



HEALTH CONSUMERS'
COUNCIL

2023/2024 Annual report

Celebrating 30 years as the independent
health consumer peak body in WA





Acknowledgement of Country

Health Consumers' Council (WA) Inc. acknowledges Aboriginal and Torres Strait Islander peoples and communities as the Traditional Custodians of the land we work on, specifically the Whadjuk people of the Noongar nation. We pay our respects to Elders past, present and emerging. We recognise that sovereignty was never ceded.

Recognition of lived experience

Health Consumers' Council recognises 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.

Diversity and inclusion

Health Consumers' Council is committed to cultivating inclusive environments for staff, consumers, and stakeholders of all backgrounds, genders, sexualities, cultures, bodies, and abilities; recognising and fighting against the systemic discrimination faced by many people within WA's healthcare system.

*We use the term 'consumer' in its broadest sense to include health consumers, patients, people with lived experience, carers, family members, and community members.

Contents

Chair and Executive Director's Report	4
» 30 years of action	
Our strategic plan	6
» Laying the foundations for the next 30 years	
Our impact	8
» By the numbers	
» Engagement	
» Case study	
Engagement	13
» A busy and productive year	
System-wide advocacy	16
» Consumers driving change	
Our 30th Anniversary	19
» An independent voice for the community	
How HCC has changed and evolved	22
» Individual Advocacy	
» Aboriginal engagement and advocacy	
» Cultural diversity program	
» Disability engagement	
» System-wide advocacy	
Our team	27
» July 2023 to June 2024	
» Management Committee	
Our thanks	29
» Thank you for your ongoing support of our vision	
Financials	30
» Treasurer's report	
» Revenue	
» Expenses	

Chair and Executive Director's report

30 years of action



This year was a year of celebrating and learning from the past, and using this learning to look to the future. Two main activities were the preparations for the celebration of our 30th anniversary which took place in April 2024, and discussions with many of our members, partners and stakeholders to inform our refreshed Strategic Plan.

Learning from the past

On 8 April 2024 HCC members, staff, friends and stakeholders from the past three decades gathered to celebrate 30 years of an independent voice on health for health consumers and the WA community.

It was a delight to immerse ourselves in HCC's proud history by talking with some of the pioneers of the WA health consumer movement and by reading our annual reports from over the decades.

In brief, HCC as an independent organisation and a 'voice' for consumers and the

community on health policy, planning and decision making, was a successor of the Health Advisory Network (HAN) and then the Health Consumers Network (HCN) that were managed by the WA Department of Health.

As the only state peak body for health consumers that is funded to provide individual advocacy support to our community, we are grateful to have been able to walk alongside tens of thousands of consumers and support them to assert their rights in health.

Reflecting on what it means to be a "voice" for the community on health in a post-referendum world

Leading an organisation set up 30 years ago to ensure people affected by individual or systemic health decisions, get to have a say in the decision making process, we



"The Minister, Peter Floss, and the Commissioner, Dr Peter Brennan, were highly committed to see an independent Consumer 'Voice' within the community. The members of the HCN had, for a number of years, been aware of some of the advantages of independence and seized upon this opportunity to 'go it alone'."

*Ann White
Chairperson
HCC Annual Report 1994*



Mallika Macleod and Clare Mullen

were disappointed in the Voice to Parliament Referendum result. HCC will continue to work as allies and champions in elevating and championing the voices of Aboriginal people in health, and this year we resumed our work on our Reconciliation Action Plan.

Looking to the future

While learning about the achievements of the past 30 years, we also revised our Strategic Plan to take us into the future. We spoke with members, friends, partners and funders to inform our new Plan for the period 2024-2027.

Towards the end of this financial year, we initiated some changes to enable us to move towards delivering on this strategy in the years to come.

It is an immense privilege to be able to play a part in maintaining a strong and vibrant health consumer movement and community in WA. Thank you to the HCC team who often go above and beyond to support consumers to be heard. Thank you to the Management

Committee for their support in ensuring HCC is well governed and maintains the trust of the WA community and our funders.

Mallika Macleod

Mallika Macleod
Chair

Clare Mullen

Clare Mullen
Executive Director

Our strategic plan 2024 to 2027

Laying the foundations for the next 30 years

A major piece of work this year was refreshing our Strategic Plan to take us into the future. We spoke with members, friends, partners and funders to inform our new Plan for the period 2024 to 2027.

What we heard

What's clear is that the argument for including consumer perspectives in policy, planning and decision making has been largely – although not entirely! – won. It's rare that any significant piece of policy or service planning would now take place without seeking consumer input in some way.

But what's also clear is the need to go beyond the "consultation" to the "partners in change" paradigm. The current pressure being experienced by public hospitals around the world is a clear signal that how we organise our society to deliver positive health outcomes needs to change significantly. In Australia, today's healthcare structures and systems are largely the legacy of decisions taken at least 40 years ago – when Medicare was first established.

All stakeholders reinforced the need for a strong independent voice for health consumers and the community, and many spoke to the need for increased capacity for HCC to extend our reach to more of the WA community and have a more prominent public profile.

Our refreshed Strategy responds to this context and input:

- » We have been explicit about the fact that our vision and purpose include both health care and broader health outcomes
- » We have reiterated our belief in people power, consumer partnership and leadership for driving positive change.
- » We will be focusing efforts on increasing the resources available to extend our capacity.

The Strategy is explicit about identifying activities we can undertake within our existing capacity, and those that will require additional resources before we can start them. We've also reorganised ourselves internally to free up some capacity to seek those additional resources.

Some priorities within existing resources

- » Explore safe use of AI to support people with self-advocacy
- » Increase our physical presence in the community
- » Re-establish HCC's Aboriginal Advisory Group
- » Increase awareness of HCC with existing consumer committees within WA health services
- » Strengthen our alliance with national and state / territory consumer peak organisations
- » Invest in our reconciliation journey
- » Continue to advocate for safe high quality integrated person-centred care

Priorities that need resources

- » Deliver more activities in person regionally including individual advocacy
- » Further develop our self-advocacy tools and run statewide workshops
- » Roll the Aboriginal Patient Advocacy Training project out statewide
- » Develop more and tailored materials for migrants about the health system
- » Establish CaLD and Disability Consumer Reference Groups
- » Expand the Consumer Leadership Academy to help fill senior consumer roles
- » Work with technical experts to refine our IT systems to streamline how we work
- » Expand the use of the Health Engagement Network for the WA consumer community

Vision

Equitable, person-centred, quality health care, and improved health outcomes and experiences for **everyone in WA**.

