

Health Matters

Health Consumers' Council (WA) Inc. Magazine

December 2020

**COVID-19 and the
Perth Culturally
and Linguistically
Diverse Community**

Page 6

**Reconciliation
training toward
healing and hope**

Page 19

**It only took
a pandemic**

Page 5

**Your
vision for
consumer and
community
involvement**

Page 12



HEALTH CONSUMERS'
COUNCIL



Year
in review



Contents

3

FOREWORD

4

WHAT WE'VE LEARNED ABOUT WORKING FROM HOME

5

IT ONLY TOOK A PANDEMIC

6

COVID-19 AND THE PERTH CULTURALLY AND LINGUISTICALLY DIVERSE COMMUNITY

7

AT THE HEART OF THE MATTER – A STORY ABOUT IMPACT

8

THE FOREVER GAME OF HEALTH

10

EXPERIENCE IS THE TEACHER OF ALL THINGS

12

WHAT'S YOUR VISION FOR CONSUMER AND COMMUNITY INVOLVEMENT IN HEALTH?

14

CLIMATE HEALTH INQUIRY

15

ADVOCACY YEAR IN REVIEW

16

REFRAMING THE WAY WE TALK ABOUT OBESITY

17

MAKING REFORM REAL

19

OPEN HEART, OPEN MIND

20

PRESCRIPTIONS TO OPTIMISE CONSUMER-CENTRED HEALTH CARE

22

WA HEALTH CARE OPINION SUMMARY

23

DATES FOR DIARY



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Welcome to the final Health Matters of 2020 – and what a year it's been! I won't talk too much about COVID-19 here, as we explore its impacts extensively in this edition, but I can say that even before the global pandemic hit this was always going to be a busy year for HCC.

The My Life My Choices Report has seen significant reform in the area of end of life and palliative care discussed and is now moving to implementation. The Healthy Weight Action Plan nominated HCC as one of the three Stewards of its implementation, along with the WA Department of Health and WA Primary Health Alliance, and implementation of the Sustainable Health Review has begun, in what will be a key force for driving consumer and community involvement in health service policy, planning and evaluation.

While at times during the year we've had to change how we do things, there have been some unexpected silver linings – notably, that many of our discussions with consumers have been able to reach beyond the limitations of location, allowing more regional and rural consumer and community members to join us.

So much is changing in the arena of consumer and community engagement, and there are many important levers to encourage the vital, complex and time-consuming art of effectively partnering with consumers of health services.

I'm particularly proud of the way our entire team managed to pivot to continue their important work – connecting with consumer, carer and community representatives to ensure the voices of the “hardly reached” were not forgotten during the pandemic; and continuing to provide an invaluable advocacy service for consumers during a time of great uncertainty.

Health Consumer Excellence Awards *nominate now*

After such a huge year, we're looking forward to taking the opportunity to celebrate the everyday heroes in health in WA. Nominations are now open for our Health Consumer Excellence Awards, and we hope you'll use this chance to shine a light on those who are doing amazing things for person-centred care in our state.

You can nominate in the following categories at www.hconc.org.au/health-consumer-excellence-award-nominations

- » Health Consumer Award: for consumer representatives demonstrating excellence in speaking up for the importance of a kind, patient-centred health care system
- » Aboriginal and Torres Strait Islander Award: to acknowledge outstanding service to Aboriginal/Torres Strait Islander health consumers
- » Compassionate Care Award: to acknowledge compassionate people working or volunteering in a health service providing support and/or direct patient care
- » Diversity Award: honour a healthcare organisation that has demonstrated leadership in creating and promoting diversity and inclusion to improve their service

Nominations will close on Friday 5th March 2021, and we invite you to join us as we announce the winners and finalists at an event during Patient Experience Week in April 2021 (more details to follow).



PIP BRENNAN
EXECUTIVE DIRECTOR
HEALTH CONSUMERS' COUNCIL

What we've learned about working from home

Virtual watercoolers and the new normal

Health Consumers' Council pivoted to online operation early in the pandemic for the safety of our team and the community. This meant working entirely from home for a few months, then looking to a future that incorporates the flexibility of working remotely with time spent in the office.

While this presented some challenges at the start of the year, we quickly became adept at Zoom, MS Teams and other online communications, and ended up finding some positives from the situation.

From the beginning we held a virtual daily check in and found that this was an important step in remaining connected with our colleagues. These check-ins were a chance for us to discuss any concerns around COVID-19 and how it was impacting our roles, as well as to bounce ideas off each other around our daily workloads. Over time our daily check-in became more like a virtual water cooler, a place to touch base and boost motivation – and for those of us juggling childcare with work, working alone, or missing the energy of the team, we learned how important it was to facilitate this connection.

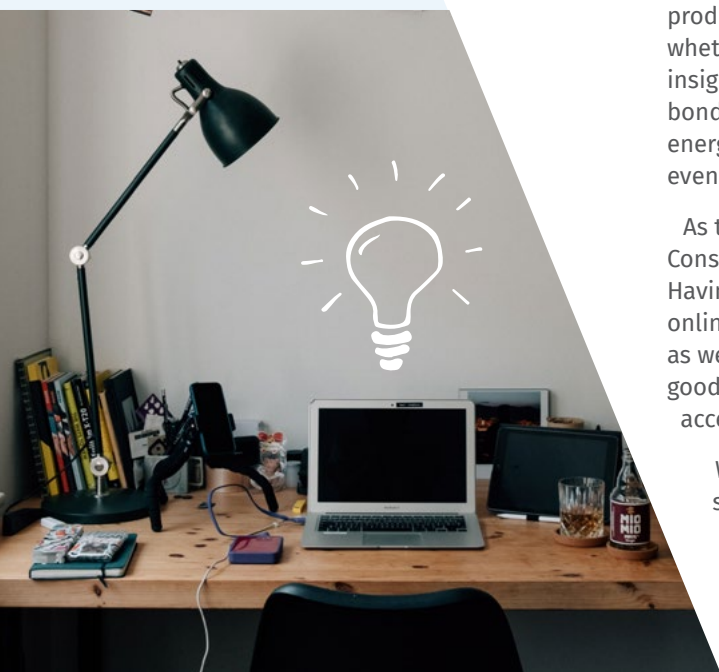
HCC regularly provides staff with the chance to give anonymous feedback to the leadership team, and this was ramped up during COVID-19. We took a benchmark survey to see how the team was feeling about the new work arrangements and then followed this up with further surveys to compare the results as the novelty of working from home wore off.

The employer engagement surveys asked about resources needed to undertake our regular work, what challenges we were facing in working from home, what we missed most about the office while working remotely, and what benefits we had experienced from working remotely.

Undoubtedly there were some challenges (unreliable internet connections, distractions at home and a lack of office equipment such as printers and scanners), but the biggest upsides included less commuting and therefore more time spent with family, higher productivity and more flexibility. There's been discussion around whether working from home has actually brought us closer, providing insights into our colleagues' home lives and creating a shared bonding experience – but on the flip side, we came to appreciate the energising effect of spending face-to-face time with our colleagues even more.

