

# Involving people in safety

A summary of learning from a Health Foundation roundtable

**Event report**

June 2013

# 1. Introduction

## Background

The various inquiries and investigations into the failings at Mid Staffordshire illustrate the devastating consequences when safety concerns are ignored, not taken seriously or not learnt from. More recently, the debate over children's heart surgery in Leeds demonstrates the need for full and rounded evidence that a service is safe today.

Patient and public involvement in safety has, to date, been limited largely to providing feedback following an adverse event or poor experience of care. Our evidence scan on *Involving patients in improving safety* explored a wider role for patients and the public in planning improvement, monitoring the safe delivery of services and informing care plans. However, there is a gap in the evidence on how effective these approaches have been.

Patients have a greater expectation today that they will be involved in matters that affect the quality of their care; there is no reason why this should not also be extended to the safety of their care.

## Towards a prospective approach to safety

The Health Foundation is focusing its effort on leading a stepwise change in thinking about patient safety. This event is part of a programme of work we are undertaking to develop a framework to answer the question – *How safe is care today?* We want to build on a culture that has historically focused on measuring past harms, and enhance this through a proactive approach that also establishes the presence of safety.

Efforts to reduce adverse events in healthcare have focused on changing people's behaviour, changing how care is structured and tackling specific harms (eg falls in hospital). We believe that in order to deliver continuous improvement in patient safety we now need a broader approach that also explores the potential for people to be actively involved in their safety.

# 2. About the event

On 1 May 2013 the Health Foundation hosted a roundtable event to explore how the public, patients, their families and carers can be involved in improving patient safety. People with expertise and personal experience of involvement in patient safety came together to share their knowledge and learning in order to build understanding in this area, and to recommend some practical next steps. A list of attendees is provided on page 5.

The event is the second in a series of roundtable discussions hosted by the Health Foundation in 2013 to lead a debate about how we can better understand how safe care is today.

## Key messages

- Patients feel subordinate in their relationship with health professionals, which can lead to a sense that the feedback they are providing about potential safety concerns is somehow not legitimate. Patients and the public should be seen as citizens and not simply as recipients of care, with a role in deciding what the fundamental standards of care should be and a right to raise concerns when these are not met.
- The patient is the single most important safety barometer and the issues they raise can be an early warning to a later risk. The unhelpful distinction that has traditionally been made between care and treatment has led to a view that some complaints are 'only about care', leaving staff unable to understand the risks to safety from patient feedback.
- Recent changes to the infrastructure of patient and public involvement in England are hindering local efforts to give people a strong voice. Identifying and developing local responses to these problems must be a priority for commissioners and providers.
- Patient representatives should be aware of and take steps to avoid 'going native', losing the fresh perspective they offer and becoming professionalised parts of the service. One way to do this is by having a maximum amount of time that someone can be a patient representative on a particular group or committee, or by developing new and less bureaucratic means to engage people.

- We must stop using the excuse that people might not understand performance information about healthcare providers as a reason for not publishing information. We should start from the principle that all information is made available, with a role for charities, GPs and commissioning organisations to help to make the information more easily understood.

### 3. Discussion

The discussion began with an introductory question and answer session between Elaine Maxwell, Assistant Director at the Health Foundation, and Murray Anderson-Wallace, to explain the Health Foundation's approach to facilitating improvement in patient safety. The main discussion then followed.

#### **Q. What does the Health Foundation mean by a 'broader approach to patient safety'?**

A. As a healthcare system we have tended to focus on counting the number of falls or blood clots in hospitals, for instance, to assess the safety of care. However, we really need to incorporate a broader measure of how safe people feel, whether this is in hospital, in the community or at home. People who have the most interest in safety are those receiving care and their families and carers, but currently they are a significantly underused asset.

#### **Q. Is the system receptive to this new approach?**

A. It will be a challenge to move to this new approach, but the findings and recommendations of the Francis Report present an opportunity to make the change. We must explore ways in which trust can be built between care providers and the wider population, not limited to patients. People in this country are proud to have an NHS and feel a vested interest in making it as safe as possible.

