

Annual Report

2019/20



HEALTH CONSUMERS'
COUNCIL

THE YEAR WE NEVER EXPECTED





Introduction

The Health Consumers' Council WA is committed to cultivating inclusive environments for staff, consumers and carers. We celebrate, value and include people of all backgrounds, genders, sexualities, cultures, bodies and abilities. We believe our commitment to diversity and inclusion makes our teams, services and organisation stronger and more effective.

We are committed to providing accessible services to people from culturally and linguistically diverse backgrounds.

Black Lives Matter Solidarity Statement

We, the Health Consumers' Council (WA) Inc., acknowledge the reality and impact of systemic racism that Australia's Aboriginal and Torres Strait Islander peoples, and other People of Colour have experienced, and continue to experience. We know this to be a reality in our health services, and this is noted in our state's Aboriginal Health and Wellbeing Framework 2015-2020 which states "Racism and discrimination experienced by Aboriginal people in the delivery of health services contributes to low levels of access, engagement and compliance with treatment (Awofeso, 2011)."

Numerous other scientific and peer-reviewed research studies identify the impact of structural and individual racism and systemic oppression ingrained and evidenced in Australian society and the wider global community.

The Health Consumers' Council avows the inherent value of all human life. Our solidarity with the Black Lives Matter Movement is an acknowledgement that until Black Lives Matter, equality and inclusivity is not possible. Ethnicity, religion, culture, gender, orientation, disability, age, or status does not negate that accessible and culturally safe health care is a basic human right.

The Health Consumers' Council stands firm in its vision of equitable, person-centred, culturally responsive quality health care for all Western Australians. We understand that in order to be an ally to Aboriginal and Torres Strait Islander peoples we have to move towards anti-racism, which includes initiatives such as developing a Solidarity Statement. We operate by these principles and encourage members of the community to contact us if you are not receiving the high quality health care that you deserve.

Vision

Equitable, person-centred, quality health care for all West Australians.

Purpose

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

Values



Respect



Kindness



Equity



Working Together



Integrity



Empowerment

Contents



| | |
|----|---------------------------------|
| 4 | Chair Report |
| 5 | Executive Director Report |
| 6 | Strategy |
| 7 | Care Opinion Annual Snapshot |
| 8 | Advocacy Case Studies |
| 9 | Advocacy Outcomes |
| 10 | Advocacy Outputs |
| 11 | Engagement |
| 16 | Engagement Outcomes |
| 18 | Systemic Advocacy |
| 20 | Partnerships |
| 21 | Meet our Team |
| 22 | Statement of Financial Position |
| 23 | Our Financial Year |



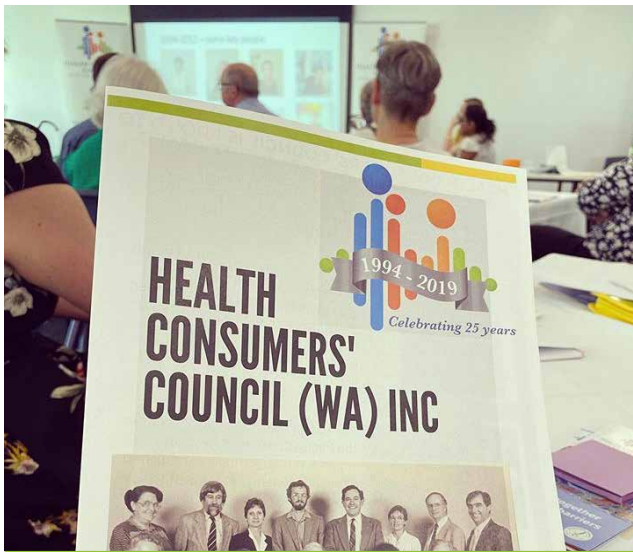


Chair Report

Well, nobody saw that coming...

Mallika Macleod, Chair

Our Annual Report is a welcome chance to reflect on the year that no-one anticipated, and reflect on what we achieved, despite COVID-19.



HCC 25th anniversary, Photo by Sam Bradder

2019 AGM – 25th Year Celebrations

HCC's 2019 Annual General Meeting (AGM) marked our 25th year, and gave us the opportunity to thank those who helped HCC to establish and thrive, and set a solid foundation for consumer involvement into the future. Michele Kosky and Anne MacKenzie were among invited guests to be honoured on the day.

Nigel D'Cruz, Marlon Fernando and Cheryl Holland stepped down from the Management Committee at the AGM. Cheryl was available to be thanked and presented with a well-deserved floral tribute.

Existing Board Members Richard Brightwell, Rebecca Smith, Danae Watkins, Rebecca Carbone, Sam Bradder and myself remained on the Board. Steven Walker joined us to provide financial and social enterprise expertise, Erin Moore joined to provide legal expertise, Christine Sindely to bring her Aboriginal cultural knowledge and business acumen, and Tina Tuira-Waldon has brought her significant cultural, community development and

consumer representation experience to our Management Committee. We also took the opportunity at the AGM to confirm a Management Committee membership of 8-10 people and tweaked our Membership procedure to better reflect our processes. These changes were accepted and we have updated our rules accordingly.

Our Management Committee in 2019-2020

Steven Walker took on the Treasurer Role and chairs our Finance, Audit and Risk Management Committee, while Rebecca Smith chairs our Policy Review and Nomination and Governance Committees. We instituted a Portal for Management Committee members to stay in touch, and commenced online meetings from April 2020.

During the year Martin Crowley filled a casual vacancy, bringing his legal expertise to our Management Committee after Erin Moore resigned.

In another world of 6 March 2020, we hosted the CEO of Health Issues Centre Victoria to share his experience and knowledge of developing a fee for service arm for the Health Issues Centre in Victoria. Further work on our strategy has been paused during COVID-19 but we are looking to finish strongly in 2020 with a review to our Strategic Plan in the works before the end of 2020.

Amazing HCC Team

We were so proud of how well the incredibly dedicated HCC Team pivoted to online operation during COVID-19, without missing a single deliverable. It has been a very unpredictable and challenging time, and it is wonderful to see how many positives were extracted from this difficult situation. Our Advocacy Team continues to deliver consumer-driven advocacy interventions, and our Engagement Team continues to drive greater engagement with consumers in our health system.

Not everyone on the Team gets paid, and we would like to acknowledge our many volunteers, who together added more than 450 hours of invaluable service.

Executive Director Report



From the chalk rainbows to the hoarded toilet paper, from the “we’re all in it together” memes, to the stark contrasts in equity that COVID has shone a light on – the world has changed in 2020. As this Annual Report goes to production, restrictions are easing again in Australia, while numbers are climbing in Europe and the Americas. We hope that this finds you well in both mind and body, as COVID has taken, and will take, a mental toll on us all.

Sustainable Health Review

In the 2018-19 Annual Report we talked about the Sustainable Health Review Report’s launch, and how we looked forward to the next phase – implementation. It is always preferable for us as an agency to be working towards practical action, rather than a written report. Due to the logistics of standing up a piece of reform of this size, as well as COVID-19, there has been little opportunity for consumers and community to be part of the implementation process over this last financial year.

However, just after the close of the 2019-20 financial year, the Sustainable Health Review is now open for external business – consumers, carers, the community at large, and the community sector. What is very encouraging is that the Sustainable Health Review is considered to be the blueprint for our state’s COVID-19 health recovery plan. As noted in the Systemic Advocacy section, it is a key platform for positive change. We are looking forward to being able to report real wins in creating a more sustainable health system with an increased focus on prevention.

Individual Advocacy

Health Consumers’ Council continues to be the only state peak body in our nation which offers individual advocacy for health consumers who are seeking access to or redress from our health system. We believe independent advocacy to be one of the most important social equity tools we have in our society. Each year we aim to quantify and qualify the work our Advocates undertake to achieve the outcomes consumers are hoping for. I am so proud of how well our Advocates maintained unbroken support to the people seeking our advocacy support during COVID-19, and continue to show such dedication despite the lack of resourcing to meet community demand. Even with zero advertising, our wait list for advocacy always hovers between 2 and 4 weeks.

