

# Engaging Patients for Patient Safety

## ADVOCACY BRIEF









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## Advocacy brief

Engaging patients for patient safety: advocacy brief

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## Approach to the development of this publication

WHO worked jointly with a working group comprised of patient representatives and patient safety experts to plan, coordinate and co-lead the development of this advocacy brief.

Its content was structured to follow the outline of the Global Patient Safety Action Plan 2021–2030, which defines and makes recommendations to stakeholder groups. Background information was developed following a detailed search of the global literature on patient engagement and patient safety. References were scrutinized individually and relevant figures and conclusions were selected for citation in the brief. Priority was given to systematic reviews and publications taking a broad overview of global patient safety statistics and the role of patient engagement in the improvement of health care safety and quality. After the zero draft was developed, the document underwent a review process by the responsible technical unit (Patient Safety Flagship Unit) and the World Patient Safety Day 2023 planning group (a subset of the World Patient Safety Day 2023 steering committee).

### Declarations of interest

All external experts involved in the development of this publications submitted a declaration of interest to WHO, which discloses any potential conflicts of interest that might affect, or might reasonably be perceived to affect, their objectivity and independence in relation to the subject matter of the normative guidance. WHO reviewed each of these and concluded that none could give rise to a potential or reasonably perceived conflict of interest related to the subjects covered in this guidance.



## Summary

Patient engagement<sup>1</sup> in health care is defined as “the facilitation and strengthening of the role of those using services as co-producers of health, and health care policy and practice” – that is, active patient involvement both in individuals’ own health care and in the improvement of the health system (1). This is a multi-layered concept that encompasses the many ways that patients and families interact with health systems, and understand and care for their own health. For example, it includes human interactions in relation to surgical procedures and hospital stays, conversations in the offices of health and care workers, health literacy at home, and the daily lives of elderly people in care homes.

Patient engagement is increasingly recognized as being crucial to improving health outcomes and the overall quality of life of patients and their families (2). If successfully implemented, patient engagement can significantly contribute to a reduction in adverse events (3), which place a significant burden on patients, health systems and even economies. Patient engagement has been shown to reduce health care costs, positively influence patients’ experiences with health care, improve patient outcomes, and improve the performance of health systems (2–4). However, a dedicated effort, supported by appropriate resources and policies, is required to support the engagement of patients as valued partners at all levels of health care provision. Several strategies to improve patient engagement in patient safety are well known, yet uptake has been slow in almost every country. The *WHO Global Patient Safety Action Plan 2021–2030* (5) identifies patient and family engagement as one of the key strategic objectives for achieving the maximum possible reduction in avoidable harm due to unsafe health care. Recognizing the central role that patients, their families and caregivers play in promoting safer care, “**Engaging patients for patient safety**” has been selected as the theme for World Patient Safety Day 2023 with the slogan “**Elevate the voice of patients!**”

This advocacy brief aims to raise awareness and calls for action to step up patient engagement in health care, in line with the objectives of World Patient Safety Day 2023. It encourages action by various stakeholders, including policy-makers, governments, organizational leaders, health and care workers, patients and patient advocates, nongovernmental organizations, and civil society organizations, and highlights the role of these stakeholders in successfully engaging patients to improve patient safety.

## The burden of harm

Patient harm exerts a high public health burden worldwide. In high-income countries, around 1 in 10 patients are harmed while receiving hospital care; low- and middle-income countries carry an even heavier burden of mortality and morbidity due to adverse events (6, 7). Globally, medical errors and low-quality health care cause more deaths and disability than does lack of access to care (8). It is estimated that more than 3 million deaths occur annually due to unsafe care, causing a burden of harm equivalent to the burden of major infectious

diseases or traffic injuries as measured in disability-adjusted life years (9). The financial cost for health systems and economic loss due to patient harm have been estimated at trillions of US dollars annually (6).

A wide range of patient safety measures are urgently needed to address this major global public health challenge and reduce patient harm, and patient engagement and empowerment are being seen as among the most effective approaches for doing so.

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<sup>1</sup> In the context of this document, ‘Patient engagement’ also includes the engagement of family members and caregivers.

