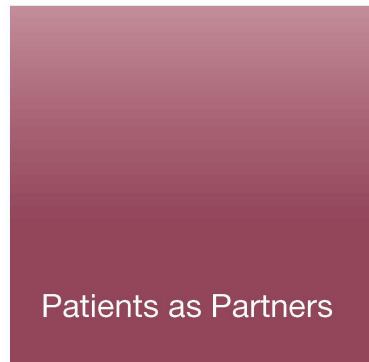


Patients for Patient Safety

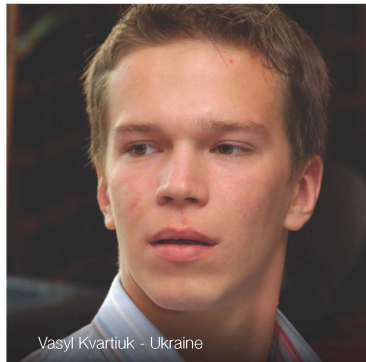
Partnerships for Safer Health Care



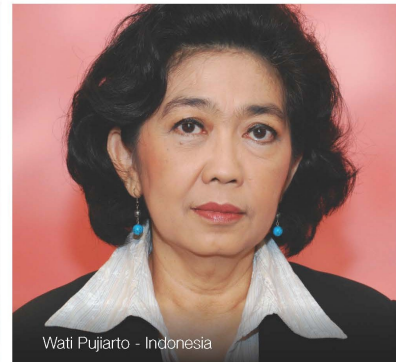
Adoración Carpintero - Spain



Patients as Partners



Vasyi Kvartiuk - Ukraine

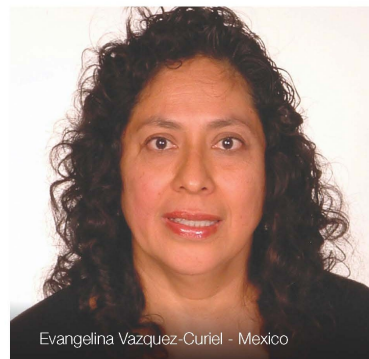


Wati Pujiarto - Indonesia



Les patients en tant que partenaires

与病人并肩合作



Evangelina Vazquez-Curiel - Mexico



J. S. Arora - India



El paciente como aliado

المرضى كشركاء



Christine Perera - Sri Lanka



Hussain Jafri - Pakistan



ПАЦИЕНТЫ КАК ПАРТНЕРЫ



Robinah Kaitirimba - Uganda



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Patients for Patient Safety

Partnerships for Safer Health Care

Patient safety is a global health issue. Every year millions of patients are harmed by unsafe health care. In developed countries, 5–10% of hospitalized patients acquire an infection; between 7.5% and 10.4% of patients in acute care experience an adverse drug event. About 5–15% of HIV infections in developing countries are due to unsafe blood transfusion. More than 500 000 women die each year during pregnancy or childbirth, 99% of them in the developing countries. Globally, 5.5% of injections are given with syringes and needles reused without sterilization.

But patient safety is not just about statistics. Adverse events damage the lives of real people – patients and families – who are affected, harmed or die as a result of that unsafe care. Unsafe care also places a large and needless financial burden both on patients and on the health-care systems that treat them.



The World Alliance for Patient Safety was launched in October 2004 with Professor Sir Liam Donaldson as its founding Chair. The Launch ceremony saw the participation of Dr E. Samba and Dr M. Rosas, Former Regional Directors of AFRO and AMRO/PAHO respectively, Dr Carolyn Clancy, Former Director of the Agency for Healthcare Research and Quality, Ms Susan Sheridan, PFPS Founder, now Director of Patient Engagement at the Patient-Centered Outcomes Research Institute (PCORI) and the Late WHO Director-General, Dr Lee Jong-wook. In 2009, it was renamed the WHO Patient Safety Programme, with Sir Liam Donaldson taking on the role of WHO Envoy for Patient Safety in 2011.

