



CHF | SUMMIT
2021



Shifting Gears

18-19 March 2021

*The inaugural Australia and New Zealand Consumer
Experience and Leadership in Healthcare Summit*

CHF Consumers Health
Forum **OF** Australia



e-summit program booklet

ACKNOWLEDGEMENT TO COUNTRY

CCHF acknowledges the Traditional Owners of country throughout Australia where the Summit attendees work and live. We recognise their continuing connection to land, waters and community and pay our respects to them and their cultures; and to elders both past and present. We acknowledge the ongoing contribution Aboriginal and Torres Strait Islander peoples make to the health and wellbeing of our communities and our environment and recognise the importance of self-determination and community-centred services for good health outcomes for all Australians, including Aboriginal and Torres Strait Islander people.

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SUMMIT WELCOME

Successful health strategies, policies, research and programs depend on consumer involvement at each stage of development. Consumer advocacy has already contributed in many ways to shaping our health system. As the pace of health reform accelerates, driven by digitisation, consumer expectation, and the advent of genomics and precision, personalised medicine, we must continue to ensure that this remains the case. Against this backdrop, the Consumers Health Forum of Australia (CHF) is proud to introduce the Shifting Gears Summit. The scope and scale of this inaugural Australasian health consumer conference is unprecedented. In 21st century health, we are 'shifting gears' in both consumer experience and leadership - the over-arching themes of the conference. We are bringing to you an exceptional range of speakers from not only Australia and New Zealand, but also Canada and the United Kingdom.

Why it is time to re-imagine health and social care is the question we will pose at the conference opening. We will be sharing ideas and experiences that reflect the developing role that consumer insights and leadership is playing in health care both in practice and system co-design.

This Summit presents an expansive menu - six parallel streams on themes of consumer-based health care; leadership; research; enablement; COVID and New Zealand innovative developments.

Consumer health issues of the moment ranging from how consumers define value-based healthcare, to the importance of consumer and community engagement in the COVID vaccination strategy, health literacy, consumer power and influence in health care and digital health, will be among the wide variety of topics discussed.

On behalf of the CHF Board, I would like to thank our Program Advisory Committee who assisted us design the program, in particular Professor Lynne Maher, Innovation and Improvement Clinical Director, Ko Awatea Health System Innovation and Improvement and Dr Christine Walsh, Director, Partners in Care, NZ Health Quality and Safety Commission who went above and beyond to assist us to put together the New Zealand presence. I would also like to thank our many and generous sponsors. Without their support and commitment to person-centred care, this inaugural Summit would not have been possible.

We look forward to hosting all our delegates and hope that you find the program rewarding. As a companion to our Acknowledgement of Country, I will leave you with this Maori proverb:

e aha te mea nui o te ao

What is the most important thing in the world?

He tangata, he tangata, he tangata

It is the people, it is the people, it is the people

After all health care is based on 'the people'.



Leanne Wells
Chief Executive Officer



VIRTUAL PLATFORM ACCESS

Welcome to the *CHF Summit 2021: Shifting Gears* first virtual event. All attendees should have received personalised log-in information to the virtual platform, if you have not received this - please go to the below link and use the chat functionality located at the bottom right of the screen: <https://chf.delegateconnect.co>.

After logging in, please don't forget to edit your profile, under the account button in the top right of your screen by filling in the form. If you make your profile public, you will be able to interact with other delegates and other delegates will be able to interact with you, without activating your profile as public your details will not be viewed.

Please note all program timings are in Australian Eastern Daylight Time (AEDT), the Summit Organising Committee understands some timings may not be suitable to those located in WA or outside Australia. So all presentations will be recorded and available on the virtual platform for up to one year post event.

On the day of the event, to watch LIVE content on the virtual platform, please login to the virtual platform and click on 'WATCH LIVE CONTENT' at the top right of the screen. When we have breaks during the two day program, we encourage all participants to explore our sponsors and poster presentations located on the left-hand side of the event screen.

Tips and tricks to remember:

- If you need assistance at any time during the summit, please contact our support team via the pink chat bubble on the bottom right hand corner of the event screen
- Connect with your colleagues via the 'SEARCH' button located within the top right-hand menu
- Make sure your profile is listed as public if you want to be searchable to colleagues and other delegates!
- Want more information about a session, speakers, attendees or sponsors? These are easily accessed via the left-hand side menu
- Looking for a live concurrent session? Click on 'WATCH LIVE STREAM' located within the top right-hand menu where you can choose the virtual event room you want to enter
- During catering breaks network with other attendees in our chat rooms located in the 'CONNECT NOW' menu option at the top of the screen
- Create your own personal program by selecting favourite sessions and talks within the agenda
- Don't forget to visit the sponsors during the program breaks. Why not pre-book a meeting with them to ensure you are able to secure time for a chat and update?
- During all breaks there will be chat rooms for delegates to interact with all sponsors and attendees

If you enjoy the event - hop on your social media and share about your experience using the hashtag **#ShiftingGearsSummit**

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CONFERENCE ORGANISERS ALIGNMENT EVENT SOLUTIONS



DELEGATE CONNECT - VIRTUAL PLATFORM



PRE CONFERENCE MASTERCLASSES

Experienced Based Co-Design (EBCD) Masterclass

13:00 - 17:00, Wednesday 17 March 2021

PRE-REGISTRATION REQUIRED

Experience based co-design methods are increasingly being used within health and care organisations around the world. This interactive masterclass will provide an overview of the methodology and showcase, through case studies, how consumers, families and staff have used experience based co-design to improve health and care services.

At the end of this masterclass, participants will have built on their understanding in the following areas:

- The context, value and evidence base for working closely with staff, patients and their families;
- Use of a systematic but flexible process to engage people, capture their experiences of care, organise and identify themes for improvement and to co-design future processes;
- A range of tools utilised to understand experiences of those delivering and receiving health and care services.



FACILITATOR:

Dr Lynne Maher

Innovation and Improvement Clinical Director

Ko Awhatea, Health System Innovation and Improvement

Dr Lynne Maher has had an extensive health care career ranging from critical care nursing, operational and board posts at local and national level during which she has been able to support teams to create significant improvement in health systems. This has been specifically through her work on co-design, creativity and innovation, creating the culture for innovation, leading change and sustainability for improvement.

Lynne is the Co-design Advisor on the Steering Group for a new National Quality Safety Marker for Consumer Engagement in New Zealand. She also acted as an Advisory Board Member of the CORE Research Study on co-design at the University of Melbourne which is notably the first ever Randomised Control Trial of co-design in Mental Health Services.

Lynne is also a reviewer for the NZ Medical Journal, British Medical Quality and Safety Journal and the Journal of Clinical Nursing.

Follow Lynne on Twitter @LynneMaher1

PRE CONFERENCE MASTERCLASSES

Health Literacy Masterclass

13:00 - 17:00, Wednesday 17 March 2021

PRE-REGISTRATION REQUIRED

The half day Health Literacy Masterclass will include:

1. Introductions
2. Health literacy 101 – what it is and why it matters
3. Strategies to improve health literacy – what the evidence tells us
4. Digital Health Literacy 101 - what it is and why it matters

After the break, the Masterclass will cover recent research findings:

1. Supporting behaviour change for people with lower health literacy – use of action plans
2. Strategies to improve digital health literacy
3. COVID and health literacy - what have we learned
4. Improving multicultural health communication and COVID
5. Overall Q & A

There will be time to ask questions throughout the session.



FACILITATOR:

Professor Kirsten McCaffery

NHMRC Principal Research Fellow, Director, Sydney Health Literacy Lab,
Sydney School of Public Health, The University of Sydney

Professor Kirsten McCaffery has a national and international reputation in shared decision making, health literacy and the assessment of psychosocial outcomes, and has had four successive NHMRC fellowships.

She is Director of Research at the Sydney School of Public Health and Director of the Sydney Health Literacy Lab, a group of over 20 researchers and students at the School of Public Health. She is co-founder of Wiser Healthcare – a research collaboration of over 100 researchers across four Australian institutions (Universities of Sydney, Bond, Wollongong and Monash) and Node Leader of the Charles Perkins Centre, Health Literacy Node.

Her research focuses on psychosocial aspects of over diagnosis and over testing, health communication among vulnerable populations and behaviour change research. Her work uses quantitative methods such as randomised trials and experimental studies as well as qualitative research.

Professor McCaffery has received over \$39 million in competitive research funding since 2000 and has over 270 publications including papers published in the highest ranked general medical journals including Lancet, BMJ, JAMA and MJA.

PRE CONFERENCE MASTERCLASSES

Health Literacy Masterclass Co-Presenters



CO-PRESENTER:

Dr Danielle Muscat

B.Psych. [Hons], PhD, is a founding member and Westmead Lead of the Sydney Health Literacy Lab

Danielle currently holds a highly-competitive Westmead Fellowship (Early Career Researcher) funded by the Research and Education Network, Western Sydney Local Health District. In 2019, she was appointed as an Advisor on Health Literacy to the World Health Organisation and Health Literacy Chapter Co-Lead for the revised International Patient Decision Aids Standards (IPDAS). Dr Muscat's PhD research involved the development and evaluation of the world's first combined health literacy and shared decision-making training program for adults with lower literacy, implemented across TAFE NSW.



CO-PRESENTER:

Dr Julie Ayre

Behavioural scientist with an interest in health literacy, behaviour change for lifestyle and self-management, patient-provider relationships and mobile health Literacy Lab

Dr Julie Ayre is a behavioural scientist with an interest in health literacy, behaviour change for lifestyle and self-management, patient-provider relationships and mobile health. Her PhD explored how health literacy impacts on behaviour change strategies, and how diabetes self-management apps in primary care settings could better support people with diabetes and low health literacy. During her PhD she developed and tested health-literate action plans to reduce unhealthy snacking; these will soon be available on the Diabetes NSW & ACT website. She is currently developing an online automated health literacy editor to support health professionals to develop easy-to-read health materials.



CO-PRESENTER:

Liz Jones

Head of Collaborative Projects, Good Things Foundation

Liz has 20 years' experience working across health, government, community/not for profit and commercial sectors. For more than 10 years Liz has held senior roles delivering digital transformation of the health and non-profit sectors to improve outcomes for Australians. Most notably Liz led the consumer engagement, communications and education to support the expansion of the My Health Record system in 2018/19 to all Australians. Liz joined the Good Things Foundation leadership team in 2020.

KEYNOTE SPEAKERS - DAY ONE

Acknowledgement of Country: Kari Singers

08.45 - 08:55 - Thursday 18th March 2021

The KARI Singers are a progression from KARI's Vocal Identification Program (VIP) which comprises a talented group of young Indigenous performers. VIP identifies young Indigenous high school student vocalists from the local South West Sydney area and provides them with unique opportunities to develop and enhance their performance skills.

Each participant is mentored and supported by their coaches, who are experienced musicians. They are given the opportunity to develop their skills and learn real insights into the music industry, while also supporting their personal growth and strengthening their connection to culture with numerous songs performed in language.

The KARI Singers are formed from the alumni of the VIP program and allow the young graduates to continue to showcase their talents for corporate Australia performing at celebrations and other prestigious events.



KEYNOTE SPEAKERS - DAY ONE

Conference Welcome:

Mr Tony Lawson, Chair, Consumers Health Forum of Australia

08:55 - 09:05 - Thursday 18th March 2021

Tony has over 30 years expertise in public policy making and represented SA Government on many national inter-governmental relations projects including the establishment of national health and social programs (eg: Home and Community Care Program).

As Commissioner for Consumer Affairs he undertook a major change management program based on a customer centred focus and achieving compliance through education. Tony represented the SA Government at national meetings on consumer affairs laws, policies and programs.

As Chief Executive Officer of a metropolitan local government authority he was principal policy adviser to the Council on policies and programs and undertook a major change management project to modernise the Council's operations. Tony acted as advocate on the Council's strategic objectives and plans at high level State and Local Government meetings and forums, including giving evidence to a Productivity Commission review.

As Director of Tony Lawson Consulting for over 20 years, he advised many agencies and authorities on key policies, strategies, strategic directions and on governance frameworks and undertaken many health policy projects, served on high level advisory committees and co-authored a number of consumer health related articles.

Tony has been a member of the CHF Board since 2010 and Chair since 2014 and overseen many changes to this organisation to the extent that it is the pre-eminent peak consumer health advocacy body in Australia.

Tony has also been a Board Director of the Australian Council on Healthcare Standards, the leading health care assessment and accreditation provider, for a period of 8 years.

Tony is currently Executive Director, Palliative Care at The Hospital Research Foundation responsible for establishing a statewide basis for funding palliative care research and patient care programs.



