are significant benefits associated with the Bill. However, in the ‘worst case’ scenario, the monetized net benefits are negative. This must be weighed against the significant positive benefits associated with the Bill, in particular
relating to Support which cannot be estimated in monetary terms. Furthermore, a relatively conservative ten year period has been used for the appraisal. As costs are incurred upfront whilst benefits accrue over time, if a longer time period were to be used for appraisal, the scale of net benefits would become increasingly large.

Table 19 – Summary of costs and benefits over the appraisal period of ten years (discounted 2008/09 prices)

<table>
<thead>
<tr>
<th></th>
<th>Low estimate</th>
<th>High estimate</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Rights and Principles</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Benefits</td>
<td>£1,225,000</td>
<td>£12,254,000</td>
</tr>
<tr>
<td>Costs</td>
<td>£1,691,000</td>
<td>£1,691,000</td>
</tr>
<tr>
<td><strong>The Treatment Time Guarantee</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Benefits</td>
<td>£10,129,000</td>
<td>£50,643,000</td>
</tr>
<tr>
<td>Costs</td>
<td>£479,000</td>
<td>£958,000</td>
</tr>
<tr>
<td><strong>Support</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Benefits</td>
<td>Not assessed quantitatively</td>
<td>Not assessed quantitatively</td>
</tr>
<tr>
<td>Costs</td>
<td>£12,737,000</td>
<td>£12,737,000</td>
</tr>
<tr>
<td><strong>Overall</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Benefits</td>
<td>£11,354,000</td>
<td>£62,896,000</td>
</tr>
<tr>
<td>Costs</td>
<td>£14,907,000</td>
<td>£15,386,000</td>
</tr>
<tr>
<td>Net Benefits</td>
<td>-£4,032,000</td>
<td>£47,989,000</td>
</tr>
<tr>
<td>Benefits: costs ratio</td>
<td>0.7</td>
<td>4.2</td>
</tr>
</tbody>
</table>

56. Note that, for the Rights and Principles and Support and Recourse elements of the Bill, only a central cost range has been provided. This is because these costs are based on the forecast costs of service provision and there is no evidence base with which to suggest upper or lower values. In line with HM Treasury Green Book guidance on appraisal, this uncertainty has been addressed through sensitivity guidance.

57. The range of potential monetary net benefits is therefore between -£4,032,000 and £47,989,000. Although due to lack of certainty it is not possible to provide a central estimate of net benefits, it is clearly very likely that they are significantly positive, even before non-monetary benefits are included.

Sensitivity analysis

58. Standard sensitivity analysis has been carried out to investigate how much costs would have to increase to eliminate the monetary benefits identified above. In the best case scenario, costs would have to rise by in excess of 300% in order for the monetized benefits of the Bill to be eliminated.
Summary and conclusions

59. As has been discussed throughout this assessment, the impacts of the Patient Rights (Scotland) Bill remain uncertain. This is natural given the innovative nature of the Bill, which makes drawing lessons from other health services, either in the UK or the rest of the world, difficult.

60. The approach to assessing benefits has, therefore, erred on the side of caution. Nonetheless, despite this cautious approach, the benefits assessed for the Bill are significant, at up to £7.3 million per year (see table 12), and a present value of £62,896,000 over the ten year appraisal period. In addition to these monetary benefits, there are equally significant non-monetary benefits such as the potentially improved health care experience for patients. These benefits need to be viewed in the context of the numbers benefitting, with more than 400,000 patients covered by the treatment time guarantee and all patients benefitting from the rights set out in the Bill.

61. The costs of the Bill will take several years to be fully incurred, as new staff are trained and services such as the enhanced Patient Advice and Support Service are bedded in. They are expected to amount to a present value of £15,386,000 over the appraisal period. This figure needs to be viewed in the context of the health budget, approximately £11.3 billion per year.

62. Overall, the net impact of the Bill is uncertain. The analysis indicates that the monetized elements of the Bill provide net benefits with a range of -£4,032,000 to £47,989,000. Given this range, it is highly likely that the Bill will deliver significant positive benefits, particularly when the non-monetized social and health benefits, such as the improved patient experience, are considered. In order for the overall impact of the Bill to be positive in the worst case scenario, these benefits would have to be valued at approximately 10 pence per year by each person in Scotland, which is highly likely.
ANNEX B
COMPETITION ASSESSMENT

The Office of Fair Trading has formal guidance for conducting competition assessments, as set out in Completing competition assessments in Impact Assessments: Guideline for policy makers (August 2007). This sets out four areas where the impact of the Bill should be considered. That is, would the Bill:

- Directly limit the number or range of suppliers?
- Indirectly limit the number or range of suppliers?
- Limit the ability of suppliers to compete?
- Reduce suppliers’ incentives to compete vigorously?

The impact of the Bill in these areas is considered below.

Would the Bill directly limit the number or range of suppliers?
No. The supply of healthcare services, which are provided by NHS Scotland, will be unaffected.

Would the Bill indirectly limit the number or range of suppliers?
No. The supply of healthcare services by NHS Scotland is determined by clinical need, and will therefore not be indirectly affected.

Would the Bill limit the ability of suppliers to compete?
No. NHS Scotland is provided by the public sector and does not make use of internal markets to encourage competition between suppliers.

Would the Bill reduce suppliers’ incentives to compete vigorously?
No. NHS Scotland is provided by the public sector and does not make use of internal markets to encourage competition between suppliers.

Conclusion
Having answered ‘no’ to the for questions in the Office of Fair Trading Guidance, it can be stated that the Bill is unlikely to raise any competition concerns.
Equality Impact Assessment - Patient Rights (Scotland) Bill

What is the purpose of the proposed policy (or changes to be made to the policy)?

The Patient Rights (Scotland) Bill will provide that the health care which patients receive should meet certain criteria, according to a set of health care principles. We also intend to legislate for a patient advice and support service and Patients Rights Officers, to legislate for a treatment time guarantee, and establish a right to make complaints and give feedback about healthcare.

Who is affected by the policy or who is intended to benefit from the proposed policy and how?

The Patient Rights Bill will have an impact on anyone who accesses NHS services in Scotland. The Bill itself relates to patients, but it may have consequences for others such as carers, family and friends of patients. The Bill is relevant to primary, secondary and tertiary health care services.

NHS staff will also be affected by this policy, in the way in which they interact with patients, in terms of the way in which complaints are dealt with and administered and in terms of fulfilling the treatment time guarantee.

The Bill will also affect third party organisations that will have the opportunity to bid for the contract to provide the Patient Advice and Support Service, and Patient Rights Officers.

How have you, or will you, put the policy into practice, and who is or will be delivering it?

The aim is to introduce secondary legislation by way of regulations and directions.

Delivery will be undertaken by NHS Boards, primary care service providers and third parties.

Aspects will be taken forward by the Scottish Government.

How does the policy fit into our wider or related policy initiatives?

The Patient Rights Bill fits in with the Scottish Government's Strategic Objective of a Healthier Scotland and contributes to the following National Outcomes:

- We lead longer, healthier lives
- Our public services are high quality, continually improving, efficient and responsive to local people's needs.

It will also contribute to meeting the targets set by the following National Indicators and Targets:
- Improve the quality of the health care experience
- Achieve annual milestones for reducing inpatient or day case waiting times, culminating in delivery of an 18 week referral to treatment time from December 2011.

The following policy initiatives are also relevant:
Quality Strategy
Better Health, Better Care;
Better Together: Scotland's Patient Experience Programme;
Equally Well, the Report of the Ministerial Taskforce on Health Inequalities.

The Patient Rights Bill relates to the rights of a person in terms of his/her receipt of NHS care. Therefore the provisions in the Bill are in addition to other legislation relating to equality, such as the Disability Discrimination Act or the Race Relations Act, as well as the body of human rights law.

Disability

Evidence
20% of people in Scotland have a disability according to the definition of the Disability Discrimination Act 1995 (Office for National Statistics – Census Results – 2001). This definition covers a wide range of impairment types and conditions and as such it is important to recognise that disabled people are not a homogenous group and will have a wide range of needs and experiences. For example, someone who is a wheelchair user is likely to have very different needs to someone who is a Deaf British Sign Language (BSL) user, or someone who has mental health problems.

It is estimated that 730,000 adults in Scotland have hearing loss, of whom 533,000 would benefit from NHS hearing services. (Public Health Institute of Scotland - NHS Audiology Review in Scotland - 2003). The number of profoundly Deaf people using British Sign Language in Scotland is estimated at between 4,000 and 6,000. (Scottish Association of Sign Language Interpreters – Creating Linguistic Access for Deaf and Deafblind People: A Strategy for Scotland – 2002)

In 2008, the number of people registered blind or partially sighted in Scotland was 35,900 of which approximately 2,700 were deafblind. (Scotland's Chief Statistician - Registered Blind and Partially Sighted Persons - 2008)

It is estimated that there are 120,000 people with learning disabilities in Scotland. There is evidence that people with learning disabilities have a higher number of and more complex health needs than the rest of the population, as well as higher levels of unmet health needs and different causes of death than non-learning disabled people. (Scottish Government - Scottish Ministers’ Duty Report: Health and Wellbeing - 2008)
There are no precise figures for the number of people with mental health problems in Scotland. The Scottish Health Survey suggests that those with a “high score” on the General Health Questionnaire in relation to mental health amounted to some 13% of men aged between 16-64 and 17% of women. (Scottish Government - Scottish Ministers’ Duty Report: Health and Wellbeing - 2008). There is also evidence to show that Deaf people are 4 times more likely to experience mental health problems than hearing people, and are also less likely to be able to access appropriate services. (Scottish Council on Deafness, Making the Case: Specialist Mental Health Services for Deaf People in Scotland, 2008. P.6).

There is a complex relationship between disability and ill-health, but it is important not to conflate the two. Disabled people may experience ill-health or benefit from measures promoting good health in the same way as anyone else in the population. (Scottish Government - Report of the Disability Working Group - 2006)

In terms of health, Social Focus on Disability 2004 reports that 50 % of adults with a long term illness or disability rated their health as “not good” over the past 5 years, compared with 5% of non-disabled adults. Correspondingly, 33% of adults with a long term illness or disability visited their GP more than 10 times in the last year, compared with 5% of non-disabled adults.

Disabled people are more likely to be living in poverty than non-disabled people, and in turn, individuals in low income households are more likely to report poor health. (Cabinet Office 2004 and Prime Minister’s Strategy Unit 2005 – information taken from Scottish Government - Scottish Ministers’ Duty Report Health and Wellbeing - 2008) As such, a survey conducted by MORI in 2003 found that 90% of disabled people had used the health service in the past 3 months, which is significantly higher than the general population.

However, a survey by NOP for the Disability Rights Commission in 2003 showed that 24% of disabled people mentioned difficulties in the course of an appointment or visit to the hospital and 18% in accessing a dentist.

Consultation

As part of the consultation process for the Patient Rights Bill a focus group for disabled people was organised by the Glasgow Centre for Inclusive Living and took place on 6 January 2009. The group consisted of people with a range of impairment types. The focus group was facilitated by the research team appointed by the Scottish Government to assist with the consultation process.

The focus group described examples of times when access to certain services was restricted for disabled people (e.g. screening equipment) because of their impairment, and the question was raised as to whether patients should accept this lesser service.
The group also felt that it was important that hospitals and health care premises were accessible, and this is very important in ensuring that disabled people are able to fulfil their responsibilities and, for example, don’t miss an appointment because they are unable to access the hospital building.

It was also suggested the Patient Rights Bill should be extended to embrace all health care, meaning local authority social care as well as NHS health care.

Written Consultation Responses:

The Scottish Government received many written responses from organisations representing disabled people, including: Scottish Council on Deafness/Hearing Concern LINK, Deafblind Scotland, Scottish Association for Mental Health, RNID Scotland, Scottish Disability Equality Forum, Deaf Action, Inclusion Scotland, Depression Alliance, Epilepsy Scotland, HIV Scotland, Scottish Consortium on Learning Disabilities/Enable, PAMIS, Scottish Central Branch of the National Federation of the Blind.

There was broad support from disability organisations with the proposals in the consultation and with the aims of the Patient Rights Bill. However, there were some specific concerns and issues raised about the impact of the Bill on disabled people.

Some of the main points raised by consultation respondents were:

Waiting Times Guarantee

Waiting time guarantees should apply to mental health services too.

The waiting time guarantee might be difficult to implement for deaf people due to the lack of interpreters and communication support workers in Scotland.

A maximum wait of 18 weeks is too long for paediatric audiology. 18 weeks is almost half of the school year, having little or no hearing for half of the school year will have serious implications for a child’s education and progress and place deaf children at a disadvantage.

Steps to fulfil the waiting times guarantee such as sending patients to another area, to a private facility or abroad may be more difficult for disabled people than for non-disabled people due to the reliance on carers and support workers, and it may also be more difficult in terms of transport and access to the support networks at place in their home area. If disabled people would rather wait for treatment than go elsewhere, they should not be penalised for this.
Access and Communication

Access to services, including physical access to premises and equipment as well as access to appropriate communication support and information, was a significant issue raised by many consultation respondents.

Respondents raised the issue that disabled people need information in a suitable format, and to be communicated with in an appropriate way, otherwise they will be unable to make informed decisions about their treatment or care.

It was felt that contract staff, such as cleaners or catering staff, who have patient contact, should be adequately trained in disability equality and should be subject to the Patient Rights Bill.

Patient Responsibility

Some impairments, such as mental health problems, autism and learning disabilities, may make it difficult for the patient to behave in an appropriate manner, and they should not be denied their rights simply because they are unable to fulfil their responsibilities.

There is concern around disabled patients taking responsibility for their own care and enforcing their rights, either because they are unable to or because they do not understand their rights and responsibilities, or because they cannot communicate with health care staff. For example, deaf patients cannot take responsibility for their own care/take medication etc unless the advice is provided in an accessible format that can be accessed when they need to.

Complaints, Advice and Support, Advocacy

There was strong support for advocacy from a range of respondents and it was felt that advocacy is necessary in order for disabled people to enforce their rights and to gain equal access to the complaints system. It was suggested that the groups that advocacy would particularly help are deaf people, people with learning disabilities and people with mental health problems. Respondents felt that advocacy services should be readily available and patients should be signposted to them by NHS staff. It was also felt that there is geographic inequality of access to advocacy services.

It is important that there should be good access both to the first stage of the complaints process and to the Ombudsman.

Deaf patients should be able to feedback/complain in writing via email or SMS. Deaf people generally find it very difficult to complain, partly because of low awareness of the complaints process and also because they find it difficult to access due to communication barriers.
Other Issues

There were also other concerns and issues raised by consultation respondents, which fall outwith the scope of the Patient Rights Bill, for example, concerns about physical premises and equipment being inaccessible and lack of transport to access appointments. Obtaining adequate nutrition was also an issue brought up by many respondents, not only in terms of people with profound impairments, but also for people who were unable to cut up their own food, or for people with sensory impairments.

Many of these additional issues are also already addressed by existing legislation, such as the Disability Discrimination Act (1995) and other strategies that the Scottish Government has in place, such as the National Integrated Programme for Improving Nutritional Care, which was set up in 2008 with the aim of improving and enhancing the nutritional care of people in hospital and tackling associated issues in relation to patients who are nutritionally vulnerable. In addition, we believe that the Bill’s emphasis on patient focus will contribute to making the health service a place where patients individual needs are taken into consideration and respected, and as such, will contribute to addressing some of these issues.

Impact

Evidence shows that disabled people are likely to access health care more frequently than non-disabled people, and that they can experience problems when doing so. Results from the consultation also suggest that disabled people can face significant problems in accessing health care, often due to access and communication issues.

As such, the Patient Rights (Scotland) Bill will have a positive impact on disabled people as it will set out in legislation principles and rights that must be taken into account by health care workers and contract staff (e.g. cleaners, catering staff). This will be accompanied by a staff training programme to ensure staff are aware of the rights of patients and carers, with the aim of improving communication with disabled people and making staff more aware of a range of accessibility issues.

It is anticipated that the Patient Rights Bill will lead to an increased demand for translating, interpretation and communication support (TICS). In light of this, the Scottish Government will provide funding of £750,000 over 3 years 2010 to 2013 to support the development of TICS services. This will be provided to NHS Health Scotland to provide support, resources and guidance materials; research on needs, procurement and service standard work; community engagement and marketing; communication events, and extended partnership work across NHSScotland. Investing in the TICS infrastructure will help to ensure that all patients are aware of their rights, and are communicated with in an appropriate manner.

The Scottish Government will also take reasonable measures to ensure that any information and publicity undertaken about the Bill will be accessible to disabled people.
Advocacy

One concern raised by many consultation respondents is that the Bill does not include a right to advocacy and that without support and help, many disabled people, especially those with learning disabilities and mental health problems, will find it difficult to enforce their rights, with the result that the Bill does not have the positive effect envisaged. Consequently, it is proposed that the Bill will place a duty on Patient Rights Officers to signpost people to advocacy services where appropriate. As a result of consideration of the potential impact across a range of equality groups, we have decided to allocate £1.5 million over 3 years 2010-13 to support advocacy services to help those who need assistance in upholding their rights access appropriate support.

Treatment Time Guarantee

Some consultation respondents were concerned about the position of mental health services and the proposed treatment time guarantee. The treatment time guarantee will apply to mental health services, where they are delivered as planned and elective care on an inpatient or day case basis. This is likely to have the greatest impact in terms of child and adolescent mental health services.

The majority of mental health services are emergency admissions whether on a voluntary basis or not (rather than planned or elective care). For those patients who are emergency admissions, it would not be appropriate to have a maximum waiting time of 12 weeks. Care/treatment delivered on an outpatient or day patient (as opposed to day case) basis is primarily about ongoing care or programmes of care, rather than the one-off elective focus of the treatment time guarantee.

Another area to consider is around treatment time targets for paediatric audiology. It has been suggested by consultation respondents that 12 or 18 weeks is too long for a child to wait before being treated by audiology services. 12 weeks is just over one third of the school year, and it is suggested that to be without hearing for that length of time would have a detrimental impact on a child's educational progress and attainment. However, although audiology services (adult or children) have previously not been covered by any waiting time standards, the Scottish Government announced on 27 October 2007, that audiology services would be covered by the 18 weeks referral to treatment target (RTT) which is due to be delivered by the end of 2011. This means that the Scottish Government has expanded the cohort of patients who will be covered by the treatment time guarantee, bringing patients with hearing difficulties within waiting time targets. Both the 18 weeks RTT and the proposed 12 week treatment time guarantee are maximum waits and it is expected that most patients will be seen quicker than these. Within these waiting times it is for the consultant to decide the patient’s clinical priority taking account of the individual’s particular needs.
A further issue raised was that if a patient’s home Health Board could not meet the treatment time guarantee, and they were offered an appointment in another Health Board area, there was concern raised that some patients (including disabled patients) would find it harder than others to go for treatment outwith their home Health Board. There was concern that these groups could be penalised if they refused to go to another Health Board for treatment, or that they would not get treatment within the 12 weeks for this reason. Current New Ways Guidance is clear that if treatment cannot be undertaken locally and the patient needs to travel elsewhere, the patient should be made aware of this as early as possible. This should ensure that the patient is part of the decision making process. Where a patient has to travel, appropriate transport and accommodation arrangements for patient and carer (if necessary) should be resourced by the patient’s Health Board. Moreover, the Scottish Government is keen to ensure that once the Bill becomes law, Health Boards must monitor the delivery and impact of the treatment time guarantee and collect information to aid in the assessment of any differential impact on patients according to the equality strands.

It is expected that Health Boards will specify a requirement to ascertain from patients whether they would be prepared to travel outwith their Health Board area for treatment. This should be done at the time of agreeing to treatment. This should ensure that in the small number of cases where the treatment time guarantee is unable to be fulfilled locally, that Health Boards can identify patients who are prepared to travel to another hospital outwith the local Health Board area, and allow for patients who are unable to travel or do not wish travel to be seen locally. This should ensure that no patient is disadvantaged.