Engagement

So much is changing in the arena of consumer and community engagement. There are many important levers to encourage the vital, complex and time-consuming art of effectively engaging with consumers of health services. The Australian Commission on Safety and Quality in Healthcare’s Standard Two – Partnering with Consumers has been a key lever for some years. Now we also have Recommendation 4 from the

Sustainable Health Review which focuses on new ways of engaging with consumers and carers, and we are looking forward to the opportunities that this will create.

In this first half of 2020, COVID-19 has meant that we needed to pivot to online engagement in order to continue to connect with consumer and carer representatives across our vast state. The Engagement Team did a wonderful job to change how they worked to ensure they continued to deliver engagement activities, and innovated to ensure the “hardly reached” were not forgotten during COVID-19.

Systemic Advocacy

Even before the challenge of COVID-19, there have been many calls on HCC’s time. The My Life My Choices Report has seen significant reform being planned and now moving to implementation. The Healthy Weight Action Plan has nominated the Health Consumers’ Council as one of the three Stewards of its implementation, along with the WA Department of Health and WA Primary Health Alliance.

2020-2021 for HCC will be all about Sustainable Health Review. It is going to be a key platform for driving enhanced consumer and community involvement in health service policy, planning and evaluation.

HCC Team

We are so very blessed with the dedicated and hard-working team at HCC. It is incredible how much work this small team can carry out. Our team can expand and shrink at times as we undertake project work with staff on fixed term contracts, but overall the team is very constant. We are always looking to improve our staff’s experience at HCC and find ways to live our values.

Leadership

In 2019-2020, HCC’s Leadership Team consists of the Executive Director, Advocacy Manager, Engagement Manager and Operations Manager. This shared leadership model has been developing well over the last year and this experienced and diverse group is supporting HCC to continue to grow, develop and improve.

Sustainable Organisation

HCC has continued to aim to develop new sources of income through fee for service engagement activities. We invited our colleague from Victoria, Health Issues Centre CEO Danny Vadasz, to come to Perth just before COVID-19 stopped all travel and share his knowledge about how they have pivoted to have around half their income through fee for service work. While we already undertake some fee for service engagement work, our efforts to upscale this have not progressed during COVID-19 but will be a renewed priority for 2021.

Strategy



On 3 February 2020 we held a Strategic Planning session with our Management Committee and Leadership Team to discuss where we were at and what we wanted to focus on next. As the Strategic Plan was developed for 2015-2020 and was refreshed in 2017, many of the activities have been completed, or are no longer a high priority. At this session, we discussed our top priority to focus on for this year as resources and time allow.

We will be convening again in November 2020 to refresh the Strategic Plan for 2021-2025. We have recently been advised that our core contract with the WA Department of Health sits under the Clinical Excellence Division. This clarity has been important to drive our discussions on the renewal of this contract, which is currently due to expire in 2021. We are still aiming to pursue the Social Enterprise to create diverse sources of income but have not been able to progress during COVID-19.

Support individuals and community through advocacy and health literacy

Self-advocacy workshops for consumers



Drive effective consumer, community, clinician and stakeholder engagement

Develop a network of Consumer Leaders -
Invest in people who can rally communities over issues

- Local leaders
- Cultural leaders



Identify and communicate health trends and awareness to key stakeholders

Establish Citizen Senate/ Citizen's Jury Panel



Maintain an effective and innovative organisation

Develop a new contract proposal



Care Opinion

in Western Australia



Impact Report FY 19/20

1,151
STORIES
SHARED

STORIES THAT
RECEIVED A
RESPONSE

92%

ENTIRELY
POSITIVE
FEEDBACK

56%

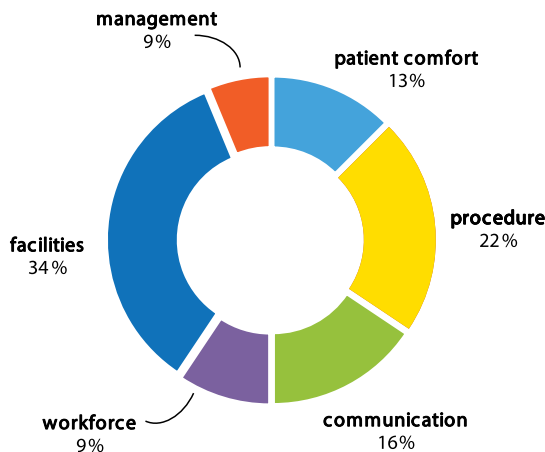
31

STORIES LED
TO CHANGES

322,188

TOTAL PUBLIC VIEWS

Change Actions Taken



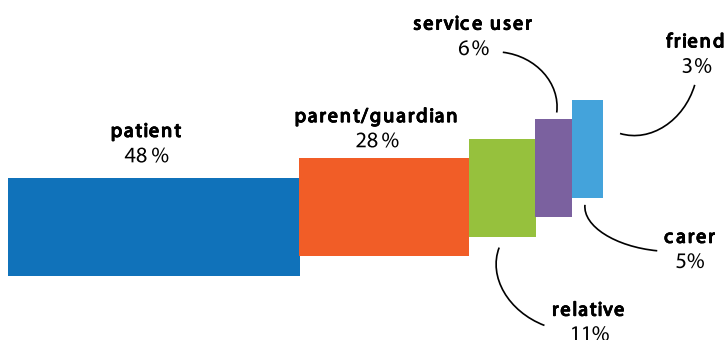
Common Concerns

| | |
|----------------|-------------|
| communication | 229 stories |
| staff attitude | 140 stories |
| information | 134 stories |
| timely care | 119 stories |
| treatment | 114 stories |

Top Change Actions

| | |
|---------------------------------|---|
| communication information | 4 |
| facilities signage | 4 |
| facilities equipment | 3 |
| procedure care | 3 |
| workforce learning | 3 |
| facilities cleanliness/upkeep | 2 |

Story Author Identity



Story Responses

stories that received a
response within 3 days
of publication

99%

stories that have 2 or
more responses

10%

Advocacy Case Studies



The power of support

The Consumer 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 whilst accessing a public mental health service. They described incidents of confidentiality breaches, misdiagnosis, and misrepresentation. The Consumer believed that mental health professionals formed their assessments based upon 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 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 period took place over several meetings, the advocate invested significant time to this case.

The Consumer also attended HCC's Legal Information Session where he 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.”

Collaborating for care

A parent contacted HCC on behalf of her son who had a pre-existing chronic health condition and had recently sustained injury from a sporting accident. The Mother was seeking guidance regarding issues around the duty of care with her son's treating hospital. The Mother was concerned that the hospital had failed to formulate a care/treatment plan at the time of her son's admission to the Emergency Department. A delay with the confirmation of his private health status compounded the problem and he did not have surgery until 28 hours after the Emergency Department admission.

Due to this delay, major infections arose, and subsequent hospital stays eventuated. Correspondence with the hospital to ascertain the reasons for the delays in treating her son's injury proved difficult and inconclusive, hence the Mother's request for advocacy to help navigate the complaint resolution process. For over two years, the HCC Advocate supported and advocated for the family by way of communicating to the Hospital. Eventually, after much effort, a satisfactory outcome was achieved.

