

# 2016 ANNUAL FORUM

leadership

partnerships

engagement

**HCQ**  
HEALTH  
CONSUMERS  
QUEENSLAND

**Disruptions  
in health to  
drive better  
health outcomes:  
the role of the  
consumer  
movement**

# PROGRAM

PROUDLY  
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**THURSDAY 19 MAY, 2016 • 8.00AM – 5.30PM**  
**ROYAL INTERNATIONAL CONVENTION CENTRE**  
**600 GREGORY TERRACE BOWEN HILLS, BRISBANE, QUEENSLAND**

## Welcome from Chair



Welcome to Health Consumers Queensland's first Annual Forum, provocatively titled "*Disruptions in health to drive better health outcomes: the role of the consumer movement*".

Health Consumers Queensland is the peak health consumer organisation representing the interests of Queensland's health consumers and carers. We are committed to a health system which delivers quality and safe health services and values the voice of consumers in how health services are designed and delivered.

Our priority focus is on consumer engagement that influences and leads improvements and delivers better health outcomes for all Queenslanders.

As such, we invite you to learn from the experiences of consumers, carers and health service staff from across Queensland and internationally, as they share the findings of their initiatives aimed at improving and strengthening consumer engagement in Queensland.

We look forward to your contribution today through the many question and answer sessions and workshops including the beginning of the review process of our Consumer and Community Engagement Framework. We hope the forum increases your knowledge of best practice engagement and assists health service staff in their role, as well as our passionate and engaged consumers and carers who are the positive disrupters and the health consumer movement in Queensland.

**Mark Tucker-Evans, Chair, Health Consumers Queensland**

## Agenda

<b>Time</b>	
<b>8.00–8.45</b>	<b>Registration, networking, stalls, tea/coffee – Main Foyer</b>
8.45–8.50	<b>Mark Tucker-Evans, Chair, Health Consumers Queensland</b> <i>Welcome</i>
8.50–8.55	<b>Aunty Carol Currie</b> <i>Welcome To Country</i>
<b>Keynote Speakers–International experiences of co-design transforming health services – Main Hall A</b>	
8.55– 9.35	<b>Dr Lynne Maher, Director of Innovation, Ko Awatea and Honorary Associate Professor of Nursing, University of Auckland, New Zealand</b> <b>Renee Greaves, Patient &amp; Whanau Care Advisor, Ko Awatea, New Zealand</b> <i>New Partnerships, New Leaders: New Zealand</i>
9.35 –10.00	<b>Tracey Johnson, CEO Inala Primary Care and Churchill Fellow</b> <i>New roles for consumers in primary care: Canada &amp; UK</i>
10.00–10.10	<b>Keynote speakers Q&amp;A</b>
<b>10.10 –10.30</b>	<b>Morning Tea – Outside Foyer</b>
10.30–11.00	<b>Hon Cameron Dick, Minister for Health and Minister for Ambulance Services</b> <i>Address</i>



## Future visioning – Main Hall A

Health Consumers Queensland “Consumer & Community Engagement Framework” Review Workshop <i>Group consultation &amp; feedback</i>					
	Breakout room 1	Breakout room 2	Workshops	Breakout room 3	Main Hall A
11.00–12.00					
12.00–12.25	<b>Consumer &amp; Health Staff Partnerships</b> Mater Young Adult Centre Brisbane: <i>A service for young people shaped by young people</i> Kelsie Drummett, Mater Youth Consultancy Greg McGahan, Manager	<b>Consumer &amp; Health Staff Partnerships</b> Caboolture and Kilcoy Hospitals: <i>Ward 3B: the critical role of the consumer voice in designing a ward for those living with cognitive impairment</i> Christine Bryden, Dementia Advocate Suzanne Michaels, Project Manager, Caboolture and Kilcoy Hospitals	12.00–1.15	<b>Workshop #1</b> <i>Panel – Lessons from the mental health consumer workforce and peer support</i> Central Queensland, Wide Bay, Sunshine Coast Primary Health Network Metro South Addiction and Mental Health Services Brisbane North Primary Health Network	<b>Workshop #2</b> <i>The National Standards as a tool for disruption to improve patient safety and centred care</i> Naomi Poole, Program Manager, Partnering with Consumers, Australia Commission on Safety and Quality in Health Care



<p>12.25 -12.50</p>	<p><b>Consumer Leadership</b> The Prince Charles Hospital Adult Cystic Fibrosis Centre <i>Breathing fresh air into the system</i> Douglas Porter, Consumer Representative</p>	<p><b>Consumer Leadership</b> West Moreton Hospital and Health Service: <i>How consumers have shaped and influenced services by seeking engagement with health services, to strengthen the consumer voice and drive better health outcomes in Queensland</i> Bernadette Praske, Principal Engagement Advisor, West Moreton Hospital and Health Service Len Lamprecht, Convenor, Ipswich Prostate Cancer Support Group</p>			
<p>12.50 -1.15</p>	<p><b>Consumer &amp; Health Staff Partnerships</b> Patient Safety and Quality Improvement Service, Clinical Excellence Division, Queensland Health: <i>Ryan's Rule, A statewide patient, family and carer escalation system</i> Shaune Gifford – Consumer Representative</p>	<p><b>Consumer &amp; Health Staff Partnerships</b> Aboriginal and Torres Strait Islander Health Cairns and Hinterland Hospital and Health Service: <i>Djiji Bipperra (See us, Hear us)</i> Simon Costello, Senior Project Officer Cultural Capability</p>			
<p><b>1.15-2.15pm Lunch – Outside foyer</b></p>					

Showcases	Breakout room 1	Breakout room 2	Workshops	Breakout room 3	Main Hall A
2.15-2.40	<p><b>Consumer &amp; Health Staff Partnerships</b> University of the Sunshine Coast: <i>A new era: practical and productive engagement of consumers in scientific research</i></p> <p>Dr Catherine Itman, Council Member of Society for Reproductive Biology and Lecturer in Human Physiology, University of Sunshine Coast</p>	<p><b>Consumer &amp; Health Staff Partnerships</b> West Moreton Hospital and Health Service: <i>How partnerships between consumers and health service staff have been successful in improving health outcomes</i></p> <p>Kaitlin Davies, Community Engagement Coordinator Belinda Barrie, Consumer/Carer Representative</p>	2.15 – 3.30	<p><b>Workshop #3</b> <b>Leading effective meetings with consumers</b> Michael Morris, founder and Managing Director of the Samuel Morris Foundation</p>	<p><b>Panel #4</b> <b>Language and culture: Health services increasing the participation of diverse voices</b> Facilitator: Dean Johnson, Indigenous Health Coordinator and Professional Lead for Indigenous Health Services at West Moreton Hospital. Chandima Powell, CALD Consumer/Carer Consultant, Queensland Transcultural Mental Health Centre Simon Costello, Senior Project Officer Cultural Capability, Cairns and Hinterland Hospital and Health Service Julie Rogers, Cultural Capability Team, Children's Health Queensland Hospital and Health Service Jermaine Isua, Cultural Capability Team, Children's Health Queensland Hospital and Health Service</p>
2.40-3.05	<p><b>Consumer &amp; Health Staff Partnerships</b> Lady Cilento Children's Hospital: <i>The development of the Oncology Family App in partnership with families</i></p> <p>Penelope Slater, Program Manager Philippa Fielden, Clinical Nurse Consultant, Oncology Services Group</p>	<p><b>Consumer Leadership</b> Consumer/Carer Representative: <i>Beyond a seat at the table</i></p> <p>Pat Ryan, Carer Representative, Partners in Recovery Consortium Neil Ryan, Carer Representative, Partners in Recovery Consortium</p>			

3.05–3.30	<p><b>Consumer &amp; Health Staff Partnerships</b></p> <p>Gold Coast Primary Health Network: <i>Designing, implementing and measuring a successful Community Advisory Council. The Gold Coast PHN experience</i></p> <p>Kellie Trigger, Planning and Stakeholder Engagement Program Manager</p> <p>Noela Baglot, Chair Community Advisory Council</p>	<p><b>Consumer &amp; Health Staff Partnerships</b></p> <p>Royal Brisbane and Women's Hospital: <i>Consumer Perspectives on Clinical Handover</i></p> <p>Faileen James, Consumer Representative</p> <p>Helena Lake, Consumer Representative</p> <p>Lisa Mitchell, Clinical Handover Coordinator</p>		
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**3.30–3.50** Afternoon tea – Outside Foyer