Achieving safer health care requires global leadership, concerted efforts and a commitment to learning from errors and patients' experiences. In 2004, in response to World Health Assembly Resolution 55.18, the World Health Organization (WHO) established the World Alliance for Patient Safety (renamed WHO Patient Safety in 2009) to coordinate and accelerate global efforts to improve patient safety.

Patient and community engagement was one of the six initial core priorities of the World Alliance for Patient Safety and remains a core priority of WHO Patient Safety today.

Patients and families – the untapped resource

Health-care systems are increasingly complex and every point in the care process contains some inherent risk. Adverse events or harm may result from problems in practice, products, procedures or systems and are not usually the fault of the provider. A patient may receive care from different facilities and multiple care providers from different disciplines. The patient and family are the only people who are present throughout the full continuum of care. They are a repository of critical information and, when engaged and empowered, can play a significant role in ensuring a positive health-care experience. For the same reason, engaging patients and families who have experienced harm can provide insights and learning concerning system failures. It is therefore essential to ensure that the patient voice is heard in the global arena of health care.

To achieve changes with lasting impact, patients must be at the very centre of the quest to improve patient safety.



Evangelina Curiel (Mexico) collaborates with government officials to raise awareness of patient safety at policy level.

“Facts do not change feelings and feelings are what influence behavior. The accuracy, the clarity with which we absorb information has little effect on us. It is how we feel about the information that determines whether we will use it or not.”

(Vera Keane, Bulletin of Nurse Midwifery, 1967)



Nagwa Metwally (Egypt) works with patients, health-care professionals and government, and has in particular successfully encouraged wider use of the WHO Surgical Safety Checklist.

Patients for Patient Safety – a WHO programme

The Patients for Patient Safety programme is a core priority of the WHO Patient Safety Programme (PSP). Guided by an Advisory Group made up of patients and with the Secretariat based at WHO, the programme supports a global network that brings together patients, families, health-care professionals and policy-makers who work in partnership to improve health-care safety. Patients for Patient Safety is a unique approach within WHO to engage and empower patients in the belief that by sharing experiences and expertise, each individual and organization can learn and improve. Patients for Patient Safety (PPFS) uses the patient experience as a learning tool and promotes patient leadership and involvement in patient safety efforts at all levels.

Patients for Patient Safety



Partnerships for safer care

Patient safety is a major public health issue. Globally, millions of patients experience preventable harm every year.

Evidence supports the importance of the role of engaged patients in the drive to improve safety.

Patients for Patient Safety is a WHO programme that aims to incorporate the patient voice in all levels of health care.

Patients for Patient Safety empowers and facilitates patients and their families to advocate for change collaboratively.

Encouraging partnership, empowerment and inspiring action on patient safety worldwide ©WHO, 2013

Patients for Patient Safety programme information postcard.

“Engaged, empowered patients - A learning health care system is anchored on patient needs and perspectives. It promotes the inclusion of patients, families, and other caregivers as vital members of the continuously learning care team”

Best Care at Lower Cost: The Path to Continuously Learning Health Care in America. (Institute of Medicine 2012)



Participants in the first PFPS workshop, London, November 2005.

The London Declaration (2006)

“In honour of those who have died, those left disabled, our loved ones today and the world’s children yet to be born, we will strive for excellence, so that all those involved in health care are as safe as possible as soon as possible. This is our pledge of partnership”

Patients for Patient Safety – a network

The *Patients for Patient Safety* global network was created following the first WHO Patients for Patient Safety workshop, held in London in November 2005, which brought together 24 patients and professionals from 20 countries. The participants’ collective passion led to the development of the “*London Declaration*”, which enunciates the common vision, guiding principle and a commitment for positive engagement. Ever since, participation in a PFPS workshop, a structured orientation programme, and accepting the “*London Declaration*” has been the centerpiece of the Patients for Patient Safety membership initiation.

