

Victorian Healthcare Quality Association

May 28- 29 2015, St Kilda, Victoria

Consumer Participation: What it really looks like and how organisations are achieving it

Stephanie Newell

Consumer Advocate

Chair, Partnering with Patients Advisory Committee,
Clinical Excellence Commission of New South Wales

Patient Safety Champion, Patients for Patient Safety
World Health Organization

Personal

Collaboration

Consumer - led



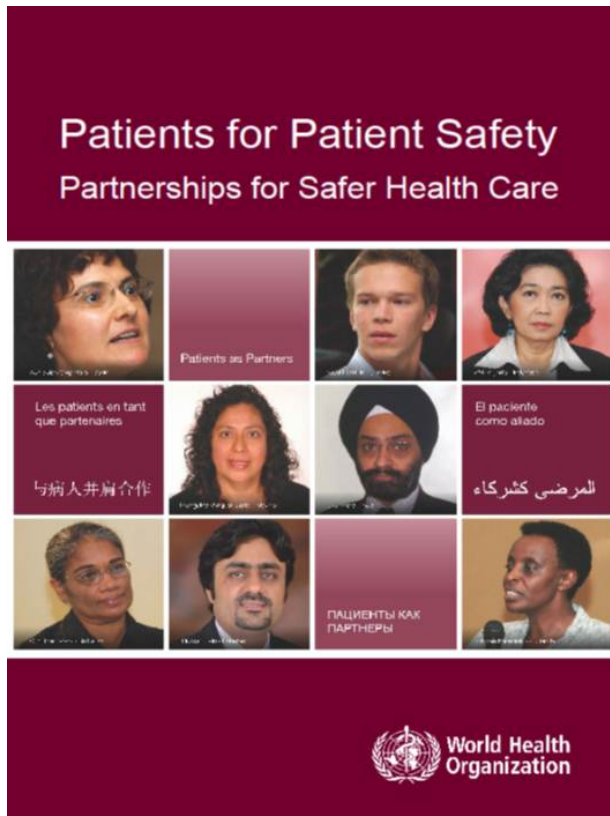
Marcus Newell

Born 5th March 2002

Died 5th March 2002

Patients for Patient Safety (PFPS)

- An approach to empower and capacity build patients and families as informed and knowledgeable health-care partners
- A platform to bring the patient voice to health care
- A mechanism to facilitate and foster collaborations - patients, families, communities, health-care providers and policy-makers



SERVICE DELIVERY
& SAFETY



World Health
Organization

Inaugural Patients for Patient Safety meeting London 2005



**SERVICE DELIVERY
& SAFETY**



**World Health
Organization**

Roles of WHO in patient, family and community engagement



WHO HQ

PFPS Network	Strengthen capacity, communication, advocacy
Policy-makers	Collaborate with WHO, national, international organisations
Academic institutions	Create and share knowledge through research, education and training
Health-care providers	Facilitate patient-engagement at hospitals and health-care facilities
Civil society and NGOs	Collaborate with NGOs and professional organisations

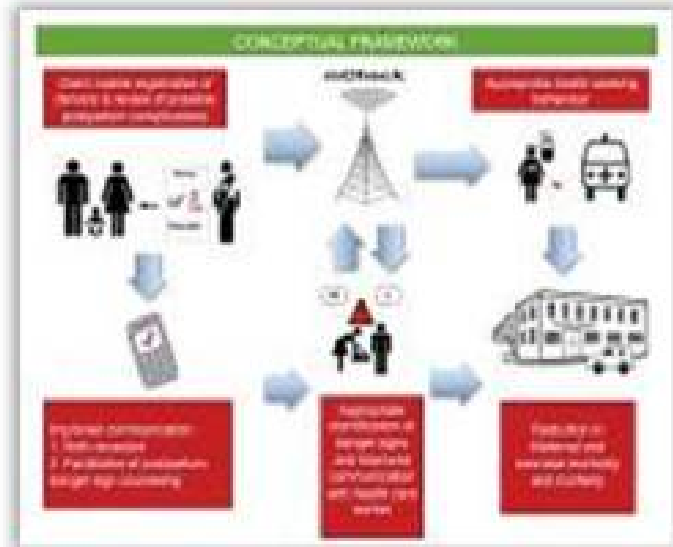


Patient For Patient Safety Champions

Mother and Newborn Safer Care Tool

- Consumer – Led research
- For consumers by consumers
- Empowering mothers and their families in the first 7 days following childbirth

