

Agenda

Health Consumer Council

Venue: Kawakawa Room, Education Centre,
889 Cameron Road, Tauranga or via [Zoom](#)

Date: 14 April 2021, 10:30am to 1:00pm

Chair	Lisa Murphy	Minutes	Maria Moller
Members	Grant Ngatai, Deputy Chair Adrienne von Tunzelmann, Deputy Chair Sue Horne – Tauranga John Powell – Mount Maunganui	Florence Trout – Tauranga Rosalie Liddle Crawford – Mount Maunganui Terehia Biddle – Whakatāne Tessa Mackenzie – Katikati Theresa Ngamoki – Whakatāne	
In attendance	Debbie Brown, Senior Advisor Governance & Quality Tim Antric, Kaiwhakahaere Takawaenga a Hāpori People-centred Experience Lead Jerome Ng, Clinical Director Maria Moller, PA to Senior Advisor Governance & Quality		

Item No.	Item	Lead	Page
	Morning Tea		
1.	Karakia timatanga	Grant	
2.	Welcome		
3.	Presentation – Jerome Ng – Clinical Governance	Jerome	
4.	Apologies		
5.	Interests Register	Chair	
6.	Minutes of Meeting: 10 March 2021	Chair	4
7.	Presentation - Tim	Tim	
8.	Matters Arising - Attached	Chair	8
9.	Matters for Discussion/Decision		
a.	• Chair's Report		14
b.	• CHF Virtual Summit 2021: Shifting Gears		15
c.	• Covid Campaign		
10.	Correspondence	Chair	
11.	Health Sector Update	Tim	
12.	Reports of participation in other groups		
a.	Youth and community health.	Chair	
b.	Other	Rosalie	
13.	General Business	Chair	
14.	Next Meeting: Wednesday 12 May 2021	Chair	
15.	Karakia Whakamutunga	Grant	

HEALTH CONSUMER COUNCIL MEMBER ATTENDANCE

2020/21

Member	April	May	June	July	Aug	Sept	Oct	Nov	Dec	Jan	Feb	Mar
Terehia Biddle		●	●	A	●	A	A	-	A		-	-
Rosalie Crawford		●	A	A	●	●	●	●	●		-	●
Sue Horne		●	●	●	●	●	●	●	●		●	●
Theresa Ngamoki		●	A	A	●	A	●	●	A		●	●
Grant Ngatai		NS	●	A	A	A	●	●	●		●	●
Tessa Mackenzie		●	●	●	●	●	●	A	●		●	A
Lisa Murphy		●	●	●	●	●	●	●	●		●	●
John Powell		●	●	●	●	●	●	●	●		●	●
Florence Trout		●	●	●	●	●	●	●	●		●	●
Adrienne von Tunzelmann		●	●	A	●	●	●	A	●		●	●

- Attended.
- A Apology received.
- Absent, no apology received.
- NS Had not started.

Minutes

Whānau & Consumer-centred Healthcare Council

Venue: Kawakawa Room, Education Centre,
889 Cameron Road, Tauranga or [Zoom](#)

Date: 10 March 2021

10:30am - 11:30am: Health Consumer Council

11.30am – 1.00pm: Whānau & Consumer-centred Healthcare Council

The meeting is in two parts. The first section is for community representatives – this group is known as the Health Consumer Council. The second section involves community representatives and Hauora a Toi BOPDHP leaders – this group is known as the Whānau & Consumer-centred Healthcare Council.

Membership

	Health Consumer Council	DHB Leaders
Co-Chairs	<ul style="list-style-type: none"> • Lisa Murphy 	<ul style="list-style-type: none"> • Bronwyn Anstis, Chief Operating Officer
Members	<ul style="list-style-type: none"> • Grant Ngatai, Deputy Chair • Adrienne von Tunzelmann, Deputy Chair • Sue Horne – Tauranga • John Powell – Mt Maunganui • Florence Trout – Tauranga • Rosalie Liddle Crawford – Mt Maunganui • Terehia Biddle – Whakatāne • Tessa Mackenzie – Katikati • Theresa Ngamoki – Whakatāne 	<ul style="list-style-type: none"> • Marama Tauranga, Manukura • Julie Robinson, Director of Nursing • Sarah Mitchell, Executive Director – Allied Health, Scientific & Technical; Strategic Architect • Kate Grimwade, Chief Medical Officer • Luke Bradford, Chief Medical Officer • Jerome Ng • Linda Brown
In attendance	Maria Moller, PA to Senior Advisor Governance & Quality Tim Antric, Kaiwhakahaere Takawaenga a Hāpori People-centred Experience Lead	