As things in Western Australia return to a new normal, Health Consumers' Council proudly embraced a "moving forward" approach. Having seen so much value and opportunity come from hosting online events, we want to continue to ensure this remains an option as we return to in-person opportunities. What we're hoping for is a good mix of ways to engage and connect so that our activities remain accessible to consumers all across WA.

We will continue to review work plans in light of the current situation and will make changes as required to ensure we are serving our community and promoting the voice of consumers, carers and community members in this changing situation.



The COVID-19 pandemic has irrevocably changed life for people around the world. Even in Western Australia, where our remote location afforded us much lower transmission rates than many other locations around the world, the effects were felt throughout communities as we braced for the unknown.

While we would never suggest that any of the positives that came out of this time in any way balance out the loss of lives and livelihoods, there are some silver linings that bring a glimmer of hope to what has been an awful event in world history.

We've seen across Australia a transformation in digital health that has been a long time coming, with an update in telehealth that will hopefully lead to it continuing to

become more accessible (with the infrastructure and training needed to truly make digital health part of the WA health landscape).

There's been a greater focus on mental health and wellbeing than we've seen in recent history, and this is a focus that we expect will continue into the future.

And it only took a pandemic for a greater appreciation of health care and more understanding around the importance of caring for the most at-risk people in our population.

Earlier in the year we put out a survey to consumers asking 4 questions, and these were some of the responses:

It only took a pandemic

What did health services START doing during COVID-19 that we want them to STOP?

- » Elective surgery cancellations
- » Phone app which makes some people feel like big brother is watching them
- » Hospital visitor restrictions rather than management
- » Panicking
- » Not consulting enough before devising and implementing policies
- » Consumer engagement being used for feedback not policy design
- » Having to use Telehealth when a face-to-face consultation would be more helpful, and not allowing it to be a choice between the provider and consumer about what is most appropriate
- » Consultations held in make-shift locations due to distancing rules or having to wait in the car before appointments
- » Temperature checks before entering premises and uncertainty around the use of gloves and masks

What did health services START doing during COVID-19 that we want them to KEEP on doing?

- » Concierge at the front doors stocking PPE for staff
- » Increased communication through social media, television, commercial and community radio
- » Telehealth and telephone appointments (and the associated Medicare rebates) for GPs, specialists, mental health and allied health
- » More out of hours appointments for allied health services, such as social work, to better suit some patients and service providers
- » Virtual meetings for health department and health organisations, allowing greater involvement for regional people
- » Better handwashing and hygiene by clinicians and consumers in healthcare settings
- » Reminders to tell people not to attend appointments if they are unwell as they may put others at risk
- » Ability to work from home if unwell so as not to expose other people in the workplace
- » Temperature checks and health screenings for certain procedures and appointments
- » Removal of toys in waiting rooms
- » Checking in with people regarding their mental health and connectedness
- » Texts and calls (from public hospitals) regarding appointments made and changed
- » Promotion of flu vaccine (and associated uptake)
- » Public and private hospitals working together and procuring supplies together (where appropriate)
- » Prescriptions written after phone consultation and sent directly to pharmacy
- » Health administrators discussing policies with consumers at a state and national level, and increased work and communication between sectors

What did health services STOP doing during COVID-19 that we want them to NEVER DO AGAIN

- » Taking a long time to implement changes (when it became clear change could be made quickly)
- » Bad attitudes towards consumers wanting to speak to a doctor on the telephone
- » Public hospital ONLY sending letters in the mail to arrange and move appointments
- » Running hospitals beyond 100% capacity
- » Acting in silos – seeing public health, primary health, tertiary health, public and private providers as all being separate

What did health services STOP doing during COVID-19 that we want to START again?

- » Engaging with consumers (including some CAG meetings)
- » Lung function tests in public hospitals (private ones cost a fortune!)
- » Some waiting room comforts such as magazines (which people can use or not use depending on their own risk profile and habits)
- » Hospital visitors
- » Multiple birth support persons
- » Access to Allied Health, elective surgery and emergency services on a needs basis
- » Maintaining contact, being patient focussed
- » Implementing the WA Cancer plan 2020-25
- » Consumer choice to see clinicians
- » Having the option for face-to-face consultations
- » Waiting rooms



COVID-19 and the Perth Culturally and Linguistically Diverse Community

*"We are all in the same storm
but not in the same boat"*

is a COVID-19 quote which resonated with me early on in the pandemic due to my own health conditions and risk factors, and having family overseas.

I quickly began to hear about some of the problems being experienced in Culturally and Linguistically Diverse (CaLD) communities in Perth; increasing racism, increasing family and domestic violence, the uncertainty around expiring visas, the lack of Jobkeeper subsidy or financial assistance for people on visas, etc. When the second wave hit Melbourne and media reported underinformed CaLD communities in Melbourne as hotspots, we began to think about the possibility of a second wave in Perth, whether we were prepared and whether our CaLD communities had (or will have) what they need.

In September 2020 Health Consumers' Council held two group discussions on COVID-19 and the CaLD community, one aimed at Perth CaLD facing organisations and one aimed at Perth CaLD community leaders.

Our discussions found that translated information had been slow to come out and be made publicly available. We found that simpler messages were needed, perhaps including infographics and pictorials. There was particular confusion about local (WA) rules and testing requirements, due in part to communities listening to or reading information from their country of origin and partly because health messaging from Victoria was being made readily available to those in WA via the SBS multicultural COVID portal.

Participants at these discussions felt information was not always easy to find or that it was hard to know what the 'right' information was. Through talking about what worked, what did not work and the lessons learned, we came up with the following suggestions for a second wave or future pandemics:

- » Translated information (particularly information about local restrictions) is needed more quickly and is most helpful if it is available from one central, known place (such as the Office of Multicultural Interests website).
- » Information needs to be sent out directly to community leaders (rather than putting the onus on them to find the correct information via websites). Local Governments and key Not for Profits can be important for building and maintaining relationships with community leaders so that incident response teams can access them in a time of crisis. It is the community leaders who are trusted and who meet community members face to face in places of congregational prayer and social gathering and also generally know how best to reach their communities in times of no face to face contact, via 'phone trees', Whatsapp groups or social media pages.
- » Local (in language) radio can be used for dissemination of important public health messaging.
- » CaLD facing organisational staff, interpreters, translators, bicultural workers, community leaders and English Language Teachers could benefit from information sessions on understanding COVID jargon so they can provide information to their communities. This could include explaining terminology like quarantine and self-isolation in community languages, and could look similar to a training project which the Victorian Government has recently funded.
- » More public awareness is needed around the costs of testing and treatment for COVID, in WA, including what is covered by Medicare and what happens if you don't have Medicare.

