The Health Foundation
Inspiring Improvement

Evidence scan:

Involving patients in improving safety

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Identify Innovate Demonstrate Encourage

Contents

Key messages

Much is being done to improve safety in healthcare. Patients themselves can help to safeguard their own wellbeing and promote change. This evidence scan describes ways that patients have been involved in improving safety.

The scan includes 75 empirical studies sourced from five bibliographic databases searched in September 2012.

The main approaches to involving patients in safety improvement include:

– collecting feedback retrospectively

– asking patients to help plan broad service change

– encouraging patients to help identify risks when they are receiving care.

There is little comparative information about the pros and cons of these approaches.

Providing feedback

We identified 32 studies about feedback. Evidence suggests that patients can provide useful feedback retrospectively about safety issues. The most common approaches include surveys or discharge feedback about safety incidents. Formal incident reporting systems for patients have been studied to a limited extent.

Planning change

There is less research available about proactively involving patients in planning to improve systems or services (nine studies). Some services have involved patients in planning committees, patient and public involvement groups or prospective surveys to encourage change.

Safeguarding individual wellbeing

The most evidence is available about initiatives to help patients take an active role in their own safety (34 studies). Examples include educational leaflets, videos or posters to help patients feel more confident questioning professionals about hand hygiene, comment cards to help identify individual safety issues and encouragement to tell staff if the patient has any concerns.

A number of studies have explored the extent to which patients and professionals feel comfortable with involving patients in safety. A key finding is that patients may feel more comfortable when they do not need to speak directly to a health professional about their concerns – patients do not want to appear to be challenging professionals or to be seen as difficult. The attitudes and support of professionals can go a long way to make patients more confident. Strategies to involve patients further may therefore need to concentrate on: ensuring that professionals have positive attitudes, are supportive and ask for feedback; that the infrastructure is in place to do something about patients' comments; and that patients feel able and encouraged to take part. In short, greater patient involvement may require changing the culture of healthcare so that patients and professionals are working as partners in a joint team.

1   Scope

In the UK, health services help one million people every day. But some people are also harmed by medications, infections or errors. A lot can be done to guard against such harms. This evidence scan provides examples of how patients have been involved in improving safety in healthcare.

1.1   Purpose

Patients and their carers are privileged witnesses of healthcare, at the centre of their treatment. Patients and carers therefore have a potential role to play in improvement[1] and have brought significant safety issues to the attention of health services in the past. However, much work in patient safety has focused on the role of healthcare professionals rather than patients.

Over the past 50 years there has been an increasing acknowledgement that healthcare can inflict harm as well as benefit and that many of these harms can be prevented.[2–7] Although strategies to reduce errors and adverse events focus mainly on changing systems of care and professional behaviour,[8–10] there is growing interest in involving patients in safety initiatives too.

This evidence scan describes research about the ways that patients have been involved in improving the safety of healthcare in the UK and elsewhere.

The scan addresses the questions:

– How have patients and carers been involved in improving safety in healthcare?

– Is there any evidence that patient involvement leads to improved safety?

1.2   Methods

The scan focuses on readily available research published in journals in the UK and internationally. It was completed over a two-week period in September 2012.

To identify relevant research, one reviewer searched five bibliographic databases for studies of any design published between January 1990 and September 2012. The databases comprised Medline, Embase, the Cochrane Library and Controlled Trials Register, Google Scholar and Web of Science.

Search terms included combinations of patient safety, improving safety, reducing risk, reducing error, reducing harm, patient, carer, patient-centred, patient involvement, patient-led, patient role, patients as partners, participation, patient report, patient incident reporting, error reporting, hand hygiene, self-report, engagement and similes.

To be eligible for inclusion, studies had to include empirical research. Articles that described approaches to involving patients in improving safety but did not contain empirical data were not included.

More than 5,000 articles were scanned. Seventy-five empirical articles met the inclusion criteria and additional contextual material was also summarised.

All of the evidence was sourced and compiled systematically, but the scan is not a systematic review and does not seek to summarise every study about this topic.

Findings were extracted from all publications using a structured template and studies were grouped according to key themes to provide a narrative summary of trends.

1.3   Scope

For the purposes of the evidence scan, 'improving patient safety' focuses on attempts to minimise or avoid errors, adverse events or harm to patients. The emphasis is on avoiding discrete and direct harms rather than the broader definition of patients being harmed by not receiving all of the care they are entitled to or would benefit from.[11,12]

The simplest definition of a healthcare adverse event or harm is a negative effect of care, whether or not it is evident to or impacts on the patient's wellbeing. Some studies differentiate between errors (mistakes or unintentional actions) and adverse events or harms (actions with some form of negative impact for processes, staff or patients). Some studies use these terms interchangeably and others have very specific

definitions of what they are measuring in terms of error or harm. In exploring how patients have been involved in improving safety, it was not necessary to have a precise definition of safety incidents. Therefore, the scan uses the definitions of patient safety, error and harm listed within individual studies.

For ease of summarising, initiatives were divided into three categories:[13]

– those where patients or carers retrospectively provided feedback about safety events (32 studies)

– those where patients or carers were proactively involved in planning changes to improve the safety of services or wider systems (nine studies)

– those where patients were proactively engaged in safeguarding their own individual care (34 studies).

General research about the extent to which patients viewed healthcare as safe was not included because the Health Foundation is undertaking other work on measuring patient insight and this review looked beyond highlighting that there is a problem.

1.4   Things to bear in mind

When interpreting the findings it is important to bear in mind several caveats.

Scope
Firstly, the scan is not exhaustive. It presents examples of readily available empirical studies. It does not purport to represent every study of this nature. The purpose is to give a flavour of available research rather than to summarise every study in detail.

It is also important to note that only studies explicitly focused on involving patients in safety improvement are included. A number of studies have explored initiatives such as shared decision making, involvement in quality improvement initiatives or patient and public involvement more generally. These initiatives may well have an impact on patient safety, but were not included in the scan unless the explicit primary aim was to improve safety.

Furthermore, there are many descriptions of initiatives to involve patients in safety, such as using patient stories in team meetings, seeing care through the patient's eyes or using feedback to guide improvement. Such descriptions were not eligible for inclusion in the evidence scan unless they were based on empirical research. This means that there may be many types of patient involvement taking place that are not included here, merely because there is little empirical research published about them.