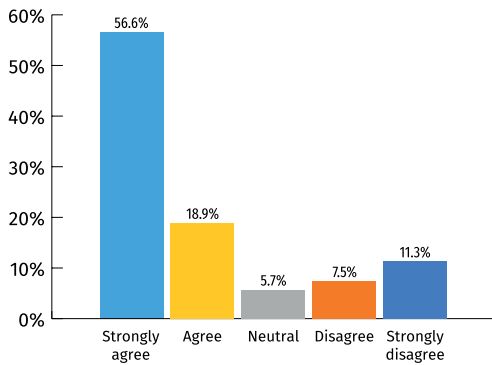
In the Mother's own words;

“ The Advocate has been very informative and professional at all times. Her advice and guidance has been fair and persistent and resulted in a satisfactory resolution, in favour of my son, being reached. At all times the Health Consumers' Council were objective and professional in their approach to our complaint and I would have no hesitation in recommending them.”

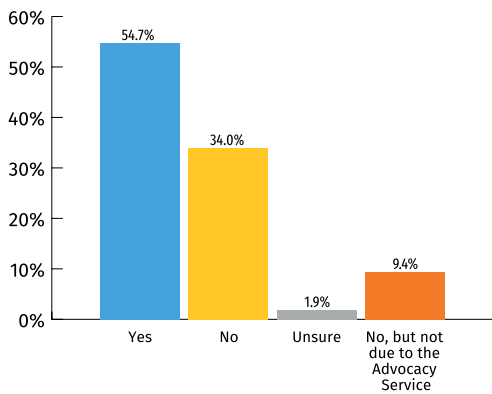
Advocacy Outcomes



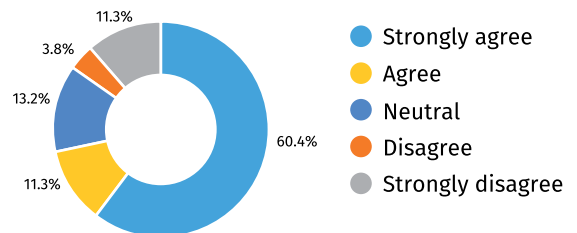
The HCC Advocacy Service was able to assist you with the issue you were concerned about



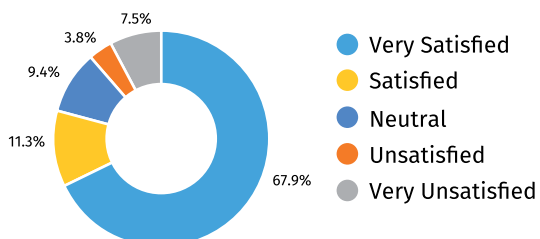
The HCC Advocacy Service helped you reach a desired outcome



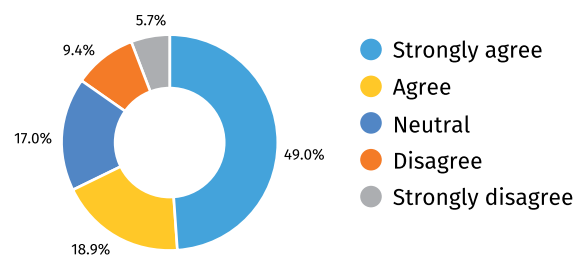
The advocate was successful in communicating your point of view to health professionals



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



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



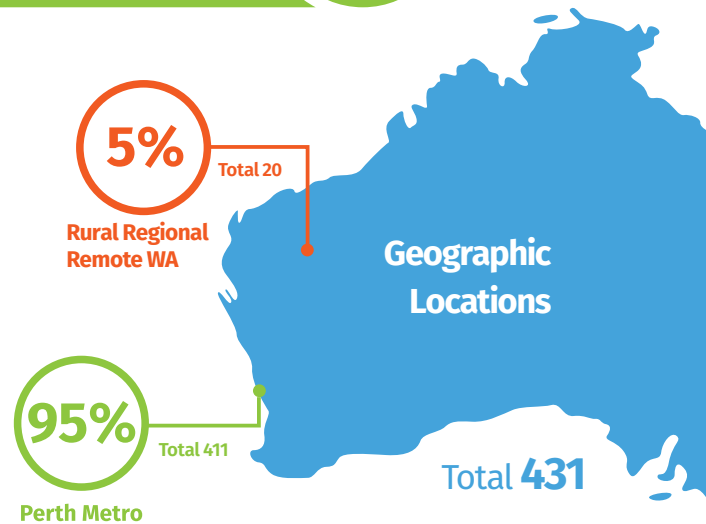
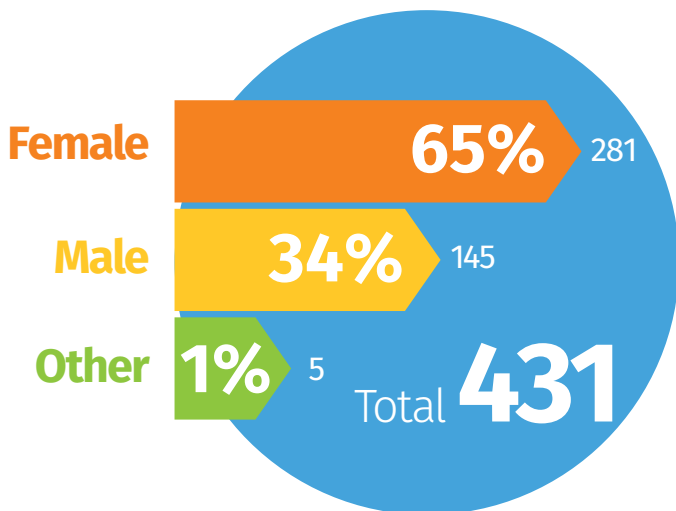
Advocacy Outputs



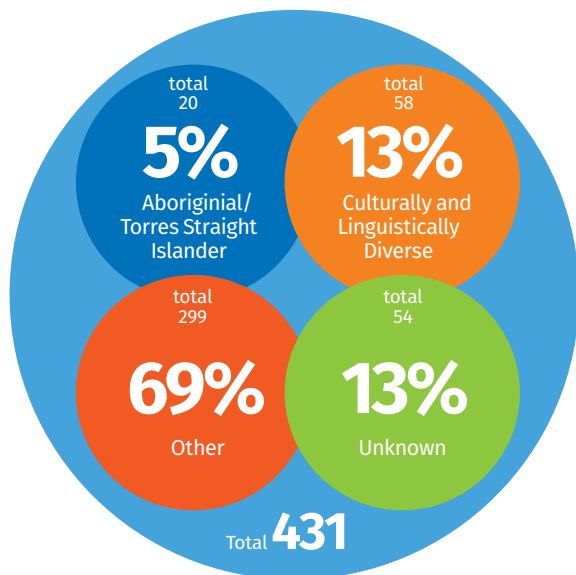
*percentages have been rounded to the nearest whole number