KEYNOTE SPEAKERS - DAY ONE

Conference Welcome:

Dr Lynne Maher, Innovation and Improvement Clinical Director, Ko Awatea

08:55 - 09:05 - Thursday 18th March 2021

Lynne has had an extensive health care career ranging from critical care nursing, operational and board posts at local and national level during which she has been able to support teams to create significant improvement in health systems. This has been specifically through her work on co-design, creativity and innovation, creating the culture for innovation, leading change and sustainability for improvement.



Lynne is the Co-design Advisor on the Steering Group for a new National Quality Safety Marker for Consumer Engagement in New Zealand. She also acted as an Advisory Board Member of the CORE Research Study on co-design at the University of Melbourne which is notably the first ever Randomised Control Trial of co-design in Mental Health Services. Lynne is also a reviewer for the NZ Medical Journal, British Medical Quality and Safety Journal and the Journal of Clinical Nursing.

Follow Lynne on Twitter @LynneMaher1



KEYNOTE SPEAKERS - DAY ONE

Keynote 1:

Vincent Dumez, M.Sc, Co-Director and Patient Partner, Centre of Excellence on Partnering with Patients and the Public (CEPPP), University of Montreal

09:05 - 09:30 - Thursday 18th March 2021

Vincent Dumez, MSc, holds a finance degree and a Master's degree in Management Science from Montreal's international business school, Hautes Études Commerciales. Until 2010, he was an associate in one of Montreal's most influential consulting firms, specialising in organisational design.

In October 2010, Mr. Dumez became the first director of new Office of Patient Partner Expertise of the University of Montreal's Faculty of Medicine. Since summer of 2016, Mr. Dumez now co-directs the new Centre of Excellence on Partnering with Patients and the Public of University of Montreal. The mission of the centre is to make collaborating with patients and the public a science, a culture and the new standard to improve the health of all and the (health) experience of each.

Living with multiple chronic diseases for more than four decades, and thus a significant user of healthcare services, Mr. Dumez has been actively involved in developing the concept of "Patient Partnership." He first explored the concept in his Masters' dissertation and now in his Ph.D thesis.

Since then he has pursued to deployment of the concept by helping patients to engage meaningfully in education, research and care. He's also on the boards of renowned health organisations and a keynote speaker in national and international health conferences.



Keynote 2:

Dr Ashley Bloomfield, Director General Health, New Zealand - invited

09:30 - 09:55 - Thursday 18th March 2021

Dr Bloomfield qualified in medicine at the University of Auckland in 1990 and after several years of clinical work specialised in public health medicine. His particular area of professional interest is non-communicable disease prevention and control, and he spent 2011 at the World Health Organization in Geneva working on this topic at a global level.

Dr Bloomfield was Chief Executive at Hutt Valley District Health Board from 2015 to 2018. Prior to that, he held a number of senior leadership roles within the Ministry of Health.



KEYNOTE SPEAKERS - DAY ONE



Keynote 3:

Susan Pearce, Co Chair, Elevating the Human Experience Steering Committee, NSW Health Re-imagining Human Experience

09:55 - 10:20 - Thursday 18th March 2021

Susan is the Deputy Secretary of the Patient Experience and System Performance Division at the Ministry of Health, a position she has held since November 2015. In this role, Susan is responsible for the oversight of front-end service delivery and system management across NSW Health. Part of this role is also the commissioning of services and negotiation of service agreements with NSW Health entities including all Local Health Districts and Specialty Health Networks. NSW Health is the best-performing jurisdiction in the country across a range of independently reported measures.

Transforming and improving patient experience is a key part of Susan's role and an area she is committed to improving. In 2013, Susan produced a short film called Small Acts of Kindness that continues to be used across NSW Health and in undergraduate programs teaching compassion and kindness.

Since the establishment of the State Health Emergency Operations Centre (SHEOC) in March 2020 to respond to the COVID-19 pandemic, Susan has also held the role of SHEOC Controller. She is responsible for directing and overseeing NSW Health's operational response to the pandemic which has included significantly expanding the state's intensive care capacity, managing changes to service delivery, standing up COVID testing clinics, overseeing hotel quarantine arrangements, and implementing actions to give effect to border state restrictions.

Susan started her career as a registered nurse across rural, remote, and metropolitan areas of NSW and remains registered to practise to this day. She has held a number of senior executive positions in NSW Health including Executive Workforce Director in Northern Sydney and Central Coast Area Health Service, Director — Operations at Northern Sydney Local Health District as well as the NSW Chief Nursing and Midwifery Officer. In these roles, Susan has managed large portfolios, including: acute health services, mental health, public health and health promotion, workforce, clinical training and education, and Aboriginal health.

Susan's commitment to drive change in the public health system makes a positive difference to patients' health outcomes and care; this is while maintaining a keen interest in the wellbeing of staff across the NSW Health system.

Susan has qualifications in Law and was admitted to the Supreme Court of NSW as a solicitor in September 2019.

KEYNOTE SPEAKERS - DAY ONE



Keynote 3:

Craig Cooper, Co Chair, Elevating the Human Experience Steering Committee, NSW Health Re-imagining Human Experience

09:55 - 10:20 - Thursday 18th March 2021

Mr Craig Cooper has been living with HIV since 2003 and successfully commenced treatments in 2004. He was also diagnosed with HCV in 2014 and in recent years was successfully cured by the new Hepatitis C treatments. His patient (health consumer) advocacy has occurred through a range of non-government sector representative positions.

Populations he represents are: people living with HIV; Gay Men; and people living with HCV. Other health consumers Craig works on behalf of include: LGBT people; people involved in the criminal justice system; vulnerable children and young people; Aboriginal people; and people from Culturally and Linguistically Diverse backgrounds; and people with disability. Most of his work has occurred in population health (blood borne viruses and sexually transmitted infections) and alcohol and other drug programs (court diversion) programs in the criminal justice system.

Craig is a member of Health Consumers NSW and an ACI/CEC Consumer Council Member. Craig holds a post graduate diploma in Clinical Drug Dependence Studies from Macquarie University and a Master of Public Administration from the University of Sydney. He is currently employed by Barnardos Australia as the Head of Commercial & Business Strategy.

KEYNOTE SPEAKERS - DAY ONE

Plenary 2: Introducing the Themes

Facilitator: Ms Amanda Cattermole, PSM, CEO, Australia Digital Health Agency

11:00 - 12:30 - Thursday 18th March 2021



Amanda Cattermole is the Chief Executive Officer of the Australian Digital Health Agency, a role she commenced in September 2020. Prior to this Amanda was the Chief Operating Officer at Services Australia (formerly the Department of Human Services). Amanda served as interim Chief Executive Officer during the 2019/20 bushfires season. Amanda held several other senior roles at Services Australia, including an extended period as Deputy Secretary, Health and Aged Care, responsible for the delivery of more than \$60 billion in annual payments and services to Australians under Medicare, the PBS and in the aged care sector.

Amanda has also held senior roles in the Commonwealth Departments of Treasury, Prime Minister and Cabinet and Families, Housing, Community Services and Indigenous Affairs, and the Victorian Department of Health and Human Services and the Western Australian Department of Indigenous Affairs. In her earlier career Amanda worked as a lawyer in Victoria, the Northern Territory and Western Australia.

Amanda holds a Bachelor of Laws, a Bachelor of Commerce, a Master of Laws and a Master of Business Administration. Amanda received the Public Service Medal for outstanding public service leading reform in providing housing for Indigenous people in remote communities and the National Gambling Reform laws.

Consumers as Researchers

Ms Anne McKenzie AM, Leader – Consumer and Community Involvement and Engagement

11:10 - 11:20 - Thursday 18th March 2021



Anne McKenzie AM is the Community Engagement Manager at the Telethon Kids Institute in Western Australia. Anne has held professional and voluntary roles as a consumer advocate for the past three decades.

Since 2004 Anne has worked in research organisations to increase the community voice in research. She is a senior consumer representative and serves on key national health and research committees. Anne is a Life Member of Health Consumers Council WA and in 2015, she was appointed to the Order of Australia for her work in health service and research.

KEYNOTE SPEAKERS - DAY ONE

Consumer-Based Health Care: Australian Perspective

Jo Watson, Deputy Chair CHF and Consumer Advocate

11:20 - 11:30 - Thursday 18th March 2021



Jo Watson is the inaugural Deputy Chair of the Pharmaceutical Benefits Advisory Committee (PBAC) and has been a consumer nominee on this Committee since 2013. She is also the Chair of the HTA Consumer Consultative Committee, Office of Health Technology Assessment, Australian Government Department of Health; and the Deputy Chair of the Consumers Health Forum.

Jo has been a community representative and patient advocate in the Australian HIV response, from the early nineties, including as the Executive Director of the National Association of People living with HIV Australia (NAPWHA) from 1998 to 2014.

Jo is an Honorary Life member of NPS MedicineWise, a Special Representative for NAPWHA, and a Director of the Board of the AGPAL group.

Consumer-Based Health Care: New Zealand Perspective

Rosalie Glynn, Chair, Consumer Council at Counties Manukau Health

11:30 - 11:40 - Thursday 18th March 2021



Rosalie Glynn was born in New Zealand and had five children (now adults) with high health needs which has meant frequent and ongoing use of the health system. Through these experiences she has learnt to be an advocate for those whose voices are not always heard. Counties Manukau DHB has shown a commitment to being patient /whaanau (family) focused and she wants to continue to be part of shaping the future of health care for our community.

She has been Chair of the Counties Manukau DHB Consumer Council since March 2015. At CM Health Rosalie is a consumer representative on the Quality Safety Marker group and the Patient and Whaanau Centred Care Board (PWCC).

Rosalie is also a consumer member for service credentialing at Counties Manukau DHB, as well as being the consumer member for the accreditation of PGY1 medical students.

Consumer Leadership

Kellie O'Callaghan, O'Callaghan + Co

11:40 - 11:50 - Thursday 18th March 2021



Kellie is recognised for her strong leadership in health, community services & governance. She is a well-respected authentic community leader with a passion for health consumer & community engagement. Kellie served for many years as the Chair of a Regional Health Service Board, has served on a range of State & local health focused governance Boards & Committees. Motivated by her extensive personal health consumer experience & with a focus on work that drives genuine improvement for patients, carers & community, she also chaired the Victorian Department of Health's Building Board Capability Advisory Committee.

KEYNOTE SPEAKERS - DAY ONE

Consumer Enablement

Dr Lyndal Trevena, Professor Primary Health Care, University of Sydney

11:40 - 11:50 - Thursday 18th March 2021



Lyndal is a GP and Professor Emerita at the University of Sydney. She is nationally and internationally recognised for her work on shared decision making and is passionate about partnering with consumers to enable them to be more involved in their healthcare. She has particularly worked with vulnerable populations such as the homeless, refugees and communities in low income countries.

Lyndal is also a cancer survivor, a daughter of ageing parents, a wife, a mother and grandmother.

BIG IDEAS FORUM

Panel Discussion: Featuring Lead Consumers Exploring their Big Ideas to Improve Healthcare in Australia and NZ Regions

15:30 - 17:15 - Thursday 18th March 2021



Facilitator: Ellen Fanning, The Drum, ABC TV

In her 20 years as an award winning public affairs journalist, Ellen Fanning has interviewed every Australian Prime Minister from Sir John Grey Gorton to Malcolm Turnbull.

She has reported politics from Canberra to the White House while her broader career has taken her to locations as diverse as the North Pole, an airline refuelling fighter jets over Bosnia and a Collins Class submarine deep in the Indian Ocean.

She spent the first ten years of her career at the ABC where she presented both the AM and PM current affairs radio programs. She also served as the ABC's Washington correspondent. She was later a reporter on the Nine Network's 60 Minutes and the last presenter of Nine's Sunday program.

Ellen co-presents ABC TV's "The Drum" and is regularly seen and heard on ABC TV's 730 and on ABC Radio around Australia.

Ms Ellen Fanning appears by arrangement with Claxton Speakers International.





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A New Kind of Consumer Leader

18:00 - 19:30 - Thursday 18th March 2021

Mark Doughty, Senior Consultant, Leadership Development, Kings Fund UK

Mark Doughty works at The Kings Fund where he supports VCSE/Third Sector health and care leaders, including citizen leaders to effectively work with other key organisations and statutory bodies to achieve personal, place based and system change. At the heart of this work is the development of collaborative and partnership relationships and working practices involving co-production and social design.



Mark is the joint author of the Collaborative Pairs program at the Kings Fund. A program focused on developing collaboration and partnerships between health and social care professionals and patient/citizen leaders.

Mark has recently worked with the Consumers Health Forum of Australia to support the development and delivery of their Collaborative Pairs Australia program and has worked with the NSW Agency for Clinical Innovation coaching a team working on developing collaborative/partnership with patients/consumers.

