HEALTH AND SPORT COMMITTEE

AGENDA

29th Meeting, 2010 (Session 3)

Wednesday 6 October 2010

The Committee will meet at 10.00 am in Committee Room 4.

1. **Subordinate legislation:** The Committee will consider the following negative instruments—

   - The Nutrition and Health Claims (Scotland) Amendment Regulations 2010 (SSI 2010/307);
   - The Addition of Vitamins, Minerals and Other Substances (Scotland) Amendment Regulations 2010 (SSI 2010/308); and
   - The National Health Service (Travelling Expenses and Remission of Charges) (Scotland) Amendment (No. 2) Regulations 2010 (SSI 2010/319).

2. **Patient Rights (Scotland) Bill:** The Committee will take evidence on the Bill at Stage 1 from—

   - Jacqueline Richardson, Patient Focus and Relations Manager, NHS Forth Valley PFPI Steering Group;
   - Melanie Hornett, Nurse Director, NHS Lothian;

   and then from—

   - Nicola Sturgeon MSP, Cabinet Secretary for Health and Wellbeing, Lauren Murdoch, Patient Rights Bill Team Leader, and Kathleen Preston, Health and Community Care Solicitor, Legal Directorate, Scottish Government.

3. **Patient Rights (Scotland) Bill (in private):** The Committee will consider issues to be covered in its forthcoming Stage 1 report.

4. **Draft Budget Scrutiny 2011-12 (in private):** The Committee will consider its approach to the scrutiny of the Scottish Government's Draft Budget 2011-12.
The papers for this meeting are as follows—

**Agenda Item 1**

Paper from the clerk  
HS/S3/10/29/1

**Agenda Item 2**

Note by the clerk  
HS/S3/10/29/2

Submission from NHS Forth Valley  
HS/S3/10/29/3

Submission from NHS Lothian  
HS/S3/10/29/4

**Agenda Item 4**

PRIVATE PAPER  
HS/S3/10/29/5 (P)
Overview

There are three negative instruments for consideration. SSIs 307 and 308 are technical amendments to existing nutrition, vitamin and mineral regulations. SSI 319 updates various allowances and travel expenses for NHS students.

<table>
<thead>
<tr>
<th>Name</th>
<th>Deadline</th>
<th>Motion to Annul</th>
<th>Purpose</th>
<th>Drawn to attention by Subordinate Legislation Committee (SLC)?</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Nutrition and Health Claims (Scotland) Amendment Regulations 2010 (SSI 2010/307)</td>
<td>25 Oct</td>
<td>No</td>
<td>These Regulations amend the definition of “the Regulation” contained in regulation 2 of the Nutrition and Health Claims (Scotland) Regulations 2007 (“the 2007 Regulations”). The effect of the amendment is that the reference in the 2007 Regulations to the Regulation now includes any subsequent amendments to its Annex, which consists of the list of authorised nutrition claims and conditions relating to their use.</td>
<td>The SLC had no comments to make on this instrument</td>
</tr>
<tr>
<td>The Addition of Vitamins, Minerals and Other Substances (Scotland) Amendment Regulations 2010 (SSI 2010/308)</td>
<td>25 Oct</td>
<td>No</td>
<td>These Regulations amend the Addition of Vitamins, Minerals and Other Substances (Scotland) Regulations 2007 to the effect that where those Regulations refer to “the EC Regulation”, that reference will be ambulatory to a specified extent. Any such reference will be to Regulation (EC) No. 1925/2006 of the European Parliament and of the Council on the addition of vitamins and minerals and of certain other substances to foods as that Regulation may be amended from time to time by changes made to its Annexes I (vitamins and</td>
<td>The SLC had no comments to make on this instrument</td>
</tr>
<tr>
<td>The National Health Service (Travelling Expenses and Remission of Charges) (Scotland) Amendment (No. 2) Regulations 2010 (SSI2010/319)</td>
<td>25 Oct</td>
<td>No</td>
<td>These Regulations are being made in exercise of the powers conferred on the Scottish Ministers by sections 75A, 105(7) and 108(1) of the National Health Service (Scotland) Act 1978. The Regulations update references to student funding regulations in England, Wales and Northern Ireland. These set out the entitlement to grants and loans available to students. Certain amounts of student maintenance grants are disregarded in calculating the entitlement of students to the payment of travel expenses and the remission of charges under the 2003 Regulations.</td>
<td>The SLC had no comments to make on this instrument</td>
</tr>
</tbody>
</table>

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

Background

1. This is the Committee’s third and final evidence taking session as part of its Stage 1 consideration of the Patient Rights (Scotland) Bill.

