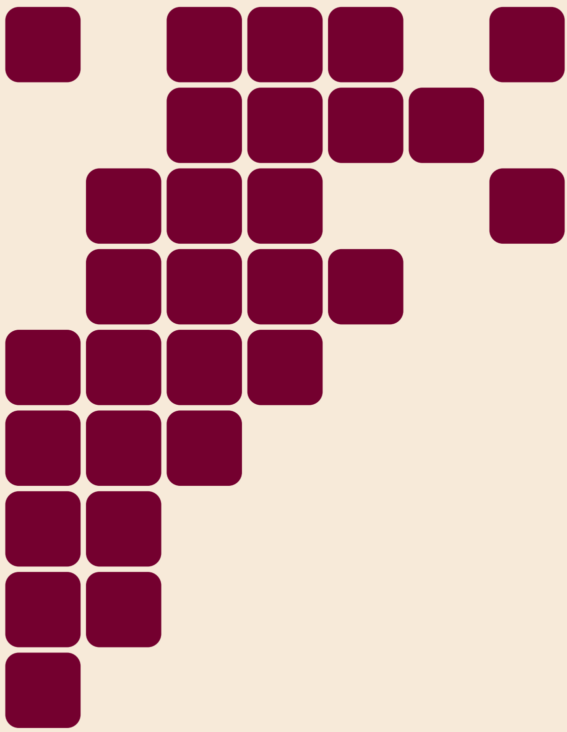

Patient Engagement

Technical Series on Safer Primary Care

World Health Organization

Patient Engagement: Technical Series on Safer Primary Care

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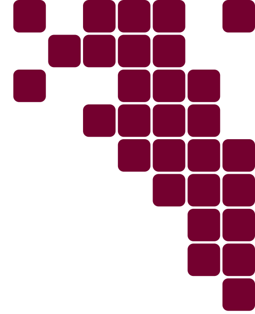

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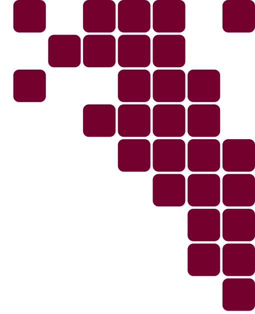


Preface

Safer Primary Care

Health services throughout the world strive to provide care to people when they are unwell and assist them to stay well. Primary care services are increasingly at the heart of integrated people-centred health care in many countries. They provide an entry point into the health system, ongoing care coordination and a person-focused approach for people and their families. Accessible and safe primary care is essential to achieving universal health coverage and to supporting the United Nations Sustainable Development Goals, which prioritize healthy lives and promote well-being for all.

Health services work hard to provide safe and high quality care, but sometimes people are inadvertently harmed. Unsafe health care has been recognized as a global challenge and much has been done to understand the causes, consequences and potential solutions to this problem. However, the majority of this work up to now has focused on hospital care and there is, as a result, far less understanding about what can be done to improve safety in primary care.

Provision of safe primary care is a priority. Understanding the magnitude and nature of harm in primary care is important because most health care is now offered in this setting. Every day, millions of people across the world use primary care services. Therefore, the potential and necessity to reduce harm is very considerable. Good primary care may lead to fewer avoidable hospitalizations, but unsafe primary care can cause avoidable illness and injury, leading to unnecessary hospitalizations, and in some cases, disability and even death.

Implementing system changes and practices are crucial to improve safety at all levels of health care. Recognizing the paucity of accessible information on primary care, World Health Organization (WHO) set up a Safer Primary Care Expert Working Group. The Working Group reviewed the literature, prioritized areas in need of further research and compiled a set of nine monographs which cover selected priority technical topics. WHO is publishing this technical series to make the work of these distinguished experts available to everyone with an interest in *Safer Primary Care.*

The aim of this technical series is to provide a compendium of information on key issues that can impact safety in the provision of primary health care. It does not propose a "one-size-fits-all" approach, as primary care is organized in different ways across countries and also often in different ways within a given country. There can be a mix of larger primary care or group services with shared resources and small services with few staff and resources. Some countries have primary care services operating within strong national support systems, while in other countries it consists mainly of independent private practices that are not linked

or well-coordinated. The approach to improving safety in primary care, therefore, needs to consider applicability in each country and care setting.