Quantity of research
Another important point to note is that there are relatively few studies that provide specific details about how patients were involved and the impact of this involvement. For instance, there is little research available about how patients have been involved in proactively planning service development. The relative pros and cons and the cost effectiveness of various strategies is also uncertain.

Quality of research
There are some issues with the quality of the studies included. Many of the studies are small and the methods used mean that it is not possible to draw conclusions about effectiveness or other outcomes.

Making comparisons
Finally, it is difficult to make comparisons between studies because differing definitions of patient safety may have been used and because the initiatives tested vary greatly. The studies also took place in differing healthcare contexts. Things that have worked well in North America may not be easily transferrable to the UK – and things that work well in hospital may not be immediately adaptable to primary care.

The methodological issues and study differences limit the extent to which we can suggest that one approach to involving patients in safety improvement is more effective than others. Therefore, the scan concentrates on giving examples of how patients have been involved, rather than trying to draw conclusions about the most effective methods.

2 Providing feedback

This section provides examples of how patients have given feedback retrospectively about safety issues as a way to support improvement.

The strategies for engaging patients in improving safety can be viewed along a continuum, from those that are relatively passive and retrospective to those that are more proactive. Approaches that use retrospective feedback about patient experiences fall at one end of the continuum. We identified research about two main approaches in this regard.

– Initiatives where professionals or managers themselves use patient experiences or feedback as a tool to spark professionals' own ideas about improvement.

– Asking patients to provide information about their experiences or safety events, which is then used to guide improvement.

Thirty-two studies are summarised in this section.

2.1 Tools for professionals

Examples of where professionals have used patient views or roles as a tool to spark their own improvement ideas include:

– using written or videoed patient stories to encourage discussion in team meetings or board meetings[14]

– simulated patients such as written scenarios or actors or lay people taking part in activities or role plays[15]

– considering issues from the patient point of view, with professionals attempting to put themselves into this role.[16]

Although such initiatives are commonly used, there is little empirical research evaluating their effectiveness.

Taking on patient role

Sometimes professionals attempt to take on the patient role or to think about things from the patient perspective. This does not engage patients *per se,* but aims to help professionals think about patient safety in a different way.

For example, in England 179 medical students were asked to imagine themselves as patients. They were surveyed about three types of interactional behaviours (asking factual or challenging questions, notifying doctors of errors, notifying nurses of errors) and three non-interactional behaviours (choosing a hospital based on the safety record, bringing medicines and a list of allergies into hospital, reporting an error to a national reporting system). Medical students' willingness to participate in safety activities was affected by the action required and whether the patient was engaging with a doctor or a nurse. Students were least willing to ask challenging questions to doctors and nurses and to report errors to a national reporting system. Encouragement from doctors and nurses increased willingness to participate in safety behaviours.[17]

Researchers in the US compared different ways to motivate health professionals to wash their hands. They compared the effectiveness of signs about hand hygiene that emphasised professionals' personal safety ('hand hygiene prevents you from catching diseases') or patient safety ('hand hygiene prevents patients from catching diseases'). Measuring the amount of soap and hand sanitising gel used and observing professionals' behaviours found that hand hygiene among health professionals improved when they thought about the implications for patients but not when they were reminded of the implications for themselves.[18]

Simulated patients

Another approach is to use simulated patients such as actors or lay people taking part in activities with professionals or using hypothetical patient case studies or scenarios. For instance, simulated patients were used in the US to help leaders make decisions about investing in safety initiatives. Leaders took part in scenarios using simulated patients as part of decision-making projects. Research found that this worked well to show the human impact of decisions.[19]

Simulated clinical environments have been found to be useful in medical education, by helping professionals to role play situations and think about things from other perspectives.[20,21]

Patient stories

Another slightly more active way to involve patients is to use patient stories as a component of safety improvement initiatives. For example, the US Institute for Healthcare Improvement's 'Boards on board' programme suggests that having written or videoed stories or asking patients to attend a board meeting to describe their experience can put a human face on safety issues and encourage healthcare managers to promote change.[22] While this is becoming a more common practice, little published research is available that evaluates impacts.

All of these strategies are limited in the extent to which real patients and their families are involved – and the degree to which they engender change remains uncertain. While professionals and managers may say patient stories or role plays help them to think about things from a different perspective, there is little research about whether this results in improved processes and increased safety outcomes.

2.2   Retrospective feedback

Moving along the continuum of patient involvement, patients have been asked to provide one-off feedback about their experiences of safety incidents. Methods to gain feedback retrospectively include:

– surveys about safety events[23]

– interviews[24]

– incident reporting systems[25]

– online tools.[26]

Surveys

There are numerous examples of surveying patients to support change. For example, researchers from Spain examined the frequency of adverse treatment events reported by primary care patients. Telephone surveys were conducted of 15,282 patients from 21 primary care clinics. Of these, 18% of adults and 14% of children reported adverse or unexpected reactions to treatment. Key findings about the detrimental impact of consultation length and insufficient information about medication risks was used to improve safety processes in these primary care practices.[27]

This type of survey is much more common in hospitals and is often undertaken as part of multi-faceted improvement programmes. For example, a hospital in England used benchmarking, patient feedback and Lean approaches to improve quality and safety. Gaining feedback from patients in a structured way and promoting staff ownership of safety improvement processes reportedly helped to raise standards of care.[28]

Elsewhere in England, 80 medical and surgical patients from one hospital were surveyed prior to discharge to assess reports of errors or problems in their care. Patients' medical records were also reviewed. An average of three undesirable events per person were reported. These included interpersonal problems, medical complications and healthcare process problems. Patients identified 83% of the safety events that were reported in the medical records. Patients also reported events that were not recorded in the medical records. This demonstrates that patient surveys can bring things to the attention of teams that they may otherwise be unaware of.[29]

In Japan and Denmark patients were surveyed about their views of adverse events and the actions of healthcare staff involved. Patients tended to think that doctors would hold back on providing information to patients about a medical accident. This feedback helped to raise awareness among professionals and develop new safety protocols about minimising risk.[30]

Other researchers in Japan compared patients' and professionals' identification and reporting of patient safety incidents. Patients at six hospitals were surveyed. Nine per cent of outpatients and 11% of inpatients experienced 'uneasy–dissatisfying' or 'unsafe' events. Around one-third had reported the unsafe events to professionals. Only 17% of unsafe events reported by inpatients were identified by in-house reporting systems of adverse events and near misses. The team concluded that patients may be a good source of information about adverse events in hospital but may not feel confident to report incidents to health professionals.[31]