Previous consideration by the Committee

2. At its first meeting on 8 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).

3. At its second meeting on 29 September, the Committee took evidence from three panels of witnesses representing voluntary organisations, the medical professions and the Law Society of Scotland.

4. The Law Society of Scotland undertook to provide the Committee with information on the various existing rights of patients, which it had identified. This information is attached in the annex to this paper.

Issues arising from evidence session on 29 September

5. The issues raised during the second evidence session included—

- Patient rights and health care principles
  - As with the evidence from the first panels of witnesses on 8th September, much of the discussion in this session focussed on the requirement for primary legislation in this area and whether the Bill, as introduced, would deliver any real benefit for patients in the attainment of their rights;
  - Many witnesses focussed on the issue of establishing a culture of mutuality in the health service in Scotland, where the rights and responsibilities of both patients and health care professionals were equally recognised and respected. There was widespread agreement that the aim of all stakeholders should be to improve and strengthen the current system of patient rights. However, witnesses differed on whether primary legislation in general, and this Bill in particular, could play a role in effectively delivering this aim;
  - Witnesses from various organisations, such as the Law Society of Scotland; the Royal College of Nursing (“RCN”); the British Medical Association (“BMA”) and the Royal College of GPs (“RCGP”) considered that a patient charter, similar to the approach taken by the NHS in England, might be a more suitable means of seeking to
reinforce patient rights, rather than attempting to enshrine certain rights in an Act;

- Other organisations such as Inclusion Scotland; the Long Term Conditions Alliance Scotland ("LTCAS") the Royal National Institute for the Deaf ("RNID") the Royal National Institute for the Blind ("RNIB") all supported the use of primary legislation to help promote and enforce patient rights. Much of the evidence from these organisations focussed on whether the Bill, as drafted, would achieve this objective;

- Irrespective of whether or not primary legislation on patient rights is enacted by the Parliament, the RCN stressed the need for the Government and other stakeholders to continue the development of a system of comprehensive patient rights in Scotland. RCN also submitted that all government policy should be “dignity proofed” and expressed some concern that the delivery of healthcare to patients might be skewed by the tendency of the health service to prioritise the "minimum legal requirements" for patients. This tendency may be exacerbated, the RCN felt, in an environment where the NHS in Scotland will face increasing pressure on its resource;

- The BMA cited an example of this by referring to cases where a patient may be moved from the busy surgical list of a given surgeon to the list of another, perhaps at short notice, in order to meet a specific treatment target. While this may ensure that targets and other requirements, are complied with, it is questionable as to whether this is always beneficial, especially where a patient finds themselves being treated by a surgeon with whom they may have had no prior clinical relationship;

- The RCGP highlighted the numerous legal and professional requirements which already exist in relation to healthcare professionals. While welcoming greater clarification for patients and healthcare professionals on rights and responsibilities, the RCGP opposed further codification and legislation in this area as, in its view, the various professional standards and codes of conduct which exist are more than sufficient;

- The RCGP also pointed to the fact that those patients most likely to be aware of their rights, and determined to pursue them, are often not the patients who require to be further empowered. Those patients least able to represent and speak for themselves may be the very patients who could lose out as a result of any potential imbalance created by legislation on patient rights, as more empowered patients actively engage to secure their legal rights;

- The Law Society expressed concern that the Bill may lead to a situation where patients and healthcare professionals view the rights set out in the Bill as the only rights to which patients are entitled. The Law Society had identified numerous existing patient rights, many of which are not specified in the Bill (see annex);
The RNIB expressed the view that there is a fundamental systemic imbalance in the operation of the healthcare system. Currently, the onus is on the patient to “actively” pursue their various rights. The RNIB considered that the Bill may go some way to helping to redress this imbalance as the self regulation of the health professions has not delivered the change needed. While acknowledging the limitations of primary legislation in delivering all the changes which may be required, the RNIB felt that only the force of statute would bring about the cultural changes necessary to deliver a fairer healthcare system for patients;