Health Consumer Council 10.30am-11.30am

Item No.	Item	Lead	Page
1.	Karakia timatanga - Grant	Chair	
2.	Welcome		
3.	<p>Presentation – Pete Chandler: Hauora a Toi Our Priorities</p> <p>Introductions.</p> <p>Sharon is keen for member wisdom to come through. How do DHB connect with members? How do we change the BOPDHB health system for the future? Collective purpose if the wellbeing of the community. Waiariki members, police, education, health are collaborating. Will send out one-page diagram. Specific for DHB but will evolve for BOP health system. Many strategies that need to brought together in four main areas. *Connected system - *Equity - *Health Thriving Workforce - *Provide Safe, Compassionate Care.</p> <p>Media has reported that there will be less DHBs? DHB is not aware of what this, the Prime Minister’s transition team will implement this. DHB need to show a path and develop strategies in readiness for future changes. BOPDHB shares</p>		Maria

Item No.	Item	Lead	Page
	<p>similar ideas to Lakes and Taiwhawhiti. Major decisions or changes may not occur in the near future due to Covid.</p> <p>Update of IT? Needs updating and progress is being made in this area.</p> <p>Private sector partners. Need more private sector partners, this will benefit public system.</p> <p>Members should challenge the DHB and draw to our attention things that you think need to be.</p>		
4.	Items for Discussion	Tim	
	a. Proposed amendments to Terms of Reference – to be discussed at next meeting.		
	<p>b. Why do we need two health consumer councils?</p> <p>It came from a need for time/space for HCC members to discuss matters. Is funding available to have a half day meeting to discuss and resolve this issue? The consumer voice needs to feed in to the DHB leadership. Members agree that this is needed.</p> <p>Will arrange meeting to discuss further.</p>	Florence	
	<p>c. What is the modus operandi for the HCC and WCHC parts of the meeting, e.g. Protocols, participation etc.</p> <p>This will be discussed at next meeting.</p>	Adrienne	
5.	Reports of participation in other groups	Chair	
6.	<p>Apologies:</p> <p>a. Apologies – Tessa Mackenzie. Moved: Sue. Seconded: John</p> <p>b. Absent: Terehia Biddle</p>		
7.	<p>Confirmation of previous minutes</p> <p>Amendments - Change address of Sue Horne to Mount Maunganui.</p> <p>Page 2, d. Housing Shortage - Change to: "EBOP- a lot of people in this area live in insecure and poor housing. Need to consider these people. Comment made re: government funding to support Maori housing initiatives. Response is that this funding is very difficult to access and dependent on Maori Land Court processes with delays due to the multiple ownership structure of Maori land. Also need a high level of financial investment before you qualify for grants". Delete: "Tuhoe are taking a lead with housing."</p> <p>Moved: Adrienne. Seconded: Sue.</p>		
8.	Conflicts of Interest: None.		
9.	Matters arising – Attached.		
10.	Closed: 11:30am		

