On 6th June 2012, La Trobe University’s Centre for Health Communication and Participation and the Institute for Social Participation held a day of discussion forums to explore how the power of evidence and personal experiences can intersect, rather than compete.

Participants were invited to discuss the issues and to come up with ideas for people to take away. Attending were consumer and carer advocates, policy makers, and clinicians and health professionals from health services, non-government organisations and local government.

This is a report of the key themes and ideas raised by participants in the discussion forums. The report has links to the opening presentation from Associate Professor Dawn Stacey of University of Ottawa, and to all the web-based resources that were mentioned during the day.

We gratefully acknowledge our sponsors: the Quality, Safety and Patient Experience Branch, Department of Health, Victoria, The Victorian Cancer Agency, and the Institute for Social Participation, La Trobe University.

Final Report prepared by Sophie Hill and Jessie Kaufman, Centre for Health Communication and Participation, La Trobe University, Melbourne, with acknowledgement to the facilitators and note-takers in the discussion forums.

10 September 2012
Festival of Evidence & Experience

Final Report

*How can the power of evidence and experience intersect rather than compete?*

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Participants were invited to discuss the issues and to come up with ideas for people to take away. Over 140 people attended – representing a wide range of interests: consumer and carer advocates, policy makers, and clinicians and health professionals from health services, non-government organisations and local government.

**Opening and launch of ‘YourHealthNet’**

Ms Frances Diver, Executive Director, Hospital & Health Service Performance, Department of Health Victoria opened the day and gave the welcome to country.

First, she launched the website ‘YourHealthNet’, a new website developed by the Centre for Health Communication and Participation to explain systematic reviews in a clear way – and to provide stories from consumers on using Cochrane reviews for their health. [Cochrane reviews are systematic reviews of the evidence on the effects of interventions, published in *The Cochrane Library*.]

Frances Diver then introduced the guest speaker, Associate Professor Dawn Stacey. Dawn is from the University of Ottawa, Canada, and is the lead author of the Cochrane decision aids systematic review.

**Guest speaker, Associate Professor Dawn Stacey**

Dawn Stacey talked about using evidence and experience to inform patients’ involvement in health decisions. Her talk showcased many leading innovations from health care initiatives around the world.

*Access Dawn Stacey’s talk here.*

Dawn’s talk set the scene for two forums:

- Morning forums: To debate the limits to both evidence and experience

  *Forum 1.* Experience as evidence: uses, challenges and opportunities

  *Forum 2.* What is happening with decision aids and other tools in Australia to help people make informed decisions?
Main themes

The main themes follow. Appendix 1 contains detailed notes for each forum.

EXPERIENCE AS EVIDENCE

Within evidence-based health care, systematic reviews and randomised controlled trials sit at the top of the evidence tree. The experience of clinicians or experts sits down the bottom, while the experiences of patients are rarely even acknowledged.

Yet, patient experiences are powerful. The experience of others is a highly sought after and legitimate form of evidence to many people facing health care decisions.

Increasingly, health care organisations are looking to understand the experiences of their patients and other users. And the scientific community is wrestling with how to incorporate evidence of patient experience along with evidence of effectiveness in providing a more complete understanding of health care interventions.

The aim of Forum 1 was to explore the meanings, uses and intersections of experience as evidence and identify some key challenges and opportunities.

Forum participants asserted that the term ‘health experiences’ encompasses a vast range of experiences across many settings, including interpersonal interactions, treatment experiences and the journey of health care.

But if we are capturing experiences, we need to think about diversity and participants wanted a more serious effort by the health system to recognise diversity and consider its consequences. It was argued we need a bottom up AND top down approach to tackling these challenges. Patient experience data needs to be better valued, and managers and clinicians need to acknowledge the strengths of patient-centred care.

One idea was to use triangulation as a way of researching patient experiences. Traditional forms of evidence – the ‘numbers’ needed to make well-informed policy decisions – could be used alongside the experiences of patients and health professionals. This led to the suggestion that health experiences of consumers should be recognised as a formal level of evidence. This could be achieved by not allowing researchers to call their work ‘evidence-based’ unless it included patient experiences.