Inclusion Scotland also supported the use of primary legislation in redressing this imbalance and pointed to the “paternalistic” nature of professional bodies within the health service, especially in relation to concept of mutuality when dealing with people with disabilities. Without the resources to “level the playing field” no real engagement on the development of mutuality between patients and healthcare professionals is possible. Having the legal backing that specific primary legislation provides is a key element in this equation. In relation to the Bill, Inclusion Scotland felt strongly that it does not go far enough in empowering patients. Indeed, by specifically excluding many categories, such as those with mental health needs, it may be seen as reinforcing the unequal nature of engagement which many people with disabilities encounter;

RNID highlighted the need for any legislation to improve the way in which the health service communicates with patients who have sensory impairment. Too often health professionals lack both the skills and equipment to be able to directly communicate with patients with a hearing impairment.

The RNIB reiterated the point and stated that many of their surveys found that most patients with a visual impairment still rely on family or friends to assist them with tasks such as dealing with correspondence. This often places patients in a position where their right to privacy in relation to their healthcare is compromised as the NHS does not have the capacity to communicate with them in a way which does not require third party assistance. Consequently, while levels of knowledge regarding patient rights are often quite high amongst people with sensory impairment needs, they are often disempowered by the inability of the health service to provide them with equal access to services;

Enforcement issues and the definition of what constitutes a “right”:

Questions were put to the witnesses regarding what benefits, if any, the legislation would have on patient rights when it restricts recourse to the courts for the enforcement of those rights;

The Law Society pointed to the fact that while none of the rights contained in the Bill would be legally enforceable, a declaratory judicial review could still be pursued by a patient;
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- Both the RCN and the RCGP expressed concerns about the concept of emphasising legal enforceability of certain rights, and cautioned against the atmosphere it may create in the relationship between health professionals and patients. UNISON also expressed concern about the wisdom of focussing on litigation in a debate centred on fostering mutuality in the health service.

- The 12 Week Treatment Time Guarantee (TTG):

  - One of the main topics of debate during the meeting was the decision to include mental health/cognitive behavioural therapy (“CBT”) in the list of exemptions under the 12 week TTG. Several witnesses commented on this decision and its potential implications.

  - Witnesses from the Law Society of Scotland pointed to the possible discriminatory nature of this decision. While the TTG may apply to Child and Adolescent Mental Health Service (“CAMHS”), it will not apply to adult services. The Law Society also questioned the wisdom of this exclusion and the potentially invidious position this creates for adults with CBT needs;

  - The Law Society also pointed to the possibility of a health board being advised on ways to circumvent the provisions of the TTG relating to the agreed starting date for treatment. Legal counsel to a health board, it was suggested, could advise a board not to agree to a course of treatment, until such time as the board was certain that such treatment could commence with the 12 week TTG period. While such action would comply with the provisions of the Bill it would, however, completely negate the purpose of the TTG. As a result, it was suggested, it was doubtful whether the TTG would help to address waiting times for patients;

  - In response to questions from members, some witnesses pointed to the potential practical difficulties in the operation of the TTG. The RCGP agreed that health boards would be required to develop a mechanism to monitor the application of the TTG for treatment delivered wholly, or mostly, within the primary care sector. The 12 week TTG period would commence with the agreement between a GP and a patient on a specific treatment. However, a question arose as to how that agreement could be recorded by a health board in order to ensure the target was met?

  - SAMH pointed to the lack of data on waiting times for CBT treatment as it is also excluded from the provisions of the 18 week referral-to-treatment target. Under the Bill CBT treatment will also be excluded from the 12 week TTG. This, SAMH suggested, may present serious human rights implications for the legislation as it could be seen a discriminating against people with mental health treatment needs;
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- The Patient Advice and Support Service ("PASS"); Patient Rights Officers ("PROs") and the patient feedback and complaints system:

- The Law Society expressed the view that the current system for handling patient complaints against the NHS could be changed without the need to resort to primary legislation;

- The BMA expressed the view that the independence of the current Citizens Advice Bureaux’s Independent Advice and Support Service (“IASS”) was a benefit to patients;

- SAMH pointed to the need for PROs to receive specific training in the needs of patients with CBT/CAMHS needs to ensure that they are capable of providing advice and dealing with complaints in this specific area;

