

HEALTH CONSUMERS'
COUNCIL

HEALTH CONSUMERS COUNCIL 2020/2021

2020

ANNUAL REPORT

2021

CHAMPIONING POSITIVE CHANGE
THROUGH CONNECTION AND COMMUNITY





Supporting
positive change
in
Healthcare

HEALTH CONSUMERS'
COUNCIL

VALUES

Acknowledgement of Country

We acknowledge the Traditional Custodians of the land we work on, the Whadjuk people of the Noongar nation. We pay our respects to Elders past and present, and extend our respect to all Aboriginal and Torres Strait Islanders.

HCC acknowledges WA always was, always will be Aboriginal land.

Acknowledgement of lived experience

Health Consumers' Council acknowledges the individual and collective expertise of those living with health challenges.

We recognise their vital contribution at all levels and value the courage of those who share this unique perspective for the purpose of partnering to achieve better health outcomes for all.

Statement of inclusion

Health Consumers' Council is committed to cultivating inclusive environments for everyone including staff and consumers.

We celebrate, value and include people of all backgrounds, ages, genders, sexualities, cultures, bodies and abilities; recognising and fighting against the discrimination faced by many people within WA's healthcare system.



RESPECT



EQUITY



KINDNESS



INTEGRITY



WORKING TOGETHER



EMPOWERMENT

VISION

Equitable, person-centred, quality healthcare for all West Australians.

PURPOSE

To increase the capacity of all people to influence the future direction of healthcare and to make informed choices.



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CHAIR REPORT

Leading in uncertain times

I would like to thank my Management Committee colleagues who have overseen another year of uncertainty and change.

While our meetings have largely remained online, we have been able to remain a close knit team to endorse the strategic plan and oversee another successful audit.

We have continued to benefit from the Leadership Team's cohesion and advice to keep us on track, and the work of the HCC Advocacy and Engagement staff is a constant inspiration to us.

I am grateful for the wisdom and commitment Pip brings to every conversation, and for our continued positive and rock solid working relationship.

Farewell and welcome

We have had some changes in our Management Committee during the last year.

In June of 2020 we welcomed ethics lawyer Michael Crowley to fill a casual vacancy left by Erin Moore to ensure HCC has legal expertise on our Management Committee.

Our Treasurer Steve Walker obtained a new position which meant he was no longer able to commit to his role on our Management Committee.

We welcomed Ian Ludlow as Treasurer from January 2021 as he has stepped in to fill this casual vacancy.

Strategic Plan

We are excited to unveil our updated Strategic Plan which has set forth a clear vision for HCC and is a well-thought-through meld of front line knowledge and strategic Management Committee level insight.

Work on the Social Enterprise that was first heralded in our previous Strategic Plan continues proactively with a Lotterywest funded market analysis process to inform our next steps.

Reconciliation Action Plan

The Management Committee has been proud to support HCC's ongoing Reconciliation Journey.

Last year's Annual Report featured the Black Lives Matter Statement created with Management Committee and staff. In December 2020, we built on this work when staff underwent cultural awareness training with Community Spirit Development's Danny Ford and Tim Muirhead.

A key next action from this training was the formation of a Reconciliation Action Plan Working Group with membership of both staff and Management Committee. This group met for the first time in June 2021.

At that meeting, Management Committee member Christine Sindely offered to deliver pro-bono training for staff and RAP Working Group members which was held just after the financial year ended. We are well on the journey to create our Reflect RAP.



EXECUTIVE DIRECTOR REPORT

As we continued to adapt to the unpredictable nature of living through a pandemic, we're reminded of how much a small but dedicated team can achieve, and, as always, how much work there still is to do.

Aishwarya's death and a renewed focus on safety and quality

In April 2021, the death of 7-year-old Aishwarya Aswath sent shock waves through the community and the health sector.

As a health consumer organisation, we were heartbroken by her death and challenged ourselves to think about how we can best partner to create real change, while supporting the family's goal to drive safety and quality improvements.

Focus on driving implementation

It has been said that WA is facing not just a pandemic, but a perfect storm of reform. We have the Sustainable Health Review as a key health sector reform document and our state's COVID Recovery plan.

Other key reports include the Western Australian Mental Health, Alcohol and Other Drug

Services Plan Update 2018, the State Disability Plan, the Royal Commission into Aged Care, the WA Healthy Weight Action Plan, the WA Cancer Plan, and NDIS reforms...in all of these reports lie the blueprint for doing what needs to be done rather than what we have always done.

As Dr Paul Batalden pointed out *"every system is perfectly designed to get the results it gets"*.

We see the Sustainable Health Review – and the other reforms that are underway – as an opportunity to change the system, not just its parts. And system change requires courage and commitment from leaders at all levels to tackle all the uncertainty and complexity of making it real.

I am excited to be one of the few external Co-Leads for this reform, leading Recommendation Four – Citizen and Community Partnership.

This is one of the key initiatives that is relevant to each and every Recommendation – as well as everything that happens across health services in WA. WA Health Networks are supporting the implementation of Recommendation Four and the partnership is very positive.

Our Deputy Director Clare Mullen is working closely with Recommendation 16 on high value healthcare.

Since 2018 we have also been working as partners with WA Health and the WA Primary Health Alliance on the WA Healthy Weight Action Plan. That work is a foundational building block of SHR Recommendation 2a and we commend our partners for recognising the value of having lived experience perspectives front and centre through this work.

Engagement – relationships are key

The Sustainable Health Review sets the scene for a new citizen and community partnerships with the health and social care sector.

Health Consumers' Council knows just how important it is to have an established network of partnerships to drive the engagement activities that ensure the lived experience voice is at the decision-making table in health.

This is why we will be focusing our efforts on continuing to widen our circle to amplify the voices of people who experience health inequities, as well as building capacity and amplifying good practice in engagement in health and social care.

MEET THE TEAM



During another unpredictable year, the Health Consumers' Council team continued to show their dedication and flexibility, adapting to short, sharp lockdowns, online events and changes in the healthcare landscape with grace and determination.

We are incredibly proud of each and every member of the HCC team - the Management Committee, our Executive Director Pip Brennan, Deputy Director Clare Mullen, our incredible Advocacy Team, our Engagement Team and not forgetting our Administration staff that make sure our organisation runs smoothly.

THANK YOU!

for your contributions towards the achievements and outcomes explored in this report.

