Patient Engagement for Safer Primary Care: A roadmap for change


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We would like to thank Susan Hrisos (Newcastle University, Newcastle, United Kingdom) and Anthony Chuter (Chair of the Board of Trustees at Pain UK) for their extraordinarily helpful review and comments.

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Please cite as:


Foreword

Health care systems are complex, fragmented and they involve multiple stakeholders. The only constant force in the journey along the care pathway is the patient who experiences the process and the outcomes of care, who has an essential role as co-producer of health and who, together with their carers and families in their community, holds key information vital for process, systems and policy improvement. Tapping into such rich and invaluable resource is a challenge that holds promising results.

This report aims to review the evidence for patient engagement in primary care and identify recommendations for change. This work was commissioned by the World Health Organization (WHO) for the ‘Safer Primary Care’ initiative and conducted by a multidisciplinary team including researchers, patient safety experts, clinicians, pharmacists and patients from different countries. A summary version of this document has been edited by and published as the WHO Technical Report, which was presented in a WHO Webinar on ‘Safer Primary Care’ which took place on 16 December 2016.


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1. WHY IT IS IMPORTANT TO ENGAGE PATIENTS AND THEIR FAMILIES

Patient engagement is receiving increasing recognition as an integral part of health care and a critical component of safe, high quality, integrated, patient-centred health services. In particular, it is a crucial component of patient safety and quality improvement for the World Health Organization (WHO), as demonstrated by the Patients for Patient Safety (PFPS) initiative (1).

What is patient engagement?

There are multiple definitions of “patient engagement” which vary depending on context and purpose. They range from actions (to promote adherence to drug or treatment prescription) to a cognitive, behavioural, emotional and social construct (which fosters patient self-management), sometimes equated to behavioural activation to a measurable marker of patients’ compliance and/or clinical results (2-4).

All these representations of patient engagement share the same underlying theme: the facilitation and strengthening of the role of patients as co-producers of health and health care, from the individual’s own care to the wider forum of health care policy, practice and education.

Engagement also frequently includes carers, family members and communities as they are present alongside patients in the whole care journey. For parsimony, we will refer in this document to patient engagement as engagement that is not limited to patients but that includes carers, family members and communities.

Why is patient engagement important?

The increased interest in patient engagement in health care in the last decades has been driven by the recognition that it is essential for achieving care that is safe, high quality and patient-centred, that is, care that is “respectful of and responsive to individual patient preference, needs and values” (2, 5-7).
Patients themselves are increasingly asking for a more responsive, open and transparent health care system and expect individual practitioners to engage them in the decision-making process, although individual patients may vary substantially in their preferences for such involvement.

Engaged patients would be better able to make informed decisions about care options. As knowledgeable partners, their increased involvement would make health care interactions more efficient and productive. Available resources may be better used if they are aligned with patients’ explicit priorities of engaged patients and this is critical for the sustainability of health systems worldwide.

**Why is patient engagement critical in patient safety?**

In our increasingly complex health systems, patients are the only individuals who are present along the entire care journey. They provide a link between different health services (sometimes the only such link) and a critical repository of clinical, health and social care information.

While health professionals may be exposed to incentives that if not appropriately aligned may *appear* to conflict with patient safety (organizational, reputational, financial, self-esteem, and many others), patients themselves have the greatest incentives to ensure that patient safety is a priority in the health care they receive. Patient engagement may also promote mutual accountability.

In the most unfortunate circumstances, when the patient has passed away, they are in many cases mobilized to advocate for policy changes (1).

**What are the specific features of patient engagement in patient safety in primary care?**

Primary care is in most countries both the first point of contact to the health care system and the major provider of care. This results in patients and health care professionals developing mutual knowledge and interpersonal relationships over time. Building up on these existing relationships in primary care offers an excellent starting point for further development of engagement in patient safety throughout the system.