The Patients for Patient Safety network now has over 250 members spread across 52 countries. Many of them are patients or families who have been affected by unsafe care. The motivation is often to give some meaning to tragedy by sharing their experience and expertise to raise awareness and catalyze change. They are global “*champions*” for patient engagement and empowerment, representing the patient voice at medical school councils, on hospital boards, at policy tables and at professional conferences around the world. Some write newsletters and journal articles and develop educational materials; others have set up their own patient-led organizations, and teach medical students and work with health care professionals to change systems. They take this advocacy role on an individual basis, reflecting their personal experience. They do not speak for WHO or represent WHO, but they advocate for WHO policy on patient safety and quality improvement.



Participants in the PFPS in-country meeting, Toronto, March 2013 (Photo: Canadian Patient Safety Institute).



PFPS members on a trek to raise awareness and promote patient safety.



Dr Arora (India) participating in the SEARO regional PFPS workshop, Jakarta, July 2007.

Patients for Patient Safety Strategy

Patients' perspectives are valuable in identifying gaps in service, evaluation and the development of solutions that are responsive to patients' need and are authentically patient-centred. Therefore, patient engagement must be embedded in all the steps of health-care programme design, service delivery and policy development, implementation and evaluation.

In 2010, WHO reviewed how patients advocated for patient safety improvement. Through a survey and key informant interviews, the review captured the variety of activities and roles related to patient safety with which Champions were involved. It also identifies areas where the Patients for Patient Safety network required support and guidance to enable effective partnership and collaboration with stakeholders. The results were used to inform the PFPS Strategy, which sets objectives for the programme for 2012-2015. This Strategy is also in alignment with the WHO Patient Safety Programme overall strategic plan.



A PFPS member educating community members about health rights.

The Patients for Patient Safety Strategy 2012-2015

- Raising awareness of patient engagement
- Building up resources to support advocacy
- Building & strengthening capacity of patients for effective engagement
- Evidence-based tools and interventions that promote empowerment and partnership

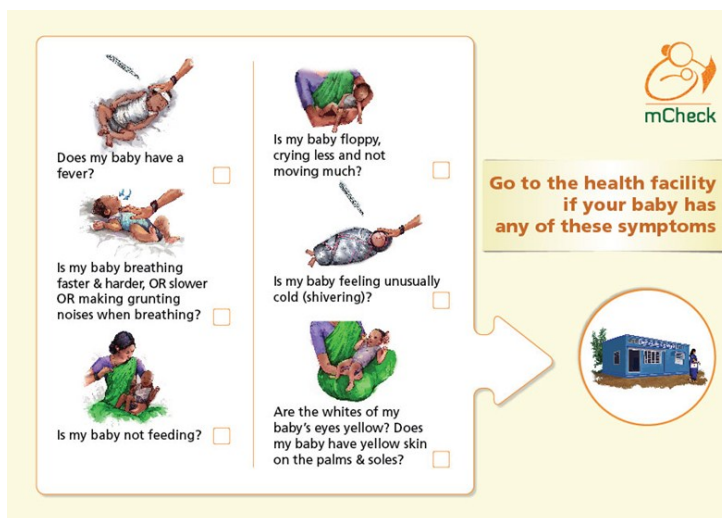
Patients for Patient Safety core values

- Collective action
- Openness
- Honesty
- Collaborative partnership
- Meaningful engagement and empowerment

Patients for Patient Safety projects

The following are some of the projects in which patients are currently engaged:

- **5 May Save Lives: Clean Your Hands:** PFPS collaborates with colleagues in the WHO Patient Safety Programme to promote patient participation in improving hand hygiene practices worldwide. This campaign is a flagship activity of the WHO's first Global Safety Challenge - Clean Care is Safer Care.
- **WHO Mother-Baby 7 day mCheck Tool:** Patients for Patient Safety collaborated with colleagues in the WHO Reproductive Health Research department to create a patient-held tool aimed at empowering mothers and families to identify danger signs in mother and baby during the first seven days after birth so that they can seek appropriate health care.