MANAGEMENT COMMITTEE



MALLIKA MACLEOD
CHAIR



RICHARD BRIGHTWELL
DEPUTY CHAIR



IAN LUDLOW
TREASURER



REBECCA CARBONE
SECRETARY



TINA TUIRĀ-WALDON
MEMBER



REBECCA SMITH
MEMBER



CHRISTINE SINDELY
MEMBER



MICHAEL CROWLEY
MEMBER



DANAE WATKINS
MEMBER



SYSTEMIC ADVOCACY

OUR ROLE IN WA TODAY

WORKING FOR LONG-TERM CHANGE TO SUPPORT THE
HEALTHCARE RIGHTS OF ALL WESTERN AUSTRALIANS.

DIGITAL HEALTH

The Digital Health Strategy set out for WA under Recommendation 25 of the Sustainable Health Review hinges on a missing piece of a complex jigsaw – an Electronic Medical Record (EMR).

This refers to the records that hospitals and health services hold, as distinct from My Health Record which is being driven federally. In WA, aside from Fiona Stanley Hospital's digital medical record, mostly we rely on paper based records.

HCC was asked by WA Health to develop a Consumer Charter for an EMR to drive this decade-long piece of complex reform.

To guide development of the WA Electronic Medical Record Consumer Charter, Health Consumers' Council held a series of Kitchen Table Discussions across the state.

These discussions informed a consumer group in designing the WA EMR Consumer Charter.

89 CONSUMERS Involved in the Kitchen Table Discussions and design of the Charter



DIVERSITY OF KITCHEN TABLE DISCUSSIONS

44 ATTENDEE EVALUATION RESPONSES, ATTENDEES IDENTIFIED AS:



WHAT WAS SAID AT KITCHEN TABLE DISCUSSIONS

| | | |
|--|-------------------------|--|
| | 8 GROUPS | ACCESSIBLE ONLY TO STAFF INVOLVED IN YOUR CARE Discussed the importance of restricting and monitoring access to their identifiable health information to only the necessary staff. |
| | 7 GROUPS | HEALTH INFORMATION KEPT SAFE Discussed the importance of keeping health information safe from unintended access. |
| | 9 GROUPS | ACCESSIBLE TO OTHER HEALTH SERVICES WITH CONSENT Discussed the importance of sharing information to other healthcare providers if consent is given. |
| | 4 GROUPS | HEALTH INFORMATION IS NOT SHARED TO THIRD-PARTIES WITHOUT CONSENT Discussed the importance of not sharing their health information to third-parties without consent. |
| | 3 GROUPS | ACCESSIBLE ONLY TO STAFF INVOLVED IN YOUR CARE Discussed the need for an EMR system to be designed to enhance a clinicians decision-making. |
| | 3 GROUPS | ACCESSIBLE IMMEDIATELY WHEN REQUIRED Discussed the need for an EMR system to allow immediate access to their health information when required. |
| | 2 GROUPS | SENSITIVE INFORMATION MANAGED APPROPRIATELY Discussed the need for an EMR system that allows sensitive information with restricted access. |
| | 2 GROUPS | USED TO IMPROVE SAFETY AND QUALITY OUTCOMES Discussed the need for an EMR system to allow monitoring and improvement of safety and quality outcomes of their healthcare provider. |
| | AT LEAST 1 GROUP | ASSISTS WITH SELF MANAGING CARE Discussed the importance of an EMR system that enables consumers to better manage their own care. |



SEXUAL HEALTH AND BLOOD BORNE VIRUSES

There are always windows of opportunity in working on particular topics, and the formation of a Sexual Health and Blood Borne Viruses Advisory Committee under the new Health Promotion Act provided one such opportunity.

HCC had a Deputy Chair and currently Chair role which has allowed the issue of consumer involvement in this sector to be promoted. As well as putting three people on this Committee, significant work has gone into developing a wider network of people to ensure there is a more diverse voice informing the Committee.

Significant time was spent to work with people with lived experience to define what problem we were hoping to solve and how we could do that.

We have landed on the concept of a co-design project to bake in consumer involvement into the contracts WA Health has with health services. As the year closes out we are co-designing with WA Health an e-learning module for health service staff focusing on stigma and people living with blood borne viruses.

AISHWARYA'S CARE

HCC has provided strategic lived experience input into the many initiatives and work done by Child and Adolescent Health Service in the wake of Aishwarya Aswath's death.

We have also undertaken an independent survey of 1,000 West Australians who had attended an Emergency Department or outpatient appointment to reveal that 80-90% of the population had not heard of CARE (*Call and Respond Early*) Call.

Just as this report is being completed we undertook a Rapid Consultation within a week's timeframe to test key concepts of the revamped scheme.

The consumer voice is driving the implementation of Aishwarya's CARE to ensure there is a clear way for people to raise concerns when their child or loved one's condition is deteriorating.

MY BABY WA APP

HCC and WA Country Health Service partnered with Women's and Newborns Health Service to deliver an app to help women and families make the right birth choice for them.

It was launched in June 2021 and gives women across the state access to evidence-based information and links to local services throughout their whole pregnancy. It supports informed maternity care choices.

The project is being expanded as a partnership right across the health system and will continue to be developed and enhanced.

HEALTHY WEIGHT ACTION PLAN

Since 2018, HCC has been consulting and partnering with consumers through the development and implementation of the Healthy Weight Action Plan. Roll-out of the plan is being co-ordinated and stewarded by HCC, Department of Health and WA Primary Health Alliance (WAPHA). We know that lots of people in the WA community have experience relating to the health issue of overweight and obesity (*approximately 67% of adults and 25% of children*),

and we want to make sure that work on changing health services in this area is informed by those diverse experiences. A partnership approach to governance from the outset allowed HCC to advocate for consumers as the project was scoped, planned and now implemented.

One major theme of feedback from consumers is around the experience of stigma, which can affect how they seek and experience healthcare. Weight stigma is based on ill-informed assumptions about the drivers of overweight and obesity – and is in evidence at every level of decision making in the health system, from people's individual experience of healthcare from clinicians, through to the low level of funding for early intervention and weight management treatments, despite the widespread prevalence of this health issue. Please refer to *'Empowering Voices for Change'* and *'Pushing Forward on the Equity Agenda'* for more on this project.