It was also brought up by consultation respondents that D/deaf people and others who require the support of an interpreter to access health care may not be able to get their treatment within the maximum 12 weeks because of lack of British Sign Language (BSL)/English interpreters. The Scottish Government is clear that Health Boards should ensure that any additional support requirements are put in place before the patient is admitted to hospital and this should not in any way impact on the treatment time guarantee.

However, the Scottish Government is very aware of the barriers and problems some deaf people face in terms of accessing health services and having their needs met. We have been working for some time to improve the collection, transfer and use of information on patients’ communication needs and requirements across the NHS.

In addition, the Scottish Government is providing £750,000 of additional money over 3 years 2010-13 to support the development of the Translation, Interpreting and Communication Service (TICS), which will help to ensure that interpreters and communication support workers are available, although we acknowledge that there is a shortage of British Sign Language (BSL)/English interpreters in Scotland. To help address this problem, the Scottish Government, in conjunction with the British Sign Language and Linguistic Access Working Group (BSL&LAWG) is currently providing funding to train additional BSL interpreters and to develop the infrastructure and strategic direction of BSL/English interpreter training pathways in Scotland.
Patient Responsibility

One further area where it was felt that the Bill could have an adverse impact on disabled people was in terms of patient responsibility, where many consultation respondents pointed out that some disabled people will be unable to take responsibility for their own health care or medication because of their impairment, or because information has not been given to them in an appropriate way. There was concern that disabled people could be penalised or be denied their rights if they did not discharge their responsibilities. The Scottish Government notes that the rights of any individual are subject also to meeting the rights of others (this is similar to the concept of qualified rights in the European Convention of Human Rights). The aim of this is also to address concerns about staff-patient interactions and to allow a Health Board’s responsibility to the individual to be balanced against the Health Board’s responsibility to all the patients in its area. However, the Scottish Government is clear that even if a patient cannot or does not fulfil their responsibilities, they will still receive the highest possible standard of health care.

Complaints

Some disabled people, especially deaf people, find it hard to complain because of inaccessible systems and processes, or because they are not aware of the process, and there was concern that disabled people would therefore not benefit from having a right to make complaints. Currently, NHS bodies in Scotland must ensure that their services recognise and respond sensitively to the individual needs, background and circumstances of peoples’ lives and in doing so must comply with the terms of existing equalities legislation. This requirement extends to local arrangements for handling complaints. As such, staff involved in the implementation of the NHS Complaints Procedure should use the Equality and Diversity Impact Assessment Toolkit to ensure that their local arrangements fully meet the needs of potentially disadvantaged individuals or groups: this includes ensuring ready access to translation and interpreting services, including those for people with sensory impairment, and the provision of appropriate independent support and advocacy services for all who need it.

In addition to what is already in place (described above), the Bill proposes the provision of a Patient Advice and Support Service (PASS), including Patient Rights Officers, who can help and support patients when making a complaint and signpost to further support and advocacy services. It is recognised that PASS and the complaints system must be accessible to all and that Patient Rights Officers will also need to be accessible and responsive to the individual needs, background and circumstances of people’s lives.
Age

Evidence
Scotland’s population is ageing, and life expectancy for men and women is expected to increase by around 6 years by 2031, by which time the number of men and women over 75 is expected to be 1.75 times the current level. In the 10 years from 1998 to 2008, the ageing of the population was reflected in the number of children under 16 reducing by 9%, and the number of people aged 75 and over increasing by 13%. (The Registrar General's Annual Review of Scotland's Population - 2009)

The age profile of Scotland’s population will continue to change over the coming decades. The number of people of pensionable age is projected to rise by around 31%, from 0.98 million in 2006 to 1.29 million in 2031, which equates to approximately 20% of the population.

In 2006, approximately 25% of Scotland’s population was recorded as being less than 19 years old. (Office for National Statistics – Census Results – 2001).

The proportion of people with a long-term illness or disability increases with age: 13% of people aged 70 years and over have both a long-term illness and disability compared to 2% of 30-39 year olds. (Scottish Executive - The Scottish Health Survey 2003. Volume 2: Adults - 2005)

As such, an ageing population tends to increase the demand for health care, although its effects are being offset to some extent by the fact that older people are, on average, healthier than they have ever been. The main impact of the age profile will be on the type of demand for services since older people have a higher incidence of chronic disease and on average a greater number of long term conditions. (Scottish Government - Better Health, Better Care: Action Plan - 2007)

However, we also know that both younger and older people experience barriers in accessing health care. (NHS – Fair for All Age and Health Guidance – 2007)

Mental Health problems are an issue in both younger and older age groups. Almost 15% of people over 65 report living with major depression which disrupts their lives, and more than 700,000 people have dementia. For young men (15-34) the main cause of death is suicide, and this is 6 times higher for gay and bi-sexual men. (NHS – Fair for All Age and Health Guidance – 2007)

Sexual health problems are also increasing among younger people. For example, the incidence of sexually transmitted infections (STIs) for females is highest for those aged 20 to 24 years (37% of all female diagnoses). The incidence of STIs for males is also highest for those aged 20 to 24 years (37% of all male diagnoses). Between 2000 and 2005, the most marked increase in incidence of STIs occurred for both men and women aged between 15 to 19 years and 20 to 24 years. (Scottish Government - High Level Summary of Equality Statistics: Key Trends for Scotland – 2006)
Consultation

As part of the consultation process for a Patient Rights Bill a children and young people's focus group was organised by Callander Youth Project. It was held on 25 November 2008. There were eleven participants, (six females and five males) with an age range between 11-17 years.

Another group focusing on age (and gender) took place in Dumfries on 27 November 2008. This group consisted of ten people (five women and five men) with an age range from 20s to 60s. Both focus groups were facilitated by the research team appointed by the Scottish Government to assist with the consultation process.

The focus groups agreed with the main principles of the consultation, and the young people’s group raised some specific issues:

Some young people felt that they were sometimes given less favourable treatment because of their circumstances, saying that young people should be treated with respect and that health care services should not treat older people better. Young people also felt that the way in which they are communicated with is important.

Written Consultation Responses:

Several written responses were also received from organisations involved with this community, including Scotland’s Commissioner for Children and Young People, Action for Sick Children (Scotland), Children in Scotland, Help the Aged in Scotland, Alzheimer’s Scotland, British Geriatrics Society, and Better Government for Older People in South Lanarkshire,

The responses were in broad agreement with the proposals in the consultation, but there were some specific points relevant to older and younger people that were raised.

Older People

Information needs to be communicated in a way patients can understand, especially patients with Alzheimer’s or dementia. The availability of advocates for people in this position should be encouraged.

Consideration needs to be given to people with Alzheimer’s or dementia who may not behave appropriately because of their condition. It is important that they are given dignity and respect, and that their care and treatment does not suffer. Also, the ability of patients with dementia to comply with advice on medication and treatment and to raise concerns about the safety of their care will depend on them being enabled to do so by carers, home care staff and advocates.
Older people may not be in a position to take responsibility for their own care and are less likely to be able to travel to other Health Board areas for treatment. This needs to be taken into account in planning their care and treatment, and ensuring this is on an equitable basis.

**Younger People**

There is a lack of particular mention of children and young people in the consultation. Children and young people need specific support to access health care services and they should be specifically mentioned in the Bill so that health care staff are aware that the Bill also applies to children and young people.

Health services need to recognise that teenagers and young adults may also have special needs, and that the transition between children’s and adult services can be in itself a disruption, while at the same time are facing the changes of adolescence and stressful periods at school.

Children and young people would benefit from the support of advocacy services.

Children are not always able to discharge their responsibilities independently of their parents.

**Other Concerns**

There were also other concerns and issues raised by consultation respondents, which fall outwith the scope of the Patient Rights Bill, such as access to transport for older patients, the right to food and adequate nutrition and transitions for teenagers between children and adult services. The Scottish Government believes that the Bill’s emphasis on patient focus will contribute to making the health service a place where patients’ individual needs are taken into consideration and respected, and will contribute to addressing these issues.

**Impact**

The Patient Rights Bill will have a positive impact on older and younger people, as it will set out clearly in legislation principles and rights that must be taken into account by health care workers and staff contracted by health care providers such as cleaning staff, and will be accompanied by a training programme which will make staff more aware of the rights of patients and carers, with the aim of improving communication with patients and making staff more aware of a range of accessibility issues. The Scottish Government is clear that the rights set out in the Bill relate to everyone, including children and young people. The Bill will not supersede existing legislation on children’s rights, and we will endeavour to ensure that we encourage health care providers to be aware of these and to communicate with children in a manner appropriate to their level of understanding and capability.
A further positive impact on young people is that mental health services are included in the 12 week treatment time guarantee where they are delivered as planned and elective care on an inpatient or day case basis. This is likely to have greatest impact in respect of child and adolescent services which make greater use of planned admissions than other mental health service areas where services tend to be accessed quickly in the context of crisis.

One concern raised by consultation respondents is that the Bill does not include a right to advocacy, and that without support and help, some older and younger people, especially those with dementia, will find it difficult to enforce their rights with the result that the Bill does not have the positive effect envisaged. As such, it is proposed that the Bill will place a duty on Patient Rights Officers to signpost people to advocacy services where appropriate. As a result of consideration of the potential impact across a range of equality groups, the Scottish Government will allocate £1.5 million over 3 years to support the development of advocacy services, to ensure those who need assistance in upholding their rights can access appropriate support.

In addition, if a patient’s home Health Board could not meet the 12 week Treatment Time Guarantee, and they were offered an appointment in another Health Board area, there was concern raised by consultation respondents that some patients (including older people) would find it harder than others to go for treatment outwith their home Health Board. There was concern that these groups could suffer if they refused to go to another Health Board for treatment, or that they would not get treatment within the 12 weeks for this reason. Current New Ways Guidance is clear that if treatment cannot be undertaken locally and the patient needs to travel elsewhere, the patient should be made aware of this as early as possible. This should ensure that the patient is part of the decision-making process. Where a patient has to travel, appropriate transport arrangements for patient and carer (if necessary) should be resourced by the patient’s Health Board.

The Scottish Government expects Health Boards to ascertain from patients whether they would be prepared to travel outwith their Health Board area for treatment. This should be done at the time of agreeing to treatment. This should ensure that in the small number of cases where the treatment time guarantee is unable to be fulfilled locally, that Health Boards can identify patients who are prepared to travel to another hospital outwith the local Board area, and allow for patients who are unable to travel or do not wish travel to be seen locally. This should ensure that no patient is disadvantaged.

Consultation respondents also pointed out that some older people, particularly those with dementia, will be unable to take responsibility for their own health care or medication. There was concern that patients could be penalised if they did not discharge their responsibilities. The Scottish Government notes that the rights of any individual are subject also to meeting the rights of others (this is similar to the concept of qualified rights in the European Convention of Human Rights). The aim of this is also to address concerns about staff-patient interactions and to allow a Board’s responsibility to the individual to be balanced against the Board’s responsibility to all the patients in its area. However, we are clear that even if a patient cannot or does not fulfil their responsibilities, they will still receive the highest possible standard of health care.
**Race**

**Evidence**

According to the 2001 Census, the size of the ethnic minority population was 2 per cent of the total population of Scotland showing an increase from 1.3 per cent in 1991. Scotland’s ethnic minority populations are considerably younger than the general population: 57% are aged under 30 compared with 36% of the white group.

However, this figure is likely to have increased, especially in the Greater Glasgow area, as asylum seekers were not included in the census figures, and the number of migrant workers has increased since 2001. (Scottish Government/National Resource Centre for Ethnic Minority Health – *Equal Services?* - 2005).

According to an analysis of the 2001 Census, Chinese people are the group that have the highest proportion of people who assess themselves as having good or fairly good health (96%). This is closely followed by people in the "Other Ethnic" group and by Africans with 95% of people reporting good or fairly good health. In contrast, 90% of White Scottish people and only 86% of White Irish people reported good or fairly good health. (Scottish Government – *Analysis of Ethnicity in the 2001 Census: Summary Report* – 2004)

As of January 2009, there are an estimated number of 1,590 Gypsy/Travellers living in Scotland, although it is difficult to obtain accurate counts, due to the mobile lifestyle of this community. Studies of Gypsies/Travellers, such as the 2004 health study of Gypsies/Travellers by Sheffield University and the 2009 Accommodation Needs Assessment of Gypsies/Travellers in Grampian both point to a lower life expectancy and high incidences of chronic ailments among this population.

A Health Scotland working group has recently produced a report paper and from the available evidence we know that health outcomes for Gypsy/Travellers differ for a variety of reasons including:

- access to health services may be affected by: a limited understanding of services; cultural or attitudinal barriers; practical barriers e.g. traveller communities facing difficulties in registering with a GP; the need for key health care messages to be communicated in a culturally sensitive way;
- cultural factors such as diet or attitudes towards exercise;
- mental health - many studies have focussed on the impact of difference, disadvantage or isolation on mental health and the lack of a culturally sensitive response or a lack of understanding of health care providers to respond appropriately to need. (Health Scotland - *Health in our Multi-Ethnic Scotland - Future Research Priorities* - 2009)

Significant inequalities are observed in people from ethnic minorities in both incidence and mortality from Scotland’s biggest killers (cancer, stroke and coronary heart disease). For example, South Asian men have a 45% higher incidence of heart attack and South Asian women have an 80% higher incidence, compared with the rest of the Scottish population. (Scottish Public Health Observatory - Cited in *Scottish Government Race Equality Scheme 2008-11* - 2008)
Consultation

As part of the consultation process for the Patient Rights Bill, a minority ethnic communities focus group was organised by BEMIS (Black and Ethnic Minority Infrastructure in Scotland) and was held on 3 December 2008, in Glasgow. There were nine participants representing Jewish, Asian (4), Eastern European/Roma, Gypsy Travellers, Arab and Persian communities. The focus group was facilitated by the research team appointed by the Scottish Government to assist with the consultation process.

Members of the focus group felt strongly that there should be increased training on cultural differences for all health practitioners. Group members also raised the issue of access to appropriate food and some felt that hospitals should put the necessary arrangements in place to allow food to be brought in from home.

A member of the Gypsy-Traveller community said that the biggest concern for this community is access to services and especially accessing a GP.

There appeared to be concerns around respecting different cultural needs and wishes. Special dietary requirements, in particular, appeared to be poorly catered for in hospitals e.g. Kosher and Halal. Other examples given were women who did not want to see a male doctor, and circumcision not being carried out at the required age (according to religious vows) because of waiting lists. These things were thought to be simple yet important.

The group felt that information is often communicated in words that are too complicated for many people to understand. This could be because of language barriers or educational barriers. All verbal and written communication should be in plain English. How information is communicated to the community is also important, with participants suggesting that it is not enough to simply translate information into different languages.

Written Consultation:

Written responses were also received from organisations involved with this community, including Chinese Community Development Partnership, BEMIS (Black and Ethnic Minority Infrastructure in Scotland) and Amina Muslim Women’s Resource Centre.

Consultation responses were broadly supportive of the Bill, although there are still some concerns as to how people from ethnic minority backgrounds are treated in the NHS and how culturally sensitive services are.

Comments included:

Patients should be told that they have the right to ask for an interpreter. Healthcare Staff should be aware that if they send letters and appointments out in English, they might need to be translated by a family member, potentially breaching patient confidentiality.
Health services should not assume that family members will interpret at appointments etc. When an interpreter is provided, staff should check the interpreter is not known to the patient.

It should be recognised that patients can only comply with advice on medication and treatment if their rights to communication and access have been upheld.

Other Concerns

There were also other concerns and issues raised by consultation respondents, which fall outwith the scope of the Bill, such as access to food that is culturally appropriate. There is already significant work underway on these issues outwith the Bill. For example, the Scottish Government has published a National Catering and Nutritional Specifications for Food and Fluid Provision in Hospitals in Scotland, which is part of an overall programme of work to improve the nutritional care of patients in Scottish hospitals. The document has a section dedicated to special and personal diets, including information about Halal diets. There is an expectation that where special diets are required, they will be provided.

More generally, the Scottish Government believes that the Bill’s emphasis on patient focus will contribute to making the health service a place where patients individual needs are taken into consideration and respected, and will contribute to addressing these issues.

Impact

Communication

From the evidence gathered, and our consultation work, we know that people from minority ethnic backgrounds often experience difficulties in accessing services that are culturally sensitive and may also experience problems understanding advice or information given to them, due to language barriers. Therefore, as for the other equality strands, the Patient Rights Bill will have a positive impact on the experiences of people from minority ethnic backgrounds when using health services, as it will set out in legislation principles and rights that must be taken into account by health care workers and contract staff (e.g. cleaners, catering staff). This will be accompanied by a training programme to make staff more aware of the rights of patients and carers, with the aim of improving communication with patients and make staff more aware of a range of accessibility issues, which will include cultural awareness and race equality.

In addition, the Scottish Government is providing £750,000 of additional money over 3 years 2010-13 to support the development of the Translation, Interpreting and Communication Service (TICS), which will help to ensure that interpreters and communication support workers are available and that all patients are communicated with in an appropriate manner.

The Scottish Government will also take reasonable measures to ensure that any information and publicity undertaken about the Bill takes into account language needs and cultural issues.
Treatment Time Guarantee

In terms of concerns raised by consultation respondents about waiting times for religious circumcision, all circumcision, whether undertaken for religious or medical reasons is included in the 12 week treatment time guarantee. This means that patients will not have to wait longer than 12 weeks for treatment from the date they agree the treatment with the consultant. The exception to this is where the patient is under 6 months old. In Scotland, doctors agree that circumcision should always be carried out under a general anaesthetic, and as there are clinical concerns about performing general anaesthesia on children under 6 months of age, the procedure will not be performed until the child is at least 6 months old. The operation will usually be carried out as soon as it is safe for the child, at the optimum ages of between 6 and 12 months old.

Gender

Evidence
Data from the 2001 Census shows that 48.05% of the population are male, and 51.95% are female.

The Scottish Health Survey 2003 said that overall, women were more likely than men to have consulted a GP in the past two weeks (20% vs. 16%) but the reverse was true among those aged 65 and over. Over a third of men and women had visited hospital as an outpatient during the previous 12 months; 9% of men and 13% of women had been admitted as inpatients.

The survey also showed that 42% of men and 54% of women aged 16 and over were taking at least one prescription medication (excluding contraceptives) and the use of medication increased with age. One in five women aged 16-54 were using contraceptive medication.

Inequalities due to some aspects of diversity are well understood. For example, coronary heart disease admission rates in Scotland among men are nearly double those of women, and on average, men develop heart disease 10 years earlier than women. (Equally Well: Report of the Ministerial Task Force on Health Inequalities - Volume 2 - 2008) However, women are 2.7% more likely than men to develop an auto-immune disease such as diabetes. (Fair for All - Improving Gender Equality Practice in NHS Scotland – 2008)

Mental health problems affect more women than men. Specifically, women experience higher rates of depressive disorders than men. However, men are more likely to complete suicide and experience earlier onset of schizophrenia with poorer clinical outcomes than women.
Evidence suggests that the cultural constructions of masculinity can have a negative effect on health, and may contribute to the reluctance of men to access health services or seek help for problems at an early stage for fear of appearing 'weak'. Research suggests this may make men more likely to self-medicate with drink and drugs than accept they have a mental health problem etc. (Equally Well: Report of the Ministerial Task Force on Health Inequalities - Volume 2 - 2008)

Gender is also has a significant influence on the NHS workforce which is disproportionately female. Data from NHS Workforce statistics 2008 shows that 77.9% of the total NHS workforce (including GPs and dentists) in Scotland is female.

Consultation

As part of the consultation process for a Patient Rights Bill a group focusing on gender (and age) took place in Dumfries on 27 November 2008. The group consisted of five male participants and five female with an age range from 20s to 60s. The focus group was facilitated by the research team appointed by the Scottish Government to assist with the consultation process.

