



Annual Report 2020-2021

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This report reviews the activities and achievements of Health Care Consumers' Association of the ACT (HCCA) during the period 1 July 2020 to 30 June 2021.

The report is also available on our website at https://www.hcca.org.au/about/governance/annual-report. If you would like a hard copy of this report please contact the office at adminofficer@hcca.org.au.

Acknowledgement of Country

The Executive Committee and staff of HCCA acknowledge the Australian Aboriginal and Torres Strait Islander peoples of this nation and acknowledge them as Australia's First Peoples and as the Traditional Owners and custodians of the land and water on which we rely. We acknowledge the traditional custodians of the Ngunnawal land on which our organisation is located and where we conduct our business. We pay our respects to elders, past, present and emerging, and recognise the ongoing contribution of Aboriginal and Torres Strait Islander people to the life of this city and this region.

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Front cover captions - clockwise from top left: 1. Kate Gorman, Kathryn Briant and Lou Bannister March 2021

- 2. Kate Gorman, Anna Tito, Sarah Spiller, Geraldine Manser and Monica Stonebridge
- 3. Wendy Armstrong and Sue Andrews June 2021
- 4. C Moore Carers Thank You event June 2021

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Our Purpose

The Health Care Consumers' Association (HCCA) is a health promotion charity and the peak health consumer advocacy organisation in the Canberra Region. We have supported and developed health consumer perspectives and policy since incorporation in 1978.

We strive to improve the quality and accountability of health services by giving consumers the opportunity to participate in and influence health policy, planning and service delivery. We routinely consult with consumers and communicate their priorities and issues of concern to the ACT Government, Primary Health Networks, Commonwealth Government and other organisations.

HCCA works closely with consumers and supports consumer representatives to put forward consumer perspectives.

We work to improve health literacy in our community. We also undertake research into consumer experiences of health care.



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 for 2021-2024 was updated during this reporting period. The new version was endorsed by our Executive Committee in June 2021. We want to thank all our members and stakeholders for their input during the review of the Strategic Plan. A copy can be found on our website: https://www.hcca.org.au/about/governance/strategic-plan-2021-2024/



Goal 1

HCCA continues to be a strong and credible voice for consumers on health care



Goal 2

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



Goal 3

High levels of health literacy in Canberra communities



Goal 4

Our members, staff and stakeholders regard HCCA as a strong and responsive organisation

Executive Committee

The Executive Committee are members elected by the membership to take responsibility for the governance and strategic direction of the organisation.

The Executive Committee is responsible for defining and monitoring HCCA's strategic direction, including strategic business planning and risk management. The Executive Committee also oversees the adoption and review of policies relating to the organisational management of the HCCA.

- HCCA met all our 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. The Executive Committee reviewed and endorsed 35 organisational policies.
- Eight Executive Committee meetings were held.

Members of the Executive Committee are:

President: Alan Thomas

Vice President: Dean Hewson **Treasurer:** Indra Gajanayake

Other Executive Committee Members:

Louise Bannister

Bernard Borg Caruana

Bea Vann

C Moore

Linda Trompf

Emma Baldock



Full biographies of the Executive Committee are available on the HCCA website at https://www.hcca.org.au/about/governance/executive-committee/

HCCA members at General Meeting -September 2021



President's Report

Health Care Consumers' Association (HCCA) has had another successful year. We continue to represent a strong consumer voice that delivers on consumer rights and engagement with the ACT Health System.

We have been influential in changes to the design and development of the Canberra Hospital Expansion Project which means the facility will be more attuned to the needs of the consumer. Our work to achieve high levels of health literacy in Canberra communities has continued with the development and operation of the Canberra Health Literacy website and network. The Health Policy and Research Advisory Committee, together with our staff, have been particularly active in providing comments on draft Government policies and the development of research strategies.

The various Consumer Reference Groups and regular consumer forums continue to be a fertile mechanism for members to engage with the work of HCCA. They provide the backbone for members participation in the work of HCCA, together with internal HCCA committees, ACT Health Committees and other external health related committees.

We have excellent relations with the Minister for Health, Ms Rachel Stephen-Smith, and her office, the Opposition Health Spokeswoman, Ms Guilia Jones and the ACT Health Directorate. Relations with Canberra Health Services have had its challenges this year, but I am pleased to say our relationship has improved in the last 4-5 months and they are now very productive and collaborative.

HCCA has consistently advocated for the increased funding of ACT Health Services. It is pleasing, therefore, to see such an increase in the 2021-2022 ACT budget. The budget will also fund a patient navigation system, a proposal that HCCA put forward in our budget submission. It is also noteworthy that money has been allocated to progress the development of a Northside Hospital, for a new carpark at the CHS and expansion of the CHS emergency department. The Canberra Hospital Expansion Project, and other infrastructure projects already progressing or planned, will continue. HCCA will continue its work to ensure the consumers' voice is heard at all stages of the planning and development of the Territory's health care facilities.

I reported last year that the Executive Committee and the Consumer Participation Committee (CPC), working closely with HCCA staff, would be evaluating the results of a survey of members on their experiences and involvement with the work of HCCA. As a result of the survey the process for nomination to various committees has been simplified and streamlined. I believe we have also made progress in recruiting members to serve on higher level ACT Health committees.

This year we have reviewed our membership and the CPC recommended some ways to encourage new members to join HCCA, such as HCCA's attendance at general community forums where we can highlight our work. We have also been building our networks with other community organisations to strengthen our work.

In terms of the governance of the organisation, the Executive Committee continues to function smoothly and has overseen a revision of the Constitution to bring it up to date, and the production of a new Strategic Plan that will apply from 2021 to 2024. The organisation's finances remain sound, as can be seen from the Treasurer's report.

Looking to the future, our three year Service Funding Agreement with ACT Health will expire at the end of June 2022. This agreement funds HCCA's core business and enables us to implement our Strategic Plan. I don't anticipate any problems in negotiating a new Agreement. Whilst I understand the Government is considering moving to a five year grant for peak organisations, I think this will make future longer term planning for HCCA easier and more secure.

We do have a challenge with our accommodation arrangements at the Hackett Community Facility. Better Practice Education Group, known as the Blue Gum School, has applied to purchase all 3 buildings at the Hackett site. HCCA, along with the eight other community groups who are tenants at Hackett, are vigorously opposing this application. Members will be encouraged, as part of this campaign, to write to the Territory's MLAs and Ministers opposing the application by Blue Gum.

The Executive Committee continues to function smoothly and has overseen a revision of the Constitution to bring it up to date, and the production of a new Strategic Plan that will apply from 2021 to 2024".

I thank all members of the Executive Committee for their work and support during the year. Bernard Borg-Caruana is stepping down after four years on the committee. Bernard is always very thorough in his approach to the work of the Committee. Louise Bannister's term has also expired. She has been a member for six years and her experience and steady advice and thoughts have been a boon for the Committee. Indra Gajanayake's six year term as Treasurer has also expired. Indra has done an outstanding job as Treasurer and her eagle eye and attention to detail will be missed

As ever Darlene Cox and our staff have continued to do the important work of supporting our members and delivering on the Strategic Plan. Their support for our members and the work of the organisation has been outstanding and has kept the organisation running smoothly.

The introduction of the COVID lockdown in early August 2021 has had a significant impact on how members and staff carry out the work of HCCA. Darlene Cox, our Executive Director, is a member of the ACT Health Clinical Health Emergency Coordinating Committee. Darlene's appointment is a recognition of the respect that both she and HCCA have as an important voice for consumers and the community in the ACT Health environment. This is a very important committee for the management of COVID in the ACT and it has added a significant extra workload for Darlene and other staff. The pandemic has also had an impact on how members can participate in the activities and work of HCCA. It is probable that this arrangement will continue until at June 2022.

As usual it will be a busy time for HCCA in the coming year. Apart from continuing with our core business, we will be negotiating a new Service Agreement and codesigning with ACT Health the patient navigation system. There will be an increase in work on the planned health infrastructure program, and we will continue to participate in design of health services. We will also continue to undertake research into the consumer experiences of care, and provide consumer input into health policies. As usual we will provide community information sessions and webinars as part of our health literacy program.

HCCA is the strong and vibrant organisation it is today because of the hard work and dedication of our members, and I acknowledge their outstanding work in ensuring HCCA remains an effective voice for consumers' rights in the health system.

Dr Alan Thomas **President**





Executive Director's Report

2019-20 was about responding to the challenges of the bushfires and then the pandemic. 2020-2021 has been about consolidating our response to the health crisis brought about by COVID-19. We have worked hard to ensure a consumer-centred public response to COVID-19.

This has included work on visitation to health facilities, involvement of family, telehealth and identifying issues of concern to consumers that needed a response. Living with this level of uncertainty has been very difficult for people and there is a level of fear and confusion we need to acknowledge and address.

COVID-19 continues to be a strain on our health system, health care workers, consumers, families, and our communities. This has a significant impact on the accessibility and experience of health care. We know this also puts pressure on the wellbeing of health care staff and their ability to provide the standard of care they would like for patients and families. The response by the ACT Government has been excellent, and we are fortunate to have had so few infections for as long as we did. Colleagues in community services also sustained an enormous workload, focussing on the needs of people and communities most at risk of infection and poor outcomes. The response to COVID-19 has truly been a community effort.

I am a member of the Clinical Health Emergency Coordination Centre (CHECC), as the NGO and Community Liaison representative. This role started in March 2020 and has continued during the Public Health Emergency. The CHECC provides advice to the Chief Health Officer on the clinical response to COVID-19 in public and private hospitals as well as services delivered in Walk in Centres and community health centres. Anna Tito and Kathryn Briant have represented consumers on the COVID-19 Primary Care Emergency Response Working Group. We have also provided input to communications and key messages, and raised issues of concern for consumers about testing, vaccination and accessing health care during a pandemic.

