

**2ND PATIENT CONGRESS REPORT
BARCELONA MARCH 2006
EXECUTIVE SUMMARY**

Michele Kosky

**International Association of Patient Organizations 2nd Patient Congress
Barcelona March 2006 National Health Service: Public/Patient Participation
London March 2006.**

General Observation

Western Australia has demonstrated genuine leadership in health safety and quality issues in Australia. The complexity of a public/private mix of health services in Australia poses particular challenges that were less apparent in the National Health Service. These of course are general comments after a very short visit. Consideration should be given to addressing more equitably our regional obligations in the Indian Ocean areas. The visit to both Barcelona and London has developed opportunities for Health Consumers' Council and the Office of Safety and Quality to engage in international dialogue and action in the areas of public and patient participation in health decision making and safety and quality of care.

Key learnings

1. The Health Consumers' Council consider adopting Declaration on Patient Centred Healthcare and if adopted to promote to members and a range of stakeholders, including Community Advisory Councils, Consumer Representatives, District Health Advisory Councils and Clinical Networks.
2. The Health Consumers' Council consider the establishment of a Healthy NGO Network in 2006-2007.
3. The Office of Safety and Quality WA Health consider holding a WHO Indian Pacific Conference in 2007/2008 working with World Alliance for Patient Safety. Health Consumers' Council to encourage and support this initiative.
4. Should Health Consumers' Council involve the NGO not-for-profit health sector more in selecting consumer representatives? Need to review/critique current approaches to consumer representation at Health Consumers' Council.
5. What is the role of Community Advisory Councils in understanding the 'new' communities accessing hospital/health services? Health Consumers' Council to promote this knowledge through development of CAC training courses.

6. The importance of interviewing family members when an adverse event occurs as part of 'talking to everyone' and that this be a strong recommendation to the Office of Safety and Quality WA Health.

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Background

In late 2005, Office of Safety and Quality agreed to fund Michele Kosky, Executive Director, Health Consumers' Council \$2,500 to participate in 2nd Global Patients Congress of International Association Patients Organisations (IAPO) Barcelona, Spain in February 2006.

Report 2nd Global Patients Congress

The theme of the Congress 'Together We Can' was fully supported by 130 participants including patient organisations (majority of delegates) healthcare representatives and people from World Health Organisation with the goal of working together to develop strategies to bring patients to the centre of the healthcare system. The Declaration on Patient Centred Healthcare was adopted at the Congress by all delegates. Health Consumers' Council WA had been part of the working group that developed the Declaration (see attachment 1).

The variety of participants was breathtaking, predominantly European/UK but with good representation from South America, USA and Africa. One delegate was from Hong Kong, a couple from India/Pakistan.

It was difficult to assess at the Congress just how and to what level patients/consumers were involved in the different organisations. Patient centred should equally apply to 'patient' organisations as well as healthcare organisations.

Learnings from the Congress

Patient Centred Health Care is not doctor centred, it is not technology centred, not hospital centred but answers and respects the needs of patients.

There is a strong emphasis on self management and health literacy.

The Health Consumers' Council has agreed to consider adopting Patient Centred Healthcare as part of the WA Consumer/Community Engagement Framework document. In addition, Health Consumers' Council will consider promoting the Declaration through the Clinical Network process through Community Advisory Councils and the District Health Advisory Councils of WA Country Health. In

addition, Health Consumers' Council will be holding a workshop on Patient Centred Health care for the NGO health sector in 2006-2007.

It was clear that the Pharmaceutical Companies and Medical Device Companies were major sponsors of the Barcelona Congress. Pfizer, Novartis and PRMA were the major companies.

Session

Networking and Networks

There was considerable discussion in this session about the social capital of developing networks to share knowledge and information and to share support. The time and resources in setting up networks was noted, and the requirement to balance individual interests and the common good.

Roger Steer – Involve UK – promoting public involvement in NHS, public health and social

Talked about networking to increase public involvement in National Health Service etc which will lead to research that is:

- More relevant to people's needs and concerns
- More reliable
- More likely to be used

Learning from Congress

There have long been concerns in WA that there is no strong united non-government, not-for-profit network. WACOSS have not established such a network, focusing on welfare, poverty, housing issues.

Action for Health Consumers' Council

That Health Consumers' Council board consider the establishment of a Healthy NGO Network and in 2006-2007 survey the sector to establish usefulness.

In addition, that Cancer Council WA Consumer programme be made aware of website Reach to Recovery International.

A paper from Emma Rigby International Association Patient Organisations IAPO examined role of IAPO representing 370 million patients worldwide, including state, national, regional, crossing borders and diseases.

One suggestion in this session was that IAPO could take an active role in fund-tracking in developing countries where funds committed to improving health never arrive and where donor governments and NGOs appear reluctant to alienate host governments.

Patient Safety Session

Patient Safety now a global issue. Sir Liam Donaldson Chair, World Alliance for Patient Safety made the observation when will health care pass the orange wire test?

THE ORANGE WIRE TEST

Imagine that an aircraft engine contained an orange-coloured wire essential to its safe functioning. Imagine that an airline engineer doing a pre-flight inspection spotted that the wire was frayed in a

way that suggested a systematic fault rather than routine wear and tear. Imagine what would happen next. It is likely that most similar engines in the world would be inspected – probably within days- and the orange wire, if faulty, renewed. Like airlines, hospitals take charge of people's lives many times a day. Yet, health care has lagged behind other industries in putting safety first in dealing with its consumers. A systematic fault that put patients' lives at risk discovered in one country would not surely be rapidly and simultaneously corrected by health services across other countries throughout the world.

Martin Fletcher WHO World Alliance for Patient Safety noted:

1. Same errors repeated;
2. Action to improve too slow;
3. Reporting is in its infancy;
4. Understanding of causes limited.

Policy challenges for patient safety and quality:

- Awareness of the issue;
- Identify the patient safety problems;
- Will to change systems, processes, tasks, behaviour;
- Understand the causes;
- Develop solutions;
- Implement change;
- Embed in every day practice.

Margaret Murphy whose son Kevin 21 died as a result of system failures in Dublin, Ireland in 2001 gave a moving address Margaret was speaking with 'the wish to make things better..'

'Every point of contact with the health system failed Kevin.'

'His diagnostic testing was selective and incomplete.'

Margaret noted 'the loyalty to colleagues' and the 'impact of admission on a weekend.'

'People are left heartbroken, fighting a David and Goliath battle.'

Learnings

That the Office of Safety and Quality consider holding WHO Indian Pacific Colloquium/Conference/Workshop in 2006/2007 and working with World Alliance for Patient Safety to organise this. The objective of the Conference is to share knowledge, experience and learning and to assist countries in the Indian Ocean region to establish patient safety systems mentored and supported by WA Office of Safety and Quality.

Action

That the Health Consumers' Council encourage Office of Safety and Quality to consider the above proposal.

