

Identifying risks and monitoring safety: the role of patients and citizens

Jane O'Hara and Ruthe Isden

In this thought paper, Jane O'Hara and Ruthe Isden consider the role of patients and citizens in the identification of risk and the measurement and monitoring of safety within healthcare. The paper discusses opportunities for patients, their families and carers, as well as the wider public, to become part of an integrated system for ensuring the safety of care. The authors also consider the challenges and barriers to this involvement, the fundamental paradox of considering the 'patient perspective' on safety within the current clinical risk paradigm, and the need for a shift towards valuing the non-clinical voice.

The Health Foundation is calling for a stepwise change in thinking about patient safety. This paper forms part of a programme of work we are undertaking to help answer the question *How do we know care is safe?* We want to build on a culture that has focused almost exclusively on measuring past harm and enhance this to incorporate approaches to measurement that also establish the presence of safety.

Health Foundation thought papers present the authors' own views. We would like to thank Dr O'Hara and Ms Isden for their work, which we hope will stimulate ideas, reflection and discussion.

About the authors

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Introduction

This paper considers the role of patients and citizens in the identification of risk, and the measurement and monitoring of safety within healthcare.

We will look at this in the light of a framework proposed by Charles Vincent and colleagues¹ (see figure 1). We will discuss our views on the opportunities this framework presents for patients, their families and carers, as well as the wider public, to become part of an integrated system for ensuring the safety of care. We will also consider the challenges and barriers to this involvement, the fundamental paradox of considering the ‘patient perspective’ on safety within the current

clinical risk paradigm, and the need for a shift towards valuing the non-clinical voice.

In their report, Vincent and colleagues¹ present a compelling argument for widening our approach to both the measurement and ongoing monitoring of safety within healthcare. The main thrust of their argument is that traditionally within healthcare we have measured safety retrospectively – what harm has occurred – to the neglect of more sophisticated systems of prospectively predicting future safety performance. Vincent and colleagues provide us with a simple framework for how healthcare organisations might move forward to construct a more integrated and comprehensive system for ensuring safer care.

Figure 1: A framework for the measurement and monitoring of safety



At first glance, one might struggle to see how patients, families or, indeed, the public in general (in this paper referred to as ‘citizens’), could be involved in the five dimensions of this framework. However, work by health services and academics over the past decade has begun to evidence that not only would such involvement be possible, it might also be crucial if we are to understand fully the current and future state of patient safety.

Why involve patients and citizens?

Let us take a moment to reflect on why we should involve patients and citizens in the measurement and monitoring of safety. Most people would agree that those experiencing healthcare can comment on what it was like – the ‘quality’ of the service. What has taken longer to take root is the idea that patients and citizens are in a position to provide feedback on the safety of their care experience or indeed that ensuring safety may be described as a partnership activity. But the individual patient is the one common denominator across all their care experiences, making them a natural source for information across healthcare boundaries, health professionals, services and care settings. Unruh and Pratt² nicely summarised this with the observation that:

Patients are the only actors physically present during every treatment and consultation... as they move through a distributed system of care (pS242).

Given this unique observational position, perhaps a more pertinent question is, why has it taken so long for patients (and

citizens) to be asked about, and be actively engaged in, the safety of care?

Part of the answer no doubt lies with the continued lack of patient and citizen engagement in healthcare. A review of evidence and practice undertaken by the Richmond Group of Charities in 2010 concluded that shared decision making and engagement in service design remained one of five principal barriers to improving quality of care for people with long-term conditions.³

While emphasis on patient involvement continues to grow in national and international policy, the picture on the ground remains resistant to rapid change. The proportion of people reporting that they were definitely involved as much as they wanted to be in their care has been slow to show progress. In 2012, 55% of patients agreed with this statement,⁴ up from 52% in 2004;⁵ progress yes, but hardly overwhelming improvement. Involvement of family members and carers in decision making looks broadly similar. A survey of people who care for friends or relatives with dementia found that almost half said that neither they nor the person they were caring for were involved in decisions about care as much as they would like to be.⁶ The UK also continues to compare unfavourably to international counterparts on the degree of engagement people can expect from their clinical teams.⁷ The barriers are well documented⁸ and range from cultural barriers (‘patients don’t want it or will want inappropriate treatments’) to lack of training (‘we already do it’) to perceived system barriers (‘no time/incentive to do it’).