**Panel Discussion – Main Hall A**

**3.50–4.30**

**Panel – Consumer engagement: wicked problems, disruptive solutions**

*Facilitator: Melissa Fox, Health Consumers Queensland*

*Darlene Cox, Executive Director, Health Care Consumers Associations ACT*

*Aideen Hanly-Platz, Person Centred Care Coordinator, Holy Spirit Northside Private Hospital*

*Michelle McAllister, Community Integration Coordinator, Central Queensland, Wide Bay, Sunshine Coast Primary Health Network*

*Helen Mees, Consumer Representative*

*Christine Petrie, Manager Consumer and Community Engagement, Metro North Hospital and Health Service*

*Gabrielle Quilliam, Guest Services/Cofounder, Hummingbird House*

*Dr John Wakefield, Deputy Director General, Clinical Excellence Division*

**4.30**

**Close and Evaluation**

**4.45–5.30**

**Networking, refreshments & drinks – Main Hall**

## **Health Consumers Queensland: our services**

### **For Consumers and Carers**

- Consumer representative training
- Notification of consumer representative vacancies
- Invitations to attend networking events
- Opportunities to have a say such as online surveys, focus groups, workshops
- Resources and information that enables you to drive changes in health service improvements

### **For Health Services**

- Strategic advice on effectively partnering with consumers
- Support with recruiting skilled, connected consumers for committees, advisory groups, focus groups, workshops and clinical networks.
- Tailored training and skills development programs for staff and consumers
- Facilitation of consumer workshops and focus groups

Join our Network for regular updates and to receive our e-News: [www.hcq.org.au](http://www.hcq.org.au)



## Annual Forum 2016 on social media

Share your comments and key learnings throughout the day on Twitter with the hashtag: #HCQAF16

Follow us on Facebook ([www.facebook.com/healthconsumersqueensland/](http://www.facebook.com/healthconsumersqueensland/)) and Twitter (@HCQconsumerorg)

## Stallholders

Be sure to visit the consumer and community groups in the Main Hall, to receive information, brochures and other promotional materials about their key activities.

## Musical entertainment by the Stairwell Project

The Stairwell Project is driven by the notion and well researched evidence that live music and art is an essential element in the healing process and general wellbeing of patients, staff and public in hospitals and medical centres.

With a vision to bring Live Music and Visual Art into the public spaces and wards of the Royal Brisbane and Women's Hospital, a six month volunteer experiment – with the full support of the hospital executive – began in June 2015. Working with students, graduates and lecturers from the Queensland Conservatorium of Music, Queensland University of Technology, the University of Queensland and the Queensland College of Art [Griffith University] the project offered live music every Monday morning in the hospital stairwell, admissions department, campus cafes and Outpatient Cancer Chemo/Radiation Wards. Visual art was added towards the end of the 6 month trial project and noted harpist and Music Therapist Donald Hall began performing on Monday and Thursday afternoons. The Queensland Conservatorium of Music Centre of Research has expressed a very strong interest in working with the Stairwell Project in 2016. Their research will then be made available to hospital policy and budget departments.

The project is suitable to be expanded into other hospitals, public and private. For information contact: Peter Breen, Curator – The Stairwell Project.

[www.jugglers.org.au](http://www.jugglers.org.au)



## Getting to the Royal International Convention Centre, Bowen Hills

Just 1.6kms from the CBD, the Royal ICC is located at the **Brisbane Showgrounds** which is bordered by Bowen Bridge Road, O'Connell Terrace, St Paul's Terrace and Gregory Terrace at Bowen Hills.

### Address

600 Gregory Terrace, Bowen Hills Brisbane.  
Find a map to the Royal ICC here –  
<http://www.royalicc.com.au/attending-an-event/venue-info/getting-to-royal-icc.aspx>

### Parking

Car parking is available directly underneath the venue for \$13 per day (payable by EFTPOS upon entry).

### Venue Layout

Main sessions will be held in Hall A. Breakout sessions will be held in meeting rooms 1–3.



## **PROGRAM**

8.00 – 8.45      **Registration, networking**

Outside Foyer

8.45 – 8.50      **Mark Tucker-Evans, Chair, Health Consumers Queensland (Hall A)**

Hall A            *Welcome*

### **Bio**

**Mark Tucker-Evans** has been involved with Health Consumers Queensland since its inception in 2008. He was the inaugural Chair of the Ministerial Advisory Committee and became the first Chair when Health Consumers Queensland was established as an independent organisation. Mark is the Chief Executive of COTA (Council on the Ageing) Queensland, Chair of the Queensland Council of Social Service (QCOSS), Director of the Australian Council of Social Service (ACOSS); CheckUp Australia, and Institute of Healthy Communities Australia and an Executive Member of the Queensland Clinical Senate.

Previously Mark has held CEO roles within research, media, industry and professional associations in NSW and Queensland and developed significant expertise in issues related to consumer and community engagement and age-friendly cities and communities.

8.50 – 8.55      **Aunty Carol Currie**

Hall A            *Welcome to Country*

8.55 – 9.35 **Keynote Speakers – International experiences of co-design transforming health services**

Hall A ***New Partnerships, New Leaders: New Zealand***

Dr Lynne Maher, Director of Innovation, Ko Awatea and Honorary Associate, Professor of Nursing, University of Auckland, New Zealand

Renee Greaves, Patient & Whanau Care Advisor, Ko Awatea, New Zealand

Co-design is a way of bringing patients, families and staff together to share the role of improving health services. Lynne (via video) and Renee (in person) will share how they work together in their Auckland-based health service to create new partnerships between health consumers and health professionals to transform patient experiences and healthcare through co-design. Renee will showcase the impact of this co-design through case studies which highlight the enablers for these staff, consumers and families to positively disrupt the way they have previously worked and enabling them to influence their futures.

### **Bios**

**Dr. Lynne Maher** is the Director of Innovation at Ko Awatea, Auckland, New Zealand. She is a successful visionary leader illustrated through an extensive health care career ranging from critical care nursing, operational and board posts at local and national level during which she has been highly influential in creating significant improvement in health systems. Lynne is recognised as an international leader of innovation and improvement and is sought after to provide advice on a variety of aspects relating to change management, service design, innovation and improvement in Canada, Europe, America and Australasia. Lynne has published guidance on innovation, patient experience, improvement and change management and has worked with a wide range of health care organisations and charities. Lynne is also Honorary Associate Professor of Nursing at the University of Auckland. Additionally, she acts as an Advisory Board Member of the CORE Research Study on co-design at the University of Melbourne and is a reviewer for the NZ Medical Journal and BMJ Quality and Safety Journals.

**Renee Greaves** is a consumer advocate from New Zealand. Her personal experience of health services led her to start disrupting the system to improve care. She is now employed as the Patient & Whanau (Family) Care Advisor for the Counties Manukau District Health Board and co-leads the direction of consumer engagement, co design, patient experience and patient and family centred care. Her growing expertise in change management and leadership has led to an increase in consumer engagement at multiple levels of the organisation which has led to improvements at the front line of care, in organisational design and has influenced the new strategy and values for the organisation.

09.35 – 10.00     **New roles for consumers in primary care: Canada & UK**  
Hall A             Tracey Johnson, CEO Inala Primary Care and Churchill Fellow

The Aged and Domiciliary Care Sectors and soon the Disability Sector will be wrestling with Client Directed Care. This represents a quantum shift for those providers. General Practitioners and Allied Health groups involved in primary care already have consumer choice in play in their fields of operation so few are talking about consumer movements in those settings. After all, it is the provision of care to individuals which triggers a Medicare Payment, private health insurance claim or voluntary contribution on behalf of patients. In theory this predominantly private sector, consumer choice model should generate very patient focussed consumer inclusive healthcare delivery. Is this true? What can we learn from other countries in terms of consumer engagement in the planning, oversight and co-design of health services? This session will provide examples from Canada and the UK of new possibilities for consumer engagement in primary care.