Our role as a trusted partner with Government means that we have played - and continue to play - an important role in the COVID-19 response. This has all reinforced the importance of powerful partnerships and trusted relationships between consumers and those working in our health system for the benefit of us all. We are well placed to provide key insights at such a critical time in our community's history.

We have also contributed to a number of priority projects of the ACT Government, including master planning and expansion of Canberra Hospital, the procurement and configuration of the Digital Health Record, as well as participating in high level governance committees across the ACT health system.

The expansion of the Canberra Hospital has been an area of focus. We are working with Canberra Health Services, Major Projects Canberra and Mulitplex to provide consumer input into the design of the new Critical Services building and other works. Kate Gorman chairs the Consumer Reference Group and has coordinated the consumer and community representatives who have been involved in committees, workshops, focus groups and user groups. Our work will continue until the buildings open in 2024.

I want to thank the HCCA staff team for their professionalism and passion for the work we do. They consistently perform at a high level and their work makes a difference."

Digital health has continued to be a key focus this year with our involvement with the ACT Digital Health Record. This is an important development for the ACT and will change the way care is delivered. I am a member of the Digital Health Record Program Board, Kathryn Briant chairs the Consumer Experience Steering Committee and Dean Hewson is a member of the Clinical Steering Committee. We have

established a Digital Health Consumer Reference Group to support our work on the broad range of issues and projects we are involved in. I look forward to seeing this develop with the help of Jess Lamb. The Digital Health Record will go live in late 2022.

For many years we have advocated for more meaningful consumer involvement in research as we know it has many potential benefits, including: research that is more relevant to consumer needs: greater accountability; and improved quality and outcomes with a stronger focus on research translation. We have seen progress on the research agenda in the ACT during this year. The work of HEALTHAnswers is continuing to build. We have worked with Canberra Health Services to develop their research strategy and improve access to clinical trials. We have also worked with a number of universities to provide consumer input into their research projects. The ACT Research Strategy is still in development. This is now part of the remit of the ACT Health and Wellbeing Partnership Board and we are looking forward to this being finalised in the next year. Our Health Policy and Research Advisory Committee has played an important role in our work in health research and I want to thank them for sharing their time and expertise with us.

Building the level of health literacy across our communities continues to be a priority for us. The work of Claudia Cresswell and the Chronic Condition Seminar Series has been extremely well received and the feedback from participants is positive. This seminar series will form a core part of the work that we do going forward. The Community





Health Literacy project has also been highly successful, developing a range of materials for community workers, consumers, carers and health service workers to build their health literacy skills and understanding. Sarah Spiller and Geraldine Manser have worked steadily on this project since 2018 and have demonstrated the need to continue our focus on this. Health literacy is a very important part of our work as it is key to consumers being in control of our own health. Health literacy affects our capacity to make decisions and take action to manage our health, and navigate the health care system.

In February 2021, Roger Killeen died. Roger was a long time and active member of HCCA. He was a very experienced consumer representative and represented consumer interests on a variety of committees at a local and national level. This included significant work on diabetes services, point of care testing, the Walk-in Centres and

the original medical imaging system (RISPACS) at Canberra Hospital. He was also involved in training consumer representatives and served on the committee that oversaw the HCCA Consumer Representatives Program for many years. Roger's contributions to HCCA over the years were greatly appreciated by many members. A kind, generous and respectful man who was an enthusiastic supporter of HCCA and the consumer movement.

I want to thank the Executive Committee for their ongoing support and guidance. I particularly want to thank Alan Thomas, a calm and consistent presence during a challenging year. And Indra Gajanayake has been a fabulous Treasurer for HCCA. Indra finishes her term at this AGM. As Treasurer Indra was tasked with keeping the finances healthy so HCCA could achieve our vision and goals. Thanks Indra, for your questions and attention to detail. Together we have learned a great deal

about new accounting standards!

I also want to thank the HCCA staff team for their professionalism and passion for the work we do. They consistently perform at a high level and their work makes a difference. We met almost all of our contractual obligations which is remarkable given the additional pressure work and life in a pandemic has placed on all of us. The staff team have continued to work in a hybrid model, from home and the office. The time together at the office often involved sharing food and stories and we have tried to maintain that virtually.

The online environment can't replace the face-to-face meetings that so many of us value. We have found a way to use technology to continue our work and talk to consumers, listen to your stories and experiences of health care so that we can be an advocate for consumer interests. This will continue to be a key way we work for the coming years.

One of the highlights of this year was the celebration of consumer and carer representatives event at the Legislative Assembly in June 2021. This event recognised the work of HCCA, Carers ACT and the Mental Health Consumer Network. It was good to see Minister for Health, Rachel Stephen-Smith MLA, and Minister for Mental Health and Disability, Emma Davidson MLA, there to acknowledge the importance role consumers and carers have in planning, designing, and evaluating health services in the Canberra Region.

Darlene Cox

Executive Director





Treasurer's Report

HCCA ended the 2020-21 financial year with a surplus of \$152,201 after the auditor's adjustments for depreciation, the right of use for the lease, annual leave and accrued income and expenses. The effect of this surplus has increased members' equity.

The audited financial statements show that members' equity was \$689,932 at 30 June 2021. This financial year marks the highest members' equity in the history of HCCA. The chart below shows changes in members' equity over the last ten years.

The Association is in a very strong financial position and in the unlikely event of being wound up, it has sufficient reserves to settle all debts and obligations. Apart from office equipment, the Association's

assets are held as cash, with \$449,190 in operating accounts and \$33,676 in term deposits.

Total income for the 2020-21 year was \$1,285,913. This represents a 5% increase compared to the 2019-20 year (\$1,223,640).

The Service Funding Agreement with the ACT Health Directorate (core funding) remains HCCA's main source of income, comprising around 68% of total income.

Members Equity - June 2011 - June 2021



In addition, HCCA received additional funding from the ACT Health Directorate on a number of projects: Community Health Literacy, Advance Care Planning, and Digital Health. Of these projects, Community Health Literacy was the largest, with funding of \$162,449.

HCCA also worked with Major Projects Canberra to provide consultancy services to the Canberra Hospital Expansion Project (\$103,527).

Due to the COVID-19 pandemic, HCCA received the Federal Government's stimulus payments and rent relief from the ACT Government. These provided additional income of \$72,348.

Total expenditure for the year was \$1,133,712, this represents a 5%

increase compared to the 2019-20 year (\$1,075,203). Wages and related staff costs remain the Association's main expense. The total staff costs across all programs during the year was \$966,102, equivalent to 75% of the total income. The staff costs went up from \$880,903 in 2019-20. This increase is due to new positions created to service the additional project funding agreements.

I wish to thank our Executive Director Darlene Cox, contract bookkeeper Lesley Porroj and Office Manager Sandra Avila for their support in my role as Treasurer during the year.

Dr Indra Gajanayake **Treasurer**











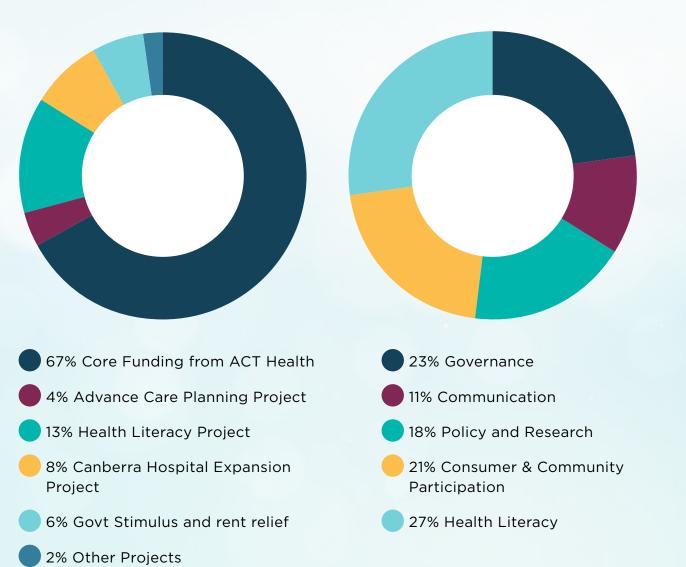


Financial Resources

HCCA is mainly funded by the ACT Health Directorate. A detailed audited report for 2020-2021 has been included in this report, outlining the funding received and how it was spent across our different programs to advocate for better health services for our communities. The following graphs summarise the sources of income in 2020-2021 and the areas in which this income was used.

HCCA Funding Sources in 2020-21

Areas in which HCCA spent income 2020-21



HCCA Members



In 2020-21 HCCA had 164 individual members



In 2020-21 HCCA had 27 organisational members.



65% of our individual members were actively engaged with the programs and activities run by the organisation.

