RESPONSE TO

SCOTTISH GOVERNMENT CONSULTATION:

PROPOSALS FOR A

PATIENTS' RIGHTS BILL

for

SCOTLAND

January 2009

Introduction

Action against Medical Accidents ('AvMA') is the independent patients' charity which has been promoting patient safety and justice for people harmed as a result of medical accidents since 1982. AvMA is registered as a charity in Scotland (number SC039683) as well as England and Wales (number 299123). AvMA has extensive experience of helping and advising thousands of patients each year who have been affected by medical accidents and of collaborative working with the Departments of Health in Scotland, England and Wales; NHS bodies; health professionals and regulators as well as fellow patients' organisations.

AvMA welcomes the overall proposals for patients' rights and responsibilities to be enshrined in a legislation in Scotland. We have concentrated in our response on the policy areas about which we have most knowledge and understanding based on our extensive work with patients and other stakeholders. The response is structured around a 'Summary of our main suggestions' and then answers to some of the consultation questions.

SUMMARY OF MAIN SUGGESTIONS

1. We are calling on the Scottish Government to use the historic opportunity which the development of a Patients' Rights Bill provides to introduce a 'Duty of Candour' (in the form of a "right to 'openness and honesty' when things go wrong") on NHS organisations, and those providing services on its behalf, together with a right for staff not to be subjected to unfair or inappropriate blame when things go wrong. A duty of candour (or "right to full openness and honesty when things go wrong") has been recommended by the Health Select Committee of the Westminster parliament and by the Chief Medical Officer for England (Making Amends, 2003). Such a measure has been called for by AvMA and others for years. We believe that the introduction of a right to candour (or 'openness and honesty' when things go wrong) would be a hugely helpful step in addressing the perceived 'culture of denial' in the NHS when things go wrong. This mitigates against learning from mistakes as well as causing injustice. We propose that to balance this new right, that a right for staff not to be subjected to unfair or inappropriate blame when things go wrong is introduced. Together, these new rights would help significantly in developing an 'open and fair' culture conducive to improving patient safety in Scotland.

2. We welcome the Scottish Government's proposal to work towards a compensation scheme for patients (or their families) when avoidable harm has been suffered in the NHS, as an alternative to taking legal action. We propose that the Bill should set out the legal framework for a scheme whilst, as proposed in the document, further work and consultation is carried out on the detail of the scheme. The terminology 'no-fault compensation' is problematic as it means different things to

different people. This is discussed in more detail below. However, we believe that the key characteristics of a good scheme would be:

- it is based on an alternative test to that used by the courts. We propose consideration of an 'avoidability test' as opposed to the legal test of 'negligence'. This would assist with the aim of improving patient safety by ensuring root causes are identified rather than apportioning individual 'blame'
- it provides an *independent* assessment of eligibility for compensation
- independent legal advice is available for patients / their families to empower them in the process
- the award of compensation is based on actual and future loss as well as pain and suffering
- participation in the scheme is entirely voluntary and does not affect people's right to seek compensation through the courts or their access to public funding to support legal action

3. We propose that other measures should be taken to improve access to redress for patients or their families affected by negligence in NHS treatment in the short term, whilst the proposed alternative compensation scheme is designed and developed. Some significant improvements could be brought about even within the existing arrangements. We propose that the Bill commits the NHS bodies in Scotland to a protocol to ensure early admissions of liability where appropriate and offers of appropriate compensation, without the need for a legal claim to be pursued in the courts. We further propose that the Scottish NHS is committed to disclosing relevant evidence and any legal arguments for not admitting liability for a claim to the pursuer in the spirit of helping avoid unnecessary litigation and legal costs. Consideration should also be given to an arrangement similar to the Welsh 'Speedy Resolution' scheme, which reduces the cost of litigation and ensures early settlement of smaller and less complicated claims.