Whanau & Consumer-centred Healthcare Council 11.30am-1.00pm

Item No.	Item	Lead	Page
1.	Welcome	Chair	
2.	Whakawhanaungatanaga Introductions: Members and DHB staff – Sarah Mitchell, Julie Robinson, Bronwyn Anstis, Kate Grimwade, Marama Tauranga, Linda Chalmers.	Chair	
3.	Background to establishing WCHC New clinical governance committee. How does consumer and whanau fit into that space. HQSC – requires consumer voice. Intention of this group is to provide this voice. Initially focused on provider arm and then roll out to whole of system.	Tim	
4.	Update on Te Toi Ahorangi Manukura provided an overview of the key strategic goals and current activities associated to Te Toi Ahorangi. A whare waka or program management office was established in 2020 to deploy the strategic initiatives, the whare waka is designed to run virtually using agile methods and lean / kaizen tools which includes implementing hoshin kanri as mechanism for keeping line of sight on strategic priorities as they pertain to the Te Toi Ahorangi strategy. The programs of work that are underway are: 1. Authentic partnership – governance level work between Board and Rūnanga, due for completion end of June 2021. 2. He Pou Oranga Tangata Whenua – igniting this framework, developing a system / model of care to be used within BOPDHB, due for completion end of June 2021. Note; models of care have significant impact and benefits realised to whanau and community quality of experience. 3. Toi Ora Investment –Reviewing current investment and the result / benefits for Māori, engaging stakeholders in various MOH to look at opportunities for partnering. 4. Toi Ora outcomes and indicators – about to go to Rūnanga for endorsement to proceed to community engagement 5. Mental Health Transformation, Transformation & Redesign Mental Health & Addictions Programme, 2020 – 2023 (MHAS) is in the second phase of a five phase programme. The initial phase was completed in Oct 2020 producing independent reports, from subject matter experts, kaupapa Māori MHA providers, general stakeholder groups and Tangata Whaoria (service users). The second phase, aligns with Te Toi Ahorangi, due for completion in June 2021. The multi-stakeholder (20) MHA Leadership group is being established to design and lead the ‘transformation’. The communication plan will be initiated in April. 6. Quality – review of adverse events, partnership with Quality and Safety team.	Marama	
7.	Feedback from other consumer groups	Chair	
a.	<u>Tauranga Community Liaison Group</u> was established by Tauranga Hospital many years ago. Has a wide range of representatives from all over the community?	Julie	
b.	Mental Health Consumer Group – No Report		
8.	Items for Discussion/Decision	Tim	
a.	Terms of Reference for HCC and WCHC – A meeting will be set up to discuss. Consumer engagement QSM report for HQSC - How DHB is performing? Need to complete survey rating ourselves. Are we actively involving community, community representation - 1. Feedback – members agree. Equity – a work in progress -2. HCC hasn't been formally evaluated – 2. Diverse workforce – 2. Responsiveness – 1. Community Voices – 1. Improvement capability – 1. Health literacy – 1. Experience – 1. Diverse feedback options – 1.		

Item No.	Item	Lead	Page
	b. Whānau & Consumer-centred Experience Programme – Will discuss at next meeting.		
	c. Meeting format (1-hour HCC:1.5 hours WCHC – any changes?) – Will discuss at next meeting.	Tim	
	d. Update on Work Programme – Will discuss at next meeting.		
9.	Confirmation of previous minutes (none)		
10.	Matters arising (none)		
11.	Karakia Whakamutunga	Chair	
12.	Meeting Closed: 1:03pm		

Health Consumer Council Monthly Meeting Matters Arising December 2020

Meeting Date	Action required	Who	Action Taken	Completed / in progress
09.12.20	Health & Disability System Review – members to read and feedback to DHB about where the consumer council should be involved.	All		
09.12.20	National Trauma Network correspondence – circulate to members.	Sue		
09.12.20	Webinar link for sharing with members.	Sue/Tim		
09.12.20	Meeting Summaries – find out if HCC has it's own email address and who monitors it?	Maria	Emailed address, no response. IT advised that Pritika, Averil and Tim have access to this email address. Not sure if anyone is monitoring it. The email address is Consumer.Council@bopdhb.govt.nz . Relevant emails are forwarded to the chair. Will enquire again if this is happening.	
14.10.20	Update groups you attend on Connex.	All	<i>Members to check Connex, working area "HCC Community Connections" and add details.</i>	

Meeting Date	Action required	Who	Action Taken	Completed / in progress
09.09.20	Housing Shortage - Accessible Housing took over from Housing New Zealand. How is that going?	AV		<i>Ongoing.</i>
09.09.20	TOR: a) Recruiting Maori consumer members. Contact Marama for guidance. b) Source flowchart to be annexed.	TA TA		
14.10.20	Arrange for a member of the Tauranga Community Liaison Group to attend December meeting.	JP	JP & SH to extend invitation	Completed.
14.10.20	Perspectives sought on Consumer Engagement Quality and Safety marker and Whānau – centred co-design draft paper. Tim to send out zoom meeting invite and slides to discuss further with members.	All	On-going - led by Tim.	Completed. Paper circulated to Council.
09.12.20	Meeting payments to members – are these correct?	Debbie /Maria		All payments taxed. Rates will depend on what you entered on your Tax Code Declaration when you first started. If you are being taxed incorrectly, it will correct

