HEALTH AND SPORT COMMITTEE

AGENDA

27th Meeting, 2010 (Session 3)

Wednesday 29 September 2010

The Committee will meet at 9.30 am in Committee Room 6.

1. **Decision on taking business in private:** The Committee will decide whether to take item 5 in private.

2. **Patient Rights (Scotland) Bill:** The Committee will take evidence on the Bill at Stage 1 from—
   
   Hilary Patrick, Vice-convener of the Mental Health and Disability sub-committee, and Katie Hay, Law Reform Officer, Law Society of Scotland;
   
   and then from—
   
   Dr Sally Winning, Deputy Chair, British Medical Association Scotland;
   
   Theresa Fyffe, Director, Royal College of Nursing Scotland;
   
   Dr Bill Mathewson, Deputy Chair (Policy), RCGP Scotland;
   
   John Gallacher, Secretary, Health Committee, UNISON;
   
   and then from—
   
   Jim Elder-Woodward, Board Member, Inclusion Scotland;
   
   Shelley Gray, Director of Policy and Campaigns, Long Term Conditions Alliance Scotland;
   
   Carolyn Roberts, Head of Policy and Campaigns, SAMH;
   
   Delia Henry, Director, RNID Scotland;
   
   Mhairi Thurston, Lecturer in Counselling, University of Abertay, and Alan Thurston, Reader in Education, University of York, RNIB Scotland.
3. **Subordinate legislation:** The Committee will consider the following negative instruments—

- SI/1614 General Pharmaceutical Council (Appeals Committee Rules);
- SI/1615 General Pharmaceutical Council (Fitness to Practise and Disqualification etc. Rules);
- SI/1616 General Pharmaceutical Council (Statutory Committees and their Advisers Rules);
- SI/1617 General Pharmaceutical Council (Registration Rules);
- SI/1618 General Pharmaceutical Council (Transfer of Property, Rights and Liabilities, Fees and Grants);
- SI/1619 Pharmacy Order 2010 (Registration – Transitional Provisions);
- SI/1620 Pharmacy Order 2010 (Approved European Pharmacy Qualifications);

*Not before 11.00 am*

4. **Alcohol etc. (Scotland) Bill:** The Committee will consider the Bill at Stage 2 (Day 2).

5. **Work programme:** The Committee will consider its work programme.

6. **Palliative Care (Scotland) Bill (in private):** The Committee will consider its approach to the scrutiny of the Bill at Stage 1.

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Douglas Wands  
Clerk to the Health and Sport Committee  
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The papers for this meeting are as follows—

** Agenda Item 2 **

Note by the clerk
Submission from the Law Society of Scotland
Submission from the British Medical Association Scotland
Submission from the Royal College of Nursing Scotland
Submission from the Royal College of GPs Scotland
Submission from Inclusion Scotland
Submission from the Long Term Conditions Alliance Scotland
Submission from SAMH
Joint submission from the RNID, RNIB and NDCS
Submission from Age Scotland
Submission from the General Medical Council
Report from the Finance Committee
Submission from UNISON Scotland

** Agenda Item 3 **

Paper from the clerk

** Agenda Item 5 **

PRIVATE PAPER

** Agenda Item 6 **

PRIVATE PAPER
Patient Rights (Scotland) Bill

Background

Previous consideration by the Committee
1. This is the Committee’s second evidence taking session on its Stage 1 consideration of the Patient Rights (Scotland) Bill.

2. At its first meeting on 8th September, the Committee took evidence from two panels of witnesses consisting of officials from the Scottish Government Bill team (panel 1) and Citizens Advice Scotland; Consumer Focus Scotland and the Scottish Public Services Ombudsman (panel 2).

Issues arising from evidence session on 8th September
3. Some of the issues raised during the first evidence included:

- Patient rights and health care principles:
  - Discussion took place as to whether this legislation is required given that, based on some of the views expressed by those organisations who made written submissions to the Committee, the Bill does not appear to grant any new rights to patients, over and above the establishment of a 12 week treatment time guarantee. Scottish Government witnesses pointed out that, while existing patient rights will not be affected by the Bill, it does seeks to clarify certain rights and health care principles for patients;
  - Issues were raised in relation to the status of rights set out in the publication *The NHS and You*, produced by Health Rights Information Scotland (HRIS) and how the legal status of those rights may be affected, or appear to be affected, by the Bill. In response to questions, Scottish Government witnesses pointed out that publications of HRIS have no legal status, whereas the Bill, if enacted, would have;
  - The question also arose as to whether the Cabinet Secretary for Health and Wellbeing already has sufficient legal powers under the National Health Service (Scotland) Act 1978, and other legislation, to enforce patient rights, without requiring further primary legislation?
  - The issue of whether NHS boards, and other bodies such as GP contractors, would be bound by the health care principles established by Bill was also discussed. While all NHS bodies must ‘have regard to’ the health care principles established in the Bill, adherence to these principles will not be mandatory. Scottish Government witnesses pointed out that NHS bodies cannot ignore such principles when deciding on how to deliver healthcare. They would have to give reasons, on a case by case basis, if those principles are not adhered to;
Concerns were also expressed by Consumer Focus Scotland, Citizens Advice Bureaux and the Scottish Public Services Ombudsman ("SPSO") on the appropriateness of setting out specific patient rights in primary legislation. Witnesses pointed to the fact that many patient rights do not specifically originate from primary legislation (e.g. rights acquired via the common law, case law; professional regulation/codes of conduct or human rights/equality legislation) and these are not set out in the Bill. This, it was feared, might lead to a reduction in the awareness of, and application of, those ‘non-statute’ rights, both by patients and by healthcare professionals;

- This concern was reflected in the view that, in relation to patient rights, the primary objective of government and the healthcare system should be the effective promotion and implementation of all patient rights, rather than a specific focus on whether some specific rights should be set out in primary legislation.

- Enforcement issues and the definition of what constitute a ‘right’:

  - The lack of enforcement powers to support patient rights, particularly the prohibition on taking action through the courts (Section 18 of the Bill), was also discussed. Both panels of witnesses supported the view that the Parliament should not seek to create a ‘lawyers charter’ which might encourage the development of a litigious culture around healthcare in Scotland;

  - The SPSO expressed concerns that a culture of fear exists amongst healthcare professionals regarding the potential for legal action by patients. This culture makes it difficult for healthcare professionals to acknowledge and apologise for errors or failings in the provision of patient care for fear of encouraging legal action against them;

  - Reference was made to written evidence from Age Scotland which questioned whether patient rights, as defined in the Bill, could truly be considered ‘rights’ if the Bill limits patients from having recourse to the courts over failure to deliver those ‘rights’?

  - Questions were also put to witnesses as to whether a breach of the rights set out in the Bill might form the basis for negligence claims by patients, which could then become enforceable?

  - Scottish Government witnesses were questioned on the appropriateness of including reference in the Bill to ‘waste of resources in the provision of healthcare’ given the purpose of the Bill is patient rights? This, it was pointed out, was considered in the context of what might constitute patient responsibilities towards the NHS and healthcare professionals? Written evidence received by the Committee also raised questions as to how patient responsibilities might be defined in law, and what mechanisms of redress, if any, could be applied to patients who to fulfil their responsibilities.
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• **The 12 Week Treatment Time Guarantee (TTG):**

  - Some discussions took place around the treatments and services which would be excluded from the 12 week TTG, such as X-Rays; dialogistic tests and outpatient treatments. Scottish Government witnesses pointed out that the 12 week TTG would be incorporated into the 18 week referral-to-treatment target;

  - Questions to the witnesses highlighted a potential conflict between the ability of a patient to take legal action for failure to meet the current 18 week referral-to-treatment target, and whether the prohibition in the Bill on legal action in respect of failure to meet the 12 week TTG would compromise the right to take legal action in respect of the 18 week referral-to-treatment target?

• **The Patient Advice and Support Service (“PASS”); Patient Rights Officers (“PROs”) and the patient feedback and complaints system:**

  - Citizens Advice Bureaux raised concern during the evidence session regarding the establishment and role of the PASS and PROs. One of the principle issues highlighted was the potential loss of the holistic service currently provided to patients by multi-disciplinary Citizens Advice teams under the Independent Advice and Support Service (“IASS”). Currently, Citizens Advice Bureaux can provide advice and support to patients on a wide range of issues, such as management of financial debt and claiming social welfare benefits. Such issues, it was felt, can have as an important impact on an individual’s health as the quality of healthcare provided by the NHS. The proposed PASS service will not be in a position to provide the same level of multi-disciplinary support and advice to patients in these areas;

  - Scottish Government witnesses stressed that one of the main benefits of the proposed PASS system would be the uniformity of service it would provide across all health board areas in Scotland. A key element in this would be the development of a single national contract for patient advice and support service, irrespective of the service provider in question. It was pointed out that the current IASS system has developed across the various NHS board areas at differing stages. This has given rise to some inconsistencies in the service, both in terms of the range provided and in the level of funding from specific NHS boards. There was agreement by all the witnesses that a mandatory duty on NHS boards to provide, and fund, a consistent advice service across the country would be beneficial for patients;

  - The SPSO highlighted a concern, based on previous experience of public perception of newly established advice/complaint systems, as to whether patients would view the proposed PASS service and the PROs as being truly independent of the NHS. This, it was felt, may impact on the use of the new services by patients;
- Questions were put to witnesses regarding the role of PROs and whether they would become involved in advocacy and resolution of complaints for patients, or whether they will simply act as ‘signposts’?

- The SPSO also expressed concerns that the proposed complains system could become more bureaucratic than the present system, which may dissuade patients from making a complaint. Some witnesses felt that there was also a risk that patients may come to view the rights stated in the Bill as being the only rights they had in relation to the provision of healthcare;

- Citizens Advice Bureaux made reference to the potential need for a fast track system of complaints handling for patients who are undergoing medical treatment. The aim of a fast track system would be to avoid requiring patients to needlessly go through the entire complaints process, which may and unnecessary stress and delay. NHS Borders was cited as a good example of a health board which operates a fast track complaints system for patients undergoing treatment;

- In response to questions from members, both Citizens Advice Bureaux and the SPSO referred to the issue of no-fault compensation, and the need to have a wider debate on its use as a mechanism for resolving complaints. Citizens Advice Bureaux pointed out that very few of the complaint cases they handle involve the use of no-fault compensation;

- The SPSO referred to the General Medical Council’s guidance on making an apology as a good example of a system to enable front line healthcare staff to deal with patient concerns before they develop into complaints;

- The need for healthcare providers to act in timely fashion, both in response to complaints and in addressing failures identified in systems, was also raised in questions. The example of the system of compliments, complaints and concerns (3Cs) currently operated by The State Hospital (Carstairs) was cited in questioning to witnesses as a good model for a successful complaints system. Citizens Advice Bureaux pointed to the importance of a successful patient feedback system as a tool for improving healthcare.

Oral evidence
4. On 29 September the Committee will take oral evidence is from three groups of witnesses representing voluntary organisations, the medical professions and the Law Society of Scotland. Written evidence received from the witnesses is included in the papers of the meeting (HS-S3-10-27-2 to HS-S3-10-27-12).

Seán Wixted
Assistant Clerk
INTRODUCTION

The Law Society of Scotland has considered the draft Patient Rights (Scotland) Bill and has the following comments to make. The Society is generally supportive of the Bill but submits that it could be improved by making its provisions enforceable and clarifying certain terms.

COMMENTS

Enforceability

The Society’s biggest concern is that the Bill contains valuable principles and guarantees but does not contain the necessary provisions to make them enforceable.

In an enhanced rights environment, one of the objectives should be to ensure people are aware of their rights. The Bill goes a long way to meeting that objective and to enhance awareness of these entitlements. The Society is pleased to see sections which focus on informing patients about rights to the treatment time guarantee, facilities for complaints and feedback and provisions relating to the patient advice and support service.

However, if rights are to be grounded in reality and not just aspirational, there needs to be greater provision for enforcement to back up those rights. Section 18 confirms that the act does not give rise to any new liabilities to pay damages, right of action for specific implement, right of action for interdict or right of action for suspension.

The same concerns apply to section 3, which states each relevant NHS body must “have regard to the health care principles in so far as they are relevant to the functions being performed.” The bill should clearly define what is meant by ‘have regard to’ and should also contain provisions setting out how this duty will be enforced.

Proportionality

Section 2(2)(b) requires the “desirability of action in delivering health care [to be] proportionate”. The Society believes that the term “proportionate” should be clearly defined.
Mental Health Services

The Society supports the treatment time guarantee and is generally in agreement with plans for mental health services set out at paragraph 38 of the Policy Memorandum. However, the Committee also believes that the treatment time guarantee should be made available for psychological services, including talking treatments, which are generally in short supply and for which there are long waiting lists at present particularly in some areas of Scotland.

Linda Anderson
Senior Administrator, Law Reform
The Law Society of Scotland
13 May 2010
Patient Rights (Scotland) Bill

British Medical Association Scotland

Introduction

The British Medical Association is a registered trade union and professional association representing doctors from all branches of medicine. The BMA has a total membership of around 140,000 representing 70% of all practising doctors in the UK. In Scotland, the BMA represents around 15,500 doctors.

BMA Scotland welcomes the opportunity to provide written evidence to the Health & Sport Committee setting out our position on the Patient Rights (Scotland) Bill. BMA Scotland supports the Scottish Government’s intention to encourage a stronger sense of public ownership of the NHS and welcomes the renewed commitment to a service which is publicly funded and owned, and free at the point of delivery. As such we welcome the commitment to articulate the rights and, to some degree, the responsibilities of all those using and providing NHS services as outlined in the health care principles. Many of these reinforce long-standing values and principles embodied by the NHS. They also reflect doctors’ established professional standards as set out in the General Medical Council’s Good Medical Practice.

During the consultation process, the BMA questioned the need for legislation on patient rights and we remain unconvinced of the purpose of legislating in this area. Instead, we believe that many of the rights listed in the Health Care Principles are more suited to a patients’ charter style approach, particularly since there are no rights to legal recourse set out in this Bill.

We are also deeply concerned over the proposals to enshrine an inflexible 12 week treatment time target in law which, we believe, will have adverse consequences and is likely to distort clinical priorities in order to satisfy a political imperative which is contrary to the objectives of this Bill.

Patient rights and healthcare principles

BMA Scotland supports the move to strengthen and clarify the rights of patients in accessing and receiving NHS services. The policy memorandum supporting the Bill accepts that rights already exist for patients but these are articulated in disparate ways. Many of the health care principles detailed in the schedule are already covered by professional codes of conduct and in existing legislation (e.g. Human Rights Act and Data Protection Act). As such, few of these are new principles or aspirations and there are already processes in place to take action, such as reporting a professional to the regulatory body or making a complaint to the health board or ombudsman. The only possible benefit of having these principles stated in legislation would be if there was a new process of redress for patients who believed that these principles have not been met. However as the Bill makes clear that nothing in the Bill is enforceable by legal action (Section 18(2)(a)). While we accept that

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1 General Medical Council (2009) Good medical practice
there is always room for improvement to the existing processes, BMA Scotland believes that this supports our position that there is no need to legislate and that producing a charter to bring together these rights and responsibilities in a single document would be equally effective and would give these principles the enhanced status desired by Government.

**Health care principles**

While these principles or ‘rights’ are commendable it remains to be seen how they can be defined in the legal sense. For example, while nobody would disagree with the principle that patients should be treated with dignity, it is hard to define what this might mean in a legal sense as there are strong elements of subjectivity involved in its assessment.

Under the proposals of this Bill, every NHS body has to have regard to the health care principles when performing health service functions (Section 3(1)(a) and (b)). We would request the Committee to seek assurances from the Government and perhaps consider amending the Bill to explicitly state that clinical judgement will prevail. At present, it is not clear how the Government intends to evaluate decisions made by Boards and, should this Bill become law, we would be keen to be consulted in developing guidance on this matter, particularly for the implementation of Treatment Time Guarantees.

The results of the *Patient Experience Programme: priorities for inpatient care*, published in 2009 found the top priority for patients was a clean ward. Preventing healthcare associated infections is a priority for patients and NHS organisations and therefore should be considered as a principle for inclusion e.g. that “Patients are treated in a safe and clean environment”. It is our view that this could apply equally in the hospital, community or general practice environment. However, again we would restate our opinion that these principles and rights would be equally effective in a Patients’ Charter.

A mutual NHS should be one in which all those involved have both rights and responsibilities – patients who use services, those who work in the NHS and provide services, and all of those who pay for the NHS through taxation. As such, we believe it is important that any measures which strengthen rights should also reinforce appropriate responsibilities. As with patient rights, we are unconvinced that legislation is the best way to articulate these responsibilities, but if this is the approach the Committee wishes to support, we would at least ask it to consider strengthening the healthcare principle number 12 to remove the word ‘encouraged’.

**12 Week Treatment Time Guarantee (TTG)**

For individual patients waiting for NHS treatment can be a difficult time and it is important that those with the greatest clinical need receive appropriate care within a reasonable timescale. BMA Scotland has welcomed recent waiting times figures that demonstrate the commitment and hard work of NHS staff to achieve targets.

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However, we do not believe that any political guarantee regarding specific waiting times should be placed in legislation and would recommend the removal of this entire section of the Bill. The widespread use of centrally imposed treatment time targets has many unintended consequences, distorts clinical priorities and harms patients\(^3\). All centrally-set targets have the potential to distort clinical care. Any objective which encourages clinicians to take actions which are potentially not in the patient's best clinical interests is unhelpful. This is even more problematic if there are associated managerial imperatives which may further distort clinical decision making. As an overarching principle, clinical decisions should take precedence and clinicians should be supported in making such decisions\(^4\).

It has been difficult to pin down exactly what the TTG is and when the clock starts. It is our understanding that the 12 week clock begins when the doctor and patient agree on a course of treatment. However this treatment guarantee falls within the existing (non-legislative) 18 week Referral to Treatment (RTT) target. Again we are unclear what this legislation adds.

The current waiting time targets contain ‘tolerances’ at the margins to make allowances for cases that do not achieve the target, e.g. 95%. This provides Boards with flexibility where the target cannot be achieved. Systems are also in place to enable the Cabinet Secretary for Health and Wellbeing to intervene in cases where waiting times targets are not achieved. However there is no flexibility within the legally binding TTG and Boards will be expected to meet the guarantee in all cases, this inflexible system increases the likelihood of distortion to clinical priorities. It is not yet clear what interventions the Cabinet Secretary will where Boards fail to achieve the TTG.

Doctors tell us that waiting times targets and the subsequent distortion of clinical priorities can result in patients with less serious complaints being treated before those with more complex medical problems. We believe that without a significant increase in resources, and the provision of extra capacity in the system for periods of unexpected activity, legally binding treatment time guarantees could be of detriment to those who may be most in need of urgent care. Reductions in waiting times have only been achieved through substantial investment in the NHS, including significant increases in the number of staff. There is little recognition of these costs in the financial memorandum. To ensure that all Boards fully comply with the legally binding TTG (and risk breaking the law if they do not) it will be necessary to increase resources.

As we enter a period of constraint in public sector funding, such an increase in resources is likely to be unaffordable and the BMA does not believe that these guarantees can be justified, particularly in this financial climate.

The TTG will apply only to planned/elective inpatient and day case services. Therefore only patients awaiting surgical interventions will benefit from this

\(^3\) BMA (2009) ARM 2009, 144
new 'right', patients requiring medical interventions will not. There should be guarantees in place to ensure that those services not covered by the TTG are not disadvantaged. For example, services where admission is generally not elective or planned are often required by the most vulnerable members of our society (services such as care of the elderly, learning disability and some mental health services. This will create a difficult balancing act between the rights of different patients and there is a risk that others with more serious conditions will have to wait longer.