Purpose

To amplify and champion the voices of WA health consumers to **drive positive outcomes** in health and health care.

Focus

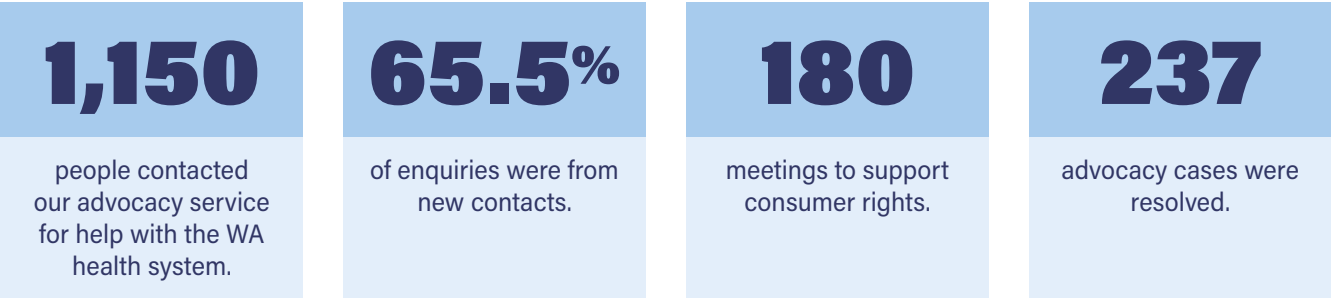
- » Deliver **individual advocacy** and health rights information
- » Advocate for the **collective interests** of health consumers at a **systemic level**
- » **Harness and build people power** through **consumer partnership and leadership**
- » Strengthen our **financial sustainability**
- » Ensure a **strong and agile** organisation

Input into HCC's strategy planning



Our impact - individual advocacy

By the numbers



As always, it's been a busy year for advocacy.

Our individual advocacy service is available to anyone facing issues within the WA Health System. We provide independent support to safeguard healthcare rights, working alongside or directly representing clients through speaking, acting, or writing on their behalf.

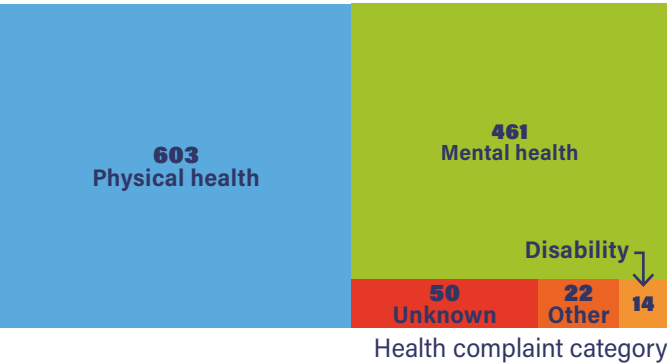
We continued to see an increase in the amount of people seeking advocacy support, with almost 70% of the consumers who contact us for support being new to our service.

During this past financial year, we made the difficult decision to close our waitlist for advocacy for 10 weeks. This decision, although never taken lightly as we understand the benefits and need for advocacy, was essential in allowing us to

get on top of our extended wait times for advocacy. During this period, we continued to advocate for consumers who had previously contacted our organisation, offered information, system navigation and resources and support for individuals to self-advocate who contacted us during our closure, and continued to offer advocacy to people who were deemed a priority during our waitlist closure.

In the 2024/25 financial year, we are investing in building and refining our advocacy resources so that we can offer more robust information for individuals to advocate for themselves and others.

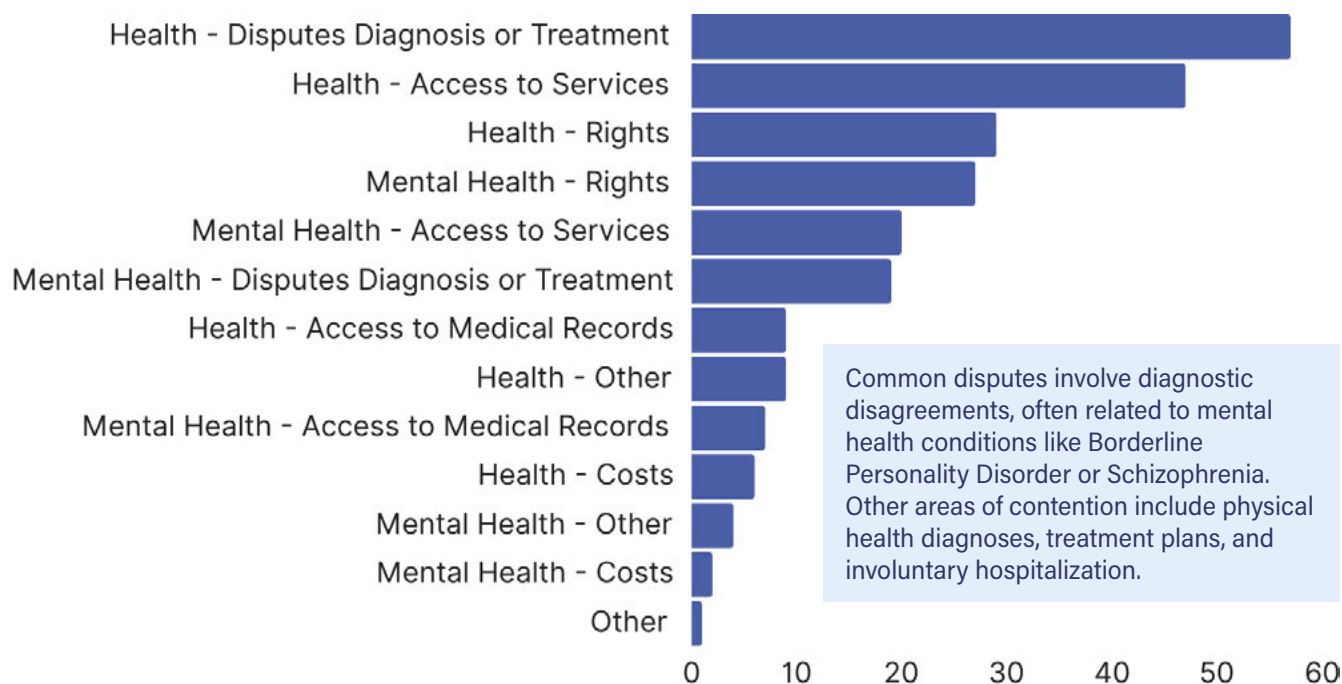
This past financial period, we said goodbye to one of our long-term advocates, and received a small, short-term funding boost to advocacy, which has enabled our team to grow for the 2024/25 financial year.