This technical series covers the following topics:

Patients

- Patient engagement

Health workforce

- Education and training
- Human factors

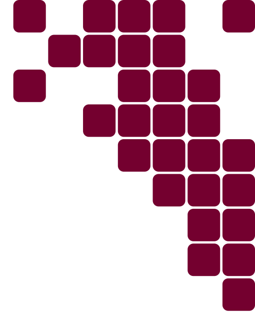
Care processes

- Administrative errors
- Diagnostic errors
- Medication errors
- Multimorbidity
- Transitions of care

Tools and technology

- Electronic tools

WHO is committed to tackling the challenges of patient safety in primary care, and is looking at practical ways to address them. It is our hope that this technical series of monographs will make a valuable and timely contribution to the planning and delivery of safer primary care services in all WHO Member States.



1 Introduction

1.1 Scope

Health care systems are complex and include multiple stakeholders and providers. People using health care services have an essential role as co-producers of their health and indeed they represent the only consistent factor throughout the care pathway. They also hold key information vital for process, systems and policy improvement. Tapping into such a rich resource could contribute significantly to improving safety in primary care.

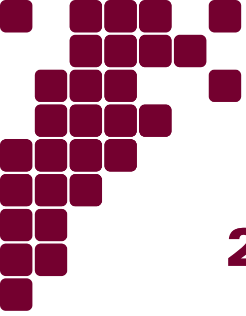
This monograph examines why it is important to involve people using services in improving safety and how this might best be done. The term "patient engagement" is used throughout this document and refers to the process of building the capacity of patients, families, carers, as well as health care providers, to facilitate and support the active involvement of patients in their own care, in order to enhance safety, quality and people-centredness of health care service delivery.

There are many definitions of patient engagement, but all share an underlying theme: the facilitation and strengthening of the role of those using services as co-producers of health, and health care policy and practice *(1)*.

1.2 Approach

To compile information for this monograph, the team searched for systematic reviews in PubMed, the Cochrane Library and specific websites and databases. Feedback from experts was obtained and further references were identified through the peer review process. Information was drawn from 39 reviews about patient engagement in safety, although most were not specific to primary care settings. The original studies included in each of these reviews were read to ensure a focus on primary care. For brevity, not all citations are listed.

International experts in delivering safe primary care provided feedback, shared examples of strategies that have worked well around the world, and gave practical suggestions about potential priorities for the World Health Organization (WHO) Member States to improve the safety of primary care services.



2 Patient engagement

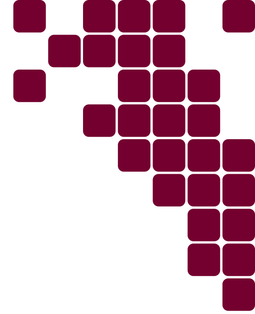
Patient engagement is increasingly recognized as an integral part of health care and a critical component of safe people-centred services. Engaged patients are better able to make informed decisions about their care options. In addition, resources may be better used if they are aligned with patients' priorities and this is critical for the sustainability of health systems worldwide.

People using health services are increasingly asking for more responsive, open and transparent health care systems. They expect practitioners to engage them in the decision-making process, although individual patients may vary substantially in their preferences for such involvement.

Health practitioners have multiple competing priorities, which may sometimes appear to conflict with patient safety. These may include organizational, reputational, financial priorities and self-esteem, amongst others. However, patients have their safety and well-being as primary drivers and thus, they can raise this as a priority in the health care they receive.

Patient engagement may also promote mutual accountability and understanding between the patients and health care providers. In most countries, primary care is often the first point of contact of patients with the health care system. Therefore, primary care offers a good starting point for further engaging patients throughout the system.

Primary care providers are ideally placed to engage patients in a dialogue about their health conditions, circumstances, health needs and personal values and preferences. Informed patients are more likely to feel confident to report both positive and negative experiences and have increased concordance with mutually agreed care management plans. This not only improves health outcomes, but also advances learning and improvement, while reducing adverse events.



