

Patient Engagement in Patient Safety: A Framework for the NHS

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Why a framework for patient engagement in patient safety?

The involvement of patients in their care is a top priority for the NHS, highlighted in the NHS Constitution¹ and the NHS Five Year Forward View². Healthcare providers are encouraged to develop different relationships with patients and communities to help empower them and engage them in their care. This same approach applies to patient safety in healthcare where greater engagement of patients is seen as one of the building blocks for improvement. Indeed, a checklist for safety improvement produced by the Health Foundation in 2015 includes supporting patients, carers and families to play an active role in patient safety³.

Doing this well is not without its challenges. A recent literature review⁴ concluded that there is considerable evidence that patients and the wider public can be involved in many different ways at most stages of healthcare and this can have a number of benefits. However there is still uncertainty about why and how to do engagement well, how to evaluate its impact and how to involve a diversity of individuals, rather than a select few, in ways that allow them to work in partnership to genuinely influence decision making.

The framework outlined in this document provides a structure for thinking about engaging patients in patient safety and gives examples of how this can be achieved. It is mindful of the criticisms of approaches to patient engagement in patient safety⁴ and is a first step towards adopting a theoretical approach to this context. Some factors which influence engaging with patients in patient safety which were identified from this work are also presented.

What is a framework for patient engagement in patient safety?

The framework describes three levels of patient engagement in patient safety across three levels of the NHS healthcare system. It also presents real-world examples of patient engagement in patient safety and applies these to the framework.

For the purposes of the framework:

Patient safety is defined as freedom from healthcare associated preventable harm⁵.

Patient engagement is the encouragement of patients, carers and families to work with healthcare professionals, healthcare service providers, commissioners and policy makers to improve health and healthcare. Descriptors of three levels of patient engagement are presented in the framework.

Patients may be someone receiving care and giving 'real-time' feedback, patients who have previously received care or treatment, patients who have experienced harm, or members of the public.

Who is the framework for?

The framework is intended to be a guide for healthcare professionals, healthcare service providers, commissioners and policy makers to help them to think about how they might engage patients, carers and families in making healthcare safer. It may also have wider applicability in patient safety education providing teachers and trainers across all healthcare disciplines with additional guidance for any students learning about patient engagement in patient safety.

If, for example, you were a frontline health professional you might be interested in how you could engage patients in keeping themselves safe or in providing feedback on safety. Examples of these strategies are available here (under the 'safety of own care' heading). If on the other hand, you are a member of a Trust Board you may find the section on 'service provider' engagement of patients more useful for ideas on how patients could be involved in influencing or making decisions.

There are many fewer examples of the engagement of patients in policy or system redesign for safety but as this is a live document there is potential to add these examples as they become available.

How was the framework developed?

The framework was developed from the Multidimensional Framework for Patient and Family Engagement in Health and Health Care⁶. A modified rapid review method⁷ was used. The steps were as follows:

1. Literature search to identify examples of patient engagement in patient safety
EMBASE, key patient safety and patient engagement journals and conference proceedings were searched between the dates of January 2010 to end September 2015. Websites of relevant organisations were also searched.
2. Screening and selection of examples to be included in the framework
3. Populating the original framework⁶ and identification of factors which influence patient engagement in patient safety
4. Consultation with Stakeholders
Members of the Patient Engagement in Patient Safety group reviewed the populated framework and offered additional examples of patient engagement in patient safety for potential inclusion.
5. Refinement of the framework
The descriptors of the three levels of engagement and three levels of the NHS healthcare system were finalised. Examples of patient engagement in patient safety were selected for inclusion.

How do you use the framework?

Levels of engagement and levels of the NHS healthcare system

- The framework comprises nine cells – three levels of patient engagement (information, involvement, partnership or shared leadership) and three levels of the NHS healthcare system (own care, service provider, system).
- As you move from left to right in the framework the level of patient engagement increases from receiving information to active partnership. The level of patient power also increases.
- As you move from top to bottom in the framework the level of the NHS healthcare system broadens from the individual patient to the policy level.
- The level of patient engagement and the level of the NHS healthcare system will influence who can be involved, which engagement activities can be used, and the support that patients need in order to be effectively engaged.