Mark became disabled in his mid-20's. This experience guided the subsequent direction of Mark's work and has focused on working with people who are living with illness, injury and disability and the organisations and bodies associated with them. Initially Mark supported them to find ways of living well with their condition/s. He then supported those seeking to access meaningful employment opportunities as well as those already in work who wanted to achieve their leadership aspirations.

In recent years he was involved in co-founding the Centre for Patient Leadership where I supported those who wished to develop their confidence and competence as patient leaders largely within the context and remit of the National Health Service. Mark's current work at The Kings Fund brings together his personal and professional interests in the health and wellbeing of local communities and their citizens who have lived experience of health and care issues and who wish to and are leading change.

COCKTAIL NETWORKING



Quality
Innovation
Performance

Louisa Walsh, PhD candidate and Research Officer, Centre for Health Communication and Participation, La Trobe University
18:00 - 19:00 - Thursday 18th March 2021



Louisa Walsh is a PhD candidate and Research Officer from the Centre for Health Communication and Participation at La Trobe University, and is a sessional lecturer at both La Trobe University (communications) and Monash University (physiotherapy).

She completed a Bachelor of Physiotherapy at the University of Melbourne in 2003 and completed her Master of Strategic Communication at La Trobe in 2016. Her PhD research is examining how social media can be used to engage consumers in health service design and quality improvement.

Louisa is also a person with cysticfibrosis, and underwent a double lung transplant over 10 years ago as a result of her CF. She has held consumer leadership roles within her chronic illness communities, including board appointments in disease-specific organisations. Louisa is also one of the consumer facilitators of CHF's Collaborative Pairs program.

As both a life-long and frequent user of health services, and a health professional, Louisa brings unique experience to her work around consumer engagement. She has a keen interest in how consumers and clinicians can work together to lead health service change, and also how consumer groups can collectivise independently of health services to influence services to become more person-centred. She is also interested in digital health, chronic disease self-management, and issues of equity within healthcare.

KEYNOTE SPEAKERS - DAY TWO

Panel: Global Trends in Safety and Quality

Facilitator: Dr Lynne Maher, Innovation and Improvement Clinical Director, Ko Awatea

09:00 - 10:00 - Friday 19th March 2021



Jeffrey Braithwaite, Director, Australian Institute of Health Innovation and President, International Society for Quality in Health Care (invited)

09:00 - 10:00 - Friday 19th March 2021

Professor Jeffrey Braithwaite, BA, MIR (Hons), MBA, DipLR, PhD, FIML, FCHSM, FFPHRCP (UK), FAcSS (UK), Hon FRACMA, FAHMS is Founding Director of the Australian Institute of Health Innovation, Director of the Centre for Healthcare Resilience and Implementation Science, and Professor of Health Systems Research, Faculty of Medicine and Health Sciences, Macquarie University, Sydney, Australia. He has appointments at six other universities internationally, and he is a board member and President of the International Society for Quality in Health Care (ISQua) and consultant to the World Health Organization (WHO). His research examines the changing nature of health systems, which has attracted funding of more than AUD \$145 million. He is particularly interested in health care as a complex adaptive system and applying complexity science to health care problems.

Professor Braithwaite has contributed over 640 refereed publications and has presented at international and national conferences on more than 1,020 occasions, including over 110 keynote addresses. His research appears in journals such as The BMJ, JAMA, The Lancet, Social Science & Medicine, BMJ Quality & Safety, and the International Journal for Quality in Health Care. He has received over 50 different national and international awards for his teaching and research.

We have been working with 152 countries looking at global trends in healthcare. We will discuss five key trends affecting care everywhere: sustainable health systems, genomics, information technology, changing demographics, and new models of care.



Professor Anne Duggan, Clinical Director, Australian Commission on Safety and Quality in Health Care

09:00 - 10:00 - Friday 19th March 2021

Conjoint Professor Anne Duggan is a Clinical Director at the Australian Commission on Safety and Quality in Health Care and Conjoint Professor, School of Medicine and Public Health, University of Newcastle. Dr Duggan is a highly respected Gastroenterologist with significant operating and leadership experience in a range of healthcare settings. She is passionate about improving health care services through sharing knowledge and collaborating across all aspects of the health system.

Professor Duggan leads the development of the Australian Atlas of Healthcare Variation series.

KEYNOTE SPEAKERS - DAY TWO

Panel: Global Trends in Safety and Quality

Facilitator: Dr Lynne Maher, Innovation and Improvement Clinical Director, Ko Awatea.

09:00 - 09:10 - Friday 19th March 2021

Jennifer Zelmer, Chief Executive Officer, Canadian Foundation for Health Improvement
09:00 - 10:00 - Friday 19th March 2021



Dr. Jennifer Zelmer is the inaugural President and CEO of the new organisation formed in 2020 through the amalgamation of the Canadian Foundation for Healthcare Improvement and Canadian Patient Safety Institute to achieve safer, higher quality and more coordinated patient-partnered healthcare. Jennifer's long-standing commitment to improving healthcare quality and safety, as well as expertise in spreading and scaling innovations that deliver better outcomes, will help to create this new organisation with an expanded capacity to improve healthcare for everyone in Canada. Jennifer joined CFHI as its President and CEO in September 2018. She has been a C.D. Howe Research Fellow for several years and is also an adjunct faculty member at the University of Victoria, as well as a member of several health-related advisory committees and boards.

Jennifer served on the first (2004) Safer Healthcare Now! National Steering Committee convened by CPSI when she was at CIHI. She also served on CPSI's former Health System Innovation Advisory Committee, and more recently, Jennifer served on the National Patient Safety Consortium Steering Committee during her time at Infoway.

Dr. Zelmer received her PhD and MA in economics from McMaster University and her B.Sc. in health information science from the University of Victoria.

Dr Christine Walsh, NZ Health Quality and Safety Commission
09:00 - 10:00 - Friday 19th March 2021



Chris has spent most of her working life in health. She trained initially as a psychiatric nurse before becoming a comprehensive trained nurse. Her undergraduate degree is in Education, her Masters in applied social science research and her PhD in nursing. After clinical nursing and teaching undergraduate nursing her career moved into nursing education at Victoria University, Wellington NZ, where she spent 12 years teaching post graduate nursing students. Much of this teaching was with mental health nurses where the importance of hearing multiple consumer voices guided her teaching and work. Her consumer work became much more focused when a diagnosis of breast cancer in 2006 prompted an awareness of poorer treatment options and outcomes for NZ women who were diagnosed with breast cancer. As a result of her advocacy around this in 2010 she was awarded a Member of the New Zealand Order of Merit in the New Year's honors for her contribution to women's health.

KEYNOTE SPEAKERS - DAY TWO

Keynote 4:

Kate Mulligan, M.Sc, Assistant Professor, University of Toronto, Canada

15:00 - 15:25 - Friday 19th March 2021

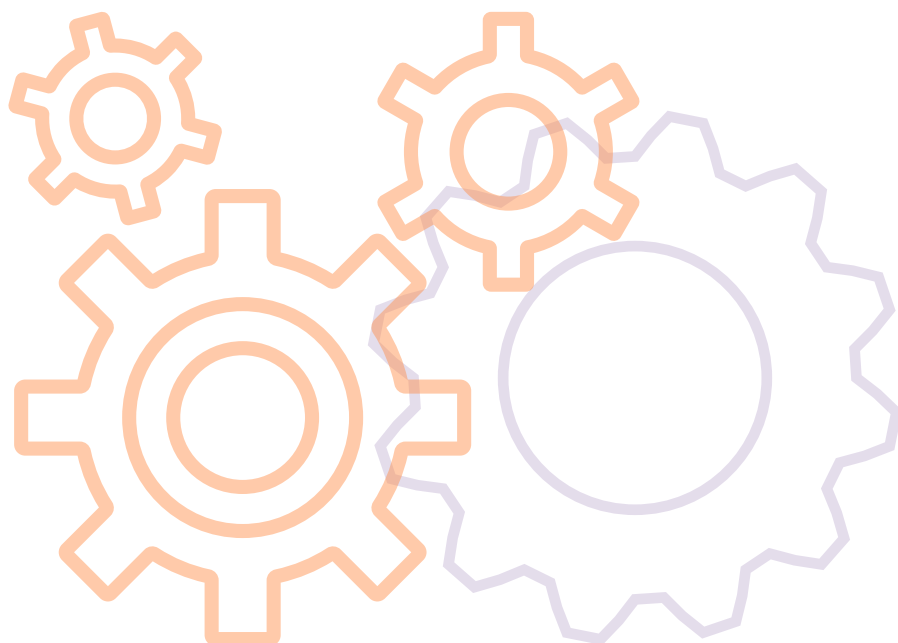
Dr. Kate Mulligan is an Assistant Professor at the Dalla Lana School of Public Health (DLSPH) at the University of Toronto. With the Alliance for Healthier Communities, Kate has directed Canada's first large-scale social prescribing project, implemented in community health centres across diverse urban, rural, Francophone, and Northern regions in the province of Ontario.

This initiative, winner of the first International Social Prescribing Award, aims to improve health outcomes for marginalised and socially isolated people and to reduce health systems utilisation by creating a clinical pathway between mainstream health systems and community and voluntary supports. The work is showing promising results and has galvanised wide interest and support across Canada.



Kate's presentation will share the Canadian social prescribing journey to date, with stories and results from the Rx: Community project, the work of social prescribing and health equity throughout the COVID-19 pandemic, and the work toward scaling up across the country and around the world. Key areas of focus will be the role of clients and community in co-creating social prescriptions, the importance of data collection and research.

Follow Kate on Twitter @KateMMulligan.



KEYNOTE SPEAKERS - DAY TWO

Panel: Future Horizons Panel

Facilitator: Suzanne Robinson, Professor and Theme Leader, Health Systems and Health Economics, Curtin University

15:25 - 16:30 - Friday 19th March 2021

Professor Suzanne Robinson is a leading researcher in health systems and health economics research. She has a track record in collaborative research activity and extensive experience of working with consumers, policy makers and clinicians in using research to inform practice.



Suzanne is passionate about consumer participation in research working closely with consumer organisations and consumers in research activity.

Suzanne is leading a collaboration with CHF, Digital Health CRC and Deloitte entitled Reimagining healthcare in Australia: the journey from telehealth to 21st century design. This consumer focused project aims to define the priority activities required to ensure Australia embeds virtual/tele/digital capabilities into the 'new normal' of healthcare delivery.



Harry Iles-Mann, Youth Health Advocate & Member of CHF

15:25 - 16:30 - Friday 19th March 2021

Harry Iles-Mann is a Patient/Health Consumer Advocate, Speaker, Committee Member, and Co-Design and Engagement Consultant. He has over 20 years of experience as a patient relying on health systems for the treatment and management of several serious chronic physical and mental health issues.

In addition to working closely with Australian and International Government, Private, and not-for-profit health organisations, Harry is Consumer Representative on, and chairs a number of Australian State and Federal Committees to provide Health Consumer focused insight on large scale system change, quality and safety, and health innovation and policy initiatives.

KEYNOTE SPEAKERS - DAY TWO

Panel: Future Horizons Panel

Facilitator: Suzanne Robinson, Professor and Theme Leader, Health Systems and Health Economics, Curtin University

15:30 - 16:30 - Friday 19th March 2021



Dr Rob Grenfell, Director, CSIRO Health and Biosecurity

5:25 - 16:30 - Friday 19th March 2021

Dr Rob Grenfell is a public health physician and the Director of Health and Biosecurity at CSIRO, Australia's national science agency.

At CSIRO he leads a broad portfolio covering nutrition, eHealth, medical technology, diagnostics and biosecurity, which delivers solutions to lift Australia's preparedness and responsiveness to health and biosecurity threats, creating a resilient population and health system. Most recently, his team was responsible for the preclinical evaluation of two COVID-19 vaccine candidates, including the Oxford-AstraZeneca vaccine which will soon be rolled out across Australia. He has broad ranging public health experience and was previously National Medical Director at BUPA Australia New Zealand and National Director Cardiovascular Health at the Heart Foundation.

Professor Tim Shaw

Director of Research and Workforce Capacity, Digital Health CRC

15:25 - 16:30 - Friday 19th March 2021



Tim Shaw is Professor of Digital Health at the University of Sydney and Director of Research at the Digital Health CRC. As Professor of Digital Health he has completed over 60 research and consultancy projects in collaboration with health services, government agencies, professional colleges and industry partners. In the last 5 years he has been a CI on over \$124M of research programs and published over 60 journal articles.