Decisions to seek care and care management decisions in a timely fashion are crucial aspects of patient safety in preventing, for example, diagnostic delays.
Primary care professionals are ideally placed for engaging their patients in a dialogue about their health conditions, circumstances, health needs, personal values and preferences. The physician can then offer appropriate options and the patient can make an informed decision, which will enhance their positive experience with the care they receive. Informed patients are more likely to report both positive and negative experiences and adhere to the prescribed treatment or medications, which not only improve health outcomes, but advance learning and improvement while also reducing adverse events\(^8\).
2. MODELS OF PATIENT ENGAGEMENT

It would appear therefore that the maxim ‘nothing about us, without us’ should be applied to all aspects of care. The importance of patient and family engagement is well recognized by health systems in high-income countries but less so in low and middle-income nations, where the scope for engagement has more frequently been limited to the role of patients in self-managing their conditions and to a more passive engagement in decision making. Partnership and collaboration in the WHO Patients for Patient Safety (PFPS) initiative aims to address these issues and provides a relevant template for reviewing engagement models.

Collecting information on patient experience and outcomes of care may be the starting point for engaging patients. Collected through surveys, online feedback, interviews or focus group discussions, patient experience provides insight into patients’ needs, preferences and values, which will be valuable for organizational design and improvements.

Although patients’ input into clinical audits is a potentially productive approach to engaging patients, current practice does not yet routinely consider the patient experience as a validator of other audit processes.

Engagement is particularly promising in the area of health care education. The articulation of their experiences by real patients resonates with the students’ eagerness to go beyond acquiring knowledge and mastering skills to appreciating both the patient perspective and the importance of preserving trust between clinician and patient. These core values are essential to care that is compassionate, quality assured and above all, safe. Feedback from students, those engaged in continuing professional development, frontline staff, and policy makers suggests that exposure to the patient experience directly from the patient is not only welcomed, but is valued as an adjunct to the formal processes and is considered to be motivational in relation to enhancing the quality of clinical practice.

At organizational level, patients and families may be engaged in the design or development of patient-centred processes and systems by being engaged in memberships to governing boards or advisory committees, which contribute to health care improvement at the process and system levels\(^6\). Patient and family engagement in policy development and implementation has also gained increasing recognition. About two-thirds of PFPS champions reported being engaged as a member of working groups, governing boards or advisory committees at local, national or
global levels\(^9\). Patients’ views are often sought in the development and dissemination of tools, information and educational materials\(^9, 10\). Their experience and expertise are sought in research as a source of data, as co-researchers contributing to research design and/or the planning and execution of research\(^9,11\).

Patients’ access to their own electronic health record is increasingly being considered in high-income countries where resources and infrastructure are available. Engaging patients in monitoring and updating their medication or treatment plans also has the potential for increasing treatment concordance as well as enabling physicians to timely review and intervene, if needed.

In low and middle-income nations where resources are scarcer, patient and family engagement may begin with educating and empowering them to recognize their health needs and seek health care timely and appropriately. Engaging them in the design and development of tools helps enhance their understanding of health issues and encourages them to make use of the relevant tools. A prime example of such tools is the WHO 7 Day Mother Baby mCheck Tool, which aims to increase safety during the high-risk postnatal period for mothers and babies. Relevant examples of such countries where patient engagement is an official requirement are Colombia and Argentina. Organized groups of health service users are active in primary care in countries such as México \((avales)\), Ecuador \((veedurías)\) and Peru, and they aim at supporting the evaluation and development of health services.
3. OVERVIEW OF THE EVIDENCE BASE FOR PATIENT ENGAGEMENT

In order to examine the currently available evidence base for patient engagement in patient safety we conducted a review of literature reviews (umbrella review). We searched for relevant systematic literature reviews in PubMed, the Cochrane Library and specific web sites and databases, including those set up for dissemination of specific projects (last update 30 May 2014), complemented with feedback from experts, and further references identified through the peer review process. We identified 39 literature reviews addressing a range of different issues concerning patient engagement in patient safety (4, 12-49). Most of them were not specific of the primary care setting, and more than half specifically focused on interventions for improving patient adherence to medical treatment. Given the paucity of evidence from systematic reviews with a specific focus on patient engagement in primary care patient safety, we identified, and wherever possible examined, all original studies included in the reviews addressing specifically this topic (50-70).

We summarized available evidence both from the systematic reviews and the original studies into two themes: barriers and facilitators, and effectiveness of interventions.