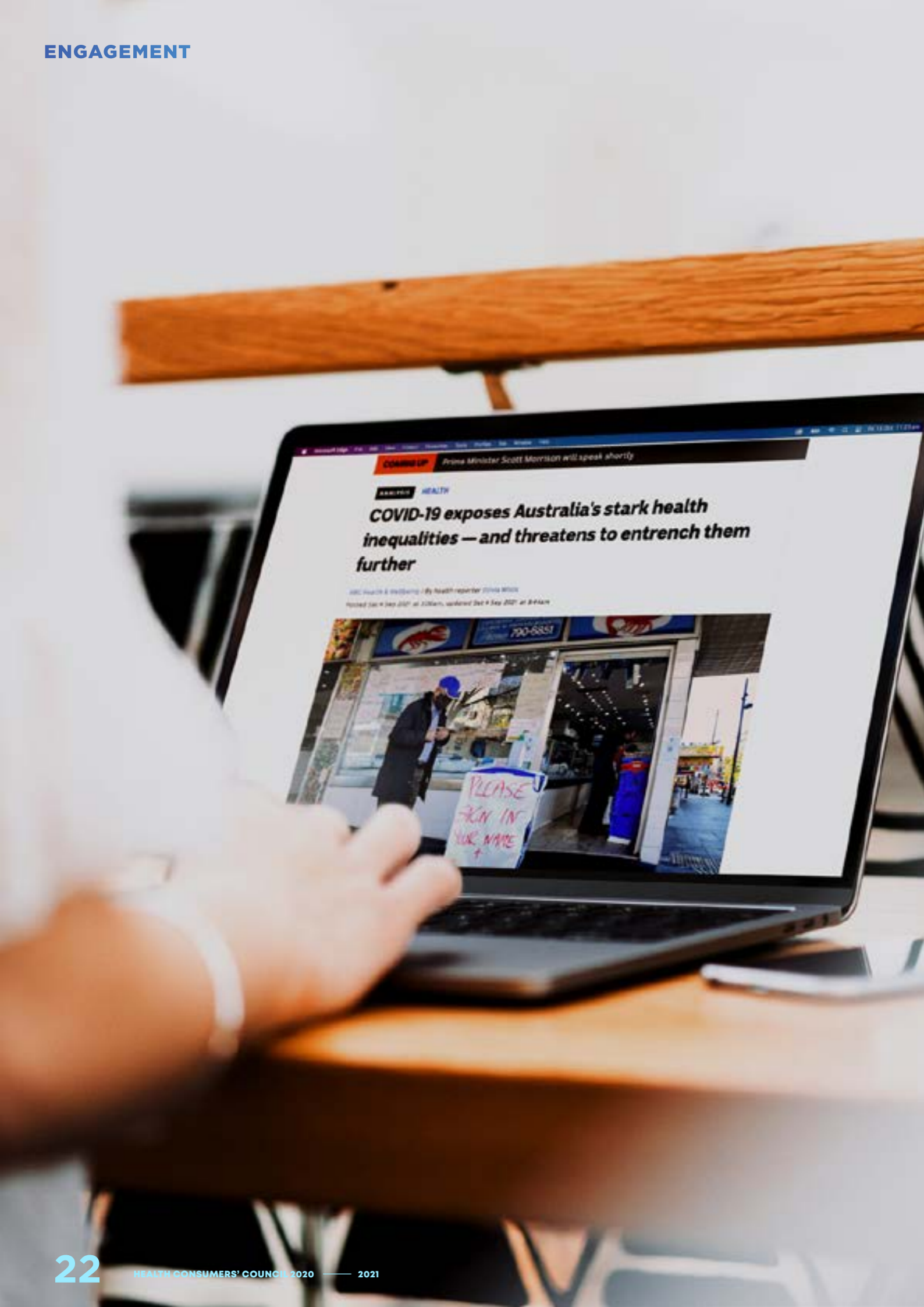
The project is being expanded as a partnership right across the health system and will continue to be developed and enhanced.

ENGAGEMENT

PUSHING FORWARD ON THE EQUITY AGENDA

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The response to COVID-19 has highlighted the difference in health outcomes and health service access across Australia, as well as underscoring the role of the social determinants of health.

At HCC we're often asked to provide advice on plans to seek input from consumers on a range of health service activities. A key question we always ask is –

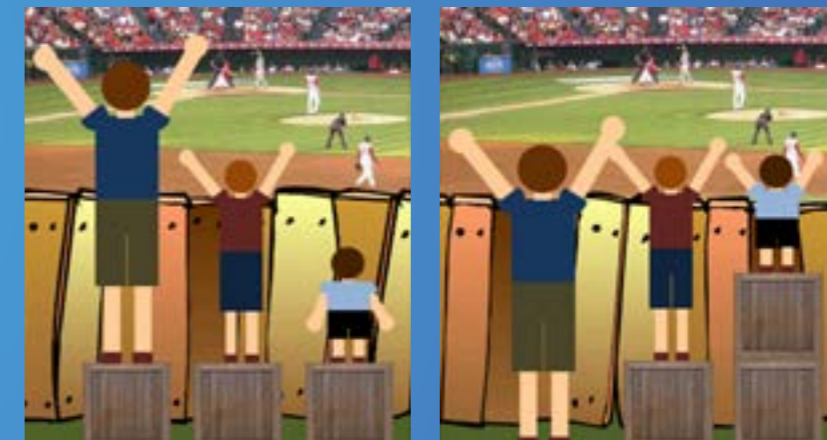
what do you know about how this issue might impact different groups of people in different ways?

Often the answer is – ‘we don't know’. In which case, we would always advise that targeted consultation is done in order to understand differences of experience.

There are many groups that experience health inequity, with some people experiencing

multiple layers of exclusion or disadvantage because of the intersectionality of their experience.

These groups can include Aboriginal people, people from culturally and linguistically diverse backgrounds, people with disability, people experiencing financial hardship or homelessness, people from the LGBTQIA+ community, people living regionally, young people, and older people.



This image demonstrates the difference between equity and equality. In the first image, everyone is being treated the same. In the second, people are receiving the support they need to overcome the structural barriers (*the fence*) to be able to have the same experience as others who may not experience the same barriers.

We talk about this concept in the training workshops we run

with consumer, carer, family, community and lived experience representatives (*consumer representatives*). For lots of reasons – some systemic and some individual – there are some groups where there may be very few people with that experience who get involved as representatives.

We do this to raise awareness of the fact that while someone in a consumer representative role

may have a seat at the table, it is important they are aware that there may be some perspectives missing from the discussion.

We advise consumer representatives to encourage their health service partners to consider how they will ensure that they also involve people from a wide range of backgrounds and perspectives.

HARDER TO REACH - OR HARDLY REACHED?