As Director of Research in the \$110M Digital Health CRC he oversees a research program across 80 partners including governments, service providers, technology companies and 16 Universities. His research focuses on how digital technologies are used to change behaviour and support new models of care. His applied research focuses on two inter-related areas. The first being how digital technologies can be used to change consumer behaviour. Projects in this area have looked at cancer rehabilitation, management of stress and anxiety in cancer patients, improving palliative care services and developing new approaches to cardiovascular disease management. The second being how health professionals and teams use health and outcome data to reduce variation in care and improve value. This includes how clinicians make sense of data, how data can drive targeted education, through to how the use of data by teams and individuals can be linked to professional accreditation. With colleagues in North America he has led the establishment of a new discipline called practice analytics.

KEYNOTE SPEAKERS - DAY TWO

Rapporteur Report on Summit

Consumer Rapporteurs to sum up the conference themes and highlights, including a representative from Youth Health Forum Consumer Rapporteurs: 16:30 - 17:00 - Friday 19th March 2021



Professor Judi Walker

- Distinguished reputation in higher education, research and research translation, rural health leadership, academic and public sector governance, and strategic policy development in Victoria and Tasmania, nationally and internationally.
- Highly experienced in regional policy and service development in health services, particularly integrated primary health care, chronic health, healthy ageing, community engagement and community wellbeing.
- Extensive skills in governance, health consumerism, quality and safety, clinical leadership, with an understanding of the complexities of diverse health service delivery and appreciation of the values of public health and community health.



Roxanne MacDonald

Roxanne is a youth health advocate with lived experience of mental ill-health and chronic illness, as well as being a young carer for her brother. She is an inaugural member of the CHF's Youth Health Forum and was appointed to the CHF board in 2019.

Like many young people, Roxanne has struggled to access adequate mental health services despite reaching out. Driven by her experiences and the stories she hears from other young people, Roxanne is a fierce advocate for young people being meaningfully involved in all areas of the health system. She is passionate about eliminating barriers to accessing care, addressing social determinants of health, and empowering young people to advocate for themselves and become consumer representatives. Roxanne is interested in how alternative models of care and co-designed digital services can work alongside storytelling to address these issues.

Prior to CHF, Roxanne was a member of Orygen's 2017-2019 Youth Advisory Council. She has worked with a number of other organisations including Children's Health Queensland, Batyr, and Health Consumers Queensland, and has also had the opportunity to consult on several initiatives including the National Mental Health Services Planning Framework, the National Women's Health Strategy and the 10-year Primary Healthcare Plan.

Roxanne currently lives on Gubbi Gubbi land, on the Sunshine Coast, where she enjoys the views and avoids the sand.

Renza Scibilia

Tony Lawson

CONCURRENT SESSIONS - DAY ONE

CONCURRENT SESSION ONE:

13:30 - 15:00 - Thursday 18th March 2021

Consumers as Researchers

Facilitator: Luke Escombe

13:30 - 15:00

AHRA / ACTA SPONSORED WORKSHOP - LIVE STREAM



Professor John Zalcberg OAM, Cancer Research Program
School of Public Health and Preventive Medicine at Monash

Anne McKenzie, Community Engagement, Manager at the Telethon Kids Institute



Professor Gary Geelhoed, Executive Director, Western Australian Health Translation Network. Joined by the Australian Health Research Alliance Consumer and Community Involvement Initiative Project Stream Representatives:

Jo Wilkie, Dr Darshini Ayton and Associate Professor Angela Todd

Panel Discussion


Lillian Leigh, Anne McKenzie, George Kiossoglou and Associate Professor Ed Litton

This will be a joint session delivered by the Australian Clinical Trials Alliance (ACTA) and the Australian Health Research Alliance (AHRA), concluding with a 30-min panel discussion. Both organisations will share an overview of their continued efforts to make consumer and community involvement core business within health and medical research (including clinical trials).

Facilitated by Luke Escombe, the panel discussion will bring together consumers and researchers to explore the factors which help to facilitate meaningful consumer and community involvement in health and medical research.

ACTA is the national peak body supporting and representing networks of clinician researchers conducting investigator-initiated clinical trials, clinical quality registries and clinical trial coordinating centres within the Australian healthcare system. The ACTA vision is to achieve better health outcomes through best evidence, therefore involving end-users in the design, conduct and dissemination of clinical trials, is an essential component of this strategy.

To date, ACTA has engaged and co-designed many resources with consumers and researchers, to strengthen consumer involvement in clinical trials. Key outputs include the Consumer Involvement and Engagement Toolkit (primarily for researchers but with a dedicated consumer page), a clinical trial diversity project, and guidance on the use of more simplified consent approaches in low-risk clinical trials.



The National Health and Medical Research Council has accredited seven Australian Health Research and Translation Centres and three Centres for Innovation in Regional Health bringing together health services, community, research institutes, universities and government to more effectively use health and medical research to improve patient care and health outcomes for everyone. These ten centres formed AHRA to work together on national collaborative initiatives. One of these initiatives is strengthening the involvement of consumers in health and medical research across Australia, in collaboration with the Consumers Health Forum of Australia.

Four consumer and community involvement priority areas have been identified and work is underway to develop a handbook to guide stakeholders through the steps to embed consumer and community involvement in health and medical research; establish a knowledge hub to share resources and expertise; identify and test approaches that show if involving consumers in health research makes a difference (and the kinds of effects it has in different settings); and establish formal alliances with international agencies promoting consumer and community involvement in health research.

CONCURRENT SESSION ONE:

13:30 - 15:00 - Thursday 18th March 2021

Consumers-Based Health Care

Facilitator: Leanne Wells

NSW HEALTH SPONSORED PANEL DISCUSSION - LIVE STREAM

13:30 - 15:00



Belinda McLeod Smith

Safer Care Victoria

The thought of 'engagement capable' organisations is music to our ears. As a consumer advocate working from the inside, Belinda would like to share her mix-tape for organisations who are ready to stop, collaborate and listen even when it's tricky because when it comes to health, not only are we all in this together - we're better together.



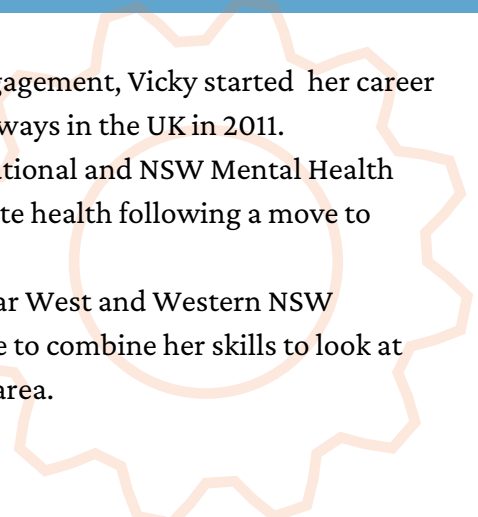
Victoria Smyth

Western NSW PHN

A passionate advocate consumer and community engagement, Vicky started her career developing patient-centered social prescription pathways in the UK in 2011.

On moving to Australia, she worked with both the National and NSW Mental Health Commissions and found a passion for rural and remote health following a move to Orange NSW in 2015.

As Partner Lead on leading communications for the Far West and Western NSW Collaborative Commissioning project, she is now able to combine her skills to look at how to support best outcomes for consumers in this area.





Liz Newton

NSW Agency for Clinical Innovation

Liz is Patient Partner with the NSW Agency for Clinical Innovation (ACI). Her role is to build capability within the organization and its partners around partnering with consumers in health care design and delivery. Prior to starting with ACI she had 18 years' experience working with Hunter New England Local Health District (HNELHD) in education and consumer partnership roles. During her time as Senior Consumer Advisor with HNELHD she set up the first Consumer Participation Unit in the state; Focused on systemic advocacy to drive human-centred health care; Co-led innovations and reform including Police and Ambulance Early Access to Mental Health Triage via Telehealth, the Hearts in Health movement and Towards Zero Suicide. Liz has lived experience of mental illness and suicidality as both a consumer and a carer. This experience spans across her lifetime and is what led her to focus her energies in the field of consumer partnership and engagement. She is a storyteller and uses human experience to bridge the clinical and operational world of healthcare to the personal, individual experience of healthcare.



Herbert Down

Australian Commission on Safety and Quality in Health Care

Herbert is the program director for the Partnering with Consumers stream at the ACSQHC. He has a clinical background as a pharmacist and combines this experience with his knowledge of the Australian healthcare system to deliver consumer focused improvements in safety and quality.



Carol Fancott

Canadian Foundation for Health Care Improvement

Carol Fancott is the Director of Patient Partnerships and Engagement at the Canadian Foundation for Healthcare Improvement-Canadian Patient Safety Institute where she leads the development, delivery, and evaluation of patient engagement programs, designed to improve the patient experience and quality of care. Carol began her career in healthcare as a physical therapist, and has held many roles as a clinician, educator, researcher, and health leader. She obtained a PhD in the Institute of Health Policy, Management, and Evaluation at the University of Toronto. Her doctorate explored how healthcare organisations gather and utilise the experiences of patients and families through storytelling methods for organisational learning and improvement to change processes and systems of care.

CONCURRENT SESSION ONE: CONTINUED

13:30 - 15:00 - Thursday 18th March 2021

Consumers Leadership

Chair: Jan Donovan, CHF Board Director

15 minute Pre-Recorded Presentations



Person-Centred Care in a Large Emergency Department: A Report on a Consumer-Led QI Project

Jane Pearce, Fiona Stanley Hospital

Co-Author: Julie Walker, Fiona Stanley Hospital

13:30 - 13:45

The Emergency Department Consumer Advisory Group at Fiona Stanley Hospital is a unique collaboration between consumers and Emergency Department clinicians. Established in response to NSQHS Standard 2 'Partnering with Consumers', a key focus of consumers' involvement has been to develop projects aimed at improving the experience of patients, family members and carers who attend the ED. The Patients at Risk project demonstrates the positive outcomes possible when consumers work closely with clinicians as partners and leaders to create a better patient experience. The presentation will share insights about engaging successfully in collaborative practice, based on experience of this project.



Consumer Leadership: An Innovative Approach to Cancer Consumer Representative Training

Vicki Durston, Breast Cancer Network

13:45 - 14:00

Breast Cancer Network Australia has run an internationally recognised consumer representative program, Seat at the Table (SATT). SATT recruits, trains, appoints, and supports women with breast cancer to work as consumer representatives. In 2019 BCNA undertook a project to innovate the training model from a three day intensive face to face program to a blended learning approach comprising of online learning courseware and workshop's which complement the opportunities for practical application of learning, discussion and connection with others. This program provides relevance to a wider audience.



Lived Experience: Journey of a Consumer Advisor

Ray Newland, Western Health

14:00 - 14:15

This consumer presentation traces the lived experience of a severe stroke, the journey as a consumer representative at a large public hospital to contributing as a consumer leader and mentor in the health service. It emphasizes key milestones of the journey from novice consumer representative to experienced consumer advisor, collaborative partner, leader, presenter and mentor within a major health service provider in the Western suburbs of Melbourne.



Consumers as Partners in Research: 2021 and Beyond

Elisabeth Kochman, Cancer Voices NSW

14:15 - 14:30

The decision to implement an external review of Cancer Voices NSW's Consumer Involvement in Research (CIR) Program was made during the early stages of the COVID-19 pandemic. Its devastating effects on tertiary-level research institutions made the conduct of the Review all the more crucial for CIR's current operation, and to help ensure that it is sufficiently robust to continue into the future. The presentation will outline the Review including its major findings, and detail the actions being taken by Cancer Voices to ensure it remains at the forefront of cancer research in Australia.



Academic Health Science Centre: Research in Partnership with the Cystic Fibrosis Community

Angela Jones, Monash Partners

14:30 - 14:45

The decision to implement an external review of Cancer Voices NSW's Consumer Involvement in Research (CIR) Program was made during the early stages of the COVID-19 pandemic. Its devastating effects on tertiary-level research institutions made the conduct of the Review all the more crucial for CIR's current operation, and to help ensure that it is sufficiently robust to continue into the future. The presentation will outline the Review including its major findings, and detail the actions being taken by Cancer Voices to ensure it remains at the forefront of cancer research in Australia.



Mentoring Program

Jemma Gonzalez, NPS MedicineWise

14:45 - 15:00

Diversity and inclusion are central principles to the NPS MedicineWise Consumer Engagement Framework. Certain groups are seldom heard, even though they are most at risk of poorer health outcomes and often have lower health literacy. A mentoring program is being developed for new and less experienced consumer representatives to increase the diversity and number of people working within the Quality Use of Medicines sector. Due to be launched in February 2021, the program will be designed in collaboration with Consumers Health Forum of Australia (CHF), NPS MedicineWise Consumer Advisory Group and consumer representatives in other NPS MedicineWise key advisory groups.