“Without [advocate] and the service, I would not have felt able to continue on until the conclusion and believe that the help that I was given was vital to me in dealing with the issue then and now.”

Advocacy client

Individual advocacy health complaint category



"Just to say thank you to everyone who did help me, the HCC advocacy service is essential to the whole health service, not just the patients. My advocate was excellent in all areas from knowledge, communication and care to me at all times."

Advocacy client

Ethnicity and location



12% of cases were for people who identify as being Aboriginal or Torres Strait Islander



16.5% of cases were for people who identify as being culturally or ethnically diverse



16.5% of cases were for people who live in regional, rural or remote WA



"[My advocate] helped greatly, she managed to get a positive result even. I tried for months and months to get my desired outcome with no progress in sight, so the help [advocate] gave me was instrumental."

Advocacy client

Our impact

Engagement

60

Events and workshops with consumers and health staff

104

People guided to craft a meaningful Acknowledgment of Country

33

People began their journey as a consumer representative

181

Culturally and linguistically diverse people, and those working with them, learned about rights, responsibilities, and choices in health care

160

Opportunities shared for our consumer representative network to have their say on health in WA

40

HCC staff participated in 40 committees or working groups to represent consumer interests

“

“I found [the facilitator] so incredibly engaging. Within 5 minutes I felt that I knew her already and was comfortable to have open and safe discussions, as were others in the meeting. I appreciate that we went over time because, although we were a small group, we had lots of questions and productive discussions. I really value the experience of joining this meeting.”

Workshop attendee

Our reach



1498

Posts



6220

Followers



93k

Page Reach



66k

Website
Page Views



Some of the WELL Collaborative members at the IPAA WA Awards lunch

We were delighted that The WELL Collaborative – HCC’s collaboration with the WA Department of Health and the WA Primary Health Alliance – was recognised in the Institute for Public Administration WA Awards in the category of Best Practice in Collaboration between Government and any other Organisation. It was great to see WELL Co recognised for its strong commitment to engaging consumers and people with lived experience alongside health professionals, policy makers and researchers across Government to improve healthcare options for people impacted by weight issues.

1,200

Standard hours of paid consumer participation

175

Meetings with senior leaders where we advocated for the collective interests of health consumers

\$47k

Paid to consumer representatives in recognition of the time they spent sharing their stories and insights

Health Rights session at Chung Wa Association



Aboriginal Patient Advocacy Training



Our impact: case study

Individual advocacy making a world of difference

A consumer who has experienced chronic back pain throughout their adult life contacted our organisation with concerns about their pain management. Despite having multiple surgeries on their back in attempts to remedy their pain, the consumer remained constantly in pain. They didn't feel their treating team was listening to their requests for pain management or was understanding of the level of pain and its impact. The consumer had a young family, and their pain hindered their ability to enjoy family life and engage in employment.

An advocacy plan was developed to support them to get a second opinion for pain management and to explore if there were other pain management options available to them. During this advocacy, other health issues also arose which were simultaneously impacting their life; their advocate assisted them to restore access to health services to address these additional issues, by assisting to get their referrals expedited.

The advocate attended multiple reviews with the consumer at their pain management clinic, and helped to organise a third opinion. As a result of these advocacy efforts, and through supporting the consumer

to clearly articulate their needs, the consumer was offered their preferred option of an alternate pain management method. This is quite rarely offered in the public health system and was previously dismissed as an option for the consumer. By using HCC's advocacy service, the consumer was able to have their voice heard, have their symptoms taken seriously, and find a sustainable way to manage their pain.

This consumer had a good level of health literacy and was an amazing self-advocate, however they still said that having an advocate attend their appointments, advocate on their behalf, and walk alongside them made the world of difference for them.

This case was taken on as a priority and it took nine months of persistent advocacy to achieve these results.

Engagement

A busy and productive year

The Engagement Team has had a busy and productive 2023/2024. The make-up of the team had remained steady over the year, and comprised of:

- » **Tania Harris**
Engagement Manager, Aboriginal and Disability Lead
- » **Nadeen**
Diversity Lead
- » **Kieran**
Engagement Officer
- » **Rachel**
Communications and Marketing Lead
- » **Tania B**
WELL Collaborative Digital Marketing
- » **Pip**
Electronic Medical Record Consumer Consultant

The main focus of the Engagement team is to partner with consumers and provide them opportunities to contribute to work where consumer voices and preferences are heard by health services in the design, delivery and evaluation of health services.

We do this by providing training for consumers in their roles as consumer representatives, by providing training with health service staff on how to effectively partner and work with consumers and consumer representatives. We also host workshops and feedback sessions to get consumer input into various topics and issues, and we deliver health rights information to the community. HCC also hosts consumer networking events, which give consumers who participate in consumer representative work get the chance to build their knowledge and network with each other.

Members of the team also sit on various panels and in working groups ensuring that the perspectives of WA health consumers are heard and considered.

During this reporting period we were asked to deliver 14 sessions in the community focused on supporting consumers to increase their knowledge of their health rights and promote the ways Health Consumers' Council can help consumers. 12 of these sessions were delivered face to face with the other two being delivered online. These sessions were presented to a range of consumers, including people with disabilities, culturally and linguistically diverse and people from a refugee background, Aboriginal communities, people with an interest in COVID-19, people with an interest in sepsis and post sepsis recovery and people with an interest in pediatric cancer survivorship.

We provided training in Intro and Advanced Consumer Representative training to 50 WA health consumers during this reporting period.

We provided 7 Consumer Networking activities across the reporting period, with 129 people participating in these activities.

We also delivered training to health service staff that helps them better engage and work with consumer representatives, and hear from consumers about issues and topics that affect them.

Our Partnering and Engaging with Consumers sessions are well attended. We ran this 2 times during the year and had 94 attendees from across the Health Service



Management Committee and HCC staff strategy workshop

Providers and the Department of Health as well as attendees from universities and non-government health and community services providers.

We delivered workshops to staff on the challenges around cancer diagnoses and treatment in culturally and linguistically diverse communities, and another on Supporting Cultural Diversity in healthcare.