At the heart of the matter

a story about impact

CCIPROGRAM



**Dr Lois Balmer, Snr
Lecturer and Research
Scholar from the School of
Medical and Health Sciences,
Edith Cowan University**

“I have learned in the past few weeks that anything you assume should not be firmly held to until you are able to confirm it.”

– Edith Cowan University student

For the past 2 years, the CCIProgram* (Consumer and Community Involvement Program) through CCI coordinator Corinna Musgrave, has facilitated student forums with award winning Dr Lois Balmer from Edith Cowan University (ECU). One of Lois’ duties at ECU is teaching the Masters of Bioinformatics course.

At the semester 2, 2020 forum, one of CCIProgram’s registered consumers, Caz Boyd, shared her own engaging, funny and sometimes harrowing lived experience of Cystic Fibrosis with Lois’ students. Students were then asked to submit a reflection on their learning from the forum.

Lois explained why she chose to involve consumers when working with students; “I had a student with Ehlers Danlos syndrome in my unit who spoke about her condition and I recognised the engagement and attitude change of the audience when the student spoke. Wanting to develop this further, I decided to contact the CCIProgram for support.”

To demonstrate the impact of consumer involvement on the students, Lois shared one of their learning reflections with Caz and the CCIProgram:

“When I started this unit, I’ll admit that my knowledge of Cystic Fibrosis was limited to a very low level. I was thinking ‘Well, they have lung problems, that’s all’. The learning of the content was not enough alone, the independent reading was not enough alone, they needed to be accompanied by the information from Caz. I look forward to using these reflections in future when I think I know things, or try to rely on a limited understanding of a topic.”

Caz read the reflections and responded with: “Oh my goodness this is beautiful. This is the reason I share my life story. Unfortunately with other talks I have done, I don’t get any feedback and I often wonder if sharing my story really makes any difference. However, reading the responses I know for sure it certainly does.”

For Lois, the impact is significant; “Teaching can move people to experience something unexpected.” She is delighted when students say “The way I interact with someone with a disability has changed forever.”

The impact for our team at the CCIProgram is profound. These experiences capture the reasons we do what we do; bring together researchers and consumers, to achieve the best possible health outcomes and to bring empathy, understanding and an open mind to research. It’s a joy when we get to see this first-hand.

We wouldn’t be here without our incredible consumers, people who are prepared to share the expertise that comes with their lived experiences with researchers. Consumers have such an important place in informing, and collaborating with researchers in order to make inroads into health. We are your voice in health research – and we thank you for the honour.

The CCIProgram is an activity of the Western Australian Health Translation Network (WAHTN). We support consumers, community members and researchers in partnership to make decisions about health research priorities, policy and practice, aiming to improve health outcomes and ensuring community involvement becomes standard practice. The CCIProgram supports researchers at universities, research institutes, health service providers, and the WA Department of Health.

Led by Debra Langridge, the team facilitates, develops and supports involvement strategies, events, training programs and resources for researchers, consumers and community members, underpinned by the National Health and Medical Research Council’s (NHMRC) statement and framework on Consumer and Community Involvement.

The forever game of health

Enduring strategies of the Sustainable Health Review

From July this year, the work began in earnest on a 10-year process of implementing the Sustainable Health Review. Health is a “forever” game, and that’s why we like the fact that the Report lists ‘enduring strategies’ (see below).



As a consumer, there is really just two A4 pages you need to be across – the Enduring Strategies and the Recommendations that sit below them (see overleaf).

The commitment to new approaches to support citizen and community partnership should open many doors for consumer, carer and community representatives to be involved. In order to support us to be effective, we have all of the relevant Sustainable Health Review updates and information in one place on our Sustainable Health review Consumer View web page.

www.hconc.org.au/what-we-do/policy-development/sustainable-health-review-consumer-view

Why we are excited about implementation:

1. This is our current best opportunity for expanding and developing consumer and carer involvement.
2. Transparent Reporting is also threaded throughout (Recommendation 4, 16, 20, 21).
3. The Review is about the underlying causes of health issues, not just the symptoms, e.g. Recommendation 3a is about poverty.
4. Collaboration will be required as WA Health can’t do this alone.
5. The Review quantifies an increased investment in prevention.
6. The review hasn’t forgotten environmental sustainability with an Inquiry plus a report released recently with recommendations (fits under Recommendation 5).



Commit and collaborate to address major public health issues

- 1 Increase and sustain focus and investment in public health, with prevention rising to at least five per cent of total health expenditure by July 2029.
- 2 a) Halt the rise in obesity in WA by July 2024 and have the highest percentage of population with a healthy weight of all states in Australia by July 2029.
b) Reduce harmful alcohol use by 10 per cent by July 2024.
- 3 Reduce inequity in health outcomes and access to care with focus on:
 - a) Aboriginal people and families in line with the *WA Aboriginal Health and Wellbeing Framework 2015-2030*.
 - b) Culturally and Linguistically Diverse people.
 - c) People living in low socioeconomic conditions.
- 4 Commit to new approaches to support citizen and community partnership in the design, delivery and evaluation of sustainable health and social care services and reported outcomes.
- 5 Reduce the health system's environmental footprint and ensure mitigation and adaptation strategies are in place to respond to the health impacts and risks of climate change. Set ongoing targets and measures aligned with established national and international goals.



Improve mental health outcomes

- 6 a) Prioritise and invest in capacity to balance early intervention, community, step-up/step-down, acute and recovery mental health, alcohol and other drug services.
b) Immediate transparent public reporting of patient outcomes and experience.
c) Ensure clear accountabilities for joint planning, commissioning and service delivery for more integrated services.
- 7 Implement models of care for people to access responsive and connected mental health, alcohol and other drugs services in the most appropriate setting.



Great beginnings and a dignified end of life

- 8 Health actively partner in a whole-of-government approach to supporting children and families in getting the best start in life to become physically and mentally healthy adults.
- 9 Achieve respectful and appropriate end of life care and choices.



Person-centred, equitable, seamless access

- 10 Develop a partnership between the WA Primary Health Alliance and the Department of Health, and partnerships between Primary Health Networks and Health Service Providers to facilitate joint planning, priority setting and commissioning of integrated care.
- 11 Improve timely access to outpatient services through:
 - a) Moving routine, non-urgent and less complex specialist outpatient services out of hospital settings in partnership with primary care.
 - b) Requiring all metropolitan Health Service Providers to progressively provide telehealth consultations for 65 per cent of outpatient services for country patients by July 2022.
- 12 Improve coordination and access for country patients by establishing formal links between regions and metropolitan health service providers for elective services including outpatients and telehealth, patient transfers, clinical support and education and training.
- 13 Implement models of care in the community for groups of people with complex conditions who are frequent presenters to hospital.
- 14 Transform the approach to caring for older people by implementing models of care to support independence at home and other appropriate settings, in partnership with consumers, providers, primary care and the Commonwealth.
- 15 Improve the interface between health, aged care and disability services to enable care in the most appropriate setting and to ensure people do not fall between the gaps.