- Inclusion Scotland voiced concerns that there would be an insufficient number of PROs in each health board area. This could pose a particular problem in geographically large health board areas, where many patients may live a considerable distance from urban centres, where most PROs will, most likely, be based. Inclusion Scotland also felt that the PASS and PROs had too few powers under the Bill and that the absence of a role as an independent advocate for patients was a real disadvantage. In its view these provisions of the Bill required to be greatly strengthened before it was passed into law;

- Inclusion Scotland pointed to the need for people with disabilities to have the maximum level of legal support and resources available to them when engaging with the health service, otherwise there can be no genuine engagement by disabled patients in pursuing their rights. Inclusion Scotland pointed to Article 25 of the UN Convention on the Rights of Persons with Disabilities which states, “persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability” as a basis for policy in this area;

- The LTCAS pointed to the duty the Bill will place on the Government and the health service to monitor and enforce the application of patient rights. This would be a benefit change from the current situation, where much of this monitoring function falls to the voluntary sector to carry out on behalf of patients;

- The RNIB pointed out that many people with sensory impairment needs do not make complaints about the quality of the healthcare they receive, or their experience of engaging with health professionals. This is not because of a lack of knowledge or a willingness to engage on their part, but stems rather from a cautiousness of engendering resentment against them, or, from a sense of fatigue in having to actively engage with a system which might be lengthy and complex. The RNIB expressed the hope that the Bill would go some way towards addressing this by placing the responsibility on clinicians to actively deliver patients rights.
Oral evidence

6. On 6 October the Committee will take oral evidence from witnesses representing NHS boards. The oral evidence taking on the Bill will conclude with evidence from the Cabinet Secretary for Health and Wellbeing, Nicola Sturgeon MSP.

Seán Wixted
Assistant Clerk
Supplementary Evidence from the Law Society of Scotland

September 2010

INTRODUCTION

Hilary Patrick, the vice-convener of the Society’s Mental Health and Disability sub-committee gave evidence to the Health & Sport committee at the Scottish Parliament on the Patient Rights (Scotland) Bill on 29 September 2010. At the evidence session, Ms Patrick made reference to a number of statutory or common law rights conferred on patients which are either not referred to in the bill, or are alluded to in weaker terms than the rights which are otherwise conferred elsewhere.

As requested by the convener of the Health & Sport committee, the annex to this document contains a wider list of patients’ legal rights, where they derive from and the extent to which, if at all, they are referred to in the bill.

The Society would reiterate its concern that even if the bill fulfils the policy intention envisaged by the government, namely “to send out a strong message” that patients have rights, it does not give a full enough picture of what those rights are. The numerous other rights conferred on patients both under statute and common law run the risk of being overlooked or forgotten if people assume that the Patient Rights (Scotland) Bill is where to go for a comprehensive list of their rights.
### ANNEX 1

<table>
<thead>
<tr>
<th>NATURE OF RIGHT</th>
<th>REFERRED TO IN BILL</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Access to records</strong></td>
<td></td>
</tr>
<tr>
<td>Right to access medical records</td>
<td>No</td>
</tr>
<tr>
<td>Medical reports issued for insurance purposes</td>
<td>No</td>
</tr>
<tr>
<td><strong>Advocacy</strong></td>
<td></td>
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<tr>
<td>Right to advocacy services (for mental health service users)</td>
<td>No</td>
</tr>
<tr>
<td><strong>Autonomy</strong></td>
<td></td>
</tr>
<tr>
<td>Right to consent to or refuse treatment</td>
<td>‘Allow and encourage’ patient to participate as fully as possible</td>
</tr>
<tr>
<td>Right to adequate information about treatment, side effects and risks (‘informed consent’)</td>
<td>‘Have regard to’ need to provide information necessary for patient to participate</td>
</tr>
<tr>
<td>Right to appoint welfare attorney / make advance directive</td>
<td>No</td>
</tr>
<tr>
<td><strong>Confidentiality</strong></td>
<td></td>
</tr>
<tr>
<td>Legal right to confidentiality under common law / Data Protection Act / professional codes of conduct</td>
<td>‘Regard should be had’ to confidentiality</td>
</tr>
<tr>
<td><strong>Equality and respect for patient’s needs</strong></td>
<td></td>
</tr>
<tr>
<td>Right not to be discriminated against</td>
<td>‘Have regard to need to’ consider patient’s abilities, characteristics and circumstances</td>
</tr>
<tr>
<td>Right to reasonable adjustments for disabilities</td>
<td>As above</td>
</tr>
<tr>
<td><strong>Human rights</strong></td>
<td></td>
</tr>
<tr>
<td>Right to life (e.g. treatment rationing)</td>
<td>No</td>
</tr>
<tr>
<td>No degrading treatment</td>
<td>‘Have regard to need to’ treat patient with dignity and respect</td>
</tr>
<tr>
<td>Privacy</td>
<td>‘Have regard to need to’ respect privacy and confidentiality</td>
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## Rights under NHS legislation / government directions and statements