A number of studies have used one-off surveys with patients to collect information about safety issues, which then feed into improvement initiatives. A large-scale example analysed the predictors of medication error in Australia, Canada, Germany, New Zealand, the Netherlands, the UK and the US based on a survey of 11,910 people, of whom 11% had experienced a medication error in the past two years. Analysis of people's feedback found that predictors of medication error included poor coordination of care, cost barriers to medical services or medicines, seeing multiple specialists, multiple long-term conditions, hospitalisation and multiple A&E visits.[32]

Attempts have also been made to move away from surveys for one-off research projects towards a more regular feedback and improvement process. In Switzerland a survey has been developed to help collect feedback more routinely from hospital patients. The survey was developed by a team of experts and patients. It was tested with 125 patients at two hospitals and 18 patients who reported an incident were then interviewed. Of those surveyed, 23% reported some concerns about their safety. About three-quarters reported experiencing some sort of safety incident such as poor hand hygiene, allergic drug reaction, unavailability of documents and infection. Many patients reported problems and incidents related to food and dietary intake. However, patients sometimes felt reluctant to report undesirable events. They often did not communicate about errors or near misses with staff and some patients even developed strategies to improve their safety but did not disclose these to staff.[33]

The same team examined the frequency of patient reported medical errors by surveying 1,306 people. Eleven per cent reported at least one error in their care in the previous two years. Poor coordination of care was frequent.[34] It is hoped that the survey will be incorporated into routine data collection after hospital discharge.

Feedback from families at the time of discharge is another mechanism for gaining information about patient safety. In Canada, all families of children discharged from one hospital over a one-year period were asked to complete a survey about adverse events and near misses during the hospital stay. Half of the adverse events reported by families were found to represent legitimate patient safety concerns. Only 2.5% of the adverse events reported by families were also reported by professionals. The extent to which professionals reported events was compared with professionals' reports from the previous year to see if professionals changed their behaviour when they knew families would be reporting. There was no significant increase in reports by professionals when they knew families would also be providing feedback.[35]

There is work underway to increase the robustness of systems to collate and use patient and carer feedback for safety improvement. For instance, in the UK a team is developing a patient survey to measure organisational safety. Researchers have reviewed literature and undertaken focus groups and interviews to develop a survey tool with about 60 items spread across ten domains.[36]

Work is also underway to examine the relationships between organisational quality improvement systems, patient empowerment, organisational culture and professionals' involvement with the quality and safety of hospital care throughout Europe. This includes examinations of patient involvement in safety initiatives.[37]

Incident reporting

Incident reporting systems are another way of gaining feedback from patients about their experiences.[38]

In the UK, researchers examined patient safety incident reporting systems based on a survey of 351 risk managers in England and Wales, three case studies and an audit of clinical risk staff newsletters from 90 organisations. Most incident reporting systems did not include feedback from patients themselves. The team concluded that incident reporting systems need to be more robust and be supported by patient and professional education.[39]

Although they are uncommon, there are examples of incident reporting systems set up specifically for patients. One hospital in the US has tested a process for gaining feedback from patients about critical incidents. Patients were asked to give feedback about events also reported by professionals so that various perspectives were available about the same incident. This worked well to inform error prevention strategies.[40]

Researchers in Sweden examined all the patient safety incidents reported in hospital A&E departments over a one-year period. Data were analysed from national authorities, patient advisory committees and local incident reporting systems. The study found that patients reported a greater number of incidents to national authorities than did professionals and that incident reporting by patients could add extra details to help improve safety.[41]

Analysing complaints systems can unearth patient safety incidents. The UK has a system that allows patients to make official complaints against GPs without seeking compensation. The Netherlands uses a similar system. An analysis of 250 complaints from this Dutch system found that many related to a wrong diagnosis, insufficient care or a wrong treatment.[42]

Another study examined methods of patient reporting of adverse drug reactions in 11 countries. Data were collected using telephone interviews and field visits. There was wide variation in the schemes. Australia set up patient reporting schemes in 1964 whereas these were introduced in Norway as recently as 2010.

Most countries have three ways for patients to report reactions: a paper form, an online form or by telephone. Most organisations do not give personalised feedback to patients making reports. None of the organisations seek medical confirmation for each patient report. There was no comparative information about the effectiveness of the varying systems.[43]

Research about incident reporting systems more broadly suggests that, in order to be effective, such systems need to have an inbuilt feedback mechanism. There is wide-scale implementation of incident reporting in healthcare, but evidence suggests a need for better analysis and use of information to improve safety. Reporting, analysis and investigation should result in timely corrective actions that address vulnerabilities in existing systems. Providing actionable feedback that visibly improves systems is important for promoting future reporting.[44] These findings are likely to apply equally to incident reporting systems based on patient feedback.

Interviews

Interviews have been used to good effect to collect one-off information from patients that is then fed into improvement initiatives.[45] For instance, in England researchers examined patient perceptions of errors in care for people with long-term conditions. Interviews with 33 people with long-term conditions identified errors of access such gate-keeping and problems gaining access to primary care consultations, diagnostic tests and specialist care. Potential harms included delayed diagnosis or delayed delivery of specialist care. Errors of interpersonal care included patients' perceptions of not being taken seriously. This included perceived failure by professionals to respond to reports of adverse drug reactions or accounts of painful symptoms. Errors were also noted at transitions between primary and secondary care, including failures of information transfer and communication.[46]

A team in Spain examined whether patients are a good information source about the occurrence of adverse events. Twenty-eight patient interviews were combined with record review; 10 patients had experienced an adverse event and 18 had not. The researchers concluded that patients can contribute to identifying adverse events affecting them with reasonable accuracy.[47]

A group in the US examined whether patients who reported poor service quality were at increased risk of experiencing adverse events and medical errors. Data were collected using 228 patient interviews and chart reviews. Those who reported deficiencies in quality were more likely to have experienced an adverse event, close call or low-risk error. Poor coordination of care was a risk factor for adverse events.[48]