The focus group broadly agreed with the rights as laid out in the consultation and felt that the rights around information, communication and participation were closely linked.

Written Consultation:

Written responses were also received from organisations involved with women or with issues that primarily affect women, including Scottish Federation of University Women, the Scottish Women's Convention, Glasgow South Soroptimists, National Childbirth Trust and the Family Planning Association. There were no responses from any organisations specifically representing only men, although some of the organisations mentioned here deal with both men and women.

Responses were positive and in favour of the principles outlined in the consultation, although there were some concerns about the impact on women.

One consultation respondent was concerned that women need to access abortion and emergency contraception well before the 12 week waiting time guarantee. They suggested that the maximum waiting time for abortion services recommended by the Royal College of Obstetricians and Gynaecologists (3 weeks) should be incorporated as a right in the Bill.

Women are more likely to have caring responsibilities than men, and therefore may not be able to take up treatment in another Board area as a result. It is important that women are not penalised for this or put back to the start of the waiting list.
Impact

We know that men and women can have different attitudes towards health and health care, and that this can affect the way they access health care services, and their health outcomes. As with other equality groups, the Patient Rights Bill will benefit both men and women, as it will set out in legislation principles and rights that must be taken into account by health care workers and staff contracted by health care providers, such as cleaning or catering staff. This will be accompanied by a training programme which will make staff more aware of the rights of patients and carers, with the aim of improving communication with patients and making staff more aware of a range of accessibility issues.

As we know that the majority of the NHS workforce is female, making patients more aware of their responsibilities in terms of treating staff with dignity and respect is likely to have a greater impact on women than on men. However, male staff will also benefit.

Treatment Time Guarantee

Similarly to concerns raised by disabled people and older people, there was concern that as women tend to have more caring responsibilities than men, they could be adversely affected by the treatment time guarantee, in that they may be less able to travel outwith their own Health Board area for treatment. There was concern that these groups could be penalised if they refused to go to another Health Board for treatment, or that they would not get treatment within the 12 weeks for this reason.

Current New Ways Guidance is clear that if treatment cannot be undertaken locally and the patient needs to travel elsewhere, the patient should be made aware of this as early as possible. This should ensure that the patient is part of the decision making process. Where a patient has to travel, appropriate transport and accommodation arrangements for patient and carer (if necessary) should be resourced by the patient’s Health Board. Moreover, we will seek to ensure that Health Boards monitor the delivery and impact of the treatment time guarantee and collect information to aid in the assessment of any differential impact on patients according to the equalities strands.

We expect that Health Boards will specify a requirement to ascertain from patients whether they would be prepared to travel outwith their Health Board area for treatment. This should be done at the time of agreeing to treatment. This should ensure that in the small number of cases where the treatment time guarantee is unable to be fulfilled locally, that Health Boards can identify patients who are prepared to travel to another hospital outwith the local Health Board area, and allow for patients who are unable to travel or do not wish travel to be seen locally. This should ensure that no patient is being disadvantaged.

It was suggested by a consultation respondent that the 12 weeks treatment time guarantee was not appropriate in the context of abortion and emergency contraception services, and that the Bill should contain a right to an abortion within 3 weeks, as per the current guidance from the Royal College of Obstetricians and Gynaecologists (RCOG).
However, the RCOG guidelines have already been adopted in Scotland, and are a Key Clinical Indicator for the Sexual Health Strategy and an NHS Quality Improvement Scotland standard. Therefore women are already able to access abortions within the RCOG recommended waiting time.

As emergency contraception is not an inpatient or day case treatment in that the patient does not need to be admitted to hospital, this is therefore not included in the treatment time guarantee. In Scotland, systems are already in place to allow access to emergency contraception within 72 hours through GP surgeries, pharmacies, sexual health and family planning services.

**Lesbian, Gay, Bisexual and Transgender (LGBT)**

**Evidence**

There are no precise figures as to how many lesbian, gay, bisexual and transgender (LGBT) people live in Scotland. According to Stonewall Scotland, there are around 300,000 gay people in Scotland which equates to 6% of the population. Scottish Public Health Observatory figures record that around 5% of men and women report ever having had a same sex partner. It is generally accepted that LGBT people make up 5 to 7% of the population of Scotland. (Cited in Scottish Government - *Challenging Prejudice: Changing Attitudes towards Lesbian, Gay, Bisexual and Transgender People in Scotland* – 2008)

The NHS Inclusion Project found in 2003 that 25% of LGBT people in Scotland had experienced inappropriate health advice or treatment due to their sexual orientation or gender identity and that this can have a negative effect on self esteem, leading to mental and physical ill-health.

Stonewall’s report, *Towards a Healthier LGBT Scotland* (2003) found that: “Low self-esteem, anxiety and depression are common experiences for many LGBT people. These in turn can be linked to other health concerns including higher than average rates of suicide and self-harm, and homelessness, often associated with prostitution and academic underachievement, is also linked.” A health needs assessment of young LGB people in Glasgow found rates of self harm of 29% among men and 65% among women; this is compared to rates of around 10% for the general population.

According to the report of the LGBT Hearts and Minds Agenda Group, LGBT people are also at greater risk from poorer sexual health as they fear ‘coming out’ and lack appropriate and inclusive education. It is also well documented that LGBT people are more likely to drink, smoke and use illegal substances than the general population. (Scottish Government – *Challenging Prejudice: Changing Attitudes towards Lesbian, Gay, Bisexual and Transgender People in Scotland* – 2008)
Discriminatory attitudes, low disclosure rates of sexual orientation and the limited knowledge of service providers result in LGB people using health services less than the general population. Those transgender people who do access services tend to use them more due to ongoing health care needs. International surveys show that LGBT people are likely to access health care services after specific problems arise, and present later in an illness when it is potentially more difficult to treat. A lack of targeted health promotion and poor information on the risk of certain conditions can lead to reduced screening for LGBT people on a range of issues (NHS Scotland – Towards a Healthier LGBT Scotland – 2003)

Transgender people reported very positive experiences of using sexual health services, but were least satisfied with NHS24 and mental health services. This related to fears of how unfamiliar medical professionals would react to disclosure of transgender status (NHS24) and lack of understanding and knowledge about transgender issues by general psychiatrists, leading to inappropriate treatment and long delays in accessing assessment by an experienced gender specialist. (Scottish Transgender Alliance – Transgender Experiences in Scotland Research Summary – 2008)

Consultation

As part of the consultation process for a Patient Rights Bill a focus group for lesbian, gay, bisexual & transgender (LGBT) people took place in Edinburgh on 2 December 2008. There were eight participants who were recruited from both the LGBT Centre for Health and Wellbeing and the Equality Network’s contact lists. The focus group was facilitated by the research team appointed by the Scottish Government to assist with the consultation process.

Participants were broadly in favour of the rights outlined in the consultation, and some specific points raised were:

- Some participants felt that there should be explicit mention of gender reassignment, gender identity or gender expression in the consultation document, because there is a big problem with how transgender people are treated by hospital staff.
- Concern was expressed about privacy and confidentiality of medical records, and staff who did not need to know finding out someone’s sexual orientation or gender identity.
Written Consultation:

Organisations in this community did not submit any written responses to the consultation, although 2 LGBT organisations were emailed specifically to draw the consultation to their attention. This indicates that the consultation may not have been promoted enough to these communities, or through the right outlets, or there may be other barriers to response within the LGBT sector. It may be that LGBT communities did not feel the consultation had any relevance for them, despite all we know about LGBT access to health and the problems and barriers that many experience. It may also be that organisations within the LGBT sector are less well resourced than some other equality groups, and don’t have the capacity to respond within the timeframes. These are issues that require further consideration for any further consultation and engagement work undertaken on the Patient Rights Bill, and also during the parliamentary stages.

Consultation Post-Introduction

As a result of not receiving any written consultations from organisations representing the LGBT sector, Scottish Government officials met with 2 LGBT organisations (Equality Network and Scottish Transgender Alliance) post-introduction of the Bill to Parliament. The main points raised were:

- There should be specific mention of equality in the primary legislation, for example, like the equality clause in the Housing Act (Scotland) 2001.
- However, it is difficult to enforce or regulate equality
- When the Common Services Agency (CSA) procures the Patient Advice and Support Service (PASS), need to ensure that they pass on the equality duties they are subject to in the procurement process and contract.
- The contract for PASS should include a clause on equality training.
- Patient Rights Officers should have specific training on transgender issues, as there is a historical exclusion of this group of people.
- There should be a clause in the secondary legislation that specifically includes transgender people, as there is a fear they will be excluded unless explicitly included.
- Transgender people are concerned that although not the SG current intention, gender reassignment surgery will end up being tucked into the groups excluded from the TTG. For example, at the moment the procedures are excluded from the 18 weeks Referral to Treatment Target, because the procedures have been included in the Aesthetic Referral Protocol. The transgender community disagree with this categorisation and see these procedures as part of the treatment for a medically recognised condition (gender dysphoria) rather than as a cosmetic procedure. Transgender people are already experiencing considerable difficulty accessing surgery in Scotland and are concerned that the introduction of the TTG will not help this issue.
Impact

We know that LGBT people often face barriers to accessing health services, and often report receiving inappropriate treatment and services. Therefore, similarly to other equality strands, the Patient Rights Bill will have a positive impact on LGBT people, as it will set out in legislation principles and rights that must be taken into account by health care workers and staff contracted by health care providers such as cleaning or catering staff. This will be accompanied by a staff training programme which will make staff more aware of the rights of patients and carers, with the aim of improving communication with patients and making staff more aware of a range of accessibility issues, including LGBT equality.

The Scottish Government’s discussions with LGBT organisations indicate that as described above, the Patient Rights (Scotland) Bill should have a positive impact on LGBT people. However, there are also some potentially less positive impacts, particularly for the transgender community.

General Principles

It was suggested that there should be an equality clause in the primary legislation of the Bill. Currently, equal opportunities is reserved to the UK Government, therefore the Scottish Government has limited scope to introduce equality issues into primary legislation. However, one of the principles focuses of the Bill is to provide more support to patients when they receive healthcare, and to ensure that the healthcare received takes into account the individual needs of the patient, which the Scottish Government believes will help to make the health service more equitable and accessible. It is the Scottish Government's intention that there will be more specific mention of equality issues in the secondary legislation to the Bill.

It was also suggested that there should be specific mention in secondary legislation that transgender people are included in the Bill. The Scottish Government is clear that the rights set out in the Bill relate to everyone, including transgender people. The Scottish Government will endeavour to ensure that it encourages health care providers to be aware of the needs of transgender people and that training on transgender and other equality issues will be part of the staff training packages attached to the Bill.

Treatment Time Guarantee

In the post-introduction consultation, the issue of treatments for gender dysphoria being excluded from the Treatment Time Guarantee (TTG) was raised. The Scottish Government is clear that the TTG will apply to treatments that are planned and elective, and delivered on an inpatient or day case basis. There will be a very small number of exclusions, which will not include procedures or treatments likely to be used to treat gender dysphoria. The TTG will start once an eligible patient and the consultant have agreed to the specific treatment. This does not affect the current procedures in place for psychological assessment and reflection which must take place before surgical or other interventions take place.
Patient Advice and Support Service and Patient Rights Officers

It was suggested when speaking to LGBT groups that when the Common Services Agency (CSA) procures the Patient Advice and Support Service (PASS), they need to ensure that they pass on the equality duties they are subject to in the procurement process and contract, and that the contract for PASS should include a clause on equality training. It was also suggested that because transgender people are a historically excluded group, that Patient Rights Officers should have specific training on transgender issues.

The needs of all equality groups will be considered in the design, development and delivery of the PASS service and the Scottish Government will expect the provider of the PASS to ensure that its employees undergo equalities training.

Training for NHS staff will be provided through NES. NES are undertaking to develop both generic person-centred approaches to training, as well as work to develop educational resources to enable staff to support particular client (patient) groups. There are particular client groups which are likely to experience barriers to accessing their rights and participating fully in their healthcare and this includes transgender people. Targeted educational materials to support these vulnerable groups will be required to help staff address their individual needs.

It is recognised that PASS must be accessible to all and that Patient Rights Officers will also need to be accessible and responsive to the individual needs, background and circumstances of people’s lives.
Evidence

According to the 2001 Census, more than six out of ten people said that their religion was Christian (65%). After Christianity, Islam was the most common faith with 426,000 people in Scotland describing their religion as Muslim. This is followed by people from other religions (27,000), Buddhists (6800), Sikhs (66,000), Jews (6400) and Hindus (5600). These groups each accounted for less than 1% of the Scottish population. Added together these groups accounted for less than 2% of the overall population.

This group is likely to face some of the same issues as minority ethnic people when accessing health care, such as lack of cultural knowledge, support and language barriers.

Research has shown that religious involvement is associated with positive mental health outcomes. A growing number of studies also emphasise the importance of spiritual beliefs and the value of support from faith communities for people with mental health problems. Other studies have found a resistance to spiritual issues within mental health services, where religious beliefs are sometimes interpreted as symptoms of illness. (NeLH in collaboration with Mentality - Models of Mental Health Promotion – 2004)

Some patients find that their religious or spiritual beliefs help them cope better with their illness. Because of this, religious beliefs often influence medical decisions, especially those made when illness is serious or terminal. Many patients would like physicians to address their spiritual needs and to support them in this area. Furthermore, a growing research database indicates that in the majority of cases, religious beliefs and practices are related to better health and quality of life. (NHS Scotland Fair for All – Religion and Belief Matter – 2007)

Consultation

As part of the consultation process for a Patient Rights Bill a religion and belief focus group took place at Central Mosque, Glasgow, on 1 December 2008 and was organised by the Scottish Inter Faith Council. There were twelve participants and the religious faiths and beliefs represented were; Baha’i, Buddhist, Christian (Catholic and Protestant), Hindu, Humanist, Islam Jain, Jehovah’s Witnesses, Jewish, Mormon, Pagan and Sikh. The focus group was facilitated by the research team appointed by the Scottish Government to assist with the consultation process.

Some of the issues raised were lack of understanding by staff of religious and faith beliefs and there was also discussion about the degree to which patients could be expected to disclose their religious beliefs to staff. Focus group members also said it could depend on how ill someone was, as to whether or not they would let staff know about their religious beliefs or needs. The group also acknowledged that there
would be circumstances when clinical need would have to take priority over religious needs.

**Written Consultation:**

Several written responses were also received from organisations involved with this community, including Scottish Churches Committee on Healthcare Chaplaincy, Amina - Muslim Women's Resource and the Catholic Bishops' Conference Scotland.

Respondents were broadly in agreement with the consultation proposals; some of the comments raised included:

- The right to dignity and respect can only be upheld if NHS staff respect the culture and beliefs of the patient.
- Muslims want to be treated by a member of staff of the same sex, and this should be respected and should not be optional.
- Muslims’ faith may be an integral part of their palliative care, and this should be understood and supported.
- Muslim women want to be examined by female staff only, and need hospital clothes that respect their modesty. They also need to be accommodated in female only wards when in hospital.
- Concerns about timely access to religious circumcision for babies.

**Other Concerns**

There were also other concerns and issues raised by consultation respondents, like the availability of appropriate meals, such as Halal. However, there is already significant work underway to address these issues outwith the Bill. For example, the Scottish Government has published a National Catering and Nutritional Specifications for Food and Fluid Provision in Hospitals in Scotland, which is part of an overall programme of work to improve the nutritional care of patients in Scottish hospitals. The document has a section dedicated to special and personal diets, including information about Halal diets. There is an expectation that where special diets are required they will be provided.

In addition, the Scottish Government believes that the Bill’s emphasis on patient focus will contribute to making the health service a place where patients individual needs are taken into consideration and respected, and will contribute to addressing these issues.
Impact

From the evidence collected and our consultation work, we know that having a religious belief may be beneficial in terms of coping with illness, but that people with religious beliefs often find that services are not sensitive to their spiritual needs. In terms of the Patient Rights (Scotland) Bill, again there will be a positive impact on this group, as the Bill aims to promote a culture of dignity and respect, and will set out in legislation principles and rights that must be taken into account by health care workers and staff contracted by health care providers such as cleaning and catering staff. This will be accompanied by a staff training programme which will make staff more aware of the rights of patients and carers, with the aim of improving communication with patients and making staff more aware of a range of accessibility issues, including awareness of and sensitivity to religious beliefs and practices.

Treatment Time Guarantee

In terms of concerns about waiting times for religious circumcision, all circumcision, whether undertaken for religious or medical reasons is included in the 12 week treatment time guarantee. This means that patients will not have to wait longer than 12 weeks for treatment from the date they agree the treatment with the consultant. The exception to this is where the patient is under 6 months old. In Scotland, doctors agree that circumcision should always be carried out under a general anaesthetic, and as there are clinical concerns about performing general anaesthesia on children under 6 months of age, the circumcision will not be performed until the child is at least 6 months old. The operation will usually be carried out as soon as it is safe for the child, at the optimum ages of between 6 and 12 months old.
Overall Conclusions

Changes to Policy?

Detail on changes we have made to the Bill, is set out in the analysis of adverse impacts and solutions for overcoming these for relevant equality groups at Step 4 of this EQIA.

The Scottish Government has considered in detail any negative or unintended effects created by the Bill, and has taken steps to mitigate and eliminate these, including by providing additional targeted resources, and by considering how the eventual implementation and communication of the rights set out in the Bill will be undertaken. The Scottish Government will continue to monitor the potential impacts on equality groups as the Bill progresses through the parliamentary stages by considering evidence presented by equality groups, and by continuing to engage with key equality stakeholders, and will consider any changes accordingly.

Promoting Good Relations

The Patient Rights Bill will provide an excellent opportunity to promote equality of opportunity and good relations across and between different equality groups. The Bill aims to contribute to a patient-focused NHS, in which individual needs are considered and where patients feel that they have a say in their own treatment, and that their wishes are listened to and respected. The Bill will contribute to building a mutual NHS, in which patients and the public are affirmed as partners rather than recipients of care, and will help to ensure that all those who work for NHSScotland respect the expertise of patients and their carers and improve the way in which they communicate and involve patients in the decisions that affect them.

The Bill will set out in legislation principles and rights that should be taken into account by health care workers and will be accompanied by a training programme which will make staff more aware of the rights of patients and carers, with the aim of improving communication with patients and making staff more aware of a range of equality issues. Training and awareness raising will include equality issues across all strands, and we envisage that this will particularly emphasise to staff the importance of access and communication issues.

Another way in which the Bill will have an impact on promoting equality of opportunity is in terms of the additional funding we will provide to support the development of the Translation, Interpreting and Communication Service (TICS). This will help to enable people to access services more easily, and to be communicated with in an appropriate manner that allows them to be partners in the own care and to understand their rights and responsibilities.
The Patient Advice and Support Service, Patient Rights Officers and the complaints process will also promote equality of opportunity by providing support and advice to people who may not otherwise be able to or know how to raise a complaint or issue about the health service.

Providing additional funding to support advocacy services will also help to promote equality of opportunity by enabling more people who cannot uphold their rights on their own to be supported when using the health service, or when making a complaint.

Is a Further Impact Assessment Needed?

There is sufficient evidence of the interaction between equality groups and access to and experiences of health care services to be able to undertake a meaningful EQIA. The Scottish Government has also consulted extensively as part of the Bill consultation, and has met separately with organisations representing equality groups, particularly with those representing disabled people. There will be further engagement with people and organisations from across the equality strands as part of the ongoing parliamentary process, and we will reflect on any issues identified in the EQIA.

One group with which there has been the least engagement is lesbian, gay, bisexual and transgender (LGBT) people and organisations, although there was a focus group with LGBT people as part of the Bill consultation process. The Scottish Government believes that the Bill will have a positive impact on LGBT people, but is aware that there will need to be further engagement as the Bill enters the parliamentary stages which we will reflect in the EQIA.

