patient safety learning

Patient Safety Learning's response to the draft Framework for involving patients in patient safety

Patient Safety Learning is registered as a charity with the Charity Commission Registration number 1180689

Patient Safety Learning
SB 203 China Works
100 Black Prince Road
London SE1 7SJ

e: hello@patientsafetylearning.org
www.patientsafetylearning.org

As part of its Patient Safety Strategy, published last year, the NHS identified the involvement of "patients, staff and partners with the skills and opportunities to improve patient safety throughout the whole system" as a key element to achieving its future safety vision.[1] This included plans to create a patient safety partners framework and, earlier this year, it published a consultation on its draft Framework for involving patients in patient safety.[2]

As set out in Patient Safety Learning's *A Blueprint for Action*, we share the view that patient engagement is key to improving patient safety, with this forming one of our six core foundations of safer care.[3] We envision a patient-safe future as one where patients are actively engaged throughout their care and whenever things go wrong, where:

- Patients and professionals are equipped and enabled to engage in safe care.
- Governance arrangements are in place that support, encourage and enable patient engagement in patient safety.
- Patients, families, and staff are supported and cared for at every stage after an incident of unsafe care.

In responding to this consultation, we will consider the two core components of this Framework: Part A – Involving patients in their own safety and Part B – Patient safety partner involvement in organisational safety. We will subsequently reflect on the importance of measuring and monitoring performance in these areas and provide some concluding comments.

Involving patients in their own safety

As we describe in *A Blueprint for Action*, we believe it is vital that patients are effectively engaged for patient safety during the care process and if things go wrong. There is clear research evidence that active patient engagement reduces unsafe care, and we welcome the intention of the Framework to improve the NHS's approach to this. In outlining important features of involving patients in their own safety, we were particularly pleased to see strong references to:

- Encouraging patients to ask questions about problems that occur, or in cases where they suspect there may be problem.
- The value of patient information leaflets and information videos as tools to assist in patient engagement, and the importance of patient involvement in co-producing these tools.
- Patients at discharge being given clear information about future test results and follow-up appointments.
- The role of patients' incident reports and complaints as a source of learning.

Complaints

Turning specifically to the Framework's reference to the use of patient complaints, we share its view that complaints are "a valuable resource for monitoring and improving patient

[1] NHS England and NHS Improvement, The NHS Patient Safety Strategy: Safer culture, safe systems, safer patients, July 2019. https://improvement.nhs.uk/documents/5472/190708_Patient_Safety_Strategy_for_website_v4.pdf

[2] NHS England and NHS Improvement, Framework for involving patients in patient safety, 10 March 2020. https://engage.improvement.nhs.uk/policy-strategy-and-delivery-management/framework-for-involving-patients-in-patient-safety/

[3] Patient Safety Learning, The Patient-Safe Future: A Blueprint for Action, 2019. https://s3-eu-west-1.amazonaws.com/ddme-psl/content/A-Blueprint-for-Action-240619.pdf?mtime=20190701143409

safety".[4] Having in place an effective complaints system provides an important opportunity to learn from incidents of unsafe care. Patients' experiences can be used to help identify patient safety problems, ascertain their causes, and put in place remedial measures to prevent them from recurring.

The Framework notes the importance of complaints and patient safety teams working more closely to fully utilise the learning from patient complaints. We would add that it is important that the Framework is joined up with the ongoing work of the Parliamentary and Health Service Ombudsman (PHSO) in this area; the PHSO has recently completed a consultation on a new Complaints Standard Framework for the NHS.[5] The creation of a new Complaints Framework opens up the opportunity to embed patient safety into these processes. We responded to the PHSO consultation, highlighting the importance of this.

The NHS complaints system will need to provide organisations with the means to share learning from complaints widely and effectively if we are to reap the benefits of this renewed emphasis on patient involvement in patient safety.

Patient safety incident reporting

When discussing the role of patients in reporting patient safety incidents, the Framework states that, currently, patients are encouraged to report their concerns directly to the relevant healthcare provider but that they can also submit them to the National Reporting and Learning System (NRLS). It notes that the latter is in the process of being replaced by a new Patient Safety Incident Management System that will be accompanied by "new tools to more easily participate in the recording of patient safety incidents and to support national learning".[6]

While we welcome plans to simplify reporting systems for patients in future, this does not address the cultural barriers which prevent patients from reporting concerns. Patients often feel treated as a "passive participant in the care process" with the assumption that they have little expertise to offer in regards to their own care.[7] More needs to be done to encourage patients to report issues and for them to feel assured that their stories and testimonies are welcome.