CONCURRENT SESSION ONE: CONTINUED

13:30 - 15:00 - Thursday 18th March 2021

Consumer Enablement

Chair: Christine Walker, CHF Board Director

15 minute Pre-Recorded Presentations

Consumer Roles in Living Evidence

Professor Julian Elliott, Cochrane Australia

13:30 - 13:45

Living Evidence is a new paradigm for understanding science, giving society knowledge that is both trustworthy and up to date with the latest research. The National COVID-19 Clinical Evidence Taskforce is using this approach to update national clinical guidelines every week, in partnership with Consumers Health Forum and 32 national peak health groups. Consumers are active partners in Living Evidence projects and in the rapid processes established by the Taskforce. As this approach continues to evolve there will be substantial opportunities for consumers to shape how the Living Evidence model can best serve the needs of society.



The Feedback Loop and The Feedback Figure-8: From Complaints to Continuous Improvement

Rosemary Joiner, West Gippsland Healthcare Group

13:45 - 14:00

After a history of mixed-outcomes to feedback, in 2018-2019, West Gippsland Healthcare Group looked at feedback and complaints through a continuous improvement lens. They developed a Consumer Stories program, where the stories of consumers are captured and shared (through workforce training and other approaches) in an effort to enact meaningful change in the fields of feedback and complaints, consumer engagement, and diversity and inclusion.

This led to a significant positive impact on relationships and collaboration between the organisation and the community, including diverse community stakeholder groups. This has in turn led to further, integrated improvement projects throughout the organisation.



Empowering Consumers to Ask Questions about their Health Care: A Choosing Wisely Australia Experience

Kitty Yu, NPS Medicine WISE

14:00 - 14:15

Choosing Wisely is an initiative that encourages health care providers and consumers to start conversations about unnecessary tests, treatments and procedures. Consumers play an important role in this decision-making partnership by asking questions about their care, however research indicated the perceived lack of permission felt by consumers remains a major barrier. This presentation describes the consumer engagement research undertaken by Choosing Wisely Australia, the process of creating and refining consumer campaign concepts and how the campaign enables consumers to feel more supported in asking questions about their health care.



Human and Digital Navigators to Improve Access to Healthcare for People with Multimorbidity

Dr Nana Folman Hempler, Senior researcher and team leader

Brian Oldenburg, Director, NHMRC CRE in Digital Technology to Transform Chronic Disease Outcomes

14:15- 14:30

People with multimorbidity (MM) often have complex healthcare needs. Also, they are expected to coordinate services and information from multiple healthcare professionals which stresses the importance of a healthcare system being responsive to their needs. A strategy to improve care coordination is by cross-sectoral navigators that can assist and support people with MM in various areas, including communication with HCPs, health sector transitions and access to and utilisation of healthcare and preventive services across sectors. This research project aims to co-design and test a human and digital navigator intervention aiming to improve access to and utilisation of healthcare and preventive services across sectors for people with MM. The target group consists of adults between 18-65 years of age living on the Danish Island of Bornholm. The project intends to improve the understanding of human and digital navigation models and may inspire Australian healthcare services.



The Power of Public Online Feedback: Building Connection Not Just Data Collection

Assoc. Professor Michael Greco, Care Opinion

Jan Child, Bass Coast Health

14:30- 14:45

In our communities, it's paramount that consumers can provide feedback in a safe and timely way so that providers can learn how to listen, respond to and act on that feedback. Whilst many health and social care organisations have feedback mechanisms in place (eg surveys, focus groups, PREMs/PROMs), it seems that their processes are more about collecting data (for the purpose of measurement and hopefully improvement) rather than bringing together the consumer and provider in a conversation. Whilst the former approach is important, the latter approach sees feedback as more of a two-way process (a dialogue) rather than a one-way process of collecting data. In addition to the above, most feedback mechanisms tend to be 'in-house' rather than more public or transparent, so that everyone can learn from the feedback (providers, other consumers and various stakeholders). This again touches on the question about the purpose of feedback. Care Opinion, now in several countries, is about a new way of consumer feedback that is more than just data collection. Rather, its purpose is to provide a platform of CONNECTION, where the storyteller can engage with the service in a safe, public, transparent, and meaningful way. As a result, the process of feedback and engagement is more citizen-centric in that the consumer receives something from the process of feedback (eg they can see who is reading their feedback, how it is being responded to, and whether it makes a difference).



Plugging the Holes of Healthcare

Kelly Foran, Friendly Faces Helping Hands Foundation

14:45- 15:00

Real life personal journey from health consumer to CEO of Foundation who now supports approx. over 10,000 people a year. From consumer to change maker, advocate and Health Consumer delegate.

CONCURRENT SESSION ONE: CONTINUED

13:30 - 15:00 - Thursday 18th March 2021

COVID-19

Chair: Jo Root, Policy Director CHF

PANEL DISCUSSION: LIVE STREAM

13:30 - 15:00

COVID-19 Vaccination Strategy: how can we get consumer and community engagement right?

The session looks to explore how best to engage the broad community and health care consumers in the rollout of the COVID-19 vaccination program to ensure we get their buy in and informed participation. It is important to maximise the proportion of the community that gets vaccinated and to do that we need to have messages that resonate with the different groups within the community and targeted mechanisms to get those messages to them.

The session will draw on the expertise and experience of the panelists, looking for examples of what has worked and what has not and what needs to be done differently.

The panelists will offer their views on how best to do that, for both the broad community and for the population groups they work with.

The panelists will cover health literacy, consumer engagement and involvement across the community as well as giving a perspective of working with people from culturally linguistic and diverse backgrounds, First Nations people and people who are socially and economically disadvantaged.

The session is designed to be interactive with each panelist initially presenting on their three key issues or concerns followed by a panel discussion on issues arising from their presentations and those raised by the audience.

At the end of the session we should have some clear pointers as what a robust engagement strategy should include.



Associate Professor Holly Seale

Deputy Chair, Collaboration of Social Science and Immunisation

Associate Professor Holly Seale is an infectious disease social scientist at the School of Population Health at the University of New South Wales in Australia. She is also the Deputy Chair for the Collaboration on Social Science and Immunisation.

She has over 15 years of experience in undertaking social science research focused on improving confidence and engagement of different at-risk groups with immunisation and other prevention strategies. Projects include developing and testing interventions and evaluating policy/programs and communication strategies. Her current research is focused on children and adults with medical comorbidities, refugees and migrants and healthcare workers.

**Dr Susannah Morris**

Consumer Health Representative, Breast Cancer Network Australia (BCNA), Health Consumers' Council of WA, All.Can International

Dr Susannah Morris is a consumer representative and advocate in the field of health, specialising in cancer care. She is a social policy expert by profession who now works to improve the experiences and outcomes of person-centred and person-led care following her own diagnosis with cancer. As a social scientist Dr Morris is committed to evidence-based policy and as a health consumer she advocates for and presents the perspectives of those who may not have a voice.

As a representative of Breast Cancer Network Australia Susannah has considered the safety and efficacy of the COVID-19 vaccination for people with cancer alongside senior clinicians and policy makers. The COVID-19 Vaccine Roundtable, convened by Cancer Australia, is developing resources to assist the information needs of both clinicians and consumers in the rollout of the vaccination program.

Dr Morris has also examined the wide-ranging implications of the COVID-19 pandemic for consumers as a CHF Commissioner investigating the challenges and opportunities COVID-19 presented for reform in Australia's health system which resulted in the 2020 publication Making Health Better Together.

In Western Australia, where she is based, Susannah is the Health Consumers' Council of WA representative to the Department of Health for the development and implementation of the cancer strategy for WA from 2020-25. She is also an advisor to a major research project examining the genomic testing of cancer tumours to improve the diagnosis and personalised care of those affected by cancer in Australia.

Internationally, Dr Morris is a member All.Can International, a multi-stakeholder not-for-profit organisation working to improve the efficiency of cancer care by focussing on what matters to consumers whose experiences and outcomes are central to the provision of sustainable and value-based health care.

Dr Nicole Allard

Clinical lead, Cohealth COVID response, General Practitioner, cohealth
Medical Epidemiologist, Victorian Infectious Diseases Reference Laboratory

Nicole Allard (MBBS, MPH, PhD, FRACGP) is a General Practitioner and researcher at Peter Doherty Institute for infection and immunity. In 2020 she worked across areas of the COVID response including in testing clinics focusing on homeless population and developing policy with Central Australian Aboriginal Congress. In July she worked at the cohealth established primary health clinics in the public Housing Towers that endured a severe and sudden lock down. She gained experience looking after people with COVID in a community setting. She then expanded her role to become clinical co lead at cohealth for COVID and was instrumental in the establishment and implementation of a program in the North Western Melbourne PHN to ensure people diagnosed with COVID had access to social supports and medical care from either their regular general practitioners, virtual wards in hospital or Hospital in the Home. She has been involved in policy working with DHS Victoria advocating for a person-centred approach to public health challenges presented by COVID. She has an honorary appointment at University of Melbourne in the Department of General Practice and Department of Medicine. Her areas of research interest include Hepatitis B, Hepatitis C epidemiology and interventions in primary care.



Professor Richard Osborne

Director, Centre for Global Health and Equity, Swinburne University of Technology

Richard is an epidemiologist and Director of the Centre for Global Health and Equity at Swinburne University of Technology, Melbourne. He holds a prestigious NHMRC Principal Research Fellowship focusing on development and implementation of health literacy-informed interventions to reduce inequalities.

He is an advisor to the World Health Organisation.



Mohammad AlKhafaji

CEO, Federation of Ethnic Community Councils of Australia (FECCA)

Mohammad Al-Khafaji was born in Iraq, grew up in Iran and lived in Syria before arriving in Australia in 2003 as a refugee when he was 13 with his family. He completed a Bachelor of Software Engineering at the University of Adelaide in 2012. He is the former Chief Executive Officer of Welcome to Australia and is now the Chief Executive Officer of Federation of Ethnic Communities' Council of Australia (FECCA), and member of the Ad Standards Community Panel. Mohammad is passionate about changing the national conversation around refugees and people seeking asylum to a positive one. In 2008, Mohammad was a delegate at the Federal Government's 2020 Youth Summit in Canberra, was awarded the South Australian Governor's Multicultural award for youth achievement in 2012, and was South Australia's 'Young Australian of the Year' Award finalist in 2018.

Emily Phillips

Project Officer, Communicable Diseases

National Aboriginal Community Controlled Health Organisation

Emily has a background in Medical Science and Public Health, working as a Scientist and program coordinator at the Flinders University International Centre for Point-of-Care testing, before relocating to Canberra to work at the National Aboriginal Community Controlled Health Organisation (NACCHO) as a project officer in communicable diseases in 2020.

Emily has a special interest in Aboriginal and Torres Strait Islander health, communicable disease and epidemiology and has on the ground experience working with Aboriginal and Torres Strait Islander communities, through her involvement with the Enhanced Syphilis Response (ESR) and the COVID-19 PoC testing program, which operates across a number of Aboriginal Community Controlled Health Organisations (ACCHOs) across Australia. Since joining the NACCHO Emily has been taken on a number of roles within the communicable disease teams, with a primary focus on Sexually Transmitted Infection (STI) and Blood Borne Virus (BBV) programs. More recently, Emily has been heavily involved in the COVID-19 response in ACCHO sector, including participating on the COVID-19 Aboriginal and Torres Strait Islanders Advisory Group. She has been a key member of the NACCHO COVID-19 team, working closely with the Australian Government, to coordinate the roll-out of the COVID-19 vaccine to Aboriginal Community Controlled Health Organisations (ACCHOs).

CONCURRENT SESSION ONE: CONTINUED

13:30 - 15:00 - Thursday 18th March 2021

New Zealand Stream

Chair: Chair: Dr Lynne Maher

30 minute Pre-Recorded Presentations

Opening Karaki

LJ- National Consumer Group

13:30 - 13:35



Are we there Yet and How will we Know? A Quality and Safety Marker for Consumer Engagement

13:35 - 14:00

Chris Walsh and Deon York, NZ Health Quality and Safety Commission

There is evidence that patient experience, clinical effectiveness and patient safety are all linked. There are also various measures to determine patient satisfaction with health care such as patient reported outcomes and experience measures. However, nothing internationally exists for understanding what effective consumer engagement looks like and what influences consumer experience. We set about developing a measure in the form of a quality and safety marker (QSM) to answer the question: 'what does successful consumer engagement look like and how does it improve the quality of services?'

Introducing something new and innovative, with a focus on consumers, takes time. It is important to identify the key stakeholders early and involve them in the work.

Consumers and providers have different understandings and priorities about what partnership means and how it should be implemented. We now have a national framework which gives consumers leverage in participation and decision making.

Services are required to report data which is monitored.

This presentation is about measuring how successful consumer engagement is in health and disability services across New Zealand. By 31st March 2021 services are required to submit data which will ultimately be visualised on a national dashboard. The framework that informs this measure was developed in partnership with consumers and providers.