HCCA STRONGLY VALUES THE SUPPORT OF OUR COLLEAGUES IN THE FOLLOWING ORGANISATIONS:

- · ACT ME/Chronic Fatigue Syndrome Soc. · Alcohol, Tobacco and Other Drug
- · ACT Mental Health Consumer Network
- · ACT Lymphoedema Support Group
- · Bosom Buddies ACT
- Canberra Alliance for Harm Minimisation and Advocacy (CAHMA)
- · Canberra Lung Life Support Group
- Canberra and Queanbeyan Attention
 Deficit Support Group
- · Canberra Region Kidney Support Group
- · Carers ACT
- · Council of the Ageing ACT
- · Heart Support Australia
- Pain Support ACT (Arthritis ACT)
- · People with Disabilities ACT
- · Women with Disabilities ACT
- · Women's Health Matters
- ACT Council of Social Services (ACTCOSS)

- Alcohol, Tobacco and Other Drug Association
- · Asthma Foundation ACT
- · Australian Catholic University
- · Australian National University
- · Calvary Health Care ACT
- · Canberra Multicultural Community Forum
- · Capital Health Network
- · Community Medics Australia Ltd
- · Hepatitis ACT
- · Key 2 Learning College
- Mental Health Community Coalition ACT (MHCC)
- Meridian (formerly AIDS Action Council ACT)
- Palliative Care ACT
- · Parkinson's ACT
- · Public Health Association of Australia

- Self Help Organisations United Together (SHOUT)
- · Sexual Health and Family Planning ACT
- · Stroke Foundation
- · Tresillian
- · University of Canberra
- · Youth Coalition of the ACT

Government Partners:

- · ACT Government
- · ACT Health Directorate
- · ACT Office for Mental Health
- · ACT Human Rights Commission
- · Canberra Health Services



Communication and Promotion

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

Newsletter https://www.hcca.org.au/news/publications/



Our newsletter, Consumer Bites, is the main form of communication with our membership and networks. HCCA published 24 issues in 2020-2021.

HCCA Website www.hcca.org.au



Page views compared to 20,219 in 2019-2020



Sessions compared to 10,972 in 2019-2020



Users compared to 8,327 in 2019-2020

Canberra Health Literacy website https://cbrhl.org.au/

The Canberra Health Literacy website was launched in August 2021. It shares practical resources and information to support health and community professionals, and consumers and carers. In 2020-21 it had 4,371 page views, 2,141 sessions and 1,614 users.



Page Views



Sessions



Users



Blog https://www.hcca.org.au/news/hcca-blog/

HCCA posted 15 blog posts during this reporting period compared to 10 blog posts in 2019-20



Facebook https://www.facebook.com/HCCA.ACT

973 followers compared to 843 in 2019-2020 826 likes compared to 748 in 2019-2020



Twitter https://twitter.com/healthcanberra

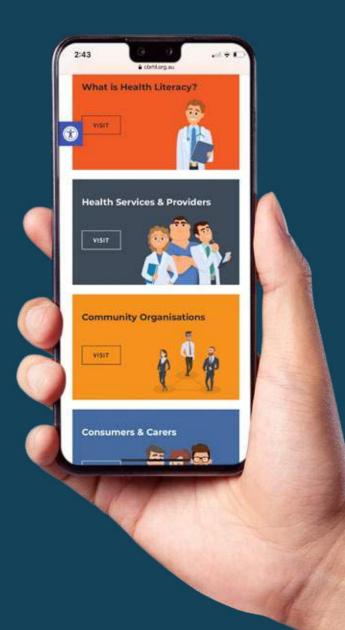
1,047 followers compared to 1,029 in 2019-2020

Feedback from Consumer Bites' subscribers:

Please pass on my personal thanks to Darlene Cox and Kate Gorman and your team at HCCA. I just read the note of Thanks to all the Government Authorities. I want to express my thanks for the Updates we have been receiving during Covid times from HCCA. The information has been well reported and given us a factual picture of the changed environment in which we are currently living. The team there are obviously working hard to keep us well informed and covering an amazing number of topics in their presentation".

Awesome, thanks HCCA. Canberra is doing so well with communication!"

Thanks so much. As always really interesting".



Health Policy Highlights

Policy Priority Areas

Each year the Executive Committee sets policy priority areas to guide the work of the organisation. In 2020-21, the policy priority areas were: Quality and Safety in Health Care, Health of Older People, Primary Health Care, Mental Health and Cost of Health Care.

survey were shared with our stakeholders. Thanks to HCCA's Health Policy and Research Advisory Committee for their input and support for this work. Reports from the five surveys can be found at: https://www.hcca.org.au/policy/consumer-information-about-covid-19/

HCCA Position Statements

During 2020-21, the Health Policy and Research Advisory Committee (HPRAC) updated the HCCA Consumer Based Research Framework. The updated version was endorsed by the Executive Committee in September 2020. It is available on the HCCAwebsite at: https://www.hcca.org.au/policy/research/.

Input to the COVID-19 Pandemic Response in the ACT

Follow-up COVID-19 Information Survey

During March and April 2020, early in the COVID-19 pandemic in Australia, we conducted four surveys to help us, and staff in our health system, give consumers in the ACT and surrounds the information they needed during the Coronavirus pandemic. In August-Sept 2020, we conducted a follow-up survey to identify any changes over time. The results of this

Membership of the COVID-19 Primary Care Emergency Response Working Group

Beginning in February 2021, staff member Anna Tito provided consumer input as a member of the COVID-19 Primary Care Emergency Response Working Group. The purpose of the group, convened by the Capital Health Network, is to help support primary care providers during the COVID-19 response. This is a valuable avenue for HCCA to raise issues important to consumers. This includes addressing communication issues, and questions and concerns about COVID vaccination processes across the ACT.

ACT Health COVID-19 Ethical Framework

Beginning in March 2020, Kate Gorman and Darlene Cox were involved in the development of the COVID-19 Ethical Decision-Making Framework for the ACT. This work is focussed on how decisions will be made to allocate intensive care resources should the demand outstrip supply in the ACT. HCCA organised,

encouraged and supported consumer and community organisations in the ACT to participate in the consultation process. The ACT Framework for Ethical Decision Making for The ACT COVID-19 Response was finalised in November 2020.

HCCA would like to acknowledge the contribution of Sue Schreiner to this work. Sue died in September 2020. Sue was a longstanding member of HCCA, and a member of the Canberra Health Services Clinical Ethics Committee. We valued Sue's compassion, good judgement and legal knowledge in this and many other projects that HCCA has been involved in over the years.

Digital Health Record

The development of the ACT Digital Health Record is underway. The ACT Digital Health Record will record all services and care provided in ACT public health services. This includes Canberra's major hospitals, community health centres and Walk-in Centres. The ACT Digital Health Record will be a personal record that can be accessed by the health care team at any service location. This will allow staff to have faster access to information which will help to improve care, and reduce errors and duplication. Staff will have more time to focus on the person requiring care, rather than searching for key health information stored in different places.

Consumers will be able to access their own Digital Health Record through a secure website or a mobile app. This will allow them to access and update their information from home and manage future appointments. They may also be able to access patient education materials tailored to the information on their record. In the future we expect that people will be able to talk to their care team through telehealth appointments if they are unable to attend a service in person.

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

Given that the ACT Digital Health Record is expected to go-live in late 2022, this is intensive work. We hope that the introduction of the Digital Health Record will help to transform and streamline health care for consumers in the ACT.





Health Policy Submissions

Local Policy Submissions

ACT Health Directorate

- Regulation and Licensing of Health Care Facilities ACT (September 2020)
- ACT Mental Health Charter of Rights (October 2020)
- Isolated and Remote Worker Guideline for ACT Health Services (January 2021)
- Feedback on Draft Territory Wide Health Services Plan (February 2021)
- ACT Health Protection Services Storage of S8 medicines in RACFs (May 2021)
- · ACT Health Data Strategy (May 2021)

- ACT Health Clinical Services Plan (June 2021)
- ACT Government Project on Options for the Prohibition of Deferrable Medical Interventions on Intersex People (June 2020)

ACT Legislative Assembly Inquiry

- Review of ACT Health Programs for Children and Young People (June 2021)
- Inquiry into ACT Drugs of Dependence (Personal Use) Bill (June 2021)

Canberra Health Services

- CHS Language Services Procedure on Interpreters and Translated Materials (July 2020)
- Review of Oral Health Services Model of Care and Governance (July 2020)
- Draft CHS Advance Care Planning (ACP)
 Guideline (August 2020)
- CHS COVID Visitation at end-of-life (August 2020)
- CHS Consumer Privacy Policy 2nd version (August 2020)
- CHS Pharmacy Department Medicines List (September 2020)
- CHS Medication Reconciliation Policy (October 2020)
- · CHS Consumer Privacy Handout (December 2020)
- CHS Consumer Feedback
 Regarding Tube Feeding Resources
 (January 2021)
- Older Person's Mental Health and Wellbeing Strategy (February 2021)
- Draft consumer handout consultation (March 2021)
- CHS Volunteer Services Policy (March 2021)
- CHS Clinical Incident Management Policy and Procedures (April 2021)
- CHS Elective Surgery Access Policy (June 2021)
- · CHS Falls Guideline (June 2021)
- CHS policies Pregnancy and Labour
 (5 policies reviewed) (June 2021)

National

Australian Commission on Safety and Quality in Health Care

- National Disability Strategy (input via survey) (November 2020)
- National Safety and Quality Primary Healthcare Standards (January 2021)

Department of Health (Australian Government)

 Private Health Insurance (second wave reforms) Consultations (February 2021)

Australian Medical Council

- AMC Dermatology Curriculum Review (July 2020)
- RANZCR Interventional Radiology Standards (February 2021)

Royal Commissions

 Letter of Support WWDACT - re Royal Commission into Violence, Abuse, Neglect and Exploitation of people with Disability (August 2020)

Therapeutic Goods Administration

TGA Medicines Shortages
 Communication to consumers
 (November 2020)

Health Policy and Research Advisory Committee

HCCA's Health Policy and Research Advisory Committee (HPRAC) plays an integral role in our policy and research work. The Committee met seven times during this reporting period.

Members of the Health Policy Advisory Committee are: Linda Trompf (Chair), Fiona Tito-Wheatland, Margaret Norington, Marion Reilly and Wendy Armstrong.