Drive safety, quality and value through transparency, funding and planning

- 16 Establish a systemwide high value health care partnership with consumers, clinicians and researchers to reduce clinical variation and ensure only treatments with a strong evidence base and value are funded.
- 17 Implement a new funding and commissioning model for the WA health system from July 2021 focused on quality and value for the patient and community, supporting new models of care and joint commissioning.
- 18 Establish an agreement between the Departments of Treasury and Health for a sustainable funding footprint to support the necessary change and reinvestment required in the health system in particular over the next three to five years.
- 19 Continue to seek a fair allocation of resources from the Commonwealth while partnering on common areas of reform.
- 20 Address key short to medium term capacity pressure points and develop system planning to ensure a comprehensive long-term plan for the health system to best meet community needs.



Invest in digital healthcare and use data wisely

- 21 Invest in analytical capability and transparent, real-time reporting across the system to ensure timely and targeted information to drive safety and quality, to support decision making for high value healthcare and innovation, and to support patient choice.
- 22 Invest in a phased 10-year digitisation of the WA health system to empower citizens with greater health information, to enable access to innovative, safe and efficient services; and to improve, promote and protect the health of Western Australians.



Culture and workforce to support new models of care

- 23 Build a systemwide culture of courage, innovation and accountability that builds on the existing pride, compassion and professionalism of staff to support collaboration for change.
- 24 Drive capability and behaviour to act as a cohesive, outward-looking system that works in partnership across sectors, with a strong focus on system integrity, transparency and public accountability.
- 25 Implement contemporary workforce roles and scope of practice where there is a proven record of supporting better health outcomes and sustainability.
- 26 Build capability in workforce planning and formally partner with universities, vocational training institutes and professional colleges to shape the skills and curriculum to develop the health and social care workforce of the future.
- 27 Remove barriers to equity, flexibility and transparency in workforce arrangements.



Innovate for sustainability

- 28 Establish a systemwide network of innovation units in partnership with clinicians, consumers and a wide range of partners to quickly develop, test and spread initiatives delivering better patient care and value.
- 29 Ensure that future research activities and investments are linked to the priorities of the WA health system and are actively translated into practice.



Implementation

30

Ensure a robust, disciplined and integrated approach to the implementation of endorsed Sustainable Health Review Recommendations.

*WA leaders share their
visions for consumer
involvement*

Experience is the teacher of all things

At the Health Consumers' Council AGM in November, we hosted a panel discussion asking WA leaders about their vision for consumer and community involvement in health.

We were joined by Deputy Premier and WA Health and Mental Health Minister, Roger Cook; Opposition Leader Zak Kirkup (although this was the night before this was confirmed – he had been invited as Shadow Health Minister); and Greens member Rachel Siewert, who talked about the importance of community engagement in healthcare.

This insightful panel highlighted how important it is that genuine and meaningful consumer engagement be a priority across every level of health, and how service design and delivery can only be improved through more consumer input.

Minister Cook spoke about some of the work done already to incorporate the consumer voice into everything the government does in healthcare, speaking largely to Care Opinion.

"When we first came to government I demanded that all government service providers become part of what is now Care Opinion [previously known as Patient Opinion], and we became the first jurisdiction in Australia to have all our health services on the Care Opinion platform," Minister Cook said.

"The vision around that was to set our health system afloat on a sea of customer feedback data. I firmly believe that any health system which is successful is one that looks outward and responds to the community which it's there to serve."

The Minister highlighted how the Care Opinion platform is important not only for feedback about what needs to be changed in health services, but also for the positive feedback that encourages and motivates services.

"Julius Caesar once said "Experience is the teacher of all things" and I want to make sure that the health system continues to incorporate the consumer voice at all levels," Minister Cook said.

Senator Siewert took the opportunity to speak to the Community Affairs Legislation Committee that she is chairing in the senate. Senator Siewert said the enquiries had highlighted the importance of making sure everything in health is person-centred, across all levels of policy.

"People need to be believed," she said.

"What I've come across so often is that the person isn't at the centre of things, the person isn't necessarily believed; I've lost count of people who've told me they weren't believed, that it's all in their head, and when you sit and listen to a group of people about their experiences and they're not believed, that is a deep failure of the health system in our country," she said, referring to her work Chairing the Pelvic Mesh Inquiry. In that role she saw and heard the stories of the awful pain experienced by many women who were treated with mesh.

"I want to make sure people are truly at the centre of our health system, that they are involved in every level of decision making, and that people are believed and they are able to contribute to decision making at a meaningful level."

In addressing his vision for consumer and community involvement, Zak Kirkup spoke of ensuring a patient focus across the whole WA health service. He shares some of his experience with the Inquiry into Palliative Care in WA and his family's Aboriginal heritage, and the gaps identified that need to continue to be a focus.

"What we found is there is an overwhelming need to redouble our efforts in making sure that those Aboriginal communities in remote and regional Australia can have their say," he said.

He said that Care Opinion is a fantastic resource, but there are limits around literacy, technology and access that prevent some people from using it.



HEALTH CONSUMERS'
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"There's a piece of the puzzle missing the further we get away from Perth. We need a mechanism to make sure all people can have a say and have their voice heard, particularly in remote Aboriginal communities, so that we can actively approach patients in a culturally safe way to share their experiences.

“*Ultimately, all of us want the patient voice at the centre of care.”*

There was a refreshing accord in the panel, with Zak Kirkup acknowledging the current government's COVID response. When the conversation turned to hospital parking, Kirkup was brave enough to name that his government had approved the Wilson car park at Sir Charles Gairdner/Perth Children's Hospital site. Alas there were no hospital car park breakthroughs but it was a welcome change from the political discord with which we have been bombarded internationally.

There was an important discussion on the experiences of people with disability in hospital and health services as well. Again Rachel Siewert's reflections as former Chair of the Senate Inquiry into disability reflected the importance of change and improvement especially in relation to people with developmental disability and decision making.



WE HAVE PUT AN AUDIO
RECORDING UP ON OUR WEBSITE
– IT IS NOT PERFECT BUT IF YOU
WANT TO HAVE A LISTEN IT IS ON
THE WEBSITE HERE:

www.hconc.org.au/recordings

After posing this question to political leaders at our AGM, we wanted to hear what you had to say.

What's your vision for consumer and community involvement in health?

"Both parties need the necessary training and support as to how this collaboration is to be implemented for it to be effective. Consumer advocates need to be paid just as any other consultants are compensated for their time.

An integrated system where nothing is done to us without us."

– HOWARD, SIR CHARLES GAIRDNER HOSPITAL
COMMUNITY ADVISORY COUNCIL

"Understanding our community for the wellbeing of our community."

– PAMELA, ESPERANCE DISTRICT HEALTH
ADVISORY COUNCIL

"The community know who their representatives are."