As a part of Health Consumers' Council's commitment to equity and improving the outcomes of Aboriginal and Torres Strait Islander people in our healthcare systems, we regularly engage the consumer representative community in opportunities to keep growing their cultural awareness and understanding of the issues that can exist for Aboriginal people. We run 2 workshops a year for consumer reps to learn how to design and deliver a personal and meaningful Acknowledgement of Country. These workshops are well attended and valued by the attendees.

This year, in recognition of the then upcoming Voice Referendum we hosted a session for health service staff and consumer representatives called The Voice 23 – how to support Aboriginal patients, consumers and staff. This 1-hour panel discussion included 2 senior Aboriginal health staff, an Indigenous consumer representative and Clare Mullen from HCC. This panel was delivered online, and we had 73 people attend.

The feedback was very positive, with people welcoming the opportunity to hear from First Nations people and learn practical ways to support people during and post the referendum. Later, Clare hosted a lunch and learn with consumer reps which was also valued by the attendees.

We also hosted one of the Aboriginal Patient Advocacy Training workshops during this reporting period. This training is a partnership between HCC, Aboriginal Health Council of WA and the National Justice Project. This training develops health advocacy

skills, health rights knowledge and raises awareness of the barriers experienced by Aboriginal people in our health services and systems. This training is always oversubscribed and very well attended. We had a full contingent of 26 attendees.

Some of our fee-for-service work this year has included:

Safer Baby Bundle

- » Consumer interviews

WACHS Southwest Consumer training

- » Training session for consumer reps

Cancer Services Framework

- » Multiple consumer interviews
- » Multiple workshops with consumers

Emergency Access Response

- » Consumer Reference Group

Electronic Medical Records

- » Consumer Reference Group
- » Workshops for consumers
- » Consumer Consultant

Outpatient Reform

- » Consumer Reference Group

Healthy Lifestyle Program

- » Consumer workshops
- » Cultural Advisory Group

Genetic Services WA

- » Multiple consumer interviews
- » Multiple workshops

WELL Collaborative

- » Consumer advisory groups
- » workshops
- » Development of networks and consumer groups

What the Doctor Said

- » Multiple consumer interviews
- » Workshops

2023/24 was a busy year for the team, and we look forward to the next year being just as busy. We would like to acknowledge the many consumers and consumer representative colleagues that we have worked with this year and thank you for your generosity and willingness to share your experiences to improve the services for all of us. We would also like to thank the health services staff who engage so willingly with consumers and with us.



Tania Harris

System-wide advocacy

Consumers driving change

Overview

Changes in how we have organised society, as well as a healthcare system that was designed around a largely medical model 40 years ago, mean that some parts of our current system are under significant pressure. And with a funding model that divides the responsibilities between different parts of the health system between the Commonwealth (national) Government and the State government, it is often down to the individual trying to coordinate their care across a highly fragmented system.

There is lots of important and meaningful reform work happening in different parts of the system. But while each part of the “system” tries to address the problems as they see it (whether that’s lots of people seeking care through Emergency Departments, too many people not able to move out of hospital when they no longer need hospital treatment because there aren’t suitable supports in the community, or not enough suitable places in residential aged care homes), it is consumers who experience all of the challenges along that care path. As well as the conditions in our communities and neighbourhoods that get in the way of us staying healthy.

And so it’s critically important that consumers are able to influence change across all of these reform programs. What we hear consistently across all the discussions we are part of with consumers is that people want:

- » Their health rights to be met
- » Their care to be joined up

- » To receive care that is free of judgement, bias or stigma
- » To be treated compassionately
- » Care that is safe and high quality
- » Living conditions that contribute to health and wellbeing

HCC’s systemic advocacy involves HCC staff participating in a lot of committees and working groups, as well as hosting consumer advisory forums to gather a wide range of views to influence change across the system.

Digital health

The future – and some would say the present – of health is digital. For HCC it’s critical that digital health initiatives are shaped by the perspectives and needs of diverse consumers – and that the needs of the WA community for whom digital access is limited or non-existent, continue to be met by healthcare providers.

The WA Government is committed to investing in a statewide electronic medical record (EMR) across all public health facilities. HCC has partnered with WA Health to ensure consumers are involved in every step of this project. In 2021, HCC hosted kitchen table discussions to inform the development of the WA Health EMR Consumer Charter. This year, as the EMR project gathered momentum, we hosted eight webinars and interviews to help WA consumers and consumer representatives learn more about what an EMR is and what are the important issues for consumers to consider. From a consumer perspective, interoperability – meaning our information

can be viewed in public and private hospitals, GPs and residential aged care – is top of our list. All replays and/or summaries are available on this page: <https://www.hconc.org.au/systemicadvocacy/digital-health-2/>.

We also host an expert consumer advisory group who provide a range of perspectives to inform key parts of the project. Pip Brennan returned to HCC on a casual basis as the Consumer Consultant for this project, co-located with the WA Health EMR Program, giving the project team flexibility to check in and get a consumer perspective as issues arise. This model – of a lead consumer consultant plus a diverse consumer group – is working well as it ensures that the people who are involved in this long-term project (it will be 5-8 years before the EMR is fully implemented) are kept informed and involved along the way, and are supported to deepen their understanding of some of the technical aspects of the work as it unfolds.

Systemic advocacy priorities

HCC has ensured diverse consumer perspectives have influenced change in these areas in 2023-2024:

- » WA Health System flow and reform – Emergency Access, WA Virtual Emergency Department, State Health Operations Centre, Community Services Strategy, Long Stay Patients
- » WA Health Electronic Medical Record
- » New Women and Babies Hospital project
- » WA Safety and Quality Strategy
- » Sustainable Health Review Rec 4 - new

approaches to support citizen and community partnership

- » COVID and Long COVID
- » Healthy Lifestyles for Aboriginal families
- » WA Health Cancer Clinical Services Framework
- » Cancer resources for people from culturally and linguistically diverse backgrounds for WA Health – in partnership with the Cancer Council WA
- » Clinical Deterioration



Improving access to emergency health care

Many hospitals around the world are experiencing a high level of demand for care, with many people in Australia accessing that care through Emergency Departments.