The highlights for the committee include the following policy work:

- Review of two position statements:
 Health Literacy, and Climate Change
 and Health
- Updates to the HCCA Consumer Based Research Framework, along with the HCCA Policy Development Process.
- Provided governance for HCCA's Health Literacy Project
- Provided input to HCCA
 Election Platform and ACT Election
 Forums held online
- Completed a Policy Submission
 Evaluation on HCCA's Submission
 to TGA 2019: Access to ingredient
 information online
- Completed Survey 5 (and subsequent reports) as the final of a series of surveys on Consumer Experiences of Looking for Information about COVID-19 (Coronavirus) https://www.hcca.org.au/policy/consumer-information-about-covid-19/

HPRAC also provided advice on a range of ACT Health policies, including:

- Feedback on Draft Territory Wide Health Services Plan
- ACT Health Clinical Services
 Plan Consultation
- Submission to ACT Health Protection Services Consultation on Storage of S8 medicines in RACFs
- Input to the development of the ACT Health Research Strategy
- Submission to Review of ACT Licensing and Regulation of Health Care Facilities

HPRAC was involved in the following policy work with Canberra Health Services:

- CHS Clinical Incident Management Policy and Procedure
- Submission to CHS on ACT Mental Health Charter of Rights
- Focus group and report on Pharmacy Re-design at Canberra Hospital
- Submission on CHS Consumer Privacy Handout

HRPAC provided significant input for submissions to two ACT Legislative Assembly Inquiries:

- Review of ACT Health Programs for Children and Young People
- Inquiry into ACT Drugs of Dependence (Personal Use) Bill

Other local ACT policy input from HPRAC included:

- Involved in consultation on ACT
 Protection of Rights Services Review
- Advocacy for progressing the ACT Auditor General's report on management of care for people living with serious and continuing illness

HPRAC provided input to four national policy consultations:

- Private Health Insurance (second wave reforms) Consultation
- RANZCR review of draft Interventional Radiology Standards
- AHPRA Consultation on Revised Regulatory Principles



In 2020-2021 our policy team have been busy providing feedback on 36 health policies that are priorities for consumers at an ACT and national level.

This has included private health insurance reforms, regulatory principles for the National Scheme (Ahpra & National Boards), priorities for the ACT budget and a submission as part of the Inquiry into the Drugs of Dependence (Personal Use) Amendment Bill 2021. HCCA members - look out for emails from our policy team for opportunities to help shape our policy submissions!



HCCA members at the 2020 Annual General Meeting

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 this reporting period HCCA had five active Consumer Reference Groups in the areas of Health of Older People, Quality and Safety, Access & Design and eHealth.

Health of Older People Consumer Reference Group

The Health of Older People Consumer Reference Group only met three times during the 2020-21 period due to the pandemic. Topics of discussion at meetings during this period included:

- Experience of COVID-19 and Residential Aged Care Facilities
- · Impact of COVID-19 on mental health
- Older people with malnutrition in hospital
- · COVID-19 vaccines
- · Retirement income policy
- · Death doulas and funerals
- · Advance Care Planning and end of life
- Older Persons Mental Health Model of Care Project
- Aged care nursing

Accessibility and Design Consumer Reference Group

The Accessibility and Design
Consumer Reference Group met four
times during the 2020-21 period with
a significant number of members
responding for comments out of
session. A core group of 6-8 members
usually attend meetings to raise their
concerns and respond to Canberra
Health Services presentations and
issues. During this period Canberra
Health Services (CHS) staff presented
information about Walk-in Centres,
telehealth, master planning, content and
design for the new CHS website, and
carparking and transport.

Members discussed and contributed to:

- Consumer Patterns of Design, a project led by HCCA staff to list criteria that would satisfy consumer needs in design across locations within health services
- User testing for the proposed new Canberra Health Services website
- CHS master planning and the Canberra Hospital Expansion Project
- · Signage in Building 3 at the Canberra Hospital.

Access issues due to changes across the Canberra Hospital site are of great concern to members. These issues include the closing and then partial re-opening of Hospital Road and the relocation of bus stops, the difficulty of gradients from bus stops on the roads that border the hospital, and the closure of the electronic door under Building 3.

Access and design will continue to be hot topics among HCCA members due to ongoing changes at the Canberra Hospital and the restrictions imposed by COVID-19.

Quality and Safety Consumer Reference Group

The Quality and Safety Consumer Reference Group met six times and was chaired by Sue Andrews, Kate Gorman and Darlene Cox during the 2020-2021 period.

This group meets to learn about quality and safety issues in health, provide consumer input on those issues and related projects, to inform HCCA advocacy work, and to provide support to the consumer representatives who sit on quality and safety committees.

During this period the group met online and, as COVID restrictions eased, met in a hybrid format allowing people to either join meetings in person or online.

Accessibility and Design Consumer Reference Group and presenters - August 2021



Topics have included:

- Information for consumers about medicines, on discharge from hospital
- Discussion on what matters to consumers in clinical handover and ensuring patient admission information reaches consumers
- · Accreditation of health services
- Consultation on National Standards for Primary Health Care Services
- Discussion about the use of nonaccredited/certified TIS interpreters in health services
- Providing feedback about the licensing of ACT private health facilities
- Feedback on the CHS Clinical Incident Management Policy
- Presentation about the CHS Choosing Wisely Project



e-Health Consumer Reference Group

The EHCRG was chaired by Russell McGowan. The group had its 70th and final meeting in August 2020. The EHCRG provided informed advice to the ACT Health Directorate, Canberra Health Services, Calvary Public Hospital, Capital Health Network, and to health consumer representatives, about e-Health proposals and projects. At the last meeting members were thanked for their involvement and significant contributions to e-Health in the ACT through the work of the EHCRG since its inception in 2009. Special mention was given to Russell McGowan, whose expertise and vision established the group in 2009, and Sandra Cook, Digital Solution Division, ACT Health, who has a commitment to consumer participation and a long involvement in e-health in the ACT.

A new group was established in August 2021 - HCCA's Digital Health Consumer Reference Group. This new group will focus on the implementation of the ACT Digital Health Strategy, the ACT Digital Health Record, and other digital health initiatives in the ACT and nationally.

The various Consumer Reference Groups and regular consumer forums continue to be a fertile mechanism for members to engage with the work of HCCA. They provide the backbone for members participation in the work of HCCA, together with internal HCCA committees, ACT Health Committees and other external health related committees."

Research Projects Highlights

There's what your doctors say, and then there's the real world: Long-term conditions self-management and support

In 2021, as part of our Community Health Literacy Project, HCCA completed a research project, There's What Your Doctors Say and Then There's the Real World: Long-Term Conditions Self-Management and Support in the ACT. We heard from more than 130 people who have one or more long-term conditions and who use health services in Canberra through a survey (100+ respondents) and more than 30 in-depth conversations with individuals.

"Self-management" of long-term conditions is often seen as part of the answer to the growing incidence of long-term conditions and growing need for chronic conditions care. But what does 'self-management' really mean to people with long-term conditions?

People we spoke to told us that for them, self-management is about more than managing, monitoring and reducing their symptoms. It also means coping with and thriving despite the impacts of ill-health on their lives, learning to get the most out of their interactions with health professionals, and working out how to get what they need from a complex health and human services system. For many people we heard from, COVID-19 made self-management harder – and they were early adopters of a range of

practices to protect themselves (such as mask-wearing and social distancing). However, COVID-19 also presented some unexpected innovations that can support self-management. Participants were particularly positive about telehealth and electronic prescribing, because for many - though not all - their convenience can help simplify self-management.

You can read the full report and recommendations to support self-management in the ACT on the <u>HCCA</u> and <u>Canberra Health Literacy</u> websites.

Finding good health information online

This year HCCA worked in partnership with the Australian Commission on Safety and Quality to provide consumer advice on new national resources on the topic of Finding Good Health Information Online. We shared the draft resources with consumers and heard from more than 50 people and consumer organisations. This advice gave us some clear feedback to share with the Commission on ways to improve the resources. We then shared a revised draft with consumers for user testing. This process led to practical improvements in key messages as well as the 'look and feel' of the resources. This is a great example of the benefit of involving people in developing information meant for them! We appreciate the opportunity to contribute to and support the Commission's national work on health literacy.

Breathing Easier - improving care for people with COPD

This year the Executive Committee allocated funds to complete a research project on the consumer experience of Chronic Obstructive Pulmonary Disease (COPD) in the Canberra region. This research developed from discussion with members of the Canberra Lung Life Support Group. We were fortunate to work with Fiona Tito Wheatland from Enduring Solutions on this project. Canberra Health Services had identified the need to improve the integration of care for people with chronic conditions

but this work has not progressed because of the disruption caused by the pandemic. We chose to continue to investigate the current approach to COPD care in the ACT and best practises used in other places in Australia and overseas. We also interviewed people in the ACT and their carers about their lived experience of COPD, with a focus on what works and what doesn't, and what could improve their care. The outcomes of the research will be published in late 2021. Our hope is that this work will influence the future development of COPD services to better reflect the needs of people living with COPD and their families and carers.

For many years we have advocated for more meaningful consumer involvement in research, as we know it has many potential benefits, including: research that is more relevant to consumer needs; greater accountability; and improved quality and outcomes with a stronger focus on research translation. We have seen progress on the research agenda in the ACT during this year."



Consumer involvement in research

In addition to our own research projects, this year HCCA involved consumers in research by:

- Supporting consumer representatives who contribute to research governance and project advisory committees in the ACT
- Promoting the value of consumer involvement in research
- Providing advice to researchers from a wide range of areas of health and medical research who want to strengthen their work by involving consumers.

