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Rebecca Lawton & Gerry Armitage

The role of the patient in clinical safety

In this thought paper, Dr Rebecca Lawton and Dr Gerry Armitage look at ways to involve patients in clinical safety and the readiness of patients and health professionals to adopt new roles. They discuss the importance of involving patients in the development of patient engagement and involvement strategies.

At the Health Foundation, we know that genuine patient involvement in their own care requires a fundamental cultural shift in the relationship between patients and clinicians. We have conducted research and designed and delivered improvement programmes that promote these new relationships. In 2012 we will open up a wide-ranging discussion about the practical implications of the challenges and opportunities for the doctor-patient relationship.

Health Foundation thought papers are the author's own views. We would like to thank Dr Lawton and Dr Armitage for their work, which we hope will stimulate ideas, reflection and discussion.

About the authors

Dr Rebecca Lawton
Dr Rebecca Lawton is a health psychologist. In 1994, she was awarded a PhD from the University of Manchester. In 1999, she took up a post at the University of Leeds as a lecturer and was later promoted to Senior Lecturer in Health Psychology. Her current research interests focus on applying psychological theory to improving health and healthcare services. More specifically, she carries out research on human factors and patient safety, patient involvement in patient safety, and the uptake of evidence-based practice, as well as more traditional health psychology research.

Dr Gerry Armitage
Dr Gerry Armitage has worked as a registered nurse for more than 13 years, largely in acute children's services and in both junior and senior positions. He is Senior Lecturer at the University of Bradford and has also worked as Senior Research Fellow at the Bradford Institute of Health Research since 2007. He holds lead investigator and co-applicant roles on national research grants and is currently supervising three PhD students whose work is embedded in quality and safety.

Summary

There are now international (World Health Organization), government (Department of Health) and patient-led (eg, Action against Medical Accidents (AvMA)) imperatives to empower patients to act as partners in their healthcare. Patient safety is no exception. Cynics might argue that this shift of emphasis is more about transferring some responsibility to patients for their care (eg, managing long-term conditions via telehealth) in order to reduce healthcare costs. Others, however, would counter that a paternalistic approach centred on the notion of professional infallibility is no longer relevant in a consumerist 21st century.

Strategies to involve patients in clinical safety fall into three categories. First, is the option for patients to intervene directly to promote patient safety (eg, challenging staff to wash their hands). Second, is the notion of educating patients so that they are better able to manage their treatment regime safely (eg, self-management of oral anticoagulants).[1] Finally, is the invitation for patients, having a predominantly outsider's perspective, to provide feedback on the safety of their care, which potentially offers a source of information to help staff plan improvements.

This article will touch on the first two approaches before focusing on the latter – a largely unexplored aspect of patient involvement. In doing this, we consider the barriers and facilitators to involving patients in clinical safety (eg, the readiness of patients and health professionals to adopt new roles). We also discuss the importance of involving patients in the development of patient engagement/involvement strategies, referring specifically to our work on patient incident reporting and the development of a patient measure of organisational safety.

Patients intervening directly to promote safety

Reducing levels of preventable harm across healthcare systems remains a major priority.[2] Traditionally, patient safety has been viewed as the remit of health professionals, with patients as the passive recipients of care. However, an ageing population demanding more resources of an increasingly limited NHS budget, coupled with patients who are more informed and have particular expectations of quality and choice, demands a different relationship between health professionals and patients. Patients are now often granted a level of expertise in their condition, have more of a role in treatment choices, and are encouraged to be more questioning or even to provide feedback about their care.

This changing relationship requires a shift in the attitudes, beliefs and behaviours (ie, the culture) of patients and health professionals alike. Such cultural shifts have already been made and there are clinical areas where this approach is the norm rather than the exception (eg, neurosurgery, renal patients, oncology and patients with mental health problems). What these patients have in common, however, is a more regular or longer-term interaction with the healthcare provider. There is a recognition that the psychological and physical status of the patient are, in a sense, symbiotic, and have an equal impact on the patient's health. Moreover, the long-term outcomes for these patients depend as much on their own health motivation as on the treatment they receive. It is no surprise, then, that involving these same groups of patients in safety is rather more advanced. Such patients might sit on clinical governance groups, give input to local decision making bodies, and be consulted about changes to care pathways (eg, The Royal Marsden, London, and NHS Wales).[3]

One area that is perhaps more contentious and untested is the role for patients in expressly contributing to the maintenance of their own safety at an individual level in partnership with their care team. Implicit in this is the need for a shared understanding, with the patient, of the nature of risk, ranging from preventable risks (eg, a direct injury resulting from error) to unpreventable risks associated with the nature of the illness or procedure.