Meeting Date	Action required	Who	Action Taken	Completed / in progress
				itself in your end of year tax return to IRD. You can check this with IRD if you don't currently file a return.
09.12.20	Health and safety training – who needs to update?	Maria	This will only be relevant to those who are staying on as members. Tim to advise Maria.	Completed: Consumer council members are not DHB employees there is therefore no requirement for health & safety training.
09.12.20	Clinical Governance Meetings – large workload for members who attend. Look at reducing.	Tim	Tim met with the Acting Chief Medical Officer and Debbie Brown regarding policy and protocol consultation. A better and more inclusive system is needed.	The permanent Chief Medical Officers have now been appointed. Jerome will continue to support improvements to the clinical governance system. Members should raise this issue with the committee chair.
09.12.20	Grand Round Presentation – Jerome Ng. Send video recording link to members for viewing. Members to give feedback once watched.	Maria All	Emailed to members on 22.12.20	Complete
14.10.20	Chair to attend Tauranga Community Liaison Group meeting – last Wednesday of month 4.30pm. Email details.	SH JP	SH attended meeting.	Complete
09.12.20	Send link to Grand Round Presentation by Jerome Ng out to members.	Maria	Emailed link 22 December 2020	Complete
09.12.20	Advise CEO of Chair and Deputy Chair appointments.	Sue	Letter sent to Pete Chandler 22 December 2020.	Complete

Meeting Date	Action required	Who	Action Taken	Completed / in progress
14.10.20	Summary of September meeting to go out to community groups for feedback and on website.	All MM		
09.09.20	Term for Council Members – when do these expire?	TA & SH	14.10.20	Complete
09.09.20	Clinical Governance, Member Participation at Meetings – Clarification of members' concerns.	TA	11.11.20	Complete
14.10.20	Finalised TOR to be emailed to members then CEO and Chair.	SH	04.11.20	Complete
12.08.20	Summary of feedback to be provided to members from focus group "Papamoa Link" regarding referrals to Whakatane Hospital.	RC	14.10.20	Complete
12.08.20	Promotion of HCC to Community Groups – Some dialogue be extracted from minutes to share with community groups such as TCHT/Ngati Ranganui/Homeless Trust. To be distributed among member's networks. Some examples to be prepared	John	14.08.20	Complete

Meeting Date	Action required	Who	Action Taken	Completed / in progress
	for consideration.			
12.08.20	Orthopaedic project update. Awaiting response from Dr Mitchell.		19.10.20	Complete
09.09.20	Engaging Effectively with Maori Course – Submit HCC feedback on Course.	TA	09.20	Complete
09.09.20	Communication between Board and Council. a) Enquire with other Consumer Councils to see how they achieve good two-way communication with their DHB's. b) Write letter to CEO/Board enquiring as to how many/who are consumer representatives involved in DHB activities.	SH SH & JP	06.10.20 28.09.20	Complete Complete
12.08.20	RSA Flats – Generic statement to go to TCHT and Homeless Strategy Group showing our interest in the issue.	Sue		Completed.

Meeting Date	Action required	Who	Action Taken	Completed / in progress
12.08.20	RSA Flats – Acknowledgement of Interim Chair letter and response asking that if there are any decisions to be made, the Council be kept informed, c.c. Interim CEO.	Sue	24.08.20	Completed
12.08.20	Letter to be sent to Clinical Auditor with questions around auditing process.	Sue	24.08.20	Completed
12.08.20	Letter to be sent to Chair of Clinical Governance Committee asking for clarification around member input.	Sue	24.08.20	Completed
12.08.20	Letter to be sent to Interim CEO congratulating him on his tenure as Interim CEO.	Sue	25.08.20	Completed

Health Consumer Council - Chairs Report March 2021

Key Topics:

- Establishment of the Whanau & Consumer-centred Healthcare Council
- CEO Pete Chandler: Hauora a Toi Our Priorities
- DHB future planning – continued interest in being involved with co design initiatives
- CHF Virtual Summit 2021: Shifting Gears
- Reporting of meetings attended
- Consumer Engagement Quality and Safety Marker and current projects
- Update of HCC profile page
- Finalised Terms of Reference

The Whanau & Consumer-centred Healthcare Council has been established and the first meeting held in March. The development of this governance council is ongoing.

HCC members met with the recently appointed CEO, Pete Chandler. Discussed were matters relating to how the DHB can connect with members, how we change the BOPDHB health system for the future, and the collective purpose, the wellbeing of the community. The HCC continue to express their eagerness to be involved with co design initiatives.