However, other studies have questioned the value of interviews with patients for identifying safety issues. One study compared four methods of detecting medication misadventures at one US hospital: resident doctors' reports during their morning conference, nursing reports during shift changes, patient reports at discharge interviews and standardised medical record review. All methods were compared with the hospital's electronic medication misadventure reporting system. Forty-seven per cent of admissions experienced at least one medication misadventure. There was little overlap among the four reporting methods. No single method captured all incidents and only 20% were reported by more than one method. Fifty-one per cent of incidents were identified by medical record review, 11% by patient interview, 9% by doctor reports and 8% by nurse reports. Of five life-threatening adverse drug events, all were preventable but only one was reported by a patient at discharge.[49]

Root cause interviews

Root cause analysis with patients has been found to identify potential causes of medication errors in primary care. In the US, 22 patients were interviewed about the perceived causes of adverse drug events in primary care. Diagrams were used to map the root causes and information was displayed as a composite causal diagram. Patients suggested 164 causes of adverse drug events in eight categories: medication non-adherence, prescriber–patient miscommunication, patient medication error, failure to read medication label/insert, polypharmacy, patient characteristics, pharmacist–patient miscommunication and self-medication.[50]

Online tools

Online tools are another method for gaining feedback from patients about safety issues. In the US, an automated health assessment system for patients has been used to identify adverse events. Over a two-year period, 44,860 adults entered information online. People were asked to describe any adverse events experienced during the previous year. Around 1% of patients reported possible adverse events. The proportion of adverse events was eight times higher for patients with the greatest burden of illness than for those with the least. Experts thought around 9% of adverse events were serious enough to warrant legal recompense.[51]

Researchers from the Netherlands described the use of an online community to help understand patient safety issues when using an existing drug for a different condition (that is, a condition for which it is not usually prescribed). The online community had 82,000 members and helped users make treatment decisions, manage symptoms and improve outcomes. Members entered demographic information, treatment, symptoms, outcome data and treatment evaluations that were then compiled into reports about various treatments. Data entered by patients were used to evaluate the potential off-label uses of medications, including side effects. This process reportedly worked well to identify common side effects.[52]

Overall, the evidence from 32 studies about gaining patient feedback through surveys, interviews, incident reporting and online tools suggests that these approaches can provide useful data that may not be available from other sources. However, the impact of these approaches depends largely on what is done with the information after it is collected – and whether a structured approach is taken to create tangible changes in patient safety. Less interactive forms of feedback such as surveys and online tools may be unlikely to result in significant changes to patient safety unless there is a committed team actively using the information to push forward with improvements.

3 Planning improvement

This section provides examples of how patients have been proactively involved in planning safer services or systems.

Some argue that it is essential to put patients at the heart of a team-based approach to the prevention and management of errors, but that this will only happen when staff are motivated by real rather than hypothetical needs.[53] If patient safety engagement programmes are to work well for people from diverse socio-economic, demographic and ethnic groups, it is important that they are informed by the perspectives and experiences of patients from a wide variety of different backgrounds.[54]

Patients have been proactively involved in improving the safety of services and systems. However, there is limited empirical research about the impact of these initiatives. Nine studies are described in this section.

3.1   Service development

Some of the research available about engaging patients in service development to improve safety involves one-off data collection from patients rather than ongoing involvement. The difference between this and the feedback described in the previous section is that feedback initiatives involve collecting information about events that have already happened, whereas the approaches covered here focus on prospectively collecting information to support specific developments.

As an example, researchers in England interviewed 14 patients in the community and in nursing homes to explore how their perceptions of safety could be used to reduce safety incidents within organisational care transfers. Patients said that in order to feel safe they wanted communication, responsiveness and avoidance of traditional safety risks. Ideas about communication and responsiveness were used to develop new strategies to guard against safety incidents.[55]

As well as one-off involvement, methods have been tested to engage patients over a longer period. For instance, researchers in the US tested engaging patients in improving the accuracy of medication lists in the outpatient setting. Patients from five clinics helped to develop and test strategies such as education, personal medication lists and medication bags. Compared with a group of 68 non-random control clinics, the intervention clinics had more accurate medication lists.[56]

One health centre in England set up a number of initiatives to help patients participate in developing better quality and safer services. Dilemmas surrounding patient participation included ways to reward volunteers, how doctors and patients can share knowledge, how participation is affected by professional boundaries and whether or not a regular group meeting is the best way to involve patients in decision making.[57]

In the UK, patients have been involved to a limited extent in collaborative improvement programmes across multiple healthcare organisations.[58]

In Ireland, seven patients from the haemophilia service at one hospital took part in a programme to improve quality and safety. Patients took part in discussion groups to identify issues of concern. The haemophilia care team worked on improving these issues and patients then took part in another discussion group to help address outstanding issues. A patient panel was developed so there was an ongoing partnership.[59]

Many policymakers, managers and practitioners advocate the value of involving patients in planning and improving health services, but the extent to which patients are involved is somewhat limited. There may be a number of barriers to engaging patients in higher-level safety development. Researchers in Canada explored stakeholder beliefs about patient participation in the selection of safety and performance indicators. Thirty people with cancer and health professionals from two hospitals were interviewed. Patients and professionals thought that patients, not members of the public, should be involved in selecting indicators. They favoured ongoing interactive methods such as taking part in committees rather than single passive efforts such as surveys. Health professionals and older patients

thought that patients should have an advisory rather than decision-making role. The researchers concluded that variable patient interest and the attitudes of health professionals may act as barriers to patient involvement in planning for quality improvement and safety.[60]

However, the more patients are engaged in planning and developing safety improvements, the more accepted this may become among both patients and professionals. Researchers from England examined the impact of engaging patients in service development on healthcare professionals' and service users' attitudes toward engagement. Focus groups with patients and professionals before and after an intervention where lung cancer teams were supported to engage with patients and family members found that staff and patients who participated had more positive attitudes towards involvement than those who did not participate.[61]

Hazard analysis

In England, hazard analysis has been tested as a way of involving patients and staff in identifying safety issues across care pathways. Hazard analysis takes into account the views of users (staff and patients) to determine where potential hazards may lie. A supported discharge programme for chronic obstructive pulmonary disease (COPD) was used as an example. Data were collected from care process mapping, interviews with patients and staff and a Delphi study with staff. Safety concerns were mostly raised in relation to communication between teams, difficulties in accessing hospital records, information transfer to primary care and failure to communicate medication changes to primary care.[62]

3.2   Involvement in education

While current evidence in this field is limited, there is emerging interest in how to involve patients in educating professionals about safety. For example, a randomised trial is underway in England to test incorporating a patient-led component into the mandatory training of junior doctors about patient safety. Patients who experienced a safety incident in the NHS were recruited and trained to talk with small groups of trainees about their experiences. The aim is to increase the awareness of patient safety issues amongst doctors.[63]

Overall, the evidence about involving patients in planning or developing safer services is sparse. The nine studies included here suggest there are limited empirical descriptions of how patients have been involved in this way and even fewer published evaluations of outcomes.

