



ANNUAL REPORT 2023-2024



Annual Report 2023-2024

This report reviews the activities and achievements of Health Care Consumers' Association of the ACT (HCCA) during the period 1 July 2023 to 30 June 2024.

The report is also available on our website at www.hcca.org.au.

If you would like a hard copy please contact the office at adminofficer@hcca.org.au.

Acknowledgement of Country

HCCA acknowledges Aboriginal and Torres Strait Islander people as the Traditional Custodians of the lands and waters throughout Australia.

Our office stands on the land of the Ngunnawal people. We value their cultures, identities, and continuing connection to country, waters, kin, and community. We pay our respects to Elders past, present, and emerging and are committed to making a positive contribution to the well-being of Aboriginal and Torres Strait Islander people by being welcoming, safe, culturally appropriate, and inclusive. We are committed to contributing to closing the gap in health outcomes.

We also acknowledge that we have much to learn from the wisdom of Aboriginal cultural practices and beliefs around health.

Health Care Consumers' Association

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www.facebook.com/HCCA.ACT



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Health Care Consumers' Association of the ACT

Our Purpose

The Health Care Consumers' Association of the ACT (HCCA) was incorporated in 1978 and is both a health promotion charity and the peak consumer advocacy organisation in the Canberra region.

HCCA amplifies the voice of health care consumers on health issues and provides opportunities for consumers to participate in all levels of health service planning, policy development and decision making.

HCCA involves consumers through:



Supporting consumer representation and promoting the consumer perspective in health care



Undertaking consumer and community consultations



Disseminating information on behalf of member organisations and health services



Facilitating training and education for consumers, carers and service providers



Delivering community forums and information sessions about health services



Conducting and participating in research into consumer experiences of human services



Our Vision

Consumers in control of our own health.



Our Mission

Improve the safety and quality of health care to meet the needs of consumers and communities.



Our Values

We value our members' knowledge, experience and involvement in our organisation and the consumer movement. The values of Integrity, Collaboration, Equity and Inclusiveness underpin our work.

HCCA Strategic Plan 2021 - 2024

Our Strategic Plan sets out the priorities the organisation will pursue over the 2021-2024 period. The Executive Committee uses this document as the foundation of its work. The Strategic Plan acts as a contract between the Executive Committee and HCCA's members. A copy of the Strategic Plan can be found on our website at: <https://www.hcca.org.au/publication/strategic-plan-2021-2024/>

Priority Action Areas:

The Executive Committee has identified five issues of strategic importance for the 2021-2024 period. They are:



Quality and
safety of
health services



Infrastructure



Digital
health



Environmental
sustainability
of health care



Value based
health care

In addition to these Priority Action Areas the organisation will continue to focus on the key areas of self-management of chronic conditions, out-of-pocket costs for consumers, and the health of older people.

HCCA is committed to being both focused and flexible, being clear about the long-term goals of the organisation while recognising the importance of responding to the environment in which we operate.



Goal 1

A strong and credible voice for consumers on health care



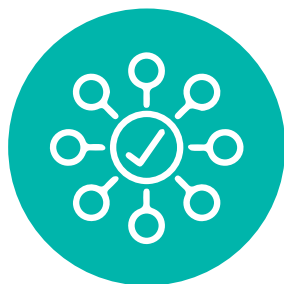
Goal 2

Effective consumer participation in health policy, research, health service planning, design, and governance



Goal 3

High levels of health literacy in Canberra communities



Goal 4

A strong and responsive organisation

Executive Committee

The Executive Committee are responsible for the governance, financial and risk management, and strategic direction of the organisation. This includes ensuring that the work of HCCA meets the aims and objectives outlined in the organisation's Constitution and achieving the goals outlined in the Strategic Plan.

The Executive Committee consists of a President, Vice-President, Treasurer and six (6) other Members, who are elected by the membership in accordance with the Constitution of the Association.

Key Achievements in 2023-2024



In 2023-24 HCCA met all governance obligations and contractual requirements.



The Executive Committee continued to review HCCA organisational policies to ensure they remain up-to-date and relevant for the organisation.



Eight Executive Committee meetings were held between July 2023 and June 2024.

Executive Committee Members for 2023-2024

President: Linda Trompf (from 30 November 2022)

Vice President: Dean Hewson

Treasurer: Tony Krizan

Other EC Members:

Bea Vann

Emma Baldock

Karen McKernan

Isabel Moss

Peta Harbour

Karin Calford

Full biographies of the EC are available on the HCCA website at www.hcca.org.au/about/executive-committee/



Annual General Meeting 22 November 2023 Canberra Yacht Club



President's Report

What a year! 2023-2024 has been another very busy year for Health Care Consumers' Association (HCCA). The organisation continues to provide a voice for consumers to influence and contribute to the development of strategic policies and services in the ACT health system.



The organisation is strong and healthy and continues to attract new members who are keen to be involved in our work. These new members bring a range of experiences and skills that will help support HCCA into the future. We welcome them and look forward to having them involved in our activities.

In terms of the governance of the organisation, the Executive Committee continues to function smoothly. We have a robust risk management strategy and an ongoing program to review and update the policies and procedures that govern our work to ensure they remain current and fit for purpose. The organisation's finances remain sound, as can be seen from the Treasurer's report. There is no risk of insolvency or a failure to meet our obligations as and when they fall due.

I would like to thank all EC members for their ongoing commitment and the level of skill, expertise and consideration they bring to our planning and decision-making endeavours. Special thanks this year to Bea Vann who is completing her six-year term and will be stepping down from the EC. Bea has been a very active member of the EC and her contributions will be missed.

Under our current funding agreement, there is an increased focus on our role as a peak body. This means we may see some changes in some of our work and programs. In planning for that, the Executive Committee has funded a significant piece of work this year to help us develop a new 5-year Strategic Plan. This plan sets out priorities, goals and strategies to guide us into the future.

We have also progressed a project to explore HCCA's impact on health services in the ACT. This has been a great piece of work and provided an extensive report, outlining our achievements, giving us an understanding of what has worked well and where we might place our energies to best achieve our desired outcomes. The information in this report has also provided some valuable background that has contributed to the new Strategic Plan.

You, our members, are the heart and soul of this organisation. We rely heavily on your input through our internal committees, consumer reference groups and member forums. The contributions from these groups help us to make informed decisions about programs and services to deliver our strategic priorities.

The EC maintains excellent relationships with the Executive Director (ED) and her staff. The ED provides us with detailed reports of the organisation's activities to facilitate our ability to monitor performance and risk, and to ensure our decisions are based on the most current information. Under the ED's leadership, the staff continue to create high quality programs that deliver on our strategic plans and support our members. None of what we do would be possible without them and I thank them for their outstanding work and commitment to the organisation.

This year the work of our dedicated staff has continued to be of the standard we have all come to expect, despite the disruptions caused by the ongoing presence of Covid in the community and the need to find alternative accommodation and to set up and transition to new premises. Despite some teething problems, the move to our new Chifley premises has gone well and our work has continued unabated. I would like to thank all members of staff for their efforts in making this happen. We are happy with the new accommodation, but one of the things still on our agenda is to continue to work with the ACT Government to find an appropriate longer-term solution for accommodation into the future.

While work in our core programs of consumer representation and health literacy remains strong and will continue as key in our ability to support consumers to be in control of their own health, there are a couple of newer programs worth noting here.

- 1 The first is the Chronic Conditions Network which has continued to grow over the past 12 months, bringing together a number of community organisations dedicated to support and advocacy for people living with chronic conditions. The network enables organisations to share information, training, reduce duplication of effort, and support a coordinated approach to advocacy and engagement across the sector.
- 2 At a national level, HCCA played a lead role in the consortium that secured two grants for a Quality Use of Medicines project to support consumer health literacy and improve the use of medicines in Australia. The Consumer Health Literacy Grant, led by HCCA, will ensure consumers' needs and perspectives are reflected in national resources for both consumers and health professionals. This is a very exciting piece of work.

HCCA is also undertaking a research project called Experiences of Older Adults with Dementia and Behavioural and Psychological Symptoms of Dementia (BPSD): Understanding Healthcare Access in Residential Settings. It aims to understand how people living with dementia access care when living in a residential aged care setting, particularly if there is has been a need to access acute services. This project aligns with our ongoing commitment to the health of older people more broadly and the need for a planned approach for older Canberrans who might need acute services, especially when coming through the emergency department.

These are just a few of the highlights of another busy year for HCCA. Our new Strategic Plan will guide our work into the future. We will continue to seek member input into determining our priorities and look forward to working together to advocate for and support consumer engagement in all levels of the health system in the ACT.

Linda Trompf
President

Executive Director's Report

This has been a massive year. The enormity of change and activity was experienced across the health system, as well as for HCCA.



There was the continued implementation of the Digital Health Record, the planning for the Canberra Hospital expansion and critical services building, as well as the acquisition of Calvary Public Hospital and the transition to the North Canberra Hospital. And of course, the pandemic continued which added pressure to health services, health workers and many people in the community who are at higher risk of severe disease from COVID.

In September 2023 there was fire at Maitland House, the building where HCCA was located. The fire was caused by an arsonist and there was extensive damage to part of the building. While HCCA equipment and furniture was mostly undamaged, it caused significant disruption. HCCA offices were closed for the remainder of 2023 and as of August 2024, we are still unable to return to our offices. We mostly worked from home with a small office at the Grant Cameron Community Centre in Holder. In May 2024 we were able to permanently relocate to the Chifley Community Hub. We are still settling in and bedding down our meeting rooms, internet and video conferencing. This was a challenging time and yet the HCCA staff team were impressive and continued to meet our obligations. The Executive Committee were very responsive and supportive which made all the difference.

Even with these challenges there were some wonderful achievements and highlights over 2023-2024.

We finalised our work on the HCCA research project into Integrated Care. This is the second report focussed on consumer perspectives in the ACT Region. This work provides insight into what "integrated care" means to consumers with complex and chronic conditions in the Canberra region. It also identifies what consumers in the ACT region need the health system to integrate to allow them to make managing their health and wellbeing easier. We are using this across our work to advocate for consumer interests.

In August 2023 we were successful in our application for a Consumer Health Literacy grant with the Commonwealth Quality Use of Diagnostics, Therapeutics and Pathology (QUDTP) Program. We started working with the Quality Use of Medicines Alliance on

this project to bring together health professional and consumer organisations to co-design educational programs and complementary resources to address medication issues for millions of Australians.

We were pleased to see the success of the Paediatric Liaison and Navigation Service (PLaNS) that HCCA was heavily involved in establishing in a co-design partnership with Canberra Health Services and a dedicated consumer reference group. Our work on this project finished in mid 2024. The service is designed to help children (under 18 years old) and their families in the ACT and surrounding regions coordinate health care from a variety of providers both in the ACT and interstate. It acts as a point of contact for parents and carers to help link them with services in the ACT and New South Wales. The work was informed by the HCCA report on The Kids Interstate Shared Care Project Final Report (2020) and intensive work over several years. The service opened in late 2022, with recent work focussing on the production of resources for consumers, and monitoring and evaluating the service. It is making a difference to the lives of many children and families and demonstrates the value of co-design.