Consumer representatives and HCCA this year contributed to:

- Canberra Health Services' Research Strategy
- The ACT Health Directorate's Research Strategic Plan
- The ACT Health and Wellbeing Partnership Board's Research Working Group - which brings together decisionmakers to agree on shared priorities and drive collaboration across health, tertiary education and research in the ACT.
- HealthANSWERS Implementation
 Working Group HealthANSWERS is
 a network of ACT and regional NSW
 health, support and research agencies
 working to address challenges in
 regional health and healthcare.
- Consumer Advisory Group Peer Influence on Chronic Illness Self-

Management Behaviours of Baby Boomers (this is the PhD research project of Mrs Peta Harbour, Senior Lecturer in Nursing at the Australian Catholic University, Signadou)

Consumer representatives shared their time and knowledge with these projects to help make sure that health and medical research in the ACT and region aligns with consumer priorities, offers tangible consumer benefit, and reflects good practice in consumer involvement. We do this work so that the benefits of consumer involvement for everyone - researchers, research funders, communities, and consumers and carers – are realised. Thank you to the members of HCCA's Health Policy and Research Advisory Committee who have offered their advice and guidance on our work this year.





Health Literacy Program

Increasing Health Literacy Among Consumers

During this period, HCCA delivered 12 information sessions for consumers on health system topics to a total of 190 people. These included standard HCCA seminars to help consumers understand and learn how to use our health system, such as *Stretching Your Health Dollar* and *Navigating the Health System*, as well as HCCA's Chronic Conditions Seminar Series which are intended for people living with chronic conditions.

Increasing Health Literacy in the Health Environment

HCCA staff and consumers are regularly asked to comment on signs, website content, and written communication from Canberra Health Services (CHS) to make them easier to understand.

We have given lots of input to CHS to help consumers find their way to and around Canberra Hospital. The new CHS Wayfinding Working Group includes the HCCA Health Literacy Project Officer and is largely driven by consumer issues that were highlighted in previous year's First Impressions reports. HCCA can take some credit for wayfinding being firmly on the CHS agenda for improving their services.

HCCA staff and members contributed to the improvement of:

- · CHS Parking information
- · CHS Transport parking brochure
- · CHS website content and design
- · Outpatient letters
- Signs and maps in the Emergency
 Department
- · Signs in Building 3 at Canberra Hospital
- · CHS social media

Chronic Conditions Seminar Series

The Chronic Conditions Seminar Series is a series of evening seminars for people with chronic conditions who may not be able to attend daytime sessions. HCCA took over the running of these seminars in 2018 from Pain Support ACT and the RSI and Overuse Injury Association, who continue to be involved in the planning of these sessions.

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

These sessions are well received and during this reporting period there was an increase in attendance as online delivery gave us a greater capacity for participants.

During this reporting period, six sessions were delivered to 158 participants. Topics during this period included:



Looking After Your Feet



Stretching Your Health Dollar



Living and Exercising with a Long-Term Condition



Gut Health



Managing Anxiety & Depression

HCCA is grateful to the health professionals who volunteer their time to present these sessions and answer questions from participants.

The Chronic Condition Seminar Series have been extremely well received and the feedback from participants is positive. This seminar series will form a core part of the work that we do going forward."

Advance Care Planning Program

HCCA continued to provide information to the ACT and region about Advance Care Planning with funding from the ACT Health Directorate.

HCCA delivered 15 sessions on Advance Care Planning during this period to 309 people, including multicultural communities, seniors, people with chronic conditions and the general public.

Our presentation, A Conversation for Everyone, covers why someone would want an Advance Care Plan, the steps involved and where people can go for help. A staff member from the CHS

Advance Care Planning team now often attends the online presentations to share information. Consumers gave extremely positive feedback, including 'de-mystified the process' and 'don't feel confused about it now.'

HCCA now offers these sessions to the public via the online platform Zoom. Many groups, such as Rotary and multicultural groups, prefer face-to-face sessions. When COVID-19 restrictions permit, HCCA staff present sessions in person.

Claudia Cresswell

Health Literacy Officer







presentations to community groups

From 2020-2021 our health literacy team delivered 33 presentations to community groups. This includes Chronic Conditions Seminars, Advance Care Planning, Navigating the Health System and Working in Multicultural Communities.



Community Health Literacy in the ACT

Our Community Health Literacy Project aims to build health literacy in ACT communities, health services and community organisations – so that it's easier for people to get thehealth information and services we need.

The project includes the Canberra Health Literacy Network, Canberra Health Literacy website, and health literacy training for community workers. In 2020-21 we also completed research on long-term conditions self-management and support.

This project was funded for three years by the ACT Government. It will be completed in early 2022.

Community Workers Health Literacy Training

This year we piloted a five module training package delivering workshops

online (using Zoom) and face-to-face. We greatly appreciate the advice of our Steering Group, which brought together representatives of Meridian, Woden Community Service, ACTCOSS, Toora Women and the staff from Woden Community Services and Toora Women who gave their time to provide feedback in the pilot sessions. Participants rated the content, presentation and resources as excellent. HCCA's Health Literacy Program now offers an introductory training session (on Zoom) as part of our ongoing community education activities and can offer community worker training tailored to each organisation's needs.

Canberra Health Literacy Network

The Canberra Health Literacy Network offers learning, development and a peer network to consumers, carers and health and community professionals with an interest in health literacy. This year the Network's main activity was a series of lunchtime webinars. Topics have included:

- Network virtual launch (deferred from April 2020 due to COVID-19), with ACT Health Minister Rachel Stephen-Smith and Professor Kirsten McCaffery from the University of Sydney and Sydney Health Literacy Lab.
- Involving Children and Young People in Health Decision-Making (speakers from the Association for the Wellbeing of Children in Health Care, ACT Down Syndrome Association and Down Syndrome Australia)
- Health Literacy for Nurses and Midwives (with Professor Karen Strickland and Caroline Hall from the University of

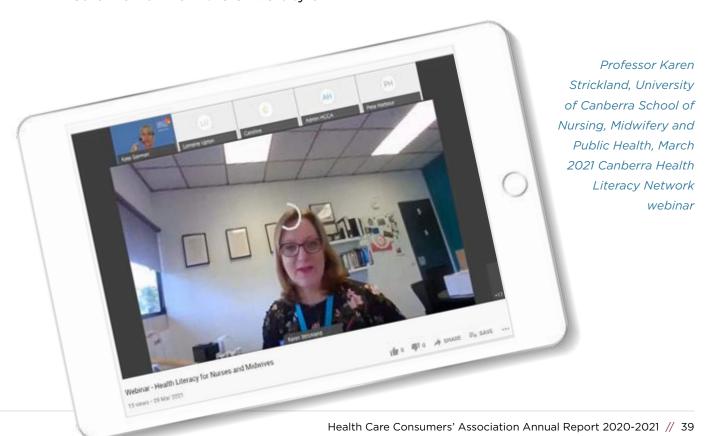
- Canberra, and Peta Harbour from the Australian Catholic University)
- Focus on Health Literacy to Improve Safety and Quality (Herbert Down, AustralianCommission on Safety and Quality in Health Care)
- Improving Health Information for Consumers and Carers (Dr Sophie Hill, La Trobe University Centre for Health Communication and Participation)

We now typically have over 100 registered participants for each session. They consistently tell us that they learn something new from the webinars:

I feel like I have some practical things to try next time"

Great speaker!"

Very practical tips, clear information and useful resources."



Canberra Health Literacy website (cbrhl.org.au)

The website is a central point for practical, skills-oriented information about health literacy. The website has information for consumers and carers, and for health and community professionals. This year we have made some improvements to the website to

make it more accessible for readers, and maintain our compatibility with the international Web Content Accessibility Guidelines (2.1). Work this year has included development of new resources including a guide to health care complaints in the ACT.



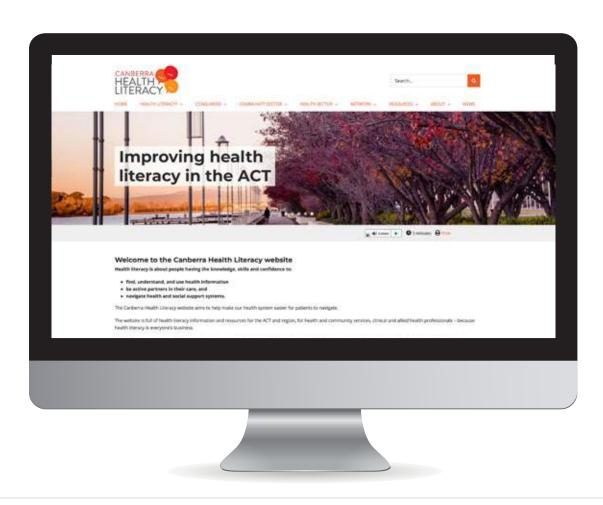
Access to online health literacy resources and current research.



Information about what health literacy is, why it's important, and what you can do to improve it.



Helpful information for health services, GP's, allied health, community services, community workers, consumers and carers, community groups and support groups







5 webinars Did you know that this year we've run three online webinars as part of the Canberra Health Literacy Network?

These webinars focused on topics surrounding health literacy including safety and quality, nurses and midwives and involving young people in health decisions.

Consumer and Community Participation Highlights

In this period HCCA supported 49 consumer representatives in 109 roles and 9 organisational representatives (staff members) in 98 roles. This was on 179 separate committees across ACT and national organisations (some committees had more than one HCCA member over time or at the same time).



HCCA made 57 endorsements of consumer and organisational representatives to committees, of which 26 were consumer appointments, and 31 were organisational appointments. 36 of these endorsements were made to new committees, or committees where HCCA has not previously had a representative. The remainder were made to replace consumer representatives who resigned from their committees or to add an additional consumer representative to a committee.