Update – Since the Bill was introduced to the Scottish Parliament, the Scottish Government has met with Equality Network and Scottish Transgender Alliance, both organisations representing the LGBT community in Scotland, to discuss the Bill and its implications for LGBT people. The groups were generally positive about the potential of the Bill to have a constructive impact on the way that health care is provided to LGBT people, but concerned about how the Bill would be enforced. For a fuller discussion of the issues raised, please see the LGBT section of this EQIA (above).

Monitoring

The Scottish Government will be monitoring the impact of the Patient Rights Bill through a number of avenues. One of the ways in which compliance with patient rights legislation will be monitored is through the "Participation Standard", which NHS Boards in Scotland will have to meet from April 2010 to show that they are involving the people who use their services. The Participation Standard consolidates existing standards, guidance and practice statements into a more structured and cohesive framework, focusing on three key areas: Patient Focus; Public Involvement; and Corporate Governance of Participation. Each key area is supported by a wide range of criteria against which Health Boards must demonstrate the actions they have taken.
Better Together: Scotland’s Patient Experience Programme will provide a measure of progress against the delivery of patient focussed services by health boards, which reflect the principles raised in the Bill. Better Together will use an evidence-based approach, including surveys, focus groups and the collection of patient stories, to find out about patients’ experiences of their care in the NHS. Results from the patient experience surveys will be published by different equality strands where it is statistically valid to do so. Further work will be undertaken with those who may find it difficult to complete surveys for communication, impairment or other reasons.

Furthermore, as part of the government’s work developing the proposed Quality Strategy for NHS Scotland, we have committed to exploring a range of measures that will demonstrate improvements in the delivery of patient-focused care. We are investigating the possibility of using a Patient-reported outcome measures (PROMS) based approach to do this.

In terms of the Patient Advice and Support Service (PASS), the contract specification which will be drawn up by the Common Services Agency will include details of how the service will be monitored and the statistical information that Health Boards should receive from the service, which will include equality monitoring. Currently the Scottish Health Council has a role to monitor the existing Independent Advice and Support Service, and it is envisaged that this role will continue for PASS.
1. Summary of key points

2. Introduction

3. Concerns and recommendations:
   - Complaints (section 11)
   - Patient Feedback (section 12)
   - Patient Advice and Support Service:
     - Establishment and Funding (section 14)
     - Patient Advice and Support Service (section 15)
     - Patient Rights Officers (section 16)
   - Duties to Share Information (section 17)

Summary

4. Citizen Advice Scotland (CAS) welcomes the ethos and health care principles that underpin the Patient Rights (Scotland) Bill. However, we have specific concerns with some of the main provisions of the Bill.

5. CAS supports the following features of the Bill:
   - The introduction of the Patient Advice and Support Service (PASS);
   - The creation of the post of Patient Rights Officer;
   - The introduction of the right to make complaints and provide feedback;
   - The commitment to providing patients with details on the support and advice available to them and information on how they can make complaints (section 1, clause 8, part 2c);
   - The commitment to ensuring that those making a complaint are given details of the advice and support available to them, that the details of this advice and support is publicised, and that complaints should be monitored (section 1, clause 11, part 3).

6. CAS has concerns regarding:
   - The lack of obligation on the NHS to provide feedback on submitted complaints;
   - The lack of detail provided on the role and structure of the Patient Advice and Support Service and the Patient Rights Officers;
The lack of clarity on whether and how the service standards set by the Independent Advice and Support Service (IASS) will be undertaken and maintained by PASS;

Patient Rights Officers covering level one and two complaints about the NHS (see appendix).*

7. Although the Bill will improve patient rights in Scotland, we are concerned that the NHS is not under any obligation to proactively provide information to patients on the progress of complaints and concerns raised. In addition, there is no obligation on the NHS to provide this information to the Patient Advice and Support Service either when the service has assisted the patient in filing complaints, concerns or comments.

8. There is also a lack of clarity on how the new advice and complaints service will affect the holistic support and advice work currently being carried out by the Independent Advice and Support Service.

Introduction

9. Citizens Advice Scotland (CAS) is the umbrella organisation for Scotland’s network of 83 Citizens Advice Bureau (CAB) offices. These bureaux deliver free, impartial and confidential frontline advice services through more than 200 service points across the country, from the city centres of Glasgow and Edinburgh to the Highlands, Islands and rural Borders communities.

10. In 2008/09, the Scottish CAB service dealt with just under one million client issues resulting in 2,677 enquiries handled by bureaux across Scotland each day of the year. The sorts of issues dealt with by bureaux include welfare benefits, housing, debt, consumer and employment. The CAB service in Scotland strives to ensure that people have access to information about their rights and responsibilities.

11. Last year the CAB service in Scotland dealt with over 29,000 sickness benefit issues and 59,260 disability benefit issues. In this period the service also dealt with a total of 324,800 debt issues, 257,444 benefit issues, 86,897 housing issues and 74,017 employment related issues accounting for 76% of all client issues.

12. The Independent Advice and Support Service (IASS) is a part of the CAB service in Scotland. Funded by local NHS boards, IASS offers advice and support to all NHS users and their families in relation to any concerns and complaints they may have regarding care received from the NHS. The service also provides general advice and has a holistic outlook to supporting its clients, as patients’ health concerns are frequently interlinked with other issues they are experiencing such as debt or employment issues which can have a significant impact on people’s health and well being.1

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1 Greater Glasgow and Clyde Citizens Advice bureaux report assisting with 1154 issues through the IASS service in 2008/09.
13. CAS welcomes the Patient Rights (Scotland) Bill, although we have serious concerns about the following:

- NHS feedback following submission of a complaint;
- The role and structure of the Patient Advice and Support Service (PASS);
- The role of Patient Rights Officers;
- The lack of provision for independent evaluation of PASS and the outcomes that it produces.

**Concerns and Recommendations**

**Section 11: Complaints**

14. CAS is concerned that the Bill does not explicitly include a requirement for the NHS to provide feedback to patients who have submitted a complaint, commented on their experiences of the NHS, or raised concerns about its services.

15. We recommend the inclusion of a requirement for the NHS to provide feedback both directly to patients and to the Patient Advice and Support Service (PASS) when it has been involved in supporting a patient. This would allow PASS to monitor the NHS's response to the complaints and comments it receives, and measure the impact that PASS has had on any improvements made to the services provided by the NHS.

**Section 12: Patient Feedback**

Please note that the concerns and recommendations we outlined above in relation to section 11 of the Bill also apply to this section.

16. While CAS welcomes the establishment of PASS, which builds effectively on the work already being carried out by IASS, we have some concerns about how this service may operate.

17. The precise role and possible structure of PASS is unclear, as provision on both a local health board basis and national basis are mentioned in the Bill, associated explanatory notes and memoranda.

More clarity is also required on how Patient Rights Officers would be managed by PASS, both in health board areas and across Scotland.
18. It is essential that the service is impartial, independent and confidential. Based on our experiences with IASS, we therefore consider that the service will need to have in place the following elements:

- Reliable, quality assured, current and comprehensive information sources;
- Effective training and support for staff;
- Independent quality control systems and clear criteria against which its management, administration, service provision, advice and information provision can be measured and reported on;
- Clear systems for collecting performance information and statistics for reporting to the NHS, the Scottish Government, the Scottish Health Council, with this information made available in the public domain;
- Delivery structures that ensure consistent service provision across the whole of Scotland (avoiding any postcode lottery or variation in standards) and that ensure local access to support wherever possible;
- Systems to ensure that the service is well publicised.

19. The establishment and maintenance of a central support service to cover the whole of Scotland will be crucial to the effective delivery of PASS. IASS’s experience to date indicates that central provision is required to:

- Gather, collate and report on statistics and other data in relation to the performance of the service on both a health board and Scotland-wide basis. Without a central resource, consistency of reporting will be lost and it will not be possible to gather data for national stakeholders with which to measure, benchmark and compare performance;
- Provide standardised training programmes to ensure that all Patient Rights Officers have the appropriate knowledge, skills and competencies;
- Provide social policy information in terms of trends, patterns, and issues raised by users of the service for use by the NHS and others in policy development;
- Market the service consistently across the whole of Scotland to potential users, NHS staff, agencies who are likely to refer patients, and to the general public.

Section 14: Patient Advice and Support Service: Establishment and Funding
Please note that the concerns and recommendations we outlined above in relation to section 12 of the Bill also apply to this section.

20. CAS strongly recommends that PASS continues with the provision and delivery of general information, advice and support service to patients, their families and carers as currently provided by IASS. Feedback from a sample of IASS users suggests that the holistic advice and information provided by this service is highly valued. Furthermore, Aberdeen University published a report a few years ago outlining the positive impact bureaux outreach services had on patients and their families in Aberdeen.2

21. Independent research evidence3 clearly demonstrates that the provision of information and advice about, for example, welfare benefits, debt, housing and employment assists people in the following ways:

- It reduces anxiety and stress and helps users to feel more in control of their situation;
- This in turn reduces the need for prescriptions such as anti-depressants, required by some patients to help them cope, and reduces the number of visits that they make to GPs and other health professionals;
- It can help people to move out of health care accommodation and back to their homes by assisting them to access both the support services and adaptations to their homes that they need in order to do so.

22. It will be important that the budget for PASS includes costs relating to marketing, training, performance reporting and provision of information.

Section 15: Patient Advice and Support Service (PASS)

Please see our comments on section 14 (above).

23. IASS is currently delivered by bureaux across Scotland. General advice and information on welfare benefits, debt, employment, housing, relationships and access to health services is delivered alongside information and advice on level one and level two complaints about the NHS. The Bill suggests that all such work would be carried out by paid Patient Rights Officers. We are concerned that this will result in:

2 Farmer, Jane and Lucy Kennedy, ‘CAB outreach services evaluation: A report on the impact of Citizens Advice Bureau outreach services at Aberdeen Royal Infirmary and Banff and Buchan on client health and professional workload’ by Jane Farmer and Lucy Kennedy, University of Aberdeen, Department of Management Studies, May 2001.

• Loss of integration of complaints and patient rights associated work with a broader, more holistic service which caters to users’ social and economic needs as well as their NHS-related ones;

• Reduced access to the service, particularly in remote and rural areas. At present, NHS users can access IASS through over 200 outlets across Scotland and they can be referred for specialist help by an IASS caseworker from any one of these locations. Any immediate or urgent concerns can be dealt with on the spot, prior to a referral being made;

• Higher service costs. A considerable amount of the work assigned by the Bill to Patient Rights Officers could actually be very effectively dealt with by local CAB advisers. This would create economies of scale and cost savings that would not be present if the service were to be delivered solely by Patient Rights Officers, as outlined in the Bill;

• Patient Rights Officers are unlikely to be able to assist users with all of their information and advice needs. Users may, for example, require assistance with claiming welfare benefits or managing complex debt. IASS is built onto the existing information, advice and support structure available through the CAB service and at the moment, users can be referred to in-house specialists where relevant. It is important that PASS continues to make similar provisions available to users.

24. CAS agrees that it is important for patients to take responsibility for their own health and well-being. We recommend that PASS plays a role in assisting and educating patients through the provision of health information; assistance to access, interpret and effectively use health information; and referrals to appropriate support services.

25. We also recommend that an independent evaluation of PASS be carried out annually.

Section 16: Patient Rights Officers

Please see our comments on section 15 (above).

Section 17: Duties to share information

26. While CAS broadly welcomes these provisions, we feel that this section of the Bill could be strengthened through the following:

• Placing an obligation on the NHS to market PASS effectively;

• Placing an obligation on the NHS to provide feedback to patients and, where relevant, to PASS about changes or improvements
made as a result of the feedback, comments or complaints made by NHS users.

Conclusion:

27. CAS supports the principles of the Patient Rights (Scotland) Bill, ensuring that patients are able to exercise their rights and are aware of their responsibilities. We also welcome the creation of PASS and the new role of Patient Rights Officers.

28. We are, however, concerned that PASS may fail to provide the holistic service that is available to patients currently through IASS. If this element of service provision is omitted from the new structure, the efficiency and cost effectiveness that would have resulted from its use for level one and two complaints will be lost.

29. Consequently, we recommend that the structure and role played by PASS and Patient Rights Officers be clarified and that adequate provisions be made to ensure patient well being and the success of the service.

EXPLANATORY NOTES:

30. We strongly support the provision of education, training and awareness-raising about PASS and the role of Patient Rights Officers through NHS Education for Scotland (NES). Experience of delivering IASS has demonstrated the importance of this in ensuring take up of the support service.

Alizeh Hussain
Social Policy Officer (Parliamentary)
Citizens Advice Scotland
10 May 2010
Patient Rights (Scotland) Bill

Consumer Focus Scotland

Introduction

Consumer Focus Scotland started work on 1 October 2008. Consumer Focus Scotland was formed through the merger of three organisations – the Scottish Consumer Council, energywatch Scotland, and Postwatch Scotland.

Consumer Focus Scotland works to secure a fair deal for consumers in both private markets and public services, by promoting fairer markets, greater value for money, and improved customer service. While producers of goods and services are usually well-organised and articulate when protecting their own interests, individual consumers very often are not. The people whose interests we represent are consumers of all kinds: they may be patients, tenants, parents, solicitors’ clients, public transport users, or shoppers in a supermarket.

We have a commitment to work on behalf of vulnerable consumers, particularly in the energy and post sectors, and a duty to work on issues of sustainable development.

General comments

Consumer Focus Scotland welcomes the opportunity to provide written evidence on the Patient Rights (Scotland) Bill to the Health and Sport Committee of the Scottish Parliament. We have a keen interest in this area because Health Rights Information Scotland, a joint initiative between the Scottish Government and Consumer Focus Scotland, is based in our offices.

The project already aims to raise people’s awareness of their existing rights as patients, and works closely with NHS boards to make sure good quality, accessible and consistent information is available in healthcare settings throughout Scotland. Consumer Focus Scotland responded to the consultation on the proposal for a Bill¹ and we reiterate some of our comments in this evidence.

The Committee is seeking evidence in four areas:

• The patient rights and health care principles, and the criteria on which those rights are based, as set out in the Bill (Sections 1 to 5)

• The 12 week treatment time guarantee and the provisions to deal with breaches of the guarantee (Sections 6 to 10)

• The complaints and patient feedback system set out in the Bill¹ (Section 11)

¹ Consumer Focus Scotland, Consultation on a patients’ rights bill for users of the NHS in Scotland, January 2009.
• The patient advice system and the role of Patient Rights Officers (Sections 14 to 17)

1 Patient rights and health care principles

Patient rights
Consumer Focus Scotland starts from the position that patients in Scotland already have rights in relation to the healthcare they receive. These rights go well beyond those mentioned in or created by the Bill. For example, patients have rights:

• created by other pieces of legislation, like the right to see their health records, to be registered with a GP, or not to be discriminated against

• created by the common law, for example the right to refuse medical treatment

• based on government policy or on service standards, for example the right to expect to receive treatment within current waiting times targets.

We believe that the Patient Rights (Scotland) Bill can strengthen and support the idea that patients have rights, by giving patients “rights recognition in the eyes of the law. However, we would express caution in relation to four main points:

• it is not made entirely clear in the Bill that patients have other rights in relation to their healthcare;

• the rights of patients should not therefore be defined solely in terms of the rights of patients under the Bill, as is done in section 15(4);

• the important thing about rights is not that people have them, but that they are able to make them a reality. The way patient rights are made a reality is at least as important as the fact that some of the rights are set out in a Bill;

• the provisos contained in section 2(2) reflect the reality that in healthcare settings rights are not absolute, but depend on the resources available, and the needs of other patients.

Making rights a reality requires various actions:

• clear communication of the key message that people have rights in relation to their healthcare;

• easy access to information about what their rights are and what this means in practice;

• easy access to sources of support and advice.

While Health Rights Information Scotland (HRIS) already provides a variety of information about people’s rights, the Bill provides an opportunity to restate patients’ rights in a way which reflects the broad range of legal rights and legitimate expectations which they have, and which includes the specific commitments made in the Bill. Information needs to be provided at different levels of detail for different circumstances, and to support the key message of the Bill there will be a need for communication, focusing on a simple statement that people do have rights in relation to their healthcare. Consideration will need to be given as to whom the communication is intended to reach, and the most effective and relevant way to do this.

Our experience, through HRIS, of the way information is made available to patients suggests that even when good quality information exists, it is not always easy for patients to get that information. We consider that the Bill would be strengthened by placing a duty on NHS boards to ensure that information about patients’ rights is made available to patients when they need it.

In the Bill, it is only the patient advice and support service which is given the responsibility for providing information and advice to patients. But this service will be independent of the NHS, and most likely not located on NHS premises, so there is a danger that there will still be a gap in the provision of information to patients in the settings where they are most likely to look for it, i.e. places like their GP surgery, hospital waiting rooms etc. Placing a duty on NHS boards to provide information and advice would be a useful addition to the Bill.

Healthcare principles

These principles are set out in a schedule to the Bill. They deal with the way a person should be treated by the NHS rather than what they are entitled to from it. While they do, in general, reflect the things which matter to patients about how they are treated, we have some specific comments.

1 Anything done in relation to the patient takes into account the patient’s needs. We would prefer it if this included the words “and preferences”, to show that decisions include patients wherever possible.

6. The patient’s abilities, characteristics and circumstances are considered. This could be read as suggesting that it is acceptable to discriminate between people on the grounds of, for example, their characteristics. While it is correct that services should consider and take account of these things, they should

2 see www.hris.org.uk
not then use these as a basis for refusing or changing a service. This needs to be made clear.

7. *Regard is had to the importance of providing the optimum benefit to the patient’s health and wellbeing.*
   “Regard is had” sounds rather weak. This should be strengthened, for example by saying “consideration must always be given to …”

8. *The range of options available in the patient’s case is considered.*
   This is quite vague, and does not state who will consider them, or whether they will be discussed with the patient. We would suggest this should be strengthened to say “Where there are different options for the care or treatment of a patient, these should all be considered and discussed with the patient, family or carers.”

10. *Patients participate as fully as possible in decisions relating to the patient’s health and wellbeing.*
   We consider that patients should not be forced to participate in decisions if they do not want to, and would prefer if this was worded to say “Patients participate as fully as they want to in decisions … etc”.

16. *Waste of resources in the provision of health care is avoided.*
   This does not sit well in a list of principles about the way patient care should be provided. We would suggest that this is removed.

2 Treatment time guarantee

The treatment time guarantee which is included in the Bill relates only to treatment in a hospital as an in-patient or day case (where an overnight stay is not required). There are many other target times for particular kinds of treatment in different settings which are unaffected by the Bill. It seems curious that this one kind of treatment is singled out in this way, by making the treatment time guarantee statutory.

But what is given on the one hand, an apparent “right” to treatment within 12 weeks, is taken away with the other, when section 18 makes it clear that this right is not enforceable. Where a health board has not complied with the guarantee, it is required by section 8 to make arrangements to ensure the treatment starts as soon as possible, to explain to the patient why treatment has not started, and to provide information about advice and support and how to make a complaint. Section 18 explicitly states that nothing in the Act gives rise to any liability to pay damages, or to any right to take action to enforce the “right” to treatment.

We do not believe that including this treatment time guarantee in the Bill gives patients any more protection than is currently offered by the national waiting times targets, and is potentially confusing to patients who may think they have rights, but which they are unable to enforce in any way.

3 Complaints and patient feedback
The Bill claims to introduce a new right to complain. But in practice people already have a right to complain, even if the right is not an enforceable legal right. NHS healthcare providers are already required by policy and guidance to implement the NHS complaints procedure, to publicise this and even encourage patients, their families and carers to use it, as one of the ways in which useful feedback can be obtained on the basis of which services can be improved. Health Rights Information Scotland already refers to people having a right to complain in the information it provides.