An integral aspect of the doctor’s role is to be an advocate for their patients, providing advice and support to navigate treatment options and services. For every patient, there will be different and often unique needs and doctors are concerned that this new target, enshrined in law, will create an inflexible system that forces doctors to rush patients into treatment without consideration of the particular needs of the patient.

It is not yet clear what penalties a Board will suffer as a result of breaching the TTG, however they will be breaking the law. The BMA considers this approach to be counterproductive and of little benefit to the improvement of patient care.

Complaints and patient feedback system
The NHS is a bureaucratic organisation where even people who work in the system can find it difficult to navigate their way through. For the general public this problem is magnified. The lack of access is a barrier for people who want to find information or to make a complaint about their care. The BMA often receives correspondence from patients who do not know where to turn and have little understanding of how to have their voice heard.

There is evidence that suggests that many cases of complaints within the NHS are the result of poor communication. The BMA has welcomed moves to introduce communication skills training into undergraduate and postgraduate medical education programmes. In addition, the GMC’s guidance on Good Medical Practice already places an emphasis on the need for effective communication between doctors and their patients.

We recognise that complaints provide an opportunity to learn and believe that the structures in place should ensure that professionals and patients are dealt with appropriately and fairly. Systems should be developed to ensure that complaints are dealt with and we would seek assurances from the Scottish Government that NHS time and resources are not wasted when explanation and apology may be all that is required to resolve a complaint.

Any measures that clarify and ease the existing complaints process are welcome. We would support a mechanism that encourages local complaint resolution within the multidisciplinary team at the practice, department or ward.

6 General Medical Council (2009) Good medical practice
level. We believe that local resolution to complaints can often be found, leaving the NHS boards to deal with more complex cases. Retaining control of complaints at the local level will ensure that complaints are handled quickly and appropriately with satisfactory input from all those involved.

**Patient advice system and the role of Patients Rights Officer**

The Bill makes provision for the establishment of an ‘independent’ Patient Advice and Support Service (PASS). The aim of this service is to promote an awareness of rights and responsibilities of patients, advise and support those who wish to make a complaint and provide other information about the NHS and how to access services.

The policy memorandum supporting the Bill includes reference to an analysis of the current Independent Advice and Support Service (IASS) which found that users believed it offered a valuable resource for people who may be vulnerable. It also found that in more than half of the cases where an IASS worker becomes involved in a complaint, they are resolved or no further action is taken. It is proposed that the new PASS will ‘build’ on the work of IASS by promoting an awareness and understanding of patient rights and responsibilities, provide advice and support in relation to local resolution if things go wrong.

We are concerned that when a patient or relative wishes to complain about care or treatment, this new system creates an automatic default whereby the patient is immediately referred to the Patient Rights Officer. This ‘over formalising’ of the process detracts from the doctor-patient relationship when in fact the system should be encouraging better communication between doctor and patient.

We would like to encourage more complaint resolution locally within the multidisciplinary team, where there is the clinical expertise and knowledge to appreciate the finer details of a particular patient’s grievance rather than referring the complaint to a support worker who may or may not have clinical knowledge.

It is difficult to see why provision for this service and the Patient Rights Officers should be necessary in primary legislation, particularly with all the ensuing cost and bureaucracy to change the legislation, particularly when the existing service appears to be functioning relatively well.

**Financial Memorandum**

The Financial Memorandum that accompanies this Bill suggests that initial costs will begin at £862,000 in 2010/11 rising to around £3.5 million by 2012/13.

As stated previously, the achievement of existing waiting times targets has largely been achieved because of significant investment in the NHS. There is little recognition in the Financial Memorandum of the less obvious costs associated with ensuring capacity is available (for example, the cost of waiting...
list initiatives, the running costs of national/regional centres at Stracathro and the Golden Jubilee in Clydebank). If resources are not available, it is likely that Boards will divert funding from elsewhere in the budget to ensure that they do not break the law.

Given the current economic climate, we are concerned that additional resources will not be available and that managing patients’ expectations will become more difficult.

**Conclusion**

The BMA does support the clarification of the rights and responsibilities of NHS patients and staff and the principles of equality and compassion on which the health service is based. However we do not agree that this should be placed into law, instead we believe a modern and improved patients’ charter would serve an equally effective purpose.

The Patient Rights Bill enshrines inflexible targets as legal rights which, even without any means of legal recourse, could result in unintended consequences such as distorted clinical priorities which are detrimental to patient care. Boards which breach the 12 week TTG will be breaking the law and it is difficult to understand why this should be necessary, particularly when there are no penalties within the bill and no rights of recourse for the patient.

The BMA believes that the proposals outlined in this Bill place political achievements ahead of the needs of patients and would urge the Committee to reject the general principles of this Bill on the basis that it is unnecessary.

Gail Grant  
Senior Public Affairs Officer  
BMA Scotland  
13 May 2010
The Royal College of Nursing (RCN) Scotland welcomes the opportunity to submit evidence to the Health and Sport Committee on this key issue for health care. RCN Scotland is committed to promoting the rights of the people of Scotland to person-centred care, providing optimum benefit to health and wellbeing. We are fully supportive of patient rights and the principle of mutuality; a health service owned and supported by patients and staff together. We remain concerned that primary legislation is not the most effective means of achieving this.

The need for primary legislation?

The Policy Memorandum to the Bill states that “The Patient Rights (Scotland) Bill is intended to reinforce and strengthen the Scottish Government’s commitment to place patients at the centre of the NHS in Scotland.” RCN Scotland welcomes this commitment yet considers that primary legislation about patients’ rights will not have the desired effect on patients’ experience.

‘Patients’ rights’ language has confrontational and litigious associations. It suggests a one-sided NHS and could be construed as unbalancing a mutual approach. The language of mutuality and the Quality Strategy is more relational and therefore more appropriate to convey the rights and responsibilities for patients, staff, and the wider public as co-owners of the NHS. Delivering patient-centred care requires patients and clinicians to take on different and complementary roles. This balance should not be lost in the promotion of patient rights.

Most of the rights outlined already exist in one format or another in current legislation, regulation, or codes of practice. Some of these existing rights are summarised in Appendix 1. If the concern is that these rights are not being met, is further legislation the answer? Where existing rights are not being fulfilled this may be due to a combination of awareness, system barriers, culture, and capacity within the NHS.

Given the potential unintended consequences of legislation, we need to be sure that this Bill is clear about how it will add value. We remain unconvinced that legislation is more useful than a review of how rights and responsibilities are promoted and implemented.

The resources to provide health care principles

Care which is delivered as set out in the health care principles is dependent on staff having the time and resources to give individuals the attention they deserve. The RCN Nurses Employment and Morale Survey Scotland found that 51% of nurses say there is not sufficient staff to meet patients’ needs. Nurses wish to deliver person centred care, but work in a system where that is
often difficult to achieve. Unless barriers to person-centred care are addressed so that frontline staff have the time to attend to patients’ needs and concerns, to the standards their professionalism demands, patients rights become merely rhetoric and staff are set up to fail.

The RCN endorses the health care principles as set out in the Bill, although do not think that they require primary legislation. We are also concerned about managing expectations at a time of tightening financial resources. The patient focus section reinforces the aspirations set out in the NHS Scotland Quality Strategy. The document states that Scotland should become a world leader in person-centred health care, to improve patient experience and support people in participation in their health care.

We accept the Scottish Government’s intention that the quality strategy, including initiatives such as ‘Releasing Time to Care’, will support nurses’ desire to spend more time in direct patient care. However, this is set against the reality of current cuts in posts and expected significant further reduction in budgets.

RCN Scotland is concerned that in the face of ongoing pressure on public spending in general and on the provision of adequately trained staff, equipment and treatment measures in particular, health care professionals will increasingly become the subject of complaints relative to alleged breaches of the health care principles.

The treatment time guarantee

There remains anxiety that health boards may encourage clinicians to prioritise new patients in caseloads, over patients requiring review, or follow-up, so that 12-week guarantees could be met. RCN Scotland is concerned that the 12 week guarantee being enshrined in legislation will create perverse incentives for ‘gaming’, or other unintended consequences, as has occurred elsewhere when such systems have been introduced.

Ensuring NHS staff are knowledgeable and prepared

Experience from the implementation of the Patients’ Charter suggests that a huge amount of time and resource is required to support staff in the early implementation phase. Patients required significant time and explanation as to implications of the Charter for their care. NHS staff need to be prepared for this role.

RCN Scotland is concerned about the extent to which health care professionals, will receive training and updates on the health care principles and the treatment time guarantee as well as other legal rights and remedies

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available to patients so they are fully informed as to what is expected of them and where the responsibilities lie.

The RCN is also concerned to see that resources will be made available to enable professional bodies and trade unions representing health care workers and health care professionals to engage and collaborate with NHS bodies and organisations representing key interested patient groups, in arriving at common understandings as to how the principles are to be understood, applied and disseminated.

**Patients’ responsibilities**

RCN Scotland agrees that a mutual NHS requires responsibilities to be shared by patients as well as staff. We would like to see more discussion about expectations of patients in meeting the proposed responsibilities. The health care principles state that ‘Patients are encouraged to treat any person involved in the delivery of health care with dignity and respect’. RCN Scotland would like to see this statement strengthened replacing the word encouraged with expected.

RCN Scotland is concerned that recent extensions to the Emergency Workers (Scotland) Act have not been translated into changed behaviours at health board level. It is important that sanctions now available under the Act against those who abuse staff are taken up by boards.

For incidents of abuse that fall short of thresholds set out in the Act, there must also be avenues for staff to make complaints or seek support. It is particularly important that intolerance to abuse of any kind against staff is translated into action, with clear processes in place for managing situations where patients do not fulfil their responsibilities.

**Promoting equality**

Experience of patients’ rights legislation in other countries has shown that inequality can be an unintended consequence of legislation. Individuals with the means and motivation to pursue options of choice and redress are more likely to make use of their enhanced rights. A core principle of the NHS and a policy priority for Scottish Government is equality.

The Bill introduces patient advice and support service (PASS) with a staff of patient rights officers. We understand that the PASS and its staff will promote awareness of patient rights and responsibilities, provide advice and support to those wishing to make a complaint, raise concerns or give feedback and provide information and advice on the health service.

The RCN welcomes the enhanced support for patients through this service. We are however concerned at the extent to which patient rights officers will have the training, skill and experience to direct patients to the full range of legal remedies available to them in the light of a breach of any of their rights, including the rights under the Bill.
Applicable to the whole of the NHS

RCN Scotland is concerned that the overall model suggested has greater applicability to acute health care. Many of the specific rights, from the treatment time guarantee, to the role of patient rights officers, and measures for feedback and redress, have a more natural fit with secondary care. Given the vast proportion of health care in Scotland which is already delivered in the community, and the policy of continuing to shift the balance of care, we would expect the proposals to have a strong emphasis on community and primary care. Demonstrating the relevance and application to services in the community will be an important part of making this real for patients and staff alike.

In summary

RCN Scotland has the following concerns:

- That the Bill would unbalance relationships and work against the development of a mutual NHS;
- Health care professionals may increasingly become the subject of complaints relative to alleged breaches of the health care principles, and the treatment time guarantee;
- The 12 week treatment time guarantee could create perverse incentives for ‘gaming’, or other unintended consequences;
- The Bill could serve to increase inequalities in health care;
- The cost and time associated with training and updating staff around the health care principles and their responsibilities is severely underestimated;
- Principle 12 should be amended to read ‘Patients are expected to treat any person involved in the delivery of health care with dignity and respect’; and
- That the Bill in its current form focuses on issues of relevance to hospital based care and does not address primary and community care.

RCN Scotland would like to emphasise support for a mutual NHS, enhanced through clear, meaningful, and equitable patient rights and responsibilities which sit alongside those rights and responsibilities of staff. However, we do not believe that legislation is required to achieve this.

Elinor Jayne
Parliamentary and Media Officer
RCN Scotland
13 May 2010
Patients already have a range of legal rights which come from duties owed to them by NHS bodies and by the individuals who care for them by virtue of the common law and under enacted law. Many of these rights and duties overlap with the health care principles set out in the Bill. These rights and remedies include:

(a) the right to claim compensation, which can arise -

(i) when an NHS body or health care professional owning the patient a duty of care breaches that duty and causes the patient loss, injury and damage. That duty might arise at common law which is the basis of most clinical negligence claims, the test for which is to be found in the case of Hunter v Hanley 1955 SC 200, including claims in respect of failures to obtain informed consent;

(ii) when an NHS body or health care professional breaches their duty of confidentiality to the patient causing loss, injury and damage;

(iii) when an NHS body or health care professional breaches a duty under enacted law designed to protect the health, care and welfare of the patient, for example the Occupiers’ Liability (Scotland) Act 1960 or the Consumer Protection Act 1987.

(b) the right to seek relief or remedy, including damages for just satisfaction in terms of section 8 of the Human Rights Act 1998, given that NHS bodies are public authorities in terms of section 6, in relation to any unlawful act which is incompatible with a Convention right. Key ECHR articles in this context are:

(i) Article 2 (right to life);

(ii) Article 3 (freedom from torture and ill-treatment);

(iii) Article 5 (liberty);

(iv) Article 8 (right to protection of the home, private and family life, including autonomy in decision-making and the right to live with dignity); and

(v) Article 14 (non-discrimination).

Other human rights standards which may be relied upon by the patient include the above mentioned International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights, the UN Principles for the
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Protection of Persons with Mental Illness and the Improvement of Mental Health Care and the UN Convention on the Rights of the Child.

(c) Patients have rights to freedom of information in terms of the Freedom of Information (Scotland) Act 2002.

(d) Patients have rights to the protection of their data and their personal sensitive data and to access their medical records in terms of the Data Protection 1998 and the Access to Health Records Act 1990.

(e) Patients have rights in certain circumstances in terms of the Mental Health (Care and Treatment) (Scotland) Act 2003.

(f) Patients have rights to complaint to the Scottish Public Service Ombudsman in terms of the Scottish Public Services Ombudsman Act 2002. In terms of section 11 of the Bill which deals with complaints and other feedback nothing done under or by virtue of that section is to preclude an investigation under the Scottish Public Services Ombudsman Act 2002 in respect of any matter. (See section 11(7) of the Bill).

(g) Patients have a range of rights to complaint to professional regulatory bodies, including the NMC in relation to nurses, the GMC in relation to doctors, the GDC in relation to dentists, and the Health Professions Council in respect of 15 other health professions, including therapists, chiropodists, paramedics, physiotherapists and radiographers.

(h) Patients have the protections and rights afforded to them by the criminal law and can report circumstances to the relevant authorities, most usually the police.

(i) Patients are given protections in relation to the prescribing, dispensing and administration of medicines.

(j) Where a death has occurred as a result of a medical accident, the patient’s family and other representatives will be entitled to enter into a dialogue with the health care providers, the police and the Crown Office Procurator Fiscal Service with a view to holding a fatal accident inquiry in terms of the Fatal Accident and Sudden Deaths (Scotland) Act 1976.

This is by no means an exhaustive list but serves to illustrate the range of rights already in place.
Patient Rights (Scotland) Bill

Royal College of General Practitioners (RCGP) Scotland

The Royal College of General Practitioners (RCGP) is the academic organisation in the UK for general practitioners. Its aim is to encourage and maintain the highest standards of general medical practice and act as the ‘voice’ of general practitioners on education, training and issues around standards of care for patients.

The College in Scotland came into existence in 1953 (one year after the UK College), when a Scottish Council was created to take forward the College’s interests within the Scottish Health Service. We currently represent over 4000 GP members and Associates in Training throughout Scotland. In addition to a base in Edinburgh, the College in Scotland is represented through five regional faculty offices in Edinburgh, Aberdeen, Inverness, Dundee and Glasgow.

The consultation document was reviewed by GP members of the RCGP Scottish Council, the RCGP Scotland Executive Board, the RCGP Scotland Membership Liaison Group (MLG) and lay members of the RCGP Scotland Patient Participation in Practice Group (P³).

Overall responses received found the standards reasonable. However there were concerns raised regarding the intentions of the Patients’ Rights Bill to be used as a legal framework. It was felt that as objectives, the improvements outlined in the document have great merit, but enforcing them as statutory legislation would be perceived as unnecessarily bureaucratic. There were also concerns raised that legal costs would prove extremely high for the healthcare system. Despite the fact that a ‘mutual’ NHS is discussed, it would be highly unlikely that patients themselves would have legal action taken against them. Ultimately it was felt that the creation of legislative framework is unnecessary.

‘We are delighted the government is reviewing Patients Rights, however we remain unconvinced of the need for their codification. It must be remembered that with rights also come responsibility. These responsibilities extend to using the services appropriately and treating those who provide those services with respect.’

Dr Ken Lawton, Chair of RCGP Scotland

1. The Right to Access
12 weeks was considered an acceptable target for waiting times, though it should be noted that a member of our patient group suggested that 10 weeks for inpatient treatment and 14 weeks for outpatient treatment would also be an acceptable model.
Concerns were raised that, whilst a focus on meeting targets is desirable, the implications of implementing such guarantees in a legal sense may not necessarily be feasible and would lead to a drain on both administrative and financial resources. Members felt that current HEAT targets have been, and will continue to be highly successful in reducing waiting times. We would welcome the successful implementation of 12 week waiting targets for patients but do not feel that there is currently the need to develop these targets into legal and statutory requirements.

GP members in rural areas also raised concerns about the need to take into account patients in rural communities who may not have access to certain treatments in their own board areas. This is particularly relevant to small island communities where patients may be referred to other health board areas for (for example) certain psychiatric services. Any legislation introduced regarding patient rights must ensure that the geographical diversity of Scotland is taken into account in order to ensure that such legislation is relevant to all.

2. The Right to Respect
Members were in support of the ideas addressed in this section; however concerns were raised as to whether adequate funding is in place to guarantee this as a legal right.

Responses also raised the concern that it is difficult to define terms such as ‘dignity’ and ‘respect’, these abstract terms could prove problematic especially where legal implications would be involved. It was also felt that care must be taken to ensure extra vigilance on this issue with regards to more vulnerable patients (such as the elderly, those with psychiatric problems and children).

3. The Right to Safe and Effective Care
Overall we agree with the inclusion of the entitlements and responsibilities as laid out in the draft. However it was noted that the term ‘continuity of care’ requires definition in order to distinguish whether this refers to continuity of the person providing care or the type or care offered.

Responses also cited the need for amendment of ‘complying with advice on medication and treatment’. It was felt that this wording removes the contemporary need for transparency. It is important for both patients and clinicians to come to a mutual understanding of the treatment plan and therefore we would suggest that the section referenced above be amended to ‘patients will be responsible for adhering to agreed treatment plans.’

It was also noted that patients have the right not to comply with therapy and that health professionals may seek concordance but cannot insist on it. It may be necessary to outline this in the bill.
4. The Right to Communication
We would welcome the moves to encourage patients to ask questions and to interact in this way with members of the healthcare team.

Additionally, we feel it is important to note that it is difficult to define clear and appropriate communications as views of this may vary considerably between parties. We are also aware that currently it may not always be possible to access the services of an interpreter and feel that this entitlement should be amended to include the phrase ‘where available’.

5. The Right to Information
Respondents were generally happy with the points outlined and were supportive of the patient’s right to information. Continued investment on those for whom English is not a first language would be needed to ensure this is possible (for example by improving access to interpreter services). It was also noted that it would be time consuming and costly to copy all correspondence to a patient should they request it and that it was largely unclear who would be responsible for the administrative work involved. It will be necessary to provide a definition of ‘any letters, faxes or emails’ as the level this is set at will have a direct affect on the feasibility of this guarantee.