#### **Q. What does the new framework for understanding the measurement and monitoring of safety actually mean?**

A. The Health Foundation commissioned Charles Vincent and his team at Imperial College London to develop a framework for measuring and monitoring safety in healthcare. In broad terms, it concluded that measuring the failures of the past is not the best predictor of safety in the future (or even how safe care is today). We need to understand the reliability of services, and how we can draw all the available information together to better understand the safety of our services.

### Having the right infrastructure in place

An immediate concern raised by the group was around the variations in infrastructure for patient and public involvement following the NHS reforms in England. Some patient groups are far more developed than others. For example, while some GPs have patient panels others do not. Part of the problem may be due to having guidance for these arrangements rather than mandated requirements. As well as variations in implementation across England, there are of course structural differences across the four countries of the UK.

A debate took place around ward nurse staffing levels, where some members of the group expressed serious concerns about capacity; others felt that it was actually the calibre of individual coming into the profession, capable of being a leader, which had diminished. There was general agreement that nurses do not have enough time to address the issues that are identified in reports following serious incidents. The lack of a traditional supernumerary ward sister role means that no one has an overview of care on a ward.

There followed a discussion around which health professional had overall responsibility for care on a ward, and the group felt that nobody did, mainly because the structures now in place did not give anyone that authority. There may be 10 or more consultants visiting patients on a ward, but they do not have a lead role for all of the patient's care in the way that a care coordinator or named nurse does for mental health services, for instance. One suggestion was that there should be a safety lead for each ward on each shift. This would build on what has been learnt in other industries, where everyone is aware of their responsibility for safety.

Some members of the group lamented the abolition of the National Patient Safety Agency (NPSA), and in particular the reports they produced around concerns in hospitals and areas of care. It was however noted that compliance with NPSA alerts was variable and there were no sanctions for failure to implement. Board

papers on issues such as complaints are available if people look for them, but these tend to focus on the numbers of complaints and response times rather than patient stories and are of variable quality.

The general feeling among the group was that we must get the conditions right for safe care before we do anything else, particularly adequate staffing levels. It was also raised that we must not try to reinvent the wheel. We have seen a number of national initiatives (eg Patient Safety First) and public inquiries (eg Bristol, Mid Staffordshire) and much of what has been recommended has not been implemented. We should move forward on the issues that have already been identified and acknowledge that some trusts are simply not ready to move on, as they are not even doing the basics well.

## **Mechanisms for involving people in safety**

The overall feeling was that we must find better ways to engage people in safety, and that it is all too often put in the 'too difficult' box. The current approach was described as 'lazy', too complaint-focused and targeting specific groups rather than the general population. Organisations tend to seek feedback on particular issues or services that are of interest to them, take that feedback away and then make decisions. Surveys are often done at the time of discharge, when people are simply relieved to be well again and just want to move on.

There has been little investment in patient leadership and the early signs show significant variation in investment and implementation of local Healthwatch. The experience of some in the group was that patient groups can become professionalised, or even be described as 'going native', where they are no longer capable of providing independent support and challenge. One suggestion was to ensure membership of patient groups is continuously refreshed.

A fear of retribution persists, or inappropriate responses by staff during particularly busy periods. Concerns were heard of patients being catheterised because staff did not have the time to help them go to the bathroom. Taking the example of a hospital call bell, it was seen too often by staff as a burden, rather than a mechanism for real time feedback from patients. It was suggested that patients and the wider public could help to review and audit complaints on a regular basis.

## **Legitimising the 'citizen's' voice**

Being a patient can engender a sense of disempowerment or subordination, where patient feedback is not seen as proper or credible evidence. However, as in any good customer service industry, feedback should be treated as jewels of information, and to ignore the patient is to ignore the most important safety barometer. Issues that patients raise can be an early warning to a risk upstream, particularly when there is an accumulation of such things.