<table>
<thead>
<tr>
<th>Action</th>
<th>Yes/No</th>
</tr>
</thead>
<tbody>
<tr>
<td>To a GP</td>
<td>No</td>
</tr>
<tr>
<td>To a second opinion</td>
<td>No</td>
</tr>
<tr>
<td>To be supported by a family member / friend / carer</td>
<td>‘Have regard to need to’ provide support</td>
</tr>
<tr>
<td>Waiting time guarantees</td>
<td>Supplemented by treatment time guarantee</td>
</tr>
<tr>
<td>To make complaints to service provider</td>
<td>Yes</td>
</tr>
<tr>
<td>Access to Scottish Public Services Ombudsman</td>
<td>Not spelt out</td>
</tr>
</tbody>
</table>

## Standards of treatment (Government guidance to professionals and health boards)

<table>
<thead>
<tr>
<th>Requirement</th>
<th>Yes/No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health professionals must show due care</td>
<td>No</td>
</tr>
<tr>
<td>Guidance from government about treatments should be given due consideration (judicial review available)</td>
<td>No</td>
</tr>
</tbody>
</table>

For further information and alternative formats please contact:

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NHS Forth Valley PFPI Steering Group

Patient Rights (Scotland) Bill

Introduction

A focus group comprising members of NHS Forth Valley PFPI steering group, members of the Patient Public Panel and representatives of the PPFs was held to respond to the Call for Evidence. The following report is a summary of the feedback from the group.

1. The patient rights and health care principles.

Overall comments were positive with group members welcoming the Bill. The Bill was thought to be ‘sensible and achievable’

Some felt that the Bill does not go far enough. Particular concerns were raised about the provision of dentistry.

More information on support arrangements regarding mediation and / or an appeal system would be helpful in relation to patient rights.

The right to accessible information needs to consider low levels of literacy and particularly ‘health literacy’ amongst the population.

If person centred care is to be achieved then identifying individual’s unique needs will be fundamental. People need to be encouraged and supported to make their needs known.

Difficulty in balancing patients rights with their responsibilities. People do not always have the necessary skills or resources to help them be fully responsible for their own health care.

2. Treatment time guarantee

Need be clear about when treatment time commences. There is a need to make explicit which groups are exempt from treatment time guarantees and an explanation of why they are exempt.

The bill needs to be supported by clear and consistent information to the public. The first consultation is important in explaining to patients about waiting time targets, giving accurate timescales and managing expectations.

Need more clarification as to the consequences for Boards when targets are not met. Are waiting time targets being met at the expense of other services?
3. Complaints and feedback

Many participants felt that the Bill focused too much on complaining formally rather than on sharing experience and giving feedback. It was felt that the language is negative and gives an impression of an adversarial culture rather than one which supports local resolution at the point of the ‘complaint’.

There were comments that this may lead to staff being defensive and perpetuate a culture of complaining and litigation.

There was discussion about the numbers of people who do not complain about their care or treatment even when they are unhappy about the service they have received. Although the group agreed that having the right to complain within the Bill may make it easier for some, it was felt unlikely that it would increase the engagement of seldom heard groups.

There was also concern about the ability to challenge habitual complainers and about managing peoples’ expectations.

4. Patient Advice and Support

In principle it was agreed that this was an important role, although there were mixed views as to whether this should be a service provided directly by the Board or an independent service.

There was some discussion about whether the resources set aside would be adequate and whether there would be a significant difference from the current Independent Advice and Support Service (IASS). It was also suggested that IASS is able to act as a ‘one stop shop’ for those needing advice with benefits and housing as well as health issues. The concern was that people would have to speak to the PRO for health issues but still have to go the Citizens Advice Bureaux for other advice.

Some of the group expressed concern that there needs to be clear communication to patients and staff about the PRO role. Patients who need support should be able to access the PRO service before, for example, they feel the need to make a formal complaint to support patients to raise concerns directly with clinical service.