4. We welcome the commitment to independent advice and support for patients or their families to both to empower them to make informed decisions about healthcare and to help them to receive appropriate investigations, explanations and apologies and redress where appropriate. However, in order to make this commitment real and meaningful, we propose that the Independent Advice and Support Service ('IASS' - provided by Citizens Advice Bureaux) is expanded and strengthened to enable it to help fulfil this role. Crucially, as part of this strengthening, we propose that more specialist advice agencies are commissioned centrally to work in partnership with and provide specialist back up to the IASS service. For example, there may be a need for specialist advocacy agencies to deal with mental health and learning disability cases. In cases involving complex clinical or medico-legal issues we recommend that AvMA's services should be commissioned. AvMA has already developed a working relationship with IASS but is not funded to work in Scotland. The Scottish Government has previously signalled its desire to support a Scottish

office of AvMA, as was recommended by the 'Expert Group' of Lord Ross.

We suggest a clear distinction is made between the proposed roles of Patients' Rights Officers who will be designated by Health Boards, and the Independent Advice and Support Service.

5. We would appreciate more detail on what the implications are for the NHS not delivering on patients' rights and for patients who do not meet their responsibilities under the Bill. We propose that patients are able to have a formal investigation though the NHS complaints procedure if they feel their rights are being breached, and that if this is found to be the case that the NHS is committed to providing appropriate redress. Where possible, this should include putting right the denial of a right. Where this is not possible, there should be an ex gratia payment made to the patient and the provision of an apology and full explanation of why their rights were breached and what action will be taken as a result. We propose that NHS bodies are monitored on their compliance with patients' rights and that this forms part of an annual report on that organisation's performance.

RESPONSE TO CONSULTATION QUESTIONS

Question 1: The right to Access:

We agree with these entitlements and responsibilities.

Question 2: The right to Respect

We agree with these entitlements and responsibilities.

Question 3: The right to Safe and Effective Care

We agree with these entitlements and responsibilities.

We would point out that the right to 'safe' care is different and more encompassing than a right not to be harmed through negligent treatment or omission. This would therefore be consistent with our proposal for an 'avoidability test' to determine eligibility for redress when things do go wrong. There should perhaps be explanation that patient safety can never be entirely guaranteed and any treatment carries with it risks.

We would like to see more in this section about what the Scottish Government / NHS is committing itself to doing on patient safety: the patient safety campaign and related targets; targets on hospital acquired infections and whether there is to be improvement to the incident reporting system.

Question 5: The right to Information

We agree with these entitlements and responsibilities.

Either in this section or in the sections on Communication or Redress, we propose that a 'Duty of Candour' (or duty of openness and honesty when things go wrong is introduced. See proposal 1 in the summary of main suggestions above.

We propose that there is a new right to an investigation into a patient safety incident *without* the need to make a "complaint". Currently, it is only if one complains that one has a *right* to an investigation and feedback. We believe it is wrong to fuel a blaming and complaining culture in this way when often all that someone wants is to know that there will be an investigation and lessons learnt

Question 6: The right to Participation

We agree with these entitlements and responsibilities.

We would in particular like to see a commitment to involving and empowering patients in improving their own safety and in improving patient safety across the board in concert with the Scottish Patient Safety campaign and the patient safety Alliance. Consideration should be given to supporting the development of a Scottish in-country version of the World Health Organisation *Patients for Patient Safety* initiative, building and improving on the model used in England & Wales.

Question 7: The right to Privacy

We agree with these entitlements and responsibilities.

Question 8: The right to Independent Support and Redress

We suggest that these two issues should be addressed separately. They are related, but quite distinct issues. We deal with each in turn below.

Independent Support:
We support the right to receive independent support both in order to make informed choices and decisions in healthcare and also to empower patients or their families to get appropriate investigations and redress where appropriate. We support the expansion and strengthening of the Independent Advice and Support Service to include providing for more specialist advice and support for cases which need it from specialist agencies such as AvMA and mental health advocacy groups. See also point 4 in the summary of main suggestions above.