Draft mCheck tool, utilising text and images to illustrate danger signs.

- **PFPS Patient Training Guide:** This guide for the training and orientation of individuals wishing to join the Patients for Patient Safety network is a collaborative project between WHO and international collaborators in partnership with patients.
- **Patient Engagement Guide for Hospitals:** This is a review of ways in which hospitals can engage patients and their families in patient safety improvement efforts, intended to inform and encourage collaboration.
- **Patient Experience Library:** Patients for Patient Safety compiles patients' stories and experiences to illustrate the ways in which patients use their experience to catalyze improvements in patient safety.

"We cannot change the past, but we can use that past to inform the present and in the present we can influence the future – and isn't it so much better if we do that together, in partnership."

(Margaret Murphy 2013)



Some of the individuals who have helped to build Patients for Patient Safety



Margaret Murphy (Ireland) – founding member, 2005

Lead Advisor and Chair of the PFPS Strategy Group

Margaret Murphy's life changed in 1999 when her 21 year old son, Kevin, died due to medical error. She sees adverse events as opportunities for learning and has used her personal experience to advocate for culture and system change. She has partnered and collaborated with health professionals and policy-makers, contributing to policy-making, standard-setting, professional regulation, education and research at local, national and international levels.

Margaret contributes to WHO policy on patient empowerment and engagement, leading the PFPS Strategy Group. She fosters patient safety culture, contributing to the WHO Patient Safety Curriculum Guides and through educating health professionals, presenting to medical students, health-care professionals and at conferences. As a panel member, she brings the patient voice to the assessment of grant proposals of the National Institute for Healthcare Research (UK), influencing their research agenda.

Nationally, Margaret serves on a number of committees that create, implement and monitor policy on patient safety and health quality, as well as on professional regulation in Ireland. Margaret received the Outstanding Achievement Award in Healthcare (Healthcare Innovation Awards, 2012).



Stephanie Newell (Australia) – founding member, 2005

Stephanie Newell was motivated to advocate for all levels and all providers of health care, to partner with health consumers to create safer and more effective health care following the death of her son, Marcus, in hospital in 2002. Stephanie's focus has been in the areas of:

- Health policy – contributing to the inclusion of consumer focused elements of national policy, accreditation and standards in diagnostic imaging and safety and quality accreditation;
- Health staff education – developing and facilitating workshops on partnering with health consumers in individual care and organizational and systems improvement;
- Creating networks between health consumers and health-care providers, administrators and policy makers – in 2009 Stephanie project-managed and co-facilitated the first Patients for Patient Safety three-day workshop in Australia. Outcomes from the workshop include an educational DVD and the Perth Declaration for Patient Safety.



Barbara Farlow (Canada) - joined in 2007

Barbara's passion to advocate for health-care improvements came as a result of inappropriate care her daughter, Annie, received leading to her death at the age of 80 days in 2005. Barbara has shared Annie's story at numerous health-care conferences, workshops and universities across Canada. To give a voice to families of children with medical conditions, Barbara collaborated with two physicians and co-authored a research paper that was published in *Pediatrics* in 2012.

Barbara served as the public member of the Communication Advisory Group of the Canadian Patient Safety Institute, as an advisor to the DeVeber Institute of Bioethics and Social Research and in 2012, became the first Honorary Patient Perspective Board Member of the International Society for Quality in Health Care. Through these roles, she encourages and support policy-makers to engage patients and families in all aspects of health care.



Nagwa Metwally (Egypt) – founding member, 2005

During her time as president of the Egyptian Diplomatic Spouses Association, Nagwa became passionate about health-care standards and organized a group of volunteers to monitor care at the largest public maternity hospital in Cairo. Nagwa works at many levels and with many stakeholder groups, from medical students, patients and nurses, to doctors, hospital management and the Ministry of Health, to raise awareness of patient safety. She has championed the use of the WHO Surgical Safety Checklist and has highlighted important issues such as hygiene and patient satisfaction.