It was felt that patients might be confused between Patients Rights Officers (PRO) and Patient Relations Officers (PRO) and that there could be overlap between the roles.

Jacqueline Richardson
Patient Focus and Relations Manager
Department of Nursing - NHS Forth Valley
13 May 2010
Patient Rights (Scotland) Bill

NHS Lothian

The opportunity to comment on the proposed Bill is welcomed by NHS staff. Set out below is the response on behalf of NHS Lothian. There are some general comments at the start, followed by specific comments about the particular sections of the Bill, together with the policy memorandum where relevant. The final section refers to the financial memorandum, both the comments and financial detail contained within that memorandum, and which raises major concerns.

The patient rights set out in the Bill are supported by existing legislation, good practice and are already part of NHS Lothian’s fundamental objectives. It could also be reasonably argued that the right to make a complaint and the guaranteed treatment time do not require to be enshrined in legislation since they are already effectively in practice, e.g. only 0.7% of patients nationally needing inpatient or day case treatment were waiting longer than 12 weeks from decision to treatment at December 2009 and Boards are expected to treat within 9 weeks from April 2010. This is even more so as the legislation is not enforceable by legal action.

1. **Sections 1-5 Rights and Health Care Principles**

1.1 The rights of every patient as set out in section 1 of the Bill are supported.

1.2 In addition the health care principles, which echo the rights of patient in the Bill, but in more detail (and set out in the schedule at the end of the Bill), are also supported. The principles for example, of being treated with dignity and respect, privacy and confidentiality, are all that staff in NHS Lothian aspire to deliver.

1.3 The term “person centred” should be used rather than patient focused, which reflects the current thinking in the NHS Scotland Quality Strategy. This emphasises more the concept of partnership and mutuality.

1.4 A further patient right should be added as this is an opportunity to promote individuality aligned to Human Rights, equality and cultural sensitivity that is: have regard to the importance of age, disability, culture, gender, faith/belief sexual orientation and socio-economic circumstances of the patient in relation to the provision of care.

1.5 While feedback is mentioned at the end of the “right to make a complaint”, and within Section 12 of the Bill, this is not stated in the health care principles, where the emphasis is only on issues of concern. It would be helpful if there could be a balance with the
opportunities for positive feedback. It is a boost to staff to know that patients are satisfied with their care, while realising there are occasions when the service does not get it right. In addition the way the word feedback is used in Section 12 implies that feedback will lead to improved performance, i.e. feedback is only about things that are wrong and need to be improved. While this is sometimes the case, again this does not recognise that the health service is getting most things right most of the time and that this is valued and recognised by patients, carers and families.

1.6 NHS Lothian is in the process of modernising its complaints procedures and services in order to ensure that complaints are responded to promptly, with sensitivity and that services are improved and learning shared across the organisation. We wish to emphasise however that all staff are encouraged to respond directly to patients, carers and families at the time that concerns and complaints arise. While it is vital that there is a clear complaints procedure that is accessible to patients and relatives, the emphasis should also be on putting things right at the time that concerns and issues arise. Given the consultation on the future of a no-fault compensation scheme (similar to that proposed in Wales) it may have been more appropriate to introduce comprehensive legislation when this consultation is completed.

1.7 The Policy Memorandum states that the key to participation is that staff and health care practitioners are reciprocally treated with dignity and respect by patients. However the health care principles only recognise the patient’s perspective. The enactment of this bill would provide an excellent opportunity for the Scottish Government to give a very high profile lead on this issue, with an emphasis on mutuality. The indication in the Policy Memorandum that it will be left to Health Boards to encourage patients to treat staff with dignity and respect is disappointing. It is hard to understand why the legislation can not embody the rights of staff in the same way it can patients (given that neither would be legally enforceable in individual cases). In addition, the previous proposals consulted upon during 2008-09 also made reference to patient responsibilities, but the Bill does not make any reference to this. There are references in the Policy Memorandum to “patients recognise and accept that they have responsibilities on them to support their own health and in their use of the health system”. This needs to be explicit in the Bill. It needs to be about co-ownership and co-creation: reciprocity of behaviour and explanation.