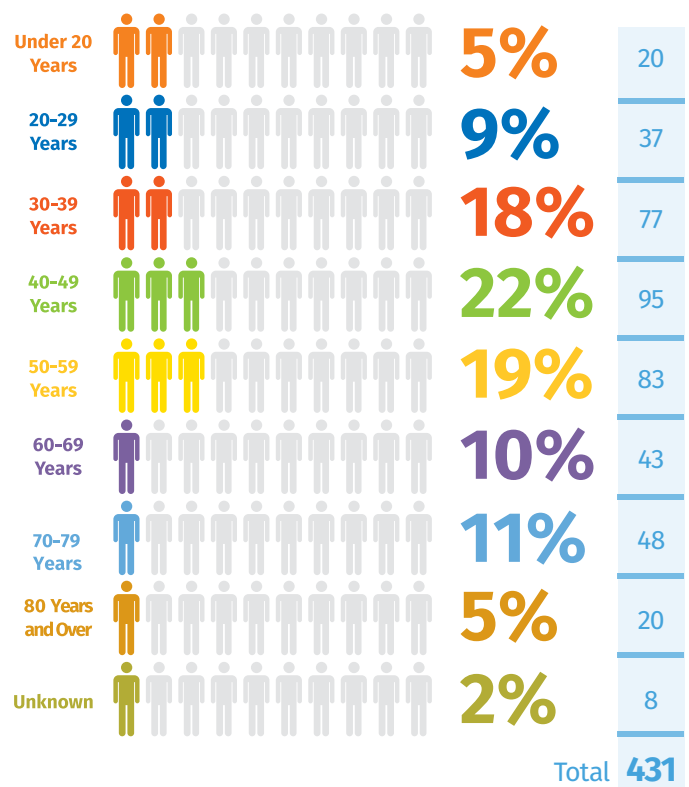
Advocacy Case by Gender



Advocacy Case by Ethnicity



Advocacy Case by Age



Advocacy Outputs



Advocacy Case by Type

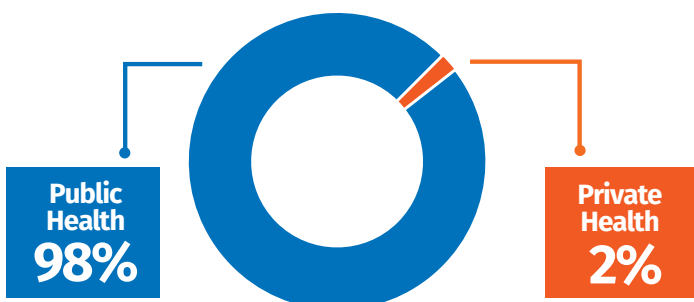
| | | |
|-------|---|-----|
| 3% | Health - Other | 15 |
| 1% | Health - Access to records | 6 |
| 6% | Health - Costs | 25 |
| 12% | Health - Access to services | 50 |
| 15% | Health - Rights | 65 |
| 25% | Health - Disputes Diagnosis/Treatment | 107 |
| 1% | Mental Health - Costs | 3 |
| 3% | Mental Health - Other | 15 |
| 0% | Mental Health - Access to records | 2 |
| 8% | Mental Health - Access to services | 35 |
| 12% | Mental Health - Rights | 52 |
| 13% | Mental Health - Disputes Diagnosis/Treatment | 56 |
| Total | | 431 |

“Many thanks to the advocate and the team for the efforts and consideration during the past few months. After making my complaint to the providers and then to the Health Complaints Office and receiving virtually a brush off after 5 months of inaction, the advocate, during this time, was the lone voice standing up for me. Even though her efforts did not bring forth a resolution of my complaint, her caring attitude and tenacity in pursuit of a resolution was not only appreciated but was also very impressive. It’s such a pity that the responsible government department does not possess the same qualities. All I can say is thank you.”

“My advocate was able to empower me (consumer) to communicate on my own.”

“(my advocate) didn’t really get a chance to speak because the doctor agreed with the plan we (the advocate and consumer) had put together.”

Advocacy Case by Health Settings



Engagement

Engaging during COVID-19



Marketing and communications

A marketing and communications survey undertaken during this time will be used to help shape the way we communicate with stakeholders and members. While response numbers were low, they showed that HCC is a trusted source of health information.

Direct emails to targeted groups, in combination with a monthly emailed newsletter, are proving to be one of the most important ways we communicate and engage with our audiences.

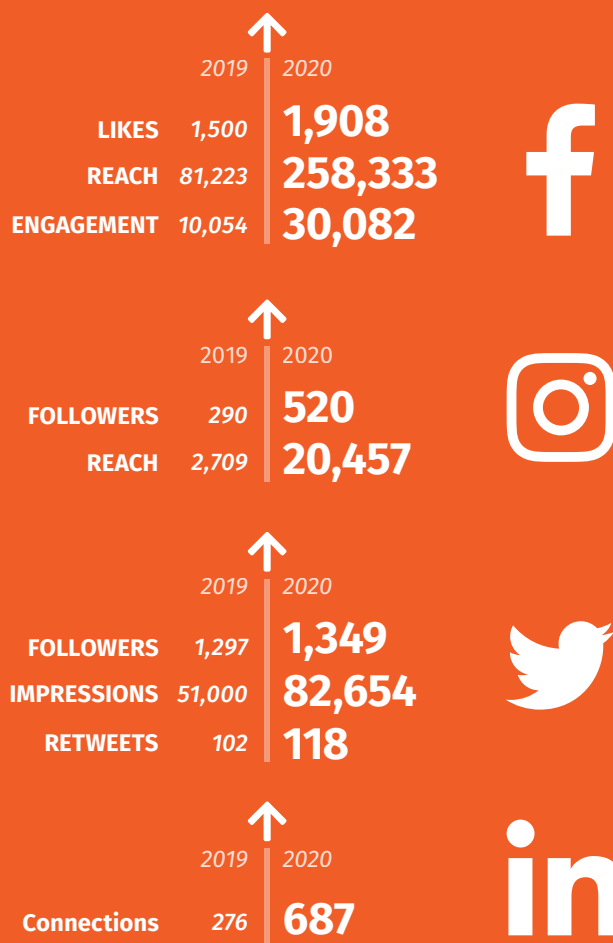
Moving forward

As things in Western Australia returned 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.

A key reflection for Health Consumers' Council in relation to COVID-19 has been the rapidity with which community engagement mechanisms were put on hold by the health system. We aim to leverage the Sustainable Health Review, as our state's Recovery Plan, to ensure that should another pandemic occur in our state, it would be unthinkable to cease all engagement activities.

Using social media to extend reach

We believe that social media is an effective, low-cost way to promote information about healthcare rights, self-advocacy and consumer involvement opportunities to a broad audience. During FY20 we began focused work to grow and nurture our Facebook groups. The three groups focus on: the Healthy Weight Action Plan; Aboriginal Health; and Consumer Representation.



Engagement

Aboriginal Engagement

HCC is committed to ensuring Aboriginal health is a core part of HCC's focus and services. With the one very valuable Aboriginal staff member (working 0.7 FTE) we have opted to focus on consumer engagement rather than individual advocacy, as this provides the best way to leverage her time. However, it is worth noting that this staff member is often approached directly by Aboriginal community members who have advocacy-like enquiries. We believe they contact her directly because of her positive reputation in the community and because this is a culturally safe way for them to get support

Justice Health Project and Cultural Competency workshops

HCC was approached by George Newhouse from the National Justice Project (<https://justice.org.au>) to design some training around Aboriginal health advocacy for community service workers and community members. The purpose of the training is to improve Aboriginal people's access to healthcare by training workers and community members in basic advocacy skills, health system navigation knowledge, health rights knowledge, and information on recognising racism that exists in our health system. The training covers complaints processes, when to refer, self-care and other important topics.

HCC partnered with the Aboriginal Health Council of WA (AHCWA) to develop and deliver the training, and it is envisaged that the training will be able to be delivered throughout Australia, wherever the need is. As well as the National Justice Project and AHCWA, this national project is also a collaboration with Bila Muuji Aboriginal Health Organisation Inc in New South Wales.

Community conversations – My Health Record

Two Health Rights sessions on My Health Record were held mid-December at Wadjuk Northside. The first session was with Elders and around 12 people were present. The group was not overly supportive of a MHR, many carry relevant medical information and care plans in hard copy form with them. The necessity of accessing through MyGov was also a barrier as most didn't have internet access or computers, or experience and had no interest in going to Centrelink for support. The second group was a Mums and Bubs group and around 6 mums were present. This group was more interested, accessed MyGov regularly and didn't have the same security or privacy concerns as the older group.

Drumming and Yarning in the Park – Mental Health Week community event

After the success of this event in 2018, we again worked in partnership to host a community event in Wellington Square as part of Mental Health Week in October.



Drumming and Yarning in the Park

Aboriginal Health Facebook group

We set up a public Facebook group for people with an interest in Aboriginal Health. This is another way for people to stay connected with HCC's work in this space.

<https://www.facebook.com/groups/2551000611789401/>



Health Consumers' Council WA
Aboriginal Health

Public group · 50 members



+ Invite

Engagement

Cultural Diversity

Work in this area aims to impact on the experience, participation and health outcomes of people who are often hardly reached. This requires investing time in building and fostering positive relationships with individuals and organisations – so that we can reach people who may otherwise not be heard or have the opportunity to be involved.