3 Key issues

3.1 Areas for patient engagement

Engaging patients and families is equally important in all countries across the world, although the relative priority placed on this concept and the manner in which it is done still differs widely at present. There are many areas of health care training and implementation where patient engagement can be implemented.

Collecting information about the patient experience and outcomes of care may be the starting point for engaging patients. Such information can be collected through surveys, informal online feedback, interviews or focus group discussions. Feedback about the patient experience provides insight into patient needs, preferences and values, which can help to improve the quality and safety of care.

Patient engagement is a promising avenue in the area of health care education. Having real patients articulate their experiences and viewpoints helps those taking part in training to appreciate the patient perspective and the importance of preserving trust between clinicians and patients. These core values are essential to care that is compassionate, quality assured and, above all, safe. Exposure to patient stories during training is valuable and helps to motivate practitioners to improve safety.

At an organizational level, patients and families can be engaged in the design or development of patient-centred processes and system, for example as members of advisory committees *(2)*.

Patient and family engagement in policy development has also gained increasing recognition. For example, patients can be engaged in the development and dissemination of tools, information and educational materials *(3)*. They can be involved in research as a source of data and as co-researchers contributing to research design or the planning and execution of research *(4)*.

Some developed countries have begun to give patients access to their own electronic health records. Engaging patients in monitoring and updating their medication or treatment plans has the potential to increase treatment concordance, as well as enabling health care providers to review and intervene, if needed.

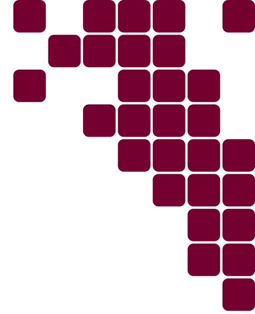
In low-income countries where resources are scarcer, patient and family engagement may begin with educating and empowering people to recognize their health needs and to seek health care in a timely manner. Encouraging people to ask questions or speak about their concerns is important. Engaging people in the design and development of tools helps to enhance their understanding of health issues and encourages them to make use of the relevant tools.

3.2 Factors affecting patient engagement

Reviews have investigated factors that support or deter patients from being willing and able to participate actively in improving patient safety or reducing harm. Five groups of factors potentially affecting patient engagement in safety have been identified. These are related to:

- patients (e.g. demographic characteristics, health literacy)
- health conditions (e.g. illness severity)
- health care professionals (e.g. knowledge and attitudes)
- tasks (e.g. whether a required patient safety behaviour challenges clinicians' clinical abilities)
- health care setting (e.g. primary or secondary care) *(5)*

A key factor that may hinder patient engagement is the patient's perception of their role and status as subordinate to clinicians. For example, patients may fear being labelled "difficult" or they may take a passive role as a means of actively protecting their personal safety *(6)*. Such challenges can be overcome by improving communication and educating both patients and health care providers to view health care as a partnership between the patient and the provider.



4 Potential solutions

Research suggests that interventions to engage patients in safer primary care fall within three broad categories: educating patients and health care providers for safer health care, obtaining retrospective or real-time feedback, and engaging for improvements in systems or services. Although there is no clear evidence about the most effective interventions within each category, this section describes promising approaches *(7).*

4.1 Educating patients and health care providers

Most research about engaging patients in safety improvement focuses on patients being proactive about minimizing harm in their own care. Interventions largely revolve around providing patient information or education. There has been a proliferation of educational programmes seeking to engage patients in safety improvement, but there is little evidence that these are successful in promoting expected behavioural changes *(8).*

In the primary care setting, most interventions tested have focused on reducing medication-related safety issues. Errors in the prescription and use of medicines are common problems and sometimes patients contribute by failing to take their medication as prescribed. There is a growing body of research about educational interventions to improve prescription concordance. Interventions in primary care have the potential to improve compliance, although the evidence is mixed *(9,10).*

Examples of educational interventions include sending electronic medication safety messages or using computerized tools to provide education. These interventions have been found to improve engagement and reduce adverse drug events *(11,12).* Education via post and telephone has also been found to reduce adverse drug events *(13,14).*

Leaflets, videos and other educational materials have been found to encourage patients to raise concerns about the safety of the care they receive *(15,16).* However, many studies focus on patient satisfaction rather than safety events or measures of harm.