Related to this, it is important that when patients do report their concerns, these are used to inform the assessment of risk and patient safety. As noted in the recent findings of the Cumberlege Review into medicines and medical devices safety, not only are incidents not being reported but the existing systems "cannot be relied upon to identify promptly significant adverse outcomes arising from a medication or device because it lacks the means to do so".[8]

[4] NHS England and NHS Improvement, Framework for involving patients in patient safety, 10 March 2020. https://engage.improvement.nhs.uk/policy-strategy-and-delivery-management/framework-for-involving-patients-in-patient-safety/

[5] PHSO, Making Complaints Count: Supporting complaints handling in the NHS and UK Government Departments, 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

[6] NHS England and NHS Improvement, Framework for involving patients in patient safety, 10 March 2020. https://engage.improvement.nhs.uk/policy-strategy-and-delivery-management/framework-for-involving-patients-in-patient-safety/

[7] Patient Safety Learning, The Patient-Safe Future: A Blueprint for Action, 2019. https://s3-eu-west-1.amazonaws.com/ddme-psl/content/A-Blueprint-for-Action-240619.pdf?mtime=20190701143409

[8] The Independent Medicines and Medical Devices Safety Review, First Do No Harm, 8 July 2020. https://www.immdsreview.org.uk/downloads/IMMDSReview_Web.pdf

To encourage the active participation of patients in patient safety incident reporting we need maintain their confidence that their input is welcome and that, by reporting issues, they can help to effect change. We believe that greater transparency around the outputs of the national reporting system - and evidence of these changes - would help to achieve this.

Patient safety partner involvement in organisational safety

Part B of the NHS's new Framework is focused on the proposed role that Patient Safety Partners (PSPs) can play in supporting an organisation's approach to patient safety, setting out the purpose of these roles and how they will work in practice. It is positive to see a clear ambition to increase the formal involvement of patients in patient safety in the NHS. However, we feel there are several areas where these proposals require strengthening if they are to be successful.

Training and guidance for staff

The Framework makes clear that, to support these new PSP roles, healthcare staff will require appropriate training and guidance. To support this it points towards the important role that patient involvement will have as part of the new National patient safety syllabus.

While we agree about the importance of having the appropriate training and guidance in place to enable staff to support PSPs, we are concerned that, in its current form, the guidance set out in the National patient safety syllabus does not provide a strong enough basis for this. As we highlighted in our response to the consultation on the draft syllabus earlier this year, it currently "lacks references to the knowledge, skills and attitudes required from healthcare professionals to understand why and how patients can be actively involved in patient safety".[9]

NHS England and NHS Improvement will need to work with the Academy of Medical Royal Colleges and Health Education England to address this gap in the National patient safety syllabus if it is to meet this expectation. We believe it could be significantly strengthened by drawing on further research and resources available in this area, such as the World Health Organization (WHO) Patient Safety Curriculum Guide.[10]

Support and peer networks for PSPs

To contribute to an organisations' work in patient safety in the way envisaged by the Framework, we consider that needs to be more clarity about the support available to PSPs.

The Framework talks about PSPs having a planned induction and being provided with training but is not specific about what this would entail, though it estimates in Appendix 2 of the Framework that it may comprise of "one-day face-to-face induction and one-day initial e-learning".[11] The scope of this training appears to be at the discretion of the organisation, with the Framework noting that staff "will need to use the recruitment and induction process to assess an individual PSP's training needs".[12] There is reference made to a "PSP handbook"

[9] Patient Safety Learning, Patient Safety Learning's response to the National patient safety syllabus 1.0, 28 February 2020. https://s3-eu-west-1.amazonaws.com/ddme-psl/NationalPatientSafetySyllabus_PSLConsultationSubmission_Issued.pdf?mtime=20200302102701&focal=none

[10] World Health Organization, Patient Safety Curriculum Guide, 2011. https://apps.who.int/iris/bitstream/handle/10665/44641/9789241501958_eng.pdf;jsessionid=7819865E90A45E2288606F9BF1F5C4F9?sequence=1

[11] NHS England and NHS Improvement, Framework for involving patients in patient safety, 10 March 2020. https://engage.improvement.nhs.uk/policy-strategy-and-delivery-management/framework-for-involving-patients-in-patient-safety/

[12] Ibid.

but it is not clear who is responsible for producing this or where content will be drawn from. We believe much greater clarity is needed.