Millennium Development Goal: Maternal and Child Health



Safe Surgery Checklist

Patient involvement in safety in surgery WHO Global Challenge

Surgical Safety Checklist		World Health Organization	Patient Safety
<div> <div>Before induction of anaesthesia <small>(with at least nurse and anaesthetist)</small></div> <div>Before skin incision <small>(with nurse, anaesthetist and surgeon)</small></div> <div>Before patient leaves operating room <small>(with nurse, anaesthetist and surgeon)</small></div> </div>			
<div> <div> <p>Has the patient confirmed his/her identity, site, procedure, and consent?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> Not applicable</p> </div> <div> <p>Is the site marked?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> Not applicable</p> </div> <div> <p>Is the anaesthesia machine and medication check complete?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> Not applicable</p> </div> <div> <p>Is the pulse oximeter on the patient and functioning?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> Not applicable</p> </div> <div> <p>Does the patient have a:</p> <p>Known allergy?</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> Yes</p> <p>Difficult airway or aspiration risk?</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> Yes, and equipment/assistance available</p> <p>Risk of >500ml blood loss (7ml/kg in children)?</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> Yes, and two IV/central access and fluids planned</p> </div> </div>			
<div> <div> <p>Confirm all team members have introduced themselves by name and role.</p> <p>Confirm the patient's name, procedure, and where the incision will be made.</p> <p>Has antibiotic prophylaxis been given within the last 60 minutes?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> Not applicable</p> <p>Anticipated Critical Events</p> <p>To Surgeon:</p> <p><input type="checkbox"/> What are the critical or non-routine steps?</p> <p><input type="checkbox"/> How long will the case take?</p> <p><input type="checkbox"/> What is the anticipated blood loss?</p> <p>To Anaesthetist:</p> <p><input type="checkbox"/> Are there any patient-specific concerns?</p> <p>To Nursing Team:</p> <p><input type="checkbox"/> Has sterility (including indicator results) been confirmed?</p> <p><input type="checkbox"/> Are there equipment issues or any concerns?</p> <p>Is essential imaging displayed?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> Not applicable</p> </div> <div> <p>Nurse Verbally Confirms:</p> <p><input type="checkbox"/> The name of the procedure</p> <p><input type="checkbox"/> Completion of instrument, sponge and needle counts</p> <p><input type="checkbox"/> Specimen labelling (read specimen labels aloud, including patient name)</p> <p><input type="checkbox"/> Whether there are any equipment problems to be addressed</p> <p>To Surgeon, Anaesthetist and Nurse:</p> <p><input type="checkbox"/> What are the key concerns for recovery and management of this patient?</p> </div> </div>			
<p>This checklist is not intended to be comprehensive. Additions and modifications to fit local practice are encouraged.</p> <p>Revised 1 / 2009</p> <p>© WHO, 2009</p>			

Patients for Patient Safety Champions

- WHO Regional & In-country Workshops
- WHO Global Challenges
 - Clean Care is Safer Care
 - Safe Surgery
- WHO programs and initiatives
 - Multi-professional patient safety curriculum guide
 - Radiation Risk Communication in Pediatric Imaging
 - International Agency for Atomic Energy Radiation Protection in Medicine
- The World Innovation Summit for Health (WISH)
- International Society for Quality in Healthcare (ISQua)

Patient-centred

care: Improving quality and safety through partnerships with patients and consumers



AUSTRALIAN COMMISSION ON
SAFETY AND QUALITY IN HEALTHCARE

AUSTRALIAN CHARTER OF HEALTHCARE RIGHTS

The Australian Charter of Healthcare Rights describes the rights of patients and other people using the Australian health system. These rights are essential to make sure that, wherever and whenever care is provided, it is of high quality and is safe.

The Charter recognises that people receiving care and people providing care all have important parts to play in achieving healthcare rights. The Charter allows patients, consumers, families, carers and services providing health care to share an understanding of the rights of people receiving health care. This helps everyone to work together towards a safe and high quality health system. A genuine partnership between patients, consumers and providers is important so that everyone achieves the best possible outcomes.

Guiding Principles

These three principles describe how this Charter applies in the Australian health system.

1 Everyone has the right to be able to access health care and this right is essential for the Charter to be meaningful.

2 The Australian Government commits to international agreements about human rights which recognise everyone's right to have the highest possible standard of physical and mental health.

3 Australia is a society made up of people with different cultures and ways of life, and the Charter acknowledges and respects these differences.



For further information please visit
www.safetyandquality.gov.au

AUSTRALIAN COMMISSION ON
SAFETY AND QUALITY IN HEALTHCARE

What can I expect from the Australian health system?