Examples of patient safety in patient engagement

- Selected examples for eight of the nine cells in the framework are briefly described with links to more information and resources. We were unable to identify any examples for the information level of engagement at the system level of the NHS.
- In making our decision about where to place each example, we focused on the level of patient engagement in its delivery rather than its development.
- The examples may be relevant to other cells in the framework as often a patient safety programme is multi-component and cuts across different levels of engagement and the healthcare system.
- Where possible the examples are from the NHS and from different sectors e.g. primary, secondary care. Where a sector is not represented this is because examples were not identified in the rapid review, not because they do not exist.
- No judgement is made on the “quality” of the examples. Instead we indicate where an evaluation has been undertaken to assess either the **acceptability** (do patients, healthcare professionals like it?) or the **effectiveness** (does it improve patient safety?). Where it is reported that there is no evaluation this is because it was not identified in the rapid review. It is possible that an evaluation does exist and we did not locate it.

What about non-NHS organisations who facilitate patient engagement in patient safety?

The focus of the framework is patient engagement in the NHS healthcare system. There are many independent organisations which support patients, carers and families to engage with the NHS about patient safety. Some examples are: Action Against Medical Accidents, Clinical Human Factors Group, Healthwatch, Innovations in Dementia and Patient Opinion.

The Framework

	INFORMATION Power lie with Healthcare Professional/Service Provider/System	INVOLVEMENT Patients have an active role but powers lie with Healthcare Professional/Service Provider/System	PARTNERSHIP OR SHARED LEADERSHIP Patients share power with Healthcare Professional/Service Provider/System
SAFETY OF OWN CARE - Engagement is in the context of the patient's own care - This is often in real-time as the patient is undergoing care, but can also occur after the care is completed when it may further influence care at the service provider level	- Patients receive patient safety information in the context of their own care - Communication is one-way from the healthcare professional/service provider to the patient [Examples 1-6]	- Patients are asked their views about patient safety in the context of their own care - Communication is two-way between the healthcare professional/service provider and the patient - It is led by the healthcare professional/service provider [Examples 7-10]	- Patients work together with the healthcare professional/service provider to improve patient safety in the context of their own care - Communication is two-way between the healthcare professional/service provider and the patient [Examples 11-13]
SAFETY OF THE SERVICE PROVIDER - Engagement is in the context of the safety of the service provider - The patient will usually, but not always, have received care from the service provider - This can be at the ward, GP practice or organisational level	- Patients receive patient safety information in the context of the service provider - Communication is one-way from the service provider to the patient [Example 14]	- Patients are asked their views about patient safety in the context of the service provider - Communication is two-way between the service provider and the patient - It is led by the service provider [Examples 15-16]	- Patients work together with the service provider to improve patient safety in the context of the service provider - Communication is two-way between the service provider and the patient [Example 17]
SAFETY OF THE SYSTEM - Engagement is in the context of safety of the system - This can be at a national or international policy level as well as across multiple organisations - The patient may have received care or have experienced harm or be a member of the public	- Patients receive patient safety information in the context of the system - Communication is one-way from the system to the patient	- Patients are asked their views about patient safety in the context of the system - Communication is two-way between the system and the patient - It is led by the system [Examples 18-20]	- Patients work together with the system to improve patient safety in the context of the system - Communication is two-way between the system and the patient [Example 21]