Educating health care professionals about the importance of the patient role and how to engage with patients is another key area of study. Evidence suggests that health care professionals can exercise power in the consultation through the use of professional or expert language or technical jargons, which may act as a barrier to communication *(17).* Providers' perceptions of a patient have been found to influence their consultation style, with more patient-centred consultations occurring with those patients who were perceived to be better communicators *(18).* Thus, targeting the attitudes and behaviour of providers through education

is important to support shared decision-making and the relationship between the patient and the provider.

4.2 Obtaining feedback

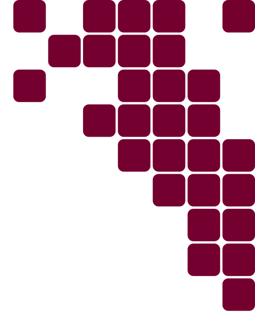
A small number of studies have examined the potential of using retrospective feedback from patients as a way to improve safety in primary care. In one of these studies, feedback was obtained through surveys or formal event-reporting systems for patients *(19).*

These approaches can provide useful data that may not be available from other sources. However, surveys, online tools and other forms of feedback with low levels of interactivity may be unlikely to result in significant changes to patient safety unless there is a committed team actively using the information to drive forward improvements. The impact of these strategies depends on what is done with the information after collection and whether a structured approach is taken to create tangible changes in systems and practices to improve patient safety *(3)*.

4.3 Engaging for improvement

Health care services have engaged patients in planning committees, patient and public engagement groups, patient advisory committees or in prospective surveys to encourage change. Patient-led education of health professionals has been proposed as a strategy to engage patients in developing safer services, but current evidence is limited about its impact.

Open disclosure of safety incidents to patients and engaging patients and their families in remedies is seen as valuable by patients *(20)*.



5 Practical next steps

Patient and family engagement is an integral strategy to develop high-quality, integrated and people-centred health services. Patient engagement is critical to shaping the way forward. It has the potential to saves lives through safety and quality improvements informed by patient experience.

The evidence suggests that leaders need to make a commitment to proactively engage patients in their own care and to implement the lessons learnt from care experiences. Health care providers and policy-makers need to create opportunities for engaging patients and their families in a dialogue at all levels: in direct care at an individual level; in organizational governance and systems design; and at the level of policy development and implementation through education, research, regulation and standard setting *(21).* Creating a culture of patient safety helps to foster openness and transparency and may strengthen the patient-provider relationship.

Meaningful and effective engagement begins with empowering patients and health care providers. Patients need to have sufficient information about their health conditions and about health care systems and processes so that they can be a knowledgeable partner in decision making. Thus, it is important for health care providers and policy-makers to ensure that patients and families have access to accurate, appropriate and up-to-date information and understand how to use this information. Patient-held records may support the engagement and empowerment of patients *(22).*

Cultural and social norms impact on the engagement process and what is appropriate and feasible in one context may not be acceptable in another. However, the underpinning principles of recognizing the value of patients, families, carers and wider communities as partners in care are important across all contexts.

Strategies that WHO Member States could consider prioritizing in order to enhance patient engagement for safer primary care include:

1. Educating health care providers about patient engagement

- educating health care providers to involve patients, both at the organizational and individual level;
- including patient engagement and safety in educational curricula at undergraduate and postgraduate level;
- developing a learning culture, rather than a blaming culture.

2. Supporting patients to become actively involved

- encouraging patients to report on safety incidents, near misses and safety concerns;

- actively promoting patient feedback systems;
- giving feedback to patients on follow-up actions taken about the issues they raised;
- considering legislation that supports patients and their families to engage in issues relevant for their safety;
- providing patients with appropriate, accurate and up-to-date information about treatment and safety issues in a user-friendly language and format.