Canada is home to the patient centred medical home and client and family centred care movements. Canadians have led initiatives to deliver patient safety, patient engagement and new healthcare governance models. Canada is the first jurisdiction in the world to completely revamp all healthcare accreditation standards to mandate a patient centred frame of reference across every aspect of healthcare design, delivery and management. The results mean:

- Reframing who does the care to which outcomes are achieved in health
- Changing reimbursement and funding systems to reflect new models of patient engagement, co-delivery and participation
- Additional training for staff and reorienting many away from doing care “for” or “to” patients to delivering care “with” patients, families and carers
- Including patient representatives on all patient safety committees including those which investigate adverse events
- Investing in patient health literacy, collaborative goal setting and governance skills

The United Kingdom is involved in some of the boldest experiments in the world to blend health and social care funding. Targeting patients and their carers, these new initiatives utilise shared decision making tools (the frameworks for which are often Canadian) to assist healthcare consumers design their own care plans. Hard to reach patients are also being engaged in co-design activities which generate supports which address real needs and transform health outcomes.

**Bio**

**Tracey Johnson** has a diverse background spanning banking, market research, education and business consultancy. All of these experiences came together just over a decade ago when working with firms commercialising medical devices and healthcare solutions. Her on-the-ground healthcare delivery experience includes establishing an integrated women’s healthcare centre and more recently becoming CEO of Inala Primary Care. Inala Primary Care is a charitable general practice in a severely disadvantaged region. The practice specialises in models of chronic disease care targeted at the aged, disabled, refugee background and mental health profile of the region.

10.00 – 10.10     **Keynote Speakers**  
Q&A

10.10 – 10.30     **Morning Tea**  
Outside Foyer

10.30 – 11.00     **Hon Cameron Dick, Minister for Health and Minister for Ambulance Services**  
Hall A             *Address*

**Session 2**      **Future Visioning**11.00 – 12.00      ***Health Consumers Queensland – A Framework for moving forward***Hall A              Melissa Fox, General Manager Health Consumers Queensland  
Georgina Lawson, Project Officer Health Consumers Queensland

Health Consumers Queensland's Consumer and Community Engagement Framework was developed in 2012 using a collaborative model with many key health stakeholders in Queensland.

Since that time it has been used by many hospital and health services in Queensland and Australia wide to inform their Consumer and Community Engagement Strategies.

With consumer and community partnership activities increasing across Queensland Health, Hospital and Health Services, and primary and private health care providers, it is an opportune time for Health Consumers Queensland's Framework to be reviewed to ensure it reflects best practice, the growing evidence base in the field and continues to effectively support and guide health services to engage with their consumers and communities.

This will be a group work session to start the framework review process. The workshop will reflect on key elements of the framework and seek ideas and feedback on how they might be updated to reflect the current and future engagement landscape.

**Bio**

**Melissa Fox** is General Manager of Health Consumers Queensland (HCQ), a consumer representative on the Queensland Clinical Senate and a Board Member of the national peak health consumer organisation Consumers Health Forum (CHF). She is a consumer representative on the Australian Commission on Safety and Quality in Healthcare (ACSQHC)'s Partnering with Consumers Advisory Committee and the Australian Council on Healthcare Standards (ACHS)'s QLD/NT State Advisory Committee. She also sits on QUT's School of Nursing External Advisory Committee, the QH Steering Committee for Medicinal Cannabis and the QH Medical Workforce Steering Committee.

**Georgina Lawson** is committed to making public systems more accessible and fair for all accessing them, in particular vulnerable and marginalised groups. She has worked in sector development in the mental health community sector and in policy and communications in social security law. Georgina is at Health Consumers Queensland to support the development of a health system all Queenslanders can participate in their health care to the extent that they wish, and that health services partner with consumers at all levels of their organisations as a matter of course. Georgina previously worked in a variety of industries including film and television and mining and travelled and worked in Ireland, Canada and the UK. She has a cat, but is not yet a crazy cat lady.



**Session 3 Showcases**

12.00 – 12.25 ***A service for young people shaped by young people***  
Breakout Room 1 Greg McGahan, Manager Mater Young Adult Health Centre  
Kelsie Drummett, Mater Youth Consultancy

**Abstract**

Mater Youth Consultancy (MYC) was formed in late 2014 as part of planning for Mater Young Adult Health Centre Brisbane (MYAHCB). The group has young adults from various cultural backgrounds, many having lived experience of the health system. We knew we wanted to engage in consumer consultation but didn't really know how or if it would work. We spent some time getting to know the group and their understanding of what we were working towards. We established terms of reference to ensure issues raised by the group were connected to the broader organisation and would be actioned. This was also important for the young people who note their participation group on their CVs. MYC don't hold back in letting MYAHCB know what's important to young people in the health setting and they have been actively involved in planning, commissioning and operational matters for the service. They bring an energy that informs our vision and future plans for the centre. Some of the key things we have worked on together are:

- Designing clinical spaces and the look and feel of the service
- Naming parts of the service
- Branding of the service and organising events with marketing
- Participating in Foundation events
- Participating in nursing staff orientation
- Giving feedback on environmental sustainability
- Developing an opt out research consent process

At our first meetings MYC talked of the difficulties their parents / carers had during the transition from paediatric care to adult care and as a direct result of these conversations MYAHCB has commissioned a research project to look at this. MYC also identified the emotional health of young people, particularly those with chronic disease as a priority and in response to this MYAHCB has developed a Young Adult Support Unit. This means Young people can now see a mental health professional on the day of their outpatient appointment free of charge. For MYAHCB these are great examples of consumers influencing service design and research.

**Bios**

**Kelsie Drummett** is a young woman studying at University who knows hospitals well. She was a founding member of Mater Youth Consultancy and has worked with the centre to advocate for the needs of young people transitioning from paediatric to adult health care. Kelsie brings a unique experience of health care that clinicians don't have and she shares that through innovative ideas and genuine interest in improving care to young people.

**Greg McGahan** is the manager of Mater Young Adult Health Centre (MYAHCB) and has over 25 years' experience in mental health nursing, project work and various management roles. He established Mater Youth Consultancy while MYAHCB was in the project phase and continues to work collaboratively with the group. He sees the value in young people shaping a young person's service and is a strong advocate for consumer participation in MYAHCB. Greg has been able to implement many recommendations from the group and integrate their views into many service development activities.

12.00 – 12.25 ***Ward 3B: The critical role of the consumer voice in designing a ward for those living with cognitive impairment***

Breakout Room 2 Christine Bryden, Dementia Advocate, Author, Speaker and Consumer Representative at Caboolture and Kilcoy Hospitals

Suzanne Michaels, Project Manager, Patient and Family Centred Care, Caboolture and Kilcoy Hospitals

### **Abstract**

At Caboolture and Kilcoy Hospitals, we are committed to Caring Together – to partnering with you to ensure you feel heard, valued, supported and respected always. When Caboolture Hospital began designing a new 32 bed ward to cater to the increasing number of patients living with cognitive impairment, the voice of consumer, Christine Bryden, was an important part of the planning process.

Christine Bryden was only 46 when she was diagnosed with dementia in 1995, and since then has written four books on living with dementia and has spoken widely on the lived experience of dementia. Over the last 12 months, Christine has played an active and equal role in the Ward 3B Working Group, attending regular planning meetings with the team from nursing, medical, engineering and the architect contractors. Christine said: “I felt privileged and honoured to be seen as a member of the team right from the beginning. From where to place the call button, to the colour of the walls and location of signage, to the importance of sight lines to the nurse’s station, my views and experiences were heard, and incorporated during the whole design and implementation process.”

“Whatever suggestion or advice I gave, whether it was about the design or even additional training the team could undergo, they not only listened but acted.”

“It is this genuine commitment to working with consumers that prompted me to withdraw from participating in the work of some other organisations, where I felt the consumer voice was not being acted upon. I now focus on activities like those at Caboolture Hospital, where I feel I can contribute to meaningful change.”

### **Bios**

**Christine Bryden** worked in pharmaceutical research and scientific publishing in Europe, before joining CSIRO as a manager linking research with the mineral, energy and aerospace industries. She became the adviser to the Prime Minister on science and technology, and had responsibility for the Cooperative Research Centres program. After diagnosis with dementia in 1995, she became an advocate, author and speaker. She is a member of the Caboolture Hospital Clinical Council, the Caring Together Consumer Network, the Steering Committee of the Statewide Dementia Clinical Network Steering Committee, the Cognitive Impairment Advisory Group of the Australian Commission on Safety and Quality in Health Care, and the Alzheimer’s Disease Research Foundation Scientific Panel.