Examples of patient engagement in patient safety

Own Care - Information

1	Duty of Candour	Formal Evaluation	Not located
Organisation	Care Quality Commission (CQC)		
Source	http://www.cqc.org.uk/content/regulation-20-duty-candour#guidance		
Description	Duty of Candour was introduced in April 2015 for all CQC registered providers (NHS bodies, adult social care, primary medical and dental care, and independent healthcare). It is a statutory regulation (Regulation 20 in the Health and Social Care Act) for patient safety incidents that result in moderate harm, severe harm or death. It requires that as soon as reasonably practicable after becoming aware that a notifiable safety incident has occurred the health service body must (a) notify the relevant person that the incident has occurred; and (b) provide reasonable support to the relevant person in relation to the incident, including when giving such notification. Patient safety incidents that result in no harm or low harm are not covered by the Duty of Candour although it is recommended that patients should still be informed of these events in line with Being Open (see Example 2).		
2	Being Open	Formal Evaluation	Not located
Organisation	National Patient Safety Agency		
Source	http://www.nrls.npsa.nhs.uk/beingopen/		
Description	The Being Open framework provides best practice guidance for healthcare staff to communicate openly and honestly with patients, their families and carers following a patient safety incident. Being Open is consistent with the Duty of Candour (see Example 1).		
3	Medicine Sick Day Rules Card	Formal Evaluation	Acceptability and Effectiveness ⁸
Organisation	Health Improvement Scotland and NHS Scotland		
Source	http://www.scottishpatientsafetyprogramme.scot.nhs.uk/programmes/primary-care/medicine-sick-day-rules-card		
Description	The Medicine Sick Day Rules Card is a credit card sized information card for patients, carers, and health professionals to raise awareness of potential harms if patients continue to take certain widely prescribed medicines whilst suffering from a dehydrating illness. It lists medicines that should be temporarily stopped during an illness that can result in dehydration (vomiting, diarrhoea and fever).		
4	Children and Young People's Safety Briefing	Formal Evaluation	Not located
Organisation	Salford Royal NHS Foundation Trust		
Source	http://www.haelo.org.uk/films/the-children-and-young-peoples-safety-briefing/		
Description	The Patient Safety Briefing is a video is based on the concept of safety advice given on aeroplanes. It is shown to children, young people and their families when they come into hospital. The safety advice focuses on things children and young people can do so that they are better equipped to help themselves including washing their hands and asking others if they have washed their hands, telling a health professional if they feel worse and keeping moving to fight pressure ulcers.		

5	PINK Patient Safety Video	Formal Evaluation	Acceptability and Effectiveness ⁹⁻¹¹
Organisation	St Mary's Hospital London		
Source	https://www.imperial.ac.uk/imedia/content/view/3257/pink---a-patient-safety-video/		
Description	The PINK Patient Safety Video is an animated video aimed at encouraging patients coming into hospital to engage in safety behaviours. It is based on four actions: Participate – Inform – Notice – Know.		

6	Getting Equipped to tackle Forgetfulness Booklet	Formal Evaluation	Not located
Organisation	Innovations in Dementia		
Source	http://www.innovationsindementia.org.uk/projects_computers.htm#equipped		
Description	Getting equipped to tackle forgetfulness is a booklet aimed at people with dementia and their carers. It offers ideas on equipment, gadgets and technology to help people with dementia remain safe.		

Own Care – Involvement

7	Patient Reported Experiences and Outcomes of Safety in Primary Care (PREOS-PC)	Formal Evaluation	Acceptability ¹²
Organisation	Royal College of General Practitioners		
Source	http://www.rcgp.org.uk/clinical-and-research/toolkits/patient-safety.aspx		
Description	The PREOS-PC is a questionnaire for patients to feedback their patient safety experiences in their GP practice. It is part of a Patient Safety Toolkit for General Practice.		

8	Serious Incident Framework	Formal Evaluation	Not located
Organisation	NHS England		
Source	https://www.england.nhs.uk/patientsafety/serious-incident/		
Description	The Serious Incident Framework explains the process and procedures to ensure that serious incidents are identified correctly, investigated thoroughly and learned from to prevent the likelihood of similar incidents happening again. It includes involving patients, victims and their families/carers who have been affected. The Serious Incident Framework is consistent with the Duty of Candour (see Example 1) and Being Open (see Example 2).		

9	Self-reporting Real-time Bedside Tool	Formal Evaluation	Acceptability and Effectiveness ¹³
Organisation	Great Ormond Street Hospital for Children NHS Foundation Trust, London		
Source	http://www.health.org.uk/journal/real-time-reporting-harm-patients-improves-safety-culture		
Description	The Self-reporting Real-time Bedside Tool is a patient centred, simple real-time tool for patients and families to report harm, with the aim of raising awareness and opportunities for staff to continually improve and provide safe care.		

10	Speak Up Patient Safety Programme	Formal Evaluation	Not located
Organisation	US Joint Commission on Accreditation of Healthcare Organisations		
Source	http://www.health.org.uk/journal/real-time-reporting-harm-patients-improves-safety-culture		
Description	The Speak Up Patient Safety Programme is a campaign to encourage patients to “Speak Up” to prevent medical, medicine and surgery errors in their care. Infographics, animated videos, brochures and posters can be downloaded from the website. Guidance for organisations on how to use the Speak Up materials is also provided on their website.		