3. Broadening the ways in which patients are involved

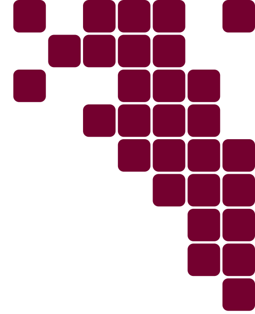
- exploring alternative ways of communicating with patients, such as telephone, e-mail and online video calls;
- putting in place systems to facilitate patient access to their health records;
- involving patient advocates, where appropriate, to support the engagement of patients at the direct care, organizational and policy level;
- supporting the work of patient-led voluntary associations;
- considering campaigns aimed at raising public awareness about the need for and benefits from the strengthened engagement of patients and their relatives in patient safety in primary care.

4. Recognizing the importance of communities

- adapting engagement strategies to the local social and cultural context;
- recognizing that patients are part of social groups, families and communities and that these broader networks can be a positive force for change.

5. Providing an enabling and supportive environment *(23)*

- encourage and facilitate interaction among health care professionals, and engagement with patients and families;
- promoting open disclosure about safety incidents to patients;
- linking patient feedback systems to organizational systems for learning and improvement, similar to staff-initiated incident reports;
- providing information and support for self-care such as counselling, peer-support groups and coaching;
- designating and supporting patient safety champions or advocates, where appropriate, to help facilitate patient engagement;
- setting up mechanisms for patient engagement at the systems level.



6 Concluding remarks

Primary care services are at the heart of health care in many countries. They provide an entry point into the health system and directly impact on people's well-being and their use of other health care resources. Unsafe or ineffective primary care may increase morbidity and preventable mortality, and may lead to the unnecessary use of scarce hospital and specialist resources. Thus, improving safety in primary care is essential when striving to ensure universal health coverage and the sustainability of health care. Safer primary care is fundamental to the United Nations Sustainable Development Goals, particularly to ensure healthy lives and promote well-being for all at every age.

Understanding the magnitude and nature of harm in primary care is important because a significant proportion of health care is offered in this setting, yet there is little clarity about the most effective ways to address safety issues at this level.

This monograph summarizes the evidence and experience about patient engagement as one of the key strategies for improving patient safety in primary care. However, this strategy would need to be implemented in conjunction with other important aspects covered in this series.

The *Technical Series on Safer Primary Care* addresses selected key areas that WHO Member States could prioritize according to local needs. This section summarizes the key messages running from all of the monographs and provides a list of 10 key actions that are likely to have the most impact on improving safety in primary care. Links to online toolkits and manuals are also referenced in order to provide practical suggestions for countries and organizations committed to moving forward this agenda.

1. Set local priorities

Countries and regions differ and a strategy that works well in one area may not transfer well to another. Similarly, issues in need of improvement in some regions may not be a priority for others. In seeking to improve safety in primary care, countries could use local information about their safety issues to identify key priorities at the national or regional level. Priority setting could be accomplished by drawing on input from patients and professionals, sourcing local statistics on safety issues and comparing key themes from the literature with local circumstances *(24).*

Checklists are also available to help identify potential patient safety issues such as environmental risks in primary care services *(25).*

One practical way to move forward is creating mechanisms for bringing together key stakeholders to consider the local information available and develop strategic and operational plans for improving safety in primary care. Communicating proposed priorities widely and amending them based on feedback from health

care professionals and patients would help to obtain their buy-in, as well as raise awareness of the importance of improving patient safety in primary care.

Regular measurement of safety related performance indicators could be considered as one of the priorities. Policy-makers can use measurements to help identify local issues where performance is suboptimal and then evaluate different types of interventions for improvements. Priorities could be reviewed every few years to ensure that they remain in line with local needs and good practice.

2. Take a wider systems approach to improving safety

Although the series has described specific technical areas, each monograph refers to interlinkages with other areas. Focusing on improving just one factor may not have a large or sustainable impact on patient safety overall. It may be important to simultaneously improve communication with patients, train health care professionals and introduce new tools to support more streamlined care.

Taking a systems approach to safer primary care means looking at how different components relate to one another and considering various factors which could influence safety. These include factors such as workforce availability and capability.

A practical systems level initiative is to focus on increased communication and coordination across different types of care including primary, secondary and also social care. This may include strengthening technical systems for sharing records and communicating what is happening.