The challenges include recognising that experiences differ and there may not be consensus. In her talk, Dawn Stacey had said it was necessary to provide both ‘good’ and ‘bad’ stories so that balance
is ensured. Finally, better research techniques and practices were needed to capture experiential information.

**DECISION AIDS IN AUSTRALIA**

Decision aids and decision support tools are increasingly being used to help people with decision making. Decision aids prepare people to participate in decisions that involve weighing benefits, harms, and scientific uncertainty. They differ from usual health education materials because they make explicit the decision being considered and provide detailed, specific, and personalised focus on options and outcomes for the purpose of preparing people for decision making. Patients tend to be more satisfied with their decisions when given decision aids and they narrow the gap between higher and lower literacy groups. For more information on health benefits of decision aids, click here: [Dawn Stacey’s presentation](#).

The aim of this session was to identify where decision aids and other tools are being used in Australia and to discuss some the enablers and barriers.

Participants identified ten clinical areas where decision aids had been developed and several health services which provided explicit support for consumers to participate in decision making. However, most people had not encountered a decision aid and there were many major barriers preventing their widespread adoption and use in Australia. Participants were also concerned with barriers faced by people with intellectual disability, barriers related to age or gender and the pressures on consumers and health professionals in many health settings.

Decision aids needed to be integrated into the process of care but needed to be supported by culture change, a more supportive environment and training.

**DEPARTMENT OF HEALTH VICTORIA CONSULTATION ON POLICY DEVELOPMENT FOR HEALTH INFORMATION AND HEALTH LITERACY**

Health literacy, like health experiences, is a broad term with a wide range of meanings. Participants talked of it as a major concept associated with empowerment as well as it having a specific focus on searching for and using health information.

The aim of the forum was to discuss how the provision of health information could be improved and health literacy enhanced. A short background paper was distributed and Catherine Harmer (of the Department of Health Victoria) introduced the session by reminding people that health literacy was a priority of the Victoria Health Priorities Framework 2012-2020. Participants were divided into groups and discussed one of four areas: improving health information; improving health literacy knowledge and education; improving clinical communication; and building health literate organisations. Within each area, participants could address improvements at the individual and community, health professional, or organisational and system levels.

There was a need for better guidelines on developing and providing health information, with funding and support for health professionals to use them. Information was also a key part of communication, an area where skills needed to be built. For consumers, emphasis should be given to at-risk groups, with a better understanding of how people seek and receive information.
These points were emphasised in the group discussing health literacy. There needed to be greater awareness of what health literacy is and for better understanding of who is vulnerable and who would have special needs. The skill of health professionals was a critical element, with discussion of tailoring information, strategies to check understanding of consumers and better use of interpreters.

The group discussing clinical communication added the need for more resources at the community level, with peer mentoring and cultural awareness training mentioned as effective strategies. At the systems level, key performance indicators were suggested as a major strategy to re-orient delivery, with a change from target/access indicators to consumer satisfaction/experience indicators.

For building health literate organisations, the last group proposed various ideas: explicitly giving people encouragement to ask questions and helping them navigate the health system. Education and strategies to help health professionals provide health information were discussed and supportive systems were those with processes to update evidence.

Across groups, the use of technology as an enabler was mentioned. The importance of involving consumers in the development of new strategies was emphasised, along with the need for intersectoral and community-based action.

**CONSUMERS AS ADVOCATES FOR THE EVIDENCE THEY WANT TO SEE**

Consumers and carers are increasingly involved as advocates for new evidence – both evidence about new treatments or therapies and evidence about patients’ experiences. And we are seeing consumers and carers involved in groups and committees where they can propose new research or different research strategies. This role requires knowledge of research as well as advocacy skills. There is some training for some consumers in the principles and practices of research. But is this enough? What else could we be doing or what more do we need? The aim of the forum was to come up with a list of strategies for helping consumers and carers to become stronger advocates for the evidence they want to see.