6. The Right to Participation
The over arching principles outlined in this section seem reasonable and members of our patient group, P3 welcomed the notion that patients are entitled to be involved in decisions about health services. The importance of ensuring that patients are aware they can withdraw consent at any time was highlighted as a positive move as many patients may not realise this to be the case.

However, there were concerns over the demand on healthcare professionals to provide full information on all options open to a patient regarding their treatment. One member asked whether a ‘care information specialist’ would be introduced for this purpose or whether it would fall onto the patient’s doctor to provide this additional service themselves. It will be time consuming for members of the healthcare team to research and provide this service to the level outlined and we feel it would be useful to see further research on how the additional appointment time required for this service would fit into the promises to drastically cut waiting times. We would also welcome a more detailed proposal on informed participation.

7. The Right to Privacy
General consensus was in approval of a patient’s right to privacy as outlined, though it was noted this section does not add anything to existing documentation. As an additional comment it was noted that it should be made clear in the document that the right to privacy is not absolute and may be overridden in
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exceptional circumstances such as that relating to statutory legislation and public interest.

8. The Right to Independent Support and Redress
Both GP and patient respondents welcomed the principles of achieving a culture of feedback and learning. We agree that staff should be encouraged to view complaints not as a threat but as a learning opportunity. We support the responsibility of patients in providing (as far as possible) positive and constructive feedback, though one response commented that negative feedback can also be of value.

We hope that these comments are useful. If you wish any further information from RCGP Scotland please contact at:

Dr. Kenneth Lawton  
Chair  
RCGP Scotland  
13 May 2010
1 Background

Inclusion Scotland is a network of disabled peoples’ organisations and individual disabled people. Our aim is to draw attention to the physical, social, economic, cultural and attitudinal barriers that affect disabled people’s everyday lives and to encourage a wider understanding of those issues throughout Scotland. We have consulted widely with disabled people to obtain their views of the proposals contained within the Patient Rights Bill.

2 Patients’ Rights & General Principles of Bill

2.1 Almost a third of Scottish NHS Service Users are disabled people. Although many receive an excellent service, many others have experienced discriminatory assumptions about their quality of life or strict adherence to a 'medical model' of disability adversely influencing the sort of service received.

2.2 Discrimination within the health service can affect disabled people from birth ranging from insensitive treatment of disclosure of disability, restrictions or refusal of treatment, to posting of unsought ‘Do Not Attempt Resuscitate' (DNAR) notices.

2.3 The Disability Agenda published by the Disability Rights Commission (DRC), found in ‘Tackling Health Inequalities that: People with learning disabilities have much lower rates of cervical screening, mammography and other routine tests than other citizens; Some groups of disabled people die younger than non-disabled people; Learning-disabled people were four times more likely to die from treatable illnesses; Learning-disabled people were 58 times more likely to die before the age of 50 than non-disabled people; Large causative factors were barriers in accessing health promotion, assessment, screening and treatment.

2.4 Over half of those taking part in the DRC’s consultation said that, as people with mental health needs or a learning impairment, they had difficulties when trying to use services provided at primary care level. A small number reported not being able to register or being struck off a GP’s list, for instance for being ‘too demanding’. It is unlikely that similar discrimination is not faced by those with mental health problems or learning disabilities north of the border.

2.5 A large body of evidence proves inequalities in health outcomes between disabled and non-disabled people and of significant problems in access, staff attitudes and quality of service. Reports published on the continuing institutional
2.6 In 2004 Fair For All Disability undertook a survey of all Scottish NHS Boards, to establish their knowledge of Part 3 of the Disability Discrimination Act 1995, which prohibits discrimination in the provision of goods & services. Results indicated poor knowledge of the Act. The conclusion was that this lack would likely lead to difficulties when disabled people attempted access to health services.

2.7 In 2006/7 inclusion Scotland surveyed our own members on their experience of the NHS. Results showed that they experienced a lack of sensitivity and understanding of their health care needs in all areas of the health service. This Bill could help ensure that such discrimination does not persist within Scotland’s NHS.

2.8 We acknowledge the commitment and professionalism of many NHS staff but we report that many disabled people are concerned at the ongoing erosion of caring attitudes, cleanliness and common sense within the NHS. At present NHS staff carry out established protocols, with their emphasis on reducing “risk”, rather than adapting the care provided to suit disabled patients’ needs. We therefore welcome the principle that health care is henceforth to be patient focused.

Example 1: When admitted to hospital a disabled person’s Personal Assistant (PA) is not allowed to be present as the NHS assumes all responsibility for care. Yet some disabled people have had food left beside their beds and been unable to feed themselves because NHS staff have been too busy or were unaware of their needs (even though previously disclosed). In such circumstances why are PAs not allowed to assist?

2.9 Disabled people report that the ‘Does he take sugar?’ habit persists within the NHS. Doctors and health staff tend to communicate with family members, carers, friends or PAs rather than disabled people themselves. Wherever possible, disabled people should be communicated with directly about their care and treatment. Advocacy support must be made available for those with learning difficulties, brain injuries or other impairments which hinder understanding. We therefore welcome the principle that patients are to participate as fully as possible in decisions relating to their own health and wellbeing.

2.10 Inclusion Scotland are extremely disappointed that the Bill will only require the NHS to “…have regard to the importance of providing such information and support as is necessary to enable the patient to participate…” instead of the stronger right to be communicated with which was included at the Bill’s
consultation stage. It effectively negates the rights of some disabled people to participate as fully as possible – for example there will be no clear right for BSL or Braille users to be communicated with in formats of their choice. Instead the NHS need only have ‘regard’ to that choice.

2.11 This weak requirement falls far short of disabled people’s rights as established under the UN Convention on the Rights of People with a Disability to which the UK is a signatory. Article 21 of the Convention states that:

“States Parties shall take all appropriate measures to ensure that persons with disabilities can…. receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice, as defined in article 2 of the present Convention, including by:

a) Providing information intended for the general public to persons with disabilities in accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost;

b) Accepting and facilitating the use of sign languages, Braille, augmentative and alternative communication, and all other accessible means, modes and formats of communication of their choice by persons with disabilities in official interactions;

2.12 The Scottish Government has a clear duty to work towards progressive achievement of these rights. The proposal in the Bill to direct NHS Boards to merely have “regard” to communication support is at odds with that obligation. Disabled people, like all other patients, should have a clear right to be provided with information and support enabling them to make informed decisions about their treatment. Anything less is an erosion of their rights and likely to result in negative health outcomes.

Example 2: A deaf BSL-user is admitted to Accident & Emergency. He is allergic to penicillin. Doctors consider providing a BSL interpreter to outline treatment options but as this will attract additional expense to the unit, after due “regard” they instead decide to proceed without one. The patient suffers an adverse reaction and dies as he was unable to communicate effectively with them.

3 The 12 Week Treatment Guarantee

3.1 Inclusion Scotland cautiously welcomes the commitment to deliver a maximum 12 week wait from referral to treatment but without additional resources it is unclear how this is going to be achieved

3.2 The adoption of a “target” culture tends to distort NHS service delivery with management more concerned with meeting targets than improved outcomes for
patients. Inclusion Scotland strongly urges the Government to monitor whether speeding up the process is genuinely delivering good medical care.

3.3 There is a feeling that some GPs delay making referrals resulting in a longer patient journey even though there is a guaranteed waiting time after referral. Inclusion Scotland urges the Government to bring forward proposals on how this potential problem will be addressed.

3.4 We deplore the Scottish Government’s failure to include mental health treatment within the guarantee. NHS Highland reported that some mental health patients wait for more than four and a half years to see a psychologist. Referrals to mental health services can be subject to considerable delays far exceeding the proposed 12 week treatment guarantee. There is no commitment in the Bill to tackle this.

3.5 The argument that access to mental health services can be adequately met by crisis admissions is dangerous and is an effective abandonment of any guarantee of treatment for mental health service users.

3.6 The Government’s case seems to be that patients with long term mental health needs (depression, anxiety, schizophrenia, bi-polar disorder) should not be guaranteed early access to recognised and effective treatments until such time as their condition enters a crisis phase when their admission is required. If there is early access to adequate mental health services there will be fewer crisis admissions. Rationing care until a crisis occurs is likely to intensify longer term psychological damage by leaving serious conditions unaddressed and untreated.

3.7 The mental health of Scotland’s population is already extremely poor compared to other developed nations. With an estimated one in five Scots seeking some form of mental health treatment last year, only the United States has a higher incidence of mental health issues (Source: World Health Organisation). Scotland also has woefully high suicide rates particularly amongst young men.

3.8 There is a strong relationship between poor mental health and the incidence of (and ability to recover from) conditions such as heart disease, stroke and cancer. We posit that poor provision of mental health services partially explains Scotland’s poor life expectancy, particularly amongst those suffering stress from poverty and deprivation.

3.9 Similar guarantees for waiting times for mental health issues must be established for the present undervalued, under resourced Scottish mental health services as those applying to physical health services. Otherwise, those with mental health issues will be treated less favourably. Such guarantees will mean investment in extra staffing requirements.
3.10 In terms of the proposals contained within the Bill we remain unsure as to the enforcement mechanism if the 12 week guarantee is not met. The Minister’s power to make directions seems reasonably powerful but lacks clarity on how, and when, it will operate in practice.

4 The complaints and patient feedback system

4.1 Inclusion Scotland welcomes the proposed establishment of an independent Patient Advice and Support Service as a step towards establishing better advocacy for patients within the NHS.

4.2 However problems exist with the integrity of the mechanism of a service whose funders are those against whom complaints will be raised. Determination to advocate on behalf of clients can be influenced by fear of jeopardising funding.

4.3 Fears were expressed that lodging complaints could jeopardise future relationships with the medical profession. It is, for example, all too easy for a GP to remove a patient from their list.

4.4 Patients need to be protected from victimisation by health professionals if they raise a legitimate complaint. This should be a robust right similar to those contained in the Equalities legislation.

5 The patient advice system and the role of Patient Rights Officers

5.1 We welcome the proposed establishment of a patient advice system and the introduction of Patient Rights Officers (but note our concerns above). However such a system cannot operate effectively without the development of parallel advocacy services for disabled people as some disabled people (e.g. those with learning difficulties; deaf/blind people) will neither be able to initiate nor pursue complaints without specialised advocacy support.

5.2 Patients Rights Officers must be able to communicate with or support patients who have communication needs (BSL, Braille, etc.) and these remain unaddressed. The officers must be required to take all appropriate measures to enable them to support and communicate with disabled patients and to provide information on their service and the progress of cases in appropriate formats.

6 Conclusion

6.1 Inclusion Scotland confirms its support for the main principles outlined in the Patient Rights Bill but calls on the Scottish Government to amend and improve the legislation in line with seeking progressive achievement of disabled people’s rights.
Footnotes:
1. The 'medical model' of disability focuses on the impairment of the individual as the core problem believing medical treatment or cures should be used to 'normalise' the individual. The 'social model' of disability aims to address the problems of social and environmental barriers in terms of society's discriminatory policies, practices and attitudes which cause social exclusion.


Bill Scott
Policy Officer
Inclusion Scotland
7 May 10
Patient Rights (Scotland) Bill  
Long Term Conditions Alliance Scotland

General comments

LTCAS welcomes action to strengthen the rights of users of the NHS. The Patients’ Rights Bill should aim to contribute towards a mutual NHS, including:

- People becoming the leading partners in their own health and care
- Users of services being central to service planning and development
- Cultural change away from the traditional model of people as passive recipients of NHS services

LTCAS strongly welcomes the commitment in the policy memorandum (paragraphs 22, 40 and 62) to increasing provision and funding of services such as independent advice/support services, advocacy, translation, interpreting and communication support services.

During the Scottish Government’s previous consultation on proposals for the Patient’s Rights Bill LTCAS raised questions over how the legislation would be turned into a reality. This issue still requires further consideration but the intention to develop a training programme for NHS staff (Policy Memorandum paragraph 60) will help to achieve this. This training should be rolled out across all levels of the NHS and mainstreamed into future undergraduate education for health staff.

Consideration should be given to producing a Code of Practice to accompany the legislation. This would help illustrate how the aspirations of the legislation should translate into reality.

Rights and health care principles (Sections 1 to 5)

- Section 1.2(a) describes ‘patient focused’ as ‘anything done in relation to the patient must take into account the patient’s needs’. This should be strengthened to state the patient’s needs should be paramount.
- It is essential that people are given information to support their participation in their own health and wellbeing, however this does not happen consistently. LTCAS therefore welcomes the provision in section 1.2(d).
- The health care principles outlined in the schedule are welcome, in particular the requirement that ‘health care is provided in a caring and compassionate manner’. However:
  - Principle 5 relates to a key issue for health inequalities. Many people experience barriers to health services, and in turn poorer health outcomes. This may be caused by lack of support for
people with sensory impairments, English as a second language, learning difficulties or people living in residential settings. The provision should be strengthened so that support is not just available but proactively offered.

- Support from a voluntary organisation can make a significant difference to people’s experiences and health outcomes. LTCAS would like to see the ‘quality care and treatment’ principles state that consideration will be given to other organisations or agencies (for example from the voluntary or local government sectors) that could support a person’s health and wellbeing.

- Self management should be reflected in the ‘patient participation’ principle, for example by stating ‘patients are encouraged to work in partnership with health professionals and to take the lead in managing their own health and wellbeing’.

**Treatment time guarantee (Sections 6 to 10)**

Timely treatment is essential for people who live with long term conditions. However this right must also apply to follow-up appointments and ongoing care. If these rights and guarantees only apply to a person’s first appointment there is a risk that people with long term conditions who require ongoing health services will be pushed to the back of the queue. LTCAS would expect to see this reflected in the further provision to be made by Scottish Ministers.

**Complaints and patient feedback (Section 11)**

LTCAS strongly welcomes provision for feedback and complaints to help inform improvements to health services. It would be appropriate if NHS Boards were required to report on how this had been done as part of their Annual Reviews.

**The patient advice system and the role of Patient Rights Officers (Sections 14 to 17)**

The patient advice and support service and Patient Rights Officers should help to make rights a reality. More information is needed on how this service would interact with the many voluntary organisations that provide information, support and advocacy.

LTCAS would suggest adding to Section 16 a line stating that the Patients Rights Officers can signpost people to support organisations relevant to a person’s health needs (for example voluntary organisations dealing with specific conditions).
About LTCAS

The Long Term Conditions Alliance Scotland (LTCAS) is an independent charity funded by the Scottish Government. LTCAS has over 170 member organisations from across Scotland and aims to ensure the voice of people living with long term conditions is heard by policy makers and service planners.

LTCAS’ vision is for a Scotland where people with long term conditions enjoy, not endure, full and positive lives, free from discrimination and supported by access to high quality services, information and support.

Shelley Gray
Director of Policy & Campaigns
LTCAS
13 May 2010
1. **SAMH**

SAMH is Scotland’s leading mental health charity and is dedicated to mental health and wellbeing for all. SAMH provides both direct services and an independent voice on all matters of relevance to people with mental health and related problems.

SAMH has over 80 services throughout Scotland which address a range of individual needs. Our services support people who have experience of mental health problems and other forms of social exclusion including homelessness and addictions.

SAMH promotes the development of legislation, policy and practice that is based on the real life experiences of people with mental health and related problems and respects their human rights.

2. **GENERAL COMMENTS**

SAMH welcomes the opportunity to comment on this consultation. People with mental health problems are currently afforded rights under the Mental Health Act, and are protected by legislation such as the Human Rights Act and the Disability Discrimination Act. However, people experiencing mental health problems continue to face significant inequalities in our society, and it remains true that they often do not receive the same level of healthcare when compared to people with physical health problems.

The Patient Rights (Scotland) Bill could go some way to rectifying this situation. The strengths of the Bill are in the creation of a set of patient rights and health care principles which will serve as the foundation of a patient centred NHS. The Bill also creates numerous provisions in relation to patient advice, support and advocacy. It does, however, remain extremely disappointing that mental health has been largely excluded from the treatment time guarantee. The Patients Rights Bill must be further developed, to ensure that it incorporates advancements in relation to mental health waiting time targets and treatment time guarantees.
3. SPECIFIC COMMENTS

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)

For too many people with mental health problems, the balance of power in terms of decision making lies with others, or decisions about their lives are influenced by legislation and the availability of treatment or services. Many people have also been treated with a lack of dignity and respect; including not being told their diagnosis, and not being given adequate information about the treatments, services and support they receive.

The patient rights and health care principles outlined in this Bill provide a platform for redressing this situation, and could go far to help improve the experiences of people with mental health problems when coming into contact with the NHS. Health care principles in relation to patient focus, quality care and treatment, participation, communication, and information are all vital in ensuring a responsive and patient centred NHS. Similarly, the inclusion of the rights to make complaints, to raise concerns, and to give feedback are all fundamental to ensure an NHS which is transparent, accountable and well equipped to deliver the level of care required.

SAMH welcomes the direct inclusion of the human rights principles of dignity and respect in the schedule of health care principles. It is greatly encouraging that discussions on the Bill have been informed by Human Rights legislation and, in particular, by Article 12 of the International Covenant of Economic, Social and Cultural Rights. While it is true that some of the conditions necessary to achieve the highest attainable standard of physical and mental health sit outwith health care, SAMH would argue that directly embedding the language of Article 12 within the schedule of health care principles would help give this right practical effect and foster a greater understanding amongst NHS staff and service users of how human rights relate to their lives and their work.

It is interesting to note that Scottish Ministers may, by order, modify the stated rights and health care principles. Given the fundamental importance of these rights and principles, SAMH would expect that any such modification would be subject to the appropriate levels of consultation and parliamentary scrutiny.

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

It is disappointing that mental health has been largely excluded from the treatment time guarantee (TTG); meaning that the vast majority of mental health service users will not benefit from this aspect of the Bill.

The Scottish Government intends that the TTG will predominantly apply to planned and elective care delivered on an inpatient basis. SAMH understands
that, in relation to mental health, admissions in this context are almost exclusively in the context of crisis and that it would not be appropriate to apply a maximum waiting time guarantee of 12 weeks to this type of admission.

It is stated that mental health care/treatment delivered on an outpatient or day patient basis is also to be excluded from the TTG. A very large proportion of mental health care/treatment is delivered on this basis; whether it be within outpatient clinics, GP surgeries, day-centres, or within peoples own homes. It is commented that the focus of the TTG is on one-off elective treatments (such as surgical procedures), while mental health treatment is primarily of an ongoing and progressive nature. Whilst it is true that many mental health problems are unlikely to adequately addressed by a brief one-off intervention, this fact alone should not preclude mental health from inclusion in TTGs. The TTG applies from the time of agreement to treatment to the actual commencement of that treatment. It is, therefore, irrelevant how long a particular course of mental health treatment may last as the focus is on the time to commencement of treatment, and not the completion of it.

It is also true that mental health problems can fluctuate and often entail varying degrees and types of support over time. Where a person requires several different types of treatment for the same mental health problem, the TTG could still apply individually each time they agreed to a particular course of treatment to the commencement of that specific course of treatment.

SAMH welcomes the Scottish Government’s recent commitment to introduce a waiting times target for access to psychological therapies. It is recognised that NHS resources are under significant strain, and that establishing waiting time guarantees applicable to the full range of mental health services is not something which can be achieved overnight. It is essential that the Scottish Ministers ensure supplementary changes are made to the Patients Rights Bill to incorporate developments in relation to mental health waiting time targets and guarantees; in accordance with the progressive obligation placed on them by Article 12 of the International Covenant of Economic, Social and Cultural Rights.