L-R: Tania Harris, Carole Kagi, Amber Bates, Jane Pearce, David Russell-Weisz, Joanne Beedie, Clare Mullen, Sonja Whimp, Kylie Ekin

As part of the Ministerial Taskforce on Ambulance Ramping, there is a system-wide program looking at Emergency Access Reform. This year, consumers were involved in discussions relating to these initiatives which include the WA Virtual Emergency Department (WAVED), the WA Community Services Strategy, and the establishment of the State Health Operations Centre. A key issue from the consumer advisory group has been the need to ensure a strong focus on compassionate safe quality care while there's a strong focus on changing how people move through different parts of the healthcare system.

Consumers influencing safety and quality at every level

In early 2023, HCC ran 8 focus groups with a wide range of consumers to gather feedback that was used to develop the WA Safety and Quality Strategy. This strategy was published in February 2024. This year the focus has switched to the implementation of the strategy which is being driven by three working groups looking at the domains of: "safe", "high-performing" and "person-centred". There are consumer representatives in all of these groups ensuring that the consumer feedback that influenced the development of the plan is able to continue to

influence how its rolled out. In particular we continue to advocate strongly for consumer input at every level, including Health Service Provider Boards and Executive, including the creation of Consumer Director roles in health services.

New Women and Babies Hospital

This year we continued to advocate strong for diverse consumer involvement at all levels of decision making on this important project for the WA community. That included facilitating a number of meetings with consumers and key decision makers including with the project team in September and with the WA Director General, Dr David Russell Weisz, and the Minister for Health's Chief of Staff in November.

We also supported the North Metropolitan Health Service team (who are leading the project for the WA Health system) to develop a job description for a Consumer Lead role – which was a result of discussions with consumers.

We look forward to continuing to support diverse and active engagement of consumer representatives and the WA community in this important project.

Our 30th anniversary

An independent voice for the community

Health Consumers' Council was launched by the Minister for Health in 1994 on World Health Day (7 April) as an independent voice for the community on health policy, planning and decision making and to provide a recognised presence for health consumers.

HCC emerged from within the Department of Health (DoH) when staff there and consumer leaders agreed it was important for there to be an independent voice for the community on all aspects of health.

Originally part of the Health Advisory Network (HAN), an innovative group that brought together consumers and providers to advise the state government, HCC evolved from this network, to become the Health Consumers' Network, still with Department of Health, before formally being established as the independent, not-for-profit organisation we know today.

Since then, we have championed and supported thousands of people to assert their rights and have their say on health.

Celebrating 30 years of HCC

On 8 April 2024, we celebrated 30 years of the Health Consumers' Council together with members, staff and stakeholders. It was a beautiful day for a celebration at Perth City Farm, where guests were able to move between the indoor and outdoor displays and activities, and catch up with colleagues and old friends.

Noongar Elder Auntie Cheryl Taylor opened the event with a Welcome to Country and

reflection, and then we heard from HCC's founding Chairperson, Ann White, and founding Advocate, Maxine Drake. Our special guest for the event was the Minister for Health, Hon. Amber-Jade Sanderson. We also heard from HCC's current Chair, Mallika Macleod, and current Executive Director, Clare Mullen. The speeches were followed by a video in which key figures from HCC's past and present shared their reflections and wishes for our anniversary.

Our guests had the opportunity to take part in activities that included sharing their hopes and aspirations for consumer and community involvement in health in a time capsule to be opened in 2034. We invited people to share a pledge about their role in shaping that future, which were used to create a pledge tree.

Throughout the venue we had displays exploring HCC's work over the years, including timelines, important moments in our history, key projects, and copies of old Health Matters magazines and annual reports.

A history of Health Consumers' Council WA

1959: Early foundations

Australian Consumers Association (now CHOICE) founded by Ruby Hutchison, first woman elected to the WA Legislative Council

1994: Health Consumers' Council WA

launched on World Health Day (7 April) 1994 as the independent "voice" on health policy, planning and decision making.



1985: Health Advisory Network

established by WA Govt to provide advice to the Minister for Health.

Consists of

- **Advisory Council of Health Service Consumers** (Chair: Janet Holmes a Court)
- **Advisory Council of Health Service Providers** (Chair: Prof E Saint)
- **Coordinating Panel** (Chair: Dr Mark Liveris)

1992: Health Consumers Network

succeeds the Health Advisory Network as the mechanism for consumer/community advisory input to the Minister for Health.

1998: Consumers in research

Prompted by the HCC Executive Director Michele Kosky, Professor D'Arcy Holman appoints the first consumer rep to UWA data linkage project. This lays the groundwork for WA to become a national leader in involving consumers in research through the work of the Consumer and Community Health Research Network and today, the Consumer and Community Involvement Program and the Consumer Involvement Team at the Telethon Kids Institute.

2006: Aboriginal Advocacy

HCC was funded to run an Aboriginal Advocacy service to ensure there was an independent organisation to provide feedback on all health services, including Aboriginal Community Controlled organisations.

2014: HCC starts tailored programs for culturally and linguistically diverse people

1996: Mental Health Consumer Representatives Training Project

HCC funded to deliver this project as a recommendation of the Ministerial Task Force on Mental Health, to develop a network of consumer representatives and support them in their consumer representation work in Mental Health Services.



2015: HCC signs five year contract with WA Health

A history of Health Consumers' Council WA

Looking to the future

HCC is renewing our commitment to ensuring that consumers and community members have a strong voice in all decisions about the health of Western Australians.

To achieve this, we're focusing on increasing our resources, building capacity in the community, and extending our support to more people across WA.

Our goals are clear: we want to ensure health rights are met, people power is rallied, and that consumers drive positive change. We're also committed to strengthening our financial sustainability so that HCC remains strong and agile.

These are the outcomes we'll be working towards in the coming months and years, and we invite our members, health consumers, and the broader community to join us – because we're stronger together.



Guests enjoyed the chance to connect and catch up



Guests enjoyed the food provided by All Good Grub



L-R Mallika Macleod, Clare Mullen, The Hon Amber-Jade Sanderson



Over 120 people attended the event at Perth City Farm



Guests were invited to share a message for the anniversary time capsule



The Minister for Health chatted with guests after the formalities – here with Ann White and Mitch Messer



L-R Kate Bullow, Martin Whitely, Laura Ekin, Carly, Maxine Drake

How HCC has changed and evolved

Individual advocacy

Advocacy Values

Ashleigh Nosedá

(Published in Health Matters, 2002)

During September 2002 the Health Consumers' Council offered a practicum placement to an ECU student. The project set for this practicum was to compile a list of agreed Advocacy Values that generally guide the individual advocacy service provision in the community based sector in Western Australia. This was done through consultation with the Health Consumers' Council and allied agency Advocates, including the WA AIDS Council, Advocare, Ethnic Disability Advocacy Centre and Headwest.

