



RESPONSE TO NHS IMPROVEMENT CONSULTATION ON ITS DRAFT FRAMEWORK FOR INVOLVING PATIENTS IN PATIENT SAFETY

October 2020

Introduction

Action against Medical Accidents (AvMA) is the national patients' charity for patient safety and justice. We provide free independent specialist advice and support to patients and families who have been affected by avoidable harm in any kind of healthcare. This provides us with a unique and extensive insight into the experience of patients and families following such patient safety incidents. We use this experience and our knowledge of the healthcare system to work with others to develop policies, systems and practice to improve patient safety and the way that patients and families are treated following avoidable harm.

AvMA has been a strong advocate for improving the involvement of patients in patient safety for many years. AvMA's chief executive, Peter Walsh, is a *Patient Safety Champion* appointed by the World Health Organisation. AvMA partnered with the National Patient Safety Agency (NPSA) in developing patient involvement in patient safety including the *Patient Safety Champions* project. This was a ground-breaking project which recruited, trained and supported 24 patient safety champions (patients with direct experience of avoidable harm or family members) to work with NHS patient safety staff in each region of England and in Wales. The project was highly regarded but came to an end due to the abolition of the NPSA. However, the report on the project made recommendations for further work to improve patient involvement in patient safety.

AvMA has also developed its own *Patient Safety Network* – a network of patients and family members with experience of avoidable harm who wish to support work on patient safety. The network consists of approximately 2,000 people.

AvMA's overarching response to the proposals in the draft framework

AvMA very much welcomes the emphasis given to involving patients more in patient safety signalled initially in the *Patient Safety Strategy for England* and in this draft framework. There is much to commend in it. However, we were disappointed that some of the proposals we submitted for the patient safety strategy on this issue were not taken up and that our offers of contributing to the thinking for the draft framework itself were not taken up. Neither is there any evidence of work that we and the NPSA did on patient involvement in patient safety and the learning from that has been taken into account. We believe that there are significant gaps in the draft framework as it stands which, if they are not addressed, will result in a missed opportunity to move patient involvement in patient safety forward in a meaningful and sustainable

way. We are also concerned that there is no mention of additional funding being made available for NHS organisations to implement the proposals in the draft framework. It seems to be assumed that NHS organisations will simply be able to find the necessary funds from their existing resources, which we do not believe is realistic or sustainable. We set out our main concerns and recommendations below.

CONCERNS AND RECOMMENDATIONS

1. Funding should be made available to ensure Independent advice and advocacy is available for patients and families who experience patient safety incidents

The draft framework briefly discusses the need to involve patients in the response to patient safety incidents including any investigation. However, it fails to acknowledge that access to independent advice and/or advocacy is vital for many people to ensure this is meaningful.

Experiencing a patient safety incident is often very traumatising, particularly when significant harm has been caused. Most patients or their families are unfamiliar with the structures and policies of the NHS or the terminology it uses; their rights; or the various processes that they need to consider or be involved in. In our experience, even the most educated, professional and usually confident people find it hard to understand let alone navigate systems or be involved fully in a patient safety investigation. Sometimes the incident itself or the way it is initially responded to will have damaged trust in the NHS. Meaningful involvement of patients/families in patient safety investigations is vital for the success of the investigation itself and for these reasons, it is important that people who experience avoidable harm have access to specialist independent advice and/or advocacy if they need it. As well as supporting patients/families involved in patient safety investigation, such a service should be able to help advise people about other potential processes/ decisions they may be faced with such as complaints, health professional fitness to practise procedures, inquests, and legal action.

There is a statutory duty under the Duty of Candour (regulation 20, CQC regulations) to advise people who have experienced moderate harm or worse of sources of independent support and advice. The Serious Incident Framework and new Patient Safety Incident Response Framework both tell NHS bodies to refer to sources of independent advice and support. However, this is inconsistently followed and even if it is, there is no funding available to ensure that independent advice or advocacy is actually available. Consequently, it is not available to most people in this situation.

The only funding that is available for independent advice or advocacy in England is for Independent Complaints Advocacy, which is limited to helping people navigate the complaints process and is for any complaint – not specifically those involving patient safety incidents. Also a small amount of funding is made available in cases of suicide or homicide investigations. The need for independent specialist advice and advocacy in the context of patient safety investigations was a major theme of the work with families in the *Learning from Deaths* program. This issue was due to be

looked at by the Learning from Deaths Board, and then the National Quality Board, but still hasn't been. The need for specialist independent advice has recently referred to in the Insight report by the Parliamentary and Health Service Ombudsman:

*"We have also heard about some concerning gaps in access to more specialist services. While it is important that individuals are supported to navigate the NHS complaints process, they may also need other forms of support and advice."*¹

2. More needs to be done to allow patients/families to escalate patient safety concerns about their own or their loved one's treatment

The draft Framework rightly discusses ways of involving patients in their own (or a loved one's) safety, including being able to have their concerns heard and acted upon, and if necessary escalated. The need for this can not be emphasised enough. Something we often see in cases that come to us is where the patient or a family member has been raising concerns about treatment/patient safety but these concerns have not been taken seriously or acted upon, resulting in harm. As well as training staff in listening and acting on concerns it would be helpful if there was a mechanism for patients/families escalating urgent concerns to a designated senior person if they have reason to believe their immediate care givers have taken their concerns seriously. This would be a more urgent way of raising concerns that could prevent patient safety incidents, and different to raising concerns via PALS or complaints which is a longer process and usually retrospective. Consideration should be given to the use of technology to facilitate this such as a special app.