As some aspects of child and adolescent mental health services may take place on a planned basis – and in particular admissions to inpatient care – these are to be covered by the TTG. There are also some aspects of adult mental health services which are delivered on a similar basis, and these should be considered for inclusion; for example, in relation to admissions for eating disorders and self-harming.

Complementary and alternative medicines are to be excluded from the TTG as, it is stated, these services are likely to be in addition to the clinical care which a patient receives; as opposed the primary basis of a referral for diagnosis and treatment. Recently, there has been a growing emphasis on how physical activity can be used to promote mental health and help people manage mental
health problems. Exercise can now be included as part of the treatment plan for a range of mental health problems, and GPs prescribe exercise sessions and activities. In addition, a growing number of innovative projects – such as Stress Centres – provide holistic and complimentary therapies, with the aim of working with people to help them manage stress levels and improve their health/well being and quality of life. Excluding these types of treatments from TTGs could send the message that they necessarily inferior to more conventional approaches, and that they should not be utilised or taken seriously.

Alcohol and drug misuse services are to be excluded from the TTG as there is a HEAT target for drug treatment of 3 weeks from referral to treatment. HEAT targets are a core set of objectives, targets and measures set for the NHS over a three year period. The Patient Rights (Scotland) Bill, in contrast, is about the fundamental rights of patients; which are not of a fleeting or transitory nature. Excluding alcohol and drug misuse services, as there is a HEAT target in this regard, confuses these distinct roles; HEAT targets are not about patients rights and do not offer any protections, rather they relate only to the allocation and management of NHS resources.

People with co-morbid problems can face particular difficulties accessing services and obtaining the help they need in a timely fashion. Often they run the risk of being turned away from mental health services if seen to have a drug or alcohol habit, and turned away from drug and alcohol services if seen to be involved with mental health services. It has yet to be seen how the drug treatment HEAT target will apply in these situations; for example, will people with co-morbidity receive simultaneous treatment for their mental health problems and addictions within 3 weeks, or would treatment only seek to address their addictions within this timescale? While SAMH greatly welcomes the 3 week target, there is a danger that this will create an inequality in access to care; where people receive timeous mental health treatment if coupled with addictions issues, while others are forced to wait until their mental health has deteriorated to crisis point before receiving support.

It could also be made clearer how the TTG differs from the current waiting time target of 18 weeks from general practitioner referral to treatment. The 18 weeks standard does not focus on a single stage of treatment, e.g. the time from referral to first outpatient appointment, or the time from being put on a waiting list until treatment starts; the 18 week standard applies to the pathway from a GP referral up to the point where each patient is actually treated.

The Bill means that, where there is a breach of the treatment time guarantee, Health Boards must make such arrangements as necessary to ensure that treatment starts at the next available opportunity; while patients must be made aware of available advice and support, and the option to complain. These provisions may help to ensure the timeous delivery of those services which are covered by the TTG. However, as nothing in the Act will give rise to any liability...
to pay damages, action for specific implement, action for interdict, or any right of action for suspension, it is unclear what the outcome of any complaints might be or how Health Boards will be held to account for breaches of TTGs.

The complaints and patient feedback system set out in the Bill (Section 11) & The patient advice system and the role of Patient Rights Officers (Sections 14 to 17)

SAMH welcomes recognition of the existing right to make complaints in the Bill. This should serve to improve patients’ awareness of their right to lodge a formal complaint and also increase understanding of how such complaints will be handled. This will be supported by requiring NHS bodies to have adequate arrangements in place for publicising the complaints procedure, as well as the advice and supports which are available to all patients.

It is vital that complaints are monitored with a view to identifying any areas of concern and ultimately improving performance. It is stated that, through secondary legislation, the Scottish Government is to set out clearer monitoring procedures and feedback mechanisms. SAMH awaits the development of this legislation, and hopes that it will be effective in establishing appropriate timescales, as well as ensuring that complaints are better utilised to improve performance.

SAMH fully supports the assertion that the Patient Rights Bill should not be allowed to become a ‘charter for lawyers’. However, as none of the rights set out in the Bill are enforceable by any legal action, and nothing in the Bill gives rise to any right of action for implement, interdict, or suspension, it remains unclear how effective the Patients Rights Bill will really be in ensuring that patient’s rights are respected, and that breaches of these rights are prevented. Without - at least some - possibility of recourse, patient’s rights may not be afforded the appropriate levels of priority and attention they deserve.

NHS bodies are to encourage patients to raise concerns or give feedback on health care, and must consider all feedback received with a view to improving the performance of its functions. Listening to, and taking on the board, the views and experiences of people using NHS services will greatly assist the NHS in creating services which are of the highest standard and responsive to individual need.

An independent Patient Advice and Support Service is to promote awareness and understanding of patient’s rights and responsibilities, and also assist people to make complaints, raise concerns or give feedback. Traditionally, mental health service users have often been ‘done to’ and their views and rights have either not been considered, or asked for and then ignored. The creation of the patient advice system and Patient Rights Officers could go far in helping to address this situation. It will be vital that patient advice and support services are
created in relation to each Health Board and that they operate effectively at a local level.

The activities that a Patient Rights Officer may undertake include providing information about representation and advocacy services. It is the case that some people may require advocacy to access the Patients Rights Officer in the first instance and greater clarification should be given as to where the responsibilities to ensure access to advocacy will sit. SAMH greatly welcomes the Scottish Government’s commitment to make further funding available to support the provision of advocacy. There is a great need for continued investment in the advocacy services across Scotland, both generally and in terms of meeting the needs of specific groups and communities. Advocates often help to address issues relating to healthcare which occur outwith hospital settings; for example, in relation to care plans, medication, or problems with services or after-care services. As such, significant investment will be required for advocacy services both within the community and within the NHS.

Patients Rights Officers will require mental health awareness training in order to ensure that they have a sound understanding of the needs of people with mental health problems, as well as how to communicate effectively with mental health service users in times of distress. It is vital that the Patients Rights Officers feel comfortable in dealing with all patients’ or carers’ queries, and know how to respond appropriately.

The introduction of the Patients’ Rights Bill serves as an opportunity to ensure that inequalities are not allowed to persist in Scotland’s NHS, and that anyone coming into contact with the NHS receives the highest attainable standard of treatment and care. SAMH welcomes much of what is proposed in this Bill but it could go much further to ensure that mental health is afforded equal priority when it comes to patients’ rights.

The continued exclusion of mental health services from the treatment time guarantee, and from the 18 week waiting time target, is a glaring inequality. The Scottish Government must give further consideration as to how it can ensure mental health service users are also able to benefit from such guarantees, and have their human rights upheld.

Mr Aidan Collins
Policy Officer
SAMH
12 May 2010
Patient Rights (Scotland) Bill

RNIB Scotland, RNID Scotland and NDCS Scotland

About us
1. RNID Scotland, NDCS Scotland and RNIB Scotland welcome the opportunity to submit evidence on the Patient Rights (Scotland) Bill.

2. There are 758,000 people who are deaf or hard of hearing in Scotland. RNID Scotland’s vision is a world where deafness and hearing loss do not limit or determine opportunity and where people value their hearing. We aim to achieve this vision by campaigning and lobbying, with the help of our members, raising awareness of deafness and hearing loss, providing services and through social, medical and technical research.

3. In Scotland there are 188,000 people with significant sight loss. RNIB Scotland is one of Scotland’s leading sight loss charities. RNIB Scotland seeks to ensure that blind and partially sighted people are able to live as full and independent lives as possible. RNIB Scotland is firmly committed to campaigning to ensure equal access to public services.

4. RNID Scotland also works with the National Deaf Children’s Society (NDCS) Scotland to support their aims of a world without barriers for every deaf child. NDCS Scotland estimates that there are around 3,500 deaf children in Scotland today.

Deafness and hearing loss
5. It is estimated that 1 in 7 of the general population has some degree of hearing loss. There are many reasons why some people are deaf or hard of hearing or lose their hearing. The most common is age-related deafness with more than 50% of people over the age of 60 with some hearing loss. Deafness can be congenital, and Universal Newborn Hearing Screening, introduced in Scotland in 2005, is identifying more deaf babies than ever before. NDCS Scotland estimates that 2.6 in every 1,000 children have a significant hearing loss, and many more have mild to moderate losses.

6. Depending on their level of deafness and on when they became deaf or hard of hearing, people who are deaf or hard of hearing use a range of methods to communicate. Between 5,000 and 6,000 deaf people in Scotland use British Sign Language (BSL) as their preferred or first language; many rely on lip reading, others use note takers or rely on equipment such as hearing aids; and some use a combination of these. For those who use BSL as a first language, often English is a second language and access to written English can be challenging.

Blindness and Sight Loss
7. In 2009, 35,588 Scots were registered with their local authority as blind or partially sighted, with 2,934 new registrations per year. Research suggests about 10 per cent of eligible people do not register suggesting the true figure is around 40,000. A further 148,000 people in Scotland are
estimated to have significant sight loss\textsuperscript{1}. By 2031, with no intervention beyond the current provision, sight loss is expected to double to almost 400,000 people with significant sight loss. This will be as a consequence of increases in the elderly population and a variety of health factors.

8. This will put significant pressure on health and social service and RNIB Scotland argues that through strategic investment in order to prevent eye disease and to ameliorate the impacts of sight loss the pressure on public budgets can be mitigated. This includes accessible health information so that blind and partially sighted people can manage their own health needs more effectively.

**Patient Rights and Health Care Principles**

9. RNID Scotland, NDCS Scotland and RNIB Scotland welcomes the patient rights and health care principles outlined in the Bill including: healthcare to be 'patient focused'; allow and encourage the patient to participate as fully as possible in decisions relating to their health care; have regard to providing information and support to enable patients to participate in their health care; and the right to make complaints, raise concerns and give feedback about healthcare received.

10. However, to make these rights a reality, health care needs to be accessible to disabled people, including people who are deaf or hard of hearing or people with significant sight loss. Currently, many disabled people still struggle to access health care.

11. For example, the Scottish Government issued its report on progress towards equality of opportunity between disabled persons and other persons\textsuperscript{2} in which it quotes the baseline study of health boards' understanding in relation to disabled people carried out by Fair for All-Disability. This shows that "effort was concentrated on making services physically accessible, though with lesser apparent activity on other aspects of accessible service delivery and some of this appeared to arise from a lack of understanding about the definition of access to services." The same report quotes a survey by NOP for the Disability Rights Commission in 2003 which showed that 24% of disabled people polled in Scotland mentioned difficulties in the course of an appointment or visit to a hospital and 18% in accessing a dentist\textsuperscript{3}. For those with sensory impairments who had faced difficulties, barriers mentioned included staff attitudes and absences of induction loops.

12. People who are deaf or hard of hearing or blind and partially sighted experience barriers when accessing NHS services, in both GP surgeries and hospitals.


\textsuperscript{3} Chowdhury, R and Worley (2003) a Survey of Disabled People's experience of access to services in Britain
13. According to the British Medical Journal, thousands of profoundly deaf people still struggle to communicate with healthcare professionals on a daily basis, while new research by RNID Scotland, *Are You Listening?*, found that having a hearing loss made it hard for patients to access health services. Two key barriers for people who are deaf or hard of hearing include staff not being deaf aware and a lack of adaptations such as induction loops.

14. RNID Scotland’s research found that 43% of respondents to our survey agreed that ‘being deaf or hard of hearing makes it hard for me to access health services’. Given that most people lose their hearing in older age, most of our respondents used health services prior to losing their hearing as well as after and their patient experience in relation to accessibility has clearly changed.

15. RNIB Scotland also surveyed its members on accessible information in the health service. RNIB Scotland discovered that only 10% of information was provided in the patient’s preferred reading format, with 91% of participants felt they had a right to a format which they could read.

**Communication Barriers**

16. Other issues of concern identified in RNID Scotland’s research mainly relate to difficulties patients who are deaf or hard of hearing experience with health care staff. For example:

- One quarter of our respondents have to rely on a friend or relative to make telephone appointments with health professionals on their behalf.
- While 46% of respondents made appointments over the phone themselves, one-third said they had difficulties communicating with staff because staff did not speak clearly on the phone (too fast or too softly).
- While 24% made appointments in person, over a third found staff did not speak clearly in person (receptionists shout or talk behind a glass partition or do not face patients so they cannot lipread).
- There is often background noise in the waiting room/reception area and loop systems are not often available which means hearing aid users cannot hear the receptionist.
- Half of all respondents said they could not hear their name being called out in GP practices while 40% could not hear their name being called out when attending hospital as an outpatient.
- 42% experienced difficulties communicating with their GPs and half of our respondents had found it difficult to communicate with staff working in audiology departments – the very place where staff should be deaf aware.

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6 Ibid
7 Thurston & Thurston (2010). *The accessibility of health information for blind and partially sighted people*. RNIB Scotland
8 Ibid, pp 5-6
Nearly a quarter of respondents did not use communication support in a health care setting (for example a BSL interpreter or a notetaker) because they did not know they could ask for it.

22% of respondents who said they did require communication support used alternatives such as lipreading, while others used relatives to act as their communication support worker.

17. Having to rely on friends and relatives to make appointments or to act as a communication support worker undermines patients' dignity and privacy as well as their independence to control and manage their own health care.

18. NDCS Scotland would also point out that whilst 90% of deaf children are born to hearing parents who support them throughout childhood in accessing NHS services, deaf children have the right to understand and be involved in decisions being made about their care. Deaf parents of deaf children also require full access to information about their child’s care.

19. In addition, for both deaf children and deaf and hard of hearing adults, experiencing difficulties communicating with health care staff even in person, again undermines the principles of a 'patient focused' health service that the Bill is trying to bring about.

20. RNID Scotland ran a consultation event in 2009 on accessing health services for our members and supporters and they told us about some of the barriers they face which echoes the findings of our research:

"My GP clinic uses a loudspeaker to call the next patient in. How can I lip read a loudspeaker?"

"When I want to make an appointment with audiology, I have to rely on a friend phoning for me"

"I had the experience of sitting in a waiting room in an audiology department and the nurse came and called out the names of the patients. Obviously, nobody was coming. I said to her: 'Why do you not write the next name on a board' but she answered: 'It would be so insulting!'"

21. The BMJ has noted that "… studies of deaf service users have shown that 70% had no interpreters in consultations in accident and emergency departments. Feelings of confusion and dissatisfaction are reported by scores of deaf people with whom this issue has been discussed."

22. In addition to this, people who are deaf or hard of hearing are also more likely to experience mental health problems. Up to 40% of the deaf community experience mental health problems at some point - nearly double the proportion in the general population of one in four. There are numerous barriers in accessing mental health services, for example, staff

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9 RNID Scotland’s consultation event on accessing health services, Glasgow, 8/01/09.
10 Paddock, M et al, Op Cit.
11 Ibid
are not always deaf aware and do not know what are the best resources available for deaf and hard of hearing people depending on their level of hearing loss.\textsuperscript{12}

23. This pressure on adult services is exacerbated by the lack of specialist child and adolescent mental health services for deaf children. It has been estimated that over 40\% of deaf children experience mental health problems, compared with 25\% of hearing children.\textsuperscript{6} If the NHS is not equipped to address mental health issues for deaf adolescents, the system will ultimately fail those deaf children who are facing difficulties in achieving emotional wellbeing, and leave them potentially requiring more acute mental health support in adulthood, of which there is a dearth for deaf adults as outlined above.

24. We hope that the Patient Rights Bill will underline the critical importance of communicating with patients in a language or accessible format they can read and understand. Adjustments necessary for people who are deaf or hard of hearing or blind and partially sighted to access to health services are relatively simple and not too costly.

Information
25. With regard to the health care principle in section 1 of the Bill on providing information to enable patients to participate in their own health care, we would like to see information made available in an accessible format. For people who are BSL users, this may include video clips in BSL or written texts in clear written English.

26. Barriers that people who are deaf may encounter when accessing websites include a lack of clear and simple language or a lack of captions or transcripts of audio on the web, including webcasts. RNID has published a guide on \textit{Deaf and hard of hearing users and web accessibility}\textsuperscript{13} with key recommendations that include: user testing (testing with real people remains essential to establish the accessibility and usability of any website); separation of content and presentation is the most important principle in designing accessible websites; or audio-visual clips should be subtitled for deaf and hard of hearing people.

27. Concerns raised by RNIB Scotland members in its research revealed\textsuperscript{14}:

- Blind and partially sighted respondents reported a loss of autonomy and privacy regarding their experience of accessing health care information.


\textsuperscript{13} RNID (2004) \textit{Deaf and hard of hearing users and web accessibility}.

\textsuperscript{14} Thurston & Thurston (2010). \textit{The accessibility of health information for blind and partially sighted people}. RNIB Scotland
• On average only 10% of all communications from health services to blind and partially sighted participants were received in their preferred reading format
• 91% (213 out of 223) of blind and partially sighted respondents thought they had a right to receive health information in a format they could read.
• 96% (219 out of 228) of blind and partially sighted respondents reported that they had a preferred reading format
• The majority of blind and partially sighted respondents did not complain when information was received in an inappropriate format.
• Blind and partially sighted respondents reported difficulty identifying and using medication.
• Blind and partially sighted respondents reported difficulty experiencing health care due to a general lack of understanding of their additional needs.
• Blind and partially sighted respondents reported frequently relying on others to help them access health care information
• The effects of not receiving health information in a preferred reading format were reported to be largely buffered by carers and relatives.

28. Again, patient focus has to be at the heart of the Bill. RNIB Scotland research highlights the following concerns on accessible health information from its members:\(^{15}\):

“For blind people, there are serious problems with different packaging of the same medicine from different suppliers. This is important!! The variable in packaging is a very serious potential calamity for the blind”

“All notices of hospital appointments are in ordinary print”

“We once had to write a sign over our son’s bed in hospital. ‘My name is Matthew. I am blind. Please talk to me and tell me what you were going to do before you do it.’ On the whole, ward staff and hospital teams are still very ignorant of visual impairment issues”

**Solutions for improving access to communication and information**

29. We recommend that for people who are deaf or hard of hearing:

• Technical solutions are implemented. These range from e-mail appointment systems; SMS used either to make an appointment or to confirm appointments; Text Relay; induction loop systems; visual displays in reception areas (instead of relying on patients to hear their name being called); to BSL interpreters via webcam or web-based communication systems.
• Procedures are in place to secure the services of personal communication support such as BSL interpreters, lip speakers or note takers. These need to be booked at the time of making an appointment.

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\(^{15}\) Thurston & Thurston (2010). *The accessibility of health information for blind and partially sighted people*. RNIB Scotland
• All written communication, such as letters confirming appointments, should be written in clear English for BSL users.
• The appointment time for deaf and hard of hearing patients is extended so that medical staff have enough time to communicate with the patient effectively.
• All medical staff, in particular frontline staff are trained in deaf awareness.

30. We recommend for people who are blind or partially sighted:

• Health care professionals need to understand that the confidentiality of patients is seriously compromised when health information is not sent in an accessible format.
• There is an identified need for education opportunities for health care staff regarding different types of blindness and the impact that this could have on communications with their patients.
• There is an identified need for improved access to health care facilities and information for blind and partially sighted patients.
• Heath care providers need to reflect on how they provide information for blind and partially sighted patients to ensure that they have access to their preferred formats for health information, appointments, medication and hospital menus.
• There is a need for further awareness raising and education amongst blind and partially sighted people to ensure that they are aware of their rights regarding receiving health information in their preferred reading format.