Putting this right into legislation does not really add anything to the rights which patients already have, and we question what is achieved by doing this. As with other aspects of the Bill, the important thing is what helps to make rights real for people. What helps or supports people to make a complaint? What would encourage people to give feedback, good or bad, on the service they have received?

The things which can help are good information about how to do these things, and easy access to people who can advise or help them. As with other aspects of the Bill, these things cannot be created by legislation, although they can be supported by legislation, for example section 11(3)(b) and (c) which require NHS bodies to publicise how complaints can be made and how they will be handled, and give patients advice and support about how to make a complaint.

We would like to see provision in the Bill for complaints to be handled through mediation where possible. It is in the interests of both patients and NHS bodies that disputes are resolved as early as possible, and the Bill provides an opportunity to encourage the use of mediation in relation to NHS complaints where appropriate. While provision for the use of mediation might be made through regulations under section 11 (4), putting this on the face of the Bill would help to raise awareness and use of mediation.

This would fit with the approach taken in other recent legislation, such as the Education (Additional Support for Learning) (Scotland) Act 2004, which places a duty on education authorities to make arrangements to provide independent mediation services to resolve disputes between parents or young people and the authority, and the Legal Profession and Legal Aid (Scotland) Act 2007, which gives power to the Scottish Legal Complaints Commission to mediate in complaints about legal practitioners. The Fit-for-Purpose Complaints System Action Group also recommended in its final report that mediation should be used where appropriate in complaints handling in public services in Scotland.

While we support the imposition of a duty on NHS bodies to publicise how complaints are made and handled, there is a danger that they may interpret this as a requirement to produce more information themselves about complaints. With HRIS already producing quality approved information for all

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3 Fit-for-Purpose Complaints System Action Group: Report to Ministers, July 2008
boards, and with NHS inform providing easy access to information for members of the public, it is important that this supportive infrastructure is supported and built on by NHS bodies, and that the legislation does not provoke a new cottage industry of information production.

4 Patient advice and support service and the role of Patient Rights Officers

The Bill proposes the establishment of a new patient advice and support service (PASS). Unlike the current service, known as the Independent Advice and Support Service (IASS), the new service will be established on a national basis, rather than each NHS board contracting with a local provider. As with IASS, the service cannot be provided by a health service body, and must be independent. The service will be staffed by Patient Rights Officers.

While Consumer Focus Scotland welcomes the proposed introduction of Patient Rights Officers, we believe that they would be more effective at intervening in situations before they escalate into becoming complaints if they were located in healthcare settings. We have previously argued that every hospital and every Community Health Partnership should be required to have a Patient Rights Officer. While we understand the desirability of patients having access to sources of independent advice and support, we consider that there are also reasons for having patient rights officers employed by the NHS working as key members of NHS teams. They would:

- provide a highly visible, responsive service for all patients, carers and members of the public
- provide information and advice about health and health services
- handle patients’ concerns early, and resolve issues and concerns informally and quickly, before they become complaints
- provide information on the NHS complaints procedure and how to give feedback
- refer patients to sources of independent advice and support, for example CAB services, advocacy services, or other patient support groups
- provide feedback to hospitals, CHPs and NHS boards about aspects of patient experience, complaints and information provision
- act as a gateway for patient focus and public involvement activity.

An evaluation of the Patient Advice and Liaison Service (PALS) in England\(^4\), which is an in-house service, showed that the service had:

- improved the patient experience
- led to improvements in services
- filtered and/or enabled complaints.

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\(^4\) University of the West of England, Developing the patient advice and liaison service2006
Functions of the PASS

Section 15 sets out the role and functions of the Patient Advice and Support Service. In section 15(4) it is stated for the purposes of the functions set out in subsection (2),

\[ \text{a reference to the rights of patients is a reference to the rights of patients under this Act.} \]

This would mean that the PASS service would not be able to promote an awareness and understanding of other rights which people have as patients in the NHS. We believe that this subsection is an error which needs to be corrected.

Patient Rights Officers are described as “providing information and advice” about various things. We think it is essential to emphasise that it is not the role of PASS or the PROs to produce information, but to make available information produced primarily by other people, and in particular the quality assured information which will be available through NHS inform.

Equally, we think it is important that there is a duty on NHS bodies themselves to provide the kind of information described in section 16 (a), and that NHS bodies should not be able to claim that this is the job of an external independent body.

5 Explanatory notes

We welcome the recognition in the explanatory notes to the Bill that HRIS will be supporting the Bill by producing new information about health rights for members of the public. This will be one of the most important ways in which people’s rights can be made a reality.

However, we are dismayed by the suggestion that the role of HRIS in the production of core national information about rights and responsibilities, NHS services, and how to use those services may not be a continuing one. We believe that the model established by HRIS for central production of information for use throughout the NHS is one which should be built on and continued. It provides a source of key information for the new NHS inform service, and we would urge the Scottish Government to ensure that the role and functions of HRIS will be preserved in the future.

Sarah O'Neill
Head of Policy Solicitor
Consumer Focus Scotland
6 May 2010

Patient Rights (Scotland) Bill

Scottish Public Services Ombudsman

Introduction
Thank you for requesting written evidence to inform the Health and Sport Committee’s consideration of the Patient Rights (Scotland) Bill (the Bill) at Stage 1.

The Scottish Public Services Ombudsman (SPSO) provides a ‘one-stop-shop’ for members of the public making complaints about organisations providing public services in Scotland. This includes complaints about the National Health Service (NHS).

The SPSO’s experience of dealing with complaints from members of the public about the NHS provides us with a unique perspective on the delivery of health services in Scotland and the concerns of service users.

The notion that patients have rights in relation to their health care is at the heart of the work we do in securing justice for individuals who experience a problem with the NHS. This submission draws on this experience to comment on the proposals in the Bill.

The patient rights and health care principles
We consider that the rights and healthcare principles included in the Bill reflect current good practice in healthcare delivery. With the exception of the treatment time guarantee, the Bill does not appear to provide any significant extension to existing rights and expectations in relation to the quality of NHS services provided in Scotland. Instead, it confirms and makes explicit rights and expectations that currently exist.

The notion of enshrining these rights and principles within primary legislation carries the risk of an unwelcome increase in legalism and litigation in disputes between members of the public and the NHS. The use of formal, adversarial and potentially expensive procedures in this context would be unhelpful. In this respect, we note that the important protections and limitations set out in Section 18 should ensure that this does not occur in practice.

Although the SPSO’s investigation reports into health complaints usually do not refer to rights as such, it is implicit that – where maladministration or service failure have been identified – a patient’s right to a high standard of service will not have been met. Recurrent themes that have emerged in our work include: the lack of dignity with which patients are sometimes treated; failures in communication with patients; and poor care for elderly patients.

The Annex to this submission contains case summaries taken from the SPSO’s Commentaries, which may provide some useful illustrative examples of our work on NHS complaints and a helpful context for the Committee’s consideration of the rights and principles outlined in the Bill.
While we recognise that the vast majority of interactions between members of the public and the NHS in Scotland are successful, we welcome any measures which will help to ensure that patients are treated fairly and that issues such as those noted above and in the Annex are avoided. While the provision of statutory rights is unlikely to achieve this in itself, it may provide a useful addition to current initiatives to assure and enhance the quality of health services provided to members of the public.

It should be noted that, although the patient rights being proposed in the Bill do not give rise to any additional legal remedies (as noted in Section 18, Sub-Section 2), members of the public will be able to bring complaints to the SPSO alleging a breach of those rights. While the SPSO is not empowered to determine legal rights and obligations, we are able to investigate whether due regard has been given to any legislative provisions (as failure to do so may constitute maladministration). Consequently, we will be able to uphold complaints where due regard has not been given to the provisions in the Bill.

In publicising the patient rights contained in the Bill, care should be taken to make clear that such rights are generally not absolute but must be balanced with the rights of others and considered in the particular circumstances of the individual concerned. This is recognised in Section 2, Sub-Section 2 of the Bill and it would be helpful if these provisions were clearly highlighted to patients to avoid the provision of statutory rights leading to unrealistic expectations regarding rights and entitlements.

The 12 week treatment time guarantee
The SPSO frequently considers complaints about delay in the provision of health services and we are aware that this can be a particular source of frustration and dissatisfaction for members of the public. Providing clarity around the timescale between a treatment being agreed by a member of the public and the treatment commencing is likely to be helpful. Members of the public with health problems, who will naturally be anxious about their conditions, are likely to benefit from the increased certainty afforded by the proposed guarantee.

The complaint and feedback system
The landscape of public sector complaints handling has recently been reviewed and proposals are currently being considered by the Scottish Parliament for the SPSO to take on the role of supporting the design and development of good practice in public sector complaints handling. A key aspect of this role will be the standardisation of practice across the public sector and ensuring that complaints systems are designed to ensure and support learning from complaints.

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2 Public Services Reform (Scotland) Bill, details at: http://www.scottish.parliament.uk/s3/bills/26-PubSerRef/index.htm
The Bill's provisions with regard to complaints and, in particular, the emphasis on monitoring complaints and informal feedback to secure service improvements, aligns with the proposed extension to the SPSO's remit. In light of this, in preparing and issuing the regulations and directions referred to Section 11, Sub-Section 4, it is hoped Scottish Ministers will work closely with the SPSO to ensure that the NHS complaints system reflects best practice and achieves coherence within the broader, simplified public sector complaints handling landscape.

Provisions to support more informal feedback are likely to be welcomed by members of the public who may not wish to complain formally, but who may nonetheless have valuable feedback to provide. Indeed, recent research has highlighted that there are many reasons why patients might not wish to complain and noted that the current system of receiving complaints could do more to capture and act on feedback.3

Concerns about complaints handling often form a secondary aspect of the complaints the SPSO receives and it may be helpful for the Committee to have an indication of the sorts of issues we have identified in this area and the recommendations we have made to Health Boards. In the last few years, we have made recommendations that NHS providers should:

- reflect on their complaints policy, review their complaints protocol and discuss how to respond to complaints from non-patients;
- ensure that information is obtained from the staff involved in a case to allow complaints to be investigated appropriately and all issues raised in complaints are addressed;
- remind staff dealing with complaints of the need to have regard to the NHS complaints procedure timescales;
- remind staff of their obligations to manage complaints in line with the NHS complaints procedure and take action to ensure that information about the NHS complaints procedure which is held locally in hospitals and clinics is up to date;
- review their complaints handling procedure to ensure that complainants are given direct answers to reasonable direct questions, that individual circumstances, distress and stated preferences are reasonably taken into account when suggesting meetings with correspondents and complainants, that it is made clear to correspondents how to set in motion the complaints procedure and that avoidable errors are reasonably eliminated, taking into account the individual circumstances of a complaint;

• consider how NHS Scotland’s publication: ‘Can I help you? Learning from comments complaints and suggestions’ should be taken into account when making decisions on complaint time limits;

• ensure that guidance to complaint handling staff emphasises the need for full disclosure of relevant information;

• when responding to complaints, take into account the need to provide as full information as possible, particularly where interviews have been held with staff;

• undertake a full review of the operation of their complaints process and the relationship of this to clinical governance, as a matter of urgency; and

• urgently establish a complaints procedure in line with the standards set out by the NHS complaints procedure.

While it is not possible to conclude that there are systemic problems in NHS complaints handling from the evidence of individual complaints, these do indicate that the standard of complaints handling in the NHS can be variable and occasionally poor. The provisions in the Bill do not address the above issues in detail, but it may be helpful for any guidance that is subsequently issued to pick up on some of the issues identified in the course of the SPSO’s investigations.

Patient advice and support service
The introduction of the Independent Advice and Support Service (IASS) in March 2006 was welcomed and supported by SPSO, in recognition of the fact that complaints about healthcare often require a level of independent support and advice additional to that required in other areas of the public sector. Recent research has shown that IASS has helped to support patients’ in complaining about the NHS. 4

The Bill’s proposals to increase the level of support currently being provided is likely to help patients feel more able to raise their concerns about the NHS. While the introduction of the new Patient Advice and Support Service (PASS) may lead to a rise in the number of complaints received by Health Boards, the new Patient Rights Officers should also help to ensure that complaints are properly directed and resolved more quickly.

Jim Martin
Scottish Public Services Ombudsman
7 May 2010

Annex

SPSO Case Summaries

**Diagnosis; follow-up care; communication; complaint handling**

**A Medical Practice, Greater Glasgow and Clyde NHS Board (200801102)**

After she was diagnosed with diabetes, Ms C raised a number of concerns about her GP Practice (the Practice)'s handling of the diagnosis and aftercare. I upheld all her complaints as I found that the Practice had not followed recognised procedures in reaching a diagnosis, or in their complaint handling. I also found that they had not arranged appropriate follow-up for Ms C, and that their communication with her about the diagnosis and test results was inadequate. I recommended that the Practice put in place protocols to ensure that diabetes is in future diagnosed in line with recognised practices, and that newly diagnosed diabetics receive appropriate follow-up care. I also recommended that the Practice take steps to ensure that in future they deal with complaints in line with the NHS complaints procedure and asked them to apologise in writing to Ms C for the failings identified in my report.

**Clinical treatment; complaint handling; policy/administration**

**A Dental Surgery (200802819)**

Mr C complained that his Dental Practice did not provide him with appropriate treatment, and that when he complained they acted unprofessionally and unhelpfully. I upheld both his complaints as I found that information about Mr C’s treatment was not adequately recorded or protected within the practice; details of his clinical treatment were missing; there was no complaints procedure in place, and the NHS complaints procedure was not followed. I recommended that the Practice urgently establish a complaints procedure and implement policies to record and protect all clinical information in future; that they ensure staff understand these; that they identify and retrieve the missing information about Mr C’s treatment; and that they apologise to Mr C for the failures identified and for their poor handling of his complaint.

**Delay in diagnosis; clinical treatment; policy/administration; communication**

**Greater Glasgow and Clyde NHS Board (200802662)**

Mrs C was unhappy with the care and treatment that her daughter (Miss A) received when she attended hospital with back pain. Miss A was treated for a chest infection and referred for physiotherapy, but was later diagnosed with a spinal infection. Mrs C complained that the infection was not diagnosed earlier. Miss A was also provided with which meant she could not be operated on. Mrs C was also concerned that surgical treatment could not be carried out, as Miss A had been provided with an anti-coagulant medicine because of a history of DVT (deep vein thrombosis). I upheld the complaint about delay in diagnosis and recommended that the Board apologise to Miss A for this and review their process for identifying and acting upon warning indicators in patients. I also recommended that they ensure that officers handling complaints accurately reflect in their responses information provided by clinicians. I did not uphold the complaint about medication, as I found that
treatment was appropriate and surgery would not have been the normal treatment for a spinal infection.

**Care of the elderly; clinical treatment; communication; record-keeping**

Lothian NHS Board (200901408)

Mr C was unhappy with the care provided to his late wife (Mrs C) by the Board. Mrs C had multiple health problems, including dementia. When her health began to deteriorate after a fall she attended a hospital Accident and Emergency unit. She was admitted to the hospital, but was transferred to a second hospital the following day. She was given a course of antibiotics, some of which she refused. No assessment was made of Mrs C’s ability to make that decision, and the antibiotics were subsequently discontinued. Mrs C's condition continued to deteriorate and she died in the second hospital just over a week later. I upheld all Mr C’s complaints as I found that the Board had not provided appropriate treatment or antibiotics, nor had they communicated effectively with Mr C about his wife’s condition or treatment, especially given that Mrs C herself did not seem to be competent to refuse treatment. I made a number of recommendations, including reviews of policy and procedures, and the provision of guidance and information to staff, all of which can be read in full in my report. I also recommended that the Board apologise to Mr C for the failings identified in my report.

**Clinical treatment; communication; policy/administration**

Tayside NHS Board (200802400)

Miss C suffered from myotonic dystrophy. She also had learning difficulties. She died in hospital after minor surgery on her parotid gland. Her father (Mr C) complained about the care provided to Miss C before and after surgery. He said that she was not properly assessed by a consultant anaesthetist before her operation and that her post-operative care and treatment was inadequate. He was also unhappy about the way in which staff communicated with the family. I upheld all of Mr C’s complaints as I found that there had been significant failings by staff, especially given Miss C’s learning difficulties. I made a number of detailed recommendations about the Board’s arrangements, policies and procedures, particularly in relation to people with learning difficulties, and these are described in full in my report. I also recommended that the Board provide an explicit, unambiguous and meaningful apology to Miss C's family for all the failings identified in this report, detailing the steps they have put into place to ensure that a similar occurrence is not repeated.
The Patient Rights (Scotland) Bill seeks to create new statutory rights for those using the NHS, and to establish a set of principles which should underpin the delivery of health care.

The Bill would also create a statutory maximum treatment time guarantee of 12 weeks and renew the legislation on NHS complaints procedures. Complaints would be supported by the creation of a national Patient Advice and Support Service which would be staffed by the newly created post of Patient Rights Officer.

This briefing sets out the background to each of the key provisions in the Bill and examines the provisions in the context of responses to the Health and Sport Committee’s call for evidence. The briefing also examines recent experiences from England and Norway.
EXECUTIVE SUMMARY

Patient Rights (Scotland) Bill
Kathleen Robson

The Patient Rights (Scotland) Bill seeks to introduce new patient rights and principles for the delivery of health care. It also seeks to create a statutory treatment time guarantee of 12 weeks, renew the legislation relating to complaints and create a new patient advice and support service staffed by ‘Patient Rights Officers’.

Patients currently have a number of rights set out in legislation, case law and convention and this is communicated in the information produced by Health Rights Information Scotland. Patients can complain to the NHS with the possibility of further referral to the Scottish Public Services Ombudsman and, in some cases, the civil courts. They can also seek advice and support from the Independent Advice and Support Service. There are a number of targets for treatment waiting times including the recently introduced 18 week referral to treatment time (RTT) target.

Under the proposed legislation all current routes for legal redress would still exist but none of the provisions in the Bill would be legally enforceable although a declaratory judicial review could be pursued. In addition, the Bill provides that none of its provisions should prejudice clinical judgement or the efficient and effective use of resources. The estimated cost of the Bill is £862,000 in 2010/11, £3.69m in 2011/12 and £3.64m in 2012/13.

The main issues to arise from the Health & Sport Committee’s call for evidence included uncertainty over the need for legislation, the lack of sanctions and means of enforcement, and the cost of enacting the Bill when the public sector is facing financial constraints.

Patient Rights and Principles (pp7-10)

The Bill sets out a number of new rights which would be in addition to existing rights. NHS Boards would not have a specific duty to comply with the rights in the Bill but they would have a duty to ‘have regard to’ a set of principles which underpin the delivery of healthcare. The Bill also contains some provisions regarding patient responsibilities but these provisions are directed at NHS bodies and the newly created Patient Advice and Support Service. These bodies would be responsible for promoting and encouraging the responsibilities of patients.

Treatment Time Guarantee (pp10-13)

The Treatment Time Guarantee (TTG) is set at 12 weeks in the Bill. The Bill does not specify who would be eligible for the TTG as this would be established in regulations. However, the accompanying documents indicate it would apply to all elective inpatient and day case
treatment, but with some exceptions such as obstetrics, organ transplantation and fertility services. An NHS Board must take all reasonably practicable steps to ensure the TTG is met, including arranging treatment in another board area or with a suitable alternative provider. If the TTG is breached then the Board must write to the patient explaining why, make arrangements for treatment to start at the next available opportunity and give the patients details on how to make a complaint. At present, relatively few patients awaiting elective inpatient or day case treatment wait longer than 12 weeks.

**Complaints and Feedback (pp13-14)**

The Bill repeals the existing legislation covering hospital complaints and gives patients a specific right to complain, raise concerns and give feedback. It then provides that Ministers must ensure that NHS bodies should have adequate arrangements in place for handling, publicising and monitoring complaints. NHS bodies must also encourage feedback from patients.