“

Advocacy has continued to be a key activity of the Council under the leadership of Maxine Drake. Many of the consumers seeking advocacy are mental health consumers seeking the right to participate in their own treatment and care. Communication, respect and lack of the kindness are the key issues for many consumers seeking advocacy support but a lack of recognition of the autonomy of mental health consumers by some medical practitioners continues to be of grave concern to this Council.”

2004 Annual report extract

Open interviews were used to establish the personal values and perspectives of the individuals involved. This information was then collated and synthesised into the following set of Advocacy Values:

- » Accountable to the person being advocated for.
- » Independent of conflicts of interest, either personal or organisational.
- » Confidence in the integrity of the advocacy action and the individuals entitlement to advocacy assistance.
- » Fairness to all parties.
- » Respectful to the consumer experience, the fundamental worth of each person seeking assistance.
- » Collaborative with peer advocacy agencies.
Flexible advocacy service according to individual need.
- » Professional in advocacy service delivery including ethical handling of individual personal information.
- » Rights based analysis of consumer needs to inform advocacy actions.

This will be presented to the board of the Health Consumers' Council for endorsement, after a consultation period during which members and others are encouraged to comment.

Aboriginal engagement and advocacy

Advocacy

In 2007, Laura Elkin and Brian Charlie pioneered HCC's Aboriginal Consumer Participation Project, with state government funding secured to manage the Aboriginal Consumer Participation and Complaints Review Projects. In its early days, this program achieved the establishment of the Aboriginal Liaison Network, an Aboriginal Consumer Consultation held in Broome.

The program also produced a well-received DVD starring radio identity, Mary G, which encouraged Aboriginal people to raise issues and share Aboriginal perspectives. The program worked to improve health services by making Aboriginal voices heard at community sessions, training opportunities, visits to Aboriginal community organisations, and metro and country hospitals.

From 2010, The Aboriginal Consumer Participation and Complaints Management Programme promoted health rights and encouraged Aboriginal people and communities to become involved in the management of their health needs. In 2012, the Aboriginal Consumer Partners Program continued to support Aboriginal health consumer groups and forums in Broome, Geraldton, Esperance, Narrogin, Kalgoorlie and Perth. The program also provided training to health staff, focused on supporting the complaints process. After community feedback, the program name was changed to Aboriginal Advocacy Program in 2013. HCC continued to provide advocacy assistance and advice to Aboriginal patients and their families across WA. It was important to HCC that we not only continue to provide a voice

for system change but also to be able to support individuals in need when able.

In 2016 Tania Harris joined the Aboriginal Advocacy Program. Changes to funding in mid-2016 saw Laura Elkin leave HCC and Tania move into the Advocacy team, and later into the Engagement team, where she remains today. We continue to seek other grant opportunities to develop a network of community advocates across the state who can provide individualised advocacy support as well as on the ground feedback about local issues.

Engagement

In 2018, HCC's commitment to ensuring Aboriginal health is a core part of HCC's focus and services saw a switch to focusing on consumer engagement rather than individual advocacy. We are focused on ensuring Aboriginal voices are heard in important conversations, to address the systemic, societal and individual racism, inequity and injustice in our health system that can lead to poorer health outcomes. We know that health advocacy plays a big part in addressing these issues, so we provide training for health services staff to gain a better understanding of the barriers and enablers for Aboriginal people in our health services and systems. We work with community to identify barriers that, when addressed, can improve access and service delivery to Aboriginal consumers.

How HCC has changed and evolved

Cultural diversity program

Engagement

At Health Consumers' Council we believe in inclusion and the best health outcomes for all. WA continues to experience higher than national average population growth through migration and over half of West Australians have one or more parent born overseas. We speak 240 languages across a vast state. We know that improved language accessibility and culturally inclusive practice can improve provider-patient communication, comfort, and trust which increases service uptake, treatment adherence, patient safety and ultimately health outcomes.

We recognise that the voices of people from Culturally and Linguistically Diverse (CaLD) backgrounds are often left unheard. We're committed to supporting consumers to navigate the health system, and supporting health services to provide effective engagement and care to people from diverse backgrounds.

History

In 2011, Louise Ford joined HCC as the Consumer Representative Coordinator, with a strong knowledge of the health needs of people from migrant and refugee backgrounds. Having identified a lack of awareness of the needs of these diverse groups in the health sector, HCC took its first steps towards addressing this, establishing Health Rights and Responsibilities sessions for CaLD people. These were followed by Diversity Dialogues, with the aim of encouraging communication and (potentially) collaboration between community members and healthcare services.

Around 2015, Louise began the Supporting Cultural Diversity in Healthcare sessions, delivering them regularly to staff at WA hospitals and health services. From this work, the Culture and Diversity program was hatched; later, under the ongoing stewardship of Karen Lipio and Nadeen Laljee-Curran, it became the Cultural Diversity Engagement Program.

Today the program consists of regular workshops to support both community and health services, as well as advice and input into health service planning and policy, and gathering feedback on particular health topics as required.

Disability engagement

Reimagining our healthcare

In December 2019 we received a grant from Department of Communities to design an art installation for International Day of People with Disabilities. We partnered with artist and disability activist, Samantha Connor, to produce a series of artworks called "Reimagining our Healthcare". Samantha spoke with disabled health consumers about their experiences and visually recorded what they wanted, what would make a difference and how it would look if their needs were met by our healthcare system. The results are honest and offer great insight into the experiences of disabled people as health consumers.

Empowering health consumers with disability

We partnered with People With Disabilities WA to deliver a project which examined health literacy materials and put them to the test of disability friendliness. The project delivered nine training sessions on Disability Health Rights for people with disabilities, and their carers, family and support people. Topics covered health rights, ideas for getting better care, where to go for help, medical records and information sharing, and navigating the health system. The training was co-delivered with members of the Disability Advisory Project group. A series of booklets and videos were produced for this project.

What would you like to see change to better involve people with disabilities in engagement activities?

"Let organisations know that there are lots of people with disabilities who are willing to share their lived experiences"

"Organisations would need to understand the life experience that a person with a disability brings to the group."

"Education of the community that there are a lot of people with disabilities who would love to be involved. It should be mandatory that all boards or committee should have at least one member with a disability."