## Patient engagement, a cornerstone for improving patient safety

Health systems typically involve multiple providers working in different settings, at different levels of care provision and providing a range of health services. Most of the time, patients and their families are the only constant as they journey through these complex systems and they can, therefore, hold critical information on and give useful insights into care processes and health system performance. Additionally, they generally allocate a greater amount of time towards self-care and taking their personal health decisions outside health care facilities. Patients therefore need to have considerable knowledge and possess certain skills to take responsibility and serve as drivers of their own health. The Organisation for Economic Co-operation and Development has estimated that meaningful patient engagement could reduce the burden of harm by 15%, saving billions of dollars every year (3).

**Patient engagement reduces harm and can lead to improved health outcomes, greater efficiency in health systems, reduced health care costs, and enhanced trust in health systems.**

Engaging patients at multiple levels of care provision carries many advantages (see Box 1): it positively influences patient experiences with health care and organizational culture, improves communication between patients and health and care workers and makes health service delivery more people-centered (2, 3, 10–12). When people are engaged, their health literacy also improves and they are better able to access health information, understand their health conditions, and communicate their health needs more effectively. This produces a ripple effect across the entire system, leading to improved patient safety, better patient health outcomes, an enhanced patient experience, improved efficiency of health systems and reduced health care costs (2, 3).

**Patient engagement extends to patients and families as advocates included on boards and committees of hospitals and organizations.**

Patient engagement calls for the inclusion of patients and families as health advocates on the boards and committees of hospitals and organizations working to improve health care services. It includes patient involvement in government and community oversight

of health care, transparency on safety issues and inclusion of patients in robust and responsive patient safety reporting systems.

Patients who feel heard are more likely to get involved, as patient advocates, in their local health facilities. When patients are engaged, communities are engaged, and will often be more likely to support health initiatives and local health care institutions.

### Box 1. Potential benefits of patient engagement

- Careful and systematic implementation of patient engagement strategies and health literacy programmes could reduce aggregate harm by up to 15% (3).
- Patient engagement can lead to a reduction in hospitalizations and litigation, and can result in improved effectiveness, efficiency, quality of health services, quality of life, and responsiveness (2).
- Patient engagement can increase patient awareness, health literacy, adherence to treatment and overall experience with health care (4).
- Engaged patients can improve health outcomes and transform health care (2).
- Patient engagement can increase the productivity of service providers (2).

## The global status of patient engagement for patient safety

While the principles and concepts of patient engagement have gained wide acceptance, patient engagement for patient safety continues to lag in practice. The findings from the Member State survey on implementation of the *Global Patient Safety Action Plan 2021–2030* (5) indicate a pressing need for policy development and resource investment at national and subnational levels, as patients' engagement in safety initiatives is unsatisfactory. Just 19% of the 102 countries that completed the survey reported the inclusion of patient representatives on committees for safety policies and programmes, even though about two thirds of the countries had identified patient organizations, networks and civil



society organizations working for patient safety. Only 13% of countries had patient representatives on the governing bodies of more than 60% of their hospitals. And while most countries had mechanisms for obtaining safety- and quality-related feedback from patients and families, only 23% reported using this feedback for improvement (13).

It is also clear that Member States are at different stages on the journey to patient engagement. The majority of countries showing advances in patient engagement are high-income countries, but even those that are farthest along have not tended to view patient engagement as a means of improving patient safety. A shift in emphasis to viewing patient safety as a fundamental human right that should take priority in patient engagement is an important principle on which to base strategies. In this regard, it is encouraging that close to half (44%) of the countries surveyed had established a patient rights charter that included patient safety (13). Nevertheless, patient harm remains too high across the globe. Especially in the wake of the COVID-19 pandemic and the resulting stresses caused to health services, it is clear that there is a need for changes to help patients, families, health professionals and policy-makers work together to confront both present and future challenges in patient safety.