**Suzanne Michaels** is the Project Manager, Patient and Family Centred Care at Caboolture and Kilcoy Hospitals. In this role, Suzanne is responsible for the continued roll out of the Caring Together program – an organisation-wide commitment to partnering with patients, carers, community and staff to ensure they feel heard, valued, supported and respected always. This involves working at all levels of the organisation to create a culture of listening to and serving our community. Suzanne’s background is in stakeholder engagement, having worked in the private sector, and local and state government for the past 13 years.



12.25 – 12.50 ***Breathing Fresh Air into the System***

Breakout Room 1 Doug Porter, Consumer Representative

### **Abstract**

The Prince Charles Hospital Adult Cystic Fibrosis Centre undertook a Cystic Fibrosis Australia funded Peer Review Panel in 2012. One of the recommendations from the review led to the formation of a Patient Advisory Committee.

In 2013 it was evident that Cross Infection was becoming a serious threat to our long term survival as a patient group.

Patients were mailed a flyer inviting them to express their interest in joining. Those who had previously suggested service improvements at the hospital and previous patient consumer representatives from Cystic Fibrosis Australia were encouraged to apply.

Representation from the following interest groups was sought and achieved:

- Regional patients
- Younger (<30 yrs) and older (>30 yrs) patients
- Patients in the Workforce
- Patients who are parents
- Both genders

The committee was the first Cystic Fibrosis Patient Advisory Committee in Australia. Meetings are now held on a two monthly basis by either video or teleconference. Medical, nursing and social work representatives attend regularly, with additional allied health staff attending as required. Doug has chaired the committee and led the development of advertising for committee membership and guidelines for selection of new committee members over the last three years.

Key outcomes:

- Pivotal consumer role in opening of new Adult Cystic Fibrosis Centre with single room accommodation
- Positive feedback and resolution of clinical issues
- Successful liaison with the hospital executive regarding internet access
- Establishment of CFPAC Facebook page and contact email account
- \$40000 raised for outfit of new ward including purchase of white goods, exercise equipment and some specialised breathing apparatus.
- The Patient Advisory Committee is an important component of the Adult Cystic Fibrosis Centre's longstanding commitment to continuous improvements in patient care.

### **Bio**

**Doug Porter** is 46 years old and was diagnosed with Cystic Fibrosis from the age of six weeks. Doug currently lives in Buderim on the Sunshine Coast with his wife and two daughters aged 14 and 20. He is still a Registered Pharmacist and is very passionate about consumers taking control of their own health. Doug is committed to working towards improving patient experience but particularly those patients facing frequent hospitalisation through suffering chronic illnesses. One of Doug's ultimate goals would be to help develop a way to keep patients happy and healthy in their own homes rather than them having to be admitted to Hospital.

12.25 – 12.50 ***How consumers have shaped and influenced services by seeking engagement with health services, to strengthen the consumer voice and drive better health outcomes in Queensland***

Breakout Room 2 Bernadette Praske, Principal Engagement Advisory for West Moreton Hospital and Health Service  
Len Lamprecht, Convenor of the Ipswich Prostate Cancer Support Group

### **Abstract**

The Prostate Foundation of Australia (PCFA) identified the following three facts regarding Prostate Cancer in Australia:

1. In Australia, prostate cancer is the most commonly diagnosed cancer in men
2. More than 3,000 men die of prostate cancer in Australia every year
3. More men die of prostate cancer than women die of breast cancer

The first formal meeting of the Ipswich Prostate Cancer Support Group (IPCSG) was held on 15th April 2004. This was the start of an ongoing relationship between the West Moreton Hospital and Health Service (WMHHS) and Len Lamprecht, Terry Carter and other men involved in a wide range of advocacy, support and educational activities in Ipswich.

Len had attended the Brisbane Prostate Cancer Support Group in November 2002 and describes this experience as a real “eye opener”. Len witnessed the relief that comes over people when they understand that people have travelled this path before them, and they are extended support and helpful information. Four men in Ipswich (three of whom had survived Prostate Cancer) got together in March 2004 and ran two awareness evenings. From this, the Ipswich Prostate Cancer Support Group commenced. By 2006 the Ipswich Prostate Cancer Support Group had become affiliated with the Prostate Cancer Foundation of Australia (PCFA).

This project’s aim is to develop and implement strategies that will improve the quality of care provision to men with prostate cancer in the Ipswich and West Moreton region.

Through the projects clinical education and awareness surrounding Prostate Cancer has been successfully achieved. Patient Education provision has also been developed to engage patient learning from diagnosis and throughout episodes of care in the West Moreton Hospital and Health Service.

### **Bios**

**Len Lamprecht** is the Convenor of the Ipswich Prostate Cancer Support Group and together with three other Ipswich men, was instrumental in the founding of this group in 2004. Len has worked tirelessly over the years to bring information and support to men and their families who have experienced prostate cancer. Len has knocked on doors and engaged with health services across the region to consult, advice and advocate for the needs men facing difficult circumstances.

**Bernadette Praske** works as Principal Engagement Advisory of West Moreton Hospital and Health Service. The focus of West Moreton’s community engagement strategy is to engage the community in health service planning, increase wider community health engagement and health literacy across the region and work to improve health outcomes of disadvantaged groups in our communities. Bernadette has a degree in Social Science from University of Queensland majoring in health and has worked extensively with disadvantaged members of the community in a variety of service provider settings.

12.50 – 1.15 ***Ryan's Rule – A statewide patient, family and carer escalation system***

Breakout Room 1 Shaune Gifford, Principal Project Officer in the Queensland Department of Health's Patient Safety and Quality Improvement Service

### **Abstract**

The Queensland Department of Health implemented a state-wide patient, family and carer escalation process as a part of a commitment to the Saunders family following a coronial inquest into Ryan Saunders' death. The procedure was named Ryan's Rule to honour the memory of Ryan Saunders and involves a 3 step escalation process to seek assistance about clinical concerns. The first step involves a local discussion with a doctor or nurse; the second step escalates the issue to the nurse in charge of the shift if the response does not address concerns; and the third step involves a phone call to a single state-wide phone number to escalate clinical care concerns that have not been addressed to the satisfaction of the patient or their family /carer.

### **Development process**

The statewide Patient Safety and Quality Improvement Service (PSQIS) coordinated the development and implementation of Ryan's Rule. Clinical Governance was crucial to the process with oversight being provided by the pre-existing state-wide Recognising and Responding to Clinical Deterioration (RRCD) Steering Committee. A specialist subcommittee was also formed to troubleshoot the development of Ryan's Rule processes and materials. Following a literature review and discussions with New South Wales (NSW) and the Australian Capital Territory (ACT) on their respective models, the Ryan's Rule subcommittee decided to base Ryan's Rule on the ACT CARE model.

### **What were the outcomes?**

The program commenced in December 2013 with a staggered commencement; by April 2015 there were 164 facilities across Queensland using Ryan's Rule. There have been over 700 calls to date, with calls increasing from seven calls/month to an average of 45 calls/ month across all facilities. With over 10,000 inpatient treatments per day across the Queensland Health network of facilities, we receive on average, between 1–2 Ryan's Rule calls per day. The patients and families who have used the service have been overwhelmingly positive in their feedback, with 89% of respondents reporting they would use Ryan's rule again. Just over half of the calls result in a clinical intervention, transfer or "other" (e.g. referral to another specialty). There was overwhelming public support for Ryan's Rule following an article published in a newspaper. The social media thread of Facebook that also reported on the story had thousands of "likes" and "shares" with many comments by the members of the public that Ryan's Rule has promoted public safety.

### **Bio**

**Shaune Gifford** has been working in the health industry for 33 years and has a clinical background in critical care and mental health nursing. He also holds a bachelor's degree in Political Science and a Master's degree in Health Planning. Shaune is a Principal Project Officer in the Queensland Department of Health's Patient Safety and Quality Improvement Service and he, in collaboration with patient safety colleagues, clinicians and consumers has coordinated the development and implementation of the Ryan's Rule – Patient and Family Escalation Process into 164 public facilities across Queensland Health.