Involving people who may not immediately come forward to traditional consumer engagement activities – such as Consumer Advisory Councils or project working groups – means that sometimes these groups are referred to as being ‘hard to reach’.

We tend to use the term ‘*hardly reached*’, to make it clear that people in these groups often can be reached with the necessary investment of time in building positive, trusted relationships with people and organisations.

TIME IS OF THE ESSENCE

This is why a lot of our work involves developing relationships with a wide range of community groups and

people who are well connected into diverse communities.

That investment of time means that when we are contacted to seek consumer participants for a particular activity – often at very short notice – we can circulate information through our networks with the aim of ensuring some of the hardly reached groups are given the opportunity to have their voices heard, even when timelines are tight.

⁹⁹ <https://www.semanticscholar.org/paper/Peer-Support-for-the-Hardly-Reached%3A-A-Systematic-Sokol-Fisher/090d48f14a6d67de8c631e6676feccd0f93efd3a8>

CONSUMER INVOLVEMENT

In this financial year, HCC received a grant from the WA Department of Health to seek the views of consumers who might be impacted by overweight or obesity to support the implementation of the WA Healthy Weight Action Plan.

In the Plan, a number of groups were identified as being more likely to be adversely impacted by overweight and obesity. These included Aboriginal people, children, culturally and linguistically diverse communities, people living in rural and remote WA, people over 45, and people with disability.

We reached out to some of our partner organisations and held discussions in trusted settings

with key groups. These included workshops at Ishar Multicultural Women’s Health Service, where we were able to hear from about 40 women from a range of backgrounds with the assistance of interpreters from four different language groups; discussions and interviews with Aboriginal consumers at Whadjuk Northside Aboriginal Corporation and Nidjalla Waangan Mia; and a meeting with some of the members of the Aim High group at Down Syndrome WA. We also reached out through our team’s networks to have conversations with some parents and young people about their experiences, and collaborated with the national Weight Issues Network so that we could amplify the voices of people impacted by severe obesity and make sure these perspectives are taken into consideration in key project consultations.

Open invitation community conversations on a range of topics meant consumers could ‘dip their toe in the water’ to get a sense of how we approached conversations about weight, before coming forward to be more actively involved. We also collaborated with the national Weight Issues Network which enabled us to hear the perspectives of some of the few people willing to be publicly identified as consumer advocates on this topic. This enabled us to advocate that the experiences of people impacted by severe obesity be taken into consideration in key project consultations.

Finally, we convened a consumer and community advisory group where we put out an invitation for people from diverse backgrounds to contribute to the development of consumer insights on talking about weight, and also on the experience of engaging with consumers on this topic.



“ I would like to help others or help others on their journey as I have lived experience. I want to have a say in **improving the system** regarding health, mental health and drug and alcohol issues. ”

“ I have a lot of **empathy** and **passion** for talking about this. Being able to have a conversation with the consumer advisory group, the pharmacist, with friends – **it’s a good thing to have and to hear other people’s experiences** ”



ENGAGEMENT

WIDENING OUR CIRCLE

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ENGAGEMENT

As the Health as a Social Movement report by Jacqueline del Castillo, Halima Khan, Lydia Nicholas, Annie Finnis says, “There is a unique power to people in social movements - one in which purposeful citizens have the determination and courage to stand up and speak out for the issues that matter to them and their loved ones”.

The health system in WA is a great system for many people.

However, if “every system is perfectly designed to get the results it gets”¹, the health system in WA is currently designed to produce “...an unacceptable difference in the

health status of many people in the Western Australian community. Aboriginal people, people living in country areas, [people with Cultural and Linguistic Diversity], people with mental health conditions, and people living in low socioeconomic conditions all experience poorer health outcomes and mortality rates than the rest of the Western Australian population”.² This is outlined in background papers for the WA Sustainable Health Review (SHR).

The SHR also states “There are complex interactions between health status and the broader social determinants of health, and the health system

cannot work alone to improve the health status of Western Australians”.³

From this it is very clear that it is time for a different approach to planning, delivering and evaluating health services if they are to make a significant impact on improving the health of everyone in the community.

¹ W. Edwards Deming, <https://deming.org/quotes/10141/>, last accessed 14/09/21

² WA Health, Addressing inequity, <https://ww2.health.wa.gov.au/-/media/Files/Corporate/general-documents/Sustainable-Health-Review/Background-papers/Addressing-inequity.pdf>, last accessed 14/09/21

³ WA Health, Addressing inequity, <https://ww2.health.wa.gov.au/-/media/Files/Corporate/general-documents/Sustainable-Health-Review/Background-papers/Addressing-inequity.pdf>, last accessed 14/09/21

WE BELIEVE IT IS TIME FOR A SOCIAL MOVEMENT IN HEALTH.⁴

We believe that members of the community have an important role as partners in this new way of working. For this reason, we are passionate about continuing to extend our reach to more of the WA community. We have an ambitious aim of a positive, effective community movement in health – a network of people ready and empowered to play their role as partners in improving the health outcomes of the WA community.

Whether that's someone taking part in a survey, attending an online workshop, making a submission to a consultation, participating as a member of a Community Advisory Council, or participating in a co-design process – we want to ignite people's interest in being part of the movement for better health, and better health services, for all in WA.

To do that, we need to continue to extend our reach: both in terms of the numbers of people who are involved, as well as the breadth of diverse perspectives from the people we reach.

Some of the ways we do this include:



Using social media as a cost-effective way to reach some audiences – we have over 2,300 followers on Facebook, around 800 more people than any other similar organisation in Australia.



We also have specific Facebook groups to reach people with specific interests including ones focused on Aboriginal Health, empowering health consumers with disability, people interested in the impact of overweight and obesity, people interested in being a consumer representative, and people with an interest in maternity services – collectively these groups have over 450 members.



Hosting events on topics of interest to the community and offering to add participants to our mailing lists. Events this year included community conversations on overweight and obesity, sexual health in the culturally and linguistically diverse community, fireside chats with senior WA Health leaders, and a discussion about election priorities in cancer care.



Attending community events to build and maintain strong networks across the community and to spread the word about our work.

We are continually looking for new ways to reach more people with our limited resources. Our future plans are to look at whether it would be possible to recruit and work with a team of volunteers who can help to spread the word across the WA community.

WATCH THIS SPACE!



“We take what people tell us into every meeting, every conversation. We keep it in our heads and in our hearts and everywhere we go.”