To some degree it is hardly surprising that a system that fails to consistently value and encourage engagement in intimate individual decisions about treatment and care also has an underdeveloped view of the role of patients in safety, an area largely seen as the clinical preserve.

Of course, patient involvement in decisions about treatment and care and support to self-care is often considered a facet of patient safety, as is citizen involvement in service design. Again, successfully involving people in service design is still patchy. In their follow-up report, the Richmond Group of Charities, drawing on the experience of the service users they represent, highlighted the need for ongoing improvement in this area.⁹ There are encouraging enclaves of co-creation around patient safety issues, notably patient involvement in designing safer environments; however a substantial challenge remains in embedding these approaches across the health service as a whole.

The language and methods traditionally employed in patient safety, however, might also tell us something about barriers to engagement. As Vincent and colleagues point out, safety has traditionally been monitored through the measurement of past harm. Past harm is overwhelmingly discussed in clinical terms and measured through clinical means – pressure sores, medication errors, healthcare-associated infections – therefore it is not always obvious what knowledge and insight patients and citizens might be expected

to contribute beyond perhaps compliance with rules designed by ‘experts’ elsewhere in the system (eg hand hygiene on the ward). The emphasis on measuring the clinical outcomes of harm that overlooks the wider array of opportunities to monitor safety conditions inevitably therefore overlooks the valuable insight patients and citizens can provide in identifying drivers of risk.

The following simple example, however, nicely illustrates the co-dependency between providers and receivers of care when it comes to safety and risk management. Malnutrition and dehydration pose serious, but frequently preventable, patient safety risks.¹⁰ They are also risks that are most effectively managed through cooperation and co-production between staff and patients. Health professionals will be fully cognisant of the harm that can occur if patients become malnourished or dehydrated as well as the risk factors and symptoms – this is expert knowledge that derives from professional training and experience. Patients and families, on the other hand, may well be unaware of the severity of the risk or recognise the symptoms, but they will certainly be aware of the barriers and risk factors created by practice and the environment that may be invisible to staff. If we acquit staff of any wilful intent to cause harm then we accept that when someone places food and drinks out of reach and provides no assistance in eating or drinking, it is because the organisation is not attuned to the possibility of harm nor managing itself in such a way as to minimise risks.¹¹ Equally, if

people are not eating because they struggle with presentation and packaging, or not drinking because they find it too difficult to get to the toilet, these are all drivers that are perceived by patients through the lens of their experience and self-knowledge that may be otherwise hidden from professionals. With the best will in the world, professionals cannot always see things as they appear to people using their services. Therefore it is only by bringing together expertise in clinical knowledge and care with the experiences and perspectives of people receiving care that many types of risk, and indeed the opportunities to mitigate risk, become fully apparent. The notion that patients and citizens might have unique knowledge and insight unavailable to professionals takes us beyond 'passive involvement' into an exploration of ways in which patients and citizens can play an active role in partnership with professionals.

Although it is often fundamental failures of patient safety that sit at the root of concerns expressed by patients and citizens, these are usually couched in terms of 'dignity' or patient experience. This can give the misleading impression that while capable of commenting on their 'soft issues' associated with their personal experiences, citizens and their stories do not provide significant 'hard evidence' of breaches of safety.

The following incident was reported as part of a survey of patient experience of dignity on the ward:

*That one man was opposite me...
One nurse would come in, get hold of
his head... and put it back, the other*

*one would get potatoes, which were
never cooked properly anyway, with a
fork, pushing it in his mouth and then
holding his mouth up there so he got to
swallow it.¹²*

The risks posed to the patient in question by the nutritional care described are patent, yet the degree to which the safety implications of this story would be drawn out and acted upon varies hugely between care settings. However, if a patient acquires a pressure ulcer – for which malnutrition is a contributory factor¹³ – then the ulcer would be recorded and measured as a safety breach.