As a board member of the organization that governs all hospitals and medical schools and as a member of a hospital board, Nagwa works closely with hospitals and universities to promote health-care leadership and accountability in patient engagement.



Robinah Kaitiritimba (Uganda) – founding member, 2005

Robinah was one of the first people from Africa to join the PFPS network in 2005. Her brother died at the age of 14 after contracting HIV/AIDS through an unsafe blood transfusion. Many of her colleagues also had sad stories to tell.

Robinah leads a not-for-profit organization, which she co-founded in 1998, to advocate for the rights and responsibilities of patients. The organization has brought together mothers, health workers, social scientists and communities to share information, discuss issues, build awareness on mutual rights and shared responsibilities and develop strategies for partnership. It has spearheaded the development of a patient rights charter, which provides a policy and legal framework for the empowerment of consumers. The patients' Charter was launched by the Ministry of Health in 2010 and it is now displayed in health-care facilities around the country.



Helen Haskell (US) - joined 2005

Helen Haskell came to patient safety through the tragic loss of her young son Lewis, who died from medical error in an American teaching hospital.

Helen has been a representative of the patient voice in American health-care policy for many years. Her work with policy-makers and health-care professionals in her home state of South Carolina led to a statewide journey of patient safety improvement that includes the universal implementation of patient-activated rapid response systems and use of the WHO Surgical Safety Checklist, among other changes. Helen writes patient educational materials and teaches classes for patients on navigating the health-care system. She regularly addresses medical and nursing students and has collaborated with professional educational organizations to produce videos that are widely used to teach nursing and medical students and health-care professionals about patient safety, nursing safety, and medication safety.



Susan Sheridan (US) – founding member, 2005

With the support of WHO, Susan set up the Patients for Patient Safety network, participating in the inaugural PFPS workshop in 2005. Her motivation to be part of efforts for health care is to honour her son who suffered Kernicterus when his neonatal jaundice was left untreated and her late husband who died after a cancerous tumor was miscommunicated as benign, resulting in delayed treatment.

Susan successfully advocated for the inclusion of universal pre-discharge bilirubin screening for newborns in American Academy of Paediatrics guidelines, and was successful in advocating for the classification of kernicterus as a 'never event' by the US National Quality Forum. Susan has co-founded patient organizations, produced various publications and is a recognized international expert on patient empowerment. She now serves as Director of Patient Engagement in a big organization dedicated to promoting patient-centred care. Her leadership and passion has provided guidance and inspiration to a growing network of patients around the world.

The London Declaration

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We, Patients for Patient Safety, envision a different world in which healthcare errors are not harming people. We are partners in the effort to prevent all avoidable harm in healthcare. Risk and uncertainty are constant companions. So we come together in dialogue, participating in care with providers. We unite our strength as advocates for care without harm in the developing as well as the developed world.

We are committed to spread the word from person to person, town to town, country to country. There is a right to safe healthcare and we will not let the current culture of error and denial, continue. We call for honesty, openness and transparency. We will make the reduction of healthcare errors a basic human right that preserves life around the world.

We, Patients for Patient Safety, will be the voice for all people, but especially those who are now unheard. Together as partners, we will collaborate in:

- Devising and promoting programs for patient safety and patient empowerment.*
- Developing and driving a constructive dialogue with all partners concerned with patient safety.*
- Establishing systems for reporting and dealing with healthcare harm on a worldwide basis.*
- Defining best practices in dealing with healthcare harm of all kinds and promoting those practices throughout the world.*

In honor of those who have died, those left disabled, our loved ones today and the world's children yet to be born, we will strive for excellence, so that all those involved in health care are as safe as possible as soon as possible. This is our pledge of partnership.

March 29, 2006



**World Health
Organization**

World Health Organization,
Avenue Appia 20,
CH-1211 Geneva 27,
Switzerland

Email: pfps@who.int
Tel: +41 (0) 22 791 5060
www.who.int/patientsafety