I have been working more closely with my colleagues in the other peak consumer organisations around Australia. We had a successful meeting in Adelaide where we shared our advocacy priorities and looked for common issues we could collaborate on. This is an important network for HCCA as we are able to learn from each other and share our challenges and achievements. HCCA has been able to provide advice to other organisations on our approach to policy submissions, the Digital Health Record, infrastructure projects and our codesign work with health services.

Since February 2020, HCCA has had a staff member providing consumer input to the Primary Care Emergency Response Working Group – originally focussed on COVID-19 and now expanded to encompass primary care's role in any emergency that impacts health – including climate induced emergencies such as floods, fires and heatwaves. The purpose of the group, convened by the Capital Health Network, is to help inform and support primary care providers during an emergency response. This has been, and continues to be, a valuable avenue for HCCA to raise issues important to consumers. HCCA has enabled a wide range of communication issues to be addressed, provided advice and examples of consumer queries about COVID, primary healthcare access, and policy.

This year we have been progressing work to strengthen HCCA's skills and capacity in monitoring and evaluating our work. A key aspect of this was engaging Collective Action to help us document and demonstrate the impact of work during 2021-2024. This involved significant efforts from the staff team in collating information, identifying key stakeholders, discussing early drafts and contributing to the final document. The Executive Committee commissioned this work as an element of their review of the work delivered and outcomes achieved over the life of HCCA's 2021-2024 Strategic Plan.

In 2023 we completed an internal review of the HCCA Consumer Representatives Program. The review drew on literature, analysis of implementation of recommendations from past Program reviews, and interviews and surveys of consumer representatives and committee Chairs and Secretariats. The Report finds that almost 25 years since its establishment, the Consumer Representatives Program (CRP) is a mature, impactful and well-regarded program. HCCA's recent experiences of partnering with health services to support project-specific consumer advisory groups (e.g. in the Canberra Health Expansion Project and Paediatric Liaison and Navigation Service) are a promising model for wider use within health services.

I want to thank the members who contribute to the Health Policy Research Advisory Committee and our Consumer Participation Committee. These groups are important to the work we do and we rely on the advice and perspectives of these committees to shape our work. Special thanks to Sue Andrews who is stepping down after chairing the Consumer Participation Committee for the past few years.

At the 2023 Annual General Meeting, Fiona Tito Wheatland was awarded Honorary Life Membership of HCCA in recognition of her many years of outstanding contribution to the organisation. Fiona has a breadth of knowledge and experience that enables her to join the dots and make connections to identify systemic issues. Her commitment to social justice and consumer empowerment means her contributions are influential. Fiona is someone that makes a difference. She is respected and highly valued and we are very fortunate to have her involved with HCCA. The award was presented by Janne Graham, one of HCCA's long standing members and the first person to be awarded Life Membership. HCCA now has four Life Members - Janne Graham, Russell McGowan, Adele Stevens and Fiona.

I want to thank the Executive Committee for their ongoing support and guidance. This has been especially valuable in such a challenging year. Big thanks to President Linda Trompf. Linda has been a very steady hand and I have valued her support during the year.

The staff team continue to impress me for their professionalism, skills and capacity to deliver on our commitments. They consistently perform at a high level and their work makes a difference. They managed the relocation to new offices really well, which I think is remarkable given the pressure of our busy work program and working remotely placed on all of us.

As always, thank you to the members who continue to support HCCA and our activities.

Darlene Cox
Executive Director



Treasurer's Report



HCCA ended the 2023-24 financial year with a surplus of \$86,773. This surplus transfers to the balance sheets and is reflected as an increase in net assets (or members' equity). The audited financial statements show that members' equity at 30 June 2024 was \$966,270, a corresponding increase upon the \$879,497 balance in 2022-23.

Income

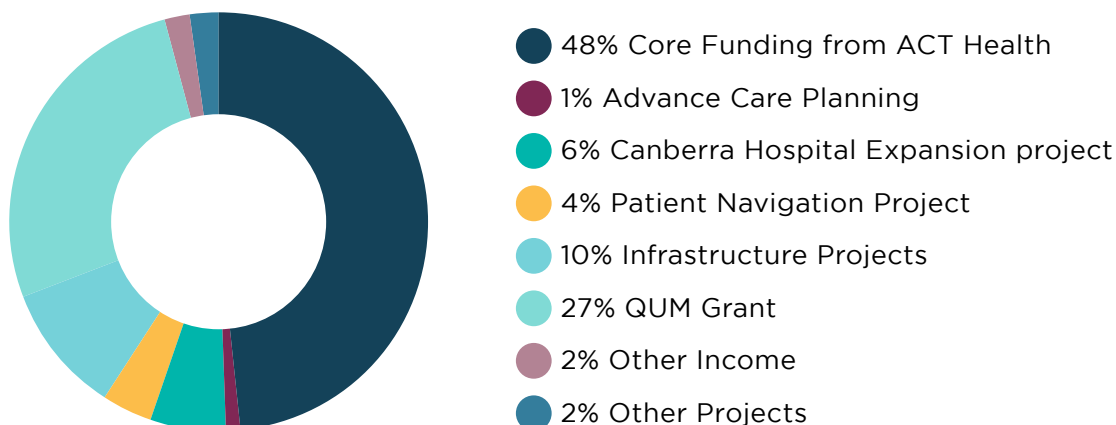
Total income for the 2023-24 year was \$1,938,393, an increase of 31% on the \$1,476,747 in 2022-23. This includes \$604,645 for the 'Using Medicines for Better Health' project (ie QUM project).

The Peak Body Deed of Grant with the ACT Health Directorate remains HCCA's main source of income (\$940,723), comprising nearly 47%. This is down from the 61% in 2022-23 and reflects additional, one-off grants. In addition to its core funding, HCCA received additional funding from the ACT Health Directorate for a number of projects, including: Patient Navigation and Infrastructure Projects. HCCA also continued to work with Major Projects Canberra to provide consultancy services to the Canberra Hospital Expansion Project.

In August 2023 HCCA received funding from the Commonwealth Department of Health for a Quality Use of Medicines (QUM) grant. This represented 27% of HCCA income for the 2023-2024 period.

The chart below summarises HCCA's income sources.

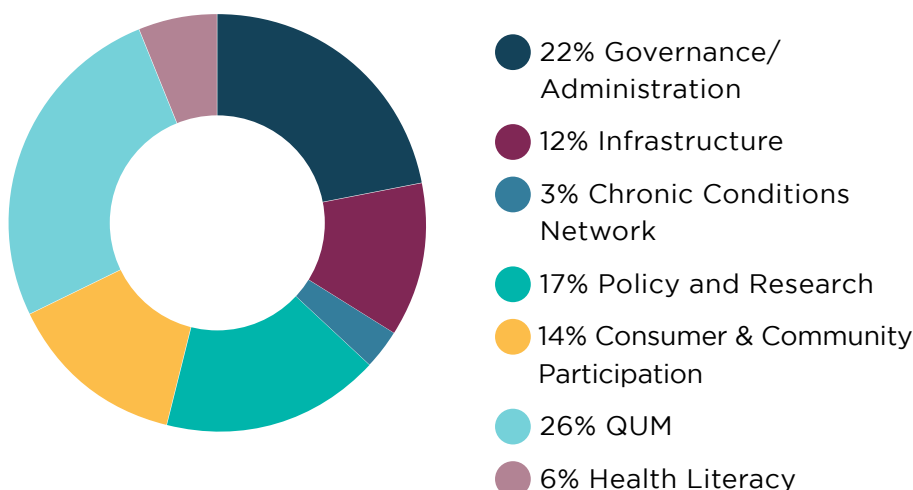
HCCA Funding Sources in 2023-24



Expenditure

Total expenditure for the year was \$1,851,620 a 22% increase compared to the 2022-23 year (\$1,440,978). The bulk of the increase in costs relate to the QUM project, with 26% of expenditure relating to this project. HCCA operational costs continue to be predominantly staffing related (66%). The chart below summarises the application of resources across key HCCA activities.

Areas in which HCCA spent income 2023-24



Net assets have increased from \$879,497 in 2022-23 to \$966,270 in 2023-24. Liabilities are effectively unchanged with a slight reduction from \$466,747 in 2022-23 to \$466,013 in 2023-34. A significant proportion of liabilities on the balance sheet relate to grant funds received in advance (i.e. 48%). The majority of assets continue to be in the form of cash and equivalents, with \$1,018,086, which is slightly increased from the \$962,981 in 2022-23.

In summary, HCCA remains financially viable to service the needs of the community, members and government.

Tony Krizan

Treasurer

\$1,938,393

Total
Income

\$1,851,620

Expenditure

\$966,270

Members'
Equity

HCCA Members

In 2023-24 HCCA had 194 individual and 16 organisational members.



Individual
members



Organisational
members

Partnerships

HCCA strongly values the support of our colleagues in the following organisations:

- ACT Disability, Aged and Carer Advocacy Service (ADACAS)
- ACT Deafness Resource Centre
- ACT Down Syndrome Association
- ACT Mental Health Consumer Network
- ACT Lymphoedema Support Group
- ACT Council of Social Services (ACTCOSS)
- Advocacy for Inclusion incorporating People with Disabilities ACT
- Alcohol, Tobacco and Other Drug Association (ATODA)
- Asthma Australia
- Australian Catholic University
- Australian National University
- Bosom Buddies ACT
- Canberra Alliance for Harm Minimisation and Advocacy (CAHMA)
- Canberra Autism Spectrum Parents and Relatives Group
- Canberra Legacy
- Canberra Lung Life Support Group
- Canberra and Queanbeyan Attention Deficit Support Group
- Canberra Region Kidney Support Group
- Cancer Council ACT
- Carers ACT
- Canberra Multicultural Community Forum
- Capital Health Network
- Community Medics Australia Ltd
- Companion House
- Council of the Ageing (COTA) ACT
- Dementia Australia
- Diabetes Australia
- Epilepsy ACT
- Haemochromatosis Australia
- The Heart Foundation - ACT
- Heart Support Australia
- Hepatitis ACT
- Huntingtons NSW/ACT
- Key 2 Learning College
- Mental Health Community Coalition ACT (MHCC)

- Mental Illness Education ACT (MieACT)
- Meridian (formerly AIDS Action Council ACT)
- mHub - Multicultural Hub
- Motor Neurone Disease NSW
- Palliative Care ACT
- Parkinson's ACT (Hospital Research Group)
- Pain Support ACT (Arthritis ACT)
- Public Health Association of Australia
- RSI and Overuse Injury Association ACT
- Safe Haven (Stride Mental Health)
- SATB2 Connect
- Self Help Organisations United Together (SHOUT)
- Sexual Health and Family Planning ACT

- Stella Bella Little Stars Foundation
- Stroke Foundation (Hospital Research Group)
- Think Mental Health - Head 2 Health
- Tresillian
- University of Canberra
- Women with Disabilities ACT
- Women's Health Matters
- Youth Coalition of the ACT

ACT Government

- Community Services Directorate
- Health Directorate
- Office for Mental Health and Wellbeing
- ACT Human Rights Commission
- Canberra Health Services



Communication and Promotion

HCCA has continued to strengthen its engagement with the community through its social media accounts and other communication channels.