We believe more thought needs to be given to the proposal to have "independent" Patients' Rights Officers "designated" by NHS Boards. If the role envisaged of Patients' Rights Officers is intended to be similar to

the role of Patient Advice and Liaison Officers (PALS) in England, it should be acknowledged that they are not independent. This is more of an internal advisory and 'customer care' role. The independent advice and support should be available from the IASS, which needs to be seen to be independent of NHS Boards.

Redress:
These comments elaborate on those made in point number 2 in the summary of main suggestions above.

We welcome the Scottish Government's intentions to provide easier access to justice, to reduce litigation costs, and to develop a culture which is more disposed to learning from errors and improving safety rather than focussing on 'blame'. However we urge extreme caution about the kind of 'no-fault compensation' scheme that might be developed. AvMA has looked at various compensation schemes which exist internationally, and this has also been the focus of work by Lord Ross's 'Expert Group' and by the Chief Medical Officer for England's review which led to his report *'Making Amends'* (both of which AvMA contributed to). Various problems have been identified with some of the so-called 'no-fault compensation' schemes, as well as the advantages. From AvMA's point of view, based on our extensive work with injured patients and their families, the essential characteristics of a compensation scheme are:

- it is based on an alternative test to that used by the courts. We propose consideration of an 'avoidability test' as opposed to the legal test of 'negligence'. This would assist with the aim of improving patient safety by ensuring root causes are identified rather than apportioning individual 'blame'
- it provides an *independent* assessment of eligibility for compensation
- independent legal advice is available for patients / their families to empower them in the process
- the award of compensation is based on actual and future loss as well as pain and suffering
- participation in the scheme is entirely voluntary and does not affect people's right to seek compensation through the courts or their access to public funding to support legal action

By 'Avoidability Test' we mean starting with the question:

"Could the adverse outcome have been avoided if the organisation responsible for the treatment had followed accepted good practice?"

If it could be demonstrated that good practice had been followed, there is no qualification for redress. If the practice is not considered to be good/in accordance with standards and guidelines in Scotland, there would be a qualification for redress, unless the NHS body could demonstrate, on the balance of probabilities, that the adverse outcome was not caused by the failure to follow good practice.

We believe this approach could have significant advantages. For example

- It moves away from the 'blame culture' / focus on pinning blame on individual health professionals which is considered a hindrance to improving patient safety
- It focuses on root causes and systems issues, meaning that one investigation should result in the answers needed to help improve patient safety as well as to whether or not someone deserves redress
- By focussing the question on 'avoidability' it moves away from the defensive situation NHS bodies are currently put in under the negligence system, whereby the question they have to ask is not "*how did this happen?*" or "*should we have avoided this*?", but "*can a credible defence argument be made against a charge of negligence?*".
- It is fairer. Most people would agree that someone who has suffered harm as a result of sub-standard treatment should be entitled to redress.
- It would drive quality improvement by making the acceptable standard 'good' practice rather than practice which is not so bad as to be deemed 'negligent'

There is research which points to the advantages of an 'avoidability test' approach which is adopted to different extents in different so-called 'no-fault compensation' schemes. Denmark is an example of a country of a similar size to Scotland which has a scheme with several of the desired characteristics. We recommend that AvMA is invited to join government officials and other stakeholders in assessing various examples and options in more detail and making recommendations.

It should be noted that the term 'no-fault compensation' is unhelpful in that it means different things to different people. It is often used as a catch-all phrase for any compensation scheme which is an alternative to litigation, whereas these differ hugely and many of them rely on establishing 'fault'. Injured patients complain that insult is added to injury by the offering of financial compensation without the formal acceptance of 'fault' or 'responsibility' for the injury.

Question 9: Other Rights

We are proposing two new rights to be included in the Bill:

- A right to 'candour' or 'openness and honesty when things go wrong'. See summary of main suggestions, number 1.
- A right to have patient safety incidents investigated and receive a report on the investigation *without* having to make a complaint. See answer to question 5 on the right to information