This year we said farewell to Karen Lipio who left in December, and we welcomed Nadeen Laljee-Curran who joined the team at the start of January.

Diversity Dialogues forum

Diversity Dialogues forums were developed to facilitate conversation, learning and understanding between members of CaLD/new and emerging communities and health service staff. We held a session on the theme of “Creating Connections” in November 2019. This session was held in partnership with WACHS and was offered via video conference (VC). Panel members came from a range of backgrounds including regionally and metro based staff.

Key resources identified in this session, including a framework on working with multicultural communities in the area of mental health, can be found on this site <https://www.embracementalhealth.org.au>. While tools and resources in working with CaLD clients can be found here <https://www.ceh.org.au/resource-hub/>

Supporting Cultural Diversity in Healthcare Workshops

This three-hour workshop is designed to assist health care staff, from front line to clinicians, to develop skills and understanding to better support people from culturally and linguistically diverse backgrounds. We held two online sessions this year in August and April. Both sessions were fully booked very soon after being advertised.



Community conversations and health rights

We convened community conversations with community members, to discuss “what matters to you?” with regards to health services. For many community members, particularly those who are newly arrived in Australia or who may not yet know much English, the first step is to learn about the Australian health system. We continued to partner with Red Cross and with a number of local government authorities to deliver this information through orientation sessions and during English language classes. From this work it is clear that there is an opportunity to provide more information to people from culturally and linguistically diverse communities to help them understand how to access and use the WA health system.

Culturally and linguistically diverse panel

This year we have been exploring ways increase the participation and involvement of people from CaLD backgrounds. We reached out to people on our database who had indicated they spoke a language other than English at home. We also identified people from recent HCC events, and circulated information in the newsletter which led to a list of almost 50 people. We have sent a number of targeted emails about upcoming opportunities and will continue to promote this panel in our work. People can sign up for the panel at <https://www.hconc.org.au/cald-community-panel/>

In light of the importance of circulating links to trusted sources of information relating to COVID-19 and associated public health measures, we circulated information to this group from the WA Department of Health, as well as links to information in a range of community languages <https://www.hconc.org.au/covid-19-multicultural-resources/>



Engagement Outcomes

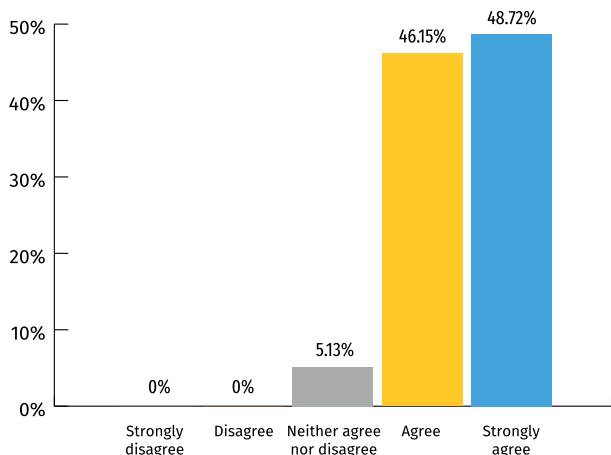


Consumer representative drop in sessions – additional COVID-19 events

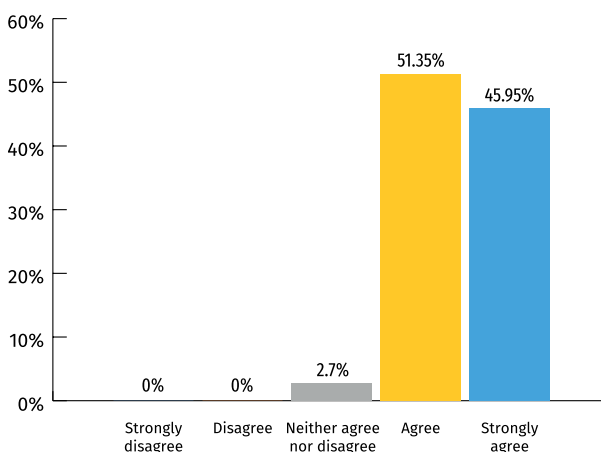
Almost 95% of attendees across all five sessions said they learned something that was relevant to their role, over 97% felt they had the opportunity to engage with issues relating to the health system in WA, and over 97% of people said the session was a valuable use of their time.

“Excellent – I’m just loving Zoom – it so much more efficient than having to travel there and back to a meeting. Gives me back my day.”

I learned something that was relevant to my role



I had the opportunity to engage with issues relating to the health system in WA

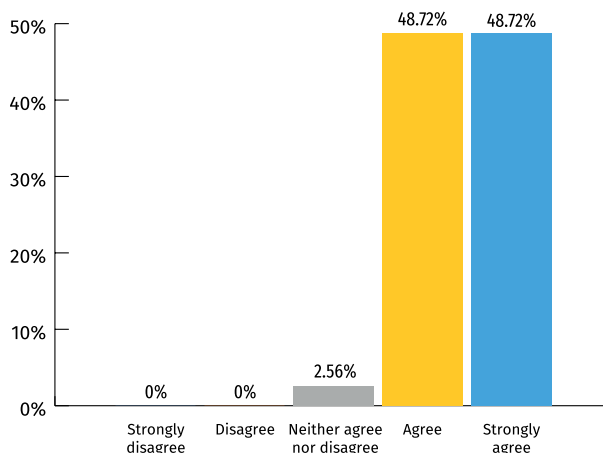


“Great, loved it. You could see who you were talking to. I think this form of meeting should be almost the default setting.”

“I am loving the zoom sessions. You can see who is sharing info and just be part of it.”

“Fantastic to meet all the consumer reps.”

Today’s session was a valuable use of my time



“I feel needed.”

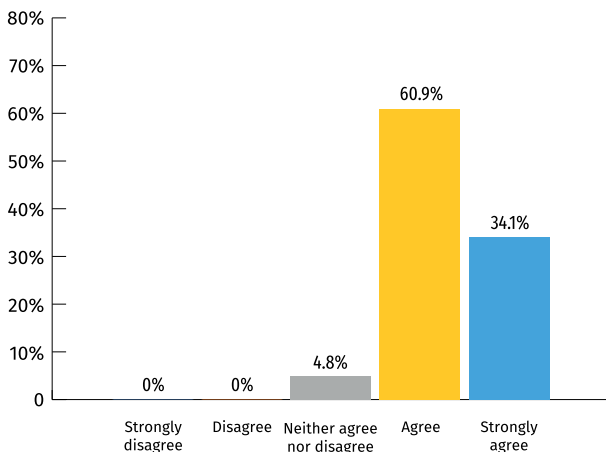
Engagement Outcomes



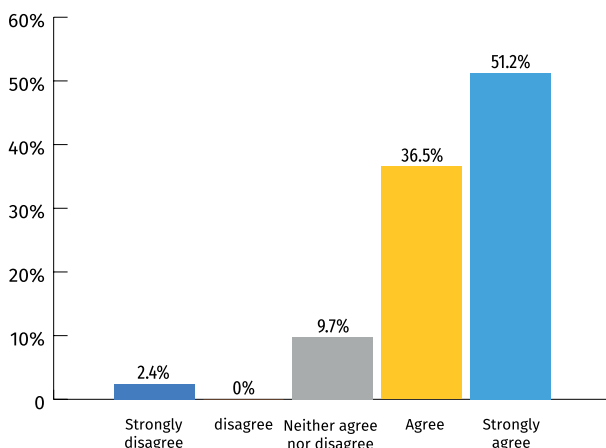
Consumer representative training

We ran two sessions on Introduction to Consumer Representative Training – in October and February. These were attended by 26 people. We also held two sessions on Advanced Consumer Representation attended by 33 people.