Early in 2024, HCCA began to use CiviCRM as a management system for our newsletters, memberships and contact lists. This new system has helped to reduce the multiple different programs we previously used to stay in touch with our community and keep our contacts up to date across many different pieces of work. As we get used to this new program, we are finding new ways to improve and streamline processes, including membership applications and newsletter subscriptions.

Newsletter

www.hcca.org.au/newsroom/newsletters/

Our newsletter, Consumer Bites, is the main form of communication with our membership and networks. HCCA published 23 issues in 2023-2024. We had 542 subscribers in 2023-24.



23 issues
published



542 subscribers
in 2023-24

HCCA Website

www.hcca.org.au

In 2023-24 our website had:



25,281 page views
compared to 21,517
in 2022-23



14,863 sessions
compared to 9,614
in 2022-23



9,518 users
compared to 7,272
in 2022-23

Canberra Health Literacy website

<https://cbrhl.org.au/>

The Canberra Health Literacy website shares practical resources and information on health literacy for and consumers and carers, and health and community professionals. It was developed by HCCA as part of the Community Health Literacy project and we continue to manage the site.

In 2023-24 the Canberra Health Literacy website had:



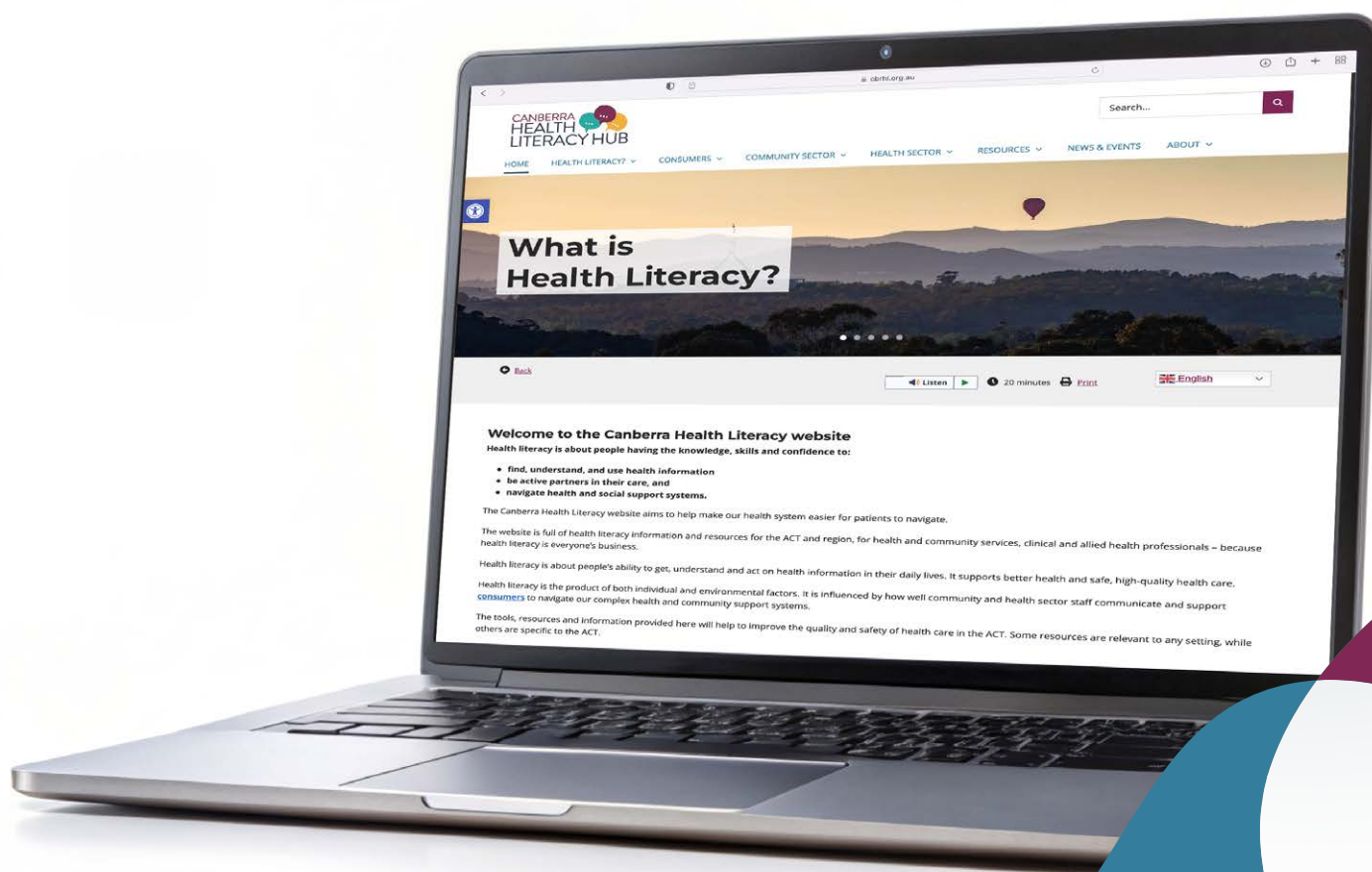
27,824 page views
compared to 16,811
in 2022-23



24,794 sessions
compared to 12,180
in 2022-23



17,516 users
compare to 10,614
in 2022-23





Facebook

<https://www.facebook.com/HCCA.ACT>

In 2023-24 we reached 1,153 followers, up from 1,090 in 2022-23.

We had 2.9k people visit our page, compared to 1.5k in 2022-23 and we reached 17.6k people compared to 17.1k in 2022-23

Our most popular posts for the year were the weekly statistics for COVID-19 in the ACT, which ceased at the end of 2023 when ACT Health changed their reporting arrangements. Posts about the Managing Your Health Seminars were also very popular, showing us that our communities are keen to learn about how they can manage their own health conditions.

2,900

Page visits

17,600

Reach

1,153

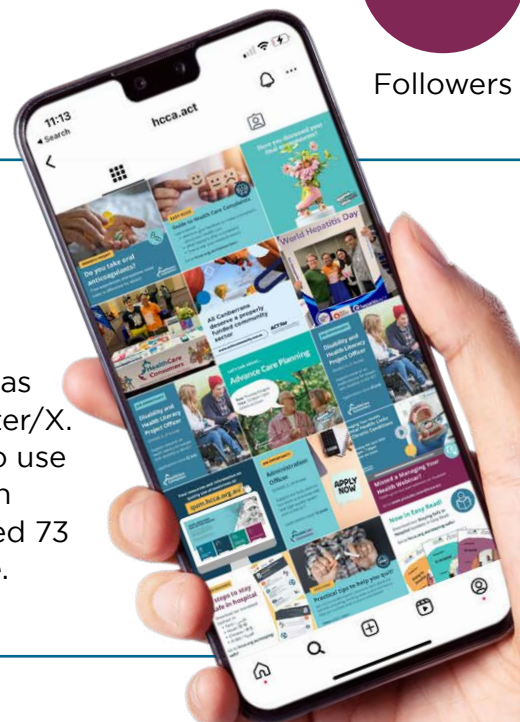
Followers



Instagram

[@hcca.act](https://www.instagram.com/hcca.act)

We started to use Instagram this year as an alternative channel to replace Twitter/X. Many of our partner organisations also use Instagram and have been tagging us in posts. Since we started, we have gained 73 followers and have reached 80 people.



YouTube

<https://www.youtube.com/@HCCA-ACT>

In 2023-24 we published 4 videos and gained 12 subscribers.

We had 685 views compared to 697 in 2022-23.

We had 4.9k impressions compared to 15.2k impressions in 2022-23. (Impressions are the number of times our videos were shown or recommended to viewers).

4,900

Impressions

4

Videos

Health Policy Highlights

HCCA Position Statements

HCCA continues to consult with our members and key stakeholders about issues of importance to the consumer experience of health care.

In 2023-24 we published two key position statements:

1

Co-design Position Statement (2023): Co-design is a valuable form of consumer participation because consumers are involved as equal partners. This helps to ensure that services, policies and programs are of high quality, and meet consumer needs and expectations.

You can find a copy of this position statement on the HCCA website at: hcca.org.au/publication/co-design-position-statement/

2

Statement of Priorities for the 2024 ACT Election (2024): Inclusive health care means equity of access for all health care consumers so that they can fully participate in their health care. For health care to be inclusive for consumers, health care providers need to acknowledge that health is determined by different experiences, identities, social connections, needs, wants, and bodies.

You can find a copy of this position statement on the HCCA website at: hcca.org.au/publication/hcca-statement-of-priorities-for-the-2024-act-election/



Health Policy Submissions

In 2023-24 HCCA provided comment on a range of strategic and clinical policies at both local and national level.



58
policy
submissions

In 2023-2024 our policy team have been busy providing feedback on 48 health policies that are priorities for consumers at an ACT and national level.

HCCA members - look out for emails from our policy team for opportunities to help shape our policy submissions!

Local Policy Submissions or Input

ACT Health Directorate

- ACT Child and Adolescent Clinical Services Plan
- ACT Disability Health Strategy
- ACT Preventive Health Action Plan
- Regulatory Accountability Framework
- ACT Health Workforce Strategy 2023-2032
- ACT Health Clinical Governance Framework
- South Tuggeranong Community Health Centre
- Voluntary Assisted Dying Bill - Impact on People with a Disability

ACT Legislative Assembly Inquiry

- Inquiry into Voluntary Assisted Dying Bill 2023
- ACT Inquiry Bushfire Preparedness
- ACT Inquiry into Climate Change and a Just Transition
- Inquiry into Loneliness and Social Isolation
- Inquiry Disability Inclusion Bill 2024
- Inquiry into Raising Children in the ACT

Canberra Health Services

- Neonatal and Paediatric Advance Care Planning
- Emergency Department Model of Service
- Palliative Model of Care
- Elder Abuse Guideline
- Intimate Body Care and/or Examination of Patients/Clients by Health Care Workers
- Virtual Care Program Model of Care
- Intensive Care Unit Model of Service
- Perioperative Model of Care
- Consumer Feedback Management Policy and Procedure
- Child and Adolescent Short Stay Unit Model of Care
- Walk in Centre Clinical Treatment Protocols
- Cardiology Model of Service
- Medical Imaging Model of Service
- Guideline Forensic Consultation and Intervention Service
- Surgical Inpatient Units Model of Service
- Emeritus Nurse and Midwife role
- Urology Advanced Practice Nurse Model of Care
- Consent for Healthcare Treatment Guideline
- Adult Community Mental Health Service Model of Care
- Information Privacy Policy
- Publicly Funded Home Birth Procedure
- Oral Health Services Review
- Cancer Rapid Assessment Model of Care
- Timing of pathology results on MyDHR
- Multiple chemical sensitivities factsheet
- Acute Medical Care Unit MOC & MOS
- Healthcare Access at Schools Program Guideline
- Residential Aged Care Placement Procedure