**Patient Advice and Support Service and Patient Rights Officers (pp14-16)**

The Bill would establish a new Patient Advice and Support Service (PASS) which would be staffed by the newly created post of Patient Rights Officer (PRO). The PASS would replace the IASS and would be responsible for promoting the rights and patient responsibilities under the Bill, as well as advising and supporting those who wish to complain, raise a concern or give feedback. The PASS would be commissioned on a national basis and each Board would be expected to have at least one PRO in its area. PROs would be responsible for providing information and advice about the PASS, the health service, making complaints and giving feedback. They would also have a role in directing people to other sources of support such as advocacy.

**English NHS Constitution (pp16-18)**

England has a constitution which sets out the rights of its patients. The content of the constitution is not set in legislation, although legislation does give the NHS a duty to ‘have regard to’ the constitution. The constitution differs from the Bill in that it includes existing key rights and tries to bring them together in one place. It also differentiates between rights (legally enforceable) and pledges (not legally enforceable). The constitution has not yet been reviewed and early indications of its effect are unclear.

**Norwegian Patients’ Rights Act 1999 (pp18-20)**

The Bill is based on the Norwegian system which is underpinned by the Norwegian Patients’ Rights Act 1999. The 1999 Act established that a patient who is referred to specialist care has the rights to be assessed within 30 days. Those who are assessed as being in a priority group then have a right to an individual waiting time guarantee set by the specialist health service. Patients also have the right to a second opinion as well as the right to choose a hospital and receive necessary transportation. The legislation can be enforced through the civil courts.

There has not been a wholesale evaluation of the Norwegian Act but a review of relevant reports and statistics shows that it is not being fully complied with. For example, a proportion of patients do not see a specialist in 30 days and many do not receive treatment within the timescale set by their doctor. The numbers of complaints made under the Act has risen sharply in recent years but it is uncertain whether this reflects greater dissatisfaction or increased interaction. Only a small number of cases are reported to have reached the civil courts.
INTRODUCTION

The Patient Rights (Scotland) Bill (Scottish Parliament, 2010a) seeks to introduce new patient rights and principles for the delivery of health care. It also seeks to create a statutory treatment time guarantee of 12 weeks, revoke, restate and modify legislation for the complaints process, and to legislate for a Patient Advice and Support Service staffed by Patient Rights Officers. The Bill would fulfil a 2007 SNP manifesto pledge:

Individuals sometimes need to be treated more quickly than the national waiting time guarantees. To ensure this happens we will introduce a Patients Rights Bill to give every patient a legally binding waiting time guarantee appropriate for their condition (SNP, 2007).

The Government states that the intention of the Bill is to ‘reinforce and strengthen the Scottish Government’s commitment to place patients at the centre of the NHS in Scotland’ (Scottish Parliament, 2010b, para 3).

CONSULTATION

Between September 2008 and January 2009, the Government undertook an extensive consultation with a wide range of stakeholders. The Government reports that there was broad support for the proposals from all groups, although some concerns were expressed by those who would be involved in implementing the Bill, or from those who felt their particular issue was not covered (Scottish Parliament, 2010b).

The Health and Sport Committee also undertook its own call for evidence and received 41 responses. Of the 19 submissions in which a clear opinion was expressed, 16 could be classed as generally supportive of the Bill. Nevertheless, responses on all sides raised a number of issues in relation to the Bill as a whole (Robson, 2010).

KEY ISSUES REGARDING THE BILL IN GENERAL

The following section outlines some of the key issues raised during the Committee’s call for evidence with regard to the Bill as a whole. For more detail on the evidence received please see the SPICe summary of evidence (Robson, 2010) and the Health and Sport Committee webpage.

The need for legislation

While many respondents welcomed the intention of strengthening patient rights, some questioned the need for legislation to do this (Royal College of Nursing, the British Medical Association, Royal College of General Practitioners, 2010). It was suggested that a Patient’s charter or Constitution (see English NHS Constitution) would be a more appropriate approach and some highlighted that the rights in the Bill reflect existing rights and practice anyway. This view was backed by other submissions which questioned what the Bill added when many of its aims and provisions are already being met (e.g. NHS Lothian (2010) in relation to the treatment time guarantee).

The Government considered this issue following its own consultation and in the policy memorandum explains that it “believes that patient rights are extremely important and that they should be given the prominence and priority that primary legislation affords” (Scottish Parliament, 2010b, para 9)
Enforcement and lack of sanctions

Section 18 of the Bill restricts the potential for legal action relating to the Bill’s provisions. A number of submissions to the Committee’s call for evidence questioned the concept of having rights with no sanctions if those rights are not met. Some went so far as to question whether they could be considered as rights at all (Age Scotland, 2010).

Although the rights within the Bill would not be legally enforceable, a patient could seek a declaratory judicial review. This is a pronouncement that an individual or body has a specific right or duty. This remedy is useful where the petitioner wants to establish that a particular right exists, or that a particular status applies, which has been doubted or denied (Harvie-Clark, 2009b). Judicial review normally has various other legal remedies available alongside declarators but in this instance other remedies would be removed by section 18, namely:

- **damages** - an order to pay financial compensation for loss
- **specific implement** - an order to do something that was agreed in a contract
- **interdict** - an order to stop something, whether currently being done or planned
- **suspension** - an order to stop something currently being done but does not prevent a repetition of the action

All rights and related courses of action set out in law at present (e.g. negligence claims) would still be available to patients.

The policy memorandum explains that the Government’s consultation on the Bill uncovered concern that the Bill would be a ‘charter for lawyers’ and encourage a ‘compensation culture’ in the NHS. For this reason it states that the Bill does not make the rights legally enforceable.

Financial implications

Another key theme to emerge was the financial impact of putting the Bill into practice. Questions were raised as to whether now was the right time given that there is considerable financial pressure in the public sector (e.g. Angus Council, 2010; BMA, 2010). The financial memorandum to the Bill sets out the estimated cost of implementing the Bill as follows:

| Table 1: Summary of recurring and non-recurring costs of implementing the Patient Rights (Scotland) Bill |
|---------------------------------------------------------------|---------------|---------------|---------------|---------------|
| **Principles in provision of services** | **2010-11** | **2011-12** | **2012-13** |
| Recurring costs | Non-recurring costs | Recurring costs | Non-recurring costs | Recurring costs | Non-recurring costs |
| Principles in provision of services | - | £112,000 | - | £860,000 | - | £810,000 |
| The treatment time guarantee | - | - | - | - | - | - |
| Support and recourse | - | £750,000 | £2,581,000 | £250,000 | £2,581,000 | £250,000 |
| Sub-total | - | £862,000 | £2,581,000 | £1,110,000 | £2,581,000 | 1,060,000 |
| Total | £862,000 | £3,691,000 | £3,641,000 |

However, the financial memorandum explains that these figures include redirected funding from other spending in this area and therefore the total new additional money allocated for the Bill is
£784,000 in 2010/11, £2,666,000 in 2011/12 and £2,666,000 in 2012/13.

As outlined in the table above, there are expected to be 2 key areas of spend which parallel 2 key parts of the Bill i.e. implementation of the principles and the Patient Advice and Support Service. Estimated costs for each of these areas are explored in more detail in the relevant sections below.

SECTIONS 1-5: PATIENT RIGHTS AND HEALTH CARE PRINCIPLES

EXISTING PATIENT RIGHTS

Ministers have an overarching duty\(^1\) to provide comprehensive and integrated health services to prevent and treat illness and to improve the health of the population. This basic duty is also complemented by specific legislation and case law which afford patients certain rights. For example, the right to confidentiality, the right to refuse treatment and the right to access medical records. More generally, the NHS must also comply with other legislation such as the Human Rights Act 1998 and UK equalities legislation, and it should act compatibly with conventions such as the Convention on the Rights of Persons with Disabilities.

As a result, patient rights are enshrined in a complex system of legislation, conventions and case law and over the years there have been a number of efforts to communicate to patients what rights they have. In 1991 there was the ‘Patients Charter – A Charter for Health’ (Scottish Office, 1991). This was then superseded over a decade later by ‘The NHS and You’ (HRIS, Online). This is produced by Health Rights Information Scotland (HRIS\(^2\)) and is intended as a general statement about what people can expect from the NHS. The statement is also complemented by more detailed information such as:

- **Confidentiality – it’s your right** (HRIS, Online)
- **How to see your health records** (HRIS, Online)
- **Making a complaint about the NHS** (HRIS, Online)
- **Consent – it’s your decision** (HRIS, Online)

NHS Boards are responsible for printing and distributing HRIS leaflets in their area.

EXISTING AVENUES FOR REDRESS

Existing avenues for redress in the NHS include the complaints procedure, with possible referral to the Scottish Public Services Ombudsman (SPSO), and various forms of legal action which can be pursued through the civil courts.

Forms of legal action include bringing a claim in respect of negligence (including, but not restricted to, medical negligence), raising action which is competent under a particular statute in specified circumstances and lodging a petition with the Court of Session for judicial review. Judicial review is a type of court action which allows parties to challenge the exercise of power by public bodies and other official decision makers. Generally speaking it is concerned with the way the decision was taken, not the merits of the decision itself (Harvie-Clark, 2009b).

The NHS in Scotland deals with approximately 11,000 complaints every year and in 2009, 231 NHS complaints were referred to the SPSO\(^3\). In addition to this, 171 clinical negligence cases were settled in 2008/09 at a cost of £26m\(^4\).

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\(^1\) Section 1 of the National Health Service (Scotland) Act 1978 (c.29)

\(^2\) A project of Consumer Focus Scotland which is funded by the Scottish Government

\(^3\) PQ [S3W-28580](https://parliament.scot/ debatedbypq/2009-05-26/s3w-28580)

\(^4\) PQ [S3W-30597](https://parliament.scot/ debatedbypq/2009-06-16/s3w-30597)
BILL PROVISIONS – PATIENT RIGHTS AND PRINCIPLES

The Bill sets out that patients have a right that the health care received:

a.) Is patient focused: that is to say, anything done in relation to the patient must take into account the patient’s needs
b.) Has regard to the importance of providing the optimum benefit to the patient’s health and wellbeing
c.) Allows and encourages the patient to participate as fully as possible in decisions relating to the patient’s health and wellbeing
d.) Has regard to the importance of providing such information and support as is necessary to enable the patient to participate in accordance with paragraph (c).

The Bill also gives patients the right to complain, raise concerns and give feedback about the care they have received (s1(3)) (see also Sections 11-13: Complaints and Feedback).

However, the above rights are qualified by section 2 which states that the rights of other patients must be taken into account and that the delivery of healthcare must be ‘proportionate’ and ‘appropriate’ for each case. It also specifies that the rights should not prejudice clinical judgement as well as the effective and efficient use of health service organisations and resources (s18(1)(a) and 18(1)(b)).

The Bill does not place a specific duty on the NHS to comply with the rights but it does give the NHS a duty to ‘have regard to’ a set of principles when performing its functions. NHS bodies will also have to consider and take account of any related guidance. The principles are set out in Schedule 1 (see Annex A) and are broken down into the categories of patient focus, quality care and treatment, patient participation, communication and complaints.

The Patient Advice and Support Service (PASS) which is to be established under the Bill would be responsible for promoting awareness and understanding of the responsibilities of patients and rights under the Bill (see Sections 14-17: Patient Advice and Support Service and Patient Rights Officers).

There are 3 provisions in the Bill relating to patient responsibilities. Firstly, Schedule 1 sets out the principles that NHS bodies should have regard to in carrying out its functions, including:

‘Patients are encouraged to treat any person involved in the delivery of health care with dignity and respect’

Section 15(5) also states that the patient responsibilities which should be promoted by the PASS include:

- The responsibility of the patient for the patient’s own health and wellbeing, and
- The responsibility of the patient to behave appropriately in the receipt of health care

Section 18 restricts the potential for legal action in relation to the Bill’s provisions and does not give rise to any new liabilities. As a result, the rights and principles in the Bill would not be legally enforceable (see Enforcement).

FINANCIAL IMPLICATIONS OF THE RIGHTS AND PRINCIPLES

The financial memorandum judges that there will be two main cost implications from this part of the Bill:
1. Staff education and the development of training materials
2. Raising awareness

Staff education and the development of training materials is expected to be undertaken by NHS Education for Scotland (NES) and the cost estimates provided are based on the costs of similar projects undertaken previously by NES. The estimate provided is £94,000 in 2010/11 and £800,000 for each of the following 2 years.

Awareness raising will be two pronged, with NES taking this forward with staff (by integrating it into existing mechanisms) and HRIS leading on the public facing information. Communication materials will include posters, leaflets and a Patient Rights information pack. The financial memorandum gives some cost estimates for public awareness raising based on previous work carried out by HRIS. However, as the future of HRIS has not yet been decided the costs given are only 'indicative'. The costs are estimated to be £18,000 in 2010/11, £60,000 in 2011/12 and £10,000 in 2012/13 (Scottish Parliament, 2010c).

KEY ISSUES IN RELATION TO RIGHTS AND PRINCIPLES

The following summarises some of the main themes to emerge from Health and Sport Committee’s call for evidence in relation to sections 1-5 of the Bill.

Other patient rights

Some respondents highlighted that the Bill only sets out some of the rights currently available to patients. Consumer Focus Scotland (2010) pointed out that the existence of other rights is not made clear in the Bill and that the rights of patients should not be defined solely in relation to the Bill. This was backed by the Scottish Disability Equality Forum (2010) which expressed concern that rights set down elsewhere may be ‘deprioritised’ and forgotten about by the NHS.

The policy memorandum acknowledges that some respondents to the Government’s own consultation wanted existing rights reiterated in the Bill, but that the chosen approach ‘seeks to avoid duplication of existing legislation’ (Scottish Parliament, 2010b, Para 18).

The information on all patient rights produced by HRIS will continue, although the future of the organisation is undecided. The policy memorandum states that ‘other methods of obtaining this service or providing public information on health rights will be considered’ (Scottish Parliament, 2010b, para 69). The Patient Advice and Support Service established under the Bill will have a role in promoting an awareness and understanding of the rights of patients but the Bill specifies that this will only be in relation to rights under the Bill (s15(4)).

Patient Responsibilities

Another theme to emerge was the extent to which the Bill includes provisions to enhance patient responsibilities. The NHS organisations and health professions were more likely to raise this point. For example, NHS Highland supported the rights and principles but felt the associated patient responsibilities needed to be strengthened. The Royal College of Nursing (2010) felt that on its own the language of patient ‘rights’ has confrontational and litigious associations which may unbalance the mutual approach that the NHS aspires to.

The provisions in the Bill regarding patient responsibilities are not directed at patients themselves but rather at NHS bodies and the Patient Advice and Support Service. The Policy memorandum to the Bill details that patient responsibilities were considered during the development of the Bill but that there are often complex reasons why a patient cannot or does not fulfil their responsibilities. The memorandum also expresses the difficulties in legislating for this (Scottish Parliament, 2010b).
The existing ‘patients’ charter’ (The NHS and You) contains broader expectations of patients such as keeping appointments and following advice and treatment. This information would still stand if the Bill was passed.

**Subjectivity**

Another point mentioned repeatedly was that the rights and principles in the Bill are subjective and indeed many respondents had comments on the wording used and proposed alternatives. Age Scotland commented that due to the subjectivity, complaints may need an arbiter and the BMA questioned how things like ‘dignity’ could be defined in the legal sense. Others suggested the inclusion of more objective and measurable rights, for example, a right to receive medicines which have been approved by the Scottish Medicines Consortium (Association of the British Pharmaceutical Industry, 2010).

There were calls for greater clarity on certain aspects of the rights and principles such as the definition of ‘proportionate’ and ‘appropriate’ in section 2(b) (Age Scotland, 2010; Association of the British Pharmaceutical Industry, 2010). The submissions also contained suggested additions and amendments to the rights and principles which are too numerous to mention in full, however some examples include:

- Patients should be treated in a clean and safe ward (BMA, 2010)
- Patients are entitled to a choice of non-pharmacological treatments (British Psychological Society, 2010)

**SECTION 6-10: TREATMENT TIME GUARANTEE**

**CURRENT WAITING TIME TARGETS**

There are a number of waiting time targets for specific treatments. However, the general target for elective inpatient and day case treatment is:

> From the 31 March 2009; No patient waiting for treatment as an inpatient or day case will wait longer than 15 weeks, reducing to 12 weeks from 31 March 2010 and 9 weeks from 31 March 2011

In addition to the above, the Government has also set a target of a maximum 18 week wait from referral to treatment (RTT) to be achieved by 31 December 2011.

The most recent data from ISD Scotland shows that at the end of the last quarter, relatively few patients had waited longer than 12 weeks for inpatient or day case treatment (n=206 or 0.2% of those seen):

**Table 2: Completed Waits for Patients Seen: Inpatient or Day Case Admission, Scotland**

<table>
<thead>
<tr>
<th>Quarter Ending</th>
<th>30 Jun 08</th>
<th>30 Jun 09</th>
<th>31 Mar 10</th>
<th>30 Jun 10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number seen</td>
<td>91,199</td>
<td>93,576</td>
<td>95,786</td>
<td>93,853</td>
</tr>
<tr>
<td>Number who waited over 9 weeks</td>
<td>Na</td>
<td>Na</td>
<td>13,215</td>
<td>2495</td>
</tr>
<tr>
<td>Number who waited over 12 weeks</td>
<td>Na</td>
<td>1,574</td>
<td>990</td>
<td>206</td>
</tr>
</tbody>
</table>
### BILL PROVISIONS – TREATMENT TIME GUARANTEE

Section 6 of the Bill provides for the creation of a statutory maximum waiting time for treatment. Much of the detail of the treatment time guarantee (TTG) would be established in regulations, although the Bill does specify the maximum wait at 12 weeks. This could be amended by Ministerial order (section 7(4)). The 12 week TTG would operate within the overall 18 week referral to treatment target (RTT) although some services not covered by the RTT are expected to be covered by the TTG (Scottish Parliament, 2010b, pg 15).

The Bill would require NHS Boards to take ‘all reasonably practicable’ steps to ensure compliance with the TTG, including that a Board may arrange for treatment in another Board area or with a ‘suitable alternative provider’ if it is unable to treat the person in its own area.

If the TTG is breached the NHS Board must:

- make arrangements to ensure that the treatment starts at the next available opportunity,
- provide an explanation to the patient as to why the TTG was not met
- give the patient details of the advice and support service and how to make a complaint

However, there would be no financial compensation if the TTG is not met and, in line with the other parts of the Bill, section 18 would ensure that it would not be legally enforceable.

Section 8(3) also establishes that a board should not prioritise the start of treatment for one patient to the detriment of another with greater clinical need. A Board should also have regard to a patient’s availability and any other relevant factors in providing treatment within the TTG.

The details of the TTG which are to be set out in regulations include:

- Who is an eligible patient
- How the waiting time is to be calculated
- Treatments and services excluded from the TTG
- Circumstances in which the TTG may be extended

Therefore, the Bill does not specify who would be considered as an ‘eligible patient’. However, the policy memorandum to the Bill (Scottish Parliament, 2010b, Pg 6) says it will apply to ‘planned and elective care, delivered on an inpatient or day case basis’ and provides a list of services the Government intends to exclude, namely:

- assisted conception
- obstetrics
- complementary and alternative medicines
- organ transplants
- direct access services (e.g. direct access X-rays)
- diagnostic tests
- outpatient treatments
- certain national specialist services (e.g. scoliosis)
- specialist services delivered in England used by Scottish patients
- alcohol and drug misuse services
The policy memorandum provides explanations for excluding such services, for example the inappropriateness of applying a TTG to such a service (e.g. obstetrics) or the existence of shorter waiting time targets already (e.g. alcohol and drug misuse services).

FINANCIAL IMPLICATIONS OF THE TREATMENT TIME GUARANTEE

The financial memorandum to the Bill explains that the Government does not anticipate that there will be any additional costs from the TTG as it is part of the ongoing work on waiting time standards, targets and associated monitoring.