MY RIGHTS	WHAT THIS MEANS
Access I have a right to health care.	I can access services to address my healthcare needs.
Safety I have a right to receive safe and high quality care.	I receive safe and high quality health services, provided with professional care, skill and competence.
Respect I have a right to be shown respect, dignity and consideration.	The care provided shows respect to me and my culture, beliefs, values and personal characteristics.
Communication I have a right to be informed about services, treatment, options and costs in a clear and open way.	I receive open, timely and appropriate communication about my health care in a way I can understand.
Participation I have a right to be included in decisions and choices about my care.	I may join in making decisions and choices about my care and about health service planning.
Privacy I have a right to privacy and confidentiality of my personal information.	My personal privacy is maintained and proper handling of my personal health and other information is assured.
Comment I have a right to comment on my care and to have my concerns addressed.	I can comment on or complain about my care and have my concerns dealt with properly and promptly.

-  Standard 1 – Governance for Safety and Quality In Health Service Organisations
-  Standard 2 – Partnering with Consumers
-  Standard 3 – Preventing and Controlling Healthcare Associated Infections
-  Standard 4 – Medication Safety
-  Standard 5 – Patient Identification and Procedure Matching
-  Standard 6 – Clinical Handover
-  Standard 7 – Blood and Blood Products
-  Standard 8 – Preventing and Managing Pressure Injuries
-  Standard 9 – Recognising and Responding to Clinical Deterioration In Acute Health Care
-  Standard 10 – Preventing Falls and Harm from Falls

Consumer – led planning & design

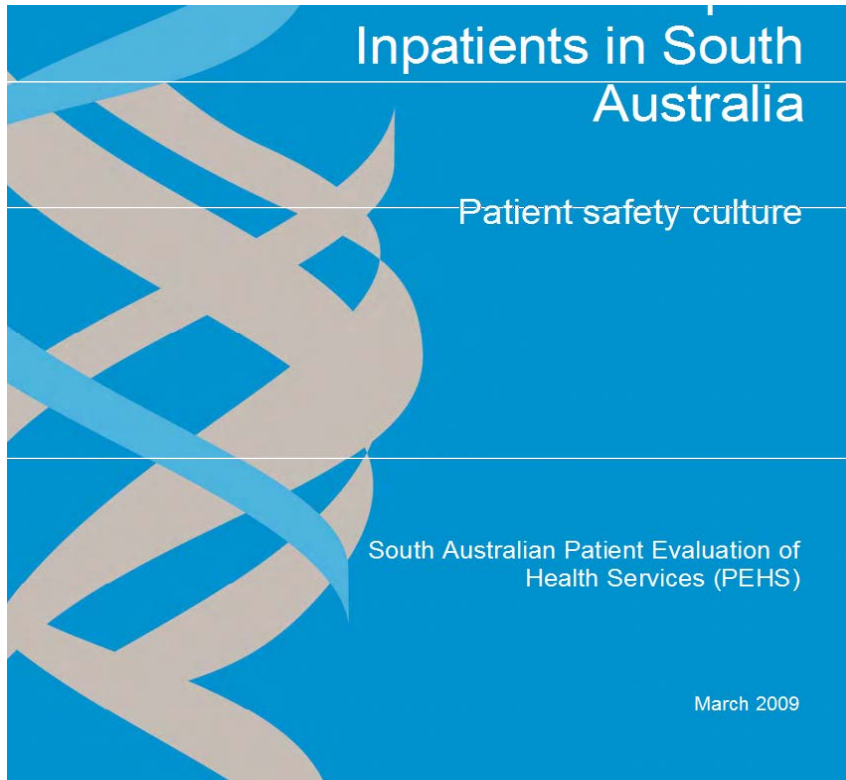
- Safety and Quality highest level
- Developed TOR's
- Work Plan
- Built meeting and reporting structure with relational committees
- Resourced – secretariat, remuneration
- Regular Communique
- Planned conferences – Open Disclosure, Aust S & Q conferences
- Radiotherapy underdosing of 862 patients – plain english website, letters, consumer outcomes
- Designed Parallel Public Hospital Inpatient Patient Safety Culture Survey to Staff Survey

