



HEALTH QUALITY & SAFETY
COMMISSION NEW ZEALAND
Kupu Taurangi Hauora o Aotearoa

Report to the Health Quality & Safety Commission

Consumer and provider leaders forum: Co-creating a national leadership pathway

24 May 2013

Compiled by Lisa Markwick, leaders forum facilitator
Mindful Adventures

Purpose

The purpose of the forum was to address the question: 'How can we co-create a national leadership pathway?' The forum was held on 24 May 2013 in Wellington.

Invitation

Personal invitations were sent to and accepted by a group of 12 leaders in their fields, who are providers or consumers with a passion and a willing voice for their sector. The group was almost exactly half consumers and half providers although all acknowledged that, in fact, in many ways the boundaries between these labels are diffuse. They were from mental health, pharmacy, medicine, hospital management, primary care, health research and other groups, and were gathered from across New Zealand.

The invitation to attend was made personally by Dr Janice Wilson, chief executive, Health Quality & Safety Commission.

The day was led by Dr Chris Walsh and Linda Gilbert.

Voices represented in this report include the following:

Consumer leaders

Vicki Burnett, Recovery Solutions Services Ltd
Gary Sutcliffe, consumer
Libby Burgess, Breast Cancer Aotearoa Coalition
John Forman, New Zealand Organisation for Rare Disorders and New Zealand Carers Alliance
David Sibley, South Canterbury District Health Board (DHB) clinical board
Chris Walsh, Health Quality & Safety Commission

Provider leaders

David Codyre, East Tamaki Healthcare
David Barker, Dunedin School of Medicine
Michal Boyd, University of Auckland
Glenn Colquhoun, general practitioner
Leanne Te Karu, pharmacist
Debbie Ryan, Pacific Perspectives

Commission representatives

Gillian Bohm, principal advisor quality improvement
Linda Gilbert, senior policy advisor consumer engagement
Chris Walsh, senior advisor consumer engagement



Forum outline

Early in the forum we established our intention to work together in a collaborative, conversational manner where all voices had equal weight and respect. We encouraged a storytelling approach and process which first focused on *what is now* (aspirations held now, and stories about partnerships that work, those that don't and from experience what characterises these) and we intentionally avoided jumping early to answers and advice.

In the afternoon we encouraged dialogue and presentations around *what could be* (next steps to forge effective pathways for leadership in this area). As we met in an incredibly creative setting (a film prop-making/ hireage outlet) we also made good use of this to stimulate creative thinking and to shift the group out of 'in the box' or status quo thinking.

What we discovered

Aspirations

The members of the group were passionate for change and passionate about their own willing involvement in co-creating that process. Aspirations fell into several broad-brush categories – values/culture aspirations, systemic shift aspirations and a few functional aspirations.

Values- and culture-based aspirations (these related to consumer behaviour/values and provider behaviour/values) included:

- equity for all
- trust and confidence
- candour and compassion
- open, honesty, trust

- integrity
- inclusivity
- safety of sharing across boundaries.

Systemic shift aspirations included:

- dream of consumers reaching the top rung of participation – where consumers control decision-making at the highest levels so health and disability services are truly fit-for-purpose
- humanity at centre of system not process and forms
- balance between health economists and the personal touch – ‘walking with me on the journey’
- consumers and clinicians, not politicians, working together as powerbrokers to make decisions
- quality determinants of health
- socioeconomic historical-level levers address inequities. A revolution has begun!
- a learning, not blaming, culture is established – flexible and responsive
- start from the top, through all the levels of the system, with robust consultation and process to gain common understanding.

Specific functional aspirations included:

- peer-led services (see Stanford self-management course)
- people with dementia are still ‘people’ within the system
- family and communities are empowered
- honest conversations, listen with generosity of heart
- ask the question of the patient – how has the experience been for you? What matters to you? Not what is the matter with you?
- caring and willingness to dare – taking time and making time to care.

What works to support partnership models?

The stories that were told drew out pertinent points in two main areas about conditions that support partnerships for quality health care:

1. the dynamics of the system and models that work
2. individual attitudes and skills that support the development of partnership and quality in practice.

These systems attributes and personal qualities lay the groundwork for potential leadership development in this area.

Systems that support partnership have these qualities:

- Organisations care for their own staff as well as their ‘customers’, and all staff including doctors feel safe.
- Use of technology to reduce barriers of locality and geography.
- Joint consumer– provider conferences and learning.
- Use of multi-professional team so that care doesn’t reside with one particular specialist.
- The health care system can occur outside context of the DHB and the clinic – in places where people feel safe, eg, Waka Ama nationals. Leaders from the community help, eg, respected leaders modelling, eg, Police and Kaumatua.
- Single-issue advocacy from consumer groups, eg older people’s care and rheumatic fever vs. mammography/cardio.
- Consumer engagement at a high level is desirable.

- Care is needed around who the consumer rep/advocate is, with regard to fitting in with cultural competence.
- Quality of cultural competence training – an ongoing challenge.
- Clinical governance is necessary in primary care to ensure it is client-driven.
- Some examples of systems that work include:
 - Hokianga health model
 - working in the community – eg, Te Hauora Trust at Te Matatini
 - Wainoa in Hawaii – this is an indigenous group keeping their own land and providing their own health care services appropriate to their needs.