People who find it difficult to communicate such as those with learning disabilities may need an advocate available to help them with this. One suggestion is that PALS could recruit, train and support volunteers to help people who have no one else available to support them take an active part in their treatment and raise concerns.

Whilst empowering patients to raise concerns about the safety of their own treatment is important, care needs to be taken not to place the main responsibility for this on them as opposed to the health professionals responsible for their treatment.

3. People with lived experience of avoidable harm need to be recruited and supported appropriately to be "Patient Safety Partners"

People with lived experience of avoidable harm have an incredibly valuable role to play but may face particular challenges. AvMA's work with the NPSA on 'patients for patient safety' and 'patient safety champions' found that staff were often very wary of involving people who had experienced avoidable harm. Whilst care needs to be taken to ensure that people with experience of avoidable harm are emotionally robust enough to perform the PSP role following the trauma that they will have experienced, efforts at PSP recruitment should specifically target this group of people and care must be taken not to make assumptions about their suitability and in

¹ PHSO, Making Complaints Count, 2.32, July 2020

<https://www.ombudsman.org.uk/sites/default/files/%28HC%20390%29%20-%20Making%20Complaints%20Count-%20Supporting%20complaints%20handling%20in%20the%20NHS%20and%20UK%20Government%20Departments.pdf>

effect discriminate against them on the basis of their experience. Staff who will need to engage with PSPs will need training in engagement and given the confidence to engage with people with experience avoidable harm.

Care needs to be taken not to unintentionally exclude people who would make good PSP's by making the person specification too restrictive. We do not think that the person specification for PSPs should make experience of working in similar roles a requirement but rather the ability to. PSPs' training can equip them to do the job.

4. "Patient Safety Partners" should be supported at a national and potentially regional level by a body independent of the NHS

We broadly support the proposals around Patient Safety Partners but believe they could be significantly improved upon. The Framework provides lots of helpful guidance on how NHS bodies should recruit and support Patient Safety Partners. However, to be effective 'critical friends' of the NHS bodies they are working with, the Patient Safety Partners need to maintain a significant degree of independence. They will also need to be able to get advice and support from someone independent of the NHS and to be facilitated to support and learn from each other to avoid feeling isolated or entirely dependent on the organisation they are working with. Patient Safety Partners should be distinctly different in their relationship with NHS bodies than volunteers who work 'for' the NHS body and are accountable solely to it.

The work AvMA did with the NPSA on the *Patient Safety Champions* project found that independent support and facilitation of the above was particularly helpful. Such support and facilitation included training and bringing 'champions' together to provide mutual support and learn from each other. A project manager was also available to advise individual 'champions' and to liaise with NHS bodies, and act as a facilitator if discussions were needed between individual champions and the NHS bodies they worked with.

5. Measures should be put in place to ensure the involvement of patients and organisations which represent them at a national and strategic level

The Patient Safety Partners proposals deal with local involvement of patients in patient safety. More work is needed to facilitate the involvement of patients at a national strategic level. This should include involvement at a policy level with the Department of Health and Social Care as well as with NHS England/Improvement.

Whilst NHS Improvement obviously is concerned with involvement in it's own and its NHS partners' work, it should use its influence with regard to what a joined up patient involvement in patient safety strategy should look like. The Cumberlege report² recommended a "patient safety commissioner" be appointed to provide a patient perspective on medication and device safety at a policy level. We think that the idea can be expanded and that consideration should be given to appointing such a patient safety commissioner for patient safety policy as a whole, potentiall with other commissioners covering specific elements of patient safety.

² *First Do No Harm, 2020*

https://www.immdsreview.org.uk/downloads/IMMDSReview_Web.pdf?dm_i=2SRY,12XNV,2YJGL2,45D5S,1

With regard to NHS Improvement/England's involvement of patients in patient safety work there are some good examples such as family engagement with the Learning from Deaths work. Patients were also involved in producing the draft Framework itself. An area for improvement which should be considered is the way that NHS Improvement engages with patients' organisations as part of its overall strategy. We have found this to be inconsistent. Patients' organisations have a great amount of intelligence from their work with many patients which can be harnessed. Involvement of relevant patients' organisations in specific pieces of work should be considered and also consideration should be given to regular liaison/involvement at a strategic level. This is not proposed instead of involving individual patients but in addition to involving individuals.

6. Sufficient additional resources must be made available to NHS to enable them to implement the new measures set out and there need to be mechanisms for ensuring consistent implementation of the measures

Given the pressures faced by NHS providers in delivering core services safely and the number of mandatory requirements they face, it is difficult to see how the framework will be consistently implemented without extra resources being made available and a degree of compulsion to implement the measures in the framework.

7. Organisational culture must be right to make the framework successful, and the framework should support an appropriate 'just culture'

Having an appropriate culture in NHS organisations will be critical to making the measures in the framework successful. For example being open to constructive criticism and expressions of concern; valuing the role of patients and families and in particular people with lived experience of avoidable harm. PSPs themselves can also play a key role in developing and supporting a just and inclusive culture in organisations. However we believe this all needs to be underpinned by a national vision of what 'just culture' means. So far, discussion of 'just culture' has almost exclusively been framed around being fair to staff. We have produced a draft vision of what 'just culture' should include from top to bottom of the NHS which we would like to be developed and then adopted. It would include the needs of patients and families as well as staff and apply to policy making right through to interactions with patients, and set the scene for the successful implementation of this framework.