This dichotomy is expressed directly through the NHS Mandate¹⁴ which is clear that improving patient safety involves improving quality of care and patient experience. Unfortunately, the measures applied to monitor system improvement remain exclusively clinically led. As Vincent and colleagues advocate, moving away from simple measurement of past harm, and placing a particular emphasis on monitoring environmental and cultural factors associated with increased likelihood of harm, opens up new spaces in which the value of patient and citizen insight could, and should, be recognised.

It is not just perceived relevance of patient and citizen insights that creates a barrier to engagement; there is historically a question mark over their value and reliability as well. In much the same way that the value of involving patients in decisions about treatment and care has not always been widely recognised in our

paternalistic clinical culture, the value of patient stories and reported experience as a form of evidence has taken time to gain traction. The combination of a dominant paradigm that emphasises the primacy of clinical trial evidence and a perception that patient and citizen reports may be driven by factors unrelated to the ‘objective’ quality of care appears to lead many to dismiss relayed experiences as a reliable source of evidence. Submissions to the Dignity in Care Commission also suggested that, even though increasing numbers of organisations have embraced patient stories as a tool for focusing attention on experience, the application of the insight to improve management and practice is still underdeveloped.¹¹ This is probably most notable in the treatment of complaints. Complaints are frequently dealt with as individual incidences, often in isolation from the relevant clinical teams, and data are not analysed for trends. However, when used appropriately, complaints data provide a rich seam of relevant information.

Before turning our attention to the more specific ways patients and citizens could make a contribution to safety in the context of the framework identified by Vincent and colleagues, it is also worth making one final point about perception of risk and harm. Measurement of past harm clearly defines harm through the eyes of professionals – you are not harmed unless the system deems you to be so according to the (chiefly physical and clinical) criteria it has identified. This paper is primarily concerned with the opportunities for

involving patients and citizens in the identification, measurement and monitoring of risk. However, it is worth introducing at least the idea that patients and citizens should have a role in defining harm and debating acceptable levels of risk. Patients as individuals exposed to risk and people in their role as the citizen who legitimise the use of public resources for the provision of healthcare have a right to be involved in that conversation. What we would argue is that there needs to be a move towards a more comprehensive framework for the collection, interpretation and use of the patient and citizen perspective of the safety of care – a new risk ‘paradigm’ that values, accommodates and acts on this new angle on safety intelligence.

Patients and citizens and the framework for measuring and monitoring safety

Having considered some of the context around the patient perspective on the safety of their care, we will now focus upon how patients and citizens might be actively engaged and involved in the measurement of safety using the framework proposed by Vincent and colleagues.

Past harm

Perhaps the most obvious role for patients and citizens in the proposed framework for the measuring and monitoring of safety is in the first dimension – measuring ‘past harm’. There is now a general consensus that patients can tell us about all kinds of experiences related to safety^{15,16} and certainly

across the categories outlined within the framework. Patients can describe in some detail problems that they have had with their care, across both hospital and community settings,^{17,18,19} while citizens have been shown to be able to recall problems with healthcare experiences in large postal surveys.²⁰ Healthcare organisations across the UK and internationally are very much beginning to realise the importance of involving patients more generally in assessing the quality and safety of services. This has particularly come into focus following recent high profile reviews of poor hospital care (such as the 2013 Francis report on the Mid Staffordshire NHS Foundation Trust²¹ and the Keogh review of 14 NHS trusts²²). These have emphasised the need to introduce better systems for capturing and responding to the patient perspective on their care. Indeed, NHS England hopes to introduce real-time feedback about quality of hospital care by 2015.²³ Online patient feedback sites, such as Patientopinion and NHS Choices, are growing in popularity all the time, and are increasingly being recognised by healthcare organisations as a legitimate and useful source of feedback on quality of care, with other social media also being seen to be potential learning sources for patient views on safety experiences.²⁴

There is no doubt that having a better understanding of the experience of care is important, but, as the extant evidence suggests that patients can tell us about more than just their experience of care, it will be important for healthcare organisations going forward to integrate feedback

specifically about the safety of care into such systems. Furthermore, there is a need for these systems to be robustly developed and evaluated in order to understand and demonstrate their effectiveness in capturing feedback, and effecting patient safety improvements.¹⁵ Indeed, one of the critiques of the recent introduction of the ‘friends and family test’ within the NHS in England has been that it is a somewhat blunt instrument, with a scoring system that can be misleading.²⁵ This demonstrates the real risk that health services introduce new systems for feedback that do not ask the questions needed to understand and improve safety, but could lead to complacency that they are eliciting the patient view.