Four members of the HCC attended the CHF Virtual Summit 2021: Shifting Gears. A Chairs report will be submitted to HCC with the April agenda.

Feedback was sent to the Clinical Director: Health Quality & Safety Service to assist in formulating an appropriate reporting mechanism from the CGC that does not breach the confidentiality of closed meetings.

DHB and HCC representatives met with Mary Bird and Jacob Mills from the Taranaki DHB.

Kaewhakahaere Takawaenga a Hāpori (Person Centred Experience Lead) provided an update on Consumer Engagement Quality & Safety Marker. HCC Chair attended the DHB Consumer Councils meeting with HQSC re consumer engagement QSM.

With the new DHB website up and running, the HCC page is in the process of being updated.

Clarification is being sought regarding the status of HCC Terms of Reference revised 2020, which had previously been sent to the CEO and Board Chairperson for consideration.

Lisa Murphy

Health Consumer Council Chairperson

Chair's report: CHF Virtual Summit 2021: Shifting Gears

Australia and New Zealand Consumer Experience and Leadership in Health Summit

It was a privilege to attend Australasia's inaugural virtual consumer health summit, which had an audience not only within Australia and New Zealand, but worldwide. The BOPDHB Health Consumer Council was fortunate to have been extended further complimentary invitations to include all members who forwarded their expression of interest. Grant, Florence and Adrienne attended.

Consumers as leaders in healthcare was a central theme of this first Australian and New Zealand Consumer Experience and Leadership in Health Summit, exploring the latest research and developments which drive health towards a consumer-centred culture. Opening address and Keynote speakers included our very own Minister Andrew Little, Dr Lynne Maher, Innovation and Improvement Clinical Director Ko Awatea, and Dr Ashley Bloomfield, Director General Health.

The key topics presented: Recruiting, engaging and supporting consumer leaders at the local level. Patient and service activation and health literacy. Consumer perspectives on value in health care. Benefits of health consumer engagement and leadership. Collaborative practice and co-design of services. Consumer collaboration in research.

Participants were able to select from six concurrently streamed plenary covering Consumers as Researchers, Consumer-Based Health Care, Consumers Leadership, Consumer Enablement and two streams, one for presentations covering COVID -19 and the other with a New Zealand focus. This meant we could move across the different plenary easily. All Australian speakers respectfully recognised their indigenous peoples.

The New Zealand stream was well appointed with excellent presentations from Chris Walsh and Deon York from the NZ Health Quality and Safety Commission, who I have been fortunate to have met previously. Together with DJ Michael Adams, Rosalie Glynn and Russ Aiton who also attend the national DHB Consumer Councils meeting with HQSC. The consumer engagement quality and safety marker was discussed in this stream.

There were times I would have liked to have listened to speakers that were 'live' at the same time, and without a pause facility as this was real-time participation, I was concerned I would miss important points while writing notes. Fortunately, we are now able to view the recorded conference and different plenary on demand for up to 12 months.

I noted reoccurring themes and points of interest across the plenary: acknowledgement of marginalised sectors of the community, addressing inequities, co design methodology should be authentic not just tokenistic, healthcare experience may not be the same as someone that works in the health field, and a positive of Covid 19 forced the rapid roll out and expansion of tele health. All with the view to reimagine healthcare with a focus on 'person' centred care.

Lisa Murphy

BOPDHB HCC Chairperson

REPORT TO CHAIR OF BOPDHB HEALTH CONSUMER COUNCIL.
Florence Trout
20 March 2021

SHIFTING GEARS SUMMIT 18-19th March 2021

Summary:

First, it was a real privilege to have participated in this virtual conference, the inaugural event for the Australia and New Zealand health consumer movement. I extend my appreciation to those staff and colleagues who enabled me to participate. Fortunately all presentations are available on the website for the next 12 months, so anyone can browse the shared wisdom. For me, it was a first experience of attending a large virtual conference. Some aspects were beneficial, other aspects I found not so beneficial. However, it beats the expense of going to Sydney for 3 days.

Secondly, themes for the organisation and presentations for health care consumers were; consumer based health care, research, consumers leadership, consumer enablement, COVID-19 and NZ focused. A large variety of types of presentations were included, using digital solutions, real health related and consumer representation experiences, and panels. Speakers were mainly Australian, with some from Canada and New Zealand. All Australian speakers acknowledged their indigenous people in some way. Listening to some sessions of course means that I could not listen to them all.