## The global response

Patient engagement was identified as foundational by WHO as far back as 1978, when the Declaration of Alma-Ata on Primary Health Care stated: “The people have the right and duty to participate individually and collectively in the planning and implementation of their health care” (14). In 2005, the Patients for Patient Safety programme was established to help embed patient engagement into WHO patient safety efforts (15). In 2016, in support of Sustainable Development Goal target 3.8 on universal health coverage, the Sixty-ninth World Health Assembly approved the *WHO Framework on Integrated People-centred Health Services*, whose first strategy is specifically about engaging and empowering people and communities (16). This was underscored by a call in the Astana Declaration on Primary Health Care (2018) for the promotion of health literacy and recognition of the right to the acquisition of information, knowledge, skills and resources needed to maintain health (17). To translate the commitments made in the Astana Declaration, an operational framework was developed

### Box 2. Global milestones in patient engagement and empowerment

**1978:** Declaration Alma-Ata on Primary Health Care supports the right of people to participate individually and collectively in the planning and implementation of their health care.

**2005:** World Alliance for Patient Safety establishes the WHO Patients for Patient Safety programme.

**2016:** Sixty-ninth World Health Assembly approves WHO Framework on Integrated People-centred Health Services.

**2016–2019:** A series of global ministerial summits on patient safety recognize the central role of patient engagement and empowerment in the delivery of safe health care.

**2018:** Astana Declaration promotes health literacy and the right to information, knowledge, skills and resources needed to maintain health.

**2019:** Seventy-second World Health Assembly adopts resolution WHA72.6 calling for global action on patient safety.

**2019–2022:** World Patient Safety Days with consecutive annual themes highlight patient engagement as a key strategy for patient safety.

**2021:** *The WHO Global Patient Safety Action Plan 2021-2030* identifies patient and family engagement as one of its seven strategic objectives.

**2023:** Fifth Global Ministerial Summit on Patient Safety sets forth patient engagement for implementation.

**2023:** World Patient Safety Day is dedicated to the theme of “Engaging patients for patient safety”.

that inscribes patient engagement as one of the levers needed to accelerate progress in strengthening primary health care-oriented systems and ultimately lead to demonstrable improvements in health for all, without distinction of any kind (18). In a series of global ministerial summits on patient safety, which began in 2016, health ministers from around the world have reiterated the fundamental role of patient engagement in achieving safer health care (Box 2) (19).

In 2019, the Seventy-second World Health Assembly passed a resolution on Global action on patient safety, which included patient engagement as a key

intervention (20). As part of this effort, WHO developed the Global Patient Safety Action Plan 2021–2030, a comprehensive framework to support progress in patient safety that highlighted the advancement of patient and family engagement as one of seven strategic objectives (5). World Patient Safety Day, established by the same resolution, is observed annually on 17 September in support of the worldwide patient safety movement. Since its inception, [World Patient Safety Day](#) has been widely celebrated and has substantially contributed to raising awareness of patient safety. WHO thus continues its pursuit of making patients partners in driving their own health a global health priority through selecting “**Engaging patients for patient safety**” as the theme for [World Patient Safety Day 2023](#), with the slogan “**Elevate the voice of patients!**”.

## Reducing harm in health care through patient engagement

The *WHO Global Patient Safety Action Plan 2021–2030* (5), with its vision of “a world in which no one is harmed in health care, and every patient receives safe and respectful care, every time, everywhere”, proposes strategies and actions under its fourth strategic objective: “Engage and empower patients and families to help and support the journey to safer health care”. This strategic objective focuses on involving patients and families at all levels, from each individual health care encounter to enhance engagement across the organizational and policy levels (5). The recommended actions align with the *WHO Framework on Integrated People-centred Health Services* (16), which proposes education and support for patients, families and communities, including outreach to marginalized citizens. The implementation strategies outlined in the Global Patient Safety Action Plan 2021–2030 include:

- co-developing policies and programmes with patients;
- learning from patient experiences for safety improvement;
- building the capacity of patient advocates and patient safety champions;
- establishing a culture of openness and transparency through initiatives such as shared decision-making, patient reporting systems, and disclosure of patient safety incidents to patients and families;

- providing patient safety and patient engagement education to patients, community members and health and care workers.