It is equally important to ensure that methods of capturing experience do not exclude those people who are at greatest risk of harm.¹⁵ For example, reliance on online data capture is unlikely to tap into the views of frail older people – 65.6% of over 75s, for example, have never used the internet.²⁶ Equally, mainstream patient surveys in some instances do not capture significant samples of the most vulnerable or have the means of disaggregating the responses of those groups, such as the ‘oldest old’ who are most likely to be mentally and physically frail and subject to greater numbers of patient safety incidents.²⁷ Even introducing greater sensitivity to mainstream methods, however, may not be enough. Physical and mental health barriers will exclude many vulnerable people from providing responses while factors such as fear of retribution or low expectations may lead others to over-report levels of satisfaction.

Reliability

Moving away from asking patients about their experience of safety as a retrospective measure of past harm, we can also consider how patients might be able to help us prospectively manage safety going forward. The second dimension of the framework, ‘reliability’, reflects the consistency of processes or systems in achieving appropriate levels of safety. This is usually measured through clinical audit although, as recognised by Vincent and colleagues, in the NHS currently both the measurement and the reliability of the systems and processes themselves can be poor. How might patients and citizens be involved in this dimension of measurement? As we have already seen, patients and their families can report on safety issues across the full range of healthcare settings, making them perfectly placed to augment traditional clinical audits. Indeed, recent campaigns encouraging patients to ask about hand hygiene (prior to examination by health professionals), recognises that patients are well placed to provide observational data on the reliability of processes requiring consistency in ‘human behaviour’.

Thinking more widely, however, there may be a role for patients and citizens in providing useful and unique information on larger-scale clinical systems. Laurence Degos and colleagues²⁸ have called for the defining of a new category of adverse events – ‘integrated adverse events’. These are adverse events that:

no longer relate only to episodic errors and failures in procedures at specific times, but also to cumulative failures

throughout a patient’s journey within a health system. (p339)

As described earlier, patients have the unique position of being the only key actor across all healthcare encounters. Thus, one might anticipate that in a future NHS, with more sophisticated systems of measurement and monitoring of integrated adverse events as well as single safety episodes, patients and their families would be very well positioned to input crucial information about their safety experience that our current fractured and complex healthcare system cannot reach, collate or respond to. Such a patient-centred approach, based on patients’ journeys rather than health services, is radical and would be a challenge to establish – crossing, as it would need to, boundaries between acute and community care, through to social care and mental health. However, if we are to make significant gains in the reliability of clinical systems, as argued by Vincent and colleagues, we may need to ‘think big’ about the way in which we assess the safety of care and putting the patient at the heart of this makes sense in moral and practical terms.

Sensitivity to operations; Anticipation and preparedness

One issue that we have already touched on – patients feeding back about their experience of safety – relates also to the third and fourth dimensions of the measurement and monitoring framework: ‘sensitivity to operations’ and ‘anticipation and preparedness’. Essentially, these two components of the framework are

concerned respectively with the day-to-day monitoring of the 'system' (and the sensitivity to subtle changes), and the related issue of anticipating, and being prepared for, future safety problems on the basis of current knowledge.

In a useful analogy, patients and their families have been described as the 'smoke alarms' of the NHS,²⁹ a sentiment echoed by many commentators following the publication of the 2013 Francis report. The idea is that patients should be engaged to alert healthcare organisations to 'smouldering' issues – ie before they cause harm. This is very much in line with these two dimensions within the framework – ongoing monitoring and anticipating future events. We know that patients and their families can provide information about their experience and the safety of their care and, indeed, it is the vision of NHS England to have all NHS organisations collecting 'real-time' patient feedback over the coming years. This will undoubtedly provide a fantastic new perspective on the traditional dashboard approach to clinical audit data. But can patients and citizens tell us about things that lead to safety problems in the future – help us to anticipate and prepare against future patient safety problems?