– MAUREEN, CONSUMER



***In one word,
what is your
vision for
2020?***

“Growth of ‘communities of interest’ to enhance communications involvement and input into health.”

– RUTH, LOWER GREAT SOUTHERN DISTRICT HEALTH ADVISORY COUNCIL

“For consumers to have a stronger voice in matters concerning them.”

– HENRY, DISTRICT HEALTH ADVISORY COUNCIL

“All Australians have the opportunity to engage and provide input into wellbeing improvement over a lifetime for our population through systems change advocacy.”

– S, CONSUMER

“Empowerment of consumers/ carers with confidence to be active participants in the planning and delivery of their health care.”

– DEBRA, WAPHA COMMUNITY COMMITTEE, CHOOSING WISELY ADVISORY GROUP, NPS MEDICINE WISE CONSUMER ADVISORY GROUP

“Collaboration for a better future.”

– MELISSA, CONSUMER ADVISORY COUNCIL

“We all own, and are responsible for, our health. We learn better life decisions, and be supported only when our health moves beyond/below our control. We contribute to planning.”

– ROD, EMERGENCY SERVICE VOLUNTEER

“A group that has authority for needed change.”

– EDDIE, CONSUMER

Wellbeing
Empowerment
Compassion
Access
Hope
Change
Transparency
Collaboration
Fulfilment

Climate Health Inquiry

PIP BRENNAN, HEALTH CONSUMERS' COUNCIL EXECUTIVE DIRECTOR

During the Sustainable Health Review, a commitment was made to undertake a Climate Health Inquiry and we are pleased to announce it has been released:

ww2.health.wa.gov.au/climate-health-wa-final-report

A media statement is also available at

www.mediastatements.wa.gov.au/Pages/McGowan/2020/12/New-health-and-climate-change-framework-for-WA.aspx

The report sets a blueprint for the next 10 years to guide the WA health system's response to the health impacts of climate change and how health services can do more to reduce emissions and waste without compromising the quality of patient care. The Inquiry sought information from the WA community, Australian and international experts to obtain the best science, data and evidence to inform the final 10 recommendations:

1. **Act early and establish a Sustainable Development Unit (SDU) in WA Department of Health**
2. **Allow and incentivise a 'new normal' in hospitals and health services**
3. **WA Health System manager to lead in reform of policy, procurement, performance, training and research**
4. **Strengthen adaptation in the specific areas of extreme weather events, heatwaves, mosquito control and air pollution**
5. **Establish data and early warning systems across environment and health, linked to effective mitigation and rapid adaptive response as required**
6. **Create new governance structure across mitigation and adaptation**
7. **Think strategically across a 10-year horizon**
8. **Communicate, consult and partner to raise public awareness of climate-health links and co-benefits of action, and reach vulnerable individuals and groups across the State**
9. **Seek complementary action at a national level in a federal system**
10. **Contribute to learning, innovation and research**



Health Consumers' Council is supportive of these recommendations and as ever is keen to see resourcing put towards their implementation. In particular, we would be interested in understanding how community is involved in the implementation. We support the Aboriginal Health Council of WA's comments in particular to ensure Elders are consulted.

As we discovered during COVID-19, consumer engagement can be the first thing to go in times of disaster, so it is essential that disaster preparedness work is undertaken with community input, insight and involvement.

This work sits within the Sustainable Health Review in the form of Recommendation 5. Like all other Recommendations, we will be keenly watching and tracking its progress, especially how it is involving consumers, carers and community in the implementation phase.

Year in review

Advocacy Service



Advocacy case study: The power of support

The consumer contacted our agency and reported that they did not feel comfortable in meeting their new psychiatrist without an independent advocate being present. They had lost trust in the system and reported that their rights had not been previously afforded while accessing a public mental health service. They described incidences of confidentiality breaches, misdiagnosis, and misrepresentation. The consumer believed that mental health professionals had formed their assessments based on inaccurate information held in their patient record. Consequently, the consumer felt they were treated with prejudice and disdain by staff. The consumer asked the advocate not to speak for, or on behalf of, them during the assessment; rather the advocate's role was to observe and take notes.

The consumer later explained that having the advocate present was a 'game changer,' in that they felt supported enough to convey themselves effectively. Given the assessment took place over several meetings, the advocate invested significant time to this case.

The consumer also attended HCC's Legal Information Session where they discussed pursuing a claim about the confidentiality breaches that had occurred.

In the consumer's own words:

"Having you there really changed the power dynamic and allowed me to better express myself and my concerns. Prior to having you present, it was clear to me that the doctor, while very kind and considerate, was making several assumptions about me and that these were guiding our interactions. While having you there I could tell that he was more conscious of those assumptions, and that it may have allowed him to reflect upon some of them. This in turn allowed me to talk more about my concerns regarding treatment and diagnosis and to express to the doctor that I had been mischaracterised, stigmatised and mistreated by other practitioners. While many of my issues with the mental health system are presently still unresolved, some recent developments have provided some hope that I will find closure and justice with respect to what has occurred. Thanks again for everything.

HEALTH CONSUMERS' COUNCIL
INDIVIDUAL ADVOCACY SERVICE
IS AVAILABLE TO ANY PERSON
WITH AN ISSUE IN THE WA
HEALTH SYSTEM.

WE PROVIDE INDEPENDENT
ADVOCACY TO SUPPORT THE
HEALTHCARE RIGHTS OF
INDIVIDUALS BY WORKING
ALONGSIDE AND/OR SPEAKING,
ACTING OR WRITING ON BEHALF
OF THE ADVOCACY CLIENT.

YOU DON'T HAVE TO BE A
MEMBER OF OUR ORGANISATION
TO ACCESS ADVOCACY.

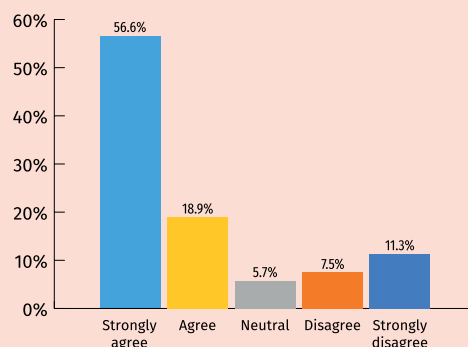
TO SPEAK TO AN ADVOCATE CALL
(08) 9221 3422, FREECALL 1800
620 780 (COUNTRY ONLY) OR
EMAIL INFO@HCONC.ORG.AU

Financial year outputs

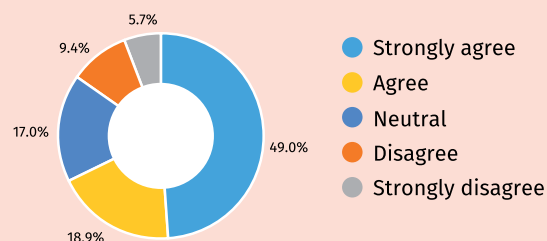
431
individual
advocacy cases

489
individuals provided with information
provision and active linkage

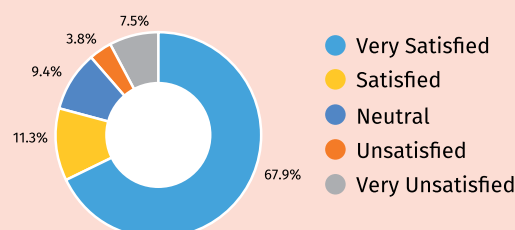
The HCC Advocacy Service was able to assist you
with the issue you were concerned about



The advocate gave you useful information about
your rights as a health consumer



How satisfied were you by the way
the advocate handled your case?