We outline the why, what and when of this work and share findings so far from pilot sites. Consumers see this framework as an opportunity to gain leverage in having their voices heard and decision-making increased. Providers see it as a way of assessing where they are at and how they can improve their engagement with consumers.




A Consumer Eye View: Being a Member on a National Group to Develop a Quality Safety Marker which Incorporates Te Tiriti

14:00 - 14:30

DJ Michael Adams, Health Quality and Safety Commission

Consumer Engagement, a consumer's point of view – a discussion on the importance of consumer involvement in the design and delivery of health products and services at District Health Board (DHB) level. As a member, and deputy chair of the Waitemata DHB's Consumer Council, DJ has been at the leading edge of the WDHB's program for Consumer Engagement and its improvement. The inaugural council convened in July 2019 and has worked closely with the Patient Experience Director, the Chief Executive and the Board Chair.



The Quality and Safety Marker (QSM) – What is it? Who is it for? This presentation is an insight into the development of the QSM through DJ's participation in the reference group made up from four Pilot DHB's – Waitemata, Counties-Manukau, Waikato and Canterbury. The Consumer Council Chairs/ Deputy Chairs group – a forum that stemmed from a series of Zui – Zoom Hui that the Health Quality & Safety Commission (HQSC) hosted to inform on the QSM. This group now meets monthly to share how each of the DHB's and their consumer councils work together in differing environments.


The Quality and Safety Marker and Te Tiriti o Waitangi – although intrinsically integrated into the QSM Framework, as part of the development work of the reference group a framework of the QSM with a focus on the partnership with Maori under Te Tiriti o Waitangi was requested. The framework was created by JJ Cootes - Consumer Council Member for Waikato DHB, and examples populated by the Consumer Network after their two-day Te Tiriti o Waitangi workshop. This framework and its examples offer the DHB's another tool that they can evaluate their consumer engagement activities particularly regarding Maori voices.



The Long and Winding Road: A Tale of Two

Consumer Councils in NZ

Rosalie Glynn and Russ Aiton, Consumer Council Chairs

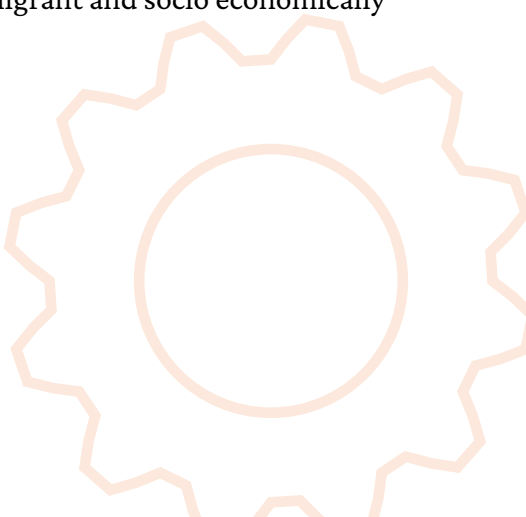


14:30 - 15:00

Rosalie and Russ will provide a brief overview of the formation of Consumer Councils in New Zealand before sharing how two Consumer Councils, one in a rural setting and the other within the city of Auckland, have forged their way to be able to represent and bring the voice of their consumer communities to influence healthcare services. Each has had a different journey but both have achieved much success.

From the West Coast- How do you (re)connect a rural DHB with its community in such a way that creates a seamless partnership and understanding of the equity issues in providing health care to the far-flung regions of the West Coast? Not exactly a Number 8 wire approach, but we have had to step away from the perhaps functional/traditional engagement enjoyed by resource rich (in comparison) DHB's and move the West Coast DHB closer to its communities.

From Counties Manukau DHB- Our challenge is bringing the voice of a diverse community to the decision making table, in way that influences change and improves health outcome for our Maori, Pacific, Asian, Immigrant and socio economically challenged communities.



CONCURRENT SESSIONS - DAY TWO

CONCURRENT SESSION TWO:

10:30 - 12:00 - Friday 19th March 2021

Consumers as Research

Chair: Associate Professor Yvonne Zurynski

NHMRC PCHSS SPONSORED - LIVE STREAM

10:30 - 12:00



Health System Sustainability

NHMRC Partnership Centre



Consumers as Researchers: Consumers' Role in Sustainable Healthcare Systems

Associate Professor Yvonne Zurynski, Associate Professor of Health System Sustainability, NHMRC Partnership Centre for Health System Sustainability, Australian Institute of Health Innovation, Macquarie University

Co Author: Jeffrey Braithwaite, Professor and Founding Director, Australian Institute of Health Innovation, Macquarie University

At the centre of the construction of a more sustainable healthcare system are the experiences and journeys of the health consumer. In this 90-minute workshop, we will outline some of the longstanding and new challenges that the health system faces, discuss the work of the NHMRC Partnership Centre for Health System Sustainability (PCHSS) in investigating these challenges and in seeking to address them, and explore what consumers can do to help build a system able to meet the health demands of today and tomorrow. We now know that simply calling for more health spending is not always the best answer. How can we work together to address the challenges that an ageing population, increasing rates of chronic disease, health system fragmentation, and expensive new health technologies bring, while increasing care quality, safety, and value for consumers?

Through consumer-led discussion we will explore how consumers can influence the health system to move from volume-based care to value-based care. You will hear from internationally recognised Health Systems and Health Services researchers Professor Jeffrey Braithwaite and Associate Professor Yvonne Zurynski from the PCHSS about the work of the centre and practical examples of where consumers have influenced health systems change.

A consumer perspective will be provided and a consumer panel consisting of consumer advocates and researchers will lead the discussion in this workshop.

Come prepared for a lively discussion! We will ask participants to cast their minds to the future – to 2031. What roles should consumers play in the health system in 2031? How will we get there? Opinion polls and question & answers will be facilitated to ensure wide interaction.

CONCURRENT SESSION TWO:

10:30 - 12:00 - Friday 19th March 2021

Consumer Based Health Care

Chair: Belinda McLeodSmith

30 minute Pre-Recorded Presentations



Using Human-Centred Design Thinking to Map and Improve the Consumer Experience with Health Services

10:30 - 10:45

Dr Lidia Najbar, Latrobe Community Health Service

In order to drive consumer-centred care and improve the consumer experience we needed to increase our understanding of our consumers as they interact with our services. This presentation will outline how human-centred design thinking framework can be used to map the consumer experience during the entire journey through a service. It will describe how we engaged consumers in co-designing better experiences with our services and clinical staff by addressing consumer needs and pain points. We will cover practical strategies of how we have implemented the service design framework to help drive a consumer-centric culture within our organisation.



Consumers as Educators in Healthcare

10:45 - 11:00

Suzie May, Giving Voice

Genuine partnership between consumers and health professionals in the governance, design, delivery and evaluation of individualised and systemic health care, needs to begin at the onset of medical, nursing, allied health and health administration training. A tertiary based training program for medical, nursing and allied health students, designed and delivered by a health consumer with 18 years' lived experience of chronic disease, has been in operation in Western Australia since 2006. Students gain an understanding of the individual and systemic value of empowered consumers, and the vital role health professionals play in shared decision making, improved health literacy and self-management.



Young People Shaping Service Design

11:00 - 11:15

Kerryn Pennell, Orygen National Centre for Excellence in Youth Mental Health

Kerryn has worked in clinical and leadership positions for over 28 years in mental health and health and has played a pivotal role in developing responses to youth mental health in Australia and globally and been a practice innovator – developing new models at Orygen (and its earlier iteration EPPIC) for youth participation and peer support, family peer support and models of care and service.

Kerryn and her team are responsible for leading Orygen's strategy and policy development and building key relationships and partnerships in Australia and globally. Kerryn has 30 years expertise in working alongside young people as key stakeholders to design and develop policy responses, services and facilities that are truly informed and designed in partnership with them.



Driving Consumer Leadership via the Collaborative Pairs

Project: Evaluating the Pilot

Helen Dickinson, Collaborative Pairs Evaluation

11:15- 11:30

This presentation reports on research that sought to evaluate the Collaborative Pairs pilot project run by the Consumers Health Forum of Australia, modelled on a program from the King's Fund. The aim of the CPADT is to bring together consumers, patients and community leaders, alongside wider health service groups (including clinicians, managers and service providers), to build productive relationships and to appreciate and practice how different roles and perspectives can bring about constructive change within the Australian context. The ultimate aim of the program is to drive culture change in order to drive improvement through the health system.



Introducing Collaborative Pairs Australia: An Overview

Jennie Parham, Consumers Health Forum

11:30- 11:45

Jennie Parham is currently the Project Lead for Collaborative Pairs Australia at the Consumers Health Forum (CHF) of Australia. CHF have completed a national demonstration trial of the Collaborative Pairs Program in Australia based on the original program developed by the King's fund in the UK. CHF have moved to the next phase of implementation which Jennie provide an overview of during this presentation.

CONCURRENT SESSION TWO:

10:30 - 12:00 - Friday 19th March 2021

Consumer Leadership

Chair: Dr Anthony Brown

WORKSHOP - LIVE STREAM

10:30 - 12:00



Beyond a Tick in the Box: Consumer Leadership in 2021

Elisabeth Kochman, Chair Cancer Voices NSW

Dr Anthony Brown and Serena Joyner, Health Consumers NSW

Shirley Baxter and Murray McLachlan, Deputy Chairs, Cancer Voices NSW

Consumer leadership is central to shifting from just a box-ticking approach to genuinely effective consumer partnerships. This workshop will bring experienced and emerging consumer leaders together to reflect on what consumer leadership is, how it can be fostered, and how participants can develop their consumer leadership practice. Consumer leaders will tell how they went from their first roles to what they are doing today. Modern perspectives on consumer leadership will be discussed, alongside results of a survey of Australian consumer leaders conducted in late 2020 by Health Consumers NSW and Cancer Voices NSW exploring how consumer themselves perceive consumer leadership.

CONCURRENT SESSION TWO:

10:30 - 12:00 - Friday 19th March 2021

Consumer Enablement

Facilitator: ThinkPlace

WORKSHOP ADHA SPONSORED- LIVE STREAM

10:30 - 12:00



Australian Government
Australian Digital Health Agency



Sky May, General Manager Agile Business Transformation, ThinkPlace
Rupert Lee, A/Chief Digital Officer, Australian Digital Health Agency

Person-centred care driving digital health.

Australia's National Digital Health Strategy covers the period 2018 to 2022. To reflect our constantly evolving digital health system, the strategy will be reviewed to align it with national priorities and address emerging digital health initiatives. This includes virtual care, mobile health, and precision medicine. As the Australian Digital Health Agency looks to the future, we seek your views to help us better understand consumer needs, preferences and ideas.

Where are we now in the digital health journey and what do we need to do to improve health outcomes for our diverse communities?

COVID-19 has been a catalyst for consumers to embrace, use and build their trust in digital health. Many consumers have used telehealth or accessed their medicine through an electronic prescription for the first time.

We recognise that healthcare experiences are as diverse as the Australian population and we know that engagement in digital health can be impacted by your social, physical, emotional and cognitive circumstances. We are interested in understanding how your circumstances impacted your digital health experience and hearing ideas for how digital health can better support your healthcare journey, and the healthcare of your family and community.

Join us for a facilitated session where a digital storyteller and live scribe will draw your experience and capture your views to inform the future direction of digital health for Australia and the development of the next National Digital Health Strategy.

Consistent with the key themes for this conference of consumer leadership and enablement, some of the Agency's independent Consumer Advisors will be actively guiding this session.

CONCURRENT SESSION TWO:

10:30 - 12:00 - Friday 19th March 2021

COVID-19

Chair: Lea Kirkwood

15 minute Pre-Recorded Presentations



Optimising Consumer and Community Involvement in Research and Healthcare Improvement in COVID-19

Sarah Carmody, Monash Partners

10:30 - 10:45

To facilitate CCI during COVID-19, Monash Partners, one of Australia's largest accredited Academic Health Sciences Centres (AHSC) launched a dedicated Consumer Advisory Committee, to facilitate CCI in a timely and supportive manner.

We developed a shared vision, terms of reference and provided training in giving feedback on project goals, processes, activities and outcomes. The Committee had an active uptake by researchers, clinicians and services, having a tangible impact on research design, healthcare practice and informing policy. Committee contributions include COVID-19 priorities for research and healthcare improvement, COVID-19 community survey design, and input into COVID-19 health service and research projects.



Consumer Heart Health in a Post-COVID Australia

Andrew Mosley, Heart Foundation

10:45 - 11:00

This presentation identifies new ways that consumers, health professionals and the broader health system are supporting consumers' heart health, accelerated by COVID-19. It maps the important next steps for better heart health, what consumers can do to seize these opportunities, and how the healthcare system can support them to reach their goals.