We also believe that there is value in PSPs having access to networks with their peers in other organisations, enabling them to share good practice and knowledge for safety improvement. In Appendix 2 the Framework states that participation in such networks for PSPs is something that would be anticipated as happening "in the longer term". We believe that it would be beneficial to create these networks alongside the new PSP roles. In addition to the benefits of sharing learning, this would help ensure that from an early stage those carrying out PSP roles have access to peer support from other patients.

We suggest that NHS England and NHS Improvement could further develop support for these roles by drawing on the experience of other programmes involving patients in patient safety. Examples include the experience of the WHO Patients for Patient Safety programme and its previous use in the UK, implemented by the National Patient Safety Agency and the charity, Action Against Medical Accidents (AvMA).[13]

Another example is Canadian Patients for Patient Safety (Canadian PFPS), which has developed into a vibrant, effective, well-supported partnership of patients and the health care system. The partnership includes the Canadian Patient Safety Institute (CPSI).[14] The Canadian PFPS have formed an Alliance to improve the safety of care through collaboration. The Alliance's collective efforts help to accelerate safety improvements. There is much to commend and learn from this approach and the significant resources available to support its adoption in the UK.

Patient Safety Specialists

One further area we believe requires strengthening is the interaction between future PSPs with the newly proposed Patient Safety Specialists. All Trusts and CCGs have been asked to register their Patient Safety Specialists with the national patient safety team by the 30 November 2020, with associated role and responsibilities being subject to consultation earlier in the year.[15]

The Framework refers to these roles on two occasions, when discussing who may be responsible for recruiting, selecting, and supporting an organisation's PSPs, and when considering which board member would be responsible for these roles. We believe that if these Patient Safety Specialist roles are to work effectively in organisations then they will need to be filled by leaders on patient engagement.

In the consultation on the Patient Safety Specialist roles earlier this year, we commented that improvements were needed to these roles.[16] There is a strong need for the Patient Safety Specialist roles to have expertise and experience of involving patients, families and carers. We believe these roles should be identified more centrally in supporting the work of PSPs in this Framework.

[13] AvMA, Patients for Patient Safety, Last Accessed 15 October 2020. https://www.avma.org.uk/resources-for-professionals/patient-safety/patients-for-patient-safety/

[14] CPSI, Patients for Patient Safety Canada, Last Accessed 16 October 2020. https://www.patientsafetyinstitute.ca/en/About/Programs/PPSC/Pages/default.aspx#:~:text=We%20are%20the%20voice%20of,levels%20in%20the%20health%20system.&text=We%20work%20collaboratively%20with%20others,our%20experiences%2C%20observations%2C%20and%20perspectives

[15] NHS England and NHS Improvement, Patient Safety Specialists, Last Accessed 15 October 2020. https://www.england.nhs.uk/patient-safety/patient-safety-specialists/

[16] Patient Safety Learning, Response to the Patient Safety Specialists consultation, 12 March 2020. https://www.patientsafetylearning.org/blog/response-to-the-patient-safety-specialists-consultation

Co-production

While the Framework makes some limited references to co-producing plans to involve PSPs in organisations and how they should be supported, we believe there should be stronger emphasis on this throughout the Framework. Co-production is simultaneously an activity, an approach and an ethos which involves members of staff, patients, and the public working together, sharing power and responsibility across the entirety of a project.[17]

Projects and patient safety programmes should always be co-produced with patients, following the key principles of:

- Sharing of power - jointly owned, people working together to achieve a joint understanding including all perspectives and skills.
- Respecting and valuing the knowledge of all those working together - everyone is of equal importance.
- Reciprocity - everybody benefits from working together.
- Building and maintaining relationships - an emphasis on relationships is key to sharing power.
- Joint understanding, consensus and clarity over roles and responsibilities.
- Value people and unlock their potential.

Measuring and monitoring performance

While we welcome the ambition of the plans set out in the Framework, Patient Safety Learning believes that, to make improvements in the involvement of patients in patient safety, we need to be able to clearly measure and monitor our progress in this respect. We set this out in our report *A Blueprint for Action*, where we make the case that organisations should be informing patients and the public about their patient safety performance.[18]

The Framework refers to a target identified in the Patient Safety Strategy that "all safety-related clinical governance committees (or equivalents) in NHS organisations are to include two PSPs by April 2021, and for them to have received the training required by April 2022".[19] Further to this, we believe organisations should be given guidance on how to report their progress in an open and transparent way.