Recent research would say yes – patients are willing and able to give health services information about factors contributing to future safety problems. Researchers in Bradford³⁰ have developed what they term a 'patient measure of safety' – a survey instrument designed to systematically collect information from patients or their families about things they experience in

a hospital ward setting, which are factors known to contribute to future error. Such factors could be problems with equipment, communication issues on the ward, or poor information sharing between professionals. Such questions are not currently asked by traditional patient experience or satisfaction measures, but this research suggests that many patients can provide good information about these issues, which are known to be contributing factors to safety problems.³¹ Such measures provide healthcare organisations with an exciting opportunity to not only collect from patients real-time data on things that have happened – their experience of care or the safety of their care – but also alert them to issues that have the potential to cause problems in the future. In this sense, such tools help structure the process of patients and citizens acting as the 'smoke alarms' for the safety of healthcare services.

Integration and learning

The last dimension within the framework – 'integration and learning' – is, in some ways, the most difficult to imagine a role for patients and citizens. As Vincent and colleagues rightly point out, healthcare organisations traditionally expend most effort in the collection of safety information, with much less given to other aspects of the safety information system: analysis, learning, feedback and action. Given this imbalance in the current system, perhaps it is too much to expect us to add the perspective of patients and citizens, adding as it would to the incredible complexity of the safety information system? Indeed, as we have

already discussed, without a fundamental shift in the valuing of the ‘non-clinical’ perspective on safety, much of the patient perspective on care would not even make it onto a dashboard of safety intelligence. However, as we have established within this paper, patients are clearly in a position to provide good information about the safety of care, so what can healthcare do now to improve involvement of patients and citizens in the integration of, and learning from, safety data?

First, as well as asking patients, family members and citizens about the safety of their care, we should involve patient representatives in their analysis. Patients are often not integral to the investigations of complaints or serious untoward incidents, which may omit vital parts of the contextual information required to understand all contributing factors. Perhaps patient representatives could form part of risk management teams, to be part of the decision-making process about the severity of harm, and informing governance processes by viewing risk through the ‘patient lens’.

Second, we should be introducing the importance of the patient perspective on safety far earlier in the training of health professionals. Education in patient safety has been slow to be established. Indeed, in their guidance for improving patient safety in postgraduate medical education,³² the Academy of Medical Royal Colleges and the Royal College of Surgeons of Edinburgh concluded that there was ‘no individual module in any postgraduate curricular on patient safety’ (p3). Although this is

now changing, given that defined patient safety training is a very new phenomenon in medical education, it is unsurprising that the patient perspective on safety is not part of training for health professionals. We believe that this should change, and there is some emergent evidence for the role of patients in patient safety education. Indeed, recent work has demonstrated that an intervention which asked patients to deliver their experiences of an adverse event to newly qualified doctors was both feasible and acceptable, and led to increased emotional engagement in the doctors taking part.³³ In short, asking patients to be involved in medical education might lead to an increased ‘humanising’ of patient safety for doctors at the start of their careers. Not only is this important in terms of integrating the patient perspective of the safety of care into the analysis and learning aspects of the safety information system, it is also a necessary step in the repositioning of the patient perspective more generally in patient safety.

Conclusion

So, what can we conclude at the end of this exploration about the current state of, and future opportunities for, patient and citizen involvement in the measurement and monitoring of the safety of healthcare? Fundamentally we believe that patients and citizens can, and indeed should, be involved and engaged in the safety of their care and in the measurement of that care. However, for this to be achieved, health services globally need to embrace and value the perspective of the patient, not just in

terms of the quality of care, but also its safety. It is possible that in the future, as we move towards a more 'consumer-led' health service where choice is central to all aspects of health service provision, patient perceptions of safety – irrespective of the clinical reality – will become ever more important. In a sense, patients may in time be asked 'how safe did you feel?' alongside 'how safe was your care?' and, in this brave new world, health services will value and accommodate both judgements within the new integrated system for the measurement of safety.

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