Partnership with patients to improve patient safety

Stephanie M Newell, Dorothy A Jones and Martin J Hatlie

"We cannot stay silent any longer, waiting and watching as more people are harmed in health care."¹

rror in health care remains a significant problem in Australia, despite more than a decade of efforts to remedy it. Since the landmark 1994 Quality in Australian Health Care Study (QAHCS),² Australian governments, both state and federal, have introduced various clinical governance, health policy and structural reforms to improve the quality of patient care and reduce preventable harm to patients. However, adverse events have not been measurably reduced. Many acknowledge that barriers to change are embedded in the culture and norms of health care. So, 15 years after the QAHCS and 5 years after a follow-up editorial in the Journal by Wilson and Van Der Weyden³ noting that health care was no safer and calling for a more imaginative strategy to improve patient safety, it is necessary to consider new approaches — not just more of the same. One such approach is to enable patients, carers and families who have experienced poor-quality care and preventable health care harm to

develop solutions in partnership with clinicians, health providers and policymakers.

In July 2009, 40 people who identified themselves as agents of change met in Perth, Western Australia, to take part in the 3-day inaugural Australian Patients for Patient Safety (PFPS) workshop, convened by the Health Consumers Council of WA, the WA Department of Health, Perth's Curtin University of Technology and the United States organisation, Partnership for Patient Safety.

The workshop was the 12th in a series of global workshops supported by the World Health Organization's PFPS program,⁴ which was launched in London in November 2005. The workshop adapted an organisational change strategy known as appreciative inquiry (AI). AI builds on meaningful personal experiences that reflect the most positive core of human systems — values, visions, achievements and best practices.⁵ Participants in an AI process mine their stories to give voice to their most desired future.⁵

Perth Declaration for Patient Safety¹

We, the participants of the inaugural Australian Patients for Patient Safety workshop, convened in July 2009 to share profound health care experiences in our lives and to take forward our call for action to improve patient safety in Australia. We are patients, family members, carers and health professionals — people from all walks of life. Each one of us is a testament to the personal experience of unintended harm in health care and its continuing impact. Much of that harm was preventable. We declare

- Policies and protocols alone have not made us safer. This problem is systemic, widespread and deep-rooted. The fact that any person or family could one day experience needless devastating harm within the health care system is unacceptable
- Action must be taken now across all aspects and all levels of health care to prevent more harm occurring to others
- Our trusted health care workers and managers must recognise that we, your patients and our families, are an invaluable asset and resource for improving patient safety. We offer our stories and experiences. Seek to learn from our hard-won wisdom and partner with us to make lasting change
- We are the owners and funders of our health care systems and have collective responsibility for them. We ask everyone in the community, including health care providers, administrators and the Government, to join us in making the right to safe health care a priority for all people, especially those who are currently disadvantaged
- Care has no borders, neither does harm. The journey through all care settings must be better coordinated as too many lives have been lost or grievously harmed on this journey
- We need to receive care that conforms to the best evidence and practice. Safe practice must be supported by the reporting of and learning from patient safety incidents, education, innovative solutions and information
- Many barriers exist for Aboriginal and Torres Strait Islander people which limit access to safe health care. Interpreter services, effective communication, transport and accommodation are all integral elements of patient safety

- Patients know their own bodies better than anybody else. It makes sense to include patients in decisions about their care and treatment. Patients must always be told the options available, the expected outcome of each option including risks and complications, and the likelihood of each outcome occurring
- Patient safety is a basic human right. When harmed, people have the right to timely apology, explanation, redress and other remedies meaningful to them
- In accepting that all humans err, we nevertheless dedicate ourselves to ensuring that effective systems are in place to
 - Track and learn from health care errors, adverse events and near misses
 - Minimise the impact of errors on all involved, including the care provider
 - > Make changes to prevent the same errors happening again
- Current reporting arrangements have failed to deliver safe health care for patients. We accept that everyone, including patients, their families and clinicians, needs to safely report patient safety issues and problems. We therefore demand the application of improved patient safety legislation, including sanctions, which enables good clinical practice and provides real safety
- We cannot stay silent any longer, waiting and watching as more people are harmed in health care. As Australians, we own this problem and will work together with actions that go beyond words. To progress this call for action to improve patient safety, we expect partnership at all stages and at every level of the Australian health care system

This Declaration is our kindling. We, the participants of the inaugural Australian Patients for Patient Safety workshop, will use it to ignite the flame of change to advance patient safety for everyone.

This is our promise. Perth, Australia

August 5, 2009

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EDITORIALS

Half the workshop attendees were patients who had suffered preventable harm in health care or lay carers of people who had been harmed. The other half were health care professionals, health system researchers, government officials and non-governmental organisation leaders interested in hearing from and working with patients to bring about change. Participants came from a variety of backgrounds and cultures (fulfilling a workshop planning goal). In an atmosphere of deep mutual respect, they shared their experiences of health system failure and the profound impact this had had, and continues to have, on their lives.

Sharing personal experiences, lessons learned and possible ways to make health care safer, participants developed the Perth Declaration for Patient Safety (Box).¹ This passionate call to action seeks to ensure that the impact of health care harm is recognised and that patients' unique experiences inform change. It calls on all who work in and shape the Australian health system to strive, in partnership with patients and their families, to improve health care safety.

Participants emerged from the workshop appreciative of one another's experience and contributions, and dedicated to working collaboratively to advance patient safety in Australia. Through the WHO, they join an international network of PFPS "champions", whose mission is to help patients be active partners in health care, not passive recipients.⁶⁻⁸

The Australian PFPS workshop and its recommendations are timely indeed, given the current push for reform of the Australian health care system. Authors of recent reports, including the proposed National Safety and Quality Framework of the Australian Commission on Safety and Quality in Health Care⁹ and the final report of the National Health and Hospitals Reform Commission (NHHRC),¹⁰ encouraged conversation with consumers about future directions. Both reports call for action more than words, a call now underscored by the Perth Declaration. The NHHRC final report specifically argues that, to create a self-improving health system, a necessary first lever is to strengthen the engagement and voice of consumers.

The PFPS workshop showed that a partnership is readily achievable when stakeholders reach through the invisible walls that separate them. Cooperation among people who are moved to attain what is possible brings new life and confidence to reform efforts.

The vision of a safer future embodied in the Perth Declaration and reflected in the workshop participants' commitment to openness, appreciation for one another's experiences and learning from patients' wisdom, must be supported. The opportunity to cocreate that future — to stop harm and save lives — is now here.

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Competing interests

Stephanie Newell received an honorarium from the Health Consumers Council of WA for her contribution to the workshop, and the same organisation met travel and accommodation expenses associated with her role as workshop co-facilitator. Dorothy Jones is employed by the WA Department of Health as Director of the Office of Safety and Quality in Healthcare. Her employer paid her for her work as a member of the workshop's steering committee and for attending the workshop. Martin Hatlie was paid for professional services as facilitator of the workshop and his expenses were paid, including the airfare from the United States.

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