**TANIA HARRIS,
HCC ABORIGINAL ENGAGEMENT
COORDINATOR**



“Appreciate the flexibility HCC can act with for consumer involvement thanks to the development of the networks you’ve established over the life of the project.”

DEPARTMENT OF HEALTH PROJECT TEAM



“Hearing from a consumer about the day to day reality of [their] experience... – I am reminded again of the layer upon layer of obstacles that some people experience as they try to access services that many people take for granted, like access to education, and access to judgement-free healthcare.”

**CLARE MULLEN,
HCC DEPUTY DIRECTOR**

⁴ Nesta, “Health as a Social Movement”, https://media.nesta.org.uk/documents/health_as_a_social_movement-sept.pdf, last accessed 14/09/21

GROWING OUR ONLINE PRESENCE THE YEAR IN NUMBERS

It's vital that we grow our reach so we can ignite interest and empower people to play a role in the movement for better health, and better health services, for all Western Australians.

While these numbers aren't everything, and the connections we have with individuals, organisations and communities remains invaluable, growing our online presence is one way to ensure we continue to reach more people, and more diverse people.

"I am continually struck by the power of social media to create community and make people feel seen and heard, and I hope we can continue to work in this space to leverage this power and make meaningful connections."

- Rachel Seeley, HCC Marketing and Communications Coordinator

EMAIL SUBSCRIBERS

JUNE 2020

1,167

JUNE 2021

1,632

FACEBOOK PAGE LIKES

JUNE 2020

1,908

JUNE 2021

2,045

LINKEDIN CONNECTIONS

JUNE 2020

704

JUNE 2021

1,191

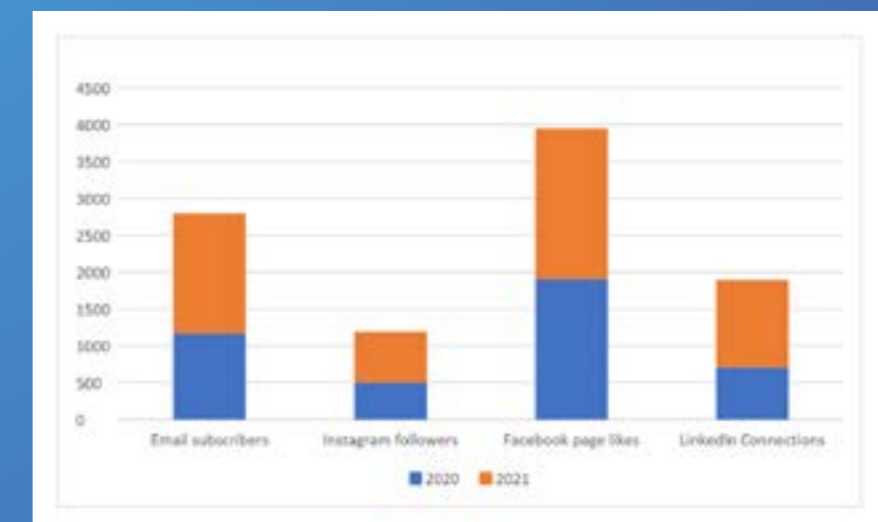
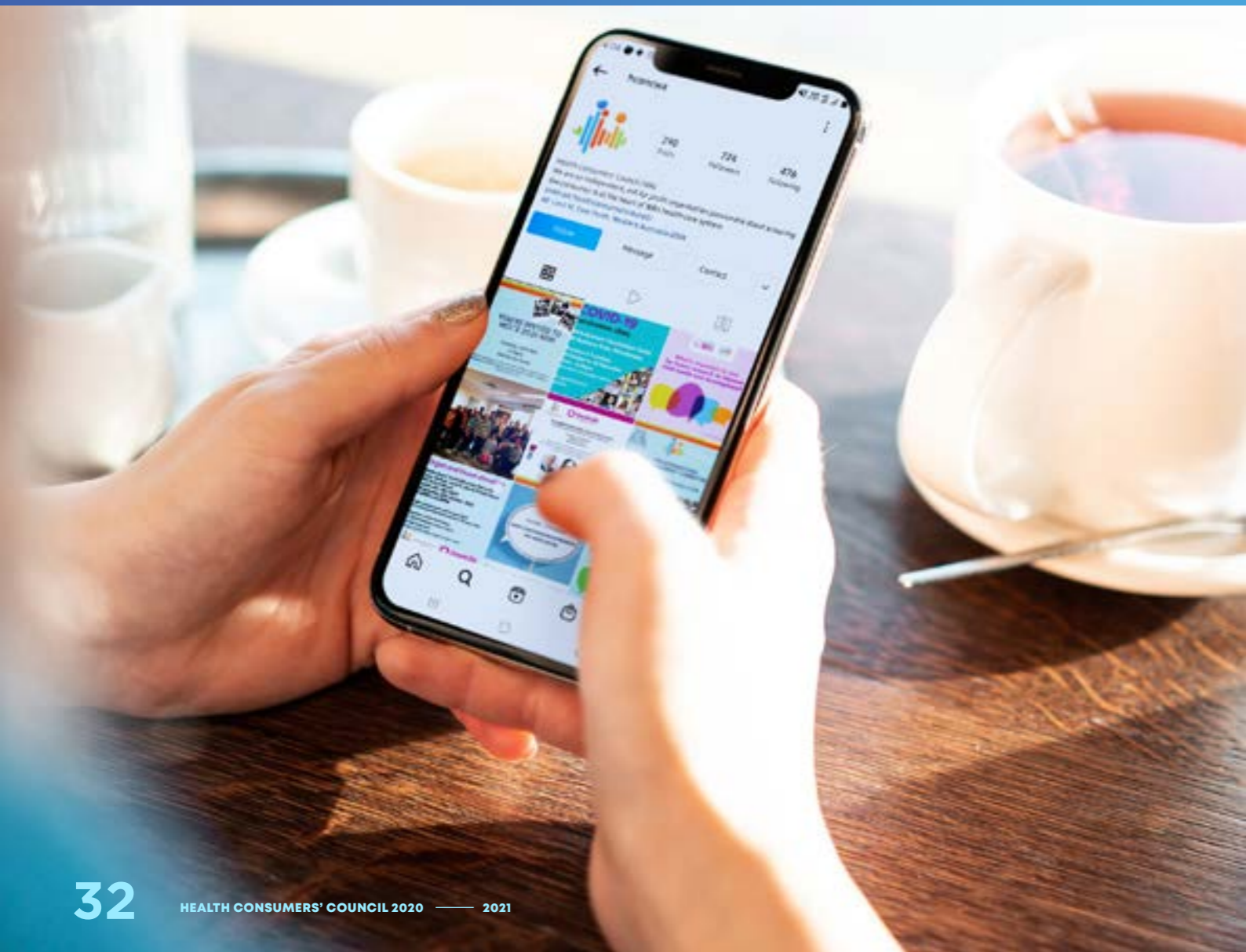
INSTAGRAM FOLLOWERS

JUNE 2020

500

JUNE 2021

691





ENGAGEMENT

EMPOWERING VOICES FOR CHANGE

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We've described elsewhere how we believe it's time for a social movement in health.