1.8 The importance of people being able to make informed decisions based on good communication is an existing legal duty, and an ethical and moral requirement. While the Financial Memorandum recognises that there are cost implications for the necessary provision of the importance of interpretation, translation and communication
support services, it does not fully appreciate both current and future demands that will rightly be placed on NHS Boards to ensure people are able to make informed decisions. We cannot underestimate the breadth and variety of support people need to help them engage with health staff about their own health and lack of it can be seen as systematic exclusion.

2. Sections 6 – 10 Treatment Time Guarantee (TTG)

2.1 We recognise that unacceptably long waits cause anxiety to patients and families. It could reasonably be argued it does not require to be enshrined in legislation since it is already effectively in practice: nationally only 0.7% of patients needing inpatient or day case treatment were waiting longer than 12 weeks from decision to treatment at December 2009 (see the ISD Scotland website http://www.isdscotland.org/isd/5619.html for the information) and Boards are expected to treat within 9 weeks from April 2010.

2.2 The issue for NHS Lothian will be in relation to services where we are not currently delivering the maximum wait of 12 weeks (e.g. IVF treatment, organ transplant) and the extent which these services are covered by secondary regulation which will specify treatments and services to which the treatment time guarantee will not apply. Careful consideration of this will be needed to avoid unreasonable and unattainable expectations. It will need to be very clearly stated where the maximum wait will not apply.

2.3 The treatment time guarantee will only apply to planned / elective care delivered on an inpatient or day case basis and therefore presumably will not apply to outpatient treatment e.g. physiotherapy, phototherapy, out-patient procedures. Given our expectation that more treatments will be available in this way in future, there may be a case for extending the potential remit of the treatment time guarantee to all treatments in due course. The guidance indicates that these will be covered by the 18 week standard only. Guidance indicates that the small number of excluded services will include assisted conception, complimentary and alternative therapies and scoliosis and other national specialist services. An opportunity should be taken to state that patient rights do not extend to non-evidence based treatment.

2.4 Alcohol and drug misuse services appear to be excluded from the treatment time guarantee on the basis that a new HEAT target for drug treatment waiting times requiring 90% of clients to wait no longer than 3 weeks is being introduced. It would be easier for staff and patients to understand if the treatment time guarantee was applied as universally as possible to all in patient and day case activity. It will be helpful for any exceptions to be agreed and defined nationally. To satisfy the guarantee more detailed local records may
need to be kept on delays, Do Not Attends (DNA) and postponements than at present, bearing in mind that in Lothian DNA varies systematically be socio-economic groups.

2.5 NHS Lothian has set local targets across a range of services where no national targets exist. There are sufficient controls from SGHD to set treatment target times with out the need for additional legislation and costly bureaucracy. This is even more so as the legislation is not enforceable by legal action.

2.6 The current system of waiting time management as set out in the Bill within section 8 (3) of taking into account the greater clinical need of another patient and having regard to the patient’s availability is supported as it is the current practice. The statement that the emphasis is on rectifying a situation and delivering treatment rather than instituting a financial penalty or compensation when the Treatment Time Guarantee is not met is also welcomed.

3. **Sections 14 – 17 Patient Advice and Support Service**

3.1 The proposal to introduce an independent Patient Advice and Support Service (PASS), its functions and the role of patients’ rights officers are noted. It is noted that the Policy Memorandum states that the provision of Patient Rights Officers will legislate to level out the balance of power between healthcare staff and patients. This seems an unfortunate tone given the emphasis in Better Health Better Care Action Plan on people and staff as partners. If this is its purpose then it is disappointing when other policy documents and guidance stress the value of NHS staff directly engaging with patients and carers. NHS Boards are expected, rightly, to engage directly with patients, carers and public and inform them about the services available, which NHS Lothian does in a variety of ways in a range of locations. NHS Lothian through various strategies wants to build on these activities, yet the proposal would see a significant sum of money allocated to a third party. While an independent service may be important, the replacement of an existing much lower cost independent service (IASS) should be questioned.

3.2 It will be important if PASS is established that it interfaces well with local complaints teams and processes and is able to relate to children and young people as well as adults. Training and cultural competence will also be important.

4. **Section 18 - Protection and Limitations**

4.1 The statements contained within the Policy Memorandum (paras 50 and 51) that this Bill will not be enforceable by legal action are welcomed.
5. **Financial Memorandum**

5.1 **Healthcare to be received in a particular manner and principles**

5.1.1 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. These include issues related to confidentiality, privacy access to health records, registration with a GP or Dentist etc. 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 enquiries where receptionists, healthcare professions, complaints staff and other staff sign post and inform people about their rights. In contrast, NHS Lothian 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.