Participants talked about the different experiences they had as advocates for research. Some were good, with confidence and skill growing whereas others had been poor, with feelings of tokenism, the process being ad hoc and with a lack of necessary training. Being an advocate required an understanding of research gaps but also a capacity to raise these, a capacity which was enhanced by collaboration with clinicians and health services.

Overall, strategies need to be embedded within research policies to facilitate a change in culture around the inclusion of consumers in research and a better understanding of the merits. Specific strategies were a new consumer research alliance or unit to identify research gaps and priorities, support for participatory research, and ways of redressing the power imbalance, particularly for marginalised groups.
CONCLUSION: ENHANCING THE UTILITY OF THE EVIDENCE AND HARNESS THE POWER OF PERSONAL NARRATIVES

There were several major themes for the day, not new in themselves but identifying the necessity of some major changes if the health system is to move to one based more on the integration of evidence and experience.

The main areas where work is needed are:

- A more serious recognition by all parties of diversity and its consequences
- Examination of structural and cultural barriers that hinder greater involvement by consumers and carers
- Greater attention to clinical communication and the skills needed
- Ideas and examples of how to integrate and link evidence and personal experience
- Health literacy policy to respond to the issue of disadvantage
- Greater range of research to capture relevant information

What participants wanted were:

- Models of care which picked up concepts such as patient-centred care
- Key performance indicators based on patients’ experiences, ie, experience as a form of data needs to be built into systems and performance
- Resources to support policy-related themes, eg in areas of health literacy, decision aids
- A consumer research alliance

Participants articulated the importance of senior level support, better resourcing along with cultural change and greater transparency.
Acknowledgements

Guest speakers

- Ms Frances Diver, Executive Director, Hospital & Health Service Performance, Department of Health Victoria
- Dr Dawn Stacey, Associate Professor, School of Nursing, University of Ottawa, Canada

Facilitators

Colleagues of the Centre for Health Communication and Participation

- Dr Tere Dawson, Senior Project and Policy Coordinator, Health Issues Centre
- Catherine Harmer, Manager, Policy & Strategy, Quality, Safety & Patient, Experience Branch, Department of Health Victoria
- Dr Carol Hart, Research Fellow, Institute for Social Participation, La Trobe University
- Lidia Horvat, Senior Policy Officer, Policy & Strategy Unit, Quality, Safety & Patient Experience Branch, Department of Health Victoria
- Maureen Johnson, Manager, Women’s Consumer Health Information, Royal Women’s Hospital
- Dr Dawn Stacey, Associate Professor, School of Nursing, University of Ottawa
- Dr Rwth Stuckey, Senior Lecturer, La Trobe University; and Monash University
- Associate Professor Lyndal Trevena, School of Public Health, Sydney University
- Dr Kim Wark, Acting Manager, Victorian Cancer Agency
- Mike Zafiropoulos AM, Chairperson, Eye and Ear Hospital Community Advisory Committee, Director, Eye and Ear Hospital Board

Staff from the Centre for Health Communication and Participation, Australian Institute for Primary Care & Ageing, La Trobe University

- Dr Sophie Hill, Head, Centre for Health Communication and Participation, and Coordinating Editor, Cochrane Consumers and Communication Review Group; Co-convenor of CAFE, Communication Access Framework and Evidence
- Jessica Kaufman, Research Officer, Communicate to Vaccinate project
- John Kis-Rigo, Trials Search Coordinator, Cochrane Consumers and Communication Review Group
- Dianne Lowe, Doctoral student, Centre for Health Communication and Participation
- Dr Megan Prictor, Managing Editor, Cochrane Consumers and Communication Review Group
- Dr Rebecca Ryan, Research Fellow and Editor, Cochrane Consumers and Communication Review Group
- Anneliese Synnot, Research Officer, IN-DEEP Project
- Natalie Willis, Research Officer, Communicate to Vaccinate project
Sponsors

Grateful appreciation to our sponsors:

The Institute for Social Participation, La Trobe University

The Victorian Cancer Agency

The Quality, Safety and Patient Experience Branch, Department of Health, Victoria

About us

The Centre for Health Communication and Participation is based in the Australian Institute for Primary Care & Ageing at La Trobe University. The Centre's mission is to improve communication with and participation by consumers and carers, through evidence-informed policy and decision making.