User Led Design

4207 inpatients

400 yes – adverse event occurred

125 – yes, event almost occurred

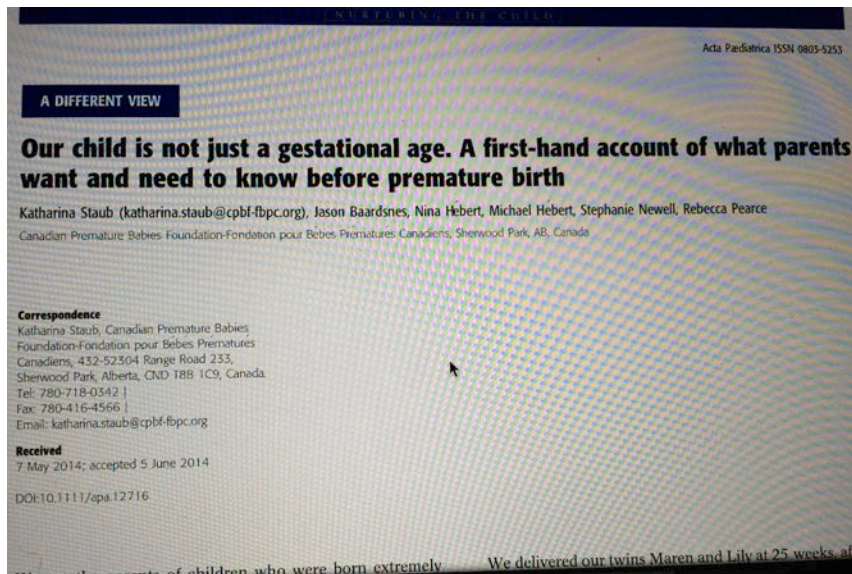


- .Wrong medication given **130**
- .Medication/treatment was not given even though it had been ordered **57**
- .Wrong procedure performed **26**
- .Wrong diagnosis **12**
- .Adverse effects meds/ treatment **75**
- .Infection – surgery/hospital stay **30**
- .Injury – (eg. Fall) result of stay **46**
- .case notes, treatment details or test results lost or overlooked **27**
- .Unnecessary surgery, procedure or treatment **14**
- .Requested diet not given **11**
- .Problems with intravenous access/fluid delivery **22**
- .Uncontrolled pain after procedure **29**

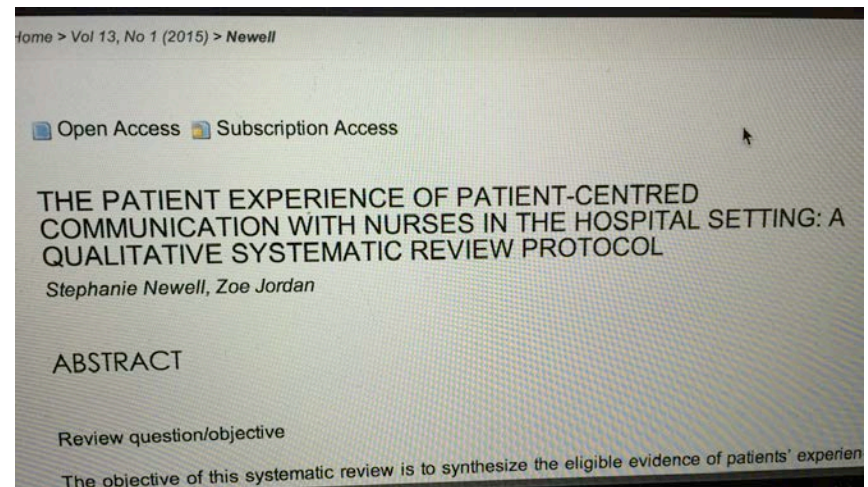
525 patients experienced an adverse event

- Nothing, did not report 197 37.4
- Questioned health care professional involved at time of incident 177 33.7
- Reported to health care professional in charge of ward/area 98 18.7
- Reported to uninvolved health professional 22 4.3
- Spoke to the patient advisory service about making a complaint 11 2.1
- Reported to the hospital 7 1.3
- Spoke to own GP about it 15 2.9

Acta Paediatr Oct 2014



Master of Clinical Science by Research



ANALYSIS

SPOTLIGHT: PATIENT CENTRED CARE

New South Wales mounts “patient based care” challenge

The Clinical Excellence Commission in New South Wales is driving person centred care by stimulating districts to compete to provide it. **Karen Luxford** and **Stephanie Newell** describe the integrated approach, its uptake, and encouraging early evidence of change

Karen Luxford director patient based care, Stephanie Newell chair, partnering with patients advisory committee

Clinical Excellence Commission, 227 Elizabeth Street, Sydney, New South Wales, 2000, Australia

The principles of patient centred care and the mantra of “nothing about me without me”¹ have gained broad support, but its proving hard to adopt and embed them in routine practice. New ways of thinking and tackling resistance to change are needed.²

across New South Wales. The commission monitors state-wide incident reporting and implements quality improvement initiatives to address key safety and quality problems identified. In 2010, a consumer adviser panel was established to actively



CLINICAL
EXCELLENCE
COMMISSION

Are you ready to take The Patient Based Care Challenge?