Safety and quality community conversations

Participants with lived experience of a disability attended the workshop to talk about safe, high-quality health care. We heard that hospitals do not feel like safe places for many people living with disabilities, and that better staff training, clinicians listening to their patients and the patients' carers more, assistance navigating a system which increases in complexity when combined with the NDIS (National Disability Insurance Scheme) and accessible, safe environments would all help improve the experience for people with disabilities.

"I know what I need most of the time, they often need to just be able to listen and echo it back."

How HCC has changed and evolved

System-wide advocacy

HCC and the Sustainable Health Review

In 2017, Pip Brennan, HCC's Executive Director was appointed by the WA Government to the Sustainable Health Review (SHR) Panel along with senior clinical and policy leaders.

An extensive statewide consultation process was undertaken – including a targeted consultation led by HCC to reach people from culturally and linguistically diverse communities, Aboriginal people, and people living in regional WA. This resulted in a comprehensive long-term plan for the future of the WA health system.

HCC is currently supporting consumer involvement in these SHR recommendations:

- » Improving timely access to outpatient services
- » Implementing models of care in the community for people with complex conditions
- » Investing in digitising the WA health system
- » Halt the rise in obesity

- » New approaches to support citizen and community partnership
- » Supporting children and families in getting the best start in life

Recommendation 4

Launched 2019, with 10 enduring strategies and 30 recommendations including "Commit to new approaches to support citizen and community partnership in the design, delivery and evaluation of sustainable health and social care services and reported outcomes."

The Executive Director of Health Consumers' Council is the Co-Lead for this Recommendation along with the Director of the Health Networks team at the Department of Health.

The work is guided by a Steering Committee consisting of the Co-Leads and three consumer representatives: Yvonne Parnell, Iqbal Samnakay, and Danielle Loizou-Lake.

Having generated a Working with Consumers and Carers Toolkit, the next focus for the Rec 4 team is the development of Patient Reported Outcome Measures and Patient Reported Experience Measures.



Our team

July 2023 to 30 June 2024

- » **Clare Mullen** – Executive Director
- » **Rebecca Smith** – Head of Strategic Projects
- » **Tania Harris** – Engagement Manager, Aboriginal and Disability Engagement Lead
- » **Nadeen Laljee-Curran** – Cultural Diversity Engagement Lead
- » **Kieran Bindahneem** – Engagement Officer
- » **Rachel Seeley** – Marketing and Communications Lead
- » **Pip Brennan** – Consumer Consultant, Electronic Medical Record
- » **Jasmina Brankovich** – Policy and Systemic Advocacy Lead (to Nov 2023)
- » **Aimee Riddell** – Corporate Services Lead
- » **Donelle Stevenson** – Administration Officer
- » **Tania Boylen** – WELL Collaborative Digital Engagement Coordinator
- » **Sam Smith** – Individual Advocacy Manager
- » **Helen** – Individual Information and Advocacy Officer
- » **Jenni** – Individual Information and Advocacy Officer
- » **Brontë** – Individual Advocate (to Mar 2024)
- » **Kerrie** – Individual Advocate
- » **Jen** – Individual Advocate (from Jan 2024)
- » **Chrissy** – Individual Advocate
- » **Rachel** – Individual Advocate (to Sept 2023)
- » **Ryuu Thet** – McCusker Intern

L-R Tania, Kerrie, Aimee, Tania, Chrissy, Helen, Jenni, Clare, Kieran, Sam, Rebecca, Rachel, Nadeen, Donelle Stevenson



Our team

Management Committee

- » **Mallika Macleod** – Chair
- » **Richard Brightwell** – Deputy Chair (to Nov 2023)
- » **Rebecca Carbone** – Secretary
- » **Ian Ludlow** – Treasurer
- » **Michael Crowley** – Member
- » **Meredith Waters** – Member
- » **Glen Knight** – Member (to Nov 2023)
- » **Natalie Borrellini** – Member (to Nov 2023)
- » **Niall Naghten** – Deputy Chair (from Dec 2023)
- » **Kim Brewster** – Member
- » **Al Muhit** – Member (from Nov 2023)
- » **Kirtida (Tina) Shah** – Member (from Nov 2023)

Some of the Board and the ED at the 30th Anniversary L-R Michael Crowley, Al Muhit, Mallika Macleod, Meredith Waters, Clare Mullen



Our thanks

Thank you for your ongoing support of our vision

We acknowledge and thank the WA Department of Health for their commitment to supporting an independent voice for the community on all aspects of health policy, planning, and decision making. We thank the WA Mental Health Commission for their contribution towards our individual advocacy service for people accessing mental health services. Working in partnership is vital to achieving positive health outcomes. These are some of the key organisations we've worked with this year:

- » Aboriginal Health Council of WA
- » Alcohol and Other Drug Consumer Community Coalition
- » Asthma Australia
- » Australian Commission on Safety and Quality in Health Care
- » Behaviour Change Collaborative
- » BreastScreen WA
- » Cancer Council WA
- » Care Opinion
- » Carers WA
- » Child and Adolescent Health Service
- » Community Legal WA
- » ConnectGroups
- » Consumer and Community Involvement Program
- » Consumers Health Forum of Australia
- » Consumers of Mental Health WA
- » Culture Care WA Inc
- » Curtin University
- » Department of Justice, Corrective Services Division Health Services
- » DonateLife WA
- » East Metropolitan Health Service
- » Enrolled Nursing Cooperative
- » Financial Counsellors Association of Western Australia
- » Foodbank WA
- » Genetic Services of Western Australia
- » Helping Minds
- » Ishar Multicultural Women's Health Centre
- » Medical Forum
- » Miracle Babies Foundation
- » National Justice Project
- » North Metropolitan TAFE
- » Office of Population Health Genomics
- » People With Disabilities WA
- » Professor Grant Waterer
- » WA Country Health Service
- » WA Primary Health Alliance
- » Western Australian Council of Social Services
- » Western Australian Health Translation Network
- » What the Doctor Said
- » William Langford Community House

Financials

Treasurer's report

It is with pleasure that I present the 2024 financial report for the year to the AGM. The Health Consumers' Council continues in a good financial position with retained earnings and cash balances available to support continuing operations and holding a great reputation with our funders and in the Community and for the work performed. In 2024 we again returned a small surplus to continue investing in resources to improve the services we deliver.