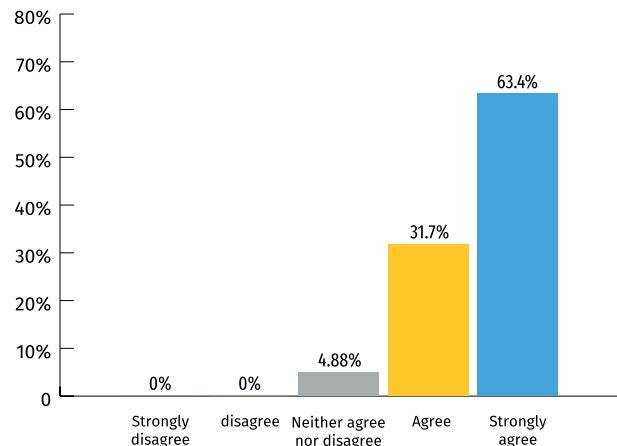
I identified ways to build on my current skills and knowledge (combined)



I will be better able to engage and work effectively in my role (combined)



I would recommend this workshop to others (combined)



Comments about what was most useful included:

“All of it, the interaction with others was so beneficial and I learned a lot from others experience.”

“The handout of the slides used, at least you can always go back to them.”

“All brilliant Organised. Effective.”

“Role definition helpful.”

Systemic Advocacy

Sustainable Health Review

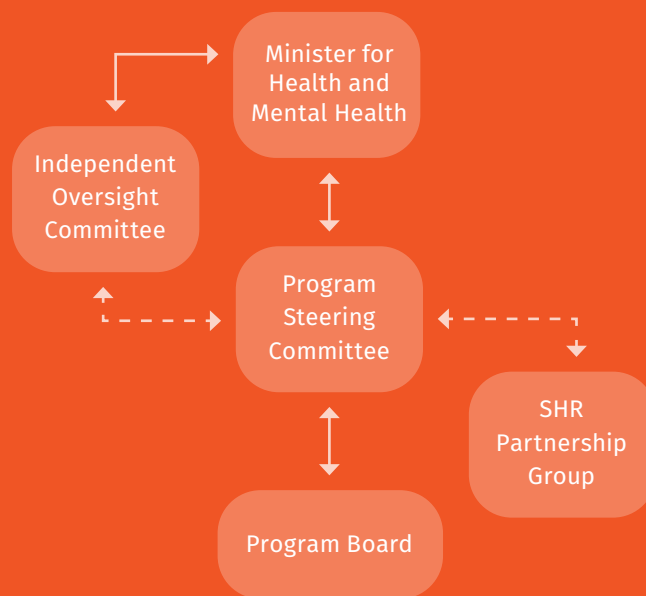
As noted in the Foreword, implementation of the Sustainable Health Review is beginning in earnest just as the financial year closes. HCC believes this is a very important opportunity for consumers and carers to be part of making this ambitious reform program real. There are 30 Recommendations in all in the Final Report, with the 30th Recommendation focusing on implementation.

- There is an Independent Oversight Committee, one of whose members is Margaret Doherty, a highly respected and effective consumer, carer and family advocate.
- The Program Steering Committee consists of all the Chief Executives of the Health Service Providers (North, South, East, Country and Child and Adolescent Health Services) and the Assistant Directors General in the WA Department of Health. They are generally the Executive Sponsors for Recommendations. They report to both the Minister for Health and the Independent Oversight Committee.
- The Program Board consists of the Recommendation Leads for all 30 recommendations.
- The SHR Partnership Group has many of the Program Board members, non-profit peak organisations and individuals with lived experience. It provides advice and tests concepts for planned strategies to address the Recommendations.

HCC maintains that Recommendation Four which focuses on citizen and community engagement is key to all the Recommendations. The Executive Director is the Co-Lead on this, and also sits on the Partnership Group. We are looking forward to providing regular updates next year, and many opportunities to be part of the Sustainable Health Review Implementation.

Giving feedback on health services

HCC worked with the Patient Safety Surveillance Unit at the Department of Health to seek feedback from consumers about their experience of giving feedback or making a complaint. We held workshops in Perth and online, as well as doing telephone interviews with people living outside Perth. Targeted feedback was



sought from Aboriginal people, people with experience of mental health services (carried out by Consumers of Mental Health WA) and people living outside Perth.

Feedback included that many people don't know how to give feedback or make a complaint; people would value more support to give feedback; requiring feedback to be written can be a barrier to people giving feedback; and that people appreciate a human response rather than a standard impersonal response. In discussion with Aboriginal community members, many people described experiences of racism when accessing health services, as well as when considering giving feedback. The value of being able to give feedback by talking with Aboriginal staff was commented on by many Aboriginal consumers.

Sexual Health and Blood Borne Viruses

Health Consumers' Council has been increasingly involved in the last year in enhancing and strengthening the voice of the consumer in the Sexual Health and Blood Borne Virus sector. Health Consumers' Council sits on the Advisory Group which reports to the Chief Health Officer. This Advisory Group now has three Consumer members, and we are collaborating on other strategies to drive consumer-led evaluation of services, and a clear consumer voice in the sector.

Advance care planning, end of life and palliative care

Since the *My Life My Choices* Report there has been a significant amount of reform in our state, and this has meant many hours planning, facilitating or participating in a large number of related activities.

While HCC is pleased to see that Voluntary Assisted Dying Legislation has passed in WA, we are also grateful for the increased focus on Palliative Care. We hope to see an increasing level of consumer, carer and community engagement as we review and resource our palliative care services.

Systemic Advocacy



Palliative Care Summit September 2019

This Summit was convened by the Minister for Health and brought together everyone interested in the delivery of palliative care in Western Australia – health professionals, general practitioners, palliative care specialists, health consumers and carers. It aimed to shape how we put into practice Recommendations 7-18 of the My Life My Choices Report, the Palliative Care Strategy 2018 – 2028 and relevant Sustainable Health Review Report 2018 Recommendations. It was agreed at this event that it should have been called Base Camp – as there is much work to do across the state to continue to explore and improve palliative models of care.

HCC undertook a short consumer survey to explore people's experiences and views on palliative care which Pip Brennan presented at this forum. There were 28 responses to the survey presented to those that attended the Summit, you can watch the 7 minute presentation at <https://www.hconc.org.au/issues/palliative-care/>

Other activities HCC has been part of include the World Café Conversation on Palliative Care in December 2019, as well as the Advance Care Planning Consortium meetings. We are on the National Goals of Care Project which interfaces closely with Advance Care Planning, and we were on the Project Control Group for the WA Country Health Service's Palliative Care project. More recently we have joined the Reference Group for a time limited research project undertaking an independent review of patient and carer perspectives of palliative care service models in Western Australia via a survey.

Advance care planning, Goals of Care and My Health Record

Staff from HCC were involved in a national and statewide initiative aimed at ensuring that people's advance care planning documents and Goals of Care documents are available to everyone in their healthcare team by uploading them to My Health Record.

A consumer and community event was held in partnership with Palliative Care WA, Health Support Services and the Cancer and Palliative Care Network at the Department of Health in February. Attendees heard about advance care planning and goals of care, as well as how to upload these documents to My Health Record. People spoke about the practical challenges of uploading documents to My Health Record, as well as the issues that get in the way of creating and finalising advance care planning documents.

Through this project it was identified that it would be helpful to do further work focusing specifically on the needs and interests of some groups of consumers including people with disability, Aboriginal community members, and consumers with mental health conditions.

Ableism in healthcare – considerations for Voluntary Assisted Dying legislation

While HCC welcomes the introduction of Voluntary Assisted Dying (VAD) legislation, we are aware through our work with People With disabilities WA and other key disability networks, that the introduction of VAD legislation has caused fear and distress through some parts of the disability community. This is based on the experience of ableism within society that is often felt in health services most painfully. Recently, during the COVID-19 crisis, patients with disability who access home based oxygen and other respiratory services were receiving "routine" check-up calls. During these calls, unsolicited Advance Care Planning conversations were being inserted into the script along the lines of "would you want to be resuscitated?"