Own Care – Partnership or Shared Leadership

11	ThinkSAFE	Formal Evaluation	Acceptability and Effectiveness ¹⁴⁻¹⁵
Organisation	Newcastle University		
Source	http://www.thinksafe.care/ http://ahsn-nenc.org.uk/project/64/		
Description	ThinkSAFE is a multi-faced, collaborative approach to involving patients in improving their own patient safety. The intervention is evidence-based, user and theory-informed and comprises four inter-related components: • A Patient Safety Video that demonstrates a range of things that patients and families can do to reduce a patient’s risk of experiencing harm • A patient-held healthcare log book, containing tools to facilitate patient-staff interactions and the sharing of information • Talk Time - a dedicated time for patients to discuss queries and concerns with staff • A theory and evidence-based educational training session for staff		

12	Active Patient Participation in improving Anticoagulant Medication Safety	Formal Evaluation	Acceptability and Effectiveness ¹⁶
Organisation	University College London Hospitals NHS Foundation Trust		
Source	http://www.health.org.uk/programmes/shine-2012/projects/active-patient-participation-improving-anticoagulant-medication		
Description	This initiative comprises two innovations to empower patients to be active partners in their own care and reduce patient harm arising from anticoagulant medication in hospital and at discharge: • A patient-led discharge summary ‘time out’ • A patient-centred run chart		

13	Listening to You	Formal Evaluation	Acceptability and Effectiveness ¹⁷
Organisation	Birmingham Children’s Hospital NHS Foundation Trust		
Source	http://www.health.org.uk/programmes/shine-2012/projects/quantifying-parental-concern-strengthen-their-voice		
Description	Listening to You is a communication bundle comprising three elements: • A leaflet for parents/carers including topics such as how to have a more effective conversation with hospital staff and a diagram to pin point what “just isn’t right” • A leaflet for staff on their role in the Listening to You project • A “Planning Care Together” form which allows parents and staff to share, discuss and document parental concerns		

Service Provider – Information

14	NHS Mental Health Safety Thermometer	Formal Evaluation	Not located
Organisation	NHS		
Source	https://www.safetythermometer.nhs.uk/index.php?option=com_content&view=article&id=4&Itemid=109		
Description	The NHS Safety Thermometer is a tool that measures commonly occurring harms in people who engage with mental health services. It completed by staff on one day each month. The data are published and patients, carers and families can access this information.		

Service Provider – Involvement

15	Patient Reporting and Action for a Safe Environment (PRASE)	Formal Evaluation	Acceptability and Effectiveness ¹⁸⁻¹⁹
Organisation	Led by Bradford Teaching Hospitals NHS Foundation Trust. Implemented by Barnsley Hospital NHS Foundation Trust, Hull and East Yorkshire Hospitals NHS Trust, and Yorkshire and Humber Academic Health Science Network.		
Source	http://www.health.org.uk/programmes/closing-gap-patient-safety/projects/putting-patient-heart-patient-safety http://www.improvementacademy.org/patient-safety/prase-patient-voice-in-patient-safety.html		
Description	The PRASE intervention was co-designed with patients and NHS staff to collect feedback from hospital patients about the safety of their care using two tools: • A 44-item questionnaire which asks patients about safety concerns and issues (Patient Measure of Organisational Safety, PMOS) • A proforma for patients to report (a) any specific patient safety incidents they have been involved in or witnessed and (b) any positive experiences (Patient Incident Reporting Tool, PIRT). Ward staff then implement their action plans in line with the issues raised by patients in order to improve patient safety and the patient experience.		

16	Trust Board Meetings	Formal Evaluation	Not located
Organisation	Mid Staffordshire NHS Foundation Trust		
Source	http://www.kingsfund.org.uk/audio-video/julie-hendry-creating-culture-ensure-good-patient-safety-quality-and-experience		
Description	Every Trust Board meeting at Mid Staffordshire NHS Foundation Trust opens with a patient talking about their experience of care and whatever action the Trust takes, it checks with the patient to ensure they have felt listened to. The meetings are held in public places and open to the public.		