4 Safeguarding individual wellbeing

This section provides examples of how patients have identified issues in their own care to safeguard their individual wellbeing.

The greatest quantity of research about involving patients in safety improvement focuses on patients being proactive about minimising harm or errors in their own care. The majority of work in this area focuses on the hospital environment.

Examples of initiatives include:

– leaflets and videos to encourage patients to ask questions or raise issues with professionals[64]

– one-to-one conversations or education sessions to help patients feel more comfortable raising issues or to encourage people to self-monitor their medications[65]

– broader educational campaigns to raise awareness.[66]

A number of studies have also examined the things that may facilitate or act as barriers to patients getting involved in safeguarding their wellbeing. Thirty-four studies are summarised in this section.

4.1 Educational tools

Studies suggest that educational tools such as leaflets or videos may help patients feel more motivated or comfortable to improve patient safety.

Leaflets

Researchers from England examined patients' attitudes towards a leaflet and video designed to encourage patient involvement in safety-related behaviours. Of the 160 patients from one hospital who took part, 80 watched a video and 80 read a leaflet. Both the video and leaflet increased people's reported comfort in engaging in some safety-related behaviours, however patients questioned whether watching a video or reading a leaflet would help to reduce medical errors.[67]

In Switzerland, 1,053 patients and 275 professionals were surveyed about a patient safety advisory leaflet used in three hospitals. Ninety-five per cent of patients and 78%

of professionals believed that hospitals should educate patients about how to prevent errors. Both groups thought the leaflet was useful.[68]

On the other hand, researchers in Scotland interviewed 50 professional and patient key informants and examined five leaflets advising patients what they can do to avoid errors and harms in their care. They found that little is known about the effects of safety leaflets for patients but there are some grounds for concern. There was a lack of attention paid to patients' perspectives when developing the five leaflets and little was included about what professionals should do to ensure patient safety. Patients were given little practical support to carry out the recommended actions and thought that the advice about checking on or challenging health professionals' actions was problematic.[69]

Videos

The benefit of educational videos has also been explored. A team in England examined patients' and professionals' views about a video promoting patient involvement in safety-related behaviours. Surveys were completed by 201 patients and 95 health professionals before and after watching the video. After watching the video patients were more positive about asking doctors and nurses if they had washed their hands and said they would be more likely to notify them about issues to do with personal hygiene. There were no changes in whether patients would tell staff if they had not received their medication or if they were in pain or feeling unwell. After watching the video doctors and nurses were more willing to support patient involvement in asking about hand hygiene.[70]

Education sessions

Other forms of educating patients about safety involvement have been tested. For example, one US organisation ran patient education sessions to engage people in safety. The focus was on helping patients

monitor their own symptoms and medications to ensure no adverse events. This was found to be feasible. Information about impacts is not available. [71]

A hospital in the US developed a patient education programme to help reduce bloodstream infection from central venous catheters. This worked well, but only as part of a broader initiative to improve safety through staff education and guidelines.[72]

Educational campaigns

Other studies have explored more general educational campaigns, such as asking professionals to speak to patients one-to-one or in small groups. A review of 21 studies examining patients' attitudes toward engagement in error-prevention and the effectiveness of efforts to increase patient participation found that patients are generally positive about engaging in their safety at a general level, but their actual behaviours vary considerably. Self-efficacy, preventability of incidents and effectiveness of actions influence patients' intention to engage in error prevention. The review concluded that some interventions in clinical settings have been effective but evidence about the effectiveness of patient educational campaigns is lacking.[73]

However, there are some positive trends. In Canada, an educational campaign provided five tips to encourage hospital patients to be more involved in monitoring their safety, such as bringing medicines to appointments and asking questions. The campaign was found to be feasible and well-regarded.[74]

In Switzerland, a programme was set up to encourage patients to remind hospital professionals to wash their hands. A survey of 194 patients found that one-third thought that if patients reminded professionals about hand hygiene, then hospital acquired infections would reduce. However, three-quarters said they would not feel comfortable asking a nurse or a doctor to clean their hands. Receiving an explicit invitation from a professional to ask about hand hygiene doubled people's intention to ask a nurse or doctor.[75]

Educational campaigns have also been tested in primary care. In Canada, a poster and brochure for patients and a toolkit for professionals and organisations was tested in six primary care clinics before being rolled out to 65 sites. The posters served as a symbol that dialogue about safety issues was encouraged. Tools were available in 15 languages and provided patients and family members with three key questions to ask in healthcare consultations, tips on how to ask questions and room for

notes and writing down medications.[76] The programme was feasible and was thought to be effective enough to roll out, but empirical data about outcomes is lacking.

Supporting families

Very little work has been undertaken to explore how family members or carers may usefully be involved in patient safety. Some small case studies suggest that this could have potential. For example, one US hospital involved family members in improving patient safety. Some units had collaborative rounds, which family members were able to participate in. Family meetings were used with multimedia sources to review patient conditions, results and care plans. There was a focus on engaging carers to identify safety issues relating to their family member.[77]

4.2   Feedback mechanisms

In addition to educational initiatives, some organisations have tested methods for generating immediate feedback from patients about their ongoing care. In Sweden, a hospital tested using a 'tell us' card to help patients report on quality and safety. Patients were asked to write on the cards what was most important for them during the day or just before discharge. This is different to the retrospective feedback mechanisms explored in section 2.2 (page 7) because this approach asked patients to provide immediate regular feedback about issues relating to their current care rather than reporting on incidents they had potentially experienced some time ago. The aim was more active participation in an ongoing manner. In effect, for patients who may not feel confident verbally raising an issue about their care with staff, this provided a written alternative. In wards using the cards, patients were more likely to think they were involved in decisions about their nursing and medical care.[78]