By that we mean a movement where consumers and community members play a critical role in creating positive health outcomes in their community. It also means that people who use health services are also able to be involved as partners in the governance and design of health services.

Health Consumers' Council creates opportunities for people who want to be involved in this to build their skills and experience:

- Each year we run training for people who are, or who are interested in becoming, consumer representatives (*consumer, carer, family, community or lived experience*) on committees or working groups. We offer introductory and advanced training.
- We also host regular networking events for people to connect with other consumers and get updates on relevant issues across the system. This year topics included

consumer feedback and complaints, an update on progress on the Sustainable Health Review, and digital rights and privacy considerations in relation to digital health. In one of the sessions, participants created the agenda on the day – the issues that emerged from the group included sharing your lived experience story to affect system change; what is good quality engagement; measuring safety and quality in healthcare – including patient reported outcome measures, and patient reported experience measures; and consumer representation at an international level.

- We send regular, relevant information to people with a range of interests – these include people who are interested in becoming consumer representatives, people with an interest in the Sustainable Health Review, and people with an interest in health issues for people from Culturally and Linguistically Diverse backgrounds.

Some feedback from participants in our training workshops about what was most useful:

“I feel I benefited most from the information... on what is expected from a... rep. I've been in meetings not knowing my purpose but I know where to look for it now.”

“Our rights. I found things out that I didn't know.”

“Influence/persuasion, meeting, connection, hearing from others.”

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This year, we received a grant from the WA Department of Health to support and promote consumer voices in the first stage of implementation of the WA Healthy Weight Action Plan.

This enabled us to do a wide range of activities aimed at empowering people with experience of overweight and obesity to be involved in plans to implement aspects of the Plan.

We invited people to join a consumer and community advisory group where we discussed what was important to consumers in this area. A small win was when feedback from consumers about the role of medication in weight gain led

to that point being included in education for GPs.

The group were also able to meet with the team at Foodbank to find out more about their programs for people in the community who are at risk of financial or social disadvantage.

Speaking out about the experience of living with overweight or obesity can be challenging because of the level of weight stigma that is in the health system and in the community. And yet there is a vital need for consumers to speak up and agitate for change.

We partnered with the national Weight Issues Network and were able to offer consumers in this area the opportunity to participate in training to explore how to create powerful personal stories.

We often receive feedback that creating an opportunity for a consumer's voice to be heard in the health system is very encouraging to people who want to see positive change. One person shared *"thanks for that opportunity - I didn't realise it was going to be put in front of GPs and they have to watch it... when you look at everything [HCC] has been doing on this project for 2 or 3 years, and now you're getting consumers stories in front of GPs - it's just great..."*

MY STORY



I am a 46 year old woman... I have three adult children that I am incredibly proud of and I have an interest in gardening, shopping and going to cafes with my partner. I also enjoy meditation and mindfulness.

I would like to help others or help others on their journey as I have lived experience. I want to have a say in improving the system regarding health, mental health and drug and alcohol issues. I am now in continual recovery as I believe recovery is life long and needs to be tended to on a daily basis. I wish to give back, learn and study more about these issues affecting people's lives...

... I think the health system needs to look at the whole individual person, not just another obese statistic.

Overweight people are human with many complexities in their lives just like everyone else and deserve to be treated as such and not to be made to feel ashamed, outcast or an object of ridicule and blame. No one

knows what each of us has been through.

Obviously looking at the whole person sitting in front of the healthcare worker and really getting to know what's really going on for the person whether this is physically, mentally, emotionally, financially, added stress, anxiety, relationships, mental health, spirituality, sexuality, community connection and therapies etc.

Addressing these issues as a whole package instead of shaming and sending them off with pills and yet another diet would be very helpful to the individual. The whole media and advertising sector needs to change their standards also.

Food is just food, the way an obese person eats and uses food are very complex ranging from addictive, emotional or physical ill health that can make them the way they are and shouldn't be made to feel that they must hide away. For me poverty and isolation is an addiction's best friend...

... To sum it all up, my hope for future outcomes is definitely a holistic model/approach. This is the way that is working for me and I'm starting to see it in the healthcare community more and more...

... I am aware that doctors and healthcare workers have limited time that's why it is like pills and out the door most of the time, but a special organisation set up much like the NDIS or what the Health Consumers' Council is doing would be ideal.

To combat the issues affecting the individual could be a possible solution. That is why I have such an interest in the work that the Health Consumers' Council is doing in their work with obesity and achieving healthy outcomes and working on ways to support the individual working with all areas of their lives.

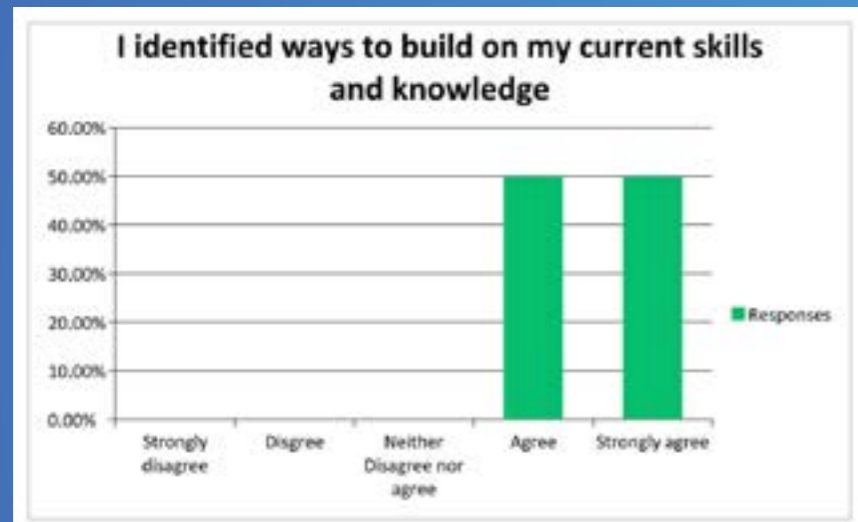
I think the HCC is a wonderful organisation for addressing all these issues