ACT - Other

- ACT Government Budget Submission
- Marisa Paterson MLA's proposed Voluntary Assisted Dying Bill 2023 Amendment

National

Australian Commission on Safety and Quality in Health Care

Chronic Obstructive Pulmonary Disease Clinical Care Standard

Ahptra

- Guide on Embedding Good Practice in Clinical Placements, Simulation-based Learning and Virtual Care in Initial Student Health Practitioner Education
- Optometry Board of Australia - Changes to Prescribing
- Medical Board of Australia - Classification of Rural Generalists

Inquiries

- House of Representatives Inquiry into the Recognition of Unpaid Carers
- Senate Inquiry Climate Change Amendment (Duty of Care and Intergenerational Climate Equity) Bill 2023
- Commonwealth Government COVID-19 Response Inquiry
- Senate Inquiry into Menopause and Perimenopause

Department of Health and Aged Care

- National Consumer Engagement Strategy for Health and Wellbeing
- National Health and Climate Strategy

Other

- Improving Alignment and Coordination between MRFF and MREA
- TGA Lifecycle Assessment Standards Survey
- NHMRC Statement on Consumer & Community involvement in health & medical research
- Australasian College for Emergency Medicine - Guidelines for Constructing a Sustainable Emergency Medicine Workforce

Health Policy and Research Advisory Committee

HCCA's Health Policy and Research Advisory Committee (HPRAC) provides oversight and advice on HCCA policy submissions and position statements. Members of HPRAC are HCCA members with personal and professional expertise and experience across a wide range of policy issues and health care settings.

The Committee met five times during 2023-24.

Members of the Health Policy Advisory Committee are: Fiona Tito Wheatland, Indra Gajanayake, Emma Baldock and Shelley McInnis.

During this reporting period, HPRAC was involved in the following work:

- HCCA 2023-24 ACT Government Budget Submission
- HCCA's priorities for the ACT election
- HCCA advocacy priorities for 2023-24
- HCCA's Integrated Care Project
- HCCA Research project: Experiences of Older Adults with Dementia - Healthcare Access in Residential Settings
- Proposed HCCA project scoping and feasibility assessment

HPRAC also provided advice on HCCA's policy responses to:

- ACT Health Directorate Clinical Governance Framework
- Canberra Health Services - ACT Pathology: timing of the release of sensitive results to patients via MyDHR
- Palliative Models of Care
- Voluntary Assisted Dying
- Commonwealth Government COVID-19 Response Inquiry
- Senate Inquiry, Climate Change Amendment (Duty of Care and Intergenerational Climate Equity) Bill 2023
- ACT Health Child and Adolescent Clinical Services Plan
- Guidelines for Constructing a Sustainable Emergency Medicine Workforce
- Canberra Health Services Elder Abuse Guideline





Consumer Reference Groups

Consumer Reference Groups bring together members, consumer representatives, and nominees from support “groups and health service organisations to inform HCCA’s position on health policy and research, and identify issues of importance to consumers.

The goal is for the consumer voice to shape the health services we use. These groups also help ensure that future health strategies and policies are, in fact, consumer driven.

During 2023-24 HCCA had two active Consumer Reference Groups:

1 Health of Older People

2 Quality and Safety

Health of Older People Consumer Reference Group

The Health of Older People Consumer Reference Group is chaired by Adele Stevens and met three times during the 2023-24 period.

This group meets to:

- Identify and advocate for the health needs of older people in the ACT and surrounding region.
- Share information and foster relationships between consumers and health services.
- Ensure consumer participation on issues relating to the health of older people across the ACT and region.
- Provide a reference point for the development of consumer centred care within health and community services.

In this period the committee has provided input on:

- Canberra Health Service Acute Integrated Palliative Model of Care
- Emergency Department Geriatric Streaming
- Quality Use of Medicines Project: Antidepressant Use
- Issues with waiting times for Aged Care Assessments

Quality and Safety Consumer Reference Group

The Quality and Safety Consumer Reference Group is chaired by an HCCA staff member. The Group met online five times throughout the 2023-24 period.

This group meets to:

- explore quality and safety issues in health care
- provide consumer input on quality and safety issues and related projects
- inform HCCA advocacy work
- provide support to the consumer representatives who sit on quality and safety committees.

In this period the committee has provided input on:

- Canberra Health Services - Consent for Healthcare Treatment Guidelines
- Australia Commission on Safety & Quality in Health Care (ACSQHC)- Aged Care Infection Prevention and Control (IPC) Guide
- Canberra Health Services - ACT Pathology timing of the release of sensitive results to patients via MyDHR
- ACT Health Directorate - Clinical Governance Framework
- Therapeutic Goods Administration (TGA) - Website user experience survey
- Australian Commission on Safety & Quality in Health Care (ACSQHC)- draft Chronic Obstructive Pulmonary Clinical Care Standards

Other topics covered include:

- Canberra Health Services – Patient Flow Plan
- Canberra Health Services - Patient Experience Videos
- ACT Health Directorate - Public Health Services monthly performance reporting
- North Canberra Hospital - Clinical Governance Structure
- Canberra Health Services – Clinical Incident reporting
- ACT Health Directorate - Quality, Safety, and Consumer Engagement Strategy
- ACT Health Directorate - Clinical System Governance Framework.
- North Canberra Hospital – Short Notice Assessment

“

“HCCA has been essential for us to make sure that our facilities cater for all. HCCA bring the advocacy and information that without which we [CHS] would not have created the best facilities or had the best ability to deliver services to the whole community.”
(HCCA Impact Report)

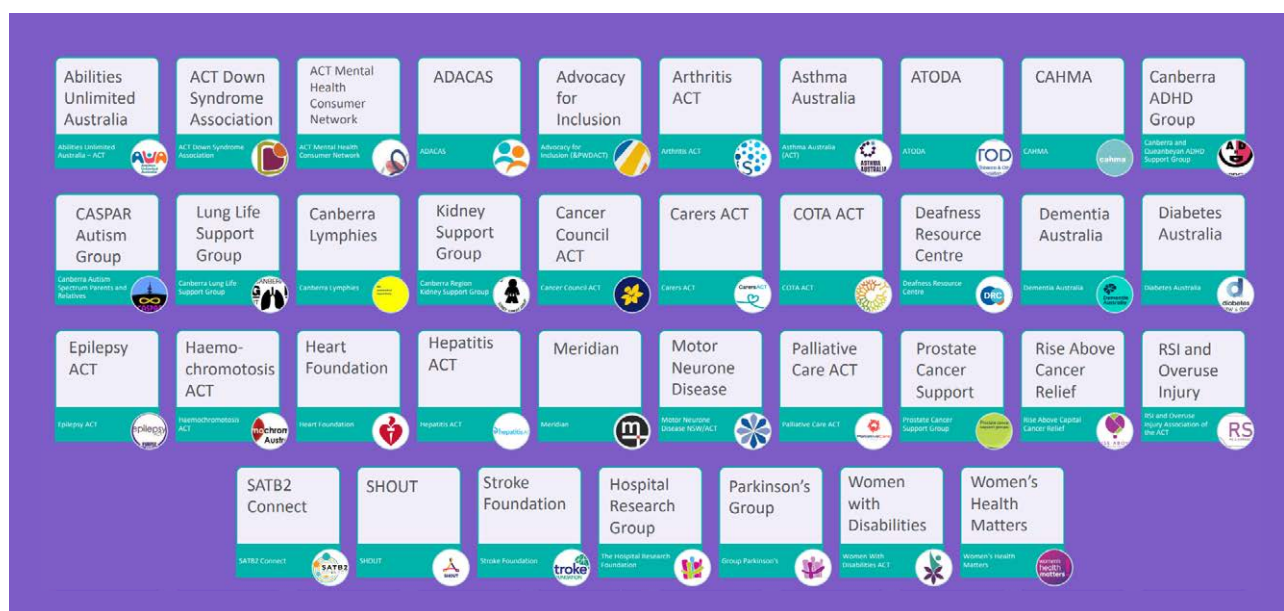


Chronic Conditions Network

The Chronic Conditions Network (the Network) was launched in May 2023 with the goal of identifying key issues affecting consumers with chronic conditions and strengthening collaboration on advocacy on these issues.

During 2023-24, the Network Coordinator position was made permanent and included in HCCA's core funding, thus cementing the Chronic Conditions Network as core part of HCCA's operations.

The Chronic Conditions Network met ten times during 2023-24 and has had engagement from the following organisations:



The key topics discussed at the network meetings were generated from within the Network based on information, advice and strategies to overcome identified challenges.

Topics included:

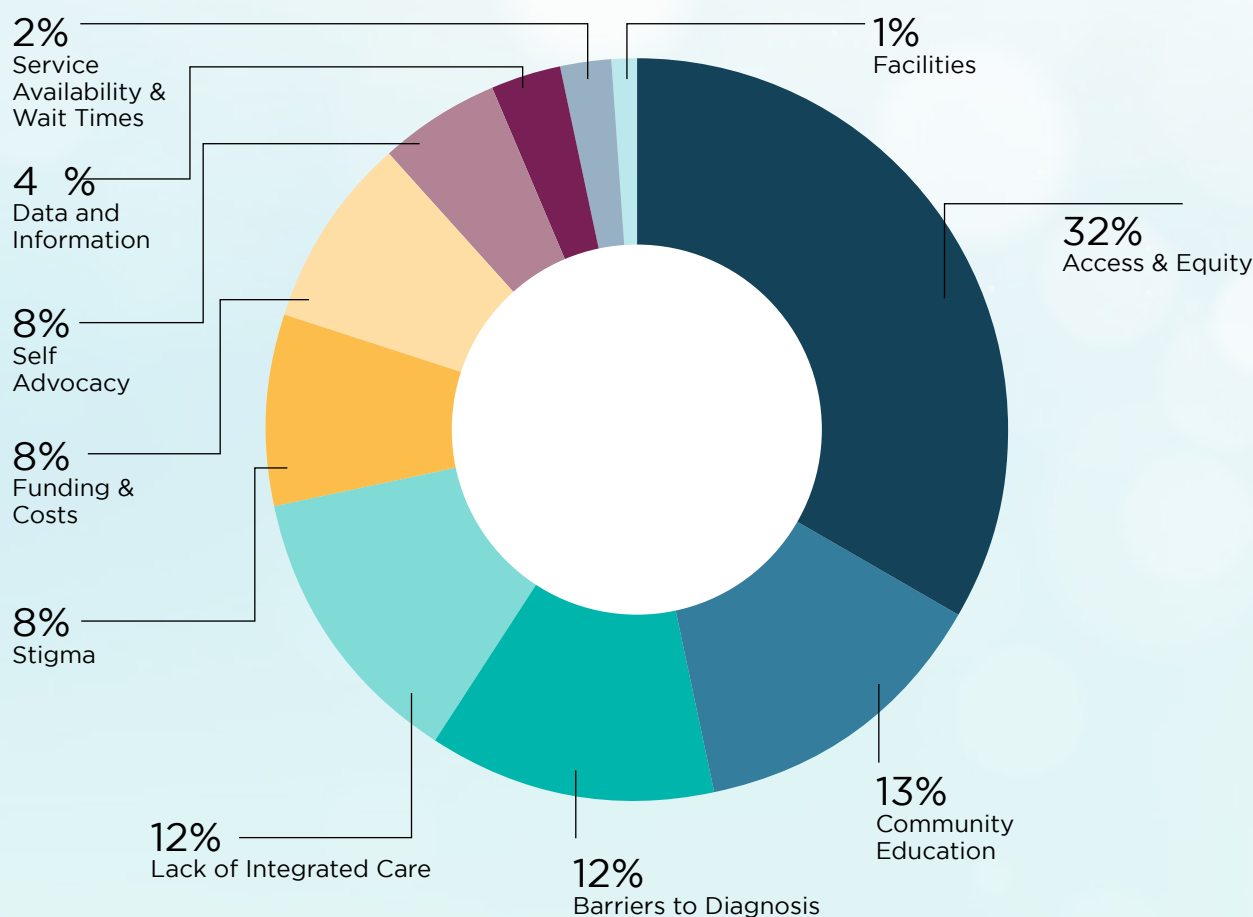
- Staying Safe in Hospital – What do your members need?
- Engaging with Canberra's Multicultural Communities.
- Self-Advocacy in managing chronic conditions in the health system.
- HealthPathways – Direct Feedback from Community Organisations.
- Chronic Conditions and Mental Health – The Head to Health Model.
- Peer Support – Challenges and Benefits of this Model.