4.3   Impact on safety

There is some evidence that when patients participate in safeguarding their own wellbeing, the quality of care received is better. Researchers from the US examined the extent to which people in hospital participate in their care, and the link between patient participation and quality and safety. Data were collected using a telephone survey with 2,025 recently hospitalised adults and medical record review of 788 of these people who consented. Most people said they participated to some extent in their care or safety. High levels of participation were associated with more favourable ratings from patients about the hospital's quality of care. Record review found that greater reported participation was

associated with fewer adverse events. Patients with high participation in their own care were half as likely to have one or more adverse events during the admission.[79]

However, overall evidence about the effect of building such engagement is limited.[80] A systematic review of 14 studies and one review of interventions to promote patient involvement in safety found that approaches that have been tested include feedback to inform the management plan, ensuring safe delivery of treatment (by health professionals and by patients) and making systems safer. Most studies focused on monitoring and ensuring safe delivery of medications by patients. The overall quality of evidence was poor. Interventions that may be associated with improved patient safety included ensuring safe delivery of treatment by patients (for example, self-management of anticoagulation, easy-read information leaflets, nurse-led education to promote self-medication in hospital, patient package insert using lay terminology) and informing the management plan (for example, individualised teaching plan by nurse and pharmacist counselling).[81]

Another review examined the involvement of patients in efforts to promote their own or others' safety. The articles studied included: 437 descriptions of interventions, 299 opinion pieces and 42 discussions or studies of patients' willingness and ability to adopt safety promoting behaviours. The review found little evidence of the impact of patient involvement initiatives on safety outcomes and few studies examined patients' willingness and ability to take part in safety-oriented behaviours. The review suggested that there are three broad routes by which patients' actions might contribute to their safety.

– Helping to make sure that their treatment is appropriate for them (informing the management plan).

– Making sure that treatment is given as planned and according to appropriate protocols (monitoring and ensuring safe delivery of treatment).

– Helping to identify and reduce problems and risks within healthcare systems (informing systems improvements).[82]

The best way to support patients to participate in this manner remains uncertain.

4.4   Facilitators and barriers

A number of studies have examined factors that may help or hinder patients from safeguarding their wellbeing.

Reviewers from England examined 68 studies about factors that support and deter patients from participating actively in reducing clinical errors. The four factors influencing whether patients were engaged in their own safety were illness severity, individual cognitive characteristics, the patient–professional relationship and organisational factors. Illness and patients' perceptions of their role and status as subordinate to that of clinicians were the most important barriers to their involvement in error reduction.[83]

Patient views

Patients often say they are willing to be more actively involved in safeguarding their wellbeing, but this may vary depending on demographic and disease characteristics.[84]

The attitudes of patients may influence their involvement in safety behaviours. US researchers explored patients' perspectives of their role in patient safety. They surveyed 491 people who had been admitted to one of three hospitals in the past three months. Twenty-three per cent of people thought that patients should follow instructions given by care providers. A smaller percentage thought that patients should ask questions and become informed about their conditions and treatments. Patients thought they should be able to trust that they are being provided with competent care rather than assuming a leadership role in their safety. In other words, some patients may assume that healthcare is safe and not want to take responsibility for safety issues.[85]

Elsewhere in the US, interviews with 21 stakeholders explored patient-centred safety initiatives. In order to get patients more involved, good communication and strong relationships were needed. Patients trusted and had various expectations about the behaviour of professionals and did not want to 'rock the boat'.[86]

In a telephone survey, 2,078 people discharged from 11 US hospitals were asked about their views of taking part in patient safety initiatives. Of these, 91% believed that patients could help prevent errors. Patients were comfortable asking about a medication's purpose, general medical questions and confirming their identity. They were uncomfortable asking medical providers whether they had washed their hands. The researchers concluded that education to increase comfort with error prevention may be necessary to help people become more engaged in patient safety.[87]

In Japan, a survey at six hospitals found that only one-third of people who had experienced an unsafe event had reported this to a health professional. Patients often felt that events were self-evident or easily identifiable by healthcare staff so did not report them. In other cases, they did not expect their report to bring any improvement or felt that reporting would create some disadvantage in their medical treatment.[88]

Researchers in Switzerland examined factors influencing chemotherapy patients' plans to engage in activities to reduce medical errors. The survey involved 479 patients from one hospital. Attitudes, the extent to which patients thought they had some influence, the perceived expectations of health professionals and the views of family members all influenced people's intentions to engage in error monitoring and reporting.[89] The fact that people felt very unwell and staff time pressure were barriers to getting involved.[90]

Reviewers from Switzerland examined the facilitators of patient participation in safety. Patient-related factors such as acceptance of a new patient role, lack of medical knowledge, lack of confidence, co-morbidity and sociodemographic characteristics were all found to affect people's willingness to participate in safety activities.[91]

In England, 80 patients from one hospital were surveyed about reminding healthcare staff to wash their hands and notifying healthcare staff if the patient is not wearing a hospital identification bracelet. The extent to which patients felt they had influence, perceived norms and the perceived severity of the safety issue were the strongest predictors of patients' intentions to remind professionals about washing their hands or inform them if patients were not wearing an ID bracelet. In other words, if patients understand why a safety behaviour is beneficial, they are more likely to think it is acceptable to participate.[92]

Teams are beginning to recognise that patients may not always feel confident taking part in safety activities and research is beginning to explore this further. In the US, a survey has been developed to measure the extent to which older people feel comfortable taking part in patient safety behaviours.[93]

Support from professionals

The extent to which health professionals are supportive may make a significant difference.[94] A team in England examined ways to involve patients in reducing healthcare associated infections. Healthcare associated infections affect at least 300,000 patients annually in the UK and may be largely preventable. Appropriate hand hygiene by health professionals has been found to be an effective prevention measure, but compliance with good practice tends to be low. The UK National Patient Safety Agency surveyed the public, hospital patients and health professionals from five hospitals about attitudes towards hand hygiene. Fifty-seven per cent of the public were unlikely to question doctors about the cleanliness of their hands because they assumed that doctors had already cleaned them. Forty-three per cent of patients said professionals should know to clean their hands and trusted them to do so and 20% said they would not want professionals to think that patients were questioning their ability to do their job correctly. Some professionals also thought that being questioned would be undermining. However, most professionals said that healthcare associated infections could be reduced if patients asked professionals if they had cleaned their hands before touching them. Patients and professionals thought that it could be useful to invite patients to remind professionals about hand hygiene by providing individual alcohol based hand rub containers and actively supporting an 'it's ok to ask' attitude.[95]