3.1 Barriers and facilitators for patient engagement in patient safety

Two systematic reviews examined the factors that support or deter patients from being willing and able to participate actively in reducing clinical errors. Five groups of factors potentially affecting patient engagement in safety were proposed, as related to: patients (e.g. demographic characteristics), health conditions (e.g. severity), health care professionals (e.g. knowledge and beliefs), task (e.g. whether a required patient safety behaviour would challenge professional clinical abilities), and, critically, setting (e.g. primary or secondary care) (16). Patients reported being more comfortable communicating with primary care professionals than with hospital staff.

The most important barriers to patient engagement in error reduction are related to patients’ perceptions of their role and status as subordinate to clinicians: patients’ fear of being labelled “difficult” and a consequent desire for clinicians’ approbation may cause patients to assume a passive role as a means of actively protecting their personal safety (17).
3.2 Effectiveness of interventions of engaging patients in patient safety

Interventions for engaging patients to stimulate safer health care in primary care fell within three broad categories: equipping patients for safer health care; provision of retrospective feedback; and engagement for planning for improving systems or services.

There was general agreement in the ten literature reviews that examined their effectiveness on the lack of evidence supporting these interventions\(^9, 14, 20, 21, 25, 29, 32, 39, 41, 45\). The majority of these literature reviews were not setting-specific, and only one of them was specific to primary care\(^{21}\). This review, which was conducted by the Linnaeus Euro-PC group in 2012, an initiative funded by the European Commission for strengthening research on patient safety in Europe, and involving partners from eight countries (Austria, Denmark, Germany, Greece, the Netherlands, Poland, Spain, and the United Kingdom), highlighted once again a remarkable lack of evidence base for these interventions.

3.2.1 Equipping patients for safer health care

The vast majority of research about engaging patients in safety improvement focuses on patients being proactive about minimising harm or errors in their own care.

Three routes have been proposed by which patients’ increased proactivity might contribute to their safety: patients helping to ensure treatment is appropriate for them (informing the management plan); patients helping to ensure that treatment is given as planned and according to appropriate protocols (monitoring and ensuring safe delivery of treatment); and patients helping to ensure that problems and risks within health care systems are identified and reduced (informing systems improvements)\(^{39}\). Additionally, patients can help by ensuring that services meet their needs, thereby addressing the access domain of patient safety. However, despite the proliferation of these type of programs, a nonspecific health care setting literature review found little evidence on their success in promoting expected behavioural changes\(^{45}\).

In the primary care setting, most of the interventions present two common characteristics: they are based in the provision of education to patients; and their aim is to tackle drug-related safety problems.

Errors in the prescription and use of medicines are indeed a common problem, and sometimes patients contribute to them by failing to take their medication as prescribed. There is a large and growing body of research on educational interventions to improve prescription
Primary care specific interventions have proved in a few studies their potential to increase compliance, but when considered as a whole, the effects of interventions are limited and the evidence is mixed.

Interventions aiming at engaging patients in the prevention of adverse drug events in primary care have also been proposed and evaluated. For example, an intervention consisting of the implementation of a system to send electronic medication safety messages to patients produced an improvement in communication about medications and in the identification of adverse drug reactions. Positive results were also observed after the implementation of an interactive computer program to teach ambulatory older adults about potential drug-alcohol interactions, observing that its use led to improvements in patients’ knowledge, self-efficacy and behaviour in relation to how to avoid interactions. Another study observed that patient-specific feedback provided to general practitioners supported by educational material mailed directly to their patients increased home medicines review rates for targeted veterans. The provision of patient counselling and telephone follow-up has also shown its potential to reduce preventable adverse drug reactions after hospital discharge.

Less frequently, non-educational interventions for reducing medication-related safety problems have been studied in the primary care setting. For example, an intervention consisting of requesting patients to bring their medications to consultations, in conjunction with the use of medication record cards showed a positive impact on the quality of information for doctors about their patients’ medications. A community-based initiative involving the provision of tools and resources for patient engagement (personal medication lists and medication bags) improved the accuracy of the outpatient medication list. The use of a patient package insert of a non-steroid anti-inflammatory drug produced a positive impact on how patients perceive, appraise and manage medication risks. The effectiveness of a multifaceted intervention (consisting of mailed letters before appointments to remind patients to bring medication bottles or updated medication lists to their visits, verification, and correction of the medication list in the electronic medical record by the patient, and academic detailing and weekly audit and feedback of performance) was assessed, observing that the intervention significantly enhanced medication reconciliation.