5.1.2 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.

5.1.3 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.

5.1.4 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.

5.1.5 Even taking into account the significant sums for training, these programmes, as is stated, will work best when integrated and delivered into existing local training plans.

5.1.6 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.

5.1.7 Paragraph 66 states NES will develop and deliver a communication and awareness raising plan for staff. It is very much hoped this is lead by Directors of Communications and localised as far as possible. Furthermore, NHS Lothian’s Director of Communications along with all Directors of Communication must be involved in the public awareness raising.

5.1.8 Translations of leaflets should be produced and paid for nationally. Alignment of patient rights and HRIS within NHS Inform would be welcomed.

5.2 Support and Recourse

5.2.1 Complaints and Patient Advice Support Service (PASS)

5.2.1.1 NHS Lothian will be implementing systematic fast, frequent feedback from patients to improve quality of care. Large scale surveys have been shown to be of variable impact for localised improvement. Small scale, frequent, real time measures which frontline staff can act upon is the direction of travel for NHS Lothian. This, coupled with the considerable infrastructure on Quality Improvement Teams and a variety of patient focused audits to test person centred care are in place or being developed in NHS Lothian.

5.2.1.2 Paragraph 97 – Our modernised complaints function will have single point access where enquiries, comments and other requests for information by phone and web will be centralised. This new Hub will have ‘feeds’ from our website and be supported by call centre type technology. Giving patients and the public access to expert advisers in our system, who are able to instantly connect with services, advise on rights and solve problems is the benchmark standard NHS Lothian is aiming to achieve.

5.2.1.3 The current funding for IASS would appear to have benefited a very small proportion of people who complain, comment or raise a concern or enquiry – see para 5.2.1.10 below.

5.2.1.4 There is a significant question as to why, with an established and well regarded organisation as the CAB, the SGHD have decided to opt for procurement for a new national structure. An alternative could also be community health and voluntary organisations being commissioned by each Board under local service level agreements.
5.2.1.5 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 resolution.

5.2.1.6 The ability of an external organisation, possibly a new PASS service provider, to become integrated in the health service is potentially problematic and bureaucratic. It is also noted that the SHC with an existing legislative duty on patient focus and a considerable budget was not asked to take on this PASS role.

5.2.1.7 Paragraph 106 and 110 describe the role of PASS as undertaking information and support on patient rights and responsibilities. Yet no patient responsibilities are detailed in the Bill. Currently most information and awareness on patient rights is undertaken by Boards.

5.2.1.8 Para 106 - Annual reporting to Boards is insufficient. PASS would need to establish very close and regular communication with the service. Otherwise people could become frustrated by an arms length independent service disconnected from Boards where the real influence and sorting of problems happens in reality. NHS Boards need to have this type of feedback as well as that from patient experience.

5.2.1.9 The Policy Memorandum states that there will be at least one Patient Rights Officer per Health Board while 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.

5.2.1.10 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.
5.2.1.11 Paragraph 112 talks of the 14 territorial Health Boards having commissioned IASS. NHS 24, Scottish Ambulance Service, the State Hospital, the Golden Jubilee all provides services to patients. It is not clear why these Boards were excluded.

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

5.3 Advocacy (para 119) and Translation, Interpretation and Communication Support (TICS) (para 127)

5.3.1 Paragraphs 119 and 128 refer to funding to national organisations 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.

5.3.2 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 TICS strategy mentioned in the memorandum has not formally been adopted nor agreed by all Boards in Scotland.

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

5.3.4 The role of Better Together is set out in paragraph 136. We understand this programme was established for 3 years to March 2011. We would however welcome more detailed discussions on audit tools which service providers could use to audit patient rights compliance currently and for the Bill.

In Conclusion

It is of concern that all the additional funding will go to national bodies. While in local service delivery Boards will face the costs of implementation:

- Heightened awareness
- Localised and additional information
- Workload pressures on enquiries and complaints teams and PFPI resources in general
- Potential demands on TICS and advocacy services

In NHS Lothian we believe that patient support is most effective when local, efficient and focused on resolution by informed caring staff. Very small
numbers of people currently access IASS in Lothian and other models of local developments could be considered.

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NHS Lothian
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