Another team in England examined 80 medical and surgical patients' willingness to take part in safety-related behaviours such as asking factual or challenging questions or notifying doctors or nurses of errors or problems (interactional behaviours) and behaviours such as choosing a hospital based on the safety record, bringing medicines and a list of allergies into hospital and reporting an error to a national reporting system (non-interactional behaviours). Patients' reported willingness to participate in safety behaviours was affected by the action required by the patient and whether the patient was engaging with a doctor or nurse. Patients were less willing to participate in challenging behaviours, but if doctors and nurses were encouraging, this increased patients' willingness to ask challenging questions.[96]

The same team found that patients were more likely to be willing to ask nurses challenging questions than doctors. The instructions a doctor gave a patient could increase the patient's willingness to challenge doctors and nurses. Women, educated patients and employed people were more willing to ask safety-related questions.[97]

It seems that the potential for patients to contribute to their safety by speaking up about their concerns depends on the quality of patient–professional interactions. Researchers in Scotland examined patients' and family members' experiences of speaking up about safety concerns, conducting 71 interviews and 12 focus groups. Participants said they had identified various safety concerns during their care and had sometimes spoken

up about these as they occurred. People's inclination and ability to speak up were shaped by how serious they thought the threat of harm was, the perceived importance given other patients' needs and staff workloads and priorities, their confidence about their grounds for concern and the likely consequences of speaking up. People's assessments were influenced by the way staff behaved and related to them. People who had spoken up about concerns reported varying responses from professionals. Some responses averted harm or provided reassurance, but others exacerbated anxieties.[98]

Similar trends are evident outside the UK. Researchers from Switzerland examined chemotherapy patients' experiences of drug administration safety in a survey of 479 patients receiving care at one hospital. Seventy-seven per cent believed that patients can help to prevent errors. Patients thought that staff were committed to providing safe care but that staff did not support patients to be involved in safety. One-quarter did not think that staff instructed them to watch for and report errors. Patients were more likely to be involved in safety behaviours if these behaviours were compatible with traditional patient–provider relations, if they thought there was a high risk of error and if they believed that patient involvement could make a difference.[99]

Given that the attitudes and behaviours of professionals are so important in engaging patients, some studies have explored staff values in this regard. For example, researchers in Switzerland examined cancer nurses' perceptions and experiences with patient involvement in chemotherapy error prevention. Focus groups with 11 nurses working on wards or in outpatient clinics found that nurses had positive attitudes about patient involvement in safety behaviours. Nurses thought that engaging patients was challenging and that there were also organisational barriers. They used a variety of strategies and patterns of language to engage patients and switch between participative and authoritative models of education.[100]

In surveys of 1,141 other health professionals from 12 hospitals, researchers from Switzerland also examined attitudes towards patients' involvement in safety-related behaviours. Each survey included two vignettes that described a potential error, a patient's reaction to that error and a professional's response to the patient. Professionals generally supported patient involvement in safety activities. However, anticipated effects on the patient–professional relationship were less positive. Professionals had more favourable attitudes towards patients intervening about a medication error than about hand sanitation.[101]

Reviewers found that acceptance and promotion of patient participation by health professionals is influenced by the desire to maintain control, lack of time, personal beliefs, type of illness and training in patient–caregiver relationships. Social status, specialty and ethnic origin also influence patients' and health professionals' acceptance.[102]

In Spain, 764 primary care patients and 327 GPs were surveyed about patient involvement in decision making and safety. Many patients preferred to take a passive role. Only one in five doctors thought they could support patients to be more involved in decisions and patient safety. The information provided by GPs did not seem to contribute to patient involvement in safety. Patients were not normally informed about medication interactions, precautions and potential complications.[103]

Overall, the evidence from the 34 studies summarised in this section suggests that when patients take an active role in safeguarding their own wellbeing, there can be changes in processes such as improved hand hygiene or increased ID checking by health professionals. Strategies tested include leaflets, videos, education sessions and promotional campaigns. While these strategies have been found to increase patients' intention to be involved in some instances, barriers may get in the way. These barriers include patients' attitudes, fears and demographic characteristics and the extent to which patients feel that professionals would welcome their engagement.

5   Summary

Patients can be an integral part of the care team, working in partnership with professionals to improve the safety of healthcare.

5.1   Key strategies

Over the past decade there has been increasing momentum to develop greater patient and public involvement in health services. People now have a greater expectation that they will be involved in their care and in ensuring the safety of their care. This may be due to social changes and government policy promoting public and patient involvement in healthcare.[104]

The drive to increase involvement in patient safety may be an important way of building a safety culture. However, progress has been slow in involving people in their own safety and in the development of safer services. Underlying factors that support and hinder involvement may be related to power inequities and control.[105]
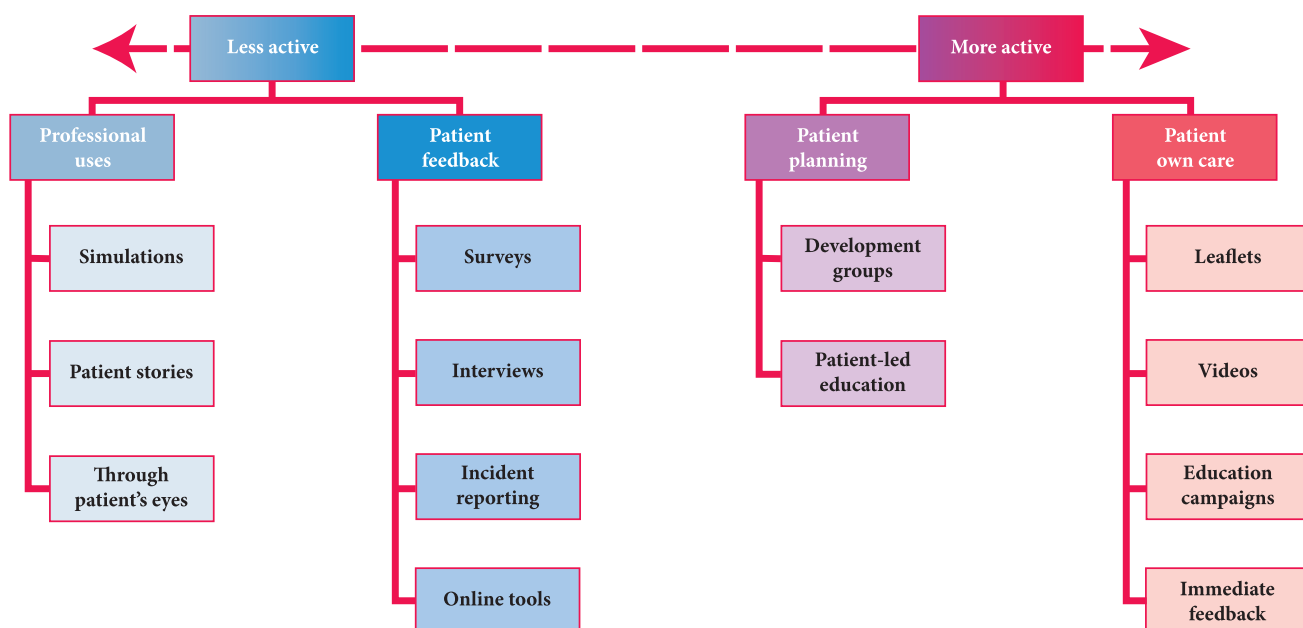
Historically, safety improvement initiatives have not emphasised the role of the patient or carer. This is beginning to change, but there is much work to do before the benefits of involving patients and carers are fully harnessed.