Participation
31. With regard to the proposal in the Bill to encourage patients to participate in their own health care, for patients who are deaf or hard of hearing or blind and partially sighted, information needs to be communicated in an appropriate way so patients are making genuinely informed decisions about their care and treatment. As highlighted above, many patients who are sensory impaired have problems communicating with health professionals.

Making Complaints
32. With regard to the Bill’s proposals on patient’s rights to make a complaint, RNID Scotland research found that while a significant proportion of our respondents experienced difficulties accessing health services, nearly a quarter did nothing about it. Some said this was because they did not like to complain, some said they did not have enough time or were too ill or tired to complain, while others felt it was useless and would not improve the situation. RNIB Scotland research demonstrates that blind and partially sighted people are very reticent about making complaint as they...
do not feel they want to cause any problems and are unaware of how the processes may work.  

33. One respondent who is profoundly deaf told us:
'Difficult to change everyone’s attitude. Try to appear strong and calm, I will say if I am disappointed with the lack of respect from the person. I hope they will see me and the next deaf person and give more patience, respect and understanding. I try to put it behind me and move on but the memory and the hurt sometimes comes back and it affects confidence.’

34. Another respondent told RNID Scotland: ‘I don’t like complaining and I understand that all services cannot be perfect’, while another said ‘it is difficult to complain without (a) making the relationship difficult in the future, (b) without feeling a burden. Ideally you shouldn’t have to complain – facilities and support should automatically be in place to make this unnecessary’.

35. We would like to see all GP practices and hospitals ensure that patients who have sensory impairments can comment or give feedback on services they have received. There should also be email addresses available as not everyone with a hearing loss is able to use the telephone. We welcome the proposed role of the Patient Rights Officer to facilitate complaints and feedback. We hope that this is a genuinely independent service to give patients confidence in the system and that the Officers are trained in deaf and sight loss awareness to make the service accessible.

12 Week Treatment Time Guarantee

36. In relation to adults, RNID Scotland strongly welcomes proposals in the Bill for the introduction of a treatment time guarantee (TTG) of a maximum of 12 weeks once in-patient or day case treatment has been agreed, within the overall 18 week waiting time period of referral to treatment. In particular, speeding up referral to audiology for hearing aids to actually fitting hearing aids will help people with a hearing loss lead a more fulfilling life as they will be able to benefit from the equipment earlier.

37. We would welcome a commitment from the Scottish Government that while audiology is included in the 18 week waiting time guarantee from referral to treatment by 2011, audiology will also be included in the 12 week TTG.

38. Notwithstanding this, NDCS Scotland believes that even a maximum wait of 18 weeks is too long for deaf children. There are 38 weeks in a school year. Eighteen weeks is the equivalent of almost half a year’s education. In the most serious of cases, this could mean a deaf child facing half an academic year with little or no hearing, which obviously has serious implications for their educational progress and ability to develop and learn

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18 Thurston & Thurston (2010). The accessibility of health information for blind and partially sighted people. RNIB Scotland
19 Op cit, p 32
20 Ibid, p 33
at the same rate as their hearing peers. Whilst in practice, NDCS Scotland understands that paediatric waiting times are very rarely anywhere near 18 weeks; we believe that this good practice should be formally recognised with a shorter maximum waiting time for paediatric audiology.

39. In addition to this, both RNID Scotland and NDCS Scotland welcome NHS Information Services Division’s recent efforts to routinely collect data on audiology waiting times. We hope that this work will continue and the issues surrounding gaps in data collection will be addressed. We further hope that data on referral times will be collected by ISD and monitored so as to give us a better indication of the whole patient journey as with other conditions that come under the 18 week waiting time guarantee by 2011.

40. RNID Scotland would like to see the Bill provide further impetus to health boards to fully modernise audiology and reduce waiting times through investment in staff, facilities and equipment. We would also like to see the Scottish Government reaffirm its commitment to ensuring that as well as achieving shorter treatment times, the quality of treatment should not suffer. This includes continued support for implementing the Adult and Paediatric Audiology Standards21.

Case study
James is very hard of hearing and has been wearing hearing aids for over 30 years. He needed to go to audiology to update his hearing aid to digital hearing aids which was important for his work as a lift engineer. He told us:

"I was told they only see emergency patients but to be classified as an emergency patient, you have to see a consultant first. It's a vicious circle. I asked my GP to be referred to another consultant but he advised me to go private. I could not afford it so I saw another GP who eventually got me another appointment with a different NHS Board and that cut the waiting time."

Conclusion
41. RNID Scotland, NDCS Scotland and RNIB Scotland welcome the opportunity to comment on the Patient Rights (Scotland) Bill. We hope the Bill will address the issues raised in our evidence which affects the 758,000 people in Scotland who are deaf or hard of hearing and the 188,000 people in Scotland with significant sight loss.

42. We are prepared to give evidence in person to the Health and Sport Committee.

Shabnum Mustapha
Communications and Campaigns Manager
RNID Scotland

and

James Adams
Campaigns Manager
RNIB Scotland
13 May 2010
Patient Rights (Scotland) Bill

Age Scotland

Age Scotland welcomes the opportunity to respond to the Health and Sport Committee’s consultation on the Patient Rights (Scotland) Bill.

Older people make up the majority of users of NHS services and as such Age Scotland has a keen interest in any effort to improve the experience, as well as health outcomes, of patients.

We responded at length to the Scottish Government’s consultation before the Bill was introduced and we are pleased that a number of our concerns have been taken into account.

Most notably, we had raised the question of what sanctions were available against patients who failed to meet their responsibilities towards NHS staff and property, particularly where there could be mitigating factors such as dementia or even mental illness. From our perspective it seemed problematic to define responsibilities in legislation whilst not also legislating for the consequences of failing to meet them. This has been taken on board and the Bill as introduced does not attempt to create legally binding responsibilities for patients. However, we strongly welcome that the Scottish Government has committed to furthering the agenda of respect towards NHS staff and property by other means: it is certainly not an issue that should be ignored or kicked into the long grass.

Responses to the specific questions posed by the Health and Sport Committee.

The patient rights and health care principles, and the criteria on which those rights are based

There is no doubt that laying out the rights and healthcare principles of patients in legislation is helpful in as much as it provides in one place a full list of patient rights as decided by the will of Parliament. However, as is stressed in the Bill and its accompanying documents, it is not intended to provide recourse to compensation or litigation where those rights are not met. In this context it is questionable whether they are in fact ‘rights’, although we would suspect that some cases where patients rights as described in the Bill are not met could fall foul of human rights law or other existing legislation.

Further to this, the rights as described in Section 1 are highly subjective. While this is in part a reflection of the fact that providing health care to patients is an enormously complex task that depends highly on the expert judgement of NHS staff, it does again raise the question of how useful the rights will be in practice. Patients and NHS staff
could have widely differing interpretations of how well the rights have been met and without a readily available arbiter it seems likely that this will simply lead to complaints.

Similarly, the health care principles are welcome and largely uncontroversial. For example, we very much doubt if requiring that health care take account of patients’ needs would garner much opposition. However, deciding whether or not the health care principles have been met in practice will often be a highly subjective decision.

There is also a question about how the Bill’s provisions would help tackle existing, well-documented problems in the provision of health care for older people. For example, nutrition is one of the key issues for older people in hospital but it is unclear how or if the provisions made in the Bill would help ensure that staff meet the existing requirements.

The 12 week treatment time guarantee and the provisions to deal with breaches of the guarantee

In responding to the original Scottish Government consultation we said we did not have a particular view as to whether there should be a treatment time guarantee (TTG) and we remain neutral on the issue. The Bill seems to imply that there will be a range of underlying criteria and contexts in which the TTG will apply and it may be the case that this creates confusion among patients and their families about whether they are eligible for it and, if not, why not.

In general we are in favour of any measure which can be demonstrated to improve the experience and health outcomes for NHS patients but we do not have the expertise to judge whether a TTG will have a significant beneficial effect for older people receiving NHS care. This is not to say that it won’t have a beneficial effect.

The complaints and patient feedback system set out in the Bill

A robust complaints system could help mitigate the subjectivity of the rights and healthcare principles in the Bill. Such a system should enable the majority of complaints to be resolved to the satisfaction of all parties and to minimise the number of complaints that need to be taken to the Scottish Public Services Ombudsman. However, the Bill lacks detail on what ‘adequate arrangements’ are in relation to the requirements set out for complaints procedures. The Bill confers powers on Scottish Ministers to specify through regulation exactly what adequate arrangements might mean in practice but at this point it is impossible to comment on their adequacy.

The patient advice system and the role of Patient Rights Officers

The patient advice system is welcome and helps explain how patients with dementia, alzheimers or other cognitive decline (and their families) would be supported to make
complaints or give feedback, as is alluded to in the healthcare principles. Similarly, the
new role of Patient Rights Officers would help reach this objective. However, it would be
imperative that Patient Rights Officers were trained and supported for communicating
with patients who have difficulty communicating for any reason. There may also be
cases where the family members of patients require support to articulate their
complaints, feedback or other concerns.

Nick Waugh
Senior Policy and Parliamentary Officer
Age Scotland
11 May 2110
Patient Rights (Scotland) Bill

GMC Response

Please accept our sincere apologies for the delay in submitting our response.

The General Medical Council (GMC) is the independent regulator for doctors in the United Kingdom. Our statutory purpose is to protect, promote and maintain the health and safety of the public by ensuring proper standards in the practice of medicine.

We are grateful for the opportunity to respond to the committee’s call for evidence on the Patient Rights (Scotland) Bill.

General Comments

In principle the GMC welcomes any measure to increase patient safety and we are happy to engage in discussion around the Bill.

With regard to the Bill as it is currently drafted, it is not entirely clear to us how the rights and responsibilities proposed within it would be implemented, measured and enforced. The Bill makes clear that it does not create any new legal rights - perhaps the Bill could usefully make clear the basis of legal rights that do currently exist.

On a related note; one of the Government’s stated objectives is to bring together and restate existing legal rights. This might be made clearer in the Bill. Some existing rights are not covered (e.g. the right to refuse treatment and the right to non-discrimination on protected grounds). It is also not clear in the Bill, what is an existing legal right and what is not.

It would appear that different language has been used in the Bill to describe current rights than is used in the relevant original, and other, legislation (e.g. the test of benefit under the Adults With Incapacity (Scotland) Act 2000 would appear to be the equivalent of ‘optimum benefit’). This is likely to be confusing and may be open to different legal interpretation by the courts.

Paragraph 25 of the Policy Memorandum to the Bill states that ‘the quality care and treatment principle will help to provide added status for quality as well as quantity of care’. We are unclear as to what is meant by ‘quantity of care’. The level of intervention is a matter of clinical judgement and case-dependent decision-making.

Overall, there is a danger in passing legislation that is not clear or enforceable that, rather than increasing the focus on person centred care, it might have the opposite effect. Clinicians and others may be led to feel that person centred care is less of a priority. There is also potential for confusion as there are existing obligations on doctors which are enforceable, including those described in our guidance.
Patient Rights

The fundamental existing legal right of patients to refuse treatment appears not to have been included. This existing right extends beyond just being encouraged to participate fully in decisions relating to health and well being, as is proposed in the Bill. On a related note the Bill does not seem to recognise the distinction between patients with capacity who have a legal right to consent to or refuse treatment, and patients who lack capacity.

Much of this section of the Bill is unclear. For example, we are not certain what is meant by the statement that anything done in relation to a patient must ‘take into account’ the patient’s ‘needs’. This is particularly true in the absence of more detailed guidance or an apparent method of enforcement. Similarly, ‘optimum benefit to the patient’s health and wellbeing’ is unclear and is not in line with other language used, either in our guidance or in legislation (e.g. the Adults With Incapacity (Scotland) Act 2000).

We welcome the recognition in the Bill that even where patients have capacity to make decisions, they may need additional support such as interpreters, advocates and the support of family, to be able to understand information and make an informed decision about whether to consent to or refuse a proposed treatment option.

We also welcome the statements in the Bill that regard must be given to the importance of providing information and support to patients. However these statements appear to be relatively weak when compared with existing GMC guidance. Patients with capacity must be given the information they want and need to make a decision about whether to consent to a proposed investigation or treatment (see our guidance Consent: patients and doctors making decisions together, paragraph 9). Information must be shared in a way that patients understand and must recognise, and be tailored to, individual needs. Patients may need additional support (see paragraph 22 of our guidance). These provisions in our guidance are key to ensuring equality of treatment, a principle which the Bill might deal with in greater depth.

Health care principles

The Bill states that each relevant NHS body, ‘must, in performing its health service functions, have regard to the health care principles in so far as they are relevant to the function being performed’ (emphasis added). The explanatory memorandum outlines some examples of this but it is not comprehensive. It would be helpful to get greater clarity about what this means and about when the principles are not relevant.

The principles state that the patient’s ability, characteristics and circumstances are to be considered. This may be referring to patients who lack capacity and the need to treat patients as individuals. Clarification of this point might be useful.
As the Bill states, the range of options available in the patient’s case should be considered. To this could be added ‘and where clinically appropriate, offered to the patient’.

The Bill asserts that healthcare should be based on current recognised clinical guidance. However, guidance is not always available. This might be because;

1. the condition is rare,

2. standard treatments haven’t worked and the doctor is offering an innovative treatment designed to meet the patient’s individual needs,

3. there is uncertainty about the best treatment or

4. treatment is provided as part of a research project.

The language we use in our core guidance, *Good Medical Practice* is ‘you must provide effective treatments based on the best available evidence’ (paragraph 3c).

The Bill emphasises that patients should participate as fully as possible in decisions about their care and treatment. We welcome this in principle. However, a patient may not always wish to participate as fully as possible. Our guidance *Consent: patients and doctors making decisions together* discusses this scenario and explains that patients will always require basic information in order to give their consent (paragraphs 13-17).

**Patient Feedback**

It would be useful to clarify whether the same rights of feedback will be available to family or carers of patients who lack capacity, e.g. to have concerns or feedback passed from a Patient Rights Officer to the relevant NHS body. As currently drafted the Bill states that this can only be done with the consent of the patient. This might be expanded to state that this can be done with the consent of the patient or the person who has made the complaint on their behalf. There is also the issue of feedback or complaints by family or carers about the care or treatment of a patient who has died and whether the complaint or feedback would be on behalf of the deceased patient or the right to feedback would be that of the carer or family member. The Bill might usefully address this point.

Section 4 of this part of the Bill states that the relevant NHS body must consider all concerns raised and feedback received with a view to improving the performance of its functions. There is also, however, the responsibility of NHS bodies to respond to complaints in relation to the individual patient. In our core guidance, *Good Medical Practice* (paragraphs 31-32) we discuss the right of patients to expect a prompt, open, constructive and honest response including an explanation and, if appropriate, an apology.
Duties to share information

This section describes the kind of information that should be shared with the proposed Patient Advocacy & Support Service (PASS). This appears to be straightforward and uncontentious. The Bill then states, however, that this information should be shared 'where reasonably practicable and otherwise appropriate'. This appears to weaken the earlier statement.

We welcome the statements on maintaining patient confidentiality. With regard to sub-section 3 there are circumstances in which a patient’s right to confidentiality might be justifiably breached in the public interest (e.g. to protect someone else from a risk of serious harm).

We hope that this response is useful. If you have any questions regarding the response please contact me.

Jane Malcolm
Head of Scottish Affairs
Finance Committee

Report on the Financial Memorandum for the Patient Rights (Scotland) Bill
Finance Committee

Report on the Financial Memorandum for the Patient Rights (Scotland) Bill

Published by the Scottish Parliament on 14 September 2010
Finance Committee

Remit and membership

Remit:

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

   (a) any report or other document laid before the Parliament by members of
   the Scottish Executive containing proposals for, or budgets of, public
   expenditure or proposals for the making of a tax-varying resolution, taking
   into account any report or recommendations concerning such documents
   made to them by any other committee with power to consider such
   documents or any part of them;

   (b) any report made by a committee setting out proposals concerning public
   expenditure;

   (c) Budget Bills; and

   (d) any other matter relating to or affecting the expenditure of the Scottish
   Administration or other expenditure payable out of the Scottish
   Consolidated Fund.

2. The Committee may also consider and, where it sees fit, report to the
Parliament on the timetable for the Stages of Budget Bills and on the handling of
financial business.

3. In these Rules, "public expenditure" means expenditure of the Scottish
Administration, other expenditure payable out of the Scottish Consolidated Fund
and any other expenditure met out of taxes, charges and other public revenue.

*(Standing Orders of the Scottish Parliament, Rule 6.6)*

Membership:

Derek Brownlee
Malcolm Chisholm
Linda Fabiani
Joe Fitzpatrick
Tom McCabe (Deputy Convener)
Jeremy Purvis
Andrew Welsh (Convener)
David Whitton

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Clerk to the Committee
Jim Johnston

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Assistant Clerk
Allan Campbell

Committee Assistant
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Finance Committee

Report on the Financial Memorandum for the Patient Rights (Scotland) Bill

The Committee reports to the Health and Sport Committee as follows—

INTRODUCTION

1. The Patient Rights (Scotland) Bill (“the Bill”) was introduced in the Parliament on 17 March 2010. The Health and Sport Committee has been designated as the lead committee on the Bill at Stage 1.

2. Under Standing Orders Rule 9.6, the lead committee at Stage 1 is required, among other things, to consider and report on the Bill’s Financial Memorandum (FM). In doing so, it is required to consider any views submitted to it by the Finance Committee (“the Committee”).

3. At its meeting on 27 April 2010, the Committee agreed to adopt level 2 scrutiny in relation to the FM (i.e. that it would take oral evidence from the bill team and seek written evidence from financially affected bodies). The Committee received written submissions from—

- Citizens Advice Scotland;
- National Waiting Times Health Board;
- NHS Ayrshire and Arran;
- NHS Greater Glasgow and Clyde;
- NHS Lanarkshire;
- NHS Lothian;
- NHS Orkney;
- NHS Education for Scotland;
- NHS National Services Scotland;
- NHS 24;
• Royal College of Nursing Scotland;
• Scottish Ambulance Service; and
• State Hospitals Board for Scotland.

4. All submissions can be found as an annexe to this report. At its meeting on 23 March, the Committee took evidence from the Bill team and later received supplementary written evidence and a copy of the Regulatory Impact Assessment. These documents are also annexed to this report.

5. The FM explains that the Bill provides that—

“…the healthcare which patients receive should meet certain criteria. It also establishes a right to make a complaint, legislates for a patient advice and support service and Patient Rights Officers and establishes a 12-week treatment time guarantee.”¹

6. The FM sets out the costs associated with the Bill under three headings—

• principles in provision of services;
• the treatment time guarantee; and
• support and recourse.

7. This report follows the structure of the FM.

SUMMARY OF EVIDENCE

Principles in provision of services

Staff Education and training

8. The significant costs arising from this area of the Bill are non-recurring costs of £800,000 in 2011-12 and 2012-13 in relation to staff education and development.² The FM explains that NHS Education for Scotland (NES) will develop a workforce educational plan, including the recruitment of staff where necessary, commissioning activity, developing educational materials and delivering training in a wide range of settings.³ The financial implications set out in paragraph 64 of the FM are projections based on NES’s experience of similar national programmes of work.