The Management Committee is focused on the strategic future, seeking opportunity and managing risks facing the organisation. The reality for all not for profits predominately funded by Government is managing the challenge that the rate of increase in Government funding does not keep pace with the rate of increase in operating expenses and particularly employee expenses. The Health Consumers' Council has operated for many years predominantly with a single Government funding contract with the Department of Health. Over the last 6 years the HCC team worked to leverage the significant knowledge and skills of the staff team to deliver additional services, training and advocacy on a fee for service basis to increase the delivery of services to the community. This sits alongside the continued drive to expand service delivery with Government funded contracts where possible and where funding is offered. We were very excited to receive additional funding commitments in June to extend services in 2025.

Key areas of focus and development in all business areas continue to be the improvement in the systems and processes that are used to deliver services to the community to improve efficiency and effectiveness. Progress continues to be made to improve the services delivered into the community. This corporate knowledge and efficiency of service delivery contributes greatly to the ability to attract further clients and Government contracts again increasing the extent of service delivery.

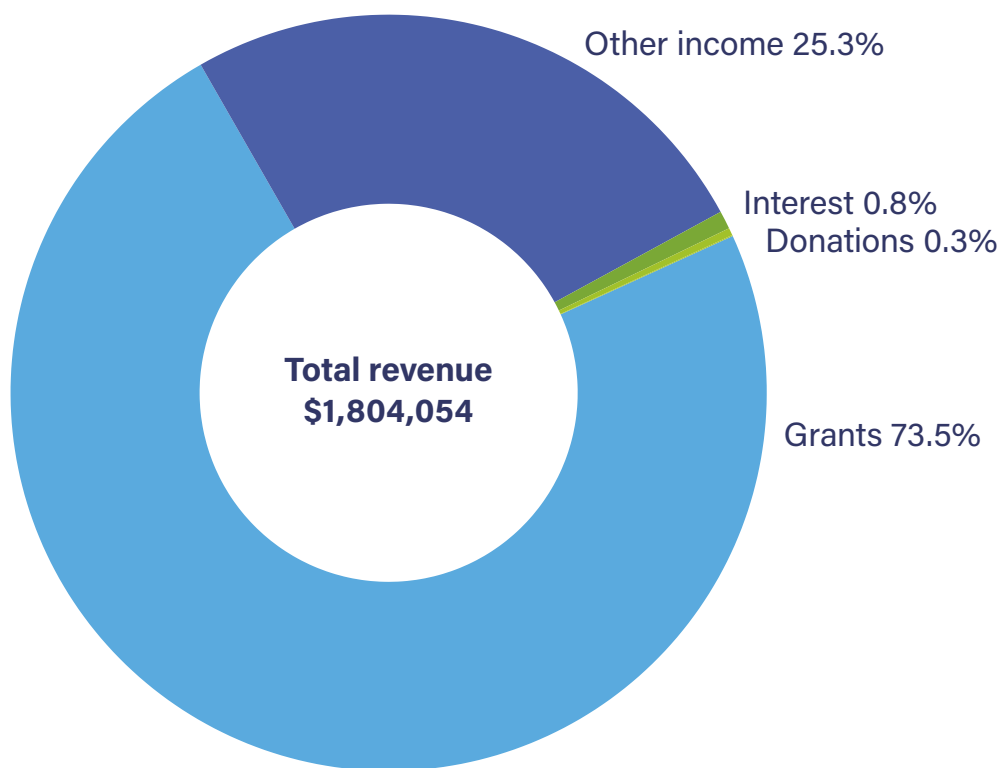
I acknowledge all of the team, the Board of Management and the Staff in working diligently towards the HCC goals.



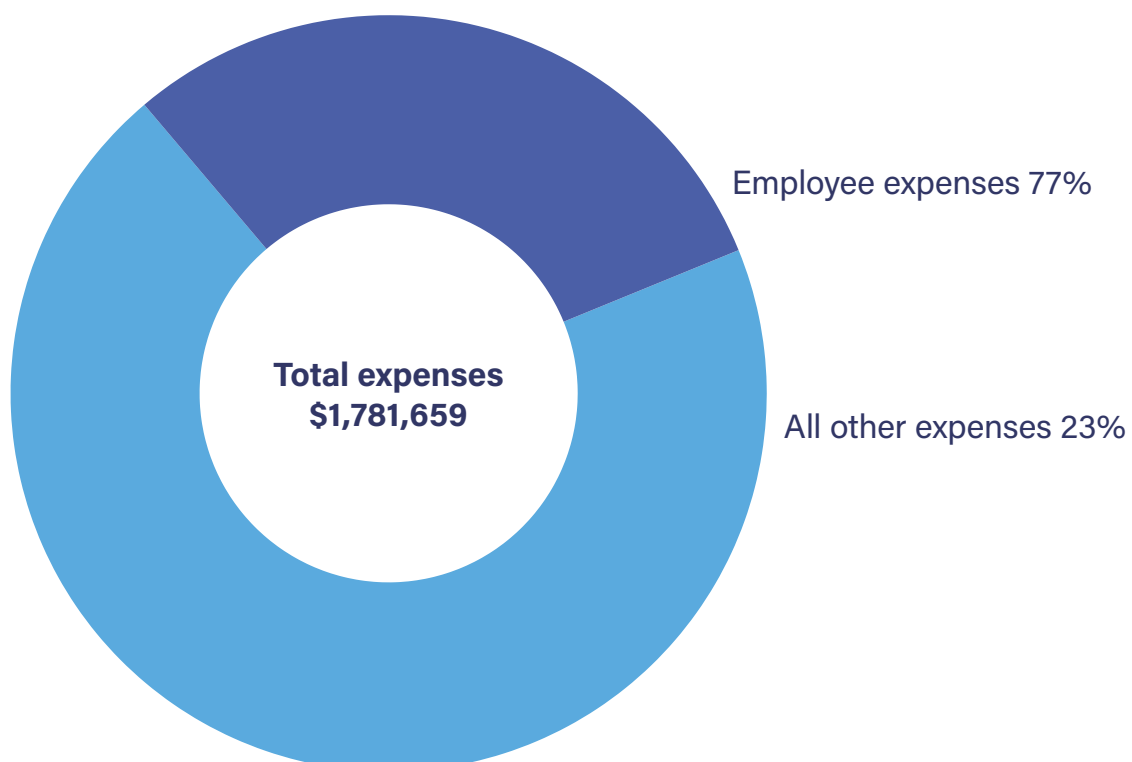
Ian Ludlow FCA
September 2024

*Full financial report is available on request

Revenue



Expenses





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COUNCIL

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