Linking communication with participation reflects a political choice. It places people at the centre of efforts to achieve a responsive health system and signals that communication is multi-directional. Information comes from people, or is shared amongst members of the public, and health consumers and carers wish to be actively involved in determining their health future. Two kinds of research evidence are needed for strengthening health systems: evidence on which interventions are effective in improving health and social outcomes and evidence about people’s experiences of health.

The Centre’s work addresses three themes:

1. Building knowledge and strengthening health systems by leading international efforts to produce and disseminate evidence for improving the experience of health and treatment;

2. Promoting individual, shared and civic forms of participation in the production and use of evidence;

3. Addressing inequities which impact on people’s interactions in health through research on the experiences and evidence of vulnerable or disadvantaged groups.
Appendix 1: Detailed notes from all forums

FORUM 1. Experience as evidence: uses, challenges and opportunities


The aim of this session was to explore the meanings, uses and intersections of ‘experience as evidence and identify some key challenges and opportunities. Within evidence-based health care, systematic reviews and randomised controlled trials sit at the top of the evidence tree. The experience of clinicians or experts sits down the bottom, while the experiences of patients are rarely even acknowledged.

Yet, patient experiences are powerful. The experience of others is a highly sought after and legitimate form of evidence to many people facing health care decisions.

Increasingly, health care organisations are looking to understand the experiences of their patients and other users. And the scientific community is wrestling with how to incorporate evidence of patient experience along with evidence of effectiveness in providing a more complete understanding of health care interventions.

What are the different meanings of the term ‘health experiences’?

Key points:

The term ‘health experiences’ can encompass a vast range of experiences across many settings. This emphasises the uniqueness of the health and illness experience of individuals, families, health professionals and entire communities.

- What kinds of personal experiences exist?
  - Personal patient stories
  - Health service stories, and the journeys within those health services
  - The clinical experiences of health professionals
  - Consumers taking part in consumer advisory groups

- Examples of experiences
  - Receiving health information through different media
  - Interacting with health professionals
  - Transitioning to health from illness
  - Fictional experiences portrayed through television or film
Sharing personal stories through social media (particularly empowering for consumers with rare illness)

Receiving conflicting advice or misinformation

The experience of palliative care for patients, family and friends

The grieving journey, denial process or the stigma of having an illness

Wellbeing and health experiences

What influences experiences?

Consumer expectations and preconceptions, culture, or religion

Language – for example, ‘death’ is documented as a negative outcome

Different life stages

The wider community

Limitations in the health care system such as lack of resources, staff shortages, surgery wait lists

Public v. private treatment

The physical environment in which the health service is offered

The support received from people close to the consumer

The cultural expectation of perfect health and immortality

How do we incorporate the patient experience without bias?

Key points:

Advance care planning is a systematic way of incorporating patient experience. But it needs to be more widespread. A good idea is to appoint ‘substitute decision makers’

Actually talking to people and eliciting views. Consumers should be more involved in research

Health experiences of consumers should be recognised as a formal level of evidence. At the moment it is often under-recognised and usually can only be found in the ‘appendix’ of a report. We can achieve this by not allowing researchers to call their work ‘evidence-based’ unless it includes patient experiences

Health professionals believe they know how to communicate, but we have a worldwide problem with communication. Physicians should be taught the right language to use. Additionally, the patient often does not know what questions to ask. So we should be teaching our physicians more about patient experiences and better communication
• Qualitative research – researchers should be more upfront about their biases and acknowledge their subjectivity

• Partnerships need to occur across sectors, not only within the health sector

What are the opportunities and challenges with using experience as evidence?