9. In its submission, NES highlighted concerns that NHS boards will have additional resource implications as a result of this area of the Bill.⁴ In addition, NHS Lothian argued that a significant proportion of the funding should be directed to boards because models of education delivery should be local, relevant and

² FM, paragraphs 62 and 64
³ FM, paragraph 64
⁴ NHS Education for Scotland. Written submission to the Finance Committee
accessible to frontline staff.⁵ NHS 24 said that the amount suggested within the FM for staff training would only cover the development of training programmes and it fails to acknowledge the additional hours boards are required to cover to give staff the time required for training.⁶

10. During the evidence session, the bill team explained that the costs were based upon NES’s previous experience in delivering similar programmes that were NHS-wide, such as the patient safety programme.⁷ In response to concerns raised regarding additional resourcing costs they said that—

“We are fairly confident that the costings are accurate. We would not necessarily expect any additional costs to health boards if we are building the training into the existing programmes and delivering it through existing training and practice managers and the like. We are quite confident that the networks and infrastructure are in place to deliver the training.”⁸

11. In addition, in relation to comments from health boards about potential additional costs due to covering normal duties, the bill team said—

“We have been speaking to representatives of NHS Education for Scotland, which delivers all the education materials and so on for the NHS. We are getting involved in pre-registration training, induction training, other training, rather than taking some people out every day to do a whole day away from their normal duties.”⁹

12. The Committee notes the comments from the health boards and the response from the Scottish Government and would encourage the lead committee to pursue the issues raised with the Cabinet Secretary to ensure that the concerns of the health boards have been taken into account.

The treatment time guarantee

13. The FM states that the Scottish Government does not anticipate any direct financial costs in relation to the treatment time guarantee. However, in written submissions some health boards argued that funding for targets has been reduced by £20 million per annum with no additional funding to health boards.¹⁰ In 2009-10 to meet targets NHS Ayrshire and Arran had to invest an extra £3.7 million of its general allocation to supplement funding from the Health Directorate. They estimated the additional funding required for 2010-11 is approximately £4 million.¹¹ The Bill team clarified that—

“As far as waiting times are concerned, the bill’s treatment time guarantee provisions are what we are discussing, and that guarantee is inextricably linked to the 18-week referral-to-treatment time target. Money that is going

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⁵ NHS Lothian. Written submission to the Finance Committee
⁶ NHS 24. Written submission to the Finance Committee
¹⁰ NHS Ayrshire and Arran. Written submission to the Finance Committee.
¹¹ NHS Ayrshire and Arran. Written submission to the Finance Committee.
towards meeting that 18-week target, as well as the waiting times, will be covered through recurring funding.\textsuperscript{12}

14. Nonetheless, the bill team acknowledged that problems exist at individual boards where extra capacity may be required. They confirmed that—

“...issues around the financing of that [the 18 week referral-to-treatment time] and the treatment time guarantee will continue to be discussed in order to ensure delivery.”\textsuperscript{13}

15. They went on to state that—

“...the £70 million has not yet been allocated. We are in discussions with boards on the appropriate allocations.”\textsuperscript{14}

16. The Committee notes the response from the bill team, but again highlights the health boards’ concerns regarding previous funding allocations for the lead committee’s attention

Support and Recourse

\textit{Patient Rights Officers and the patient advice and support service}

17. The most substantial costs arise from this area of the Bill, including £831,000 being redirected from the current Independent Advice and Support Service (IASS) to supplement an additional £1,250,000 of new funding from the Scottish Administration. This funding is to support the Patient Advice and Support Service (PASS) and the implementation of Patient Rights Officers (PROs).\textsuperscript{15} NHS Lothian argued that this is a considerable level of funding and expense for a service which in large part is currently being delivered by boards and may continue to do so.\textsuperscript{16} In response the Bill team stated—

“Patient Rights Officers are independent and do not work for boards. Case workers who currently provide such a service are employed by Citizens Advice Bureaux. Under the new system, the contract will be open—we do not know who the supplier will be. In response to the consultation, patients and stakeholders said clearly that they wanted an independent advice service and that they wanted to approach somebody who was not employed by the health service.

The contract for the service will not be funded at the expense of nurses. The Scottish Government is keen to emphasise that helping people through their health care journey—especially those people who need a bit more help; not everyone needs a bit of help, but some do—produces a better outcome. The service will assist people to access front-line services.”\textsuperscript{17}

\begin{itemize}
\item[15] Patient Rights (Scotland) Bill. FM, paragraph 104.
\item[16] NHS Lothian. Written submission to the Finance Committee.
\end{itemize}
18. In its submission, NHS Greater Glasgow and Clyde stated that, in their view, the £831,000 for patient advice and support services may be an underestimate, and that—

"NHSGGC might actually incur as much as £249,000. This would be substantially higher than the current IASS contract." \(^{18}\)

19. In response, the bill team explained the figure of £831,000 is the sum of what all the boards said they were paying for contracts in the current year.\(^{19}\) They go on to comment that going national should provide more consistency of service. The bill team state—

"For the patient rights officers, the additional money from the centre will be spread out across the boards, based partly on how the national resource allocation committee allocates funding but more on how contracts works and on the local needs of the different boards. The funding may just continue at the current level." \(^{20}\)

20. There appear to be inconsistencies in the Bill documents in relation to the number of Patient Rights Officers the enacted Bill would implement. The Policy Memorandum states 40 – 50 while the FM states 65 – 80. During the evidence session, the Committee asked the Bill team to explain this difference. They said—

"The 40 to 50 would be the additional ones, with the additional central funding. There are already 30 or so independent advice and support service workers. The 40 to 50 are the additional workers that we could provide with the £1.25 million from central funding." \(^{21}\)

21. The Committee questioned how the Bill team arrived at the figure of 65 – 80 officers. In response, the bill team said—

"Although the service will be different from the current independent advice and support service, we arrived at the figure by looking at current case worker costs and basing our look forward on that. With procurement people in NHS National Services Scotland, we are looking at the specification of a national contract for the future." \(^{22}\)

22. They went on to say—

"We have looked at the numbers and, as the contract is worked through and we discuss local needs with boards, we are trying not to be too specific by saying that we need X number of patient rights officers in every board. We are allowing for a bit of leeway, which includes how much the

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\(^{18}\) NHS Greater Glasgow and Clyde. Written submission to the Finance Committee.


organisation that will get the contract wants to spend on marketing, central support and so on. That is why we have tried to cover a range of figures."  

23. The Committee acknowledges the clarification from the Scottish Government. However, the Committee remains concerned that different figures were provided in the two documents, and that additional explanation may have been helpful in the accompanying documents.

24. In its submission, NHS Ayrshire and Arran is of the view that half the number of proposed PROs would be more appropriate because investing in these posts would be at the expense of frontline services. In response to this the bill team said—

"...we ask boards only to continue to provide their current funding level for the independent advice and support service. We will fund centrally the additional costs."  

25. In its written submission, Citizens Advice Scotland (CAS) expressed concerns there was no provision for inflation or salary uplifts over a three year period. In response to this the Bill team explained that—

"On inflation and salaries, we have produced a package with an amount that we think will take us forward. Obviously, though, we are still in discussion about the exact specifications of the contract; costs may be slightly less in the first year, which would allow a bit for an increase for inflation in future years. However, we are still working our way through that."  

26. The written evidence received from CAS shows concern that the FM does not show any marketing budget for the new organisation. The Bill team stated that—

"On marketing, other things are going on. For example, we will look at patient-facing information for people who might not go through a patient rights officer but who still want information. In addition, NHS Inform will come on stream with a national strategy to inform people of everything about their health care, including rights, patient advice and support. Again, we are going through the contract specification with the boards, and the procurement people have been speaking to Citizens Advice Scotland about what it does, so we will build in something for how we market the service locally and nationally."  

Advocacy

27. The FM shows the Scottish Government will provide a non-recurring £500,000 in 2010-11 to allow health boards to assess the provisions for advocacy

24 NHS Ayrshire and Arran. Written submission to the Finance Committee.
26 Citizens Advice Scotland. Written submission to the Finance Committee.
services required in their area. The Scottish Government will then provide £500,000 per annum of recurring new money from 2011-12 to support advocacy services.\(^{29}\) Health boards explained that they may need to provide more services than the £500,000 would fund.\(^{30}\) In response to this the bill team stated that the £500,000 allocated to boards in 2010-11 is to assess what the current situation is across each board and whether there are any gaps,\(^{31}\) and that—

“The money will then go towards addressing these gaps, which might not be the same across all boards.”\(^{32}\)

**Translation, Interpreting and Communication Support**

28. The FM explains that PROs will direct patients to relevant support services. It is anticipated that one of the main services patients will be directed to is Translation, Interpreting and Communication Support (TICS). The Scottish Government is providing additional funding of £250,000 per annum of non-recurring funds from 2010-2011 to 2012-2013 to NHS Scotland.\(^{33}\) In its written submission NHS Lothian said—

“…there needs to be an accurate costing of the implementation implications for NHS Boards. NHS Boards will continue to deliver the bulk of a “patient rights service” but with no new money to assist them. The only financial support is to national organisations. For example, the requirements for interpretation, translation and communication support cannot be underestimated. Yet there is no funding for NHS Boards to meet this increasing need, which is extremely necessary to address not only in respect of informed consent and good person – centred care, but also the legal duties under Equality and Human Rights legislation.”\(^{34}\)

29. During the evidence session the Bill team agreed that this was a valid point and said—

“Over the next year, a bit of work will be done with health boards to look at how we co-ordinate and ensure better efficiency and effectiveness in the translation of materials centrally.”\(^{35}\)

**General issues**

30. The FM shows that overall the new money being allocated is £784,000 in 2010-11, £2,666,000 in 2011-12 and £2,666,000 in 2012-13 as a result of this Bill.\(^{36}\) In light of the likely reductions in future budgets, the Committee questioned whether funds would definitely be available. The bill team stated—

\(^{29}\) Patient Rights (Scotland) Bill. FM, paragraph 119.
\(^{30}\) NHS Orkney. Written submission to the Finance Committee.
\(^{33}\) Patient Rights (Scotland) Bill. FM, paragraph 128.
\(^{34}\) NHS Lothian. Written submission to the Finance Committee.
\(^{36}\) Patient Rights (Scotland) Bill. FM, paragraph 58.
“We do not know what the spending review will provide, but the best that we
can say at the moment is that these figures are what we are working to. As
with all things, as we work our way through, we will look to see whether we
can get the same outcomes for slightly less or get better value for money
elsewhere.”

31. The Committee notes this response from the bill team and that future
allocations are dependent on the outcome of the forthcoming spending
review.

32. The Committee also asked why in the recent NHS workforce projections
published recently by the Cabinet Secretary, NES forecasts a net reduction of six
in the number of staff while the FM suggests an increase in the workload of NES.
The bill team responded in writing that—

“The development of training is to be commissioned by the Scottish
Government from NHS NES. It was noted in the Patient Rights (Scotland)
Bill’s FM, at paragraph 64, that recruitment of staff would be “where
necessary”. Given their recent workforce projections, NES may decide that
it is not necessary to recruit any additional staff, this is a matter for them.”

33. The Committee notes the explanation from the Bill team, but
encourages the lead committee to pursue the issue of the reduction in the
workforce and the suggested increase in the workload of NES with the
Cabinet Secretary.

CONCLUSION

34. The Committee directs the lead committee to the specific comments
made throughout this report on certain aspects of the FM.

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38 Scottish Government. (2010) NHS Workforce Projections 2010-11. Table 21 Available at
http://www.scotland.gov.uk/Topics/Statistics/Browse/Health/NHSWorkforceProj
39 Patient Rights (Scotland) Bill. FM, paragraph 64.
Submission from Citizens Advice Scotland

Citizens Advice Scotland and its 83 CAB offices form Scotland’s largest independent advice network. CAB advice services are delivered through 222 service points throughout Scotland, from the islands to city centres.

The CAB service aims to ensure that individuals do not suffer through lack of knowledge of their rights and responsibilities, or of the services available to them, or through an inability to express their need effectively and equally to exercise a responsible influence on the development of social policies and services, both locally and nationally.

The CAB service is independent and provides free, confidential and impartial advice to everybody regardless of race, sex, disability or sexuality

Introduction

1. 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.

2. The CAB service in Scotland strives to ensure that people have access to information about their rights and responsibilities. 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.

3. The CAB service in Scotland strives to ensure that people have access to information about their rights and responsibilities. Last year the CAB service dealt with 324,800 debt issues, 257,444 benefit issues, 86,897 housing issues and 74,017 employment related issues – together accounting for 76% of all client issues.

4. 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, their carers, and their families.

5. IASS assists patients and their families raise any concerns and complaints they may have regarding care received from the NHS. The service also takes a holistic outlook to supporting its clients, and provides advice on a range of issues, including welfare rights, employment and debt. In this way, patients’ health concerns are interlinked with a number of other issues and IASS aims to support them overall.
6. CAS welcomes the ethos and health care principles that underpin the Patient Rights (Scotland) Bill. However, we have concerns with some of the provisions in the financial memorandum of the Bill, including costs associated with the uptake of the new Patient Advice and Support service (PASS) and the transitionary services that may be required of IASS.

Financial Memorandum: Response to Questionnaire

7. CAS welcomes the opportunity to respond to the questionnaire relating to the Financial Memorandum for the Patient Rights (Scotland) Bill

Consultation exercise for the Patient Rights (Scotland) Bill

8. We did take part in the consultation exercise for the Bill, but we did not comment on the financial assumptions made therein.

9. We had sufficient time to contribute to the consultation exercise

Costs associated with the Patient Rights (Scotland) Bill

Financial Implications for Citizens Advice Scotland:

10. We are concerned that the full financial implications of the Bill for the CAB Service in Scotland - in its capacity as the current provider of the Independent Advice and Support Service (IASS) - have not been taken into account.

11. No funding has been allowed for a handover period in the event that the CAB service in Scotland does not tender for the contract or if it fails to obtain the contract. It will take time for a new service to be established and arrangements would need to be put in place to assist existing and new clients seeking assistance and support during the transition period.

12. No provision has been made during the three year life of the Patient Advice and Support Service (PASS) project for inflationary uplifts or salary increases which would mean a reduction in funding, in real terms, over the period of the contract. This could cause significant problems during the tendering process and subsequently in the delivery of the project.

13. We have the following concerns in relation to particular sections of the financial memorandum:

- Pt 104: The funds for current IASS services are approximately £500 short of what is required to run the service in this financial year. Whilst this is a small sum, if it is compounded by the lack of inflationary and salary uplifts, the deficit could become significant
• **Pt 104:** There does not appear to be a marketing budget for PASS, although this has been identified in the Bill as one of the activities to be carried out – the service provider will need to market PASS service as it will be built on the existing IASS service but under a new name. Subsequently, new marketing materials will also be required. We are unsure if this is already included in the overall funding amount.

• **Pt 108:** The current proposal redirects £134,000 presently provided to CAS to the health boards for PASS and Patient Rights Officers (PRO). It is important that some services be delivered by a central authority, including statistical reporting, marketing, and training. We are concerned that no specific provision has been made for this.

• **Pt 108:** It is unclear what the relationship between health boards and the new PASS service will be, given that contracting will be carried out nationally rather than locally. We would like clarity about whether service contracts will be in place in each health board area with the provider(s) in that area or whether there will be a single national contract. The contractual relationships and local versus national funding arrangements need to be made clear for decisions to be made with regard to tendering.

• **Pt 109:** We very much welcome the provision of additional funding of £116,000 from the Scottish Government but have concerns on how this figure was reached and what its intended purpose is.

• **Pt 111:** The salary scales outlined here are appropriate, although we believe that the £5,000 allocated to on-costs seems low when both pension and national insurance contributions are taken into account. We feel that this figure should be nearer 18% to 20% of wages paid out.

• **Pt 113:** This section pre-supposes that all existing IASS paid staff would move into the new service. Depending on which organisation wins the contract and on their existing arrangements, this may not be the case.

• **Pt 117:** There is a possibility that funds will be required to close down services provided by the current provider and/or handed over to an alternative provider.

**Can Citizens Advice Scotland meet the costs associated with the Bill?**
14. It is likely that CAS would be able to meet the financial costs associated with the Bill, although we are concerned that bureaux may not be funded to provide any temporary service that may be required during set up of the new service.

15. We recommend that consideration be given to the inclusion of funding for a transitional period of a minimum of three months to allow the new PASS to be established and, if relevant, for the IASS to transfer existing clients, systems and so on to the new provider.

16. We are concerned that funding arrangements may not be sufficient to cover inflationary and salary increases over the life of the project.

Financial Memorandum and the Margins of Uncertainty:

17. The financial memorandum does accurately reflect the margins of uncertainty associated with the estimates and the timescales over which such costs would be expected to arise, though we do feel that account should have been taken of year on year cost increases, and that account should also have been taken of the need for transitional arrangements to be put in place when IASS is replaced with PASS.

Wider Issues:

Costs and Wider Policy Initiatives:

18. We believe that the financial memorandum has taken into account costs associated with wider policy initiatives.

Future Costs:

19. It is difficult to comment on future costs associated with the Bill on any subordinate legislation and guidance until we have a clearer picture about what might be included in regulations or until we receive more detailed guidance. We would welcome the opportunity to make additional comments when further information on regulations and details on guidance have been provided.
Submission from National Waiting Times Health Board

Consultation

1. Did you take part in the consultation exercise for the Bill, if applicable, and if so did you comment on the financial assumptions made?

Yes the National Waiting Times Health Board responded to the consultation exercise.

2. Do you believe your comments on the financial assumptions have been accurately reflected in the Financial Memorandum?

Yes

3. Did you have sufficient time to contribute to the consultation exercise?

Yes

Costs

4. If the Bill has any financial implications for your organisation, do you believe that these have been accurately reflected in the Financial Memorandum? If not, please provide details.

Yes

5. Are you content that your organisation can meet the financial costs associated with the Bill? If not, how do you think these costs should be met?

Yes

6. Does the Financial Memorandum accurately reflect the margins of uncertainty associated with the estimates and the timescales over which such costs would be expected to arise?

Yes

Wider Issues

7. If the Bill is part of a wider policy initiative, do you believe that these associated costs are accurately reflected in the Financial Memorandum?

As far as aware yes

8. Do you believe that there may be future costs associated with the Bill, for example through subordinate legislation or more developed guidance? If so, is it possible to quantify these costs?
Not aware of any at the moment.
Submission from NHS Ayrshire and Arran

Consultation

9. Did you take part in the consultation exercise for the Bill, if applicable, and if so did you comment on the financial assumptions made?

NHS Ayrshire and Arran did not comment on the financial assumptions made at the time of consultation.

10. Do you believe your comments on the financial assumptions have been accurately reflected in the Financial Memorandum?

Not applicable.

11. Did you have sufficient time to contribute to the consultation exercise?

Yes.

Costs

12. If the Bill has any financial implications for your organisation, do you believe that these have been accurately reflected in the Financial Memorandum? If not, please provide details.

Paragraph 80 of the Financial Memorandum indicates no financial impact arising from the treatment time guarantee. Paragraph 84 notes that funding for access targets has been reduced from £90 million per annum to £70 million per annum and there is no additional funding to health boards for the treatment time guarantee. At 31 March 2010, NHS Ayrshire and Arran had 20 orthopaedic patients waiting longer than 12 weeks, but to achieve this NHS Ayrshire and Arran had invested in 2009/10 an extra £3.7 million non-recurrently of its general allocation funding to supplement SGHD money. For 2010/11 the additional funding required locally is around £4 million therefore there are financial implications for NHS Ayrshire and Arran.

13. Are you content that your organisation can meet the financial costs associated with the Bill? If not, how do you think these costs should be met?

NHS Ayrshire and Arran supports the extra investment in advocacy but has concerns about the recurring investment of £1 million. Paragraph 114 estimates 65-80 full time equivalent Patient Rights Officers (PROs) across Scotland and it is felt that half this number would be more appropriate, since investing in these additional posts would be at the expense of frontline services.

14. Does the Financial Memorandum accurately reflect the margins of uncertainty associated with the estimates and the timescales over which such costs would be expected to arise?
Yes.