The financial memorandum points to the money given to realise the RTT of 18 weeks. No additional money is given because the 12 week TTG would operate within the 18 week target. The money provided for the 18 week RTT up until 2010/11 was £230m over 3 years.

KEY ISSUES IN RELATION TO THE TREATMENT TIME GUARANTEE

Clinical Priorities

One of the main issues raised in the Committee call for evidence was that a statutory TTG may skew clinical priorities. Respondents pointed to the need for some conditions to be seen more quickly than 12 weeks and questioned what effect a statutory guarantee would have on such cases. Would less important cases take priority?

There were also questions around what effect the TTG would have on patients with a condition that currently has a treatment time target of less than 12 weeks (e.g. cancer and angiography). Would such a guarantee create a barrier to quicker treatment for these patients?

A similar concern that was raised is that a TTG may prioritise resources towards ‘new’ patients at the expense of existing patients requiring ongoing care (e.g. Scottish Disability Equality Forum, Long Term Conditions Alliance Scotland). Similarly, CoSLA expressed concern about what effect it may have on the drive to ‘shift the balance of care’ from the acute sector to the community:

“[It] could lock NHS Scotland into the continuation of a model of health provision which largely serves to deal with the consequences of poor health.” (CoSLA)

However, it could be argued that sections 8(3) and 18 are designed to ensure that nothing would prejudice clinical judgement or be detrimental to patients with greater clinical need.

Coverage

The other main issue raised in the Committee’s call for evidence was in relation to who would be covered by the TTG. For example, there was concern that the TTG may predominantly benefit elective surgical patients and respondents questioned why such patients should be singled out.

Most notably, many of the submissions highlighted the importance of including mental health services within the TTG. This concern is addressed in the policy memorandum as it was an issue also raised in the Government consultation. The proposed eligibility criteria for the TTG is for patients awaiting elective inpatient and day case treatment with the exception of a list of specified exclusions. Mental health services are not in the list of proposed exclusions and the policy memorandum explains that some aspects of child and adolescent mental health services would be covered by the proposed eligibility criteria (Scottish Parliament, 2010b, para 38). However, given the manner in which most mental health services are delivered (i.e. on a
crisis basis or in an ongoing manner) this may place mental health services outwith the eligibility criteria. This would be in line with any other service not delivered on an elective inpatient or day case basis.

**SECTIONS 11-13: COMPLAINTS AND FEEDBACK**

**CURRENT COMPLAINTS SYSTEM**

All complaints about the NHS are dealt with by the service itself at one of two levels:

- Level 1 - an informal stage that tries to seek local resolution, or
- Level 2 - a formal complaint involving internal review by the NHS.

There is also the option of referring further to the SPSO if the complainant is not satisfied. The key legislation covering complaints is the Hospital Complaints Procedure Act 1985 (c.42) and this is complemented by directions and procedural guidance (Scottish Executive, 2005a; Scottish Executive, 2005b).

The NHS in Scotland deals with approximately 11,000 complaints every year and operates a target of acknowledging complaints within 3 working days and handling them within 20 working days. The majority of complaints received relate to acute services (71%) and the types of issues raised are most commonly about staff (37%), treatment (29%), the environment/domestic issues and waiting times (10%). Within staff complaints, the attitudes and behaviour of staff are the most common issues raised followed by complaints about written and oral communication (ISD Scotland, 2010b).

The most recent figures show that 27% of complaints were fully upheld, 33% were partially upheld and 38% were not upheld (ISD Scotland, 2010b).

Recently, the Scottish Health Council undertook research into the processes for handling complaints in the NHS. ‘Making it Better’ was published in 2009 and among its key findings were:

- Even where people had experienced a problem with NHS care, they tended not to complain (53% had taken no action and 27% had expressed concern/given feedback)
- The most common reason given for not complaining was that ‘it would make no difference’
- People are fearful that complaining may affect future treatment and the relationship they have with health professionals
- Some are too busy coping with illness or caring responsibilities

The report concluded that changes needed to be made to the complaints procedures but that even if changes are made, many will still not want to complain and so alternatives are needed.

**BILL PROVISIONS – COMPLAINTS AND FEEDBACK**

The Bill repeals the existing Hospital Complaints Procedure Act 1985 (c.42) (the ‘1985 Act’) and gives patients an explicit right to make a complaint, raise concerns and give feedback (s1(3)).

The types of provision that were in the 1985 Act are then re-instated in s11 which sets out that Ministers must ensure that NHS Bodies have adequate arrangements in place for:

- Handling complaints
- Publicising how complaints are to be made and handled
• Publicising and giving complainants details of the advice and support available
• Monitoring complaints in order to identify areas for concern and improve performance

Ministers may make regulations in relation to any of the above. This Bill also provides that NHS bodies should encourage patients to provide feedback and raise concerns. The relevant NHS body must then consider the feedback or concern with a view to how services can be improved.

FINANCIAL IMPLICATIONS
The Scottish Government does not anticipate that there will be any additional cost from this part of the Bill.

KEY ISSUES IN RELATION TO COMPLAINTS AND FEEDBACK
In the Committee’s call for evidence, the provisions relating to complaints and feedback were broadly welcomed by respondents. Many expressed the need for the NHS to utilise feedback more and to seek local resolution at an early stage in order to prevent issues escalating to a formal complaint (e.g. SPSO). It was pointed out that many patients are reluctant to complain for fear of repercussion and so normalising the giving of feedback may prevent complaints and create a culture of learning from feedback (e.g. Chest, Heart and Stroke Scotland, 2010).

Some submissions called for these provisions to be extended to families and carers (Scottish Independent Advocacy Alliance, 2010) and to place an obligation on the NHS to provide feedback to a patient on how their complaint was handled (Citizens Advice Scotland, 2010).

The main criticism of this part of the Bill was that the provisions merely reflected what already happens and that no purpose is served by putting it in legislation (Consumer Focus Scotland, 2010). Consumer Focus Scotland expressed a preference for action to help make rights real for people, such as support for making a complaint and the provision of mediation.
SECTIONS 14-17: PATIENT ADVICE AND SUPPORT SERVICE AND PATIENT RIGHTS OFFICERS

EXISTING SUPPORT AVAILABLE TO THOSE MAKING COMPLAINTS

Prior to the National Health Service Reform (Scotland) Act 2004 (asp 7) (the ‘2004 Act’) each NHS board had a local Health Council which was tasked with involving the public in NHS decision making. Although not part of their formal remit, the local health councils also provided advice and helped patients negotiate the complaints procedure. As a result of changes to public involvement in the NHS, health councils were subsequently dissolved by the 2004 Act. The consultation on ‘Reforming the NHS Complaints Procedure’ (Scottish executive, 2003) concluded that it should be a clear requirement of each NHS Board to ensure that a suitable source of independent advice and support was available to people who use its services. Boards subsequently commissioned the Independent Advice and Support Service (IASS) from Citizens Advice Scotland to fulfil a number of support and advice functions, including replacing the complaint support functions formerly provided by the health councils. NHS Complaints Officers also assist patients in the complaints process.

The IASS is a part of the Citizens Advice Bureau (CAB) network in Scotland but is funded by local NHS boards. IASS offers advice and support to all NHS users and their families in relation to any concerns and complaints they may have regarding care received from the NHS. As the service is staffed by CAB workers it also provides general advice, interlinking health concerns with other issues which can have a significant impact on people’s health and well being, such as debt or unemployment.

An evaluation of the IASS (Myers, 2009) showed that customers were satisfied with the service they were provided and that as part of CAB it is seen as an established ‘brand’ and trusted source of information and advice. However, the evaluation did highlight a number of operational issues such as reporting mechanisms between the service and NHS Boards.

BILL PROVISIONS

The Bill proposes the establishment of a new Patient Advice and Support Service (PASS). Unlike the current service (IASS), the new service would be established on a national basis, rather than each NHS board contracting with a local provider. It would be up to the Common Services Agency (CSA) to secure the provision of the service from one or more providers that are independent of the NHS. Some funding for the service would still come from NHS Boards.

The main role of the PASS will be:

- To promote an awareness and understanding of the rights and responsibilities of patients
- Advise and support those who wish to make a complaint, raise concerns or give feedback
- Provide information and advice on matters of interest to people using the health service

However, in relation to raising awareness and understanding of rights, this role would only be in relation to the rights within the Bill and not all rights available to patients (s15(4)).

The advice and support functions of the PASS would be carried out by Patient Rights Officers (PRO). These are new posts that would be created by section 16 of the Bill.

Section 16 sets out that the role of the PROs would be:
• Providing information and advice about the services of PASS
• Providing information and advice about the health service
• Providing information and advice on making complaints, raising concerns and giving feedback
• Making persons aware of and directing them to other sources of advice and support (e.g. advocacy)
• Publicising the PASS to patients and other interested parties

The number of PROs is not specified in the Bill but the policy memorandum states that there will be at least one in each board area (although not necessary a full-time post). The number will be based on an assessment of need carried out by each NHS board, although the intention is for the PROs to be employed by the PASS (Scottish Parliament, 2010b, para 44).

The Bill would also place a duty on health boards (or any other body specified by Ministers in an order) to provide the PASS with information about its organisation, procedures and the services that it provides (s17).

FINANCIAL IMPLICATIONS OF THE PASS AND PATIENT RIGHTS OFFICERS

The total allocated funding for the PASS and the PROs is £2,081,000.

The financial memorandum details that board funding for the IASS amounted to £831,000 in 2009/10 plus £134,000 from the Government to Citizens Advice Scotland for central support functions. This money would be redirected to the new service.

The financial memorandum outlines an additional £1.16m of recurring funding will also be made available to support the PASS and the creation of an estimated 40-50 whole time equivalent PRO posts. Existing redirected funding would provide for around 25-30 PROs, thus the total number of PROs is expected to be between 65-80. It is estimated that these posts would have a salary of between £20,000-£26,000 per annum.

The Government would also provide a further £500,000 recurring funding for advocacy services and £250,000 for Translation, Interpreting and Communication Support (TICS). This is in light of the duty on PROs to direct people to other sources of support.

KEY ISSUES IN RELATION TO THE PATIENT ADVICE AND SUPPORT SERVICE

Patient Advice and Support Service

There was some questioning of the need to create a new national structure when there is already an existing service in the shape of the IASS (NHS Lothian, 2010). Citizens Advice Scotland asked for clarity on the role and structure of the service and if the standards and structure introduced by IASS will be continued. This was reiterated to some extent by NHS Forth Valley PFPI group (2010) who questioned how PASS would differ from the IASS. The Long Term Conditions Alliance (2010) also asked for clarification on how the service would interact with the many voluntary organisations providing advocacy, information and support.

Patient Rights Officers

Most submissions welcomed the creation of PROs but stressed the need for adequate training, particularly around being able to deal with patients with communication difficulties and the other rights of patients (Royal College of Physicians Edinburgh, 2010; Age Scotland, 2010; Royal College of Nursing, 2010). Many made suggestions or questioned what the role of the PRO will
encompass. However, Diabetes UK (2010) questioned whether they would just become another NHS admin role with the associated expense.

**INTERNATIONAL COMPARISONS**

The following section outlines the experiences from two countries that have been frequently referenced in relation to the current Bill, namely England and Norway.

**ENGLISH NHS CONSTITUTION**

The English NHS has a [constitution](#) which was first published in 2009 following the Darzi review (Darzi, 2008). The consultation on the constitution found that people wanted it to be short and enduring, flexible, have ‘bite’ with means for enforcement and redress and it should not be a ‘lawyers’ charter’ (Darzi, 2008, pg 78). The legal basis of the constitution is in the Health Act 2009 (c.21) which sets out that:

- those providing NHS care should have regard to the constitution,
- the secretary of State should review and republish the constitution at least once every 10 years
- the Secretary of State should consult on any changes to the constitution
- the Secretary of State should report on the effect of the constitution on patients, staff, the public and carers every 3 years
- any changes to the guiding principles should be published in regulations

Therefore, unlike the Patient Rights (Scotland) Bill, the actual contents of the English NHS constitution are not specified in legislation, although much of its content comes from statute or case law. This approach is intended to facilitate it being a ‘living document’ that is updated to reflect changes to services and entitlements (Dept of Health, 2010).

Nevertheless, the basic structure of the constitution is broadly similar to the Bill in that they both outline the general principles with which healthcare should be delivered, as well as specific rights that patients have. Where the English constitution (and its accompanying [handbook](#)) diverges from the Scottish Bill is that it mainly tries to reaffirm existing key rights available to English patients, with the addition of some new rights and pledges. It also distinguishes between what is a right (legally enforceable) and what is a pledge (not legally enforceable). As a result of this different approach, much of what is in the English constitution is not included in the Bill, for example:

- Specific mention of the right to access treatment in other EEA countries in certain circumstances
- The right to receive services free of charge (apart for limited exceptions sanctioned by Parliament)
- Specific waiting time guarantees for different conditions (e.g. 2 weeks referral for cancer) and a general guarantee of 18 weeks referral to treatment for non-urgent treatment
- The right to receive approved drugs, treatments and vaccinations
- The right to choose a GP practice and express a preference for a particular doctor
- A right to vaccination
- A right to a health check for those aged 40 to 74

The constitution also has a section on patient responsibilities which includes; recognising what contribution a person can make to their own health and wellbeing, registering with a GP practice, treating NHS staff and other patients with respect and keeping appointments.
Impact of the NHS Constitution

The first review of the NHS constitution is due in 2012 so what effect it has had is not yet known. However, early indications so far are mixed.

In November 2009, the NHS Constitution ‘State of Readiness Group’ produced a report containing research findings on awareness of and support for the constitution (Department of Health, 2009). This research found that awareness among staff and the public was relatively low (47% and 22% respectively), although support for it was higher in both groups, especially among the public (67%). The research found a common attitude among staff was ‘we are doing it already’, while the public were more likely to view it as a new development.

In responding to fears that the constitution would be a ‘lawyer’s charter’, the UK Government has said there is no evidence that there has been an increase in litigation since the introduction of the constitution (Department of Health, 2010, para 23).

More recently there have been reports of a record annual rise in complaints in the English NHS (NHS Information Centre, 2010). Between 2008/09 and 2009/10, complaints about NHS hospitals and community health services increased by 11,938 (13.4%) from 89,139 to 101,077. This could be viewed in one of two ways. Either patients are more aware of the constitution and therefore what they can expect from the NHS, or the constitution is not delivering on its aim to improve the patient’s experience of NHS care.

NORWEGIAN PATIENTS RIGHTS ACT

In 2007, Scotland’s First Minister confirmed that the system proposed was based on the system used in the Norwegian health service (Scottish Parliament, 2007, Col1497). The Norwegian system is underpinned by the Norwegian Patient Rights Act 1999.

The Norwegian Act provides that a patient who is referred to specialist care has the right to be assessed within 30 days. Patients are then prioritised according to need and those regarded as a high priority have the right to have a time-limit on when treatment will begin. This time limit is fixed for each individual by the specialist health service, although there are guidelines for specific conditions. Patients also have the right to a second opinion. The Act also provides for:

- The right to choose a hospital (including ‘for profit’ private hospitals that have a contract with the regional health authority) and receive necessary transportation
- The right to information and participation in the implementation of their care
- The right to an individual plan for patients who require long-term, co-ordinated health services
- The right to access medical records
- The right to give consent or refuse treatment
- An Ombudsman in every county

A patient who feels his/her rights have not been met can complain to the county medical officer (CMO). The CMO can withdraw any decision by a healthcare provider which they judge not to be in accordance with the Act. Decisions of the CMO can be appealed to the Norwegian Board of Health Supervision and patients may also pursue their case in the civil courts although there are no sanctions directly provided for in the Act (Magnussen et al, 2009).
Impact of the Norwegian Patients Rights Act

There has been no wholesale evaluation of the Norwegian legislation but the following outlines the findings of relevant reports and statistics.

Review of Outpatient Clinics

In 2003, the Norwegian Board of Health Supervision conducted a nationwide review of 50 somatic outpatient clinics in order to ascertain whether patient rights were being met. The review showed that many clinics had limited knowledge of the requirements for assessment, follow-up of referrals and for dealing with waiting lists and a choice of hospital. In addition, the requirements regarding the patient groups that should be given priority had not been adequately met (Norwegian Board of Health Supervision, 2004).

Compliance with Evaluation and Treatment Time Guarantees

A patient who is referred to a hospital or specialist is entitled to an evaluation of their health within 30 days to assess whether care or treatment is necessary. Figure 1 shows the proportion of referrals where this entitlement was not met.

Figure 1: Proportion of evaluations not carried out within the 30 day time period, 2006-2009

![Figure 1: Proportion of evaluations not carried out within the 30 day time period, 2006-2009](source)

If assessed as being in need of specialist care, the specialist health service must set a time limit in which the patient receives the necessary treatment. Figure 2 shows that despite the legislation, a significant proportion of patients do not receive treatment within the set time limit.

Magnussen et al (2009) report that there has been a steady increase in recent years in the number of complaints based on the Patients’ Rights Act. In 2003, the Board of Health Supervision recorded 142 complaints, compared to more than 750 in 2007. However, only a small number of cases have reached the courts. The authors interpret this trend as showing patients have become more aware of the possibility of using the Act and that it may indicate an increased trust in the procedures.

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5 Personal Communication with Stortinget, the Norwegian Parliamentary Research Service
6 For physical conditions

Title: Patient Rights (Scotland) Bill
Figure 2: Proportion of patients requiring specialist care not being seen within the required time-limit for treatment 2008-2009

Source: Stortinget, Norwegian Parliamentary Research Service, Personal Communication
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ANNEX A

SCHEDULE 1 - HEALTH CARE PRINCIPLES

Patient Focus

1. Anything done in relation to the patient takes into account the patient’s needs.
2. Patients are treated with dignity and respect.
3. Privacy and confidentiality are respected.
4. Health care is provided in a caring and compassionate manner.
5. Support necessary to receive or access health care is available.
6. The patient’s abilities, characteristics and circumstances are considered

Quality care and treatment

7. Regard is had to the importance of providing the optimum benefit to the patient’s health and wellbeing.
8. The range of options available in the patient’s case is considered.
9. Health care is based on current recognised clinical guidance.

Patient participation

10. Patients participate fully as possible in decisions relating to the patient’s health and wellbeing.
11. Patients are provided with such information and support as is necessary to enable them to participate in accordance with paragraph 10 and in relation to any related processes (general or specific).
12. Patients are encouraged to treat any person involved in the delivery of health care with dignity and respect.

Communication

13. Communication about a patient’s health and wellbeing is clear, accessible and understood.
14. Communication about general services and processes and decisions is clear, accessible and understood.

Complaints

15. Issues of concern are dealt with reasonably, promptly and in accordance with proper procedures.

Other

16. Waste of resources in the provision of health care is avoided.
RELATED BRIEFINGS

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Subordinate Legislation Committee

Remit and membership

Remit:

1. The remit of the Subordinate Legislation Committee is to consider and report on-

   (a) any-

      (i) subordinate legislation laid before the Parliament;

      (ii) Scottish Statutory Instrument not laid before the Parliament but classified as general according to its subject matter;

      (iii) Pension or grants motion as described in Rule 8.11A.1;

   and, in particular, to determine whether the attention of the Parliament should be drawn to any of the matters mentioned in Rule 10.3.1;

   (b) proposed powers to make subordinate legislation in particular Bills or other proposed legislation;

   (c) general questions relating to powers to make subordinate legislation; and

   (d) whether any proposed delegated powers in particular Bills or other legislation should be expressed as a power to make subordinate legislation.