Disability awareness education should be happening in services to ensure the disability community's point of view is understood. The judgement of "a good life" which is so often made by people without disability in the medical system is often flawed as it does not understand this demographic or their views of "a good life". For many disabled people, the need for someone to provide personal care (feeding, toileting, communication support, other activities of daily life) is a regular and typical part of their life, and doesn't lessen or negate their intrinsic value as a human being, or their ability to be productive, contributing and highly valued members of community. Doctors, clinicians and the system need to be aware of their own language and attitudes toward disability and how that plays out when treating disabled patients and consumers.

As much of the evidence to the current Royal Commission shows, hospitals can be very unsafe places for many disabled people and their families. The health system needs to listen to community and address these urgent and valid concerns. The "burden of care" narrative is very ingrained and does influence people's decisions. It is vitally important to encourage and support this community to be proactive in advance care planning. We are currently embarking on a project with People With disabilities WA and Palliative Care WA to support this aim.

Partnerships



People With disabilities WA

HCC completed our work with People With disabilities WA on a joint project, Empowering health consumers with disabilities, which aimed to empower consumers with disability to have a more positive experience when accessing the health system.

A diverse group of people with disability, their carers and families provided suggestions, advice and expertise on the communication, training needs and formats of people with disability. They also developed and delivered training workshops to consumers with disability, as well as taking part in Diversity Dialogue discussions with health service staff.



Empowering health consumers with disability

THE RESOURCES DEVELOPED AS PART OF THIS PROJECT ARE AVAILABLE AT

<https://www.hconc.org.au/projects/empowering-consumers-with-a-disability/>

WA Department of Health – WA Primary Health Alliance - Healthy Weight Action Plan

HCC is working with the Department of Health and the WA Primary Health Alliance to provide opportunities for consumer feedback on their experiences of using WA health services to help them in their weight management journey. In the past year, HCC hosted a community information session where the DoH team presented on plans to implement the plan that was published in November 2019.

We also received confirmation of funding to enable HCC to support and promote the consumer and community voice in the implementation of the Healthy Weight Action Plan over the next 12 months.



Consumer and Community Involvement – CCI

HCC works closely with the team at the Consumer and Community Involvement Program at the WA Health Translation Network. HCC staff contributed to the strategic plan as well as to a national workshop hosted by the CCI team looking at best practice in the area of involving consumers and the community in research.



HCC and CCI Program session

The Behaviour Change Collaborative

HCC has partnered with The Behaviour Change Collaborative on a number of projects, including the Consumer Experiences of WA Ambulance Services project.



L-R: Tina Tuira-Waldon, Christine Sindley, Samantha Bradder, Rebecca Smith, Danae Watkins, Mallika Macleod and Richard Brightwell at the 2019 AGM

Meet Our Team

Staff

| Name | Position | Term |
|----------------------|--|--------------------------------|
| Pip Brennan | Executive Director | 5.5 years |
| Chrissy Ryan | Advocate | 9 years |
| Carly Parry | Advocacy Manager | 7 years |
| Sheree Mears | Operations Manager | 5 years |
| Tania Harris | Aboriginal Engagement Coordinator | 4 years |
| Bronte Duncan | Advocate | 4 years |
| Kerrie Mocevic | Advocate | 3 years |
| Jenni Dlugi | Administration Assistant | 2 years |
| Karen Lipio | CaLD Engagement Coordinator | 18 mos, left Dec 2019 |
| Clare Mullen | Engagement Manager | 2 years |
| Rachel Seeley | Marketing & Communications Coordinator | 2 years |
| Kieran Bindahneem | Project Officer | 2 month contract |
| Nadeen Laljee-Curran | CaLD Engagement Coordinator | 1 year (6 months in this role) |
| Sam Smith | Advocate | 1 year |
| Ann Healing | Bookkeeper | 2 years |
| Julia Terepai | Administration Assistant | 6 months |



HCC staff

Volunteers are an essential part of our operations and we could not deliver all our services without their valuable contribution. With thanks to each one, including those on Management Committee, together you contributed more than 450 hours.

Management Committee

| Board Member | Position | Dates Acted | Eligible | Total Attended | % Attended |
|-------------------|-----------|------------------|----------|----------------|------------|
| Mallika Macleod | Chair | Jul 19 - Current | 7 | 7 | 100.0% |
| Rebecca Carbone | Secretary | Jul 19 - Current | 7 | 6 | 85.7% |
| Steve Walker | Treasurer | Jul 19 - Current | 7 | 4 | 57.1% |
| Danae Watkins | Member | Jul 19 - Current | 7 | 6 | 85.7% |
| Samantha Bradder | Member | Jul 19 - Current | 7 | 5 | 71.4% |
| Rebecca Smith | Member | Jul 19 - Current | 7 | 6 | 85.7% |
| Tina Tuira-Waldon | Member | Jan 20 - Current | 5 | 3 | 60.0% |
| Christine Sindley | Member | Nov 19 - Current | 5 | 3 | 60.0% |
| Erin Moore | Member | Nov 19 - Feb 20 | 5 | 1 | 20.0% |
| Nigel D'Cruz | Member | Jul 19 - Dec 19 | 2 | 1 | 50.0% |

Volunteers + Students

- Ellen Ebert** - Advocacy
- Brooke Pearce** - Advocacy
- Helen Hii** - Engagement
- Kieran Bindahneem** - Engagement
- Tania Boylen** - Engagement
- Trevor Jewell** - Engagement
- Archana Subramanian** - Engagement

Statement of financial position



Health Consumers' Council (WA) Inc

ABN 87 841 350 116

Abridged financial report for the year ended 30 June 2020

| Statement of financial position | 2020 \$ | 2019 \$ |
|--------------------------------------|----------------|----------------|
| Assets | | |
| Current assets | | |
| Cash and cash equivalents | 839,091 | 525,067 |
| Receivables | 64,330 | 3,801 |
| Prepayments | 16,284 | 8,233 |
| Total current assets | 919,705 | 537,101 |
| Non-current assets | | |
| Property, plant and equipment | 31,896 | 91,326 |
| Total non-current assets | 31,896 | 91,326 |
| Total assets | 951,601 | 628,427 |
| Liabilities | | |
| Current liabilities | | |
| Payables | 356,381 | 118,513 |
| Provisions | 74,323 | 68,293 |
| Total current liabilities | 430,704 | 186,806 |
| Non-current liabilities | | |
| Non-current provisions | 25,437 | 14,135 |
| Total non-current liabilities | 25,437 | 14,135 |
| Total liabilities | 456,141 | 200,941 |
| Net assets | 495,460 | 427,486 |
| Equity | | |
| Reserves | 20,000 | 20,000 |
| Retained surpluses | 475,460 | 407,486 |
| Total equity | 495,460 | 427,486 |

| Statement of profit or loss and other comprehensive income | 2020 \$ | 2019 \$ |
|--|--------------------|--------------------|
| Revenue | | |
| Grants | 1,028,840 | 1,025,796 |
| Other Income | 329,709 | 218,345 |
| Cash flow boost | 100,000 | 0 |
| Interest | 6,100 | 5,189 |
| Total | 1,464,649 | 1,249,330 |
| Expenses | | |
| Employment | (920,343) | (864,105) |
| Motor vehicles | (8,923) | (9,777) |
| Administration | (189,345) | (112,535) |
| Operating expenses | (83,486) | (95,004) |
| Premises | (117,816) | (122,223) |
| Employee benefits expense | (17,332) | (5,589) |
| Depreciation and amortisation | (59,430) | (61,896) |
| Total | (1,396,675) | (1,271,129) |
| Surplus / Deficit | | |
| Other comprehensive income for the year | \$0 | \$0 |
| Total comprehensive income | 67,974 | (21,799) |