Challenges:

• Unreceptive health care practitioners or clinician/consumer power imbalances may be barriers to consumers becoming active participants. There needs to be a shift in clinician attitudes

• Sometimes there is a lack of consensus in experiences. Differing perspectives can complicate things

• The culture of patient-centred care is prominent; however there needs to be wide-reaching support of this culture. For example, management needs to be in line with these principles for it to work and to be effective

• There are cultural issues, for instance, Indigenous populations find it difficult to trust mainstream health care

• We live in a risk averse society with significant privacy laws which can make accessing information/data on patient experiences difficult

• Patient experiences are inherently subjective and biased, which may pose problems for a fair and representative sample. We need to source a broad range of views

Opportunities:

• We must have a bottom up AND top down approach to tackling these challenges

• Patient experience data needs to be better valued, and managers and clinicians need to acknowledge the strengths of patient centred care

• Using patient experiences can help us to explore areas of research that are currently under-explored, such as suicide

• It is possible to capture experience well using qualitative methodologies. For example, discourse analysis can be used to honour the diversity of the patient experience

• We could also utilise triangulation as a way of researching patient experiences. Traditional forms of evidence – the ‘numbers’ needed to make well-informed policy decisions – could be used alongside the experiences of patients and health professionals
Forum 2: What is happening with decision aids and other tools in Australia to help people make informed decisions?


Decision aids and decision support tools are increasingly being used to help people with decision making. Decision aids prepare people to participate in decisions that involve weighing benefits, harms, and scientific uncertainty. They differ from usual health education materials because they make explicit the decision being considered and provide detailed, specific, and personalized focus on options and outcomes for the purpose of preparing people for decision making.

The aim of this session was to identify where decision aids and other tools are being used in Australia and to discuss some the enablers and barriers.

Key points:

- If decision aids aren’t integrated into the process of care they aren’t used
- Patients tend to be more satisfied with their decisions when given decision aids
- Inequities, lower literacy: decision aids actually narrow the gap between higher and lower literacy groups

Clinical areas in which people are aware of, have used or have developed decision aids:

- Fertility options for women with breast cancer
  - Breast Cancer Network Australia
- Vaginal birth after caesarean (VBAC)
  - Part of Royal Women’s Hospital clinical guidelines. Doctors are encouraged but not required to use it
- Hormone replacement therapy (HRT)
  - NHMRC
- Youth depression treatment decision aid
  - Orygen Youth Health
  - Developed for youth age 12-25
- Prenatal tests
  - Three Centres
- Unplanned pregnancy
- Vaccines
  - NCIRS
Resources to support decision making

- Peninsula Health - Speak Up program where volunteers go to patients to encourage them to ask questions to make decisions
- Peer support program for prostate cancer decision making. Trained peers who support newly diagnosed men (at The Austin Hospital)
- Physiotherapy choices website which directs people to relevant systematic reviews (http://www.physiotherapychoices.org.au/)

Experience of using or developing decision aids

- Most people have never encountered a decision aid as a patient
- There is lots of information but it has not generally been developed into a tool for patients; still patriarchal and oriented away from understanding choices and options. No one from the health care team talks about the information after it’s delivered
- Decision aid development process is difficult, time consuming
- Implementation issues need to be considered (pessimistic about use of decision aid in practice)
- Clinicians find decision aids to be very effective summaries of information, particularly for GPs who need to be across many areas
- Tools embedded in the process of care – we should allow for flexibility in how they are used to account for things such as cultural backgrounds and different informational needs

Barriers and enablers to developing and implementing decision aids

Barriers

- There are sectors in the health area that are provided with less opportunities for decision making (mental health – consumers would like to participate but they are sometimes limited)
- Disability including intellectual disability – people have decisions made for them
- Age – people who are older are not always engaged in decision making about themselves
- Evidence changes over time
- Special conditions where numbers/evidence aren’t concrete or don’t exist
- Time pressure, patients pushed through
  - Time is used differently when patients use decision aids. If patient comes already knowing about options, there is more talk time and engaged discussion in the consultation
- Complexity of decision – decisions within decisions, consequences
- Resistance in practice settings
- Payment mode (fee for service system)