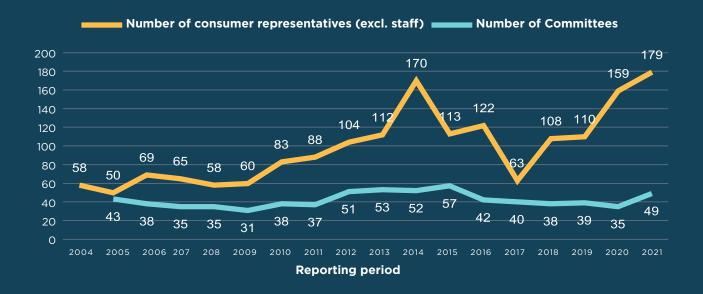
Of the 36 endorsements to new committees, 17 were made to Canberra Health Services committees, 14 were made to ACT Health Directorate committees, one to a local body, one to a national body, one to NSW Health and two to a Capital Health Network committee.

Consumer and organisational representatives spent around 1,056 hours preparing for meetings, and around 971 hours attending meetings. This does not include travel time.

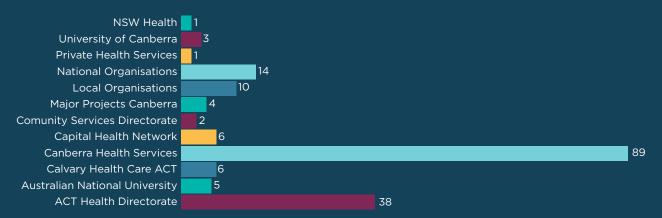


Committees where activity increased included those related to COVID-19, the Canberra Hospital Expansion Project and other infrastructure work, and ACT Health Directorate committees for the Digital Health Records program.

- · Safewards is a new program to reduce conflict between staff and patients which is being trialled across ACT public hospitals. Consumer representatives Heather Warfield and Miriam Pavic attended the Safewards training (November 2020) ahead of the rollout of this pilot programme. It is being trialled in four public hospital wards at Calvary Public Hospital Bruce and Canberra Health Services.
- HCCA staff members, consumer representatives and members have participated in a number of health service awards, grants and recruitment panels during this reporting period.
- · HCCA members, staff and project partners have spoken at webinars, meetings, podcasts and videos during this year to present consumer perspectives on health care. We're grateful to everyone who has given their time and sometimes shared part of their story to do this.
- HCCA Consumer Participation Training was delivered in February and March 2021.
- Members' forums were held in March 2021 and May 2021. HCCA Members' Forums were not held in the second half of 2020. These forums are open to all HCCA members.



Committee Numbers by Organisation





Consumer and Community Participation Program

The second half of 2020 was a time of uncertainty and pause for consumer participation activities at HCCA. COVID-19 had not yet significantly touched the ACT, however parts of Australia were managing COVID-19 outbreaks and the likelihood of this happening in the ACT was clear. Health services were focused on preparing for outbreaks, and this meant that some health service work - and consumer participation opportunities - were paused or postponed as resources were diverted to this effort.

It was clear that HCCA needed to adapt our consumer participation offerings to the online environment. This required the speedy acquisition of skills from the HCCA team, and the acquisition of technology that could support our work. Some planned events did not go ahead while we made these preparations. At

the same time, the ACT community was also learning how to participate in online events and forums. Some were quick to fully embrace this, and indeed for some - especially those who live with disability or are immune compromised - it made participation more possible than it had previously been. Other pockets of the

community were slower to adopt online participation, for cultural, financial or personal preference reasons.

By the beginning of 2021, we were ready to go with our online presentations and participation opportunities. The ACT remained free of COVID-19 and this allowed us to present some things in person, and to hold some events like chronic conditions seminars as hybrid events - with some participants online and some attending in person.

In May 2021 we filmed many of our members and friends talking about a range of health advocacy topics, including their experiences as health advocates and consumer representatives. We'll be spinning this gold into a series of videos which we will launch at the end of 2021.

Despite the challenges of this period, the HCCA Consumer Participation Team (which in this period has included our Manager Kate Gorman, Health Literacy Officer Claudia Cresswell, our Multicultural Liaison Officer Yelin Hung, Administrative Officer Monica Stonebridge and Project Officer Jess Lamb) has done an amazing job of meeting community needs for information and skills around using health services, and helping health services involve consumers in shaping their offerings.





Consumer Participation Committee

This Consumer Participation Committee (CPC) provides oversight of the implementation and evaluation of the HCCA Consumer and Community Participation Framework. It also provides input and consumer expertise to consumer and community participation activities, and endorses consumer representatives for consumer representation opportunities.

Members of the Consumer Participation Committee are: Alan Thomas (chair), C Moore, Louise Bannister, Miriam Pavic, Sue Andrews and Wendy Armstrong.

The Committee met eight times during this reporting period. The highlights for the committee included:

 Consideration of nominations for consumer opportunities and endorsement of consumer representatives. Endorsements by the CPC include for committee vacancies. conference sponsorships, and other short-term consumer opportunities for HCCA members and consumer representatives.

- Review of documents and policies including HCCA's Consumer and Community Participation Framework.
- Undertook a Members' Survey including follow up phone survey with HCCA members (in conjunction with the Executive Committee). The committee also undertook a Reimbursement Survey for all consumer representatives.
- Reviewed and improved the consumer representative nomination process for committee opportunities and event sponsorship.
- Provided feedback on the development of HCCA's adaptation of Health Consumers Queensland booklets for organisations and consumer representatives.
- Met with CHS staff regarding consumer representation on National Standards Committees.

- Planning of the Thank You Event for Consumer Representatives held at the Legislative Assembly in June 2021.
- Advising consumer participation in infrastructure work related to the Canberra Hospital Expansion Project.

Health Infrastructure

HCCA continued the existing contract with Major Projects Canberra (MPC) to provide consultancy services to Canberra Hospital Expansion Project (CHEP) (formerly known as the SPIRE project). This includes support for consumers, participation in the CHEP Consumer Reference Group (CRG), and facilitating consumer input and feedback into the design.

The CHEP CRG meets monthly and is chaired by Kate Gorman. Kate took over this role after Alan Thomas stepped down. In this capacity, Kate also attended the CHEP Project Control Group. In addition to members of community and consumer organisations, HCCA is represented on the CRG by consumer representatives, Louise Bannister and Gev Khambata and in this reporting period by HCCA staff members Anne Meuronen, Yelin Hung and Monica Stonebridge.

In November 2020, HCCA ran a series of focus groups, in partnership with Major Projects Canberra and Multiplex, to hear from consumers and consumer organisations about the building design elements that improve consumer's experience of health care. This consumer input feeds into the design work currently being done on the new Critical Services Building on the Canberra Hospital campus

as part of the CHEP. This report was also formally submitted as part of the Development Application consultation for this project. A copy of this report is available on the HCCA website.

There is increasing activity in other large health infrastructure builds on the Canberra Hospital Campus, which involve HCCA input. This includes the Women and Children's Hospital Expansion, ICU Expansion, and the Medical Imaging Refurbishment. HCCA's Accessibility and Design Consumer Reference Group advises HCCA and provides consumer perspectives on health infrastructure projects.

The Canberra Hospital Campus Master Plan has also involved significant consumer input through HCCA. In February 2021, an online consultation was held with members and consumers as part of the first phase of consultation. Feedback from consumers was provided directly to the ACT Health Directorate at the consultation and formally through HCCA's submission for this project. It is expected the second phase of consultation will commence in the second half of 2021.



Multicultural health advocacy work

In November and December 2020 HCCA worked with students on placement at Canberra Health Services to develop an End-of-Life pathway that is adapted to the needs of multicultural community members.

In 2021 HCCA delivered health literacy information via 2XX Community Radio, including information about vaccination, as one strategy to address community hesitancy around face-to-face information sessions due to COVID-19.

This year the consumer participation team has worked with the Multicultural Communities Council of Illawarra (MCCI) to deliver health literacy presentations to local multicultural communities.
Presentations on *Navigating health*services and *Getting the most out of your*appointments were delivered to 113 people
from a number of different language
groups who meet socially through MCCI,
including Mandarin speaking, Serbian,
Indian and Vietnamese communities.

In April 2021, HCCA supported Palliative Care ACT and the University of Canberra with a project to create a resource for health workers who are supporting multicultural community members and their families at end of life. HCCA invited multicultural community members to attend two focus groups to discuss end of life issues and inform this project. Their input shaped the publication <u>Cultural Approaches to Death and Dying</u>.





Consumer Participation Training

In this period HCCA staff have delivered training and information about consumer representation for 71 new consumer representatives, or people who are interested in becoming a consumer representative. HCCA ran Consumer Participation Training in February and March 2021

Training was also delivered with:

- the Aboriginal and Torres Strait Islander Consumer Reference Group at Canberra Health Services
- the Cancer Services Consumer
 Reference Group at Canberra Health
 Services
- staff and consumer representatives at the Canberra Alliance for Harm Minimisation and Advocacy (CAHMA)
- the Territory Wide End of Life and Palliative Care Consumer Reference Group, and
- consumer representatives at Calvary John James Hospital

Health services staff training

In this period HCCA staff have delivered the following training to 65 health services staff:

- Two sessions about Person Centred Care to Allied Health graduate students at Canberra Health Services
- One session about Consumer Centred Written Communication to the consumer feedback and engagement team at Canberra Health Services
- One session about Working with Consumer Representatives for Canberra Health Services staff
- Three sessions about Person Centred Care to nursing staff at Calvary Public Hospital Bruce





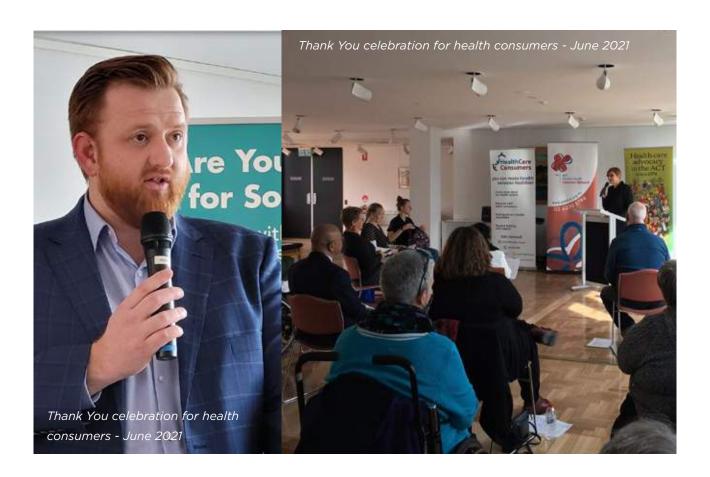
Thank You celebration

We finished this period with a thank you celebration for consumer representatives. This event was held on 9 June 2021 at the ACT Legislative Assembly with our colleagues from the ACT Mental Health Consumer Network and Carers ACT. The event was to celebrate and recognise the contribution that consumer and carer representatives make to our health system and to making health services safe, high quality and consumer focused. This opportunity provided a moment to reflect on the work we have done and continue to do and the fantastic people we're surrounded by. Consumer representatives from HCCA, the ACT Mental Health Consumer Network, and Carers ACT attended the special event.