*(Standing Orders of the Scottish Parliament, Rule 6.11)*

Membership:

Jackson Carlaw
Margaret Curran
Bob Doris
Helen Eadie
Rhoda Grant
Ian McKee (Deputy Convener)
Jamie Stone (Convener)
Committee Clerking Team:

Clerk to the Committee
David McGill

Assistant Clerk
Jake Thomas

Support Manager
Stephen Fricker
Subordinate Legislation Committee

29th Report, 2010 (Session 3)

Patient Rights (Scotland) Bill

The Committee reports to the Parliament as follows—

INTRODUCTION

1. At its meetings on 27 April and 11 May 2010, the Subordinate Legislation Committee considered the delegated powers provisions in the Patient Rights (Scotland) Bill at Stage 1. The Committee submits this report to the Health and Sport Committee as the lead committee for the Bill under Rule 9.6.2 of Standing Orders.

OVERVIEW OF THE BILL

2. The Patient Rights (Scotland) Bill ("the Bill") was introduced in the Parliament on 17 March 2010 by the Cabinet Secretary for Health and Wellbeing, Nicola Sturgeon MSP.

3. The Scottish Government provided the Parliament with a memorandum on the delegated powers provisions in the Bill ("the DPM").

4. Correspondence between the Committee and the Scottish Government is reproduced in the Annexe.

5. The Committee determined that it did not need to draw the attention of the Parliament to the delegated powers in sections: 1(4), 4(2), 11(4)(a), 14(2), 15(6), 20(1) and 22(3).

6. The Committee considered that it did not need to draw the attention of the Parliament to the powers of direction in sections: 5(3), 9(2), 11(4)(b), 12(5) and 14(2).

1 Patient Rights Delegated Powers Memorandum
Delegated powers provisions

Section 5(1) – Guidance in relation to the practical application of the health care principles

Power conferred on: Scottish Ministers
Power exercisable by: guidance
Parliamentary procedure: none

7. Section 5(1) provides that a relevant NHS body must, for the purposes of section 3 (duty to have regard to certain rights and principles), have regard to any guidance issued by the Scottish Ministers in relation to the practical application of the health care principles. The Committee sought further information from the Scottish Government as to the function of the guidance. The Committee notes that the Scottish Government intends that the guidance would provide “best practice” to relevant NHS bodies with respect to the operational application of the health care principles. Unlike directions under section 5(3), the guidance will not be mandatory although the bodies will have to have regard to it.

8. The Committee is satisfied that this delegated power is appropriate to be exercised in the form of guidance.

Section 7(1) – (Treatment time guarantee: further provision) - Duty to make provision about the treatment time guarantee

Power conferred on: Scottish Ministers
Power exercisable by: regulations made by statutory instrument
Parliamentary procedure: negative resolution of the Scottish Parliament

9. The power under section 7(1) relates to the descriptions of patients which are eligible for the guarantee and to how the waiting time is to be calculated. The exercise of the power will determine which patients will or will not be eligible to benefit from the guarantee. These are not specified on the face of the Bill, nor are criteria specified on the basis of which the descriptions of eligible patients are to be determined.

10. The Committee considers that the description of patients who are eligible (or, by default, not eligible) for the guarantee is fundamental to that guarantee, which is itself a central provision in the Bill. The Committee appreciates that flexibility may be required to allow for amendment of how the guarantee should apply, in response to different circumstances now and in the future. However, the Committee considers that a power to amend the description of patients who are eligible for the guarantee does not preclude the specification, in the Bill, of initial descriptions of patients who are to be eligible or of criteria on the basis of which such descriptions are to be determined. The Committee acknowledges that this is ultimately a policy issue for consideration by the lead committee and is content to refer this matter to it for further consideration.

11. Similarly, the Committee considers that the method of calculation of the waiting time may also be of significance. While at first sight this may appear to be
an administrative matter, the exclusion of certain circumstances from the calculation could considerably extend the practical effect of the guarantee.

12. Given the significance of the guarantee, and the significance and effect on the operation of the guarantee of the designation of eligible patients and the calculation of the waiting time, the Committee considers that affirmative rather than negative procedure would be more appropriate.

13. The Committee draws to the attention of the lead committee its view that the power to exclude patients from eligibility for the treatment time guarantee is significant. In its view, a power to amend the description of patients who are eligible for the guarantee does not preclude the specification, in the Bill, of initial descriptions of patients who are to be eligible which could be amended or of criteria on the basis of which such descriptions are to be determined.

14. The Committee recommends that the power in section 7(1) be subject to affirmative rather than negative procedure because of the significance of the guarantee and the significance and effect on the operation of that guarantee of designation of eligible patients and the method of calculating the waiting time.

Section 7(3) - (Treatment time guarantee: further provision) - Further provisions about the treatment time guarantee

Power conferred on: Scottish Ministers
Power exercisable by: regulations made by statutory instrument
Parliamentary procedure: negative resolution of the Scottish Parliament

15. Regulations made in exercise of this power may address matters of detail relating to the operation of the guarantee or be of an administrative or technical nature. However, regulations made under this power may also exclude specified treatments and services from the guarantee. The Committee considers that the exclusion of specified treatments and services from the guarantee was an important decision in which the Parliament may wish to play an active role. The Committee therefore asked the Scottish Government to consider whether affirmative procedure would be more appropriate.

16. The Committee acknowledges that treatments and services may be changing all the time and that flexibility will be required to respond to progress on waiting times and on specific treatments and services. However, the Committee does not agree with the statement in the Scottish Government response that this is largely an issue of a medical and technical nature. The Committee is of the view that the exclusion of specified treatments and services from the guarantee is an important issue of significance to patients and to the public generally (as potential patients) and that accordingly affirmative rather than negative procedure is more appropriate.

17. The Committee recommends that this power be subject to affirmative, rather than negative procedure because of the significance, through the
exercise of the power, of the exclusion of specified treatments and services from the guarantee.

Section 7(4) - (Treatment time guarantee: further provision) - Power to amend the maximum waiting time

Power conferred on: Scottish Ministers
Power exercisable by: order made by statutory instrument
Parliamentary procedure: negative resolution of the Scottish Parliament

18. The practical effect of this power is to enable the Scottish Ministers to change the maximum waiting time of 12 weeks set out in section 10 to a different time period and to allow the maximum waiting time to be different for different categories of treatment or service. The Committee accepts that maximum waiting times may have to be altered from time to time and in respect of particular treatments and services and that flexibility in this respect will be required. However, the Committee is concerned at the width of the power in that it allows the maximum waiting time to be extended (as well as reduced) and no limit is set on how far the maximum waiting time may be extended. The Committee considers that this could have a significant impact on the nature of the guarantee and on the extent of the right afforded by sections 1(1) and 6(1). The Committee was also concerned at the choice of negative procedure, given that the maximum waiting time is a central policy issue, and sought clarification on the choice of negative rather than affirmative procedure.

19. The Committee does not consider that the first element of the Scottish Government’s response, on its own, adequately addresses the Committee’s concerns with respect to the nature and width of the power. However, the Committee is pleased to note the Scottish Government’s commitment, in the second element of its response, to consider further whether an amendment should be brought forward to apply draft affirmative procedure. An amendment to this effect would address the Committee’s concerns with respect to this power since it would provide an enhanced role for the Parliament in determining any alteration of the maximum waiting time.

20. The Committee recommends that the power should be made subject to affirmative procedure given the significant impact the exercise of the power may have on the nature of the guarantee and on the extent of the right afforded by sections 1(1) and 6(1). The Committee notes the Scottish Government’s commitment to consider further whether an amendment should be brought forward to apply draft affirmative procedure.

Section 9(1) – Guidance in relation to the treatment time guarantee

Power conferred on: Scottish Ministers
Power exercisable by: guidance
Parliamentary procedure: none

21. Section 9(1) provides that health boards must, when taking steps to start the treatment of eligible patients, have regard to any guidance issued by the Scottish
Ministers which relates to the treatment time guarantee, and, in particular, health boards’ compliance with it. The Committee sought further information from the Scottish Government as to the function of the guidance.

22. The Committee notes that the Scottish Government intends that the guidance issued under section 9(1) will relate to detailed operational and practical application. The guidance will not be mandatory but health boards will have to have regard to it.

23. **The Committee is satisfied that this delegated power is appropriate to be exercised in the form of guidance.**

**Section 21(1)(c) – Power when making orders or regulations to make consequential, supplementary, incidental, transitional, transitory or saving provision within those orders or regulations.**

<table>
<thead>
<tr>
<th>Power conferred on:</th>
<th>Scottish Ministers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Power exercisable by:</td>
<td>Order</td>
</tr>
<tr>
<td>Parliamentary procedure:</td>
<td>Affirmative / Negative / None</td>
</tr>
</tbody>
</table>

24. Section 21(1)(c) provides that any power of the Scottish Ministers to make orders or regulations under the Bill includes power to make such consequential, supplementary, incidental, transitional, transitory or saving provision as appears to the Scottish Ministers to be necessary or expedient. This is not a separate stand alone power. It attaches to and applies to all powers to make orders or regulations. It is therefore subject to the procedure which relates to the order or regulation making power to which it is attached. Given the separate free-standing power in section 20(1) to make ancillary provision by order, the Committee sought justification for the need for the power under section 21(1)(c).

25. The Committee accepts the Scottish Government’s view that, without the power in section 21(1)(c), related provisions may have to be in different instruments, as the power in section 20(1) is restricted to orders and could not be combined with regulations. The Committee accepts also the Government’s explanation that, without the power in section 21(1)(c), there could be potential for conflict with respect to procedure between substantive and connected provisions.

26. However, the Committee does not consider that it is appropriate to make ancillary provision of substance in commencement orders which are subject to no procedure. It therefore asked the Scottish Government for justification of this. The Committee is pleased to note the Scottish Government agrees with the Committee that the power in section 21(1)(c) should not apply to commencement orders and that the Government undertakes to bring forward an amendment to this effect. This addresses the Committee’s concerns in this respect.

27. **The Committee is satisfied with the Scottish Government’s justification for the power in section 21(1)(c) in addition to that under section 20(1). The Committee does not consider it is appropriate to provide for substantive provision to be made in commencement orders subject to no procedure. It therefore recommends that section 21(1)(c) should be amended to this effect and notes the Scottish Government’s undertaking to do so.**
Other proposed delegated powers

Section 9(3) – suspension of the treatment time guarantee

Power conferred on: Scottish Ministers
Power exercisable by: directions

28. Section 9(3) provides that the Scottish Ministers may direct that the treatment time guarantee be suspended in such exceptional circumstances and for such periods as they consider necessary. The Committee acknowledges that it may be necessary or otherwise appropriate to suspend the guarantee in exceptional circumstances, but it was not clear to the Committee why subordinate legislation could not or should not be used for this purpose given the significance of the matter on the rights conferred by the Bill. It was also not clear to the Committee whether the suspension of the guarantee would be specific (in the sense that it would apply to a specified health board or to a specified hospital) or whether it would be of general application.

29. The Committee accepts that the Scottish Government would intend to suspend the treatment time guarantee only in exceptional circumstances. Section 9(3) makes clear that it is only in exceptional circumstances that the power may be exercised. However, the Committee notes that emergency subordinate legislation is used to address exceptional circumstances in other contexts e.g. the making of prohibition orders with respect to the use of food on public health grounds. The Committee is particularly concerned by the use of directions to suspend the guarantee given the significance of the guarantee and given that directions do not allow any degree of parliamentary scrutiny. The Committee is accordingly not satisfied from the Scottish Government's response that directions are appropriate for this purpose.

30. The Committee notes that the suspension of the treatment time guarantee could be specific (in the sense that it would apply to a specified health board or health boards or to a specified hospital or hospitals) or could be of general application, and that the position as to when powers of direction may be used is made clear by section 21(5).

31. The Committee is satisfied that the position as to when powers of direction may be used is made clear in the Bill.

32. However, the Committee is not satisfied that directions are appropriate for the purpose of suspending the treatment time guarantee in exceptional circumstances given the significance of the guarantee and given that directions do not allow any degree of parliamentary scrutiny. The Committee recommends that the power under section 9(3) should be expressed as a power to make subordinate legislation. If it is necessary for policy reasons to be able to bring that legislation into force immediately subject to subsequent endorsement by Parliament for it to continue in force, then it is possible to provide for such procedure.
Correspondence with the Scottish Government

ANNEXE

Patient Rights (Scotland) Bill at Stage 1

Section 5(1) – Guidance in relation to the practical application of the health care principles

Section 9(1) – Guidance in relation to the treatment time guarantee

The Committee asked the Scottish Government—

- Why does the Scottish Government not consider that the guidance is not more appropriately expressed in the form of subordinate legislation?

The Scottish Government responded that the health care principles are general principles to which relevant NHS bodies must have regard. They are not detailed or prescriptive. In practice, they will be implemented having regard to professional and clinical judgement and standards, which will vary according to the facts and circumstances of each case.

Section 5(1) has to be read together with Section 5(3) of the Bill which states that “Scottish Ministers may give a relevant NHS body directions as to the practical application of the health care principles; and a relevant NHS body must comply with any such direction.” Section 5(3) accordingly provides a power for Scottish Ministers to make legal requirements which are binding on a relevant NHS body regarding the practical application of the health care principles in directions. Directions are a more appropriate mechanism than regulations for imposing these requirements, as they allow more flexibility to respond to changing circumstances.

Section 5(1) provides that a relevant NHS body must have regard to any guidance issued by Scottish Ministers in relation to the practical application of the health care principles. The intention is that this guidance would provide “best practice” which would be recommended to such bodies. Unlike directions, however, such guidance would not be mandatory. The bodies would not have a legal obligation to comply with it, but they would have a legal obligation to have regard to it. The intention is that the guidance would relate to the operational application of the principles.

Section 9(1) should be read together with sections 7(1), 7(3) and 9(2), as these provide for regulations and directions in regard to the treatment time guarantee. It is intended that the guidance issued under section 9(1) will relate to detailed operational and practical application, which is more appropriate to be issued in guidance than in regulations or directions.

Section 7(1) – (Treatment time guarantee: further provision) - Duty to make provision about the treatment time guarantee

The Committee asked the Scottish Government—
• Why does the Scottish Government not consider that the descriptions of patients which are eligible for the treatment time guarantee could be specified on the face of the Bill, or, alternatively that criteria on the basis of which the descriptions of eligible patients are to be determined could be specified on the face of the Bill?

The Scottish Government responds that the intention is for the Bill to establish a treatment time guarantee of 12 weeks. The Policy Memorandum to the Bill explains the intention for which patients will be eligible. As explained in the Delegated Powers Memorandum, placing eligibility in primary legislation would not allow for the appropriate level of flexibility to amend how that treatment time guarantee should apply, in response to different circumstances, now and in the future, given the level of detail which needs to be provided.

• Given the significance and effect of the exercise of the power, why does the Scottish Government not consider that affirmative rather than negative procedure is more appropriate?

The Scottish Government anticipates that the bulk of the provisions in these regulations will relate to the detailed operation of the guarantee, together with administrative and procedural matters which will be technical in nature, and therefore that negative procedure is more appropriate.

Section 7(3) - (Treatment time guarantee: further provision) - Further provisions about the treatment time guarantee

The Committee asked the Scottish Government—

• Given that the exercise of the power may exclude specified treatments and services from the treatment time guarantee, why does the Scottish Government not consider that affirmative rather than negative procedure is more appropriate?

As explored in the Policy Memorandum to the Bill, the intention is that the treatment time guarantee will apply to planned or elective care undertaken as an inpatient or day case; it is intended that there will be a limited number of exceptions, also explored in the Memorandum. Treatments and services are changing all the time: flexibility is required to respond to progress on waiting times and specific treatments and services, such that treatments and services which are initially excluded may become included in the guarantee in the future. Given the largely medical and technical nature of this, negative procedure seems a more appropriate use of Parliamentary time.

Section 7(4) - (Treatment time guarantee: further provision) - Power to amend the maximum waiting time

The Committee asked the Scottish Government—
• Why does the Scottish Government consider it necessary to take the power to substitute any maximum waiting time for the 12 week maximum specified in the Bill and could the power not be drawn more narrowly in this respect?

• As this waiting time is a central provision, should the maximum not be set in primary legislation and only shorter periods specified by order?

Section 10 places the period of maximum waiting time of 12 weeks in primary legislation. Whilst the current policy is pushing waiting times down circumstances for future governments may change over time such that it would not be appropriate to restrict amendments to any maximum waiting times only to less than that specified in the primary legislation. In addition, it may be appropriate in the future to expand eligibility criteria and to include different or new types of treatments or services in a treatment time guarantee where a period longer than 12 weeks is the appropriate maximum waiting time for that particular treatment or service. The provisions at 7(4)(a) and (b) allow for this.

• Given that this is a power to amend the definition of ‘maximum waiting time’ in section 10 of the Bill, a central policy matter, what is the justification for the choice of negative rather than affirmative procedure?

The Scottish Government notes that negative procedure would allow for Parliamentary scrutiny whilst also allowing an appropriate level of speed and flexibility to change maximum waiting times in response to specific circumstances and changes in capacity. Whilst the general drive has been towards lowering waiting times, the Scottish Government appreciates the points the Committee have raised and will consider further whether an amendment should be brought forward to apply draft affirmative procedure.

Section 21(1)(c) – Power when making orders or regulations to make consequential, supplementary, incidental, transitional, transitory or saving provision within those orders or regulations.

The Committee asked the Scottish Government—

• Given the existence of power in section 20(1) to make ancillary provision by order, what is the justification for the need for the power in section 21(1)(c)?

The Scottish Government notes that section 21(1)(c) is needed because section 20(1) is an order making power and could not be combined with a power to make regulations (e.g. section 7(1)). Without it, related provisions might be forced to be in different instruments.

There may also be cases of a procedural clash: where the substantive order is subject to draft affirmative procedure but a connected incidental provision (under the order making power in section 20(1)) would be subject to negative procedure: this would mean that they would not be able to be combined in the same instrument with the consequence that related provisions would be spread over different instruments.
Given that the exercise of the “bolt on” power in section 21(1)(c) when attached to a commencement order will not be subject to Parliamentary scrutiny, the Scottish Government is asked whether it considers it would be appropriate to make an amendment to the effect either that section 21(1)(c) should not apply to commencement orders or, alternatively, that where section 21(1)(c) is applied to a commencement order it should be subject to negative procedure?

The Scottish Government agrees with the Committee and will undertake to bring forward an amendment to section 21(1)(c) so that it does not apply to commencement orders.

**Section 9(3) – suspension of the treatment time guarantee**

The Committee asked the Scottish Government—

- Given that the treatment time guarantee is a key part of the Bill and given that directions do not allow any degree of parliamentary scrutiny, what is the justification for the suspension of the treatment time guarantee by directions, rather than by statutory instrument?

The Scottish Government notes that it would intend to suspend the treatment time guarantee only in exceptional circumstances. An example of this might be a major transport incident such as a plane or train crash with a high number of seriously injured casualties who will require to remain in hospital for a significant period of time or some other unpredictable but critical event that would have a direct impact on a Board’s ability to deliver. Given the unforeseen nature of exceptional circumstances, and the need to be able to respond quickly, directions allow for speed of response. This would mean that the Government is doing what it can as quickly as it can to ensure that Boards are not showing as being in breach of the guarantee through circumstances about which they can do little. As regulations should be laid before Parliament for a minimum of 21 days the exceptional circumstance that required the suspension may then have passed within that time.

- Does the Scottish Government intend that suspension of the treatment time guarantee would be specific (in the sense that it would apply to a specified health board or health boards or to a specified hospital or hospitals) or would be of general application, and could this not be made clear on the face of the Bill?

The Scottish Government intends that the suspension could be made for any or all of the circumstances that the Committee lists. Given that the Bill only provides for the suspension to be made in exceptional circumstances, and that these circumstances are very likely to be unforeseen, their impact on different aspects of the service, boards or hospitals is also difficult to predict and specify. This is why application of the suspension is not detailed in the Bill.

The position as to when powers of direction may be used is made clear on the face of the Bill—see section 21(5)(a).