HCCA maintains a register of issues raised by the organisations at Network meetings, and they have informed HCCA's systemic advocacy. The issues raised by Network members have been the focus of working groups, workshops, and collaborative projects. The challenges experienced by people with chronic conditions when accessing health care in the ACT is summarised into broad themes:

- Access and Equity
- Barriers to Diagnosis
- Data and Information
- Digital Literacy / Usable Systems
- Lack of Integration / Shared Resources
- Multicultural Communities
- Self-Advocacy
- Service Availability & Wait Times
- Stigma

Access and Equity issues make up approximately a third of the listed challenges, followed by 'Community Education (encompassing health literacy)', systemic barriers to diagnosis and lack of integration in care across the health system.

CCN Issues Register 2023-2024





Research Projects Highlights



Integrated Care: Consumer and Provider Perspectives in the ACT region

This year we finalised two research projects focussing on integrated care in the ACT. The first project explored experiences and expectations of integrated care in the ACT and region. Research Officer Shivana Chandra spoke with more than 25 consumer representatives, specialist health services and community organisations to understand their perspectives on opportunities and challenges for the provision of integrated care in the ACT.

The second project explored the experiences and expectation of integrated care for people with chronic conditions and/or complex health circumstances. Research Officer, Shivana Chandra, conducted interviews with 20 adults from the ACT and surrounding region to learn about how they manage their chronic health conditions and their experiences of integrated care. The findings of this project were analysed and reviewed, and the early findings of this project were presented at the 3rd Asia Pacific Conference on Integrated Care in November 2023. The final report, *Integrated Care in the ACT Region: Consumer perspectives* was published in July 2024.

You can read the final report on both projects on the HCCA website at: <https://www.hcca.org.au/publications/>

The Health Policy and Research Advisory Committee and wider HCCA staff team have provided invaluable advice and support on this program of work. This work was supported by the ACT Health Directorate.



New Project: Experiences of Older Adults with Dementia - Healthcare Access in Residential Settings

In 2024, we commenced a new research project that seeks to explore the experiences of people living with dementia and their families and carers in accessing health care in the ACT. This project will focus on older adults who are experiencing the behavioural and psychological symptoms of dementia (BPSD) and living in a residential aged care facility (RACF).

This work is supported by the ACT Health Directorate. This project has been informed and guided by invaluable advice from the HCCA Health Policy and Research Advisory Committee, the HCCA Health of Older People Consumer Reference Group and individual consumer members of the HCCA.



Consumer participation in research

We have continued to recruit and support consumer representatives participating in a range of research projects conducted by universities and other research organisations in the ACT this year. This has included participation as members of advisory groups for research projects and in the governance of research programs.

HCCA has continued to support consumer representatives on the ACT Health and Wellbeing Partnership Board's Research Working Group which has been focussed on progressing the implementation of the ACT Health Directorate Research Strategic Plan (July 2022).

The CHS Research Strategy Guiding Group started their implementation of the CHS Research Strategy 2021–2025 in 2023, and HCCA continued to support consumer participation on the group. As part of the strategy implementation, HCCA Director, Darlene Cox participated as a member of the CHS Consumer and Community Partnership Collaborative Working Group to help inform how clinician researchers can engage with and involve consumers across all stages of research. HCCA have provided input and feedback in the development of a toolkit of resources and information for clinician researchers to support them in engaging consumers in research. In 2024, the CHS Office of Research and Education plan to continue implementation by creating a resource toolkit to support consumers who are interested in or already involved in research projects. HCCA will support consumer participation in the development of the toolkit, through consumer input and feedback.

HCCA has continued to support consumer representation on the advisory committee for the Canberra Health Services Annual Research Meeting (CHARM) held in June 2024. The advisory committee have provided oversight and guidance with identifying focus themes, keynote speakers and workshops for the 2024 program. HCCA Research Officer, Shivana Chandra was invited to present at the conference to provide updates on the research being conducted at HCCA.

Service planning and design



Paediatric Liaison and Navigation Service Project

This year we finalised our work with the members of the Paediatric Liaison and Navigation Service (PLaNS) Consumer Reference Group and the staff at the Canberra Health Services Integrated Care Program and the PLaNS staff team. Since 2022, HCCA has chaired the Consumer Reference Group and provided secretariat support.

In 2023 and 2024, our reference group provided oversight and advice on the development of a monitoring and evaluation framework to ensure the service is meeting the needs of children and their families.

With input and guidance from the Reference Group, HCCA have developed consumer resources designed to provide information for families with children with complex health needs. These resources include fact sheets when travelling interstate, and finding supports when caring for a sick child. You can find the resources on the CHS PLaNS website here: <https://www.canberrahealthservices.act.gov.au/services-and-clinics/services/paediatric-liaison-and-navigation-service-plans>

HCCA have also developed a self-paced online learning tool for parents that provides them with useful information and advice on how to manage and support their family and to advocate for their child's needs. You can find the learning module on the HCCA website: <https://www.hcca.org.au/for-patients-carers-and-families/self-advocacy-for-parents/>

The group concluded their work in June 2024. We appreciate the generous time and contribution of all the members of the Reference Group, and the trust they have placed in the process of working together with HCCA and with Canberra Health Services:

- Bec Davey, Arthritis ACT
- Suzanne Tunks, Stella Bella Little Stars Foundation
- Fiona Tito Wheatland
- Jemma Irving
- Patricia Murray & Shannon Kolak, ACT Down Syndrome Association
- Sally-Anne Clarke
- Kat King, Diabetes NSW and ACT
- Jess Lamb (HCCA Policy Officer)

We extend our thanks to our project partners at Canberra Health Services. The positive, collaborative relationship between HCCA and CHS has resulted in the creation of a new service that demonstrably benefits families who have a child with complex medical needs.



Liaison and Navigation Service

This year we also concluded our work with the Canberra Health Services Integrated Care Program team to co-design the Adult Patient Navigation Service for adults with chronic and complex health needs in the ACT and region.

The Liaison and Navigation Service is designed to support adults with multiple chronic conditions, including a mental health condition, and adults who have high rates of attendance to the Emergency Department, to access care. The service launched in late 2023.

HCCA supported the development of the service by facilitating numerous workshops with community organisations and consumers to inform the service model. HCCA have also been involved in the recruitment of staff for the project. In 2023 and 2024, HCCA progressed our collaborative work with the Integrated Care Program team and the Liaison and Navigation team to review the service model and develop an evaluation model to ensure it is meeting the needs of adults with multiple chronic health conditions.

We value the contribution that has been made to this project from:

- Arthritis ACT
- Epilepsy ACT
- Diabetes ACT
- Asthma Australia
- Canberra Lung Life support group
- Meridian
- Alcohol, Tobacco and Other Drug Association ACT (ATODA)
- Carers ACT
- Huntingtons NSW/ACT
- Canberra Alliance for Harm Minimisation & Advocacy (CAHMA)
- Women's Health Matters
- Mental Health Consumers Network





Digital Health Record

The ACT Digital Health Record was launched in November 2022. The ACT Digital Health Record includes all services and care provided by ACT public health services. This includes Canberra's public hospitals, community health centres and Walk-in Centres. The ACT Digital Health Record is a personal record that can be accessed by the health care team at any service location. It is intended to allow faster and more complete access to information, helping to reduce errors and duplication and enable service staff to focus on the person requiring care, rather than searching for key health information.

Consumers can access their own Digital Health Record (DHR) through a secure website or a mobile app called MyDHR. Consumers can access and update our own information, see referrals, test results and upcoming appointments as well as access telehealth appointments.

The DHR also provides access to patient education materials, information about prescribed medicines, and the capacity to complete pre-appointment or pre-admission surveys online. In the future, we expect that capability will increase, and consumers will be able to do things like message their care team and book some public health service appointments online.

HCCA has been involved in the development of the ACT Digital Health Record at several levels through representation on a range of committees including the Digital Health Record Program Board, Clinical Steering Committee, Consumer Experience Steering Committee and the Digital Patient Flow Program Board.

HCCA currently sits on the DHR Consumer Experience Steering Committee and the DHR Safety Management Plan (SMP) Working Group. We continue to advocate for refinement and expansion of the Digital Health Record to ensure it meets the goal of transforming and streamlining health care for consumers in the ACT.





Health Literacy Program

1

Increasing Health Literacy Among Consumers

The Health Literacy team had another huge year in 2023-24. We presented to over 781 people in 40 presentations on topics such as *Navigating the Health System*, *Making the Most of Your Appointment*, and *Managing Your Medicines*. This also includes training for health and community workers, and health students in *Health Literacy*, *Managing Medicines*, *Advance Care Planning*, *Stretching Your Health Dollar*, *Diversity and Inclusion in Health Care*, *Engaging Multicultural Communities* and *Culturally Appropriate Care*. We have also held events for Dying to Know Day (8 August) and Advance Care Planning week (late March) to promote Advance Care Planning and death literacy.

These numbers include 6 presentations to multicultural community groups. The languages spoken by members of these groups include: Dari, Kiswahili, Ukrainian, Samoan, Mandarin, Persian Indonesian, Thai, Lao, Kirundi, Vietnamese, Cantonese, Dinka, Arabic, Farsi, Spanish, Susu, Kuro, Urdu, Turkish, Bengali, and more.