Thirdly, some standout ideas/concepts/advice/examples to illustrate my stimulated thoughts from listening to the virtual Summit and thinking of the changing BOPDHB world. These 8 'thumbnail' examples are not prioritised, nor in any particular sequence. Neither do they represent the entirety of any presentation.

- Trend away from "patient surveys" towards digital solutions for any patient or carer to write their story in their own words, which is moderated and replied to by a designated health care system staff, then posted on provider intranet so that all staff can access patients' experiences and views. This has been shown to influence speedy improvements, with general community appreciation that the health provider is willing to engage in this personal way.
- Consumers are here to stay - their activities referred to as the "forever game". Players may change, but the movement continues. Rather than talking "continuous quality improvement", consumers, patients, staff should connect to create better health care for all.
- It seems that every state in Australia has an organisation to support consumer voice, clearly separated from the business of providing healthcare. This raises the question about the new BOPDHB consumer-senior management group. By definition, consumer voice should be independent of the business of providing health care. There are many things related to health happening outside the health care system, and by linking the consumer voice to operations, it may limit its (consumer voice) potential.
- Health providers could have posters everywhere that state 5 questions that patients and their families might ask about their health care. The WA example was developed from research about questions to ask. It was very impressive and created a connected dialogue.
- "Come and have a cuppa" seminars created meaningful conversations and enables professionals to ask patients/consumers how they might want to contribute to QI, research, or planning. Reports were impressive about the outcomes from this innovation. It is to support "nothing about us without us" in action. (Wallace & Teisberg 2019).
- Culture shift is from "patient today" (overloaded people) to "patient tomorrow" (consumers own their wellness and health care). Relies on partnerships in all systems in care, driven by knowledge.
- **Infodemic = living evidence**, rather than developing evidenced based practice. Melbourne based Prof Elliot used COVID-19 truths to demonstrate different ways to speed up best practice evidence for professionals to refer to. This is a remarkable change in scientific use of methods including consumer enablement connections.
- 5 levers for patient led innovation; listening to symptoms, needs and expertise, recognition of patient knowledge, digital health an opportunity not a threat, engaging at all levels at the same time for co-leadership, impacting across entire patient journey for better access, clinical efficiency, strengthening prevention and self-management. These mobilise and integrate decisions for value-based health care. Everyone has the opportunity to be involved.

Shifting Gears Summit 2021 Communique

Australasia's first health consumers conference involving over 820 delegates from Australia and around the world has given fresh momentum to consumer direction and influence in health care.

The first ever *Shifting Gears Summit* on consumer experience and leadership in health care was hosted in March 2021 by the Consumers Health Forum of Australia (CHF) – Australia's peak body for health consumers.

Many point to the need for more person-centred care – the [OECD](#), the Australian Productivity Commission in its 2017 [Shifting the Dial](#) Report and the CSIRO's [Future of Health](#) report to mention a few.

In 2018 CHF released a White Paper called [Shifting Gears: Consumers Transforming Health](#) as our contribution to this discussion.

The White Paper set out the transformational policy shifts needed to make the system more person-centred and described the many and varied roles consumers can play in shaping better policy, programs, research and services.

Summit 2021 continued that conversation.

Consumer leaders and experts with an interest in health care consumer affairs covered topics as diverse as why it is time to re-imagine health and social care; 'big ideas' for change; global trends in safety and quality in health care; and future horizons in healthcare.

Six concurrent streams demonstrated the scale and variety of consumer health issues: consumer involvement in research; consumers' role in ensuring value-based health care; consumer leadership; consumer enablement; New Zealand consumer issues and consumer and community engagement in COVID-19.

Now the focus is shifting further from consumer-centred care to consumers as partners in healthcare.