**Wider Issues**

15. If the Bill is part of a wider policy initiative, do you believe that these associated costs are accurately reflected in the Financial Memorandum?

Yes

16. Do you believe that there may be future costs associated with the Bill, for example through subordinate legislation or more developed guidance?

No

If so, is it possible to quantify these costs?

*Not applicable.*
Submission from NHS Greater Glasgow and Clyde

Consultation

1. Did you take part in the consultation exercise for the Bill, if applicable, and if so did you comment on the financial assumptions made?

Yes. *There was little detail in the consultation paper on the expected costs arising from the proposed bill. Comment was confined to reflecting the concerns of clinical staff and patient representatives that there may be duplication of existing arrangements, as well as potentially increased administrative costs that would have to be deducted from allocations towards patient care.*

2. Do you believe your comments on the financial assumptions have been accurately reflected in the Financial Memorandum?

*To a certain extent. It is clear that many of the costs identified thus far will be met by the Scottish Administration directly. However, it is not clear that all costs have necessarily been indentified in terms of the NHS Boards and there is insufficient detail in the Financial Memorandum that would allow us to determine this.*

3. Did you have sufficient time to contribute to the consultation exercise?

Yes.

Costs

4. If the Bill has any financial implications for your organisation, do you believe that these have been accurately reflected in the Financial Memorandum? If not, please provide details.

*There is insufficient detail in the memorandum to allow us to answer that question. Although the major additional costs will relate to waiting time guarantees enshrined within the Bill, the Memorandum indicates other recurring costs that are, at present, impossible to quantify. Most notably there is the introduction of new staff training modules within existing programmes and the cost of dealing with additional complaints results for publicity and awareness-raising of new systems introduced under the Bill. Without additional detail on the nature of the training and the scale of publicity to be involved, we cannot accurately scope out the implications for NHSGGC.*

*Additionally, we note that the indicated recurring cost to all NHS Boards for the introduction of Patients Rights Officers and the Patient Advice and Support Service (PASS) amounts to £831,000 annually. It is further indicated that this represents the current expenditure on contractual arrangements with Citizen’s Advice Bureaux to provide the Independent Advice and Support Service (IASS).*
It is suggested that the IASS contract will end in 2011 and will be directly replaced by PASS, and so no additional expenditure would be incurred by NHS Boards. However, we have two concerns:

- NHSGGC’s current IASS contract expenditure per annum amounts to £138,000 – previous experience suggests that NHSGGC as the largest geographical Board, providing both regional and national services, tends to incur 20 – 30% of the costs of any national initiative. Consequently, from an estimated £831,000 national spend on PASS, NHSGGC might actually incur as much as £249,000. This would be substantially higher than the current IASS contract.

- There is no guarantee that £831,000 will represent the actual national cost of PASS – progress towards implementation is at too early a stage to be able to offer a realistic estimate.

5. Are you content that your organisation can meet the financial costs associated with the Bill? If not, how do you think these costs should be met?

If any additional financial costs are incurred as a result of the Bill, this would cause severe difficulty to the NHS Board in the context of the current financial climate.

6. Does the Financial memorandum accurately reflect the margins of uncertainty associates with the estimates and the timescales over which such costs would be expected to arise?

We do not believe so – there are a number of imponderables as we have indicated above and we do not feel that this is given sufficient recognition in the Financial Memorandum.

Wider Issues

7. If the Bill is part of a wider policy initiative, do you believe that these associated costs are accurately reflected in the Financial Memorandum?

To a certain extent, given that reference is made to financial allocations linked to reductions in waiting times.

8. Do you believe that there may be future costs associated with the Bill, for example through subordinate legislation or more developed guidance. If so, is it possible to quantify these costs?

For the reasons stated above, we are unable to quantify these costs.
Submission from NHS Lanarkshire

Consultation

17. Did you take part in the consultation exercise for the Bill, if applicable, and if so did you comment on the financial assumptions made?

*NHS Lanarkshire did not comment on the financial assumptions made at the time of consultation.*

18. Do you believe your comments on the financial assumptions have been accurately reflected in the Financial Memorandum?

*N/A*

19. Did you have sufficient time to contribute to the consultation exercise?

*N/A*

Costs

20. If the Bill has any financial implications for your organisation, do you believe that these have been accurately reflected in the Financial Memorandum? If not, please provide details.

*The financial memorandum appears to recognise all relevant areas of cost. It does not quantify the increased workload on complaints officers from the expected initial increase in complaints nor does it quantify the opportunity cost or backfill cost in staff training. It makes the assumption that these can be absorbed. These are likely to have an impact, at least in terms of opportunity costs of time that would have been spent progressing other work, but it is unlikely the financial cost of these unquantified elements would be material.*

21. Are you content that your organisation can meet the financial costs associated with the Bill? If not, how do you think these costs should be met?

*Most of the costs associated with the introduction of the bill are to be met by the redirection of existing funding or by additional central funding (£784,000 in 2010-11, £2,666,000 in 2011-12 and £2,666,000 in 2012-13).*

*A general concern is that, at a time when the full extent of the reduction in public sector finances is unknown committing to new developments with no invest to save potential identified could exacerbate an already difficult situation.*

*Although the Bill makes a reasonable assessment that meeting the 12 week treatment time should be no more financially onerous than delivering the existing 18 week RTT it should be recognised that many Boards will require*
to divert resource from elsewhere to supplement the national funding to deliver this target. Based on current assumptions, NHS Lanarkshire will have to generate additional savings of around £1m from other service areas to enhance dedicated access target funding to meet the 18 week RTT. While this pressure exists independent of the Bill it is important to recognise that the Bill reinforces a target which cannot be met locally within the current level of ringfenced funding.

22. Does the Financial Memorandum accurately reflect the margins of uncertainty associated with the estimates and the timescales over which such costs would be expected to arise?

Other than the comments in 5 above, NHS Lanarkshire has no better information with which to estimate the likely costs although the estimates do appear reasonable.
Submission from NHS Lothian

Consultation

1. Did you take part in the consultation exercise for the Bill, if applicable, and if so did you comment on the financial assumptions made?

Yes, a response was submitted on behalf of NHS Lothian to the consultation exercise which took place between November 2008 and January 2009. The consultation exercise did not set out any financial information or make any financial assumptions. The consultation paper set out proposals in broad terms for what might be in a Bill of Rights. The only financial comment made in our response was to question the proposal of the Bill being legally enforceable and therefore what sanctions, including financial, might apply. In the event that there were financial implications, it was pointed out that this could prove very costly for the NHS.

2. Do you believe your comments on the financial assumptions have been accurately reflected in the Financial Memorandum?

Yes, in that the right to financial compensation is not included.

3. Did you have sufficient time to contribute to the consultation exercise?

Yes, in the 2008-2009 consultation. With regard to the time line for written submissions for evidence on the Bill to the Health and Sport Committee, the letter requesting evidence was emailed on 26 March 2010 with a closing date of 13 May. While we have submitted comments it would have been helpful to have had a little longer e.g. eight weeks, particularly as it was over the Easter holiday. The request for a response to the Finance Committee was emailed to NHS Boards on 11 May 2010. This questionnaire was not attached to the emailed letter from the Healthcare Policy and Strategy Directorate. It would have been helpful to have had longer to reply to the Finance Committee.

Costs

4. If the Bill has any financial implications for your organisation, do you believe that these have been accurately reflected in the Financial Memorandum? If not, please provide details.

4.1 No. There is no recognition in the Bill of the financial implications for NHS Boards for the reasons set out in the following paragraphs. In addition there will be implications for NHS Boards in respect of the number of staff needed by NHS Boards to deliver this agenda, while 65-80 independent patients' rights officers will be funded.

4.2 The Patient Rights Bill is a small proportion of the totality of existing legal duties and rights for patients and the public. There is a mixture of routes for raising awareness and support for individuals who wish to seek redress or question the application of rights. For the majority of existing patients'
rights people access local services or Health Boards as the first port of call for enquiries or complaints. Where formal recording is in place, NHS Lothian handles approximately 1,150 complaints. This figure excludes enquires where receptionists, healthcare professions, complaints staff and other staff sign post and inform people about their rights. In contrast, NHS Lothian Independent Advice and Support Service (IASS) service formally recorded 58 cases in 2009-2010. As well as that, NHS Lothian produces patient information for the public, Health News for each Local Authority area, regularly updates its web page and has a number of specific information leaflets about patient rights.

4.3 All Health Rights Information (HRIS) leaflets are printed and distributed by NHS Lothian. Documentation including the HRIS leaflets must also be locally relevant, produced and locally distributed. These costs are currently met by NHS Boards. It is difficult to calculate the costs to NHS Lothian to support and uphold patient rights in NHS Scotland – it is however not an insubstantial amount.

4.4 It is disappointing that the financial memorandum contains no new funding to geographic or service provision boards. Nor is it evident that there has been any detailed dialogue with Boards on what their costs base for the implementation of new patient rights. An example might be the implementation of the Carer Information Strategy to support carers’ rights, which the government funded to the sum of £9m for 3 years.

4.5 The financial memorandum sets out in paragraph 58 considerable investment, all of which is national for the next 3 years. At a time when there will be serious and significant pressures on NHS Board budgets, the case for legislation is debatable. There is however evidence that if such legislation is enacted then Boards will be involved in the service delivery and potential additional cost.

4.6 Paragraph 59 details £1.6m to NHS Education Scotland to develop materials and a workforce educational development plan. This investment, if focused on the totality of patient rights awareness and cultural competence, is to be welcomed. However if focused on only the parameters of the bill then a significant proportion of the money should be directed to Boards. Models of education delivery must be local and relevant and accessible to frontline staff.

4.7 Translations of leaflets should be produced and paid for nationally, which is not currently the case.

4.8 The current funding for Independent Advice and Support Service (IASS) would appear to have benefited a very small proportion of people who complain, comment or raise a concern or enquiry – see para 4.1 above and para 4.9 below. The vast majority of patient rights issues are dealt with by Boards. Independence becomes – and can be seen to be – an issue for a small proportion of complainants. Our complaints, patient liaison and other staff currently deliver advice and support to a high standard. Being in the
'business’ supports effective, fast communication and more importantly resolution.

4.9 The Policy Memorandum states that there will be at least one Patient Rights Officer per Health Board, yet the Financial Memorandum in para 111 refers to the provision of around 40-50 new full-time equivalent Patient Rights Officers across Scotland. In para 114 however it states that total funding is expected to provide for 65-80 full time equivalents, when the current funding by Boards to the Independent Advice Service (IASS) provided by Citizens Advice Bureaux, is added to the proposed Scottish Administration funding of over £1,000,000 per year. It is not clear how the leap has been made in numbers of rights officers from the Policy Memorandum to the numbers proposed in the Financial Memorandum. This seems a considerable number of staff without any evidence as to how the number was arrived at.

4.10 NHS Lothian funds the Independent Advice and Support Service (IASS) to the sum of £78,702, which currently supports people making complaints. This funds the 10 Citizen Advice Bureaux in the Lothians for initial advice on the complaints process before referral to an advice worker in more complex cases (approximately 15 per quarter). The Board is expected to make this sum available for the new service. This assumes that the current funding is value for money and given the current and future financial pressures that NHS services are facing it cannot be assumed that such sums available in the current year will continue. This support by 14 Boards together with funding from the Scottish Administration amounts to almost £2 million per annum. This seems a considerable expenditure for a service which in large part will actually be delivered by Boards (as explained in paragraphs 4.1 and 4.2 above).

4.11 Paragraph 112 talks of the 14 territorial Health Boards having commissioned IASS. NHS 24, Scottish Ambulance Service, the State Hospital, the Golden Jubilee all provide services to patients. It is not clear why these Boards were excluded.

4.12 It would also be helpful to know what the outputs were from the investment of £60,000 detailed in paragraph 115 to NSS Scotland.

4.13 Paragraphs 119 and 128 refer to funding to national organisations (for advocacy and interpretation, translation and communication support), which do not provide frontline services. If the Bill is enacted the pressures, already considerable on both these budget areas will be added to with increased demand, but with no additional financial support to Boards. Already advocacy services, jointly commissioned with Local Authorities are being reviewed to ensure compliance with legal duties and national guidance.

4.14 For face to face interpretation services national contracts are unlikely to demonstrate cost benefits, but national translation procurement may. This therefore is to be welcomed as is a move to reducing costs for phone
interpretation and other “e” or IT enabled solutions. The Translation Interpretation Communication Support strategy mentioned in the memorandum has not formally been adopted nor agreed by all Boards in Scotland.

4.15 Further investment to Boards for service provision to meet growing need would be preferred to additional national funding.

5 **Are you content that your organisation can meet the financial costs associated with the Bill? If not, how do you think these costs should be met?**

No, for the reasons set out in answer to question 4. As set out in answer to that question, there needs to be an accurate costing of the implementation implications for NHS Boards. NHS Boards will continue to deliver the bulk of a “patient rights service” but with no new money to assist them. The only financial support is to national organisations. For example, the requirements for interpretation, translation and communication support cannot be underestimated. Yet there is no funding for NHS Boards to meet this increasing need, which is extremely necessary to address not only in respect of informed consent and good person – centred care, but also the legal duties under Equality and Human Rights legislation.

6 **Does the Financial Memorandum accurately reflect the margins of uncertainty associated with the estimates and the timescales over which such costs would be expected to arise?**

No.

6.1 In view of the current financial situation facing both NHS Boards and the Scottish Administration, there is a substantial degree of uncertainty. At a time when there will be serious and significant pressures on NHS Board budgets, the case for legislation is debatable. This is particularly relevant in respect of the proposed Patient Advice and Support Service (PASS) as commented upon in paragraphs 4.9 and 4.10.

6.3 The estimates in the memorandum for redirected and new funding are largely going to be related to costs provided by Scottish Government administration. As such, the estimates for provision of the related services will largely rest on their perspectives on how much these services will cost to provide.

6.4 It is open to NSS/NES to commission provision of such services (such as Patients Rights Officers) from other organisations. Should that be the case, it may result in limited cost savings. However territorial boards will have to ensure that such savings do not arise from additional use of their resources under information sharing arrangements required by the Bill.

**Wider Issues**
7 If the Bill is part of a wider policy initiative, do you believe that these associated costs are accurately reflected in the Financial Memorandum?

7.1 In parallel there is a working group looking at proposals for a “no-fault” compensation scheme to provide restorative justice for patients and relatives who have a grievance against a provider Board or GP. This group reports to the Cabinet Secretary for Health with recommendations in autumn 2010.

7.2 Dependent on the model for such a scheme recommended or adopted, this could have an impact on the existing resources Boards use for settling and administering complaints and claims. This issue is not reflected in the Financial Memorandum.

8 Do you believe that there may be future costs associated with the Bill, for example through subordinate legislation or more developed guidance? If so, is it possible to quantify these costs?

8.1 There may be but unable to quantify these costs, however, a concern would be that as with the consultation on the Bill costs may emerge which are not anticipated at present.

8.2 However, see answer to question 7 above. At present it is not possible to quantify such costs as they are dependent on the model of restorative justice and complaints resolution adopted. Some schemes adopt a fixed tariff and include / exclude specific events (such as acquired infections) so the potential variation in costs is wide. In many ways such differing systems reflect the historic or developing culture towards litigation on medical matters over the last 35-40 years in different parts of the world such as in Scandinavia and the Antipodes.

Melanie Hornett
NHS Lothian
24 May 2010
Submission from NHS Orkney

Consultation

23. Did you take part in the consultation exercise for the Bill, if applicable, and if so did you comment on the financial assumptions made?

*NHS Orkney did not participate in the consultation exercise*

24. Do you believe your comments on the financial assumptions have been accurately reflected in the Financial Memorandum?

25. Did you have sufficient time to contribute to the consultation exercise?

Costs

26. If the Bill has any financial implications for your organisation, do you believe that these have been accurately reflected in the Financial Memorandum? If not, please provide details.

*We note that current funding for the Independent Advice and Support Service (amounting to £8,000 in NHS Orkney) will be redirected to the new patient advice and support service, including Patient Rights Officer, from 2011/12. However, recent experience suggests that there may be increasing costs associated with provision of communication support and advocacy services.*

27. Are you content that your organisation can meet the financial costs associated with the Bill? If not, how do you think these costs should be met?

*NHS Orkney will expect to support the new patient advice and support service at the current level of financial support to the Independent and Support Service. We note the additional funding in paragraphs 109 and 110 of the Financial Memorandum which Scottish Government will make available.*

28. Does the Financial Memorandum accurately reflect the margins of uncertainty associated with the estimates and the timescales over which such costs would be expected to arise?

*We anticipate that costs directly associated with the Bill would be incurred from 2011/12 onwards*

Wider Issues

29. If the Bill is part of a wider policy initiative, do you believe that these associated costs are accurately reflected in the Financial Memorandum?

*As part of the wider policy initiative which has more emphasis on public involvement in service provision and with increasing public awareness of*
patients’ rights, we would anticipate potential additional costs from 2011 onwards.

30. Do you believe that there may be future costs associated with the Bill, for example through subordinate legislation or more developed guidance? If so, is it possible to quantify these costs?

Yes, we anticipate additional future costs for communication support and advocacy services which we are unable to quantify at this stage.
Submission from NHS Education for Scotland

Consultation

31. Did you take part in the consultation exercise for the Bill, if applicable, and if so did you comment on the financial assumptions made?

Yes we did respond to the consultation for the Patient Rights (Scotland) Bill. We made no comment on the financial assumptions made. However, we did reiterate the issue of training, education and development for staff in order to implement the Bill and this has implications for NHS Boards resource allocation.

32. Do you believe your comments on the financial assumptions have been accurately reflected in the Financial Memorandum?

Not applicable.

33. Did you have sufficient time to contribute to the consultation exercise?

Yes.

Costs

34. If the Bill has any financial implications for your organisation, do you believe that these have been accurately reflected in the Financial Memorandum? If not, please provide details.

NES has been commissioned to deliver educational support for the implementation of the Bill. The funding for this will be met from our existing central funding and significant additional funding from Scottish Government, as per the Financial Memorandum. The additional funding fully reflects the cost implications that we have calculated in order to make the implementation of the Bill meaningful and effective.

35. Are you content that your organisation can meet the financial costs associated with the Bill? If not, how do you think these costs should be met?

With regards our mainstream education, training and development it is important that we are able to embed the healthcare principles and take account of the rights of patients in all work that we undertake. This will involve careful consideration of the ways that we deliver our core business but any financial implications will be absorbed by each of our Directorates current budgets.

36. Does the Financial Memorandum accurately reflect the margins of uncertainty associated with the estimates and the timescales over which such costs would be expected to arise?
We will only be able to deliver the educational programme to support the implementation of the Bill if the identified additional funds, as per the Financial Memorandum, are received by NES from Scottish Government. Otherwise, we would have very limited ability to impact NHS services through our core business. Any reduction in these funds would mean that we would have to reassess our specific plans developed to support implementation of the Bill.

**Wider Issues**

37. If the Bill is part of a wider policy initiative, do you believe that these associated costs are accurately reflected in the Financial Memorandum?

Developing a mutual NHS where the patient is a partner in their own healthcare, is underpinned by the rights and healthcare principles set out in the Bill. However, delivering this policy does mean a real culture shift for the NHS. This will not necessarily imply additional costs but could change the way NHS staff work and may mean additional training needs for staff. It is this training that has resource implications not just financial but also staff, ie: releasing staff time to attend training. NES has a responsibility to look at how we deliver our training programmes. We must harness and maximise the use of blended learning approaches and new technologies to ensure that all staff have the opportunity to benefit from any training, education or development available from NES.