Strategies aimed at encouraging patients to generally raise potential concerns about the safety of the health care they receive have included the distribution of leaflets, the use of videos, and/or other types of educational materials. Most of the studies observed
positive results. However outcomes measured were restricted to patient satisfaction or patient proactivity during the consultation, but did not include harder patient safety-related outcome measures such as number of safety events registered or measures of harm.

### 3.2.2 Patient retrospective feedback

Few studies have examined the potential of using patient retrospective feedback as a method to improve the safety in primary care. One of them studied the effect of a pharmacy-based post-marketing surveillance system, concluding that a patient-initiated monitoring system could prove to be a promising complement to existing physician-based surveillance systems\(^{67}\). Another study compared reports of adverse drug reactions submitted by patients with the reports submitted by doctors and pharmacists observing that the reports from patients usually contained sufficient medical information and more frequently referred to serious adverse reactions than reports by health professionals\(^{68}\).

Patient feedback was obtained most commonly through surveys, but formal event reporting systems for patients were studied to a limited extent\(^{69-71}\). The review of the evidence suggests that these approaches can provide useful data that may not be available from other sources. Surveys, online tools and other forms of feedback with low interactivity 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\(^9\). However, the impact of these strategies critically depends 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.

### 3.2.3 Engagement in planning improvement

Health care services have engaged patients in planning committees, patient and public engagement groups or prospective surveys to encourage change. Patient-led education has also been proposed as a strategy to engage patients in developing safer services. For example, a randomized trial in England evaluated an intervention consisting of incorporating a patient-led component into the mandatory training of junior doctors about patient safety. Patients who experienced a patient safety incident in the NHS were recruited and trained to talk with small groups of trainees about their experiences with the aim of increasing patient safety awareness among doctors\(^{72}\). The authors observed however that the intervention did not effectively change general attitudes to safety compared to the control group\(^{73}\).
Evidence from this type of intervention is still sparse, even more so in the primary care setting with virtually no study assessing the effectiveness of engaging patients in planning safer systems.
4. RESEARCH NEEDS

The review of the evidence base for patient engagement suggests that research is very much needed on a number of distinct areas (Box 1).

First of all, there is a clear need for studies conducive to the identification and characterization of key barriers and facilitators for engaging patients in increasing safety in primary care. Such barriers and facilitators operate at very different levels, including not only this target group itself but also the workforce, the organization of care, the policy, and the broader societal levels. They should be therefore operationalized at the very least at three main levels: patients (and families, carers and the community); the organization and provision of clinical care (including health professionals); and the health policy level. In particular, if the evidence for patient-focussed interventions is thin, the base for family, carers and the community is dramatically sparse.

**BOX 1 Priority themes for current research needs on patient, family and carers’ engagement in patient safety**

- Barriers and facilitators for patients, carers, families and community engagement in patient safety
  1. Patients, families, carers and the community
  2. Provision and organization of care
  3. Health care policy development and implementation
  4. Research methods
- Effectiveness of interventions of engaging patient, family and carers in patient safety
  1. Patient experience and the provision of feedback
  2. Engagement in organizational design, governance and planning improvement
  3. Equipping patients for safer health care
- Development of sound models of meaningful engagement for patient safety that are practical, effective and measurable
- Measurement of patients, carers, families and community engagement in patient safety, quality improvement and patient centeredness
- Evidence on impact of the interventions on health outcomes
The identification and characterization of barriers and facilitators specific to each type of engagement activity is instrumental for elucidating the key active components that successful interventions should potentially address and for understating their contextual characteristics and the mechanisms of action involved. We need both primary studies, in particular of qualitative nature, for assessing barriers and facilitators, as well as sound structured reviews, such as systematic reviews, and also realist syntheses, that distil available evidence\textsuperscript{(74)}. The latter would also enable the development of a comprehensive and sound theoretical model for patient engagement in patient safety that can be used across the board, and would inform the development of new interventions and the refinements of existing ones. Current evidence from other care settings should be considered wherever relevant, but the particular features of primary care should be taken into account, including interpersonal continuity, longitudinally, comprehensiveness and access, alongside the functions of coordination, agency function and the focus on health promotion, education and prevention\textsuperscript{(75)}.