It is also important to build relationships between care professionals. At a policy level, this may involve considering how to develop supportive infrastructure, such as having a directory of services to help build networks of professionals and align resources. If hospital, primary care and social care professionals are able to meet and discuss safety issues, this could foster supportive relationships and increase understanding of each other's roles. Regional forums or meetings could be set up so that professionals from different organizations can get to know each other and share their successes and challenges in improving patient safety.

Manuals and reference lists are available with further ideas for improving coordination and reducing fragmentation across systems *(26,27)*.

3. Communicate the importance of safety in primary care

Policy-makers, health care professionals, patients and families may not always be aware that there are important safety issues to consider in primary care. Raising awareness of this as a priority area will help stakeholders to understand why safety in primary care is essential to improve people's well-being and for safeguarding scarce health care resources.

Serious consequences due to the lack of safety in primary care, particularity relating to poor transitions of care between primary and other levels, and administrative, diagnostic and medication errors could be highlighted to raise awareness on the need to improve patient safety in primary care.

Practical ways to increase awareness include incorporating safety-related information into the training of health professionals, communicating effectively to professionals and patients through channels that would be most appropriate for them and spreading key messages through media campaigns. A communications plan could be developed in tandem with local priority setting discussed earlier.

4. Focus on building a positive safety culture

Effective leadership and supportive culture are essential for improving safety in primary care. This means creating an environment where professionals and patients feel able to speak up about safety issues that they are concerned about, without fear of blame or retribution. It means promoting an environment where people want to report risks and safety incidents in order to learn from them and reduce their recurrence, and where incidents are seen as caused largely by system failures rather than individuals. This also includes the importance of having feedback mechanisms in place to explain any improvements made after safety issues have been raised. Promoting transparency is key to building a strong safety culture.

A number of tools are available describing approaches to support the development and measurement of a positive safety culture *(28,29).*

Practical steps that could be taken to strengthen safety culture include: leadership walkrounds, whereby senior managerial and clinical leaders “walk the floor” (in this case, leaders visiting clinics and speaking with staff and patients about what is working well and not so well); starting team meetings with a patient story; using reflective practice to focus on safety issues, such as audits and having mechanisms for reporting safety issues, such as through regular team meetings. Such approaches may need to be adapted for use in smaller primary care clinics. Regardless of the specific method, the focus should be on raising awareness, encouraging safety discussions and taking concrete follow-up actions to build a safety culture.

5. Strengthen ways of measuring and monitoring patient safety

It is important to measure and monitor patient safety improvements over time. This may include having clear definitions of patient safety incidents and indicators to be measured annually, setting up national or local incident reporting systems where data is compiled regularly, or using tools to assess patient experiences and measure improvements in patient safety.

Using checklists in individual practices can both improve the quality of care and act as a structured form of record keeping. A number of examples of checklists to improve safety monitoring are available *(30).*

Data quality is fundamental to measuring improvements in patient safety. If accurate and comprehensive medical records are not kept, then errors and omissions are more likely to occur. As health systems mature, clinical governance processes tend to strengthen. This includes having processes for managing risks and identifying strategies for improvement.

A number of tools are available to measure and monitor different aspects of safety in primary care and countries could examine what is currently available and adapt materials based on local priorities *(31,32).*

6. Strengthen the use of electronic tools

The adoption of electronic tools will be critical to improving safety in many ways. Examples include the use of electronic health records for more accurate and complete patient records; timely and reliable sharing of health data; supporting the diagnosis, monitoring and management of diseases and conditions; effecting behaviour change and reduction of health risk, and empowering and engaging patients and families in their own care. eHealth can help structure communication between professionals in a way that reduces errors and improves coordination. It can reduce unnecessary consultations and hospitalizations and improve access to knowledge about health conditions and their management for both professionals and patients. However, to achieve their full potential, electronic tools need to be integrated with other parts of service delivery and adapted to the local context.

It takes time and resources to implement electronic tools, and requires the capacity to use and maintain them. It is therefore important to be strategic and to understand the foundations and design of systems in order to ensure the best return on investment. Linking the implementation of electronic tools in local settings to a national eHealth strategy is essential as it provides the foundation, justification and support needed to go forward in a coordinated way.