12.50 – 1.15

***Djili Bipperra (see us, hear us)***

***Western Yalanji Language Djili – Eye – see us Bipperra – Noise – hear us***

Reference: David Hudson Western Yalanji Traditional Owner

Breakout Room 2 Simon Costello, Senior Project Officer Cultural Capability Cairns and Hinterland Hospital and Health Service

### **Abstract**

On Friday 27 February 2015, the Senior Project Officer (SPO) Cultural Capability Aboriginal and Torres Strait Islander Health Unit was requested to attend a Cairns and Hinterland Hospital Board meeting to discuss the best way to effectively engage Aboriginal and Torres Strait Islander consumers and their carers to ensure consumer input into service planning and delivery was improved. Following this meeting the Board agreed that a review of the existing governance structure was required.

The SPO Cultural Capability facilitated a meeting on May 7 2015 at Cairns Hospital Board Room. The meeting was attended by a Yarrabah Aboriginal Shire Council representative, Aboriginal and Torres Strait Service Providers (referred to as Community Champions from this point forward), the Cairns and Hinterland Hospital and Health Board Chairperson, the Chairperson of the Community Advisory Group (CAG) and the Executive Director Information, Strategy.

The purpose of the meeting was to deliver a presentation to Community Champions and seek feedback about how best to improve the Hospital and Health Board capacity to appropriately engage with the Aboriginal and Torres Strait Islander community. At the meeting all in attendance agreed that further research should be undertaken as a priority and in order to review the current Terms of Reference (ToR) with the intent of establishing an Aboriginal and Torres Strait Community Consultation Committee.

Several meetings have commenced which led to the development of a final draft Community Consultation Committee (CCC) ToR being ratified by the Community Champions and presented to the CAG and Hospital and Health Board for comment and ratification. The Hospital Board approved the establishment of a new Aboriginal and Torres Strait Islander CCC, members have been recruited and the committee has held it's first meeting.

### **Bio**

**Simon Costello**, Senior Project Officer Cultural Capability

Simon Costello is a Nunukul man from Minjirrebah (North Stradbroke Island). He is a Senior Project Officer Cultural Capability with the Aboriginal and Torres Strait Islander Health Unit, Cairns and Hinterland Hospital and Health Service. Simon is responsible for developing systems of Aboriginal and Torres Strait Islander Consumer Engagement and Cultural Capability Continual Quality Improvement. He holds a Diploma of Education, Post Graduate Certificate in Health Management and a Masters of Public Health Degree.

2.15 – 2.40

***A new era: practical and productive engagement of consumers in scientific research***

Breakout Room 1 | Dr. Catherine Itman, Council Member Society for Reproductive Biology and Lecturer in Human Physiology, University of the Sunshine Coast

**Abstract**

The National Health and Medical Research Council (NHMRC) is the premier national body which funds research into health and medical research in Australia, to the tune of around \$845 million per year, in areas as diverse as Aboriginal and Torres Strait Islander health, bone and muscle diseases, asthma, cancer, heart disease, infertility, diabetes, mental health and more. All grants that are funded have been through rigorous review by experts and are deemed to contribute important new information about how disorders or diseases develop, how to prevent them, new treatment possibilities and/or how they impact on individuals and public health. Many diseases are now treatable, curable or preventable because of research that was funded by the NHMRC. This is referred to as 'translational' research – that is, benefits of the research investment have been delivered to the clinic or embedded within policy so that the consumer reaps the rewards. One of the most challenging areas to study is what scientists call 'basic' research. Basic research usually involves working on a topic that is highly specialised, is often laboratory-based, and is too early in development for clinical trials. Basic research does generate benefits for consumers, but these benefits may not be realized for one or two decades.

Consumer engagement in research is highly regarded by the NHMRC, however engagement levels are low, particularly in basic research. The Society for Reproductive Biology (SRB) is comprised of scientists who investigate both basic and translational science. As the first scientific society to join the Consumer Health Forum of Australia (CHF), we are committed to developing productive collaborations with consumers who will help target and strengthen our research. The goal of this workshop is to generate a realistic and practical model for aligning consumer need and research capacity to enable successful, productive and powerful collaborations between consumers and scientists, thereby driving research discoveries that will improve health and wellbeing. This workshop will define what 'consumer engagement in research' means, the difference between 'collaboration' versus 'participation' in health and medical research, the importance of consumer-scientist collaboration in research, and the valuable skills and attributes that consumers bring to research. Results from a survey of SRB members about the complexities and perspectives of scientist-consumer interactions will be presented and discussed and we will map out the types of consumer involvement that can provide valuable, and unique, insight into research projects.

**Bio**

**Dr Catherine Itman** has a strong desire to engage scientists and consumers in medical research. A lecturer in health sciences at the University of the Sunshine Coast, Catherine heads a research lab which investigates how genes and chemicals influence male health. Her particular interest is in understanding how abnormal puberty causes changes that affect male health and wellbeing throughout life. Catherine's lab has made important discoveries about the effects of phthalate chemicals on male development, which have been integrated into the U.S. EPA Integrated Risk Information System and have supported the regulation of phthalate use in the U.S. and Sweden.

2.15 – 2.40

***How partnerships between consumers and health service staff have been successful in improving health outcomes***

Breakout Room 2 Kaitlin Davies, Community Engagement Coordinator, West Moreton Hospital and Health Service

Belinda Barrie, Chair of the West Moreton Hospital and Health Service Gatton Community Reference Group

**Abstract**

West Moreton Hospital and Health Service have forged strong partnerships with the community via their community reference groups. These groups meet in Ipswich, Laidley, Gatton, Esk and Boonah and reflect health service locations. The current consumer reference groups were formed nearly two years ago and have engaged extensively with the health service to consult and advise on strategic plans, operational planning, safety and quality as well as review publications.

As Chair of the Community Advisory Committee which reports directly to the Board of West Moreton Hospital and Health Service, and Chair of the Gatton Community Reference Group, Belinda has formed a strong partnership with the health service and contributed to a wide range of health service activities. Belinda's input has been integral to ensuring that the consumer and community perspective is incorporated into planning and decision making. A wealth of evidence tells us that consumer and community engagement has direct outcomes on patient care, safety and quality and health outcomes.

In her roles Belinda has:

- Been involved in policy review in the health service to ensure that consumers and carers are included
- Advocated extensively for patient centred care – ensuring that the health service reflect the principles of listening and liaising with consumers and carers to ensure their needs and experiences are recognised in all operational areas
- Reviewed consumer and carer documents to ensure meaningful language that is clear and meets the needs of the community
- Been involved in reviewing the use and structure of the social worker family room in the Emergency Department and other areas of the hospital.
- Advocating for Continuity of Care – working to improving discharge information so the consumers GP and carer are given discharge summary and a patient handover to the carer.
- Working with her community networks to improve health information access and health literacy

**Bios**

**Belinda Barrie** is currently a full time carer who lives in the Lockyer Valley. Belinda is the Chair of the West Moreton Hospital and Health Service Gatton Community Reference Group and Chair of the Community Advisory Council which reports to the West Moreton Hospital and Health Service Board. Belinda also sits on the West Moreton Safety and Quality Committee as the Community Representative. In these roles, Belinda continues to make a significant contribution to the health service.

**Kaitlin Davies** is the Community Engagement Coordinator at the West Moreton Hospital and Health Service. For the past three years, Kaitlin has focused on the West Moreton community reference groups and is now broadening her engagement activities to include the management of West Moreton's community consultation program and West Moreton's community services sector engagement activities.



2.40 – 3.05 ***The development of the Oncology Family App in partnership with families***

Breakout Room 1 Penelope J Slater, Program Manager, Queensland Paediatric Palliative Care, Haematology and Oncology Network (QPPHON)

Philippa Fielden, Clinical Nurse Consultant, Oncology Services Group

**Abstract**

The LCCH Oncology Family App is a free app for parents of children with cancer that fulfils a need for ready access to critical information on cancer and cancer care. It engages and empowers families and patients to ensure they receive timely, safe and consistent care throughout Queensland. It includes the following support for families:

An emergency / sick management plan of when to call the hospital based on a list of clinical signs and symptoms with a click to call direct line to “000” and the oncology ward at Lady Cilento Children’s Hospital. This ensures that the family has immediate and 24 hour access to advice required if their child is deteriorating.

