



Patients for Patient Safety – Statement of Case

In October 2004 the World Health Organization (WHO) officially launched the World Alliance for Patient Safety dedicated to “bringing significant benefits to patients in countries rich and poor, developed and developing, in all corners of the globe.” The Alliance was established in response to Resolution WHA55.18, adopted by WHO’s 55th World Health Assembly in May 2002, which urged member states to pay the closest possible attention to patient safety and establish science-based systems for improving safety and the quality of care. The resolution reflects and advances various calls to action to make patient safety a public health priority. _

Including patients and families, consumers and citizens in patient safety work

Patients for Patient Safety, one of six action areas of the World Alliance, is designed to ensure that the perspective of patients and families, consumers and citizens – whichever term resonates best --in both developed and developing countries is a central reference point in shaping the important work of the Alliance. Patients and their lay caregivers see things that busy healthcare workers often do not. It follows that safety will be improved if patients are included as full partners in reform initiatives, and learning can be used to inform systemic quality and safety improvements.

Partners in advancing safe and compassionate care

There is now growing discussion in the international medical and public health community about implementing patient-centered, systems-based healthcare. When patients and families are included in gatherings of patient safety stakeholders, their primary contributions has been to share stories of preventable injury in healthcare and their impact on patients' lives. We are gratified to have made this contribution. The voice of patients and families who have suffered preventable medical injury is a powerful motivational force for healthcare providers across the globe who wish, first, to do no harm.

However, patients have much more to offer than visceral reminders to healthcare workers, administrators and policymakers that we are victims of tragic medical errors. Important as that perspective is, a victim orientation does not position us well as partners working with healthcare providers to prevent harm. Indeed, the perception that patients and their families are helpless or antagonistic victims has served to distance us from playing meaningful roles in the development and implementation of patient safety work in the past and generated fear among some clinicians who would have otherwise engaged with us. Patients and their families have needs and wants when things go wrong. We need to be told that something has gone wrong and we want healthcare service deliverers to be open and involve us in the investigation to find the root causes.

At the healthcare service delivery level, consumers who wish to contribute knowledge gained or lessons learned have often found few effective pathways for doing so. Particularly after healthcare accidents occur, a “wall of silence” may descend and productive interaction may cease. When consumers register concerns, their actions often are perceived as adversarial threats or unscientific anecdotes that lack evidence, rather than potential knowledge contributions.

Although there are notable exceptions, at the policymaking level consumer participation tends to be marginalized, often by well meaning leaders who assume consumers to be unable to appreciate the complexity of healthcare. Such an approach fails to take into account that many consumers offer the richest resource of information related to medical errors as many have witnessed every detail of systems failures from the beginning to end.

Patients and consumers who choose to partner with health care policy makers and providers are highly knowledgeable, motivated and eager to contribute. We approach our role with a profound sense of responsibility and desire to help create a healthcare system that is safe, honorable and compassionate for patients and healthcare workers alike. We are here to challenge health care to be truly patient-centered – especially when it is resistant to change or slow to make safer care a priority — but most fundamentally, we are here to partner to help make care better.

Patients for Patient Safety – Building an infrastructure for active, informed global partnership

Working through the Alliance and the WHO, Patients for Patient Safety will assist and support efforts to develop a collective voice for consumers, citizens, patients or lay caregivers who are interested in sharing their experience and lessons learned in order to improve safety. We will foster the role of consumers as partners in the delivery of care who are owed honesty and respect, and who have responsibility for respectfully contributing to policymaking activities that seek to advance systems-based, patient-centered care.

Together and integrated with the other action areas of the Alliance, we will develop opportunities for consumer voices to be heard and our participation in creating public awareness about inherent healthcare risks, educating the public about systems approaches to risk management, reporting errors or healthcare failures in ways that contribute to systemic learning, disseminating research and sharing solutions that can prevent patient harm.

By contributing our voice, our experience and our perspective, we will ensure that the work of the World Alliance for Patient Safety is authentically patient-centered. We invite patients, providers and participating nations interested in productive change through partnership to join us in carrying forward this important and transformative work.

_ See WHO Patient Safety Homepage, www.who.int/patientsafety/en/, accessed 10/04/04.

_ The IOM estimated medical error to be between the 4th to 8th largest causes of preventable death in the United States. Kohn LT, Corrigan JM, Donaldson M, Eds. To Err Is Human: Building a Safer Health System, Washington, DC, National Academy of Sciences, 1999.