Consumers shaping health

Consumers of today, partners of tomorrow

Central messages included:

- No longer weighed down with health information, lacking support to understand their choices, unaware of how new healthcare technologies will impact their health and only partially involved in the development of healthcare's future; the consumer of tomorrow will be recognised as a full actor of care, own their medical information, understand the value of evidence-based medicine, be better decision makers and be fully engaged as transformational partners.
- Consumers expect a real say in their health care and outcomes are likely to improve where consumer and care providers collaborate as partners in care. The notion of the 'wise' consumer equipped with knowledge and skills to exercise choice and control in their health and care; and the leadership skills to influence and shape policy emerged.
- The consumer is often the only individual in the care setting to have insider experience and knowledge about all aspects of their care. The best health care professionals and organisations should turn to and listen to the lived experience of consumer advocates in improving health policy and practice. Lived experience and consumer insights qualitative data are equally valid to quantitative data in research.
- Day one of the Summit coincided with National Close the Gap Day. There was strong recognition of the need for health systems to embrace the socio-ecological and community-controlled ethos of indigenous healthcare, and a call for strengthening indigenous voices in consumer advocacy and future events. Indigenous consumer rapporteur, Lara Pullin, described her Dark Emu Dreaming – a black emu defined by the stars around it, saying it is the patterns in the darkness surrounding the starlight that is important.
- Organisations need to be 'engagement capable': they must actively create environments where consumer-centred services can flourish. Culture, strategy and practices all need to work in tandem to deliver consumer-centred programs and services. Health services successful in delivering consumer-centred care focus all aspects of their organisation and exhibit several attributes including comprehensive care delivery; a clear purpose, strategy and strong leadership;

Consumers shaping health

people, capability and a person-centred culture; person centred governance systems and measurement for improvement; and demonstration of consumer/health systems partnerships in healthcare.

- We are at risk of a growing shadow of inequity as a consequence of widening wealth disparities. The development of ever more varied and expensive treatments has increased the risk of the well-off having care not available to others who are often the 'unheard yet most vulnerable'. Health consumer advocates play a vital role in pressing for quality health care to be available to all and for reforms to the system not only to make the most of medical advances but to promote wellness through preventive health measures.

What is needed now?

Several ideas to support the roles consumers can play as agents of change in shaping policy, research, programs and services were generated or reinforced:

- a more structured approach to the development of health consumer leaders, advocates and their organisations as an integral part of the health system through the establishment of an **academy** for research, education and training
- a bespoke **mentoring program** for consumer advocates
- the value of consumer advocates, their insights and advice must be recognised with appropriate **remuneration**
- the appointment of consumer representatives to health, hospital and research entities is now commonplace. While much advice is drawn from this consumer presence, when it comes to the actual decision-making and funding choices, the consumer representative can be excluded. **Leadership and education in collaborative practice** and better ways to work together and share power through leading-edge programs such as CHF's **Collaborative Pairs Australia** is needed
- The necessity of consumer voice and involvement is widely recognised but has meant that growing responsibility is placed on a relatively small number of people who have the wisdom and experience to bring user and carer knowledge to the table and often due so on a volunteer basis. A diverse and **continually refreshed national pool of consumer advocates** supported with opportunities to network, learn, and exchange knowledge is imperative.
- Further development and uptake of **tools to systematically gather and analyse consumer stories and sentiment** are required, specifically re-

Consumers shaping health

development of *Real People, Real Data* and sustainability of the Australian Health Consumer Sentiment Survey

Immediate priorities for CHF

- **Advocate** for the academy; sustainable funding for *Collaborative Pairs*; a Consumer Mentoring Program; and modernisation of *Real People, Real Data*.
- **Implement** and further adapt *Collaborative Pairs Australia* to continue to equip consumers and providers in various organisational settings to work together effectively.
- **Launch** *Consumer Link* – an initiative to support consumer representatives from across the country to network, learn and exchange information commencing with a launch webinar on 14 April.
- **Continue** to take the pulse on the issues that matter to consumers by repeating the Australian Health Consumer Sentiment Survey first conducted in 2018 and launching a Consumer Report Card on the performance of the health system in Patient Experience Week, 26-30 April.

CHF gratefully acknowledges the generous support of our sponsors.

Principal sponsors: Australian Government Department of Health; Australian Digital Health Agency, NSW Ministry of Health; and the Australian Commission on Safety and Quality in Healthcare

Gold sponsors: Telstra Health

Silver sponsors: Royal Australian College of General Practitioners and The George Institute for Global Health and Orygen: Revolution in Mind

Stream and session sponsors: AGPAL QIP; CSIRO; Australian Health Research Alliance; Australian Clinical Trials Alliance; NMHRC Partnership Centre for Health System Sustainability.

In-kind Partners: Sydney Health Literacy Lab and Ko Awatea, Health System Improvement and Innovation, Counties Manukau Health.

Consumers shaping health

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