38. Do you believe that there may be future costs associated with the Bill, for example through subordinate legislation or more developed guidance? If so, is it possible to quantify these costs?

Most NHS Boards will have additional resource implications as already mentioned. However, it is difficult to quantify these costs at this stage as we are just in the early stages of looking at educational needs to support implementation of the Bill. However, we will maximise opportunities to embed the healthcare principles and take account of patient rights in all of our core business.
Submission from NHS 24

Consultation

39. Did you take part in the consultation exercise for the Bill, if applicable, and if so did you comment on the financial assumptions made?

Answer: NHS 24 took part in the consultation exercise for the Bill. NHS 24 commented on the financial implications of:
- An increased use of telephone interpretation services for the public
- Information materials available in different formats and languages.

40. Do you believe your comments on the financial assumptions have been accurately reflected in the Financial Memorandum?

Answer: Additional funding is being made available for TICS for patients (Financial Memorandum, page 23) to research and communicate with patients and the public. Any potential increase in frontline service provision, for example, through the increase in the British Sign Language or web chat services for deaf and hard of hearing people, do not appear to be covered by this funding.

41. Did you have sufficient time to contribute to the consultation exercise?

Answer: Yes.

Costs

42. If the Bill has any financial implications for your organisation, do you believe that these have been accurately reflected in the Financial Memorandum? If not, please provide details.

Answer: NHS 24 is developing its services for deaf and hard of hearing people. The Financial Memorandum does not appear to address the need to further develop frontline services for people with specific communication needs.

The amount suggested for staff training would only cover the development of training packages and would not cover the additional hours Boards would require to cover to allow staff the time that they require to be trained.

The costs outlined for public awareness-raising appear to be low in relation to the requirement to publicise this national initiative to the public of Scotland.

43. Are you content that your organisation can meet the financial costs associated with the Bill? If not, how do you think these costs should be met?
**Answer:** At this point the scale of the demand that will be generated by the Patient Rights Bill is unknown and therefore it is not possible to calculate exactly the associated financial costs.

It is unlikely that NHS 24 will be able to meet the full financial cost of the technological changes required to make the service fully accessible to deaf and hard of hearing people. There may also be other groups of people for whom additional support may be required and NHS 24 would be unable to fund any major change to technology and service delivery processes.

We would also need to say that most of our cost will be a technology cost and NHS Health Scotland would be unable to support this.

44. Does the Financial Memorandum accurately reflect the margins of uncertainty associated with the estimates and the timescales over which such costs would be expected to arise?

**Answer:** The Financial Memorandum sets out a programme of evaluation and monitoring in relation to costs and compliance. It is this process which will highlight the margins of uncertainty with estimates and timescales.

**Wider Issues**

45. If the Bill is part of a wider policy initiative, do you believe that these associated costs are accurately reflected in the Financial Memorandum?

**Answer:** There is recognition of the wider policy initiative in the Financial Memorandum. More information is required on the detail of the costs however in order to assess whether the associated costs are accurately reflected in the document.

46. Do you believe that there may be future costs associated with the Bill, for example through subordinate legislation or more developed guidance? If so, is it possible to quantify these costs?

**Answer:** The future costs associated with the Bill may be in the provision of additional information materials, translation/support for patients and technical and service delivery changes. The intention of the Bill is to open up a more equal dialogue with patients and the public about their health. This may lead to an increase in demand for more information in a wide range of formats which will require to be funded. The level of funding required is unknown at this time.
Submission from Royal College of Nursing Scotland

The Royal College of Nursing (RCN) Scotland welcomes the opportunity to submit evidence to the Finance Committee on this key issue for health care. RCN Scotland is committed to promoting the rights of the people of Scotland to person-centred care, providing optimum benefit to health and wellbeing. We are fully supportive of patient rights and the principle of mutuality; a health service owned and supported by patients and staff together. However, RCN Scotland is concerned about the use of primary legislation to achieve this, as we do not believe this to be the most effective approach.

Consultation

47. Did you take part in the consultation exercise for the Bill, if applicable, and if so did you comment on the financial assumptions made?

RCN Scotland did take part in the consultation exercise, but did not make comment on the financial assumptions at that stage.

48. Do you believe your comments on the financial assumptions have been accurately reflected in the Financial Memorandum?

N/a.

49. Did you have sufficient time to contribute to the consultation exercise?

Yes.

Costs

50. If the Bill has any financial implications for your organisation, do you believe that these have been accurately reflected in the Financial Memorandum? If not, please provide details.

In order to support nurses and other health care professionals in their understanding of the implications of the Bill, there is work to be done by the professional bodies, in association with patient groups and the Scottish Government in arriving at a common understanding as to how the health care principles are to be understood, applied and disseminated.

In the face of ongoing financial pressure on numbers of adequately trained staff, equipment and treatment measures, and recognising that things do go wrong, RCN Scotland is concerned at the extent to which health care professionals will increasingly become the subject of complaints relative to alleged breaches of the health care principles and the treatment time guarantee.
The financial implications for the RCN, and the other unions, are significant in terms of increased need for support and representation of members. However, it is difficult to quantify these implications at this stage.

**51. Are you content that your organisation can meet the financial costs associated with the Bill? If not, how do you think these costs should be met?**

RCN Scotland would like resources to be made available by the Scottish Government to enable professional bodies and trade unions representing health care staff to engage and collaborate with NHS bodies and organisations representing key interested patient groups. These groups are likely to include AVMA (Action Against Medical Accidents), GDA (Glasgow Disability Alliance), SAMH (Scottish Association of Mental Health), GARA (Glasgow Anti Racist Alliance) and the Scottish Voluntary Sector Health Network.

**52. Does the Financial Memorandum accurately reflect the margins of uncertainty associated with the estimates and the timescales over which such costs would be expected to arise?**

RCN Scotland is particularly concerned that whilst there are always margins of uncertainty, the lessons from the *Patients’ Charter* are that the amount of work in terms of patients’ and staff education is huge. Our reading of the figures is that this has been significantly underestimated. The alternative consequences of this are either: a) no more patients are aware of their rights under the Bill than are currently aware of the excellent information contained within the booklet ‘Your NHS’, which sets out current entitlements, or b) that costs will spiral.

The explanatory notes also make clear the Government’s intention to emphasise responsibilities alongside rights in the implementation of the Bill. This is another huge piece of work which needs significant funding and extensive public engagement.

**Wider Issues**

**53. If the Bill is part of a wider policy initiative, do you believe that these associated costs are accurately reflected in the Financial Memorandum?**

The RCN has the following concerns about the figures in the financial memorandum:

(a) the extent to which the budget will enable patient rights officers to receive the training, skills and competencies to direct patients to the full range of legal remedies available to them in the light of a breach of any of their rights, including the rights under the Bill;
(b) the extent to which the budget will really enable patients and the public to be fully informed as to the principles, the treatment time guarantee and other legal rights and remedies to which they are entitled when receiving health care to achieve participation, accountability, non-discrimination, empowerment and legality;

(c) the extent to which the budget will give health care professionals time to receive training and updates on the health care principles and the treatment time guarantee, as well as other legal rights and remedies available to patients, so they are fully informed as to what is expected of them and where the responsibilities lie.

Whilst we recognise the significant budget provided for NHS Education for Scotland we are concerned that in the current climate, frontline staff will not be given the time to engage in training and development opportunities. The costs on the NHS in Scotland for staff time are far greater than the costs on NES for developing learning materials.

54. Do you believe that there may be future costs associated with the Bill, for example through subordinate legislation or more developed guidance? If so, is it possible to quantify these costs?

This Bill is linked to the NHS Scotland Quality Strategy, which describes a mutual NHS where patients are active participants in their care. As mentioned above, an emphasis on responsibilities as well as rights will require a great deal of carefully developed guidance and there is no indication in paragraphs 67-73 that this has been considered.

RCN Scotland would like to emphasise support for a mutual NHS, enhanced through clear, meaningful, and equitable patient rights and responsibilities which sit alongside those rights and responsibilities of staff. However, the cost of effective implementation of this Bill serves to reinforce our belief that legislation is not the most effective way to achieve this.
Submission from Scottish Ambulance Service

I have responded to your call for evidence in relation to the Financial Memorandum of the Patients Rights Bill on behalf of the Scottish Ambulance Service. Whilst I appreciate the aims of the bill in terms of:

- providing more information to the public relating to their healthcare provision
- providing them with guarantees in relation to treatment waiting time
- the provision of patients rights officers

I would ask that within a backdrop of tightening financial resources within the public sector generally and specifically in health, should the financial consequences and requirements of the bill not be re-examined such that a redesigned complaints system within the NHS that delivers an efficient and effective mechanism for the public to ensure their access to healthcare is appropriate is constructed.

I would be grateful if these comments could be fed into the deliberations around the Financial Memorandum of the bill.

1. Yes, the Scottish Ambulance Service participated in the consultation exercise. We did not comment on the financial assumptions made.

2. No comments made, therefore not reflected.

3. Yes, we had sufficient time to contribute to the consultation exercise.

4. If the Scottish Ambulance Service is expected to have a patient rights officer I would hope that this funding is included in the overall funding package and that this person would be able to cover the entire geography of Scotland. The ancillary costs of the post should also be included.

5. The costs of promotional material we assume will be funded by NHS Education. Anything in addition would require to be funded by SGHD. We already have a complaint’s system in place which is able to respond to the current level of activity. However, should there be a significant increase due to the patient rights officers activity. This would require to be funded by the Scottish Government as there is no financial capacity within the Scottish Ambulance Service to add to existing resources.

6. There should be an element of contingency within the costs which does not appear to be currently in place. The timescales appear appropriate.

7. In terms of patient guarantees for waiting times and perhaps more wider access to specialist services. This may create expectations in the public that are not able to be resourced by individual Health Boards.

8. The associated costs that would come from heightened public awareness and increased expectations of the Health Service through the Patients Rights bill should be factored in. This would be extremely difficult to quantify.
Submission from State Hospitals Board for Scotland

Consultation

55. Did you take part in the consultation exercise for the Bill, if applicable, and if so did you comment on the financial assumptions made?

No did not take part

56. Do you believe your comments on the financial assumptions have been accurately reflected in the Financial Memorandum?

See answer to question one

57. Did you have sufficient time to contribute to the consultation exercise?

n/a

Costs

58. If the Bill has any financial implications for your organisation, do you believe that these have been accurately reflected in the Financial Memorandum? If not, please provide details.

Para 121 £500k is to be made available to NHS Boards using NRAC formula from 2011-12 to increase support for advocacy to help patients understand the Patients Bill. This will result in a potential 10% increase. The State Hospital would not receive funding due to the NRAC formula being used but would wish to access additional funding if possible. The State Hospital advocacy contract is approximately £130k and 10% would equal £13,000.

Para 129 No specific figures are mentioned but the paragraph refers to increases in finances being made available to support translation, interpreting, and communication support. There may be a knock on effect to the State Hospital but we can accommodate this within our existing budget.

59. Are you content that your organisation can meet the financial costs associated with the Bill? If not, how do you think these costs should be met?

See answer to question 4

60. Does the Financial Memorandum accurately reflect the margins of uncertainty associated with the estimates and the timescales over which such costs would be expected to arise?

Yes

Wider Issues

61. If the Bill is part of a wider policy initiative, do you believe that these associated costs are accurately reflected in the Financial Memorandum?
Yes

62. Do you believe that there may be future costs associated with the Bill, for example through subordinate legislation or more developed guidance? If so, is it possible to quantify these costs?

No
Supplementary submission from the Scottish Government

At the Finance Committee evidence giving session by officials on the Patient Rights Bill, on 15 June 2010, Jeremy Purvis, MSP, asked why there was not consistency between the workforce planning exercise and NHS workforce projections published recently by the Cabinet Secretary and the financial memorandum [of the Patient Rights (Scotland) Bill]. The Convenor asked that we respond in writing.

The development of training is to be commissioned by the Scottish Government from NHS NES. It was noted in the Patient Rights (Scotland) Bill’s Financial Memorandum, at paragraph 64, that recruitment of staff by NES would be “where necessary”. Given their recent workforce projections, NES may decide that it is not necessary to recruit any additional staff, however, this is a matter for them.

The Convenor also asked that we submit in writing the Regulatory Impact Assessment. 41

Lauren Murdoch
Bill Team Leader

41 The RIA was published as part of the papers for the Committee’s 18th meeting 2010, can be viewed at http://www.scottish.parliament.uk/s3/committees/finance/papers-10/flip10-18.pdf
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Submission from UNISON Scotland on the Patient Rights (Scotland) Bill

UNISON supports the idea of patient rights and is supportive of many of the principles contained within the bill. We note however that many of these rights listed in the Bill already exist, and are unconvinced that legislation is the most effective way of ensuring they are adhered to. UNISON Scotland support healthcare being provided in an atmosphere of mutuality, we are concerned that a Patients Rights Bill will encourage a ‘culture of contract’.

UNISON Scotland is supportive of the idea of patients rights believing that our health service is at its best when services are designed around the needs of patients their carers and families. UNISON Scotland believes that the NHS in Scotland must listen and respond to patients if it is to be into an effective and efficient patient centred service.

UNISON Scotland believes that patients and other users of the NHS in Scotland should be the focus of the service, not as ‘customers’ but as partners with rights and responsibilities and an entitlement to be treated with dignity and respect. We are concerned that whilst creating little by way of new rights the Bill assembles those rights which do exist in a manner that suggests a relationship based on contract, rather than mutuality. The framework of the bill suggests recourse to legal redress in the event of difficulties, rather than encouraging the resolution of difficulties via mediation.

We are unconvinced of the necessity for legislation in this area. The Bill does not add significantly to the rights and standards of treatment that patients can rightfully expect. Save through an entitlement to seek judicial review - an avenue that few are likely to explore. If there is a perception on the part of Government or Parliament that patients are not enjoying all the rights to which they are entitled we think that a more productive course of action would be to examine the reasons why and seeing what can be done to tackle them.

If there are impediments to patients receiving all of their existing rights these may be down to structural issues in treatment design or application, there may be issues of organisational culture, a lack of awareness of rights on the part of staff or patients or of course issues of funding and resources. Examining and remedying which of these (or which combination of these) actually exists is likely to be more productive in making rights a reality than passing legislation.

The Bill plans he creation of a Patients Advice and Support Service may be a step forward in supporting advocacy for patients. We can accept that there may be validity in the arguments that a nationally rather than locally, constituted service could provide for a more consistent level of service. If this potential is to be realised Patients Rights Officers will require to be properly trained and adequately resourced.
We believe that the question of patients rights and standards cannot be disentangled from the issue of resources. The Scottish Government published NHS Board workforce projections in June. These estimated figures from all boards show a total predicted reduction in whole time equivalent (WTE) posts by the end of 2010/11 of 3,790 (2.8%).

The largest reductions are in nursing and midwifery (1,523 WTE) and in administration services (1,053). The figures come from management information in which the potential effect of service redesigns or changes in skill mix are assessed. The reductions will be achieved by not replacing staff who leave or retire. Services will of course have to be delivered by remaining staff.

We find it interesting that the intention that guarantees over treatment times and standards are being put on those staff via primary legislation. Yet no legislative guarantee exists to ensure that NHS staff are adequately resourced to deliver on those commitments.

Along with others we have concerns that the treatment Time Guarantee may serve to skew clinical priorities. We believe that an emphasis on outcomes and total time spent within the healthcare system may be better measures of effectiveness.

UNISON Scotland believes that highly trained and motivated staff who are ‘fit for purpose’ are the greatest resource within the NHS and need to be valued within the organisations where they work. UNISON Scotland recognises that as a result of certain illnesses, aggressive violence can occur, however what we are not prepared to tolerate is disrespect of NHS staff by some members of the public. As such we would have preferred the statement of principles of healthcare to go further in asserting patients responsibilities.

UNISON Scotland
September 2010
Abridged Subordinate Legislation Briefing

Negative Instruments

Overview

There are nine negative instruments for consideration, all of which relate to the regulations of the General Pharmaceutical Council ("GPC"). These cover various aspects of the functions of the GPC, the regulation of the pharmacy profession and the commencement of certain sections of the Pharmacy Order 2010. All of these are Orders made under the authority of the UK Privy Council.

<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>
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</thead>
<tbody>
<tr>
<td>SI/1614 General Pharmaceutical Council (Appeals Committee Rules)</td>
<td>25 Oct</td>
<td>No</td>
<td>This Order approves Rules of the functions of the Appeals Committee of the GPC.</td>
<td>The SLC had no comments to make on this instrument</td>
</tr>
<tr>
<td>SI/1615 General Pharmaceutical Council (Fitness to Practise and Disqualification etc. Rules)</td>
<td>25 Oct</td>
<td>No</td>
<td>This Order approves Rules of the GPC setting out various matters relating to the procedures to be followed by the GPC when considering allegations that the fitness to practise of its registrants is impaired, allegations that a person should be disqualified from inclusion in the register of pharmacy retail business premises kept by the GPC and allegations of criminal conduct that the GPC is under a duty to investigate.</td>
<td>The SLC had no comments to make on this instrument</td>
</tr>
<tr>
<td>SI/1616 General Pharmaceutical Council (Statutory Committees and their Advisers Rules)</td>
<td>25 Oct</td>
<td>No</td>
<td>This Order approves rules for GPC Statutory Committees and their Advisers.</td>
<td>The SLC had no comments to make on this instrument</td>
</tr>
<tr>
<td>SI/1617 General Pharmaceutical Council (Registration Rules)</td>
<td>25 Oct</td>
<td>No</td>
<td>This Order approves GPC Registration Rules which set out various matters relating to the register established and maintained by the GPC</td>
<td>The SLC had no comments to make on this instrument</td>
</tr>
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<td>Agenda Item 3 29 September 2010</td>
<td>HS/S3/10/27/13</td>
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<tr>
<th>SI/1618 General Pharmaceutical Council (Transfer of Property, Rights and Liabilities, Fees and Grants)</th>
<th>25 Oct</th>
<th>No</th>
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<tr>
<td>This Order makes provision of the transfer of the property, rights and liabilities specified in Schedule 1 from the Royal Pharmaceutical Society of Great Britain to the General Pharmaceutical Council.</td>
<td>The SLC reports that this instrument contains an error, in respect that the text of article 6(1) is incomplete, the words “by or” having been omitted where reference is made there to the (General Pharmaceutical) Council, and this being inconsistent with the terms of the earlier reference which is made in that article with respect to the (Royal Pharmaceutical) Society. The SLC notes the intention of the Westminster Department of Health at to arrange for this matter to be addressed by means of the correction slip process.</td>
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<tr>
<th>SI/1619 Pharmacy Order 2010 (Registration – Transitional Provisions)</th>
<th>25 Oct</th>
<th>No</th>
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<tr>
<td>This Order applies in respect of the renewal of entries in the register established and maintained by the General Pharmaceutical Council.</td>
<td>The SLC reports that this instrument contains two drafting errors, in respect that references contained within article 5(11) to paragraph (11) and within article 5(14) to paragraph (12) should actually be to paragraph (12) and paragraph (13), respectively. These errors are not considered likely to affect the operation of the instrument, and the SLC notes the intention of the Westminster Department of Health to issue correction slips and to amend the electronic version of the instrument on the OPSI website.</td>
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<td>Instrument</td>
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<tr>
<td>SI/1620 Pharmacy Order 2010 (Approved European Pharmacy Qualifications)</td>
<td>25 Oct</td>
<td>No</td>
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<tr>
<td>SI/1621 (C. 85) Pharmacy Order 2010 (Commencement No. 2) Order of Council 2010</td>
<td>25 Oct</td>
<td>No</td>
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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.