The Minister for Health, Rachel Stephen-Smith MLA and Minister for Mental Health, Emma Davidson MLA spoke at the event. Staff from Calvary Healthcare ACT, Capital Health Network, Canberra Health Services and the ACT Health Directorate also attended. Bianca Rossetti, Chair of the ACT Mental Health Consumer Network, Dean Hewson, Vice President of HCCA, Tony Tucker from Carers ACT and Kate Gorman, Manager of Consumer Participation at HCCA, also spoke at the event. You can read their speeches on the HCCA website. COVID-19 restrictions meant that we could not invite all of the consumer representatives, staff members and supporters as we would have liked to. We hope to be able to do this again, with everyone present next time.

Kate Gorman

Manager Consumer and Community Participation



Consumer Representatives 2020-2021

Adele Lewin Adele Stevens Adina Jordan Alan Thomas Beatrice Vann Chris Bowman David Baxter Dean Hewson Don McFeat Eliza Moloney Emma Baldock Fiona Tito Wheatland Fran Parker Geri Badham Gev Khambata Heather Warfield Helen Dvriw

Indra Gajanayake Jason Willmot Jenny Berrill Jo Bothroyd Joanne Baumgartner John Meyer Karin Calford Kate Moore Katrina Muir Kaye Powell Kerry Snell Leia Earnshaw Linda Powell Linda Trompf Louise Bannister Lvn Morlev

Margaret Norington

Marion Reilly
Michelle Banfield
Miriam Pavic
Pat Branford
Pauline Winslade
Priyanka Rai
Russell McGowan
Shelley McInnis
Sue Andrews
Sue Schreiner
Terri Warner
Tom McGoram
Trish Lord
Wendy Armstrong
Yvonne Solly

Organisational Representatives

Anne Meuronen Anna Tito Claudia Cresswell Darlene Cox Kate Gorman Kathryn Briant Jessica Lamb Monica Stonebridge Sarah Spiller Yelin Hung



41 volunteer reps



87 committees

In the first half of 2021 HCCA supported 41 volunteer consumer representatives on 87 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.

Sponsored Conference Attendance

Each year HCCA supports consumer representatives and staff to attend conferences. This year support was given to attend these events:



 COTA Australia National Policy Forum (Priyanka Rai)

MAR 2021

CHF Summit 2021:
Shifting Gears (Joanne
Baumgartner, Priyanka
Rai, Claudia Cresswell,
Monica Stonebridge,
Jessica Lamb)



- NPS MedicineWise
 National Medicines
 Symposium (Trish Lord,
 Priyanka Rai, Kathryn
 Briant)
- Value-Based Health
 Care Conference
 (Heather Warfield, Sarah
 McGoram)



1,056 hours

preparing for meetings

971 hours

in meetings

In 2020-2021 HCCA consumer reps and staff have spent 1,056 hours preparing for meetings and 971 hours in meetings providing consumer perspectives on health care.

List of Consumer and Organisational Representative Positions 2020-2021

ACT Health Directorate

ACT Child and Adolescent Clinical Services Plan Steering Committee Fiona Tito Wheatland

ACT Gene Technology Advisory Council Tom McGoram

ACT Health and Wellbeing Partnership Board Darlene Cox*

ACT Partnership Board Research Working Group Linda Trompf

ACT Health System Research Strategy Working Group Wendy Armstrong

ACT Partnership Board Workforce Education and Training Working Group Kate Gorman*

ACT Health Quality Strategy Review Steering Committee Darlene Cox*

ACT Maternal Services Advisory Network

Adina Jordan

ACT Multicultural Health Reference Group *Yelin Hung**

ACT Public Health System Data Governance Steering Committee Darlene Cox* ACT Safer Baby Bundle Working Group

Jessica Lamb*

Care Closer to Home Reference Group Adele Stevens Sue Andrews

Clinical Health Emergency Coordination Centre (CHECC) Committee Darlene Cox*

Clinical Leadership Forum Shelley McInnis

Critical Systems and Infrastructure Governance Committee *Kathryn Briant**

Culture Review Oversight Group Darlene Cox*

Drug Strategy Action Plan Advisory Group Wendy Armstrong

Eating Disorders Reference Group Kate Gorman*

Health Technology Advisory Committee Russell McGowan

NGO Leadership Meeting
Darlene Cox*
Kate Gorman* (proxy)

Nurses & Midwives: Towards a Safer Culture - The First Step Steering Committee Jessica Lamb* Nursing and Midwifery -Towards a Safer Culture Advisory Group *Miriam Pavic*

Powers of Attorney ACT Legislation Amendment Working Group Sarah Spiller*

Primary Care for Vulnerable People Working Group Wendy Armstrong

Proposed Legislative Amendments - COVID-19 Research Working Group Sarah Spiller*

Real-Time Prescription Monitoring Project Stakeholder Engagement Group Kathryn Briant*

Technology Strategy Committee

Darlene Cox*

Russell McGowan (proxy)

Territory-wide Health Service Plan Steering Committee Darlene Cox*

Medicines Advisory Committee *Kathryn Briant#*

Office of Mental Health and Wellbeing Online Youth Navigation Portal Reference Jessica Lamb*

Digital Health Record

ACT ADHA Digital Health Forums

Darlene Cox*

Digital Health Record Clinical Steering Committee *Dean Hewson*

Digital Health Record Consumer Experience Steering Committee Kathryn Briant*

Digital Health Record Program Board Darlene Cox*

Digital Patient Flow Program Board

Dean Hewson

Australian National University

ANU Medical School for the Future Taskforce *Indra Gajanayake*

HealthANSWERS Implementation Working Group Indra Gajanayake

Step Two Taskforce for the Medical School for the Future

Darlene Cox*

Medical School Advisory Board Kate Gorman*

OHIOH Health Experience Board Kate Gorman*

Calvary Health Care ACT

ACT Regional Calvary Community Advisory Council Fran Parker

Geriatric Rapid Acute Care Evaluation Steering Committee Shelley McInnis

Calvary Clinical Governance Committee Shelley McInnis

Calvary Health Care ACT National Standards Committees

Calvary Communicating for Safety Committee (NSQHS Standard) Heather Warfield

Calvary Medication Safety Committee (NSQHS Standard)

Trish Lord

Calvary Partnering with Consumers Committee (NSQHS Standard) Jessica Lamb* Kate Gorman*

Canberra Health Services

ACT Domiciliary Oxygen and Respiratory Support Scheme (DORSS) Advisory Committee Lyn Morley

ACT Equipment Loans Scheme Advisory Committee *Marion Reilly*

ACT Palliative Care Forum Adele Stevens

Advanced Life Support Training Working Group Adele Lewin

Allied Health Leadership committee

Adele Lewin

Allied Health Professional Lead Committee Adele Lewin

Arts in Health Advisory Group Geri Badham Katrina Muir Monica Stonebridge*

Bariatric Surgery Advisory Committee *Trish Lord*

Breast Screen ACT Reference Group Louise Bannister

Breast Screen Consumer Reference Group *Linda Trompf*

Breast Screen Quality Committee Louise Bannister

Canberra Clinical Genomics Advisory Board *Darlene Cox**

Cancer and Ambulatory Support Clinical Governance Committee *Indra Gajanayake* Cancer Services Consumer Reference Group

Eliza Moloney

Darlene Cox* (Chair)

Choosing Wisely and Low Value Care

Steering Committee

Darlene Cox* Karin Calford

Chronic Disease Management Clinical

Network Trish Lord

Clinical Ethics Committee

Linda Powell Sue Schreiner Terri Warner

Clinical Handover Working Group

Kate Gorman*

Clinical Review Committee Fiona Tito Wheatland

Cognitive Impairment and Delirium

Working Group
Beatrice Vann

Community Care Clinical Governance

Committee
Indra Gajanayake
Joanne Baumgartner

Consent Working Group Fiona Tito Wheatland

Consumer Handouts Committee

Helen Dyriw John Meyer Kerry Snell Yvonne Solly

Consumer Participation Working Group

Kate Gorman*

COVID-19 Decision Making Framework

Steering Group

Darlene Cox*

Critical Care Executive

Jo Bothroyd

Diabetes Service Reference Group

Kaye Powell

Dickson Walk-in Centre/CHC Project

Control Group

Claudia Cresswell*

Diversity Training Day

Yelin Hung*

Division of Allied Health Quality and Safety

Committee

Adele Lewin

Education and Training Steering

Committee

Jenny Berrill

Kate Gorman*

Electronic Prescription (EP) Co-Design

Working Group Yelin Hung*

End of Life and Palliative Care Consumer

Reference Group *Adele Stevens*

End of Life Care Research Collaborative

Workshop *Adele Stevens*

End of Life Care Working Group/Forum

Yelin Hung*

Executive/Governing Body Orientation

Working Group Kate Gorman*

Facility Wide University of Canberra

Hospital Operational Committee

Don McFeat

CHS Governance Committee

Darlene Cox*

Food Services Hazard Analysis Critical Control Points - Quality and Training Committee Yelin Hung* Monica Stonebridge*