Individual attitudes and skills that foster quality through partnership include:

- being respectful, showing humility
- having a goal
- quick prototyping, being action oriented, not endless meetings
- mutual trust in the relationship
- being comfortable with tension (realising that change doesn't come through comfort, it comes through tension)
- as a clinician, being well prepared for your patient, and intentionally responsive to the patient not the system
- patients owning their own destiny
- being brave as a clinician and brave as consumers
- honesty, reciprocity and health literacy
- holding an holistic attitude
- trust and confidence.

Specific suggestions

Suggestions regarding building a pathway towards partnerships in health care, focusing primarily on the provider or 'the system':

- When a person has complex needs there is even more necessity for a shared care plan based on the needs of the patient and informed by them. Funding needs to be flexible and based on needs.
- Peer-led services were suggested and a model based in the Hawke's Bay was referred to which significantly reduced community crisis numbers.
- An Advanced Care Planning Consortium was suggested alongside hearing and making use of the experience of service users.
- National standards need to be in place for primary care. It was suggested that a 'tool' was needed for primary care, eg, a co-designed small card for consumers.
- Resource constraints should be addressed head on.
- Practitioners should be encouraged to have experience outside the medical field.
- Knowledgeable, trained consumers should be at the decision-making table of health organisations.
- Patients should always be copied in on correspondence in a language the patient can understand; this has had very positive benefits in other countries.
- The Mid Staffordshire report (aka the Francis report, 2013) should be a reminder about the implications of not listening adequately to patients and families.
- At the tertiary training level, work with medics to put a halt to the 'god complex'.
- At the primary health organisation (PHO) level, include the consumer perspective in credentialing practitioners and as part of health promotion.
- Provide expert patient navigators in primary care and document partnership processes.

- The phrase 'patient-centred health care' could be picked up as the flag-waving slogan. It is the catch-cry of the International Alliance of Patients' Organizations (<http://www.patientsorganizations.org>).
- Ensure the culture and people of the organisation offering consultation are genuinely open to and prepared to do more than 'tick the boxes' in that process.

Suggestions focusing primarily on the consumer:

- Empower consumers – train and support them to speak with a united voice and humanise the process. The Commission is to develop a leadership programme and train consumers and providers in the capacities required to work in health care partnerships.
- Develop and train regional consumer representatives.

General suggestions:

- The Commission works at local/national/regional level and maintains some sort of national reference group.
- Link with existing networks – don't build anything new.
- Interested clinicians and consumers are needed to drive this.
- Advocate for consumers to be at high-level positions in health system alongside health practitioners or at least have consumer group input at political/executive/board level of DHBs.
- Use Health Navigator/strengthening families/whānau ora services as possible positive models.



Summary and recommendations

The energy of the group was high and constructive for the duration of this day-long forum. They offered their voices and views openly and honestly.

People in the group had both positive and negative experiences of being consumers and practitioners. The overall desires and aspirations of the group were for shift at all levels towards a more full expression of humanity in health (and disability) care. This is strongly felt by, and for, both consumers and providers. To achieve this shift requires both systemic and individual change and development. Interestingly when we look at the data collected, it is weighted heavily towards the need for systemic shift. Another common theme was for systems and processes support more open two-way communications, with some equality between localities and services. To enhance their mutual empowerment, voices and courage, consumers and providers needed personal qualities that support their capacity to work with/live with complexity. These qualities included open listening, bravery, 'everyday' language and strength of voice.

There were some specific suggestions to the Commission about carrying this work forward. The themes that emerged most strongly were to:

- support collaborative (consumer/ provider) conferences and clinical and management/leadership governance
- support and provide training for consumers (across the disciplines) in empowerment (to take charge and responsibility for their care) and voice
- focus afresh on primary care. Although it was acknowledged that secondary and tertiary care partnerships are essential, it was thought that primary care is considerably more driven by fiscal and individual needs rather than being able to focus most pointedly on the actual needs of the patient and the community at large. Specific suggestions are outlined in the body of this report (given as verbatim as possible).

Having seen the energy and willingness of this stakeholder group to be involved in this conversation, I believe the Commission has a clear remit for taking action. I suggest that another stakeholder group be gathered to validate the Commission's next steps in this area. If specific suggestions from this forum were on the table, I would anticipate ready willingness by group members to be involved. Widening the group would also be of strategic advantage. The validation of this 'prototype' should be done early – fail early, learn fast!

I also suggest that it would be useful to clarify – especially to any early validation group, and any future leaders forum – the role and sphere of influence of the Commission. Where can the Commission be most effectual and have strong agency? Where does it have influence, and what is outside its remit?

In conclusion, the Commission has the backing of a strong network of multi-stakeholder relationships. Many stakeholders generously gave a full day of their time on 24 May to offer their hearts and minds to the challenge of co-creating a national pathway towards partnerships in health and disability care. Moving ahead with one or two of these threads in close communication with this group would be powerful and effective.

Feedback

The following is some feedback received from a participant at the forum:

"I just wanted to say that it was an absolute pleasure to spend the day at Westside Studios. I realise I probably ought to mention the meeting, the other people, the outcomes etc (which were all great) but... I think that your venue choice did indeed lead to some creative thinking. I also think it helped lift us out of the day-to-day. I enjoyed the great conversations and carry them with me still. Working on a form to help people tell services about themselves, I suggested we simplify this to 'What

matters to me, who matters to me, what needs to happen when things start to go wrong', the first being a quote from the day."