### Global actions to strengthen patient engagement in patient safety

- Strengthen the WHO Patients for Patient Safety programme.
- Establish Patients for Patient Safety networks in every country.
- Embed patient engagement in the principles and practice of patient safety through national patient safety rights charters.
- Increase public awareness and provide information and education about patient safety.
- Amplify the voice of patients as a force for the improvement of patient safety.

## The role of different actors in patient and family engagement

- **Patients, families and caregivers** have an essential role to play in their own health care. At the level of direct care, patients should speak up, raise concerns and flag inconsistencies and inaccuracies in the care being provided. They can seek to build their capacity to report errors and demand full disclosure when safety incidents do occur. The lived experiences of patients and their families are a key part of success, not only to understand and avoid future occurrences when looking retrospectively at adverse events or near misses, but also in proactively building a culture of safety and evaluating and redesigning organizational systems and services. At the governance level, patients’ insights and deliberations can be used to inform national and local policies, in developing standards, designing and implementing health care delivery systems, auditing, and directing health research to ensure that health systems, initiatives and programmes are well aligned with patients’ priorities, and address their needs. Similarly, patients can work in partnership to design, develop and implement patient engagement strategies. The *Global Patient Safety Action Plan 2021–2030* (5) recognizes that patients are not the only ones who need to be engaged, but they must be welcomed and supported in order to provide central and meaningful input.

- **Governments** are responsible for developing national policies and plans, which should be developed in close collaboration with patients or their representatives, including through welcoming patients onto boards and committees at the national level. Governments play a key role in establishing regulatory and legislative mechanisms, such as patient charters, and developing standards for effective patient engagement.
- It is equally important to identify, grow and incentivize **health care leaders** with values aligned to patient and family engagement. Such leaders would then more naturally champion patient participation in their governance structures, in their strategic priorities, and in their budgets. Their moral imperative would also be to integrate patient and citizen roles into their organization's work and to create a culture of safety and respect that encourages active listening to the voices of patients within their organizations. This works both ways, in that a culture that is safer for patients will usually be safer for health and care workers too.
- **Health facilities and services** can focus on creating a transparent and receptive environment, with policies and mechanisms for people-centred care, such as shared decision-making, patient access to medical records, pathways for family escalation of care, and full disclosure of safety incidents. They can provide information and training on patient engagement and patient safety to both patients and health and care workers. They can integrate patients' perspectives throughout their operations by appointing patient representatives to their governing boards and other committees across their organizations.
- **Patient groups and other stakeholders**, such as nongovernmental organizations and academic and research institutions, can serve the cause of patient engagement in patient safety in a variety of ways: by raising awareness, by conducting relevant research, and by disseminating information. They can act as conveners for patients and patient groups and help prepare patients to serve as public speakers or on committees.
- **Health and care workers**, the facilitators of patient engagement, can best support their patients by building their capacities to become more informed, more engaged, and more proactive in their care. A cultural shift from former models of care, whereby clinicians strongly influenced patient decisions, to a more collaborative partnership between patients and health and care workers is needed.

Engaged health and care workers can assist in improving decision-making, educating patients about self-care, managing their medical conditions and maintaining good health. They can equally help to create a system that supports enhanced engagement and keeps patients fully involved in their own care. An important factor influencing the success of engagement efforts is the health literacy level of patients. This necessitates the practice of effective communication by health and care workers to better engage the diverse spectrum of patients seeking health care. Health and care workers should build collaborative partnerships with the patient and family while delivering health care.

Health and care workers are increasingly recognizing both the practical advantages of and the ethical obligation for patient engagement. Patient safety is a priority at all levels of health care provision, and engaging patients is one of the most effective and rewarding ways of improving patient safety. Getting started requires a strong commitment to contribute to the safety of health care. The time has come. Let's close the gap between the care we provide and the care we should be providing. Let's elevate the voice of patients for patient safety throughout the world!

## Call to action

Through this advocacy brief, WHO calls on all stakeholders to assume their respective roles in patient engagement for patient safety and to implement the Global Patient Safety Action Plan's suggested actions for effective patient and family engagement.

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