Health Records Advisory Committee *Pauline Winslade*

Health Services Executive Committee Quality and Safety *Kate Gorman**

Interpreter Working Group Yelin Hung*

LGBTIQ+ Health Reference Group Darlene Cox*

Maternity and Gynaecology Safety and Quality Committee *Leia Earnshaw*

Maternity Assessment Unit/Gynaecology Procedures Suite and Post Natal Working Group Jessica Lamb*

Medical and Dental Appointments Advisory Committee Margaret Norington

Mental Health Consumer and Carer Advisory Committee *Adele Lewin*

Mental Health Justice Health Alcohol and Drug Service Corporate Governance Committee David Baxter

Occupational Violence Prevention and Management Committee *Heather Warfield*

Oral Health Services Clinical Governance Committee *Linda Trompf* Oral Health Services Review of Model of Care and Governance Framework Reference Group Darlene Cox*

Organisation Wide Screening and Comprehensive Care Planning Working Group Eliza Moloney

Orientation Action Group Kate Gorman*

Our Care Safety and Quality Committee

Jenny Berrill

Our Infrastructure and Technology Committee *Darlene Cox**

Outpatient Transformation Steering Committee Darlene Cox*

Outpatient Transformation Working Group Claudia Cresswell*

Clinical Policy Committee Terri Warner

Positive Patient Identification Working Group *Karin Calford*

Quality Report Working Group Fiona Tito Wheatland

Rehabilitation and Community Care (RACC) Louise Bannister

Review of ACT Blue Book Working Group Jessica Lamb*

Safe Environment Working Group Darlene Cox*

Strengthening Health Services Response to Family Violence Steering Committee Jenny Berrill Sustainable Transport and Parking Working Group Claudia Cresswell*

TCH Building 5 Residential Services Relocation Working Group Kate Gorman*

Terminal Sedation Working Group

Adele Stevens

Fran Parker

Timely Care Steering Committee Wendy Armstrong

Transitional Therapy and Care Program
Executive Management Committee
Chris Bowman
Trish Lord

Transvaginal Mesh Review Committee Kate Gorman*

Walk in Centre Advisory Group Kate Gorman*

Wayfinding Working Group Claudia Cresswell*

Women Youth and Children Community-Consumer Consultative Committee Jessica Lamb*

Women Youth and Children's Safety and Quality Committee *Priyanka Rai* Canberra Health Services (CHS) National Standards for Quality and Safety in Health Care

Blood Management Standards Committee *Linda Trompf*

Clinical Governance Committee

Jo Bothroyd

Kate Gorman*

Communicating for Safety Standards Committee *Karin Calford*

Comprehensive Care Standards Committee Indra Gajanayake

Medication Safety Committee Kathryn Briant*

Partnering with Consumers Standards Committee Kate Gorman* (Co-chair) Yelin Hung*

Preventing and Controlling Healthcareassociated Infections Jenny Berrill

Recognising and Responding to Acute Deterioration Committee Adele Lewin

National Standards Governance Committee *Kate Gorman**

Infrastructure Committees

ACT Health Directorate

Canberra Hospital Campus Master Plan Steering Committee Darlene Cox*

Canberra Hospital Master Plan Project Control Group Anna Tito*

Canberra Health Services

Centenary Hospital for Women and Children Expansion Project Control Group *Miriam Pavic*

Centenary Hospital for Women and Children Paediatric Reference Group Anne Meuronen*

Emergency Department Model of Care Working Group Kate Gorman*

Intensive Care Model of Care Working Group Jo Bothroyd

ICU Project Control Group Kate Gorman*

Medical Imaging Project Control Group

Jason Willmot

Surgical Model of Care Working Group for CHEP

Karin Calford

The Canberra Hospital Bed Replacement Program *Kate Gorman**

Major Projects Canberra

Canberra Hospital Expansion Project
Consumer Reference Group
Anne Meuronen*
Alan Thomas
Kate Gorman*
Gev Khambata
Louise Bannister
Monica Stonebridge*

Yelin Hung* Alan Thomas

Canberra Hospital Expansion Project Control Group *Kate Gorman**

Capital Health Network

2021 Needs Assessment Working Group *Kathryn Briant**

ACT Clinical Council Shelley McInnis Sue Andrews

ACT HealthPathways Governance Committee Darlene Cox* Claudia Cresswell (proxy)*

Capital Health Network Community Advisory Council Emma Baldock Kate Moore

Capital Health Network Pharmacy in Residential Aged Care Facilities Program Governance Committee *Trish Lord*

COVID-19 Primary Care Emergency Response Working Group *Anna Tito**

Community Services Directorate

Carer's Strategy Governance group Kate Gorman*

Housing ACT Tenant Consultative Group *Yelin Hung**

Woden Community Service Stakeholder Reference Group for the National Psychosocial Support Measure for the ACT Michelle Banfield

Canberra Imaging Group Clinical Risk and Audit Committee *Marion Reilly*

Local Organisations

Canberra CALD Women's Forum Committee Yelin Hung*

Canberra Multicultural Community Forum Committee Yelin Hung*

Canberra Region Medical Education Council Sub-Committee *Emma Baldock*

Lung life Chronic Obstructive Pulmonary Disease (COPD) Reference Group Kaye Powell

Community Development Network Steering Committee Yelin Hung*

Migrant And Refugee Settlement Services (MARSS)

Yelin Hung*

Multicultural Matters Meeting (MuMaMe) Yelin Hung*

Red Cross Humanitarian Settlement Program Network Meeting Yelin Hung*

Northern Region Networking Interagency Yelin Hung*

University of Canberra

Ageo/ACE Evaluation Committee -SmartCare in Aged Care Beatrice Vann

Pharmacy Course Advisory Group Committee Pat Branford

NSW Health

Newborn Bloodspot Screening Expert Advisory Group Jessica Lamb*

National Organisations

Australian Commission on Safety and Quality in Health Care (ACSQHC) Environmental Sustainability Standards Darlene Cox*

ACSQHC Hospital-acquired Complications Curation Clinical Advisory Group Darlene Cox*

ACSQHC National Safety and Quality Primary Healthcare Standards Steering Committee Darlene Cox*

ACQSHC Partnering with Consumers Advisory Group Russell McGowan

ACQSHC Partnering with Consumers Committee Darlene Cox*

Australian Health Practitioner Regulation Agency Community Reference Group Darlene Cox#

Australian Health Practitioner Regulation Agency Aboriginal and Torres Strait Islander Strategy Group Darlene Cox#

Australian Council on Healthcare Standards (ACHS) Russell McGowan

ACHS State Advisory Committee Russell McGowan

Australian Medical Council Ethics Committee Fiona Tito Wheatland

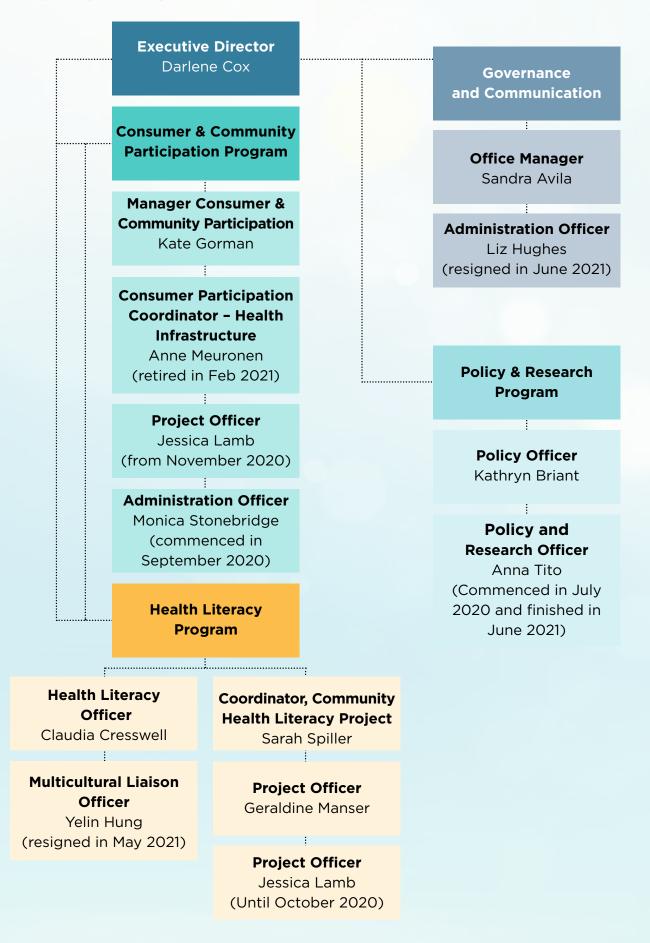
Australian Pharmacy Council Accreditation Committee Fiona Tito Wheatland Consumers Health Forum Consumer Commission - Beyond COVID-19 Indra Gajanayake

NPS Medicinewise Medication of Older People Expert Advisory Committee Darlene Cox#

NPS MedicineWise Clinical Intervention Advisory Group Darlene Cox# (Co-chair)

* HCCA staff member # Individual appointment

HCCA Organisational Chart 2020- 2021







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