Irrespective of the status of the health system, it is important to strengthen the use of electronic systems to improve patient safety. For some countries, this may involve the introduction of electronic health records to replace paper records. For others, it may mean having integrated electronic systems between primary care and hospital and social care, or making the tools easier for professionals and patients to use. Countries could draw on lessons learned from other countries about implementing electronic health records, including the challenges faced and how these were overcome, and what best practices could be applicable to their own setting.

7. Involve patients and family members

Empowering and encouraging patients to speak up, for example when something does not seem right or when a symptom is inadequately explained, can be fundamental to improving patient safety. Family members play a key role as advocates and informal carers and therefore supporting and educating them can help to improve safety.

Proactive engagement of patients and families can help to accelerate the implementation of health care safety initiatives. When systems open themselves up to patients rather than being reactive, this is likely to improve system efficiency and the quality of care.

A number of tools have been evaluated to enhance patient and family involvement and awareness, including those with limited or low literacy skills *(33-36).*

8. Strengthen workforce capacity and capability to improve safety

There is a need to strengthen the primary care workforce in many settings by training a large pool of generalist workers, including doctors, nurses and those with supporting roles.

Strengthening the workforce also involves focusing on recruitment and retention, including taking steps to enhance the physical and physiological safety of health care workers. Professional burnout, fatigue and stress can all adversely affect patient safety.

The education and training of health care professionals to manage and minimize potential risks and harm that can occur in primary care are central to improving safety at all levels of care. This includes providing training on patient safety for students (including students who may not be training to work in primary care to ensure understanding across the different care pathways), multidisciplinary and inter-professional education, as well as continuing professional development. A number of free training course materials are available to help with this *(37-39)*. As a further step, consideration could be given to making involvement in safety and quality improvement a requirement for ongoing training and professional licensure.

In addition to formal education, informal approaches could also be applied to build the capacity of health workforce to improve safety. This may include holding regional meetings and coaching sessions to review patient safety incidents and areas for improvement, and holding small team meetings to upskill staff.

9. Focus on those at higher risk of safety incidents

Some people are at greater risk of safety incidents in primary care. These include children, older people, those living in residential care or nursing homes and people with multiple health conditions. People with simultaneous mental health and physical health issues are also at increased risk of safety incidents.

Focusing on groups at higher risk may improve the quality and safety of care by providing more personalized care and ensuring smoother transitions between and within services. For instance, upskilling professionals in how to identify and treat depression may have an impact given the high rate of adverse events among those with combined mental and physical health issues.

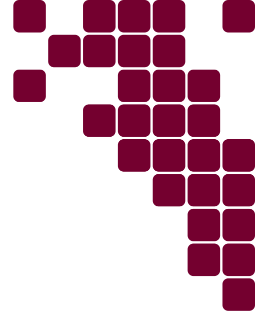
Across the world, most systems were not designed to care for people with multiple health conditions. Systems may thus need to focus more on what can be done to improve care for people with multiple conditions, including whether social interventions would be more worthwhile than increasing medicalization.

A number of guidelines and toolkits suggest practical steps to better support people at higher risk of safety incidents *(40-44).*

10. Celebrate successes and share learning with others

Local teams, regions and countries should celebrate their successes and share learning with others. Hearing what has worked well can spark ideas in others and help to continue the momentum towards safer primary care.

Ongoing research plays a key role in identifying what works best to improve safety and how to implement best practices and success stories across diverse care settings. Although the technical series has drawn together a wide range of evidence and expertise, it has also highlighted a number of gaps about what works best to improve patient safety in the primary care context. By continuing to promote learning through research, and publishing and disseminating findings, countries could contribute to knowledge in this area.



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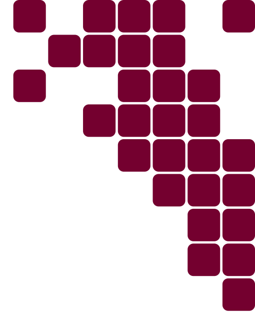

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