Enablers

- Person-centred approach
- Access
- Training/support – discussing uncertainty, evidence
• Trust in guidance
• Empowered consumers
• Generic structured aids for topics which don’t have specific decision aids
• Relevance/motivation

Forum 3. Department of Health Victoria Health Information and Health Literacy policy development: consultation on issues


Participants were provided with a short paper to focus a discussion on health literacy and how it can be enhanced in Victoria.

The importance of health literacy

General comments
• Health literacy and the Department of Health Victoria – The Victorian Health Priorities Framework 2012-2022 report identifies health literacy as a priority, including a detailed list of possible strategies and actions to achieve it. One focus is on health services becoming health literate and the implications for consumers and carers
• Health literacy is a contested space, and there is a need for shared definition
• Need to recognise not everyone is a searcher, so how do we support individuals/communities to seek, value, search for and use of health information?

Individual
• Ability to attain, process and understand information and services
• To provide individuals information to make decisions
• Empowering people to be responsible/accountable – shared between consumer and health professional
• Basic right
• Ensure informed consent

Health care organisations
• Better health outcomes for patients; health outcomes that consumers value
• Help consumers evaluate information and reduce conflicting information
• Partnership between consumer and health organisation
• Bring knowledge of health information closer to practice
• Maximise impact of services
• Improvement of skills, knowledge – community perspective
• Promotion of positive, holistic approach to health and well being
• Aboriginal health – spiritual perspective to be better understood
• Health services – better understand overuse and under use; optimal use of services; planned use of services
• Educational perspective (health promotion)
• Peer mentors/community learning -incidental learning

Key strategies
The aim of this session is to focus on the key strategy development areas of:

1. Improving health information;
2. Improving health literacy knowledge and education;
3. Improving clinical and health communication; and
4. Building health literate organisations

Within each of these areas, participants will be asked to consider health literacy in relation to 3 different levels and the improvements that could be considered at each of these levels: the individual and community level; health professional level; and health care organisations and system level, including government departments.

There is some repetition in the themes which were raised but we have reported the discussion points as they were made.

**Key strategy 1: Improving health information**

**Why health literacy is important:**
- It provides individuals with information for decision making
- It empowers individuals
- It is a basic right to have information available
- It assists to ensure informed consent

**Key priorities identified:**
- Ensuring resources to meet the needs of individuals and communities
- Inclusion of communication skills in training and capacity building
- Develop guidelines for providing information across sectors, and policy to support the guidelines, funding for the guidelines and training for practitioners to use the guidelines
- At the individual/ community level:
  o to focus on at-risk groups
  o acknowledge that a certain percentage of the population are not literate
  o identify modes of receiving information and of seeking feedback and input
- At the health professional level:
  o Ensuring that when delivering the message it is tailored to the needs of consumers
- At the organisational level:
  o Building processes to allow consumer involvement

**Barriers:**
- At the individual/ community level:
  o Language and culture
- At the health professional level:
  o Lack of knowledge of people’s illiteracy
  o Ability to develop health information
  o Keeping the evidence and health information up-to-date
- At the organisational level:
  o Processes to identify target groups
  o Foster a proactive, rather than reactive, culture

**Enablers:**
- Wide access for all three levels - eg through consumer advisory groups, committees, etc
- Access to research and tools to support health literacy
- Enabling health professionals to access research in order to keep up-to-date
• At the individual/community level:
  o Identify people within communities who are trustworthy sources of information
• At the health professional level:
  o Providing professionals with the bigger context (individual or community) to assist
    with understanding outcomes

Effective strategies:
• Facilitating research integration into practice

Key strategy 2: Improving health literacy knowledge and education

Why health literacy is important:
• The concept of health literacy is very diverse and depends on context, therefore there is a
  need for shared definitions to avoid bundling too many things together under the umbrella
  of health literacy