| Statement of cash flows | 2020 \$ | 2019 \$ |
|---|----------------|----------------|
| Cash flows from operating activities | | |
| Receipts from operations | 1,660,549 | 1,295,462 |
| Payments to suppliers and employees | (1,352,626) | (1,216,937) |
| Net cash generated by operating activities | 307,923 | 78,525 |
| Cash flows from investing activities | | |
| Acquisition of property, plant and equipment | 0 | (4,898) |
| Interest received | 6,101 | 5,189 |
| Net cash generated by investing activities | 6,101 | 291 |
| Cash flows from financing activities | | |
| Net cash generated by financing activities | 0 | 0 |
| Net increase in cash and cash equivalents | 314,024 | 78,816 |
| Cash and cash equivalents at the beginning of the financial year | | |
| | 525,067 | 446,251 |
| Cash and cash equivalents at the end of the financial year | | |
| | 839,091 | 525,067 |

| Statement of changes in equity For the year | 2020 \$ | 2019 \$ |
|---|----------------|----------------|
| Beginning retained earnings | 427,486 | 429,285 |
| Total Comprehensive income | 67,694 | (21,799) |
| Transfers from reserves | 0 | 0 |
| Reserves | 20,000 | 20,000 |
| Closing retained earnings | 495,460 | 427,486 |

Notes:

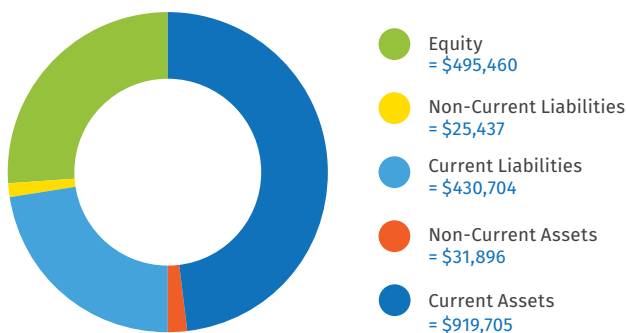
This abridged Financial Report has been derived from the reviewed general purpose report prepared in accordance with note 1 to that report

Our Financial Year



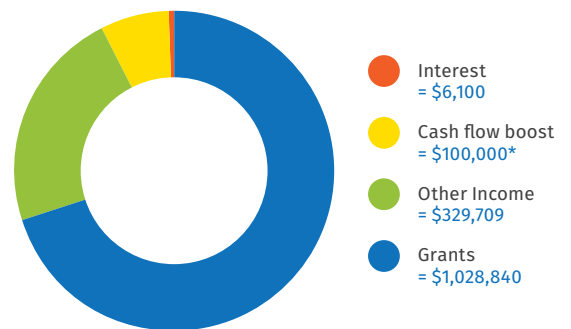
Financial Position

2019/2020



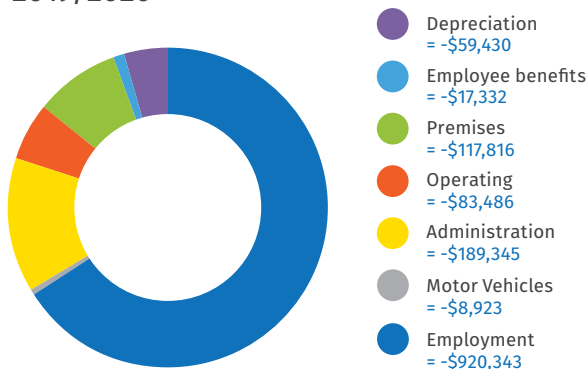
Revenue

2019/2020



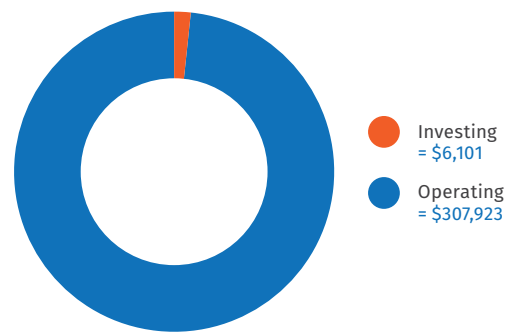
Expenses

2019/2020

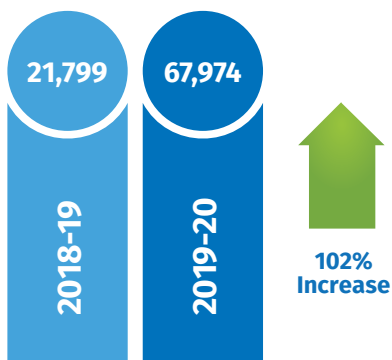


Cash Flow

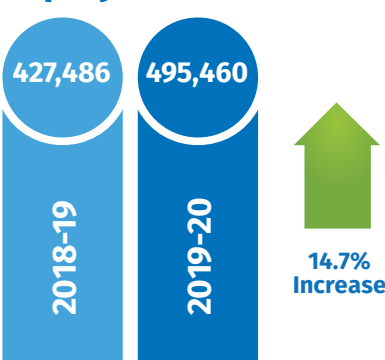
2019/2020



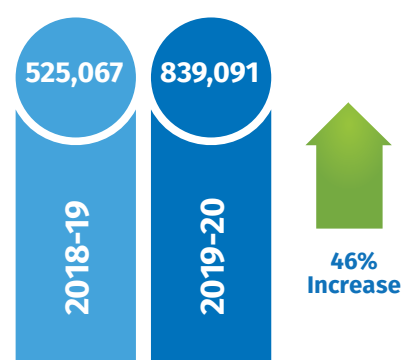
Total Comprehensive Income



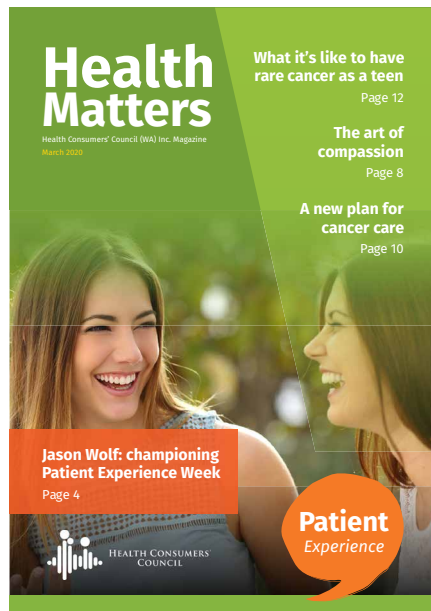
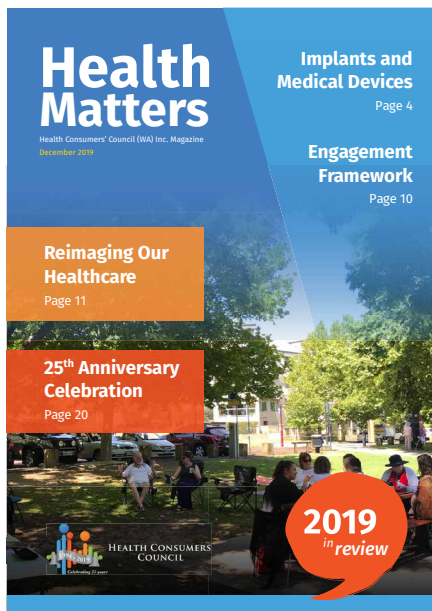
Changes in Equity



Cash Flow



*Total Comprehensive Income in FY 19/20 shows a \$67,594 surplus in comparison to the \$21,799 deficit in the preceding year. This is due to a cash boost of \$100,000 from the ATO which was the value of the Government Job Keeper support during the height of the COVID-19 pandemic in WA.



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