Quick access to a state-wide hospital directory with 24 hour emergency numbers and non-emergency contacts, hospital address details and Google maps to the nearest hospital throughout Queensland and Northern New South Wales that are part of the oncology network, with click to call features for all contact phone numbers. This ensures that the family is connected to their closest point of care at any time.

The different modules of the app engage families to produce an innovative, useful and efficient tool to access information. Families have stated that it helps teenagers take more responsibility in their own care.

Families were partners in the development process. The Patient, Family and Carer Network group worked through the app specifications. Six families were part of the team who tested the app prior to release.

In 4 months, the app has been downloaded 389 times. They are responding to family feedback during the evaluation of stage 1 to develop stage 2 features including evidence based resources, synchronising multiple devices and appointment reminders. The evaluation has been collected directly from the families through a survey on the app, and also via each family’s Clinical Nurse Consultant, as they discuss the care of their child. The app can be customised for other health facilities, allowing development for oncology families nationwide.

**Bios**

**Philippa Fielden** is a Clinical Nurse Consultant in the area of paediatric oncology at Lady Cilento Children’s Hospital (LCCH), Brisbane. She began her nursing career in the UK and moved to Brisbane in 1994. She provides clinical leadership in her role working within the multidisciplinary team to provide the best possible outcomes for oncology children and their families.

**Penny Slater** is Program Manager for the Queensland Paediatric Palliative Care, Haematology and Oncology Network, and the tertiary centre of that network at the Lady Cilento Children’s Hospital.

In that role she manages the statewide clinical network and the oncology program at the LCCH, including planning, evaluation, quality and safety, and consumer engagement. Prior to this, Penny has been with Queensland Health since 1990 in various research, planning and evaluation positions relating to diabetes, aged care, suicide prevention and oral health services.

2.40 – 3.05 ***Beyond a seat at the table***

Breakout Room 2 Pat Ryan, Carer Representative

Neil Ryan, Carer Representative

### **Abstract**

It is important that carers and health services work together to achieve the best outcomes for consumers. In our caring role we have sought to engage with GPs, psychiatrists, psychologists, community health nurses and carer support agencies. Pat and Neil have both been carer representatives on the Consortium for Partners in Recovery, Darling Downs & South West Queensland from 2012-2015, and Neil continues in that role in 2016. They provided verbal and written input to the review of the Mental Health Act 2016.

Pat and Neil recognise that change takes time and must be approached using a variety of strategies. During Mental Health Week in 2015 we partnered with consumers, carers and local community health services to bring about a public event showcasing the creative talents of consumers. Leading professionals in the mental health field joined them to talk about future directions in service provision. Supported by ABC radio and local print media, the event attracted 350 people and is still a topic of conversation on the Downs.

So as carers, Pat and Neil are definitely engaged and are at the table. They are now interested in taking that engagement a step further to being recognised as co-providers in the implementation of the policy initiatives they have helped to frame. Government and sector policy initiatives in health care emphasise consumer and carer involvement. The NDIS offers greater control over one's choices of care provider and carers have a role to play in supporting choice.

Underpinning legislation such as the state and federal carer recognition acts gives in-principle support to greater inclusion and involvement of carers. Pat and Neil look forward to full implementation of these principles in practice uniformly across the community.

Suggestions for greater involvement of carers:

- Utilise carers in the workforce. Hours can be tailored to suit caring needs and expertise, for example, reporting on success or otherwise of treatment programs.
- Consider mapping carer skills and abilities to understand how they contribute to consumer support.
- Foster greater understanding among health professionals and service providers of the role of carers as frontline staff providing daily care.
- Provide training to carers on how to talk to medical practitioners (GPs, Psychiatrists, other service providers). This can be done through peer-to-peer training and workshops providing tips and strategies for recording and sharing useful information about treatment outcomes.

### **Bios**

**Pat Ryan** – family carer, sometimes public and community sector worker, writer and broadcaster, carer representative Partners in Recovery Consortium DDSWQ 2012–2015.

**Neil Ryan** – spousal carer, carer representative Partners in Recovery Consortium DDSWQ 2012 – ongoing.



3.05 – 3.30

***Designing, implementing and measuring a successful Community Advisory Council.  
The Gold Coast Primary Health Network experience***

Breakout Room 1 Kellie Trigger, Planning and Stakeholder Engagement Program Manager, Gold Coast Primary Health Network  
Noela Baglot, Consumer Representative

**Abstract**

The Commonwealth requires Primary Health Networks (PHN) to establish and maintain a Community Advisory Council as a key condition of the Deed of Funding. This requirement presents a remarkable opportunity to strengthen the representation of health consumers within the primary care sector on a national scale.

Given the freedom for Primary Health Networks to develop and run their Community Advisory Council as they see fit, there is likely to be much variety among the approaches undertaken. Gold Coast Primary Health Network (GCPHN) is in the fortuitous position of having had a Community Advisory Committee functioning successfully since December 2014, established during operation as a Medicare Local. Drawing on the experience gained across these 16 months, we wish to share our learnings and discuss our approach.

A foundation element of the GCPHN Community Advisory Council has been the involvement of health consumers. Continued feedback and evaluation has been routine and critical to developing and maintaining strong relationships with members throughout periods of rapid change. This presentation will provide the dual views of PHN staff and Community Advisory Council members.

**Bios**

**Kellie Trigger** is the Planning and Stakeholder Engagement Program Manager with the Gold Coast Primary Health Network and has led the establishment of the GCPHN Community Advisory Council. She has a diverse background with experience in stakeholder engagement, strategic planning, population health planning, community services planning and procurement, cross sector projects, law and politics.

**Noela Baglot** is a passionate and highly active advocate for people in the community. A Registered Nurse with a long history of helping others, Noela knows the value of speaking up in this time of health reform. Making good use of over 50 years' experience in the health industry, Noela is currently a consumer representative with 6 organisations and has been involved with the Gold Coast Medicare Local and Primary Health Network group since late 2014.

**3.05 – 3.30      *Consumer Perspectives on Clinical Handover (CH)***

Breakout Room 2    Faileen James, Consumer Representative

Helena Lake, Consumer Representative

                                 Lisa Mitchell, Clinical Handover Coordinator, Royal Brisbane and Women's Hospital, Royal Brisbane  
                                 Women's Hospital**Abstract**

Having surveyed over 700 patients in the annual Patient Experience Survey, the RBWH's Safety and Quality Unit decided that more focused patient surveying in the area of Clinical Handover should be undertaken, with the aim of assessing patient involvement in, and improving patient input into, the process of clinical handover. Consequently, the consumer representatives on the hospital's Clinical Handover Committee worked with a staff member to design, develop, conduct and report on 40 patient interviews to gain their viewpoints on clinical handover.

**Aims of the project**

1. Represent consumer perspectives
2. Identify improvement areas for consumer engagement
3. Understand clinical environments and CH process
4. Target CH education strategies for the future
5. Contribute to the National Standards Audit

**Methods**

A randomised approach was undertaken for patient selection with 10 inpatients interviewed from each unit representing surgical, trauma, medical and a rehabilitation unit. Patients were aged between 23 – 92 years, with equal number of females and male patients.

**Outcome**

The interviews and the process have contributed to consumers' influence on the service provision process, strengthened the consumers' voice, and potentially assisted in driving better health outcomes.

**Bios**

**Faileen James** is the Director of James & Button Services Pty Ltd, a management consulting and legal firm specialising in the health and disability sectors. Faileen's clients include the Australian Commission on Safety and Quality in Health Care, the NSW Ministry of Health and some NSW Local Health Districts, (the previous) Medicare Locals, and various Not-for-Profits.

**Helena Lake** is a Senior Consumer Representative in 9th year of service on local (Metro North HHS), state and national levels. Helena has served on the Health Community Council in an advisory role and Health Quality Complaints Commission with focus on safety and quality of public health services and standards; community and consumer engagement; and community education in relation to the public health system.

**Lisa Mitchell** has been a clinical nurse in Haematology, Oncology and BMT for 15 years and an Oncology educator for 8 years. Lisa was Oncology certified in the US and worked for 3 years in New York City. In the last 16 years Lisa has been involved in nursing research, health systems research, drugs trials and project management with consumer involvement. Lisa has also completed her Masters of Social Science (Health Practice) through University of Queensland.

