

SPICe Briefing

Patient Rights (Scotland) Bill

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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.



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EXECUTIVE SUMMARY

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

	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 duty¹ 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 (HRIS2) 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 SPSO³. In addition to this, 171 clinical negligence cases were settled in 2008/09 at a cost of £26m⁴.

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](#)

⁴ PQ [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) Ha[s] regard to the importance of providing the optimum benefit to the patient's health and wellbeing
- c) Allow[s] and encourage[s] the patient to participate as fully as possible in decisions relating to the patient's health and wellbeing
- d) Ha[s] 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

	Quarter Ending			
	30 Jun 08	30 Jun 09	31 Mar 10	30 Jun 10
Number seen	91,199	93,576	95,786	93,853
Number who waited over 9 weeks	Na	Na	13,215	2495
Number who waited over 12 weeks	Na	1,574	990	206
Number who waited over 15 weeks	7,489	368	163	58
Number who waited over 18 weeks	636	22	67	33

Source: [ISD Scotland, 2010a](#)

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 legislation⁵ 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 somatic⁶ 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).

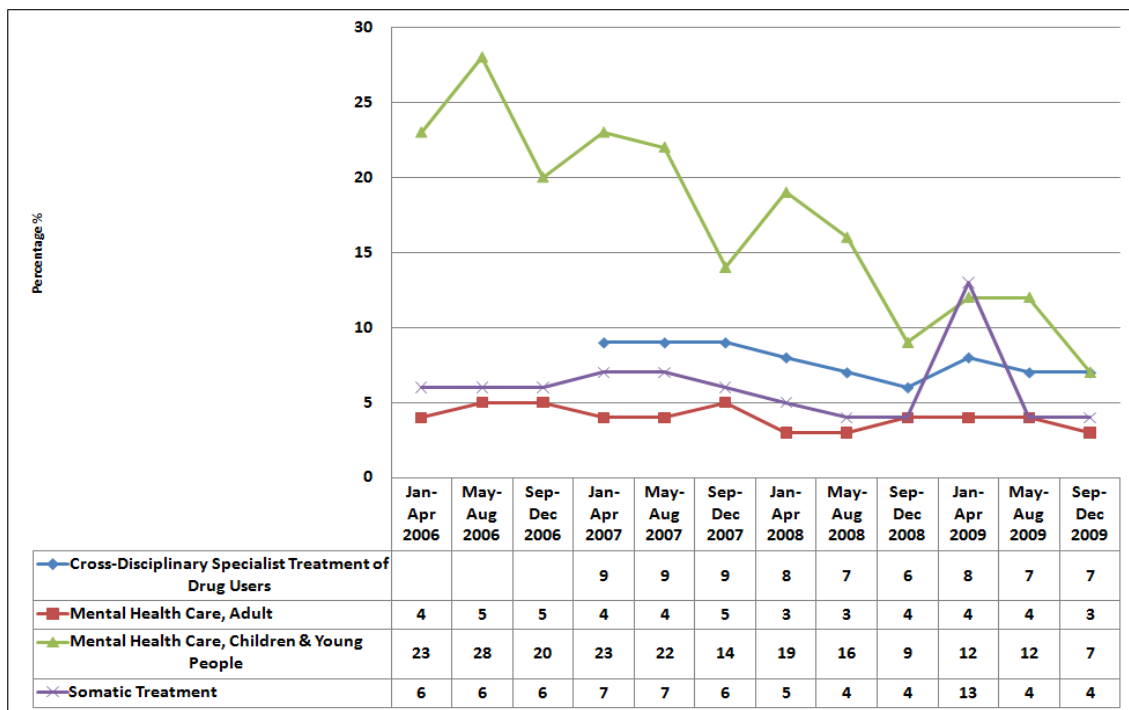
Compliance with Evaluation and Treatment Time Guarantees

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.

⁵ Personal Communication with Stortinget, the Norwegian Parliamentary Research Service

⁶ For physical conditions

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

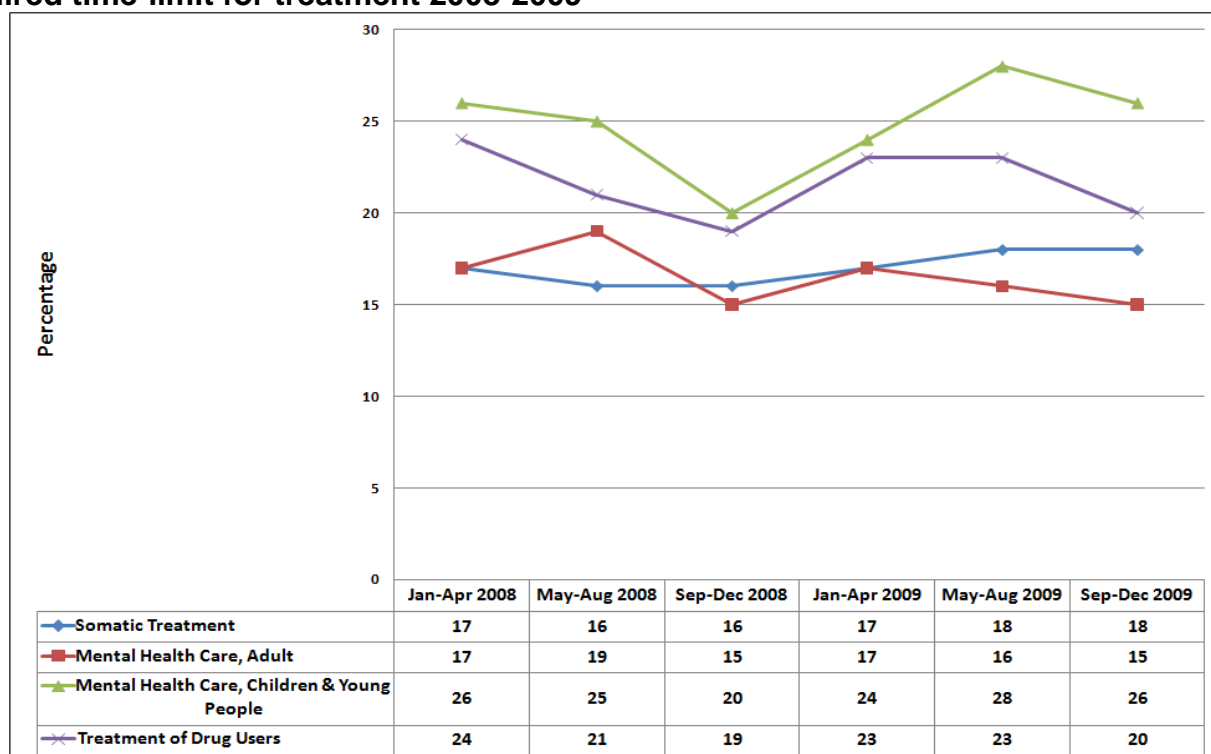


Source: Stortinget, Norwegian Parliamentary Research Service, Personal Communication

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.

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 well being.
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.

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