Service Provider – Partnership or Shared Leadership

17	Patient-led Training on Patient Safety	Formal Evaluation	Acceptability and Effectiveness ²⁰⁻²²
Organisation	North Yorkshire East Coast Foundation School		
Source	http://qualitysafety.bmj.com/content/early/2014/08/18/bmjqs-2014-002987.short		
Description	Patient-led patient safety teaching was incorporated into the mandatory training of Foundation Year 1 medical students. Patients and carers with experience of suffering harm or error to themselves, or their families, during healthcare were recruited. They attended four Patient Learning Journey workshops to prepare for the teaching programme. The teaching intervention was two x 1 hour sessions developed collaboratively with the patients and delivered to small groups of students. Each session included one patient narrative and then a facilitated discussion.		

System - Involvement

18	Choosing Wisely	Formal Evaluation	Not located
Organisation	Academy of Medical Royal Colleges		
Source	http://www.aomrc.org.uk/general-news/choosing-wisely.html ²³		
Description	Choosing Wisely is a campaign to engage health professionals and patients in conversations about unnecessary tests and procedures. For example: Do I really need this test or procedure? What are the risks? Are there simpler safer options? What happens if I do nothing? The programme originated in the US. Choosing Wisely was launched in England in May 2015. Medical Royal Colleges and Specialist Societies will identify the top five interventions within their speciality whose necessity should be questioned in discussion with the relevant patient groups/organisations. A Programme Steering Group has been established to oversee the project which includes patient group representatives.		

19	Healthcare Safety Investigation Branch (HSIB) Expert Advisory Group	Formal Evaluation	Acceptability and Effectiveness ¹⁸⁻¹⁹
Organisation	Department of Health		
Source	https://www.gov.uk/government/groups/independent-patient-safety-investigation-service-ipsis-expert-advisory-group		
Description	HSIB provides guidance to NHS organisations on patient safety investigations, and carries out some investigations itself. The HSIB Expert Advisory Group has members from a broad range of patient safety stakeholders including patients.		

20	Patients for Patient Safety Network	Formal Evaluation	Acceptability ²⁴
Organisation	National Patient Safety Agency (no longer exists) and Action against Medical Accidents (AvMA)		
Source	http://www.avma.org.uk/policy-campaigns/patient-safety/patients-for-patient-safety/		
Description	The Patients for Patient Safety Network was based on the World Health Organisation (WHO) model of WHO Patients for Patients Safety ²⁵ . This network was set up for England and Wales with 1000s of Patient Safety Champions.		

System – Partnership or Shared Leadership

21	National Advisor on Patient Safety, Culture and Quality	Formal Evaluation	Not located
Organisation	Care Quality Commission (CQC)		
Source	http://www.cqc.org.uk/content/james-titcombe https://www.gov.uk/government/publications/morcambe-bay-investigation-report		
Description	The National Advisor on Patient Safety, Culture and Quality to the CQC is someone whose experience led to the Morcambe Bay Investigation Report.		

Factors influencing patient engagement in patient safety

Some influencing factors were identified at the three levels of the NHS healthcare system. This is not an exhaustive list.

Own Care

- Patients may question how “qualified” they are to contribute to their own safety and may choose not to engage. They may also be concerned about how their engagement is received by healthcare professionals and find some patient safety activities harder to do e.g. telling someone if they feel unwell may be easier than asking a doctor if he/she has washed their hands.
- Healthcare professionals have a role in encouraging patients to engage with their own safety, reassuring them that it is important and developing patients’ confidence in performing patient safety activities.

Service Provider

- Asking patients to engage in patient safety at this level benefits from taking into consideration the needs of the patients and the amount of effort/time/resources required to engage in the patient safety activity.
- Presenting patient engagement in patient safety as a way of improving the quality of care may avoid it being viewed as a way of saving money.
- Having a consistent staff team involved in patient engagement in patient safety can help foster trusting relationships and a common purpose.

System

- Performance targets and incentives may not always be consistent with patient engagement in patient safety activities.

Developing the framework

We are keen to further develop this framework and to identify other examples of patient engagement in patient safety. Please feedback on the framework and tell us about your work by completing the short form on page 14 and email it to liz.thorp@bthft.nhs.uk.

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Feedback on the Framework

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Patient Engagement in Patient Safety: A framework for the NHS

How have you used the framework?

How can the framework be improved to be more useful?

Example of Patient Engagement in Patient Safety	
Name of example	
Organisation where example is based	
Brief description	
Information that people can access e.g. websites, reports, published papers	
Formal evaluation people can access e.g. websites, reports, published papers	