## **Session 3 Workshops**

12.00 – 1.15 **Workshop 1**

Breakout Room 3 **Panel – *Lessons from the peer workforce***

Facilitator: Andrew Blythe, Consumer Representative

Peer work has been an emerging area of practice in mental health services for the last decade. Health services more broadly are beginning to explore its value to health outcomes and creating a culture that embeds consumer participation into practice. Lessons from the peer workforce will discuss learnings from current Queensland initiatives and how these can inform its employment across the health system.

The session will be facilitated by Andrew Blythe, Consumer Representative, who will provide an overview of peer work and findings from his research, and chair a panel of mental health leaders including three local health services who are exploring peer work through research and practice; Central Queensland, Wide Bay, Sunshine Coast Primary Health Network, Brisbane North Primary Health Network and Metro South Hospital and Health Service Addiction and Mental Health Services.

Each of the groups will present a snapshot of their respective services, which will be followed by an open discussion about the recent rise of peer workers, especially within community mental health, and what that might mean for the future of health services.

### **Bios**

**Andrew Blythe** is a historian by trade who only ventured into the world of hospitals while supporting his Dad after a heart attack. Nearly ten years later that journey took a dramatic turn when—after exhausting all other treatment options—his Dad received a heart transplant.

Andrew is currently writing a memoir about the mental and physical health consequences of that event, which changed the trajectories of both of their lives. He enjoys being part of a wider ‘family’ of transplantees and their support networks. Because of these health challenges he has subsequently spent many years supporting people with mental, physical and intellectual disabilities to get their health needs met with compassion and dignity. He also enjoys telling other peoples’ stories and has run a number of writing workshops to help them find a voice.

His latest projects include collaborating with internationally-renowned photographer Steve Parish in a workshop series that supports people with mental illness to connect with their natural world and find life purpose through photography, as well as being a Queensland Health Consumers Collaborative member and working with Health Consumers Queensland to connect via story with all the diverse groups that need support in our health system.

### **Central Queensland, Wide Bay, Sunshine Coast Primary Health Network**

**Michelle McAllister** is a member of the Partners in Recovery (PIR) National Reference Group and the group’s Chair for the PIR working group on NDIS. As PHN’s Community Integration Coordinator Michelle provides regional management for PIR in Central Queensland, Wide Bay and Sunshine Coast. Michelle works from a partnership based approach and is committed to placing Consumers and Carers at the centre of policy and planning directions. Her experience in primary health care includes aged care, disability and mental health leadership.

### **Brisbane North Primary Health Network**

**Julie Acton** is a consumer representative with North Brisbane Partners in Recovery and participates in networks including the Operational Management Group and PIR Evaluation Reference Group. Julie also works as a Peer Support Worker for the Brook Red Centre and is a member of the management committee of Queensland Voice. Julie has an academic and professional background in law enforcement but has been active within the community mental health sector since 2014. Julie is a member of the Peer Participation Reference Group.

**Rebecca Wyeth** is a consumer with a living experience of mental illness and has become passionate about being a part of the Consumer/Carer Participation world in mental health. Rebecca is currently studying a Cert IV in Mental Health and Cert IV in Mental Health Peer Work as well as participating in a variety of consumer representative roles. Rebecca was employed as a consumer evaluator by Brisbane North PHN and was involved in the Consumer and Carer Engagement and Leadership Evaluation Project.

**Paula Arro** is the Project Officer for the Peer Participation Project and has over 25 years' experience working in the social and community services sector in Queensland. Most recently Paula has been a Community Development Officer in the Moreton Bay region working with community members, volunteer groups, community organisations and government departments.

#### **Metro South Hospital and Health Service Addiction and Mental Health Services**

**Karen McCann** worked as a Senior Project Officer within the statewide Mental Health Alcohol and Other Drugs Branch from 2009-2015 and was involved with the development of several statewide projects including the Consumer, Carer and Family Participation Framework, The Consumer Companion Program and The Consumer and Carer Workforce Network. In 2016 she was appointed to the role of Community Consumer/Carer Consultant for the Logan Community Care Unit (CCU), Metro South Addiction and Mental Health Services, where she provides support and professional supervision to the local Peer Recovery Support Workforce.

**Gabrielle Vilic** has worked in the NGO and Queensland Health within the mental health sector for over 20 years. Her interests include workforce development in the consumer, carer and peer area. Other interests include reduction in seclusion and restraint, sensory modulation and research. Gabrielle currently works with Metro South Addictions and Mental Health as the Director of Social Inclusion and Recovery and overlooks the Consumer and Carer Consultants and the peer workforce. Within the last 2 years the service has developed 33 new peer support positions.

12.00 – 1.15

**Workshop 2**

Hall A

***The Australian Commission on Safety and Quality in Health Care – The National Standards as a tool for disruption to improve patient safety and centred care***

Naomi Poole, Program Manager, Partnering with Consumers, Australian Commission on Safety and Quality in Health Care

The Australian Commission on Safety and Quality in Health Care (the Commission) leads and coordinates improvements in safety and quality in health care. One of the core activities of the Commission is the ongoing development of the ten National Safety and Quality Health Service Standards (the Standards), which provide a nationally consistent statement about the level of care consumers can expect from health service organisations. Since 2013, health service organisations have been required to be assessed against these Standards via a national accreditation scheme. The inclusion of Standard 2: Partnering with Consumers has led to a marked increase in the amount of consumer engagement activities within health services. The Standards are currently being reviewed and a new version is likely to contain an increased focus on health literacy and shared decision making.

This workshop focuses on the development of the Standards, feedback on their implementation, the types of changes which are expected to be integrated into the new version of the Standards and how consumers and health services can continue to use them as a tool for change.

**Bio**

**Naomi Poole** is the Director of the Partnering with Consumers program at the Australian Commission on Safety and Quality in Health Care, where she is involved in leading and coordinating national policy on partnerships with consumers, health literacy, end of life care and shared decision-making. She has a degree in psychology, and worked extensively at a national level in population health policy and program development for Aboriginal and Torres Strait Islander Health, national health screening programs, and child and youth health. She has also been closely involved in the development of costing models, healthcare indicators, and a national surveillance system for antimicrobial use and resistance.

2.15 – 3.30      **Workshop 3**

Breakout Room 3    ***Leading effective meetings with consumers***

Michael Morris, founder and Managing Director of the Samuel Morris Foundation

Consumers are invited to the table by health organisations to take part in the planning, design and evaluation of health services as regular members of steering committees or advisory groups, or for one off opportunities to take part in focus groups. In order to gain the maximum benefits of engaging with consumers in these group settings, Chairs or facilitators of groups should provide an environment where consumers feel their contributions are welcomed.

As an experienced Co-Chair of Sydney Children's Hospital Network Families and Consumer Council, Michael will facilitate a workshop on how to proactively draw out consumer input and support consumers who may be in pain or trauma from their previous experiences with the health system. He will also discuss structuring an agenda to balance giving consumer's information with ample opportunities to provide feedback and network.

This workshop is aimed at consumers who are or would like to become a Chair of meetings and staff who are or may Chair/facilitate meetings with consumers. However all attendees are welcome.

### **Bio**

**Michael Morris** is an emergency management and community services specialist with over 25 years' experience across a diverse range of emergency services, government and non-profit sectors. He is currently the Co-Chair of the Sydney Children's Hospitals Network Families and Consumers Council, Managing Director of the Samuel Morris Foundation; Australia's first charity founded to support children after non-fatal drowning accidents and to prevent future drowning deaths and disability through education and awareness. Michael is also an Inspector with Fire and Rescue NSW currently working in the Operational Capability Directorate as the Manager Operational Improvement.

2.15 – 3.30

**Panel**

Hall A

**Language and culture: Health services increasing the participation of diverse voices**

Facilitator: Dean Johnson, Consumer Representative, Queensland Health Consumers Collaborative

Chandima Powell, CALD Consumer/Carer Consultant, Queensland Transcultural Mental Health Centre

Simon Costello, Senior Project Officer Cultural Capability, Cairns and Hinterland Hospital and Health Service

Julie Rogers, Cultural Capability Team, Children's Health Queensland Hospital and Health Service

Jermaine Isua, Cultural Capability Team, Children's Health Queensland Hospital and Health Service

This panel session will examine the key barriers to consumer and carer participation from those with Culturally and Linguistically Diverse, Aboriginal and/or Torres Strait Islander backgrounds.