Specifically, it addresses the following questions:

1. How can we increase consumer involvement in their heart health care post COVID-19?
2. What are the risks and challenges?
3. How is the Heart Foundation's consumer engagement evolving?
4. How can healthcare better support consumers' cardiac care?



Collaborative Development of a Triage Process for COVID-19: Challenges and Lessons

Brett Scholz, ANU

11:00 - 11:15

In this presentation, we provide an overview of the way that consumer, carer, and community perspectives drove the key principles of the triage process for COVID-19 in the Australian Capital Territory. Although there were challenges in developing meaningful engagements between consumer, clinical, and academic partners because of the need to be COVID safe, there were many opportunities as well. We reflect on these through an evaluation of the development of the triage process.



It's Not rocket Science: it's 2021, Why is Asking Consumers a Novel Idea?

Rob Anderson, Musculoskeletal Australia

11:15 - 11:30

Musculoskeletal conditions affect over 7 million Australians, yet they're overlooked as stakeholders, policy makers and organisations presume to know what they need. In 2019 we shifted gears. We could no longer assume, we needed to hear the voices. We developed the largest Australian survey of people with, or caring for someone with musculoskeletal conditions. Respondents provided information about the important stuff – life, work/study, finances, mental and social health and so much more. This rich data will enable us to provide better services and support, and help us advocate for improved healthcare and greater recognition of the impact of musculoskeletal



At the Outset of the COVID-19 Pandemic there was Growing Concern Amongst Consumers About Rapid Research being Developed without Community Input

Anne McKenzie, Telethon Kids Institute

11:30 - 11:45

Telethon Kids Institute has provided consumer leadership by establishing a national Community Advisory Group for COVID-19 research. This has been recognised nationally and internationally as a good practice example of strong consumer advocacy and collaboration. Researchers from across Australia have experienced the value and benefit of being able to partner with experienced consumer advocates to enable research that includes the community voice and priorities for future pandemic research.

CONCURRENT SESSION TWO:

10:30 - 12:00 - Friday 19th March 2021

New Zealand Stream

Chair: Chair: Dr Lynne Maher

30 minute Pre-Recorded Presentations



From the Ground Up: A Co-Design Systemic Change 'How-To'

Esther Vallero and Members of the Transgender Team

10:30 - 11:00

The Trans Health Working Group will present on their history and the context in which they came together and were established; the successes they've had, including authoring five new clinical pathways, introducing new surgical services and a comprehensive mental health support package, and rebuilding a significant amount of community trust; and what has and hasn't worked well as a clinical consumer collaboration from day one. We hope to give some practical advice to others who want to make systemic change through collaborative processes, and move beyond talking about co-design and consumer engagement to doing the mahi (work)!

**Consumer Leadership: A Consumer Network's Reflections on
Partnering with a Crown Entity
Consumer Voices**

11:00 - 11:30

Since its establishment, the New Zealand Health Quality & Safety Commission has worked towards partnering with consumers, patients, families and whānau to understand what really matters when it comes to improving the quality and safety of the NZ health system. In this session you will hear reflections from members of the Commission's consumer network, particularly about working with a Crown entity and being a consumer leader, and from the Commission's Chief Executive, Dr Janice Wilson with an introduction from Dr Chris Walsh, Director of Partners in Care, the Commission's consumer engagement program.



**Shifting the Balance of Power – Consumer Led Procurement
Channa Perry, Executive Advisor**

11:30 - 11:45

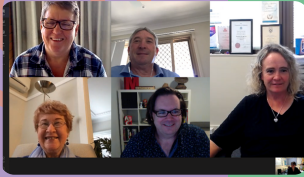
The decision to involve consumers in a procurement panel to select a new Alcohol & Other Drugs (AOD) Peer Support Service was a natural next step in a service development process that has used co-design principles from its inception. The development of a proposed Peer Support Service arose from a marae-based co-design hui in December 2019 at which people with lived experience were invited to speak and health professionals/service providers were invited to listen. The need for Peer Support – someone with lived experience to walk alongside you on your recovery journey – came through loud and clear and it was obvious that those present on the day were keen to be part of the service design journey also.

After working with an enthusiastic group of individuals with experience of addiction to develop the service model, Taranaki DHB progressed to the final stage of the project – choosing a provider. DHB procurement processes can be quite formal and must align with the Government Procurement Rules. However, with the support of MBIE, we explored how we could adjust our process to engage consumers in the procurement. We decided to do things differently – moving away from the usual paper based process and using a kanohi ki te kanohi approach with a consumer led panel. The criteria used for the evaluation of the proposals was developed by the consumer panel and used to score the presentations by the providers.

Involving consumers in the procurement process required a bit more effort – ensuring that they understood the procurement rules, providing initial orientation to the process and investing in the relationship through regular face to face meetings. However, this forced the DHB to re-think how we do things and to simplify a process that can at times seem unnecessarily complicated. This not only benefited our consumer panel but also providers who were able to present their proposal in person, on their own premises. This presentation shares our journey and what we have learnt.

CONCURRENT SESSION THREE:
13:00 - 14:15 - Friday 19th March 2021

Consumers as Researchers
Chair: Kylie Woolcock
15 minute Pre-Recorded Presentations



A New Co-Produced Capability Framework for Successful Partnerships in Healthcare Quality Improvement

Ruth Cox, Queen Elizabeth II, Jubilee Hospital

Co-Authors: Bernadette-Tanner, Elizabeth-Miller, Matthew-Molineux, Melissa-Kendall

13:00 - 13:15

Our team of consumers and health professionals conducted a literature review about capabilities needed for successful partnerships in healthcare quality improvement. A strong evidence base is particularly important for capturing the hearts and minds of many health professionals. We analysed 49 peer reviewed papers. Our resulting capability framework includes three capability domains: Personal Attributes; Relationships and Communication; and Philosophies, Models and Practices. There are 10 individual capabilities within these domains. The framework can be used to guide individual development plans or to assist organisations with developing learning strategies.



Community Co-Design: Harnessing Participatory Action Research and Modified Delphi Approaches for Service Adaptation and Innovation
Deborah Stockton, Tresillian

13:15 - 13:30

This presentation describes a study exploring the extent to which an Australian metropolitan service model for specialist child and family health services can be implemented in diverse settings including rural areas. Consumers and other key stakeholders were engaged through Participatory Action Research (PAR) and a Modified Delphi Study to ensure the voices of parents were heard and informed the co-design of adaptations to a metropolitan service model to enable contextualisation to meet the needs of local communities.



South Australian Health and Medical Research Institute
Community Advisory Group in Action: Co-Designing Resources to Support the Research Community
Agustina Gancia, Health Translation SA

13:30 - 13:45

Key Consumer and Community Engagement (CCE) resources have been developed at the South Australian Health and Medical Research Institute in partnership with community members and Health Translation SA in 2019. The Community Engagement in Research Toolkit and the Community Interest Register working groups were established to lead their development in a co-design approach. Outreach and communication efforts have been reflected in the positive uptake of these resources, an increase in CCE activities across the Institute and an increase in CCE engagement requests from the research community. The aim for these resources is for them to be used at scale across South Australian partner organisations.



Collaboration and Co-Design in the Development of the NSW Aboriginal Patient Experience Question Set

Lilian Daly, Bureau of Health Information

Co-Author: Geraldine Wilson-Matenga

13:45 - 14:00

In 2020, the Bureau of Health Information developed the Aboriginal Patient Experience Question Set in collaboration with the NSW Ministry of Health's Centre for Aboriginal Health, the Aboriginal Patient Experience Survey Program Advisory Committee and other key stakeholders. All stages of its development involved input from Aboriginal patients and stakeholders. The question set comprises 31 questions identified to be of high relevance to Aboriginal patients, the Aboriginal community and relevant stakeholders.



'Nothing About us Without us' And That Includes Research

Suzanne Robinson, Digital Health CRC and Curtin University

14:00 - 14:15

The presentation will provide a description of the consumer, industry and university partnership model. It will focus on the approach, lessons and key findings from the partnership. With specific consideration on how the model supports the consumer perspective in research. The presentation will also provide a perspective around barriers and enablers and a road map for a future agenda that puts the consumer at the heart of research.

CONCURRENT SESSION THREE:

13:00 - 14:15 - Friday 19th March 2021

Consumers-Based Health Care

Chair: Bernadette King

15 minute Pre-Recorded Presentations



How can Social Media be used as a Tool for Consumer Engagement in Hospital Service Improvement? Recommendations from a Participatory Research Project

Louisa Walsh, La Trobe University

Co-Authors: Nerida Hyett, Jayne Howley, Nicole Juniper, Chi Li, Belinda-MacLeod-Smith, Sophie Rodier, Sophie Hill

13:00- 13:15

Health-related social media use is extremely common but few health organisations have embraced its potential for engaging consumers in health service design and quality improvement (QI). This presentation will explore the findings of ongoing research examining how social media can best be used to engage consumers in Australian public hospital service improvement activities. The presentation will outline evidence-based recommendations for integrating social media as part of a suite of hospital consumer engagement activities, including how social media engagement can be embedded throughout the health QI cycle and the risks and benefits of social media for consumer engagement.



**Integrating Consumer Insights in Educational Program:
Opioid, Chronic Pain and the Bigger Picture**
Rawa Osman, NPS MedicineWise

13:15- 13:30

NPS MedicineWise and Painaustralia worked collaboratively to develop interventions for the national, Opioids, chronic pain and the bigger picture program. This partnership ensured consumer values were integrated in both the design and build phases of the program. This cohesive approach produced interventions that reflected consumer perspectives, and addressed knowledge, attitude and belief gaps. The resulting interventions were more targeted to drive better health outcomes.



**Consumers Shaping Health Policy through the
WA Healthy Weight Action Plan**
Clare Mullen, Health Consumers' Council WA
Co-Author: Helen Mitchel, Kate Iwanowski

13:30- 13:45

Consumer stories, voices, needs, and interests are at the foundation of the development and implementation of the WA Healthy Weight Action Plan.

The Plan is a collaboration between Health Consumers' Council WA, the Department of Health, and the WA Primary Health Alliance. Each team worked to their strengths and built relationships with key stakeholders within their networks.

This collaboration between community, government and primary care is imperative to address this complex health issue. In this session we'll share lessons learned about working together and embedding consumer voices at the heart of health policy and practice.



**'To Listen, Act, Make Better, Together': A Commitment to
New Ways of Patient Centred Care**
Peter King, Southern Adelaide Local Health Network

13:45- 14:00

Southern Adelaide Local Health Network (SALHN) has a genuine partnership with our consumers, community and health professional to achieve excellence in person and family centred care. Our operating principle - To Listen, Act, Make Better, Together – was developed by our Partnering with Consumers Advisory Group (PWCAAG) and guides our determination to build a system that will consistently deliver reliable and respectful health care for, and with, all members of our community.

During our COVID-19 response, consumer engagement has expanded as we work with vulnerable communities to ensure they are engaged through diverse strategies.



**Exploring Five-Year Trends in Patient Experience and Care
Improvement Initiatives**
Hayley Forbes, Bureau of Health Information

14:00- 14:15

This presentation will explore the findings of the Healthcare in Focus report, reinforcing the significant value of the feedback provided by more than 200,000 people about their experiences of healthcare. BHI has partnered with Western Sydney LHD, who will present on their active use of patient feedback to improve the discharge experience for patients. The presentation will examine how patients' experiences have changed over time, and also present a real-world example of how patient feedback has been used to improve care.

CONCURRENT SESSION THREE:

13:00 - 14:15 - Friday 19th March 2021

Consumer Leadership

Chair: Roxxanne MacDonald, CHF Director

15 minute Pre-Recorded Presentations



Bursting the Bubble: An Experience-Based Co-Design Quality Improvement Project to Address the Controlled Delivery of Oxygen in Acute Care for People Living with Chronic Obstructive Pulmonary Disease

Tara Dimopoulos-Bick, NSW Agency for Clinical Innovation

Co-Authors: Helen Kulas, Russell Winwood

13:00 - 13:15

'Bursting the Bubble' will demonstrate the application of Experience-Based Co-Design (EBCD) to a complex and international issue – the controlled delivery of oxygen for people admitted to hospital for an acute exacerbation of their symptoms for COPD. An increasing interest and use of EBCD globally, has been matched with increasing calls for more rigorous evaluations of the quality improvement method in terms of the identification of outcomes and impacts. Delegates will learn about the how, why and to what extent experience-based co-design worked and the contextual factors and conditions that supported or hindered the process for Bursting the Bubble.