Key priorities identified:
• Across all levels, an awareness of health literacy and what it is
• At the organisational level:
  o Identifying target groups and/or vulnerable groups who may have special health
    literacy needs

Barriers:
• At the individual/community level:
  o The stigma of low literacy
  o Lack of awareness of services
• At the organisational/systems level:
  o Technology/access
  o Service silos and challenges of delivering services across departments

Enablers:
• Technology
• A patient-centred care approach
• Building capacity in health literacy across all three levels
• Providing vetted health information in different formats
• Information that is tailored, focussed
• Availability of follow-up
• At the health professional level:
  o Recognise the importance of professionals’ skills in developing health literacy with
    their patients. There needs to be anticipation of diverse skills and knowledge and
    the ability to tailor information according to need
  o Encourage dialogue and the shifting of the power balance between professionals
    and consumers
  o Checking people’s understanding
  o A range of other strategies exist – eg the use of interpreters
• At the organisational/systems level:
  o Recognise the links between health literacy and education more broadly; embedding
    concepts important for health literacy in other forms of learning - eg embedding
    applied concepts in maths education

Key strategy 3: Improving clinical and health communication
Key priorities identified:
- Health literacy within the general community was the focus
- Every interaction between and individual and professional should take into account culture and spirituality
- The importance of listening to people in the community needs to be recognised
- Education was the focus
- At the individual/community level:
  - to empower individuals
- At the health professional level:
  - To ensure training is provided all the way from undergraduate levels through to Continuing Medical Education. This training must be language and culture specific.
- At the organisational level:
  - Resources and programs need to be made available

Barriers:
- Changing the health care culture: there needs to be a change in mentality

Enablers:
- At the individual/community level:
  - Asking consumers what they want to be involved in.
- At the health professional level:
  - Give professionals an understanding that questions need to be treated respectfully
- At the organisational/systems level:
  - Resources need to be made available

Effective strategies:
- Peer mentoring
- Cultural awareness training
- At the individual/community level:
  - Resources to be allocated to communities and individuals – eg to support target groups
  - Treatment plans that move with the whole treatment team (patient and organisation).
- At the organisational/systems level:
  - Changes are needed to funding models – including changes to KPIs: changes are needed from target/access-driven KPIs to satisfaction-driven KPIs)

Key strategy 4: Building health literate organisations

Barriers:
- When you can’t negotiate on the message – for example, when communicating directives or policy
- Barriers around litigation

Enablers:
- Providing information that will provide insight
- Working with stakeholder groups
- At the individual/community level:
  - Giving people permission to ask questions – eg Peninsula Health’s model
  - Assist people to navigate the health system
• At the health professional level:
  o Education
  o Delivery of health information
  o Checking people’s understanding of health information
• At the organisational/systems level:
  o Development of processes and procedures, including those to update evidence
  o Seeking consumer input, including that into developing health information
  o Use of technologies

**Forum 4. How do consumers become stronger advocates for the evidence they want to see?**

**Chairperson:** Mike Zafiropoulos AM. **Facilitators:** Kim Wark, Tere Dawson. **Note-takers:** Jessie Kaufman, Megan Pritchard, Annie Synnot.

The aim of the forum was to come up with a list of strategies for helping consumers and carers to become stronger advocates for the evidence they want to see. Consumers and carers are increasingly involved as advocates for new evidence – both evidence about new treatments or therapies and evidence about patients’ experiences. And we are seeing consumers and carers involved in groups and committees where they can propose new research or different research strategies. This role requires knowledge of research as well as advocacy skills. There is some training for some consumers in the principles and practices of research. But is this enough? What else could we be doing or what more do we need?