There is a need for research that advances our knowledge in relation to engagement for informing the management plan, and monitoring and delivering safe treatment. Particular attention should be placed in developing the evidence base for improving medication concordance, as well as for the diagnosis of serious disease and signs of deterioration of established conditions. The evaluation of strategies for ensuring patient activation other than educational and enhanced shared decision making might prove particularly fruitful, such as the use of checklists for patients and professionals as part of the agenda of the meeting/consultation process.

There is a need to engage patients, families and carers in the design and development of incident reporting systems, which use appropriate implementation strategies to ensure that information is acted upon in order to induce change, including the integration of this information in existing reporting systems for clinicians. Feedback systems should enable the reporter to recognize a potential rather than an actual harm. There is also a need for specific interventions that can target both experiences and outcomes of patient safety as well as general perceptions about safety that could potentially be used for measuring and monitoring patient engagement.

The potential effect of systematic patient feedback on safety culture in health care organizations should also be evaluated\textsuperscript{(76, 77)}. A recently completed systematic literature review on available patient reported instruments to measure patient safety in primary care found that currently
available instruments do not offer a comprehensive set of resources to measure the effects of interventions to improve patient safety in primary care from a patient perspective\(^{(78)}\). The need for instruments that enable a reliable and valid overall assessment of patient safety at general practices is therefore pressing.

The emerging interest in the engagement of patients in designing and planning safer primary care systems merits specific studies to increase the evidence base in this area including, but not limited to patient membership of planning committees, the development of patient and public engagement groups, prospective surveys, and patient-led medical education.

Research should help inform the development of methods for maximizing the benefits of anecdotal evidence, translating the anecdote to evidence base and evaluating the motivational impact of the patient story as a catalyst for change.

In addition, five common needs permeate across all areas of research on patient engagement in patient safety in primary care. The first one is the need for clarification and better definition of the concepts of meaningful engagement of patients, families and the public through consensus and well developed conceptual frameworks. The second one is the development of robust tools for the measurement of patient engagement and engagement outcomes at the individual, the health care provider and the health care system levels. Thirdly, future studies should, whenever possible, use harder patient safety-related outcome measures such as number of patient safety incidents or degree of harm. Fourthly, there is a need to learn from patients about both their preferred and alternative methods for engagement. Finally the urgent need for research in low- and middle-income countries cannot be overstressed.
5. PROPOSED ACTIONS FOR PATIENTS, FAMILIES, AND THE PUBLIC, AND HEALTH PROFESSIONALS, AND POLICYMAKERS

A few principles emerge from this overview that will be instrumental for making a positive change for effective patient engagement in patient safety. Both health care providers and policy-makers need to create opportunities for meaningfully engaging patients and their families in a dialogue at all levels – in direct care at individual level, in the organizational governance and systems designs, at the policy development and implementation level, in education, research, regulation, and standard setting.

Meaningful and effective engagement begins with empowering both patient and family and health care professionals. Patients need to have sufficient and appropriate information about their health conditions, about health care systems and processes so that they can be knowledgeable partners in a decision-making process. To this aim, healthcare providers and policy-makers must ensure that patients and families have access to accurate, appropriate and up-to-date information and that they are facilitated to understand and utilize the information appropriately. Engaging patient advocates in open disclosure communication and training may facilitate the process as they are likely to want to promote honest and open disclosure as part of the healing process for patient, family and clinician. Such disclosure is not about accepting or apportioning blame, rather it is about integrity and is a demonstration of professionalism.