Involving patients in this way is a difficult balancing act; it requires raising awareness without instilling fear, and a recognition of the valuable perspective that patients can offer without making them accountable. The Clean Your Hands campaign in the UK was an example of an attempt to involve patients in this way. This intervention involved making alcohol rub more widely available, with a poster campaign and an invitation to patients to question staff about their handwashing. The evidence from an evaluation suggests that while these campaigns might have been successful in terms of increasing the use of alcohol rub and reducing infections,[4] the impact of patient involvement in the success of this campaign was limited.[5] In fact, recent work by Pittet *et al* (2011) has revealed that the majority of patients (57%) would be unlikely to question doctors on

the cleanliness of their hands,[6] while McGuckin and colleagues (2004) found that although 57% of patients had asked a member of staff to wash their hands, this was much more likely to be a nurse (91%) than a doctor (33%).[7]

It isn't just in the area of handwashing that patients are somewhat reluctant to challenge staff. Little evidence exists about the effectiveness of the Speak Up campaign (in the USA), which focused on helping patients to be involved in preventing medical error by being vigilant about their care, asking questions and raising concerns. Moreover, research has identified a general reluctance among patients to challenge or ask a question of staff about safety, particularly among less educated, male and unemployed patients.[8] In fact, some have argued that an over-reliance on patients could also inadvertently lull healthcare professionals into a false sense of safety;[9] and the potential for increasing inequalities between those patients who do and those who do not actively play a role in their safety should not be ignored.[10]

The reluctance to challenge may be more widespread in practice than might be expected if we just ask people about their willingness to challenge. In their review of patient engagement in safety, Schwappach *et al* (2009) use the 'theory of planned behaviour' to unpick the disconnect between our positive attitudes about engaging in patient safety and our actual behaviour.[11] For example, Waterman *et al* (2006) found that while 71% of patients felt comfortable about helping healthcare professionals to mark the surgical site, only 17% actually engaged in this behaviour.[12] This is supported by anecdotal evidence from some of our colleagues in medicine who, despite their expertise, when they become patients, begin to feel a sense of unease about challenging those providing their care, even when they know something is wrong.

Educating patients to manage their treatments safely

Encouraging patients to challenge staff directly is, however, only one form of patient involvement. What other roles could patients play in promoting their own safety? A more informed and empowered patient population is being asked to take a greater role in their care, through greater involvement in decision making, and better management of their medicines and lifestyles. This greater involvement in their own care might mean, by default perhaps, that the patient becomes more responsible for their own safety. Take diagnosis, for example – is a patient who withholds vital information about their unhealthy lifestyle at least partly responsible when the doctor reaches an incorrect diagnosis?

Medicines management is another example where responsibility for safety might become blurred. Patients may be encouraged or supported by staff to continue to manage their diabetes even when in hospital. Let's assume that a competent patient routinely manages their insulin while in hospital, but they forget a dose and become hyperglycaemic. Clearly, the nurse must take some of the responsibility for this, as it is still part of

their role to record the dose of insulin in the patient's notes. Therefore, the nurse is partly responsible for not checking on the patient; but is the patient accountable in any way for this error, and if so, is staff accountability correspondingly reduced? This blurring of responsibility has been raised as a concern by patients[13] and may be a barrier to involvement for some.

Another potential barrier to involvement highlighted by Entwistle and colleagues (2005) is a lack of staff support. The first step in this process is that staff recognise and value the contribution that patients can make to safety. The second step is for staff to actively encourage patients to be involved.[14]

Our own experience of discussing the patient contribution, with patients and with staff, is that there is a certain reticence – not about the fundamental principle of a patient voice, but rather about the mechanics of 'doing' patient involvement in such a way as to maintain trust across the professional-patient relationship and ensure mutually beneficial learning about safety. This is supported by research. Medical staff, for example, may find that relinquishing 'control' to patients threatens their identity.[15] Maintaining the 'power imbalance' has also been demonstrated as a concern for nursing staff; interviews with nurses revealed that they felt they 'knew best', and that, in general, patients lacked medical knowledge, requiring them to retain their power and maintain control.[16] Indeed, fundamental to the inclusion of patients in safety is accepting that patients need to know, are allowed to know, and can understand, the very concept of safety.

Key challenges to patient involvement

There is huge potential for patient involvement in patient safety,[17] but the recent history suggests that caution should be exercised in what is a radical departure from a largely paternalistic healthcare system. Challenges that have emerged include:

- unease among patients about challenging their carers, to whom they are often unconditionally grateful
- the acknowledgement that the level of involvement may need to be personally negotiated to reflect a patient's willingness and ability to be involved
- the emotional labour for staff that comes from accepting the premise of patient involvement and making it work as part of routine practice.

It could be argued, then, that we have leapt into patient involvement in safety with both feet, and that now, a more measured and stepped approach is necessary if we are to see a shift in the culture of patient involvement which, in turn, has the potential to shift patient safety culture per se. It is possible, though, to achieve these shifts in culture. Take the case of paediatric medicine and nursing, for example – 40 years ago, resident parents were often viewed as an annoyance,[18] with the potential to interfere in the care of the children on the ward. But since the 1990s, parents have been recognised as important collaborators in the care of their children and unconditionally welcomed onto wards.[19]

So, to summarise, patient involvement interventions need to consider three thorny issues:

- the willingness and ability of patients to be involved
- the blurring of accountability that comes with greater involvement
- the unease among some staff about this new role for patients and the potential for erosion of trust.