Some services have introduced patient stories at meetings to highlight safety issues or sought feedback from patients about errors or omissions in their care as a platform for improvement. But there has been much less work done to actively seek direct patient involvement in diagnosing issues, developing solutions or supporting safer management of their own care.

The level of involvement ranges along a continuum of quite passive strategies to those that are more proactive (see Figure 1).

At the more passive end of the scale, managers and health professionals have used feedback from patients to help guide improvement initiatives. This may include using written or videoed patient stories in team meetings or board meetings, activities to help professionals 'see through patients' eyes', or role play or simulations with patients. These activities all involve managers and professionals maintaining control of the process and inserting a small amount of information purportedly from the patient perspective.

Figure 1: Continuum of strategies for patient involvement in safety

Moving along the continuum, patient feedback has been used more explicitly to support change. This includes surveys asking retrospectively about events that patients have experienced and encouraging patients to formally record errors on incident reporting systems.

At the other end of the continuum is a focus on engaging patients proactively to take some responsibility for their own wellbeing. Research has explored what helps and hinders patients from being involved in this manner. The most common initiatives tested include educational campaigns and leaflets to encourage patients to ask professionals questions about hand hygiene and other safety issues.

The evidence suggests that feedback, planning and educational initiatives may lead to short-term improvements in processes. However, the longer-term impacts are uncertain, as are any potential changes in outcomes such as infection rates or mortality.

There is little comparative evidence available to suggest whether some of these strategies are more effective than others for improving patient safety. Individual initiatives have had some success – for example, specific leaflets or videos have been found to encourage more dialogue between patients and professionals. However, the extent to which this results in reduced errors, better safety climate or improved overall safety has not been well quantified.

Another major gap in the evidence is how to engage carers in safety improvement. Almost all of the empirical research focuses on patient engagement. Studies have explored how to involve carers in service improvement, but not usually with the explicit aim of enhancing safety. As family members and friends often spend a lot of time with people who are unwell and may feel more comfortable raising issues on behalf of patients, this may be an untapped resource for ongoing safety improvement.

5.2   Success factors

An important learning point from the evidence scan is that patient engagement in improving safety is not solely about patients themselves, but also depends fundamentally on the attitudes and behaviours of health professionals and the extent to which the organisational climate and infrastructure is supportive.

Research suggests that patients may be wary about reporting safety issues or asking professionals if they have followed safety protocols. Some have tried educating patients to raise awareness about the importance of these types of behaviours. However,

educating health professionals may be just as important. Studies have found that patients are more likely to be involved when they are invited or encouraged by professionals and when their concerns are then taken seriously and acted upon. Thus, as well as educating professionals and seeking to foster a safety culture which is about improvement rather than recrimination, the evidence suggests that health services need to have systems and infrastructure in place to elicit patient involvement and to act on the suggestions or comments received.

Professionals need to be convinced that the advantages of involving patients in improving the quality and safety of care outweigh any perceived disadvantages of changing traditional practices. This includes advantages for patients, for professionals and for wider systems.[106]

Studies also suggest that a patient's preferred level of involvement may depend on a number of other characteristics. Patients may be more willing to take part in some types of patient safety activities than others, and professionals and wider structures may be more encouraging about participation in certain aspects too.

Researchers from England have begun to think about how to conceptualise patient involvement in safety. One study with surgical patients found that safety-related behaviours are made up of the following three main properties.

– The type of error the behaviour is trying to prevent (for example, drug errors).

– The action required by the patient (for example, asking questions).

– The characteristics of the action, such as whether the behaviour involves interacting with a health professional.[107]

All of these factors influence the extent to which patients might want to be involved. Barriers to patient involvement in patient safety include interpersonal, intrapersonal and cultural issues.

Reviewers from England examined factors that could affect patient participation in quality and safety issues. Five categories of factors could affect patient involvement in safety: patient factors (such as demographic characteristics), illness (for example, severity), health professional factors (for example, professionals' knowledge and beliefs), healthcare setting (for example, primary or secondary care) and task-related issues (such as whether the patient safety behaviour challenges professionals' clinical abilities).[108]

Involving patients in improving safety therefore shares many of the characteristics of involving patients in improving the quality of healthcare more broadly and of involving patients in sharing decisions about their care. Research in these broader areas confirms that in order to engage people effectively in their care, there is a need for strong leadership, changing patient and professional roles, motivated and informed patients and professionals and appropriate infrastructure.[109–120]

This implies that in order to improve patient safety, a fundamental shift is needed in the way both patients and professionals view their roles. Thus, the culture and infrastructure of the health services may be as important as the motivation, attitudes and involvement of patients and professionals.

Supporting patient involvement in safety improvement is not a panacea for all the safety issues in the NHS, nor does it negate the responsibility of health systems and professionals to provide safe care. But involving patients and carers can be an important component of broader strategies. This may be most effective when implemented as part of wider initiatives to improve safety through educating practitioners, applying best evidence, learning from other systems and using technology and organisational partnerships effectively. As patients come to be seen and treated as partners in their care, there is significant potential to make real gains in patient safety.

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