A SOCIAL MOVEMENT IN HEALTH CONSUMER ENGAGEMENT IN NUMBERS

FEEDBACK FROM OUR INTRODUCTION TO CONSUMER REPRESENTATION TRAINING IN JUNE



FINANCIAL YEAR 2020 – 2021 ACTIVITIES

| | | |
|---------------|---|---|
| 51 | ➔ | EDUCATION, ENGAGEMENT, AND PROMOTIONAL ACTIVITIES |
| 12,232 | ➔ | ATTENDEES / PARTICIPANTS / AUDIENCE |
| 86 | ➔ | PROJECTS, PARTNERSHIPS, FORUMS AND NETWORKS |
| 278 | ➔ | INTERAGENCY COLLABORATION AND STRATEGIC PLANNING ACTIVITIES |
| 42 | ➔ | POLICY ADVICE AND INFORMATION |



INDIVIDUAL ADVOCACY SERVICE

WORKING TOGETHER TO ADDRESS BARRIERS IN HEALTHCARE

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| | | | |
|---------------------------------------|---|---|--|
| <p>TEAM OF 4.9 FTE</p> | <p>370 PEOPLE WITH A COMPLEX ADVOCACY NEED SUPPORTED BY AN INDIVIDUAL ADVOCATE</p> | <p>972 PEOPLE WITH NON-COMPLEX ADVOCACY NEED SUPPORTED BY AN INFORMATION ADVOCACY OFFICER VIA INFORMATION AND REFERRAL</p> | <p>HIGHEST RATE OF CONSUMER ISSUES EMERGED FROM DISPUTES AROUND TREATMENT, DIAGNOSIS AND HEALTH RIGHTS</p> |
|---------------------------------------|---|---|--|

ISSUE SETTING

| | |
|------------------------------|-------------------------------------|
| <p>55% HEALTH</p> | <p>45% MENTAL HEALTH</p> |
|------------------------------|-------------------------------------|

GEOGRAPHICAL LOCATION

| | |
|-------------------|---|
| <p>93%</p> | <p>OF COMPLEX ADVOCACY CASES FROM PERTH METROPOLITAN AREA</p> |
| <p>7%</p> | <p>OF COMPLEX ADVOCACY CASES FROM REMOTE, RURAL OR REGIONAL WESTERN AUSTRALIA</p> |

KEY HIGHLIGHTS — OUTPUTS

PROTECTING AND EXERCISING CONSUMER HEALTHCARE RIGHTS

Despite very limited resources and periods of disruption due to COVID-19, the Individual Advocacy Service was able to maintain the spirit of HCC's vision with wholehearted compassion and tenacity. We are proud to have supported 1,342 individuals who reported experiencing issues and hurdles within the health system.

This support ensured consumers were aware of their rights as per the Australian Charter of Healthcare Rights; assisting in protecting and exercising those rights by way of vigorous advocacy, system navigation and the provision of information and referral.



CONSUMER STORY

SUPPORTING THE HEALING JOURNEY

An Aboriginal consumer from remote WA transferred to a Perth hospital for amputation surgery.

After surgery, they contacted HCC seeking advocacy around their post-operative care. HCC acknowledge the reality and impact of systemic racism and the importance of timely response, and this issue was given priority.

Following surgery, the consumer was transferred to a hostel for three weeks recovery. They described feeling worried and unsure about their future medication regime.

They shared a fear that they would be sent home too soon, which could impact the post-operative healing process, and felt it was important to stay close to Perth should any complications arise.

The consumer spoke of concerns that had emerged from stories about Aboriginal Elders who travelled to Perth from remote areas for amputation who were sent home too soon resulting in complications. The consumer also shared uncertainty around whether Patient Assisted Travel Scheme (PATS) would extend the accommodation agreement if needed, and what impact this would have on their employment.

The advocate attended multiple hospital appointments, ensuring the consumer's concerns were addressed and that the consumer understood the treating team's education on optimal wound healing, infection control, prescribed medication, and discharge plan.

Further, the advocate arranged for a medical certificate,

provided information around PATS eligibility, researched culturally appropriate community supports in the Perth area, and coordinated with the Aboriginal Liaison Officer at the hospital.

During their time together, the consumer shared that they felt lonely and tired being away from Country and family. They felt compelled to paint but were unable to do so without materials. The advocate managed to acquire art supplies for the consumer, who then produced several pieces that referenced their childhood on Country and the stories handed down from family.

Upon suitable healing, the consumer was discharged to return home. The consumer generously donated two beautiful paintings to HCC.

“HCC managed to take away some of the overwhelming feelings of stress I was experiencing while navigating the system.”

“You listened with such compassion that I felt truly safe to speak, knowing that I was being treated with respect was amazing.”

“I would like to express my appreciation and gratitude for your help and commitment to helping me achieve my goals.”

“Thank you so much for being by my side and sharing the ups and downs with me.”



THIS ARTWORK HAS BEEN REPRODUCED WITH THE ARTIST'S KIND PERMISSION



CARE OPINION

HCC is a passionate advocate for the Care Opinion platform. Care Opinion is an independent, moderated platform used nationwide and in the UK to allow people to provide feedback about their experiences in health and human services.

It was launched in Australia in 2012.

WA is the first state to have every single public hospital as a subscriber to this nation-wide website.

This means that your story will be promptly read and responded to - the usual response time is within 72 hours of it being posted. It's an absolute game changer for consumers and community in terms of reaching the large and sometimes anonymous health system and providing our feedback.

In June HCC hosted an online event with Prof Jason Leitch CBE, the Scottish Government's National Clinical Director of Quality & Improvement, and Shaun Maher, Principal Lead, Quality Improvement team, NHS Education for Scotland and Strategic Adviser for Person-Centred Care and Improvement, Healthcare Quality and Strategy, who shared their insights from the experience of implementing the Care Opinion tool across Scotland's health and social care services.

When Prof Leitch CBE said at Care Opinion Australia's inaugural virtual Conference held on 27th April 2021, during Patient Experience Week, that Care Opinion is *"the most important thing the Scottish Government has done for patient-centred care in the last 10 years"* we knew we had to hear more. Scotland has embraced Care

Opinion and the way that it allows people to share their experiences of health and care in ways that are simple, safe, and lead to learning and change.