Creating a culture of patient safety is also essential to foster openness and transparency, and may strengthen rather than challenge the patient-provider relationship. Voluntary reporting of adverse events and communicating open disclosure with the patients and families has to be the norm and is essential in acknowledging what went wrong and recognizing an opportunity for improvement. Many systems, like the one in Uganda, do track patient safety incidents but do not provide a remedy to them. This may result long term in apathy and despondence among patients. Health care professionals need a supportive environment and, crucially, appropriate incentives that facilitate and encourage their engagement with patients and families.

Filling the huge gaps in the evidence base is an essential component of the way forward, but this will be of little value if we do not succeed in implementing already available evidence. In this respect documenting and sharing of engagement experiences from the perspectives of both
health professionals and patients will be the key to success and will serve as a foundation for learning and guiding practices as well as contributing to the generation of research evidence.

Helen Keller famously reminded us that there is one thing worse than being blind and that is having sight but no vision. A commitment from leadership by health care providers and policy makers is a necessary step, which may be based on endorsing the following along these simple principles:

1. We will proactively engage patients in their own care.

2. We will capture the lessons to be learned from the care experiences of our raison d’etre (the patient)

3. Over and above that, we will embed patient and family into every aspect of our organization’s activities

*The LINNAEUS approach*

As part of the LINNAEUS collaboration\(^{(79)}\), a panel of experts made a number of recommendations addressed at professional organizations, clinicians and researchers, on the one side and policymakers and health care authorities, on the other. Some of them overlap with the research needs outlined above, and others include a variety of issues, but they all provide a specific roadmap for changes based on the above principles:

1) Integration of patient engagement and safety in the health professional curricula at both undergraduate and postgraduate level, with specific attention to the patient's perspective, health care professional/patient relations and cultural diversity.

2) Recognition of the duty of professionals to act as first movers, by asking, encouraging, inviting and welcoming the patients to be engaged, both at an organizational and individual level.

3) Encouragement to patients to provide feedback on safety incidents, near misses and safety concerns together with positive feedback.

4) Exploration of the alternative modes of communicating with patients (phone, mail etc.) to solve their questions or concerns about treatment, care or safety issues in real time.
5) Adoption of legislation that supports the rights for patients (and their relatives) to engage in issues relevant for their safety, with special emphasis on the right to access their health record as a sound basis for their informed consent to treatment.

6) Supporting patient-led voluntary associations’ work in order to contribute to the development of tools, policy etc. in collaboration with policymakers and professionals.

7) Promotion of organizations that facilitate and focus on learning and thus differing from organizations handling complaints, making it possible for patients and their relatives to report safety incidents.

8) IT-solutions that ensure patient data are compiled in databases accessible to professionals (with secure access) from all health care sectors.

9) Access for patients to high quality, intelligible information on diseases, treatment options and patient safety issues in user-friendly language and format.

10) Campaigns aimed at enhancing public attention to the need for and benefits from strengthened engagement of patients and their relatives in patient safety in primary care.
6. FINAL REFLECTION

Patient and family engagement/empowerment is a priority for WHO as it is an integral part of its efforts to help Member States to build high quality, integrated and people-centred health services. Patient engagement is critical to shaping the way forward. It is the right thing to do because it has the potential to save lives through safety and quality improvement informed by patient experience, which will benefit health care at all levels - individual, organizational and systems. Patient advocates, such as PFPS, can help minimize the barriers and be a conduit between the reality (the experience of the person in the bed) and high level policy and decision-making, provided that they are supported with adequate resources and a leadership commitment.

As Sir Liam Donaldson, WHO Envoy for patient safety, articulated “to err is human, to cover up is unforgivable but to fail to learn is inexcusable.” Patient engagement is essential in learning, in identifying health care needs and in measuring whether and how those needs are met.

Patients and family members are uniquely placed to be effective rescue team members and most would subscribe to the pledge of health care partnership contained in the PFPS London Declaration:

\[
\text{We, patients for patient safety, will be the voice for all people, but especially those who are now unheard...}
\]

\[
\text{... In honour of those who have died,}
\]

\[
\text{Those who have been left disabled, our loved ones today,}
\]

\[
\text{We will strive for excellence,}
\]

\[
\text{So that all people receiving health care}
\]

\[
\text{Are as safe as possible, as soon as possible.}
\]

\[
\text{This is our pledge of partnership – our patient and family pledge of partnership!}
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