It is therefore fundamental to the success of patient involvement/engagement strategies that patients and staff are both actively involved in the development of these strategies.

Using patient feedback to improve the safety of care

This is the approach we have taken to a patient safety intervention being developed as part of a National Institute for Health Research (NIHR) programme grant by the Yorkshire Quality and Safety Research Group. It is well documented that patients are able and willing to report on what they perceive to be patient safety incidents within their own care. This has the potential to provide useful data about the types and frequency of incidents that occur from a patient's perspective, which does not necessarily duplicate data collected in staff incident reporting systems.[20] In many studies, though, patients are asked to report on specific predefined threats to safety rather than being asked to comment on general concerns about safety from their perspective.

However, developing effective patient safety solutions also necessitates an understanding of the factors that contribute to these incidents.[21] In a recent systematic review of 94 papers that report on the factors contributing to patient safety incidents in hospitals,[22] we identified 20 main causal domains. Our patient panel told us that patients would be able to comment on many of these causal factors (eg, teamwork, physical environment, availability of equipment and supplies, workload, lines of responsibility), particularly if they were well enough to monitor the ward/unit they were on and were presented with questions that tapped each of these areas.

Over the past year, we have worked with staff and patients at Bradford Teaching Hospitals NHS Foundation Trust to develop and test three strategies for patient incident reporting (telephone line, paper and pencil, or face-to-face) and we have developed a 40-item questionnaire from interviews with 33 patients about safety. The usability and acceptability of the questionnaire was further tested by using think-aloud methods with staff and patients. For more information about the research process, please see Ward *et al* (2011)[23].

Using the preferred incident reporting tool (face-to-face reports) and the questionnaire together, between September and December 2011, 280 patients (all ages, equal numbers of male and female responders and different ethnic backgrounds) provided safety feedback across 10 different wards within the hospital (across the surgery, medical, and women and children's directorates). This represented a consent rate of 85%, suggesting that a good majority of people were willing to participate.

The data (patient incident reports and ratings of performance across 12

causal factors) are currently being fed back to ward managers and sisters. Their response has been positive, welcoming a different approach to safety that captures the views of patients. However, there are still some possible threats to adoption of this patient safety intervention that must be addressed. These include:

- the need for these tools to be available to the broad population, taking account of different levels of literacy and different languages
- the need for the data collection process to be non-threatening to patients
- the need for the data collected to be linked in to other safety data (eg, staff incident reports, routinely collected data on falls, infections, etc.)
- the need to ensure that the intervention package is clear about how best to utilise the data to make a difference to safety (ie, links between causal factors and solutions)
- the process of connecting the intervention to current governance arrangements (eg, safety walkrounds) and the trust's membership group
- the inappropriate use of the tools to make comparisons across wards where clinical context is very different (eg, comparing an acute elderly admission unit and a maternity unit).

The next step in this work is to develop a patient safety intervention based on the use of these two tools which overcomes the threats to adoption listed above. To do this, we have convened an intervention development group consisting of an assistant medical director, ward manager, patient safety lead for a local trust, three patient representatives, a senior research nurse, a health economist, an expert in research methods, and two patient safety researchers. We have already begun to address some of the threats to adoption – for example, patient volunteers will collect data from patients (an approach supported by patients and staff), and the tools will be hosted on a tablet personal computer, which will allow the questionnaire to be delivered in different languages and in spoken and written format.

This research has been conducted in close collaboration with our patient panel, members of the public who we recruited to work with us on this five-year project. They have challenged us (eg, 'what happens when a safety incident is serious and needs to be reported to a member of staff immediately?'), advised us ('the majority of patients won't be able to say anything about hospital policies or training of staff'), and supported us (reviewing and simplifying a patient information sheet). They are now working with us to develop our intervention further.

Conclusion

Reducing preventable harm from patient safety incidents is proving to be a major challenge. Innovative interventions are required, and patients can make a contribution. Developing successful patient-led interventions is not without its challenges, though. Patients have to overcome their reluctance to cross the Rubicon of formally commenting on the safety of their care. Staff have to acknowledge the worth of patients' safety knowledge, their unique contribution, and, where necessary, the need to respond with action. For some, this may mean reconceptualising professional accountability. For all, it will mean a new and initially fragile partnership, but one that is based on shared learning and mutually beneficial outcomes. We are currently engaging in research at the cutting edge of this field and, in the coming months, will be grappling with these issues as we introduce new tools that encourage patients to provide feedback on the safety of their care, and encourage and empower staff to act.

To share your thoughts about this paper, please visit **www.health.org.uk/LawtArmTP**. *You can also follow the Health Foundation on Twitter at* **www.twitter.com/HealthFdn**

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The Health Foundation
90 Long Acre
London WC2E 9RA
T 020 7257 8000
F 020 7257 8001
E info@health.org.uk

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