Other highlights include:

- Presenting on Samoan Community radio about the health system and health literacy
- Creating Easy Read translations of our *Staying Safe in Hospital* booklets and *Take Action! Guide to Health Complaints and Feedback in the ACT*.
- Speaking to medical school representatives from Australia and New Zealand about the importance of community engagement at a workshop with the Australian Medical Council.
- Running a stall at the National Multicultural Festival.
- Continuing the work of the Chronic Conditions Network, contributing to research projects and HCCA policy submissions.



2

Canberra Health Literacy Hub

We continue to maintain and update the Canberra Health Literacy Hub with resources on health literacy for consumers, community organisations and health services. HCCA members generously helped us review the consumer section of the site in early 2024 and we developed a new page on Palliative Care and End-of-Life in March 2024. You can visit it at: <https://cbrhl.org.au/>

3

Managing Your Health Seminar Series

The Managing Your Health Seminar Series is a series of evening seminars designed for people living with chronic conditions. Since HCCA began to host these seminars in 2018, we continue to tailor the topics in response to feedback from participants.

The seminars feature registered health professionals presenting on a range of topics broadly relevant to people living with chronic conditions. Occasionally non-health professionals speak on topics about consumer advocacy or health literacy.

During this reporting period, 7 sessions were delivered to 115 participants. HCCA is grateful to the health professionals who volunteer their time to present these sessions and answer questions from participants.

Our partners in this series include:

- Dr Roopa Gawarika from the Canberra Region Neurology and Pain Centre,
- Emilia Roberts and the Master of Nutrition and Dietetics students from the University of Canberra,
- Megan Layton from Simply Mindful,
- Ricky Lee from the Walking Clinic,
- Dr Srikanth Karumuri from the Dental Embassy Lyneham, and
- Dalal Dawood Baumgartner and Emma Sharman, our self-advocacy volunteers.

Our Managing Your Health series of seminars for people with a chronic health condition covered these topics in 2023-24:

- Managing Chronic Pain - July 2023
- Gut Health for Overall Health - August 2023 and June 2024
- Mindfulness and Managing your Mental Wellbeing - September 2023
- Looking After your Feet - October 2023
- Dental Health Links to Chronic Conditions - April 2024
- Self-Advocacy in Managing Your Healthcare Journey - May 2024

4

Advance Care Planning Program

HCCA provides community education sessions for people with chronic health conditions and their carers on Advance Care Planning so that they can plan ahead for their care if they are ever unable to speak for themselves. We have worked with Dementia Australia, the Hospital Research Foundation – Parkinson's and Meridian to hold sessions this year.

In 2023-24, we have worked closely with the Advance Care Planning team at Canberra Health Services to set up and advertise their clinics, where people can book an appointment for individual support with their Advance Care Plan a few weeks after the presentation from HCCA. Dementia Australia and the Hospital Research Foundation – Parkinson's now have regular sessions for their members to complete an Advance Care Plan.

5

Using Medicines for Better Health Project

In September 2023 we began work on a Consumer Health Literacy grant, awarded under the Australian Government's Quality Use of Diagnostics, Therapeutics and Pathology (QUDTP) Program. The QUDTP grants aim to support consumer health literacy and improve the use of medicines in Australia.

The Consumer Health Literacy grant funds a 2-year project coordinated by HCCA called *Using Medicines for Better Health*. As part of this project we are also working on a parallel project with Medcast Pty Ltd, who received a grant for Health Professional Education.

The aim of these projects is to develop free educational information and resources for use by both consumers and health professionals. The resources focus on four health areas where we know consumers can experience problems with medicine quality and safety:

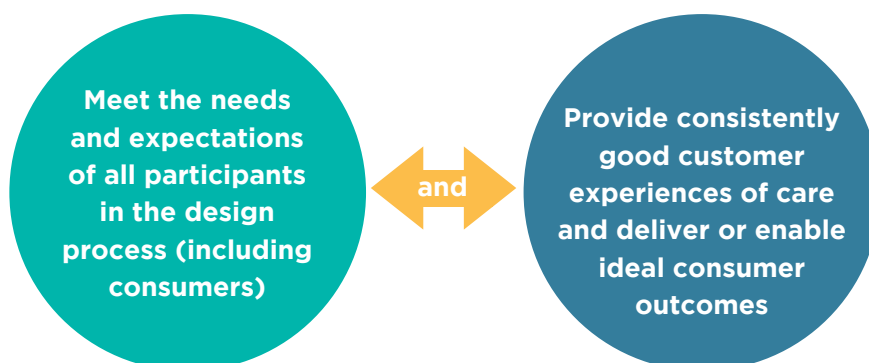
- Atopic dermatitis (eczema)
- Gout
- Antidepressants in Older People
- Oral Anticoagulants (blood thinning medication)

HCCA's *Using Medicines for Better Health Project* focuses on ensuring consumers' needs and perspectives are reflected in the resources developed for both consumers and health professionals. The grant for Health Professional Education, led by Medcast Pty Ltd, is creating a comprehensive suite of interactive learning activities and resources for health professionals.

Our work on these two grants in partnership with a number of organisations has brought together quality use of medicines expertise, researchers, education providers, colleges, peak bodies and consumer groups. This collaborative approach includes both consumer and healthcare professional perspectives at every stage of development. The shared governance processes between these two grants provides a unique opportunity to co-design educational programs and complementary resources to address medication issues for millions of Australians.

Co-design - what is it?

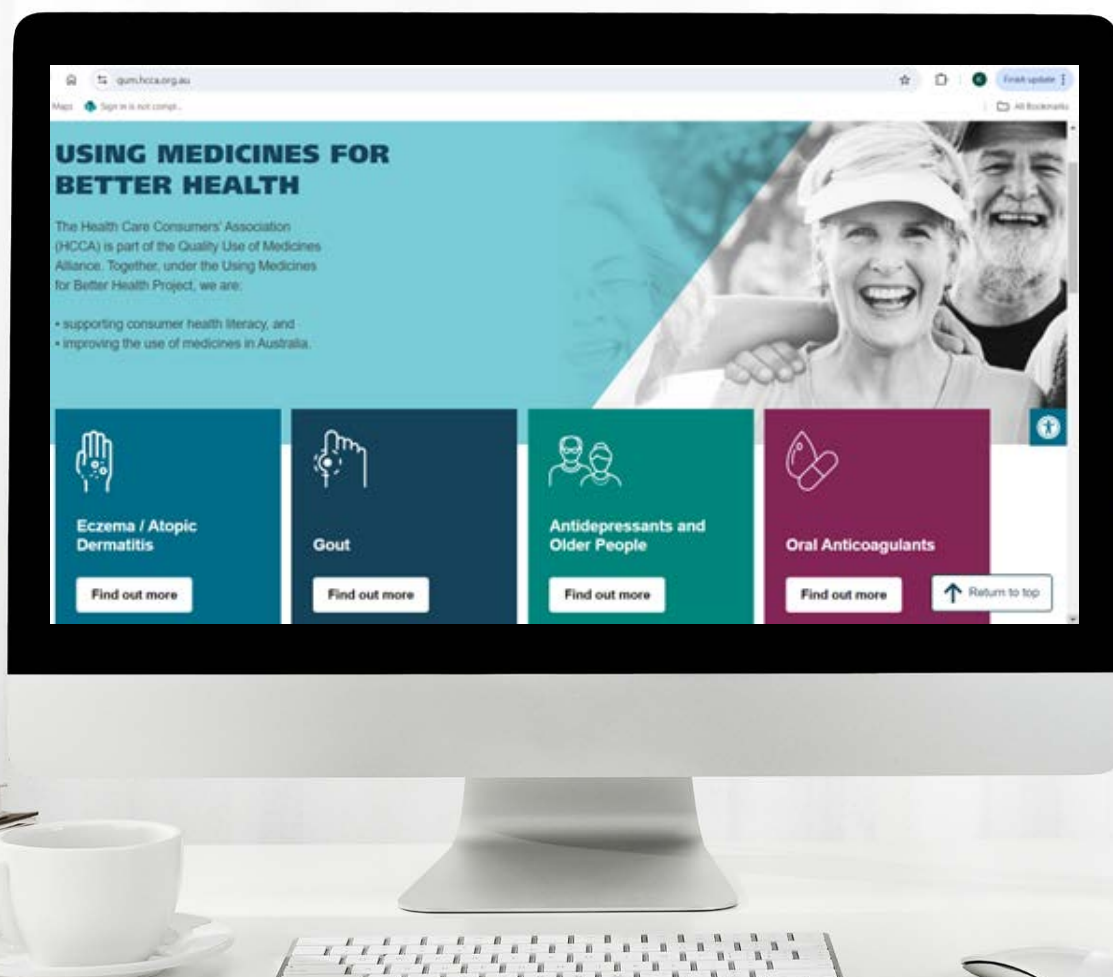
Co-design aims to ensure that services, policies and programs:



QUM Website

As part of the *Using Medicines for Better Health* project, HCCA has launched a new Consumer Hub website: <https://qum.hcca.org.au/>

The website provides high quality information for consumers developed through the project about safe and wise use of medicines .





Consumer and Community Participation

1

Consumer Representatives Program

During the 2023-24 period, our main focus was on completing a review of the Consumer Representative Program, which was finalised at the end of 2023. HCCA periodically reviews this program to ensure that it is an effective mechanism for consumer input into healthcare. We gathered feedback by interviewing and surveying consumer representatives on health committees, and health service partners to understand their experiences with the program. The review will help guide improvements and ensure that consumer representatives continue to be well supported to do this work.

You can find a copy of the review on the HCCA website at:

<https://www.hcca.org.au/publication/consumer-reps-program-review-2023/>

As part of the Consumer Representative Program review, HCCA completed a report titled Reflections on Consumer Involvement in the Canberra Hospital Expansion Project. Consumers involved throughout the project were approached to provide their insights on the experience. The report captures their reflections, along with input from community organisation representatives and HCCA staff. Consumers who participate in health infrastructure projects have specific needs for information, support and participation mechanisms. The intention of this report is to learn from this project and document the wins and improvements needed to ensure successful consumer involvement in future infrastructure projects.

You can find a copy of the report on the HCCA website at: <https://www.hcca.org.au/publication/reflections-on-consumer-involvement-in-chep/>

During this period, we also supported the establishment of three consumer consultation groups; the CHS - Oral Health Services Consumer Reference Group, ACT Health Directorate Health Infrastructure Consumer Reference Group and the ACT Ambulance Service - Consumer Advisory Group.

2

Consumer Participation Training

HCCA runs free consumer participation training each year.