 **Partnering
with Patients**

Health services rising to the Challenge

The CEC Patient Based Care Challenge

Are you up to the challenge?

1 Leadership commitment

- a) start each board meeting with a story of patient care from your service.
- b) spend more than 25% of the board's meeting time on quality.
- c) arrange for board and executive members to visit wards regularly to talk with staff and patients.
- d) provide training to senior leaders to champion patient-based care.
- e) involve patient advisors in strategic planning processes.

2 Communicate the mission

- a) develop and promote an organisational mission statement that embodies patient-based care values.
- b) communicate the mission to new staff at orientation – illustrating leadership commitment.
- c) share personal stories by senior leaders to engage staff in patient-based values.

3 Engage patients, family and carers

- a) involve patients, families and carers in governance through committee membership, including quality and risk management and advisory committees.
- b) involve patients, families and carers in process co-design, design of new facilities and staff interview panels.
- c) implement a patient-based visitation policy.

4 Support engagement to transform care

- a) encourage staff to view patients, family and carers as care team members.
- b) implement processes to support patient/family activated escalation of care for deteriorating patients.
- c) conduct handover at the bedside and involve patients and carers.
- d) involve patients in medication management and review.
- e) provide patients, families and carers with meaningful information to support care and to report on safety and quality performance.

5 Use patient feedback to drive change

- a) use patient feedback from a range of sources (surveys, focus groups, anonymous shoppers) to gauge service quality and inform all staff.
- b) review patient care experience metrics at each meeting as an indicator of quality.
- c) implement processes to provide real-time feedback to staff to enable patient issues to be addressed during care (e.g., 'patient friend' models and bedside electronic systems).

6 Focus on work environment

- a) regularly assess work culture and staff satisfaction.
- b) celebrate staff successes in a visible manner (e.g., introduce a patient-nominated award for staff member of the month).

7 Build staff capacity

- a) implement organisation-wide training in patient-based values and associated communication skills techniques.
- b) involve patients and carers in staff education, including sharing stories of good and poor experiences of care.

8 Learning organisation culture

- a) enable staff to identify care delivery issues and solutions, focussing on addressing patient feedback.
- b) ensure processes are in place to enable ongoing patient and family engagement in open disclosure following adverse events.
- c) share the learnings from tragic events with staff to improve quality of care.

9 Accountability

- a) include accountability for patient care experience in all job descriptions and provide feedback in performance reviews.