Reframing the way we talk about obesity

One year of the Healthy Weight Action Plan

Health Consumers' Council is partnering with the WA Department of Health and the WA Primary Health Alliance to implement the WA Healthy Weight Action Plan 2019 – 2024, launched in November 2019.

The Action Plan was grounded on consumer feedback, and now implementation is really kicking off.

We held a morning tea with consumers recently and the three key themes that emerged on the day were: costs and accessibility of services; clarity of information; and link around overweight and obesity with mental health and stigma.

We also held a community conversation session in December to update consumer and community members on the work done this year.

Consumer and Community Advisory Group

We have received expressions of interest from a number of people to join the Healthy Weight Action Plan Consumer and Community Advisory Group, and we look forward to finalising and meeting with this group in the New Year.

We would like to encourage expressions of interest from people living regionally, children/young people and families, and Aboriginal people, as we know people with different experiences are impacted in different ways. You can find more details at www.hconc.org.au/issues/partners-in-change-obesity-collaborative/

Shifting the way we speak about obesity

Shift. A guide for media and communications professionals was produced by East Metropolitan Health Services, funded by the WA Health Networks Unit in the Department of Health as part of the implementation of the Action Plan.

The use of respectful, positive language and imagery in communications, media, marketing and health information can reduce stigma and encourage better engagement with health professionals, leading to improved health outcomes.

The media guide is available at ww2.health.wa.gov.au/Articles/U_Z/WA-Healthy-Weight-Action-Plan

2020 projects

Earlier in 2020, a pilot of an innovative approach trialling the use of total meal replacement products and telehealth support from allied health staff was launched, led by Diabetes WA. We organised a consumer workshop around this trial, where consumers shared their experiences using these products and what they would find helpful in such a program. HCC staff are also involved in the project steering committee.

In another project as part of the Action Plan, East Metropolitan Health Service are developing training for health professionals on how to talk about weight and what support services are available. HCC staff are providing feedback on the draft course.

Healthy Life Engagement Coordinator

We're delighted to announce Apu Karajagi has joined the HCC team as the Healthy Life Engagement Coordinator.

Apu is passionate about health and wellbeing, and pursued her Master of Public Health as well as a Graduate Diploma in Health Promotion right after completing her Nutrition degree at Curtin University. She advocates for inclusion and diversity in all aspects of health, and is also passionate about sustainability, climate change, and racial justice.

Shifting the narrative on obesity

Join the conversation

WE ENCOURAGE WESTERN AUSTRALIANS WITH LIVED EXPERIENCE OF OVERWEIGHT OR OBESITY TO JOIN US IN ONGOING CONVERSATIONS AROUND THE ACTION PLAN. YOU CAN JOIN OUR MAILING LIST AT EEPURL.COM/DHEPHD OR JOIN OUR PRIVATE FACEBOOK GROUP WWW.FACEBOOK.COM/GROUPS/248123835784261/

Making reform real

PIP BRENNAN, EXECUTIVE DIRECTOR,
HEALTH CONSUMERS' COUNCIL

What really matters in the end?

Right now in WA there are many changes occurring in the wake of the End of Life Choices Report. The gap between policy and reality is where HCC work, and why we are so passionate about ensuring the lived experience voice is at the decision-making table.

As the last edition of Health Matters was released, my father passed away at home just six days short of this 95th birthday. He did get the death at home he so wanted, and the Palliative Care team plus the people from Carealot were an amazing support. But he died without an Advance Care Plan, and was transferred to Palliative Care only a short time before his death, despite having congestive heart failure and diabetes. We still have a way to go.

DOCUMENTING END OF LIFE CHOICES

There are several options for documenting end of life choices – a values statement (consumer-led), a goals of care document (clinician-led and relevant for each individual episode of care) and an Advanced Care Plan or Advanced Care Directive (the Directive is a legal document). All of these documents need to be supported by having conversations with those closest to use about what we want at the end of life.

Goals of Care

This year the National Goals of Care project was spearheaded by WA. One of the results has been the ability for consumers or staff to upload documents to My Health Record's Advanced Care Planning Document section.

In addition, a consumer video has been produced to give consumers information about goals of care. HCC staff were involved in providing feedback on the key messages and objectives as well as a draft of the film. The draft National technical guidelines for Using My Health Record to store and access advance care planning and goals of care documents is currently being finalised.

During the early stages of this project, we identified the need for tailored information for people with disability about goals of care and advance care planning, to support them to be proactive in these conversations. We are now working with People With disability WA and Palliative Care WA, as well as a group of consumers with disability, to review and adapt existing information about goals of care and advance care planning for people with disability.

A study titled A Qualitative Exploration of Seriously Ill Patients' Experiences of Goals of Care Discussions in Australian Hospital Settings found:

“Effective communication, and patients' values and expectations set the stage for goals of care discussions; however, the environment plays a significant role. Communication skills training and education designed to equip clinicians to negotiate GOC interactions effectively are essential. These interventions must also be accompanied by systemic changes including building a culture supportive of GOC, clear policies and guidelines, and champions who facilitate uptake of GOC discussions.” link.springer.com/article/10.1007/s11606-020-06233-y

Values Statements

If you haven't looked at this already, please check out the My Values website created by Associate Professor Charlie Corke, Senior Intensive Care Specialist, Barwon Health. This website allows you to work through prompt questions to tease out your values. www.myvalues.org.au If you want you can download the resulting PDF and upload it on your My Health Record. Don't forget though to discuss these with your family and loved ones.

Advanced Health Directives

This legal document, which also includes a space for values, focuses also on treatment choices. As the year draws to a close, work is progressing on finalising the changes to this form in response to the End of Life Choices Report. Other very key work in this area is community and staff education about having the conversation that always and ever precedes any documentation. Stay tuned for further updates.

PALLIATIVE CARE

The Palliative Care In Western Australia – Progress Report: Final Report of the Joint Select Committee on Palliative Care in Western Australia was released in November 2020. It noted that it is that it is now harder for people to access the practical care they need from palliative care service providers than it was 10 years ago.

The report also noted that there is a general misconception among the general public, and health professionals, around palliative care, with many believing it is solely for the elderly and imminently dying. The one thing HCC would like to communicate is that palliative care can mean a much better quality of life for people (like my Dad), and may also lead to a longer life, not a shorter one. HCC has often advocated for a different term, such as comfort care, to encourage people to access this more holistic model of care.