This year, training was offered online on:

- 4 and 11 August 2023 (11 attendees)
- 6 November 2023 - Health Infrastructure Consumer Reference Group.
- 11 and 18 November 2023 (11 attendees)
- 1 March 2024 (6 attendees)
- 18 April 2024 - Consumer training for the ACT Ambulance Service Consumer Advisory Group. (13 consumers)



“

“Almost 25 years since its establishment, the Consumer Representatives Program (CRP) is a mature, impactful, and well-regarded program” (Consumer Representatives Program Review: 2019-2023)



Consumer Participation

Consumer Participation Committee

The Consumer Participation Committee is made up of a small number of HCCA's experienced consumer representatives. Its work is to guide and review matters relating to consumer participation at HCCA. Regular tasks include:

- Review HCCA and external policies relating to consumer representation, including HCCA's Consumer Participation Framework.
- Consider and advise the Executive Committee on risks associated with consumer participation activities.
- Make endorsements of consumer representatives to committee roles, considering the best fit for each appointment.

It also advises on consumer representation issues, considers innovative ways to support and promote consumer participation in health, and oversees consumer representative training.

HCCA would like to thank the following members for their work on the Consumer Participation Committee in 2023-24: Sue Andrews (chair), Alan Thomas, Linda Trompf, Lou Bannister and Miriam Pavic

HCCA staff supporting the Consumer Participation Committee were: Nadia Owuor, Kate Gorman and C Moore.

Consumer involvement in Health Infrastructure

HCCA has been actively involved in health infrastructure in the ACT since 2008. We have contributed to the Capital Asset Development Program, Health Infrastructure Program as well as the current program. This includes the planning and design of community health centres, walk in centres, Canberra Region Cancer Centre, Women and Children's Hospital, University of Canberra Public Hospital, master planning of hospitals and the Canberra Hospital Expansion. Over this time HCCA has built considerable knowledge and expertise in consumer centred design. We have proven expertise in articulating and advocating for consumer priorities on health infrastructure, established trust with consumers and representative organisations, and mature engagement strategies. This expertise significantly enhances the quality of infrastructure projects. This year we continued to contribute to the design of the Critical Services Building as part of the Canberra Hospital Expansion Project.

The new Critical Services Building (Building 5) opened in August 2024. Some members were able to see their advocacy efforts during tours of the building before it opened. Consumers continued to work with HCCA before the opening to advise on new consumer handouts and reflect on what they learned during the project. Consumers' input shaped wayfinding, signage, lighting, and interiors, the selection of artists and concepts for art installations. This input led to designs that significantly improve the hospital's accessibility and functionality for both consumers and carers including:

- carer zones and fold-out beds, dimmable lighting, and power points to allow consumers to charge their devices in patient rooms
- a private family respite lounge with kitchenette, meeting room and showers
- improved accessibility, such as service counters at wheelchair level, better wayfinding and signage
- a reception hall, children's play zone, and sensory room in the ED
- communal spaces for visitors and personal storage areas
- a 'Changing Places' bathroom, including a ceiling track hoist system to meet the needs of people with disability and their carers.

In March 2024 Kate Gorman joined Major Projects Canberra staff on a trip to John Hunter Hospital in Newcastle, and the new Maitland hospital. The tour of John Hunter Hospital site revealed some familiar challenges to those working in health infrastructure in the ACT - a mix of old and new buildings, designed to different standards, practical needs and philosophical ideas, all vying for space and connection on a challenging site. We heard some great presentations about consumer input to the new buildings. Stand-outs were the collaboration with local indigenous communities in the design of buildings and landscape for the new infrastructure, and the innovations in sustainable health care design. At Maitland hospital we had a tour of the new build and heard some eye-opening stories about what it took to transfer an entire working hospital from the old site to the new site, kilometres away, in a single day.



“Consumer involvement throughout the Canberra Hospital Expansion Project has fundamentally altered how we [MPC] think about health infrastructure ... This work highlights the importance of a consumer-focused approach in hospital design.” (HCCA Impact Report)



Health Infrastructure Consumer Reference Group

In 2023, HCCA worked with ACT Health to establish the Health Infrastructure Consumer Reference Group (HICRG). Members identified as neurodivergent, LGBTQIA+, religious, disabled, parents, carers and having lived experience of chronic conditions, being a young carer, parent of children with disability, caring for aging parents, caring for person with dementia, mental illness, and disabilities.

This wide range of member perspectives and experiences has led to valuable feedback on issues like wayfinding, dementia-friendly design, standardisation, meeting carer needs and service delivery. There have been 5 meetings and site visits during this period, covering topics such as hospital design, site overviews, service mix selection and communication strategies.

Contribution to other infrastructure projects.

HCCA has been working to make sure lessons learned from Building 5 are informing new projects. We have been able to contribute consumer advice to projects through tailored lists of suggested design features for projects such as:

- Acute Palliative Care Ward at Canberra Hospital
- Conder and Griffith Health Centres
- Endoscopy Expansion project
- Northside Northern Block Mental Health services



“HCCA’s work partnering with health services to support project-specific consumer advisory groups (e.g. in CHEP and Paediatric Liaison and Navigation Service) are a promising model for wider use within health services” (Consumer Representatives Program Review: 2019-2023)



Consumer Representatives 2023-2024



43

volunteer reps



130

committees

In 2023-2024 HCCA supported 44 volunteer consumer representatives on 130 committees! Our consumer representatives are involved in a variety of different committees with the ACT Health Directorate, Canberra Health Services, Calvary Public Hospital, and other ACT and national bodies.

Consumer Representatives

Adele Lewin
Adele Stevens
Alan Thomas
Ankith Arun Aswath
Anthea Kerrison
Arun Aswathanarayana
Beatrice Vann
Bob Bannister
Carolyn Smith
Darryl O'Donnell
Eliza Molony
Emma Baldock
Fiona Tito Wheatland
Gev Khambata
Heather Warfield

Heidi Prowse
Helen Hudson
Indra Gajanayake
Jason Willmot
Janine Robertson
Jenny Berrill
Jo Bothroyd
John Meyer
Julia Rollings
Julie Veitch
Karin Calford
Katrina Muir
Keith Willenburg
Linda Powell
Linda Trompf

Louise Bannister
Marion Reilly
Mike McCartney
Miriam Pavic
Pat Branford
Pauline Winslade
Riley Curtin
Russell McGowan
Shelley McInnis
Terri Warner
Trish Lord
Vanessa Goss
Yvonne Solly

Organisational Representatives

The following staff represented HCCA on committees:

Kathryn Briant
Shivana Chandra
Darlene Cox
Michelle Cullen

Kate Gorman
Jessica Lamb
C Moore
Nadia Owuor

Ivapene Seiuli
Darcy Whitmore



List of Consumer and Organisational Representative Positions 2023-2024



605.87 hours

preparing for
meetings

788.7 hours

in meetings

In the 2023-24 period HCCA supported 43 volunteer consumer representatives on 130 committees. Our consumer representatives are involved in a variety of different committees with the ACT Health Directorate, Canberra Health Services, North Canberra Hospital, and other ACT and national bodies.

HCCA Staff are marked with an *

Local

ACT Health Directorate

Committee	Consumer/ Staff (*) Representative
ACT Ambulance Service Consumer Advisory Group	C Moore*
	Nadia Owuor*
ACT Child and Adolescent Clinical Services Expert Panel	Fiona Tito Wheatland
ACT Disability Health Strategy Steering Committee	C Moore*
	Louise Bannister
ACT Health System Council	Darlene Cox*
ACT Palliative Care Governance Committee	Adele Stevens
ACT Palliative Care Operations Management Committee	C Moore*
	Kate Gorman*
ACT Quality and Safety Leadership Network	Jenny Berrill
ACT Safer Baby Bundle Working Group	Jessica Lamb
ACT Virtual Care Strategy, Project Control Group	Darryl O'Donnell
Activity Based Management Project Steering Committee	Darlene Cox*
Australasian Health Infrastructure Alliance	Darcy Whitmore*
Behavioural and Psychological Symptoms of Dementia Health Advisory Network	Carolyn Smith
	Shivana Chandra*
Canberra Region Medical Education Council Sub-Committee	Emma Baldock
Canberra Script Stakeholder Engagement Group	Jessica Lamb*
	Kathryn Briant*

CHARM 2024 Advisory Committee	Shivana Chandra*
Clinical Systems Governance Committee	Linda Trompf
Community Health Infrastructure Project, Project Control Group	Darcy Whitmore*
Digital Health Record Consumer Experience Steering Committee	Jessica Lamb*
	Kathryn Briant*
Digital Health Record Consumer Experience Advisory Board	Jessica Lamb*
	Michelle Cullen*
Disability Health Reference Group	C Moore*
Health Technology Advisory Committee	Keith Willenburg
	Russell McGowan
Integrated Care Working Group	Shivana Chandra*
LGBTIQ+ Health Reference Group	Darlene Cox*
Maternity in Focus Advisory Group	Jessica Lamb*
Medical and Dental Appointment Advisory Committee	Linda Trompf
Nursing and Midwifery Leaders Network	Vanessa Goss
Nursing and Midwifery -Towards a Safer Culture Steering Committee	Heather Warfield
Phase One Nurse-to-Patient Ratios Technical Reference Committee	Heidi Prowse
Territory Wide Health Infrastructure Consumer Reference Group	Ankith Arun Aswath
	Darcy Whitmore*
	Julia Rollings
	Kate Gorman*
	Louise Bannister
Transforming Outpatient Working Group	Riley Curtain
	C Moore*

ACT Community Services Directorate

Committee	Consumer/ Staff (*) Representative
Critical Friends Group	Darlene Cox*

Canberra Health Services

Committee	Consumer/ Staff (*) Representative
ACT Equipment Loans Scheme Advisory Committee	Marion Reilly
ACT Pathology Quality & Safety Committee	Miriam Pavic
ACT Pathology, Building 10, Level 3, Expansion Project Control Group	Darcy Whitmore*
	Miriam Pavic
Acute Palliative Care Project, Project Control Group	Adele Stevens
	Darlene Cox*
Allied Health Leadership Committee	Adele Lewin
	Michelle Cullen*
Allied Health Professional Lead Committee	Adele Lewin
	Michelle Cullen*
Arts in Health Advisory Group	Katrina Muir
Bariatric Surgery Advisory Committee	Trish Lord

Standard 7 Blood Management (NSQHS Standard)	Linda Trompf
Breast Screen ACT Reference Group	Louise Bannister
Breast Screen Quality Committee	Louise Bannister
Cancer and Ambulatory Support Clinical Governance Committee	Indra Gajanayake
Cancer Consumer Reference Group	Anthea Kerrison
	Carolyn Smith
	Darlene Cox*
Centenary Hospital for Women and Children Expansion Project Control Group	Miriam Pavic
CHS Governance Committee	Alan Thomas
CHS Learning and Teaching Strategy Advisory Group	Shivana Chandra*
CHS Research Strategy Working Group	Shivana Chandra*
Clinical Ethics Committee	Linda Powell
	Terri Warner
Clinical Learning and Teaching Strategy Implementation Steering Group	Shivana Chandra*
Clinical Review Committee	Fiona Tito Wheatland
Community Care Program Clinical Governance Committee	Adele Stevens