When sharing some examples, Shaun spoke about how Care Opinion has added another dimension to their quality systems, by enhancing and strengthening the important voices of patients and their families.

While noting that Care Opinion was just one element in a range of things done in Scotland to ensure high quality care, he said feedback through Care Opinion provided a chance to do meaningful work towards making changes and connect with the real experiences of the people in the healthcare system.

"It might be a small change, but imagine that's being done hundreds and hundreds of times across the system."



This Care Opinion in WA Impact Report FY20-21 provides a snapshot of how the platform was used during the financial year.

IMPACT REPORT



READ MORE ABOUT CARE OPINION

WEBSITE



VISIT THE CARE OPINION PLATFORM DIRECTLY

SHARE YOUR STORY





Thank You!

People are the greatest asset of any organisation, and at Health Consumers' Council we value and nurture our team and Management Committee.

Our people network reaches out beyond our immediate team to an every-growing community who work collaboratively with us to achieve outcomes that benefit the health of all Western Australians.

We extend a very special thank you to all the volunteers and

students who have helped HCC support health equity in our state. Whether working directly with the team at HCC, or volunteering time on committees or advisory groups, the time and skills you have dedicated are invaluable.

One of our big focuses this year has been on widening the circle - it is only by growing our connections and reaching out into communities that we are able to hear and champion consumer voices.

On that note, we would like to thank our organisational members, hundreds of individual members, and every single person who has subscribed to our emails, followed us on social media, liked or shared our posts, forwarded information to their friends or colleagues, attended training or an event, stepped up to answer a survey, shared their experiences as a consumer representative, or helped us to spread the word.

THANK YOU!

**ALCOHOL AND OTHER DRUG
CONSUMER AND COMMUNITY COALITION**

**ETHNIC COMMUNITIES COUNCIL OF
WESTERN AUSTRALIA**

**CONSUMER AND COMMUNITY
INVOLVEMENT PROGRAM**

**NORTH METROPOLITAN
HEALTH SERVICE**

**WA ASSOCIATION FOR
MENTAL HEALTH**

JUSTICE PROJECT

KIN

RAINBOW FUTURES

OBESITY COLLECTIVE

**LANGFORD ABORIGINAL
ASSOCIATION**

**SOUTH METROPOLITAN
HEALTH SERVICE**

**WA NETWORK OF ALCOHOL
AND OTHER DRUG AGENCIES**

WEIGHT ISSUES NETWORK

**WA PRIMARY
HEALTH ALLIANCE**

**ABORIGINAL HEALTH
COUNCIL OF WA**

**WILLIAM LANGFORD
COMMUNITY HOUSE**

ANGLICAREWA

AHPRA

WADJAK NORTHSIDE

COUNCIL ON THE AGED WA

SHELTER WA

HELPINGMINDS



**HEALTH CONSUMERS'
COUNCIL**

**THANK
YOU
FOR YOUR
SUPPORT,
PARTNERSHIP AND
COLLABORATION!**

CARE OPINION

ASSETS

MENTAL HEALTH MATTERS 2

**MENTAL HEALTH
ADVOCACY SERVICE**

**WA COUNTRY
HEALTH SERVICE**

LIFELINE

MYAN WA

**PEOPLE WITH
DISABILITIES WA**

DEPARTMENT OF HEALTH

**PATIENT SAFETY
SURVEILLANCE UNIT**

**SEXUAL HEALTH AND BLOOD
BORNE VIRUSES PROGRAM**

**SUSTAINABLE
HEALTH REVIEW TEAM**

HEALTH NETWORKS

END OF LIFE TEAM

MENTAL HEALTH COMMISSION

**PEER BASED
HARM REDUCTION**

**MENTAL
HEALTH NETWORKS**

ST JOHN OF GOD MURDOCH

**YOUTH ADVISORY
COUNCIL OF WA**

**EAST METROPOLITAN
HEALTH SERVICE**

YOUTH PRIDE NETWORK

**WA HEALTH
TRANSLATION NETWORK**

**CHILD AND ADOLESCENT
HEALTH SERVICE**

ONE STOP SHOP INITIATIVE

WA COUNCIL OF SOCIAL SERVICE

**CONSUMERS OF
MENTAL HEALTH WA**



HEALTH CONSUMERS'
COUNCIL

ORGANISATIONAL MEMBERS

ST BARTHOLOMEW'S HOUSE

*NEXT STEP - DRUG AND
ALCOHOL SERVICE*

*ABORIGINAL HEALTH COUNCIL
OF WESTERN AUSTRALIA*

*ISHAR MULTICULTURAL
WOMEN'S HEALTH CENTRE*

*ROYAL FLYING DOCTOR SERVICE -
WESTERN OPERATIONS*

*CONSUMERS OF MENTAL
HEALTH WA (COMHWA)*

HELPING MINDS

*FREMANTLE WOMEN'S
HEALTH CENTRE*

CARERS WA

*PULMONARY HYPERTENSION
NETWORK AUSTRALIA*

*EVEN KEEL BI-POLAR DISORDER
SUPPORT ASSOCIATION*

PALLIATIVE CARE AUSTRALIA WA

CANCER COUNCIL WA

ACCESS PLUS WA DEAF

ASTHMA WA

*DYING WITH DIGNITY
WESTERN AUSTRALIA INC.*

AODCCC

*(ALCOHOL AND OTHER DRUG CONSUMER &
COMMUNITY COALITION)*

DONATELIFE WA

*ETHNIC COMMUNITIES
COUNCIL OF WA*

*CONNECTGROUPS SUPPORT GROUPS
ASSOCIATION OF WA INC.*

*GENETIC & RARE
DISEASE NETWORK*

*NATIONAL COUNCIL
OF WOMEN WA*

*COCKBURN INTEGRATED
HEALTH CENTRE*

HAEMOPHILIA FOUNDATION WA

WHAT THE DOCTOR SAID

LINKWEST

PEOPLE WITH DISABILITY WA

WANADA

*(WESTERN AUSTRALIAN NETWORK OF ALCOHOL
AND OTHER DRUG AGENCIES)*



FINANCIALS

The principal activity of the incorporated association is to be an independent voice advocating for patients in Western Australia.

It offers a unique perspective on health policy and service delivery matters. HCC receives funding from State and Commonwealth agencies and comments publicly on all issues affecting health consumers.

The financial statements of the incorporated association are audited by Australian Audit.



Click the link for our 2020-2021 financial year summary and **FULL FINANCIAL REPORT**





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