**Advocating**

**Key points:**
- Being an advocate requires a good understanding of the gaps and needs AND a capacity to raise these issues
- Advocacy is enhanced by collaboration between consumers and clinicians/health services
- Advocacy can be for the self or for others who lack a voice
- Advocacy is a call to action

**Experiences as advocates for research**

**Key points:**
- There were a variety of experiences, operating at a range of levels:
  o As subjects within a research project
  o Proposing the research agenda (i.e. letter to minister)
  o Reviewing grants and funding requests
  o As a research team member
  o Involved in the dissemination of research findings
- These experiences were mixed. Some of the negative experiences:
  o Consumer involvement can be tokenistic
  o Some felt there was a lack of training in what their role was
  o Can be disempowering if not done well
Some of the positive experiences:
- Respect and reciprocity between consumers and researchers is integral to overcome the inherent power imbalance
- Consumers can grow in confidence and research skills
- When consumers ideas are used to change practice it’s very satisfying

Research funding is not usually geared towards those projects that involve consumers or research consumer-generated topics. However, it was suggested that consumer-generated topics could be proposed as topics for masters students.

Strategies

Key points:
Overall, strategies need to be embedded within research policies to facilitate a change in culture around the inclusion of consumers in research and a better understanding of the merits.

The following issues and strategies were discussed:

1. Barriers to involvement
   - Poor representation (marginalised groups)
   - Consumers’ unfamiliarity with research, researchers’ unfamiliarity with consumers
   - Difficulties in communication (cultural diversity)
   - Negative attitudes and poor working relationships
   - Need a consistent way to get consumer questions into research agenda

2. Tokenistic consumer involvement and power imbalance
   - Pay consumers
   - ‘Earn and learn’ – employ consumers in learning about their illness, how to stay well (peer support workers)
   - Have consumers at every level of organisation from top down
   - People in organisations don’t truly understand/respect the value that consumers bring to the table. Need evidence that shows value of consumers
   - Consumers need to know that consumer advisory committees exist; hold public meetings to raise awareness

3. Training
   - Resources, mentoring
   - Top-down approach: participatory research paradigm (ie people with disabilities involved in all stages of research)
   - Policy-level: research agenda emphasises participatory research
   - Steering group needs to be set up inviting consumer researchers, suggest that the Health Department sets it up

4. James Lind Alliance to bring patients, carers and clinicians together to prioritise research
• Avenue to get consumers together with researchers (UK model)

5. Education programs should engage consumers/carers as teachers rather than subjects
   • Need a specific facility, collaborative entity
   • Consumer health forum already exists but needs to come together
   • More budget needed
   • Send consumers to medical schools to help train doctors so doctors meet and learn from them before they begin practicing

6. Money
   • Health care is more efficient/cost-effective if it is patient-centred

7. Utilising universities
   • Form a consumer advisory committee for involvement in research
   • All faculties of a university should have a consumer strategy

8. Involving consumer groups
   • Set up a unit of consumers to represent Victoria to identify research
   • Groups are important but not more than individuals

Other strategies:
   • Open-access board meeting annually for government – invite community to attend
   • Accreditation – core and aspirational points for consumer participation
   • Think outside metropolitan areas
   • Selection criteria for board members of health services should emphasise consumer involvement
   • Transparency of new consumer research alliance

Closing session. How can we enhance the utility of the evidence and harness the power of personal narratives?

Closing remarks: Sophie Hill

There were several major themes for the day, not new in themselves but identifying the necessity of some major changes if the health system is to move to one based more on the integration of evidence and experience.

The main areas where work is needed are:

• A more serious recognition by all parties of diversity and its consequences
• Examination of structural and cultural barriers that hinder greater involvement by consumers and carers
• Greater attention to clinical communication and the skills needed
• Ideas and examples of how to integrate and link evidence and personal experience
• Health literacy policy to respond to the issue of disadvantage
• Greater range of research to capture relevant information

What participants wanted were:

• Models of care which picked up concepts such as patient-centred care
• Key performance indicators based on patients’ experiences, ie, experience as a form of data needs to be built into systems and performance
• Resources to support policy-related themes, eg in areas of health literacy, decision aids
• A consumer research alliance

Participants had articulated the importance of senior level support, better resourcing along with cultural change and greater transparency.