Presenters will showcase services implementing best practice engagement models including the Queensland Transcultural Mental Health Centre and Cairns Hospital and Health Service.

They will also describe how they support Queensland's health workforce to be more culturally responsive in how they provide information, assist consumers to access health services, deliver health services and engage with consumers.

**Bios**

**Dean Johnson** is of Aboriginal descent and lives in Ipswich with his family. He has lived experience as a health consumer and within mental health. He is currently a consumer representative member on the Queensland Health Consumers Collaborative. He works as the Indigenous Health Coordinator and Professional Lead for Indigenous Health Services at West Moreton Hospital and Health Service.

**Chandima Powell** is a CALD Consumer/Carer Consultant at Queensland Transcultural Mental Health Centre (QTMHC). The QTMHC works with consumers and carers from culturally and linguistically inclusive engagement in the development and delivery of QTMHC programs and services as well as broader policy and program areas to ensure culturally responsive and recovery focused services. Chandima's role focuses on two areas: to represent consumer issues and make the organisation's work consumer focused and as a resource and support person with the consumer and carer workforce in Queensland. Chandima also works with the trainer of QTMHC to provide with specific training to help understand what is available from the QTMHC to support CALD Consumers and help them to be more culturally inclusive.

**Simon Costello** is a Nunukul man from Minjirrebah (North Stradbroke Island). He is a Senior Project Officer Cultural Capability with the Aboriginal and Torres Strait Islander Health Unit, Cairns and Hinterland Hospital and Health Service. Simon is responsible for developing systems of Aboriginal and Torres Strait Islander Consumer Engagement and Cultural Capability Continual Quality Improvement. He holds a Diploma of Education, Post Graduate Certificate in Health Management and a Masters of Public Health Degree.

**Julie Rogers** is proud Woppaburra woman from the Great Keppell Islands. She is a part of Queensland Health's Cultural Capability Team.

**Jermaine Isua** is a descendant from the Saibai Koedal (Crocodile) people. He is a part of Queensland Health's Cultural Capability Team.

3.30 – 3.50

**Afternoon Tea**

Outside Foyer



**Session 4 Consumer Panel**

3.50 – 4.30

**Panel – Consumer engagement: wicked problems, disruptive solutions**

Hall A

Facilitator: Melissa Fox

Some health services report a wide range of challenges when trying to engage with consumers and the community. Consumers say they have innovative solutions to the problems besieging the health system, if only someone will listen. Be sure to submit your burning question on consumer engagement to our panel of consumers and health service staff, by writing it on a piece of paper provided and putting it in the jar on the registration desk by the end of the lunch break. From the myths around engagement to the elephants in the room, no question will be too hard for our panel.

**Panel Members**

Facilitator: Melissa Fox, General Manager, Health Consumers Queensland

Darlene Cox, Executive Director, Health Care Consumers Associations ACT

Aideen Hanly-Platz, Patient Experience Manager, Holy Spirit Northside Private Hospital

Michelle McAllister, Community Integration Coordinator, Central Queensland, Wide Bay, Sunshine Coast Primary Health Network

Helen Mees, Consumer Representative

Christine Petrie, Manager Consumer and Community Engagement, Metro North Hospital and Health Service

Gabrielle Quilliam, Guest Services/Cofounder, Hummingbird House

Dr John Wakefield, Deputy Director General, Clinical Excellence Division, Queensland Health

**Bios**

**Darlene Cox** is the Executive Director of Health Care Consumers' Association Incorporated since 2008 and is a member of the Executive of ACT Council of Social Services and member of the ACT Local Hospital Network Council. Darlene has been involved in the consumer movement since the late 1990s. She is an eminent advocate for health consumers with an excellent knowledge of the health system, both locally and nationally. Darlene has a strong, practical understanding of community engagement principles.

**Aideen Hanly-Platz** is the Patient Experience Manager at Holy Spirit Northside Private Hospital (HSNPH) Brisbane. Aideen is passionate about the entire patient experience and views consumer engagement as the very essence of the patient experience. Aideen has a background in nurse management, education and quality and safety both in Australia and Ireland.

The HSNPH had many recommendations following full hospital accreditation in December 2013. Following this, the Hospital created the Patient Experience Manager position. Aideen set up the Consumer Advisory Program at HSNPH. The Hospital went onto receive five met with merits following periodic review in December 2016.

Aideen's vision is to see consumer engagement fully integrated across the Hospital and become a sustainable and measurable influence on the patient experience. Aideen also believes true engagement with consumers will enable health services to continuously learn how to provide an increasingly safe, quality and positive experience for patients and staff.

**Michelle McAllister** is a member of the Partners in Recovery (PIR) National Reference Group and the group's Chair for the PIR working group on NDIS. As PHN's Community Integration Coordinator Michelle provides regional management for PIR in Central Queensland, Wide Bay and Sunshine Coast. Michelle works from a partnership based approach and is committed to placing Consumers and Carers at the centre of policy and planning directions. Her experience in primary health care includes aged care, disability and mental health leadership.



**Helen Mees** is a consumer member of the Queensland Health Consumer Collaborative. In 2012 Helen, from Ipswich, walked 640 km to complete the Camino in northern Spain. The walk is a highlight of Helen's life and has taught her so much – that anyone can do anything. What's remarkable about Helen's achievement is that she did this just 2 years after chemotherapy treatment and while living with chronic kidney disease and understanding she may get sick during the walk. Thirty years ago Helen was diagnosed with IGA nephropathy and has been living with chronic kidney disease since. Helen is the mother of two adults living with a disability and has personal experience of the health system in many guises.

Her own experiences, coupled with listening to people's stories for many years gives her a depth of experience and understanding on a myriad of health consumer and carer issues and challenges. She hopes to bring that experience of other people's stories to the Queensland Health Consumer Collaborative

Helen has a Masters in Human Services, Rehabilitation and Disability. Helen works with Uniting Care and Lifeline and recently as a relief Statewide Community Recovery Coordinator. She is a committee member of the Kidney Health Australia consumer committee.

**Christine Petrie** has worked in consumer and community engagement in health services in Queensland and Victoria since 2002. She has a Bachelor of Social Work and Masters in Public Health. Christine has a special interest in creating supportive health service environments that embrace diversity, respond to consumer needs, and enable consumers to participate as partners.

**Gabrielle Quilliam** is one of the cofounders of Hummingbird House, along with her husband Paul Quilliam. Through their experience as foster carer's, supporting children with life-limiting conditions and complex medical care needs, they recognised a gap in community based paediatric palliative care respite and end of life care services. By contributing to the Federal and State Inquiries into Palliative Care; engaging with local and national palliative care advocacy groups; working with community and clinical services; exploring national and international children's hospices; achieving Commonwealth and State funding and partnering with Wesley Mission Brisbane for clinical operations; their collaborations have paid off and Hummingbird House is about to be opened as Queensland's only children's hospice.

**Dr John Wakefield PSM** has over 20 years' experience in clinical and management roles in rural, regional and tertiary public sector health services in Queensland. After completing a Fellowship under Dr Jim Bagian, at the National Centre for Patient Safety of the VA Health System in the United States, he returned to Queensland in 2004 and established the Queensland Health Patient Safety Centre, which he led until late 2012. He established a state-wide network of patient safety officers and successfully established a legislative framework for incident analysis; ultimately demonstrating measurable reductions in preventable adverse events. John is actively involved in national efforts to improve patient safety in partnership with the Australian Commission for Safety and Quality in Healthcare. He chaired the National Open Disclosure Pilot Project and regularly teaches Open Disclosure and other patient safety curricula. His research interests include patient safety culture, safety performance measurement and Open Disclosure. In 2011, John was awarded a public service medal for services to patient safety as part of the national Australia Day Awards. Adjunct Professor of Public Health – Queensland University of Technology. Qualifications: MB CHB MPH (research) FRACGP FACRRM FRACMA.

4.30 **Close and Evaluation**

4.45-5.30 **Networking and drinks**

Outside Foyer

## Notes

## Notes

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