Research is being undertaken at the Bradford Institute for Health Research where information is being gathered routinely to capture patient concerns. The project asks patients why they see their concern as a safety issue and it is finding that staff do not always see the same issue as a safety problem (or certainly views differ on the **severity** of the problem).

The team has been surprised to learn that wards have not seen it as a priority to engage in the research, as they assumed that all wards would have found this kind of information useful. It was acknowledged that staff time is an inevitable barrier, but even busy wards have made the time to do it. It was also acknowledged that the lack of infrastructure to address issues that arise through such work is also a barrier to progress.

The arbitrary distinction between care and treatment has led to a view that complaints are about 'care' and health professionals are unable to extract the risk from patient feedback. For example, when a relative complains that staff leave a drink out of the reach of a frail person, staff do not necessarily 'hear' the risk of dehydration and subsequent cardiac arrest.

To help rebalance the relationship between patients and professionals it was suggested that we think of patients instead as citizens, with rights as taxpayers over the services available to them. This would then have implications for the behaviour of health professionals and managers, as well as for regulators in helping to establish what should be seen as fundamental standards.

## Transparency, access and support with interpretation of data

The debate around whether or not to publish performance information on NHS providers has been based on an unfair assumption that people will not understand technical information. We should at least give people the choice, and there could be a role for charities, and certainly GPs and the new clinical commissioning groups (CCGs), to play a role in helping people interpret technical data to make it more useable.

We should start from the assumption that all information about the quality and safety of care in an organisation should be published and actively shared with the public. This would force organisations to be more outward looking, and regardless of whether people would use it to help choose services, it could help to improve organisations' safety records. It would be particularly useful for those organisations where there still exists a culture of fear for staff to raise concerns.

In the absence of information such as this, reports about the quality and safety of providers tend to come from the media, but these can be inaccurate and highly variable. On the other hand, some recent research was cited which noted a high correlation between the feedback on care through social media outlets and the clinical outcomes of organisations.

The 'friends and family test' was suggested as being the only question that needs to be asked. However, others suggested that a broad question such as this does not diagnose why the problem exists. Similarly, two trusts may have high mortality rates but it may be for very different reasons. This reinforces the importance of patient feedback to help to understand the causes of problems, and not simply their existence.

## 4. Next steps

The issues and emerging findings identified in this report will feed in to the Health Foundation's ongoing work on how we can better understand how safe care is. In particular, it will inform some work we have commissioned to test how safety is perceived and measured between different groups, from the board level to the frontline professional to the patient and family member.

## 5. Attendees

### Attendees at the event included:

Murray Anderson-Wallace	Facilitator
Jan Annan	Strategic Lead Corporate Programmes/Substance Misuse, South West London and St George's Mental Health NHS Trust
Julie Bailey	Founder, Cure the NHS
Ian Callaghan	Service User Expert, My Shared Pathway – NHS QIPP Programme
Jill Fraser	Director and Co-Founder, Kissing It Better
Jan Gould	People Development Specialist, Inspiring Growth
John Illingworth	Policy Manager, Health Foundation
Ruthe Isden	Public Policy Programme Manager, Age UK
Elaine Maxwell	Assistant Director – Patient Safety, Health Foundation
Beryl Nock	Patient Safety Champion
Jane O'Hara	Senior Research Fellow, Bradford Institute for Health Research
Marlene Omoura	Patient Safety Champion
Peter Walsh	Chief Executive, Action against Medical Accidents
Zoe Ward	Public Affairs Manager, Health Foundation

The Health Foundation is an independent charity working to improve the quality of healthcare in the UK.

We want the UK to have a healthcare system of the highest possible quality – safe, effective, person-centred, timely, efficient and equitable. We believe that in order to achieve this, health services need to continually improve the way they work.

We are here to inspire and create the space for people to make lasting improvements to health services.

We conduct research and evaluation, put ideas into practice through a range of improvement programmes, support and develop leaders and share evidence to drive wider change.

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