	Darlene Cox*
Consumer and Carer Committee	Ivapene Seiuli*
	Michelle Cullen*
Consumer Handouts Committee	Adele Lewin
	Heather Warfield
	John Meyer
Delirium Clinical Care Standard Implementation Group	Beatrice Vann
DHR Safety Management Plan (SMP) Working Group	Heather Warfield
Disability Action and Inclusion Plan Implementation Steering Group	C Moore*
Division of Allied Health Quality and Safety Committee	Adele Lewin
Education and Training Committee	Bob Bannister
	Heidi Prowse
End of Life and Palliative Consumer Reference Group	Adele Stevens
Expanding Endoscopy Services Project Control Group	Darcy Whitmore*
Food Services HACCP Training and Quality Meeting	Ivapene Seiuli*
Food Service Model Project Control Group	Darcy Whitmore*

Health Records Advisory Committee	Pauline Winslade
Implementation Working Group (IWG) for Enhanced Health Services	Jessica Lamb*
Infection Prevention and Control Committee	Kate Gorman*
Maternity Quality and Safety Committee	Miriam Pavic
Medical Imaging Project Control Group	Jason Willmot
Medication Safety Committee (NSQHS Standard)	Kathryn Briant*
Nuclear Medicine Imaging project	Jason Willmot
Oral Health Services Clinical Governance Committee	Linda Trompf
Oral Health Services Reform Committee	Linda Trompf
Paediatric Navigation Consumer Reference Group	Kate Gorman*
	Jessica Lamb*
	Shivana Chandra*
Paediatric Quality and Safety Committee	Julia Rollings
Pathology Governance Committee	Miriam Pavic
Policy Committee	Darryl O'Donnell
	Terri Warner
Policy Document Review Panel	Darryl O'Donnell

Pre-Analytical Pathology Working Group	Miriam Pavic
Radiation Safety Management Committee	Nadia Owuor*
RACC Quality and Safety Committee	Louise Bannister
Recognising and Responding to Acute Deterioration Committee (previously, Recognising and Responding to Clinical Deterioration Standard 8 Committee)	Adele Lewin
Transitional Therapy and Care Program Executive Management Committee	Jo Bothroyd
Walk-in Centre Clinical Advisory Group	Yvonne Solly
Women's Health Service Nursing and Medical Service Steering Committee	Jessica Lamb*
Women Youth and Children Community-Consumer Consultative Committee	Jessica Lamb*

Capital Health Network

Committee	Consumer/ Staff (*) Representative
CHN Clinical Council	Shelley McInnis
ACT Health Pathways Governance Committee	Russell McGowan
	Kathryn Briant*
Canberra Community Advisory Council	Karin Calford
ACT/NSW GP Workforce Planning and Prioritisation Program	Kathryn Briant*
COVID-19 Primary Care Emergency Response Working Group Meeting	Jessica Lamb*
	Kathryn Briant*

Major Projects Canberra

CHEP = Canberra Hospital Expansion Project

Committee	Consumer/ Staff (*) Representative
Major Projects Art Advisory Group	Katrina Muir
	Gev Khambata
	Ivapene Seiuli*
CHEP Consumer Reference	Kate Gorman*
	Louise Bannister
	Nadia Owuor*
CHEP Project Control Group	Kate Gorman*

North Canberra Hospital (previously Calvary Public Hospital)

Committee	Consumer/ Staff (*) Representative
Clinical Leadership Group	Darlene Cox*
Human Research and Ethics Committee (HREC)	John Meyer
Partnering with Consumers Committee	Ivapene Seiuli*
	Jo Bothroyd
Clinical Governance Committee	Kate Gorman*
	Darcy Whitmore*
North Canberra Hospital Project Control Group	Kate Gorman*
	Trish Lord
Medication Safety Committee	Shivana Chandra*

University of Canberra

Committee	Consumer/ Staff (*) Representative
Advanced Muscular Skeletal Clinic Steering Committee	Linda Trompf
Active Beginnings Project Co-design Group	Ivapene Seiuli*
Active Beginnings Project Working Group	Ivapene Seiuli*
Clinical Research Rehabilitation and Translation Research Community Partnerships Group	Mike McCartney
CRAMS (Cardiac Rehabilitation for transient ischaemic Attack and Mild-Stroke: the CRAMS randomised controlled trial) Project Advisory Group	Marion Reilly
Faculty of Health Research Committee	Indra Gajanayake
GNC Advisory Group Aged Care Transition to Practice (ACTPP) Advisory Group	Beatrice Vann
HEAL ACT Community of Practice Steering Committee	Kate Gorman
HEAL Health Systems Resilience and Sustainability (HSRAS) Theme	Darlene Cox
Knee Osteoarthritis Project Implementation Working Group	Linda Trompf
Multicultural Mental Health Review Reference Group	Ivapene Seiuli*
Pharmacy Course Advisory Group Committee	Pat Branford

Australian National University

Committee	Consumer/ Staff (*) Representative
ANU Real Price of Health Project Advisory Board	Nadia Owuor* Julie Veitch
ANU Telehealth in Primary Care Project	Mike McCartney
RACGP Education Research Grant Advisory Group	Janine Robertson

Local Organisations

Committee	Consumer/ Staff (*) Representative
ACT Council of Social Service (ACTCOSS)	Disability and Carer Policy Group C Moore*
ACTCOSS	Peaks Strategic Consultative Group Darlene Cox
Canberra Imaging Group	Clinical Risk and Audit Committee Marion Reilly Arun Aswathanarayana
Canberra Institute of Technology	Industry Advisory Group - Diploma of Nursing Eliza Molony
Canberra Region Neurology and Pain Centre	Canberra Region Neurology and Pain Centre (CRNPC) Consumer Support and Training Committee Helen Hudson
Red Cross	Humanitarian Settlement Program Network Ivapene Seiuli*
Synergy ACT	Nursing and Midwifery Research Committee Shivana Chandra*

National

Australian Commission on Safety and Quality in Health Care (ACSQHC)

Committee	Consumer/ Staff (*) Representative
ACSQHC Environmental Sustainability Standards	Darlene Cox*
ACSQHC Health Care Patient Advisory Group	Darlene Cox*
National Safety and Quality Primary Healthcare Standards Steering Committee	Darlene Cox*
Partnering with Consumers Advisory Group	Russell McGowan

Australian Council of Healthcare Standards

Committee	Consumer/ Staff (*) Representative
Australian Council on Healthcare Standards	Russell McGowan
Australian Council on Healthcare Standards State Advisory Committee	Russell McGowan

Australian Digital Health Agency

Committee	Consumer/ Staff (*) Representative
ACT ADHA Digital Health Forums	Jessica Lamb*
	Kathryn Briant*
Faster access to diagnostic imaging and pathology reports in My Health Record – Clinical Reference Group	Darlene Cox*

Australian Pharmacy Council

Committee	Consumer/ Staff (*) Representative
Accreditation Committee	Fiona Tito-Wheatland

National Health and Medical Research Council

Committee	Consumer/ Staff (*) Representative
Partnership Governance Committee	Jenny Berrill

Wiser Health Care

Committee	Consumer/ Staff (*) Representative
Consumer Reference Group	Karin Calford

HCCA Organisational Chart 2023- 2024

As at 30 June 2024

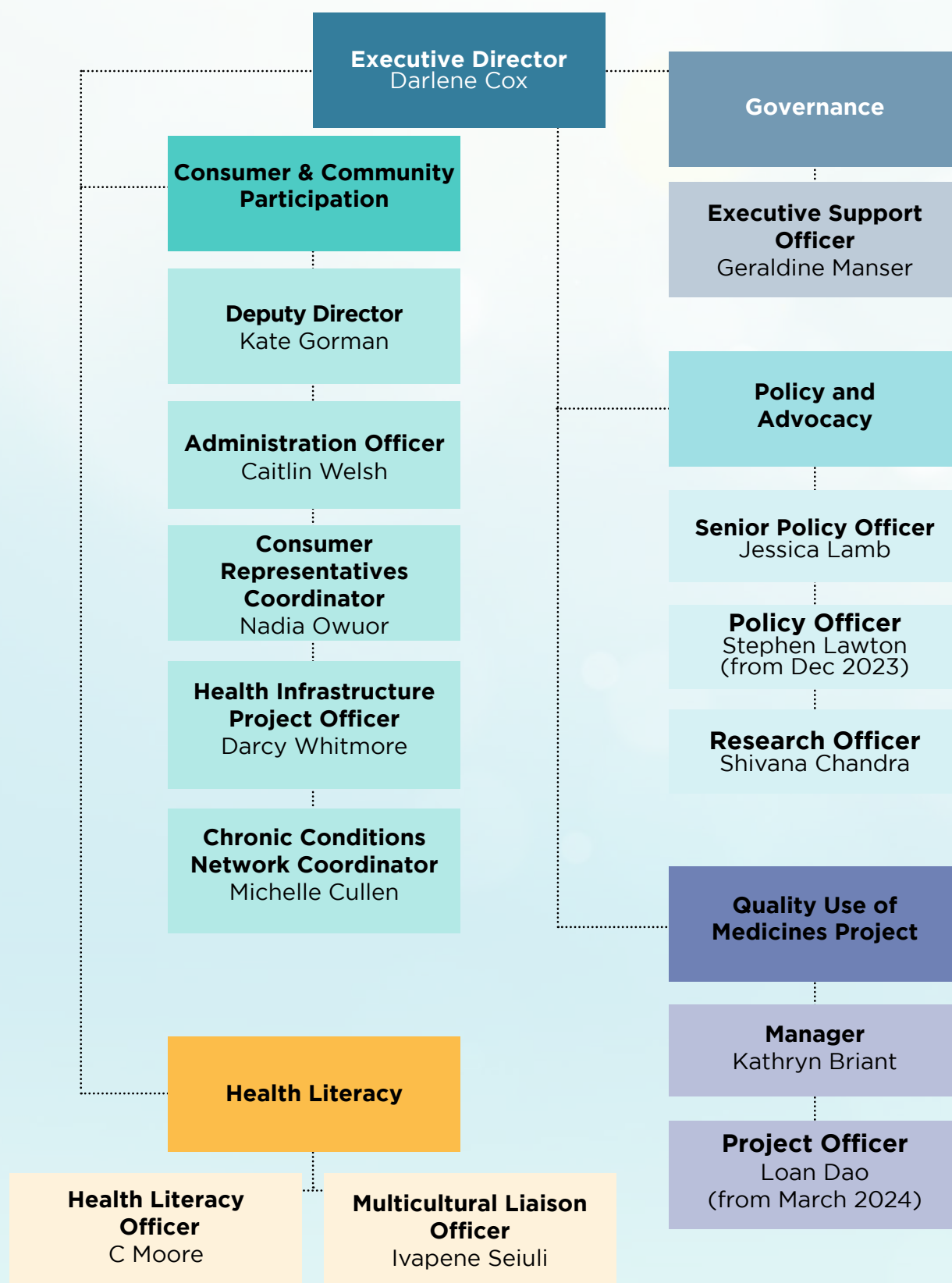


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