Making the Invisible Visible: Hidden Voices Initiate Collaboration in Research

Penelope McMillan, ME/CFS SA

Co Authors: Maria Alejandra, Ricky Buchanan, Aline Beleigoli,

Michael Lawless, Mandy Archibald, Alexandra Mudd, Alison Kitson

13:15 - 13:30

This collaboration between academic researchers and health consumer advocates lies in an area of research that is sparse. Not only is the field of study new, but also the strategies are innovative. The task of bringing hidden experiences into public view has been undertaken in a multidimensional approach, incorporating the visual as well as words and hard data. The diversity and flexibility of the team have allowed rapid responses to changes in circumstance, such as the temporary availability of telehealth to FHBP, and enabled engagement with media as well as peer-reviewed journals.



Consumer Involvement in the ANZDATA Registry:

Coproduction of Consumer-Specific Reports of Registry Data

Shyamsundar Muthuramalingam, ANZDATA-South Australian Health and Medical Research Institute (SAHMRI)

Co-Author: Emily Ducanson, Stephen McDonald

13:30 - 13:45

The Australia and New Zealand Dialysis and Transplant Registry (ANZDATA) collect and analyse consumer health data. Each year ANZDATA publishes a series of reports based on this collected data. The reports tend to be lengthy and cumbersome to read for consumers. The research highlights some practical tips and considerations to involve consumers for the coproduction of plain language summary of the reports. Six themes were identified at the core of coproducing consumer-specific output, namely: Employing consumer partner, setting clear expectations, facilitating proper communication, implementing consumer feedback, acknowledging consumers for their work and publishing in multiple formats with an evaluation strategy.



Implementing a Peer Run and Peer Delivered Mental Health Warmline Service in NSW

Irene Gallagher, Being Mental Health Consumers

13:45- 14:00

BEING – Mental Health Consumers (the NSW peak body for people with lived/living experience of mental health issues) received funding in early 2020 for a six-month pilot program to develop BEING Supported – a peer support warmline service for anyone in NSW experiencing emotional distress, particularly during the COVID-19 pandemic. As an entirely consumer run organisation, BEING – Mental Health Consumers outlines in this paper the co-design and co-production practices utilised in the development of BEING Supported, including key learnings, positive outcomes and challenges to this approach.



The National Strategic Action Plan for Rare Diseases: A Consumer Led, Collaborative, Multi-Stakeholder Approach to Effective Rare Disease Policy Reform

Nicole Millis, Rare Voices Australia

14:00- 14:15

Rare Voices Australia (RVA) is the national peak body for the two million Australians living with a rare disease. RVA led the collaborative development of the National Strategic Action Plan for Rare Diseases, the first nationally coordinated effort to address rare diseases. This presentation will provide learnings and strengths of the consumer-led, multi-stakeholder and collaborative consultation and engagement process that shaped the development of this landmark policy; and how it has remained similarly important for policy reform that has begun in response to the Action Plan.

CONCURRENT SESSION THREE:

13:00 - 14:15 - Friday 19th March 2021

Consumer Enablement

Chair: Bronwyn Smith

15 minute Pre-Recorded Presentations



Medicines Literacy: What we Know and Where we Need to Act

Dr Robyn Lindner, NPS MedicineWise

Dr Penelope Bergen, Consumers Health Forum

13:00- 13:15

The Consumers Health Forum was engaged and funded by NPS MedicineWise to carry out Consumer Health Literacy Segmentation Research. The research included a series of statements to explore the attitudes of nearly 1500 people in relation to the Quality Use of Medicines. The findings revealed the need for a coordinated approach to identifying and addressing health literacy, medication literacy and the QUM needs of higher-risk population segments. Significant social problems require multiple, multi-faceted approaches working in a coordinated way to achieve a collective impact. The research identified a suite of indicators from across the sector that can support the assessment of the impact of programs that aim to improve consumer health literacy. It asks the questions: how we can know if we're making a difference? How do we identify what we should measure? How do we plan to measure it? And how can we measure it? We know that to make a sustained impact, we need to do more and work differently. This talk presents some tangible steps already being taking to progress some of the key findings of the research.



The Patient Leadership Triangle: The Benefits of Patients and Carers as Partners for Change
David Gilbert, Director, InHealth Associates

13:15- 13:30

The Patient Leadership Triangle is a unique approach to embed 'patient (consumer) and public engagement' into the heart of a healthcare provider organisation. The model builds on the pioneering concepts of 'patient leadership' to support people with Musculoskeletal (MSK) conditions to be true partners in decision-making at all levels: delivery, improvement, governance and leadership.

The presentation will explore the role of a Patient Director (as part of the executive leadership team); a pool of paid, supported and trained 'Patient Partners' involved in improvement, governance and other functions; and a Patient and Carer Forum that oversees the 'patient-centred' work of The Partnership (e.g. patient experience, engagement, information and inclusion, personalisation).



Enabling Participation of CALD Consumers in Healthcare: A Qualitative Analysis in the Community Health Services

Reema Harrison, University of NSW

Co-Authors: Ashfaq Chauhan, Merrilyn Walton, Elizabeth Mania, Desiree Leone, Upma Chitkara, Monika Latanik

13:30- 13:45

Despite growing recognition of engagement of consumers in healthcare, consumers from culturally and linguistically diverse backgrounds continue to be excluded. In this qualitative project, we explore, with assistance of bilingual fieldworkers, the barriers, and facilitators to CALD consumer engagement across community health services in NSW. Data from focus groups with consumers and semi-structured interviews with clinicians highlights that while translation and interpretation can facilitate dialogue, these services alone do not sufficiently address the gap. Patients report feeling unsafe, poor access to services and their need for more culturally respectful care. Furthermore recognising diversity within and between CALD communities is important.



Curtin enAble Institute: Building Consumer Involvement from the Ground Up

John Fitzgerald, Curtin University

Co-Author: Ben Horgan

13:45- 14:00

Curtin University collaborated with the Western Australian Health Translation Network to engage Consumer and Community Involvement Coordinator Ben Horgan. This relationship informed the co-design process and ensures the enAble Institute's business model and governance structure truly includes the community they wish to serve. The collaboration utilised many forms of consultation, including a Community Conversation with current consumer representatives working with Curtin researchers. The result is a mandated commitment to support persons of all levels of ability to stay in their communities and live personally meaningful and enriching lives regardless of age, through research driven by their self-determined priorities.



Person-Centred Care: Taking it to the Next Level

Dr Paresh Dawda, Prestantia Health

Dr Tina Janamian, AGPAL

14:00- 14:15

In this session we will discuss four key components of person-centred care: personalised, enabling, coordinated and relational. Using a case study from a contemporary general practice we will discuss how these components of person-centred care are being achieved through the purposeful design of the environment, person-centred processes of care, and purposeful technology. Instrumental and central to the model of care is team-based care and the formation of a new role, the Patient Advocate. At the end of the presentation, we will discuss patient activation which describes the knowledge, skills and confidence a person has to manage their own health and self-care. We will learn how the Patient Activation Measure (PAM) can be used as a tool to help design and deliver touchpoints of care to support enablement. The PAM is unique in that it is an interval scale measure which enables it to be highly predictive of health outcomes and health resource utilisation. It produces a score ranging from 0-100 which can be categorised into 4-levels. In this way PAM is a key vital sign for patient-centred, value-based care.

CONCURRENT SESSION THREE:

13:00 - 14:15 - Friday 19th March 2021

COVID-19

Co-Chairs: Melissa Fox

PANEL DISCUSSION - LIVE STREAM

13:00- 14:15

The Role of State Health Consumers Peaks in the COVID Response

Melissa Fox, CEO, Health Consumers Queensland

Michal Morris, Consumer Member, COVID-19 Consumer Leaders Taskforce

Danny Vadasz, CEO, Health Issues Centre VIC

Bruce Levett, CEO, Health Consumers Tasmania

Never before has the role of consumers in shaping our health system been more important. Yet the level and depth of consumer engagement in the COVID-19 pandemic response has differed across Australia.

Join this panel discussion with representatives from state and territory peak consumers organisations as they reflect on the challenges, opportunities and how they worked together during the last twelve months.

CONCURRENT SESSION THREE:
13:00 - 14:30 - Friday 19th March 2021

New Zealand Stream

Chair: Chair: Dr Lynne Maher

30 minute Pre-Recorded Presentations



**Co-Designing Cancer Services with Pacific Women
with Endometrial Cancer**

Larissa Ferguson, Cancer & Palliative Care

Karin Jansen, Adult Rehabilitation and Health of Older People (ARHOP)

13:00- 13:30

Lung cancer for Māori and endometrial cancer for Pacific women have high incidence and mortality rates. Prior to their first treatment consumers can be overwhelmed by information, which may impact on their engagement. Counties Manukau Health joined the Health Quality & Safety Commission's co-design program to explore consumer and health professional's experiences from the time of cancer diagnosis to first treatment. Staff and consumers working in partnership identified areas within cancer care that could be improved to contribute to better engagement and experience for Māori lung cancer patients and Pacific women with endometrial cancer.



Consumer Leader Enablers

**Gary Sutcliffe, Coordinator, Health Consumer Advisory Service,
Health Navigator Charitable Trust**

13:30- 14:00

Consumer Leadership is not just about standing up and being counted. It is also about the people who, through their support and belief in us, enable us to use our voice by validating our experiences and using our voice and lived experience to inform and improve health services. In this presentation, Gary talks about his journey through mental illness, of recovery, relapse and recovery. He talks about the people who helped along the way, who encouraged him to undertake new opportunities and challenges and indeed provided those opportunities. Gary talks about how these opportunities impacted on his life and improved his understanding of the health system, particularly with regard to mental health services. He encourages consumers to consider taking up opportunities when they are offered.

Closing Karaki

LJ- National Consumer Group

14:00 - 14:05

Performing the karakia for this event is LJ Apaipo. LJ is from Dunedin New Zealand has tribal affiliations known as iwi, with Tainui, Ngati Porou and the Cook Islands.

NZ Session Closed

POSTER PRESENTATIONS

Janney Wale, Independent Consumer Advocate

- 1** Without CAG we couldn't do this?: The evolving role of the Melbourne Genomics Community Advisory Group (CAG)

Ruth Cox, Queen Elizabeth II Jubilee Hospital, Metro South Health

- 2** Partnering with meaning in research: Learning together in applying best-practice research principles
Co-Author: Elizabeth Miller

Melissa Miao, Queen University of Technology Sydney

- 3** Co-designing the implementation of complex online interventions with adults with communication disabilities and their communication partners using the Non-adoption, Abandonment, Scale-Up, Spread, and Sustainability (NASSS) framework.
Co-Author: Emma Power, Leanne Togher, Rachael Rietdijk, Melissa Brunner, Deborah Debono

Sarah Carmody, Monash Partners

- 4** Co-designing an online hub to foster consumer and community involvement in health and medical research and healthcare

Angela Jones, Monash Partners Academic Health Science Centre

- 5** Strengthening consumer and community involvement at system, organisation and individual levels

Laura Thomas, Curtin University

- 6** Developing quality standards for commissioning overweight and obesity programs

Joanne Britto, Victorian Comprehensive Cancer Centre

- 7** A shared vision: Practical tools for meaningful consumer engagement

Claude Gauchat, Chris O'Brien Lifehouse Hospital

- 8** The Empowerment Ladder - paving the way for consumer-initiated projects to enhance patient outcomes
Co-Author: Jane Cockburn

Deborah Howe, NSW Agency for Clinical Innovation

- 9** Building Collaborative Cultures of Care within NSW Mental Health Services

Angela Todd, Sydney Health Partners

- 10** Promoting consumer involvement in research - codesigning a brochure
Co-Author: Linda Komarek, Coralie Wales, Tara Lee, Helen Hughes, Mark Mathot and the Western Sydney Local Health District Consumer Council

Karen Gainey, The University of Sydney

- 11** What instructions are available to health researchers for writing lay summaries? A scoping review.

Rebecca Edwards, Sacred Heart Mission

- 12** Standing on the outside looking in - a social determinants view of policy decision-making

Stephanie Best, Murdoch Children's Research Institute

- 13** Genetic, Undiagnosed and Rare Disease community collaboration with research
Co-Author: Monica Ferrie

Darshini Ayton, Monash University/Monash Partners

- 14** Barriers and Enablers to Consumer and Community Involvement in research and healthcare improvement: Perspectives from consumer organisations, health services and researchers in Melbourne, Australia.

POSTER PRESENTATIONS

- 15** **Kylie Johnston**, University of South Australia
Partnering to develop consumer-valued messages about understanding and managing chronic breathlessness.
Co-Author: Debra Kay, Mary Young and Marie Williams
- 16** **Suzie May** Giving Voice
Consumer leadership in governance of health services
- 17** **Maria Alejandra Pinero de Plaza**, Flinders University
Exclusion from primary healthcare: a barrier to the national disability strategy implementation
- 18** **Huong Ly Tong**, Australian Institute of Health Innovation
The role of personalisation in person-centred care: A qualitative co-design study
Co-Author: Dr Juan Quiroz and Dr Liliana Laranjo