At the recent Join the Dots Palliative Care Summit convened by Palliative Care WA, one of the presentations debriefed the consumer survey on palliative care. This survey was spearheaded by researcher Samar Aoun and results highlighted that across many dimensions there are very clear benefits for people who are linked with palliative care services.

VOLUNTARY ASSISTED DYING

One of the changes as everyone will be aware, is that Western Australia passed legislation which enables voluntary assisted dying to become a choice available to eligible people in mid-2021. WA is now at the implementation phase to ensure that everything is in place. You may want to check out this web page and follow the links to subscribe for updates on the Implementation: ww2.health.wa.gov.au/voluntaryassisteddying

For easy reference listed below is the Implementation Leadership Team:

- » Dr Scott Blackwell (Chairperson)
- » Ms Noreen Fynn (Deputy Chairperson – consumer representative)
- » Dr Elissa Campbell
- » Ms Amanda Collins-Clinch
- » Ms Margaret Denton
- » Ms Stephanie Dowden
- » Assoc Prof Chris Etherton-Beer
- » Mrs Chris Kane
- » Dr Andrew Miller
- » Hon Dr Sally Talbot
- » Dr Peter Wallace

Compassionate communities

Compassionate Communities is an international movement which recognises that care for one another at times of crisis and loss is not simply a task solely for health and social services. Rather, it is everyone's responsibility.

The Compassionate Communities approach builds capacity within individual communities to support people approaching the end of their lives. This public health approach not only applies to palliative care, but also ageing and all those living with a disability or a life-limiting condition.

In this video www.youtube.com/watch?v=ubhyr5-GoS8&feature=youtu.be UK Palliative Care Consultant Julien Abel explains “Compassionate Communities are really about... how do we provide equity of care for all people who are dying?”.

He further states “death, dying and loss is an enormous public health problem... poor bereavement has really poor outcomes in terms of morbidity and mortality, including suicide, depression, chronic ill health and all that comes from social isolation and loneliness...”

This video from Allan Kellehear is very compelling about the benefits of compassionate communities www.comcomhub.com/about

Palliative Care Information and Support line

Palliative Care WA has a phone line with information and support on palliative care, grief and loss available to all members of the WA community dealing with palliative care or end of life issues.

People taking the calls have been trained to support those with a life-limiting illness and their friends, family or carers, as well as anyone experiencing grief or loss. There is no time limit on grief, and they invite calls from those who have lost loved ones recently or even some time ago.

PLEASE GIVE THEM A CALL ON **1800 573 299** IF YOU NEED THEIR SUPPORT.





Reconciliation training toward healing and hope

Open heart, open mind

How do we rebuild trust after we've hurt each other? This was a key question at the heart of the empowering and engaging reconciliation training recently undertaken by Health Consumers' Council.

In an interactive, engaging and heartfelt session delivered by Nyoongar consultant Danny Ford and Community Spirit Development Network's Tim Muirhead, we learned about history and traditional culture and the roles they play today, with a focus on exploring our own attitudes and beliefs, and how these influence our communication and work outputs.

The training was designed to stimulate genuine interest, passion and empathy to improve the relationship between organisations and Aboriginal people, and explore how we can all become more effective in working together.

Weaving together personal experiences with stories shared over many years of work in consultancy and policy, Tim and Danny provided the space to explore different perspectives as they guided us through the Journey of Wellbeing – a simple but powerful framework for understanding how history impacts people today.

This framework provides a way of understanding the depth of the challenge that we're all faced with in playing our part in Aboriginal recovery, as well as some guidance in what might contribute to that recovery.

The concept was turned into a compelling video in partnership with WA Health, which can be viewed at www.youtube.com/watch?v=cDYGjkjUdg&feature=youtu.be

The Journey of Wellbeing led into a discussion around the transition to recovery, and ways that we can speed up the process. Following an emotional interactive exercise, the session was importantly wrapped up by exploring genuine hope for the future.

We're proudly moving into the new year with more understanding, better awareness, and improved cross cultural communication skills that will not only support the work we do, but drive us to continue pushing forward in the Aboriginal engagement and advocacy space.

But even more importantly, we'll be taking with us a renewed commitment based on the understanding that we, as individuals and an organisation, still have a lot to learn and a lot of work to do – but if we approach it with an open heart and an open mind we can work with hope towards a reconciled future.



IF YOUR ORGANISATION IS INTERESTED IN DOING SIMILAR TRAINING, WE HIGHLY RECOMMEND THAT YOU DO. PLEASE VISIT CSDNETWORK.COM.AU TO FIND OUT MORE.

Prescriptions to optimise consumer-centred health care



Findings from the Consumer Commission

In the wake of the COVID-19 pandemic, Consumers Health Forum of Australia established a nation-wide Consumer Commission to ensure a strong consumer voice was helping contributed to shape shaping healthcare moving forward.

The Commission was made up of 30 consumers and health leaders, including WA consumer representative Dr Susannah Morris. We spoke to Dr Morris about the Commission and the recommendations it made in the Making Health Better Together report.

“COVID-19 precipitated the largest public policy experiment in living memory,” Dr Morris said.

“Governments and health and social welfare providers developed and implemented policies responding to the threats to economic, social, physical, and psychological well-being presented by both the pandemic itself and responses to it. This environment of rapid change provided unique opportunities for health and social welfare provision and the Consumers’ Health Forum of Australia sought to capitalise on these by forming a commission so consumers could consider and respond to the challenges and opportunities presented.”

“I was appointed as the nominee of the WA Health Consumers’ Council and was jointly endorsed by the Breast Cancer Network of Australia where I also hold a position as a consumer representative.”

“We met virtually in a series of six workshops to ‘diagnose’ the main issues facing health consumers and the health system at the present time. Together we developed ‘prescriptions’ for a range of structural and practical changes to optimise consumer-centred health care for now and the future which were published in our report Making Health Better Together.”

The key findings of the report centred on the importance of consumer input for delivering optimal health care, despite some organisations and jurisdiction pulling back from consumer involvement to a ‘command and control’ model during the height of the pandemic.

“The variation in national experience showed this was neither a necessary nor a desirable response and more work needs to be done to properly embed consumer leadership and co-design into the health system,” Dr Morris said.