This does not appear to be have been an area of focus for the Framework but is an issue that we feel requires attention. Publicly reporting on changes and improvements made through patient involvement and patient safety would help to share examples of good practice. It would also mitigate against concerns that these roles could become tokenistic in some organisations, with PSPs locked out from making a real impact.

Restorative Justice

When considering a broader approach to how patients are engaged in patient safety, many national healthcare systems and organisations are actively listening to, and engaging with,

[17] Dr Erin Walker, What should co-production look like?, 1 April 2019. https://uclpartners.com/blog-post/co-production-health-look-like/; National Institute for Health Research, Guidance on co-producing a research project, March 2018. https://www.invo.org.uk/posttypepublication/guidance-on-co-producing-a-research-project/

[18] Patient Safety Learning, The Patient-Safe Future: A Blueprint for Action, 2019. https://s3-eu-west-1.amazonaws.com/ddme-psl/content/A-Blueprint-for-Action-240619.pdf?mtime=20190701143409

[19] NHS England and NHS Improvement, Framework for involving patients in patient safety, 10 March 2020. https://engage.improvement.nhs.uk/policy-strategy-and-delivery-management/framework-for-involving-patients-in-patient-safety/

patients for learning through restorative justice. New Zealand is one country leading this approach and Canada is also doing good work in this area.[20]

Restorative justice in healthcare allows patients to be heard, listened to, and respected. The engagement of patients, clinicians, healthcare leaders and policy makers in such an approach allows trust to be re-established and provides the impetus for learning and action to be taken to prevent future harm. We commend the approach adopted by New Zealand in how it responded to harm from surgical mesh and the impact this has had on improvements in patient safety.[21]

There are some beacons of excellence within the NHS, in terms of culture change and patient engagement, with the NHS People Plan citing a specific example of good practice at the Mersey Care NHS Foundation Trust.[22] We believe that NHS England and NHS Improvement should do more to share and promote a just and learning culture, and should be asking organisations to develop and publish goals on their progress. Such steps would help to foster the conditions required to increase patient involvement in patient safety.

Concluding comments

We welcome and recognise the positive steps being set out in the Framework to improve patient involvement in patient safety within the NHS. Our comments and suggestions for improvement are mainly centred around the need to ensure other key pieces are in place to support this in practice. Specifically, that:

- Complaints and incident reporting systems enable patient insights to be effectively utilised to improve patient safety.
- Effective guidance and training is provided for staff on patient involvement.
- Appropriate guidance and support for patients enables them to participate in these improvements.
- There is joined up working with new Patient Safety Specialist roles.
- Organisation performance in this area is monitored and measured.
- Co-production is a key part of this.
- There is a restorative approach to unsafe care in the context of a just and learning culture.

Significant change is still needed. The Framework focuses on increasing patient involvement in governance and decision making. However, there is a lot of work to be done throughout every engagement with patients to ensure:

- Patients as part of the clinical team and decision-making in their own care.
- Patients supported at every stage after an incident of unsafe care, with a clear 'harmed care pathway' for patients, families, and staff.
- Patients as advocates and champions for patient safety and reduced harm.

[20] Jo Wailing, Chris Marshall and Jill Wilkinson, Hearing and Responding to the Stories of Survivors of Surgical Mesh, December 2019. https://www.health.govt.nz/system/files/documents/publications/responding-to-harm-from-surgical-mesh-dec19.pdf

[21] Ibid.

[22] Mersey Care NHS Foundation Trust, Just and Learning Culture – What it Means for Mersey Care, Last Accessed 16 October 2020. https://www.merseycare.nhs.uk/about-us/just-and-learning-culture-what-it-means-for-mersey-care/

This wider need for changes in how we engage patients in patient safety is outlined in the recently published WHO Global Patient Safety Action Plan 2021-2031.[23] It outlines a range of actions for Government's and healthcare organisations to help engage and empower patients and they families in patient safety that we would expect to see reflected in the work of NHS England and NHS Improvement.

Strengthened as we suggest, we believe that the Framework could make a big different to improving patient involvement with patient safety.

[23] WHO, Global Patient Safety Action Plan 2021-2031: Towards Zero Patient Harm in Health Care, 28 August 2020. https://www.who.int/docs/default-source/patient-safety/1st-draft-global-patient-safety-action-plan-august-2020.pdf?sfvrsn=9b1552d2_4