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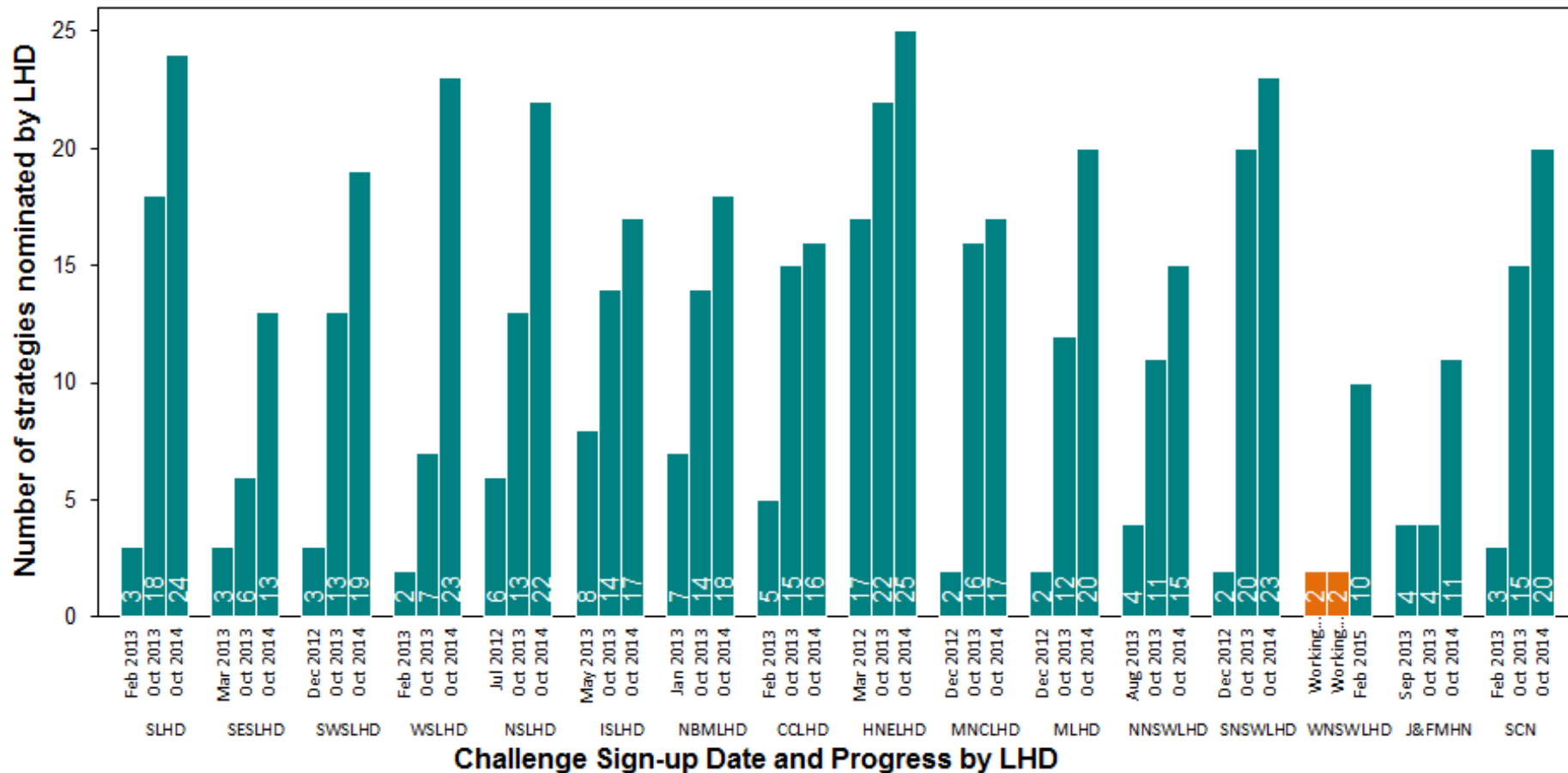
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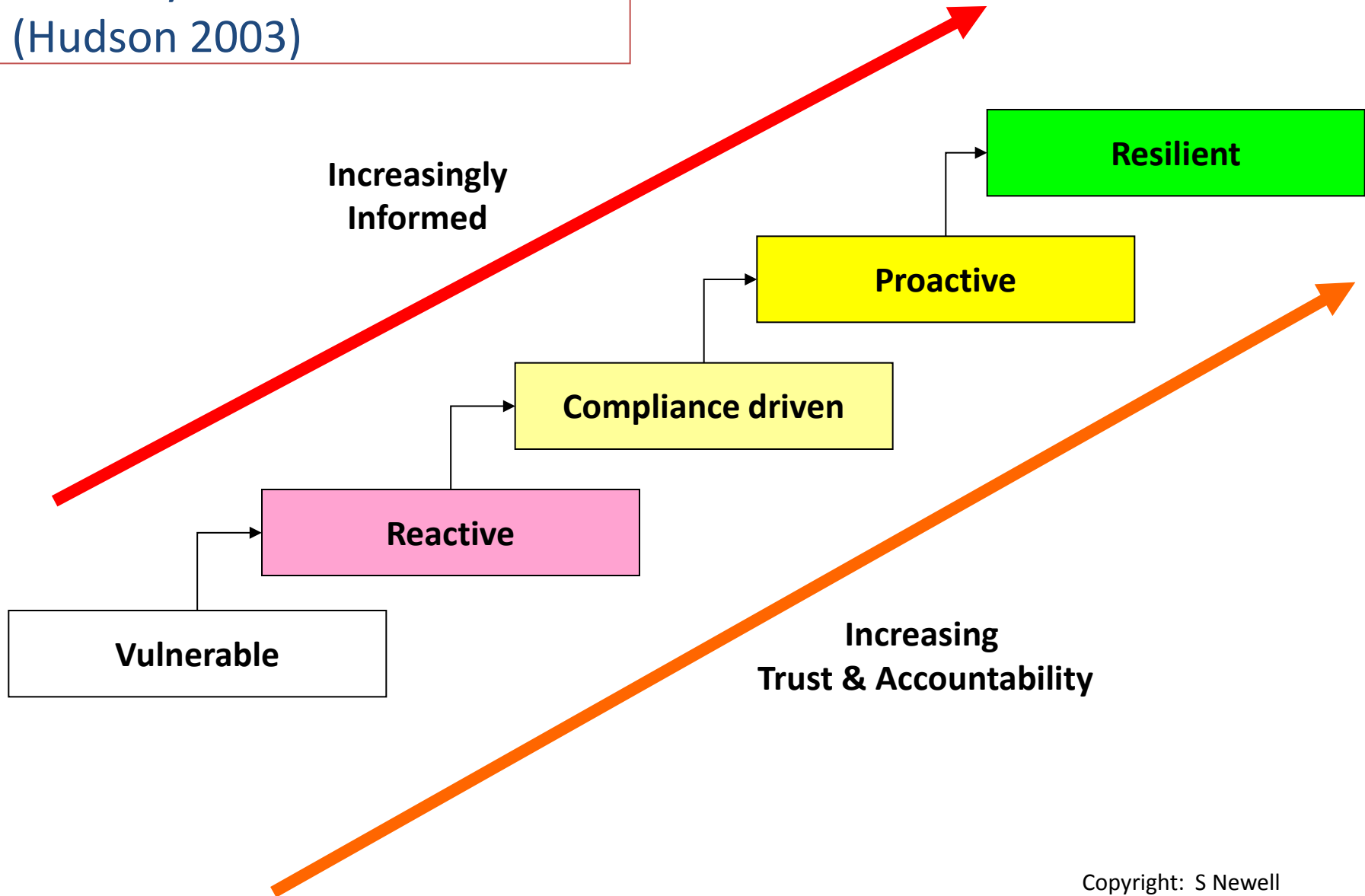