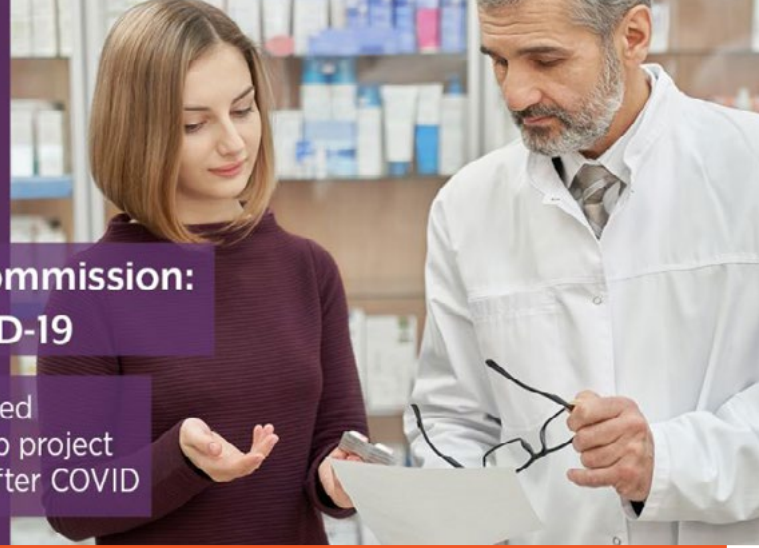
“The Consumer Commission calls for the development of ‘one health system’ focussing on the health and wellbeing of consumers, not on the barriers between different healthcare providers. The expediciencies of COVID-19 meant that previously insurmountable divisions, or silos, between jurisdictions, sectors and tiers of provision were lowered in pursuit of common goals: the Commission hopes that developments such as national responses to issues or contractual agreements between public and private providers to meet unmet demand will be built upon. At an individual level integration and care coordination were also major issues and care coordinators or navigators should be introduced to help support consumers self-manage their care as needed.”

The report also called for a Consumer Health Leaders Academy to strengthen the role of consumers in health system decision-making.

The Academy would equip consumer advocates and advisers within health consumer networks working with governments, government agencies and other organisations, where consumer involvement is vital, to further develop their skills as leaders and amplify their voice.

Consumer Commission: Beyond COVID-19

A new consumer-led
thought leadership project
on health policy after COVID



“The Consumer Commission showed us the benefit and strength of consumers coming together from across the country and from different areas of healthcare to examine and give voice to our concerns and offer practical and structural solutions moving forward,” Dr Morris said.

“Imagine how powerful we could be if consumer representatives could access a directory and network of other consumers around the country who may be working towards similar goals in their healthcare setting so that they can exchange ideas and learn from one another’s experiences and identify when issues were common and needed to be raised at a national level.”

“An academy would offer this by training and coordinating a body, or network, of consumer leaders who were skilled in collaborative practise and co-design and informed by consumer experience: they would be a resource to one another and a resource to which policy makers and providers could turn to make health better together.”

Ongoing access to telehealth has been much talked about since the start of the pandemic, when the ease of consulting with a clinician became a focus through lockdowns and social distancing. The Commission found that ongoing access to telehealth for all would be vital for healthcare in Australia, but Dr Morris warned that “the decision to use telehealth needs to be a joint decision between provider and consumer alike according to capacity and need”, noting that many consumers were not given a choice about how they accessed health care during COVID.

“Access to the necessary digital hardware and reliable internet is unequally distributed between consumers and providers: those with lower incomes may be reliant on expensive pay-as-you-go phone and data packages. There may also be variability between clinicians, with consultants getting cameras, and nurses and allied healthcare professionals being left on the landlines in a hierarchy of hardware.”

“Not only does telehealth need to be made affordable for all, both consumers and providers need more training in digital literacy to effectively use the technology and improve the quality and style of communication.”

“Bringing the world of healthcare into the home has many advantages but clinicians and consumers may be overheard by colleagues and fellow householders: the virtual consult needs to be in a safe space for all.”

“We also need to recognise that digital health is about so much more than telehealth and ensure that technology is used to help empower consumers to feed their experiences into and navigate their care pathways to outcomes of value to them.”

Dr Morris and the Commission noted that during COVID Australians recognised that private action and public health were inextricably linked and granted legitimacy to Government actions in an emergency situations, trading individual freedoms for public good. To retain this legitimacy, trust and collective action as the country moves forward, she said, “providers must involve consumers in decision making, gaining informed consent for their actions”.

Consumer Commission Report Making Health Better Together



WA Health Care Opinion

Summary for 2019/20



Government of Western Australia
Department of Health



1267

STAFF LISTENING¹



99.7%

RESPONSE RATE²



67

STORIES THAT
LED TO CHANGE³

Number of stories⁴ published for each Health Service Provider

54

Child and Adolescent
Health Service

148

East Metropolitan
Health Service

110

North Metropolitan
Health Service

22

PathWest Laboratory
Medicine WA

124

South Metropolitan
Health Service

693

WA Country
Health Service

Recognising International Year of the Nurse and the Midwife

35.4%

OF PUBLISHED
STORIES WERE
TAGGED⁵ INDICATING
NURSE, MIDWIFE,
NURSE CARE AND
MIDWIFERY CARE
WAS GOOD.

Explanatory Notes:

1. The total number of individual staff from the Health Service Providers that are set up to receive story alerts from Care Opinion as of the end of the 19/20 financial year. 2. The percentage of stories which have received a response from a Health Service Provider. 3. The total number of stories published where the Health Service Provider has responded with either 'a planned change' or has 'made a change'. Not all stories provide the opportunity to create a change but when the opportunity arises highlighting the change allows everyone to improve from one person's experience. 4. Count of stories for each Health Service Provider may result in duplicate counts when more than one Health Service provider is part of a story. 5. Percentage calculated from count of stories that were tagged where: nurse, nurses, nurse care, nursing care, nursing staff, midwife, midwives, midwifery staff, or, midwifery care, "was good" which is the most positive tag available.

Dates for the Diary

Weight Issues Network session

5 February 2021, 10am-11:30am

An online information session featuring a presentation from national consumer group, [Weight Issues Network](#), to help WA consumers develop a better understanding of the consumer perspective on overweight and obesity in Australia.

Please register at us02web.zoom.us/join/join?pwd=ZlRlcU6tqTltHtxOGjPZzeXcChfXMraDcKT

Sustainable Health Implementation – Outcome Measures

Save the date – 9 and 16 February 2020, 4:30pm-6pm

These online workshops will explore outcomes measures and the Sustainable Health Review.

More details, including registration, available soon.

Introduction to consumer representation

Would you like to use your experience as a patient or carer to create a better health system? We know that pro-active and skilled Consumer Representatives can do just that, and this introductory course will help you get started.

This training is run twice per year, and will take place in the first three months of 2021. More information will be available soon at www.hconc.org.au/what-we-do/workshops

Advanced Consumer Representation

This session is for consumer reps with at least 6 months experience on a working group, committee or Board. We recommend that people do not attend the Intro and the Advanced session in the same month. These sessions run approximately every 6 months.

The next training will take place in the first three months of 2021. More information will be available soon at www.hconc.org.au/what-we-do/workshops

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Opening hours

Monday - Friday 9.00am - 4.30pm

Closed Public Holidays

© WA Health, curated by Weight Issues Network (<http://auswin.org.au/>)



HEALTH CONSUMERS'
COUNCIL