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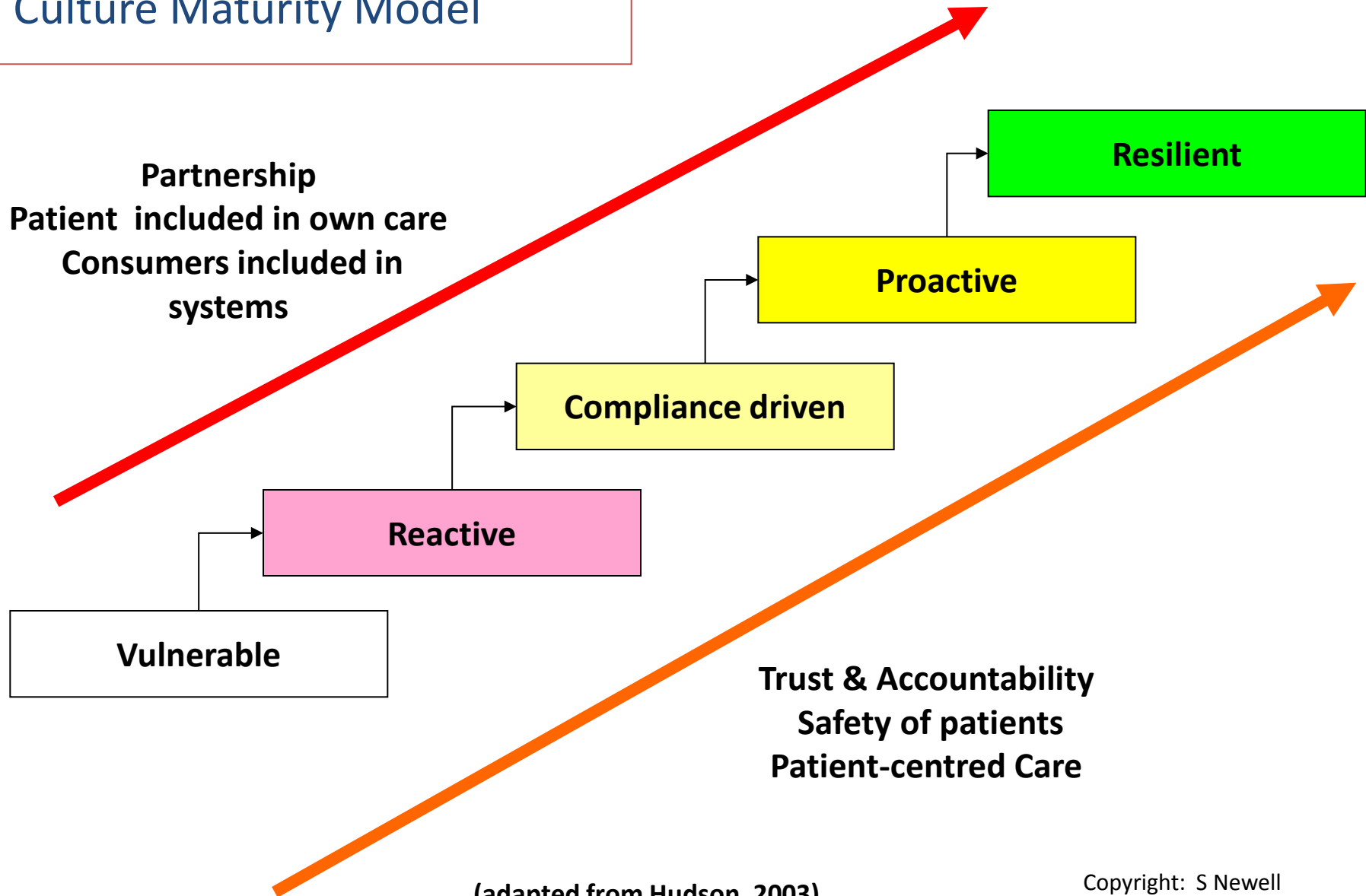
NSW Health services rising to the Challenge



Organisational Development Maturity Model (Hudson 2003)



Organisational Patient Safety Culture Maturity Model



(adapted from Hudson, 2003)

Copyright: S Newell

Vulnerable

Organisation

- Doesn't understand safety and quality
- Who cares as long as were not caught
- Patient Safety is a problem caused by people
- “Talk to the hand” attitude
- Shoots the messenger

(adapted from Hudson, 2003)

Patients, Carers & Families

- **No support, no answers**
- **No information**
- **No feedback**
- **Not included in own care**
- **No inclusion in being part of the solution**
- **Disempowered**

Consumers

- **Not included in governance mechanisms**
- **Feedback not sought**

Reactive

Organisation

- Says Patient Safety is important
- “Yes, we have to do something about that”
- “Of course we have incidents and accidents - its a dangerous business”
- “We do a lot every time we have an adverse event or error”
- “Sack the idiot who made the error”

(adapted from Hudson, 2003)

Patients

- **Views not encouraged or used to inform changes**
- **Passive - Not involved in own care**
- **Not advised of changes made to address the error**
- **No acknowledgement**

Consumers

- **Token**
- **Limited by the organisation**
- **No supports**

Compliance Driven

Organisation

- We have systems in place to manage all areas of patient safety
- Plenty of data and statistics
- Accreditation
- Management focus on economic cost
- Patient Safety issues and Patient-centred care not identified fully by workforce
- Consumers are not seen as equal 'partners'

Patients

- **Informed of Rights & Responsibilities**
- **Complete Surveys**
- **Formal Complaint acknowledged**
- **Standard is the maximum**

Consumers

- **Consumer groups in isolation**
- **Committee involvement limited**
- **Consumer groups see some data**

Proactive

Organisation

- We understand and are continuously and chronically aware of safety
- We identify and put solutions in place
- Patient partnership is the priority that informs finance and resources
- Workforce “owns” patient safety, patient-centred care and partnering with patients and consumers in roles of equal partnership

Patients & Consumers

- Outcomes important to patients
- Views and experiential knowledge actively sought and included for change
- Actively involved in research
- User led healthcare planning and design
- Consumer Reporting of incidents and near misses
- Incident Investigations
- Governance at all levels
- Policy, Procedures & Guidelines
- Patients as teachers
- Accreditation
- Staff selection and performance reviews
- Recognition, reward and reimbursement
- Design and measurement and evaluation of all dimensions of care

(adapted from Hudson, 2003)

“People involved in our care did not do
everything they could have to assist my son”

“I needed to have someone really truly **listen** to my concerns....”

“... and the fact that I could see where the gaps
were as well...”

“ ...I didn't want this to happen to anyone else..”

“ ... I wanted to see those changes happen,
I wanted to be part of those changes....”

“ To know that those changes are making a
difference to other peoples lives....”

“ ...and to know how systems were occurring
and ensure those systems worked optimally
for people”



Global Patient and Family Engagement



WHO and the Patient Care Program of the Gordon and Betty Moore Foundation collaborate to develop the WHO Framework on Patient and Family Engagement:

- guide and facilitate meaningful engagement
- respond to WHO Global Policy on:
 - Universal Health Coverage (UHC)
 - UHC: Quality and Safety
 - People-Centred and Integrated Health Services

Consumer Led Healthcare

- User led design
- Consumer Leaders
- Appropriate
- Safe
- Transparent
- Seamless
- Future oriented

[ACCESS ALL
AREAS]