

Annual Report 2019-2020

This report reviews the activities and achievements of Health Care Consumers' Association of the ACT (HCCA) during the period 1 July 2019 to 30 June 2020.

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.

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Health Care Consumers' Association of the ACT

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 providing health care consumers with the opportunity to participate in health policy, planning and service delivery decisions. We encourage consumers to identify priorities and issues of concern relating to health and we formally convey these

collective views to the ACT Government, Primary Health Networks, Federal Government and other bodies.

HCCA works closely with consumers and supports consumer representatives to put forward consumer perspectives. We hold consultative fora to enhance consumer voices and information sessions to improve health literacy in our community. We regularly communicate with our members and networks through our newsletter and social media. We also advocate consumer perspectives in health policy and undertake research into consumer experiences of health care.

HCCA Strategic Plan 2019 - 2020

Our Vision

Consumers in control of our own health.

Mission

Better health outcomes through consumer empowerment.

Values

We value our members' knowledge and experience of the health system and their involvement in their local communities.

Other values are:

- Integrity
- Collaboration
- Equity
- Participation and support
- Mutual respect
- Inclusiveness

GOAL 1: Effective consumer participation in health policy development and service design, planning, delivery and evaluation of health services.

GOAL 2: HCCA continues to be a strong and credible voice for consumers on health care.

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

- HCCA met all our governance obligations and contractual requirements.
- Eight Executive Committee meetings were held.
- 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 26 organisational policies.

Members of the Executive Committee are:

President: Alan Thomas

Vice President: Wendy Armstrong

Treasurer: Indra Gajanayake

Other EC Members:

Louise Bannister

Marcus Bogie

Bernard Borg Caruana

Shelley McInnis

Bea Vann

David Pearson (resigned July 2020)

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



Alan Thomas, Wendy Armstrong, David Pearson, Bea Vann, Bernard Borg-Caruana, Marcus Bogie, Indra Gajanayake, Louise Bannister and Shelley McInnis - 30 October 2019

President's Report



Alan Thomas

This year has been uniquely challenging with the bushfires, hail storms and particularly COVID-19. Nevertheless, members and staff have responded to these challenges and Health Care Consumers' Association has continued to influence the work of the Government so that consumers are in control of their own health, and thereby help to provide better health outcomes.

Members have adapted to new ways of participating by embracing the wonders of Zoom and WebEx meetings (although we may know more about these types of meeting than we ever wanted to). Members have participated in on-line meetings with ACT Health and HCCA's internal committees, forums and reference groups. All have been conducted on line. While this has been successful for the majority of members there is still a significant minority of members who have been unable to participate. Hopefully we will soon be able to conduct face to face meetings once again.

Despite the impact of COVID-19 the organisation has delivered on the majority of the milestones of our Service Funding Agreements with Canberra Health Service (CHS). Where we have not been able to fully meet the requirements of the Agreement CHS has readily agreed to an extended timetable and the rollover of funds.

We have had a number of significant achievements despite the difficulties we have faced. These include the launch of the Health Literacy Network and associated website, and the referencing of HCCA's Kids Interstate Project report in the Labor Party Health Policy Position Statement leading up to the recent ACT election. We also ran a successful series of online conversations with the leaders of the major parties in the lead up to the election.

I mentioned in my report last year that the way members are participating in the work of the Association is evolving with more members participating through work on HCCA consumer reference groups and internal committees.

As part of the continual evaluation of HCCA's consumer participation in health policy development and delivery of health services by ACT Health, the Executive Committee and the Consumer Participation Committee have been examining members' participation on committees, particularly the higher level ACT Health committees. Members will have received recently a survey on their involvement and experiences of working on committees. The Executive Committee and the Consumer Participation Committee will look at the results of this survey and how this can guide the work of the Association in the future.

On a personal note, I have stepped down as Chair of the Canberra Hospital Expansion Project (formerly SPIRE) Consumer Reference Group (CRG). There has been goodwill on all sides to enable true consumer participation in the design and construction of this very important project. Despite this goodwill I have been disappointed with my involvement with the CRG and the project in general. Tight deadlines have made

effective consumer participation very difficult. In addition, a different concept of what consumer consultation entails between Major Projects Canberra (MPC) and Multiplex (the contractor for the project) on the one hand, and HCCA on the other, has meant the process to date has been difficult. We will however continue to participate with MPC and Multiplex in the development of the Canberra Hospital Expansion. Kate Gorman will be replacing me as Chair of the CRG and I wish her well in this role.

The ACT has a new Labor/Greens Government and we look forward to a constructive relationship with the Government, as we have had with previous Governments. A number of policies in the Labor platform, including an additional 400 staff for ACT public health services, boosting elective surgery numbers, and the establishment of a dedicated palliative care ward at Canberra Hospital were advocated for by HCCA. The implementation of these policies will be very welcome.

I thank all members of the Executive Committee for their support and work during the year. Marcus Bogie, Shelley McInnes and Wendy Armstrong are all stepping down from the committee. Each in their own way have been great contributors to the work of the Executive Committee and I want to thank them for their contribution over the years. They will be missed.

Once again Darlene and the staff have done a sterling job under very difficult, and unique, circumstances. Their support for our members and the work of the organisation has been exceptional.

The organisation is made up of its members, who are all volunteers, and it is through their hard work and dedication that HCCA remains a vibrant and successful organisation which is a strong voice for consumer rights and the improved quality and safety of health care in the ACT.

Dr Alan Thomas
President



Alan Thomas and Rachel Stephen-Smith MLA, Minister for Health, at the HCCA Annual General Meeting - 30 October 2019

Executive Director's Report

It feels quite odd to be writing about the 2019-2020 period. The year falls between pre-COVID-19 and then life activities during the COVID-19 pandemic. Pre-COVID-19 seems such a long time ago!

Digital health has been 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. The e-Health Consumer Reference Group had its final meeting. This group has played a critical role since it formed in 2009. I want to thank the members and particularly Russell McGowan who has chaired this group from the beginning.



Darlene Cox

We have continued to see increasing demand on the public health and hospital system which has significant impact on accessibility and experience of health care. We know this also puts pressure on the wellbeing of staff and their ability to provide the standard of care they would like for patients and families.

COVID-19 was an added strain on our health system, health care workers, patients, families and our communities. The response by the ACT Government was excellent, and we are fortunate to have had so few infections. Health service staff in the ACT Health Directorate and the public health services have been amazing. They have done an excellent job at keeping us all safe. We owe them a debt of gratitude for their work. 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.

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. Their response to exceptionally challenging circumstances this year was impressive. We continued to meet almost all of our contractual obligations which is greatly appreciated. The staff made the transition to working remotely and this has become a permanent feature of how we operate as an organisation. I know that the online environment is not as comfortable for many of us and 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.

I want to thank the Executive Committee for their ongoing support and direction during this challenging year. I want to particularly thank Alan Thomas, Wendy Armstrong and Indra Gajanayake. Alan and Wendy have provided calm and reassuring leadership during the year and remained focussed on managing the risk these circumstances presented to our members, our staff and the organisation as a whole. Indra has been working tirelessly with us on the financial management of the organisation. This has been a more challenging year in terms of finances with new accounting standards, rollovers, rental rebates and a cash boost bonus. I want to thank Indra for her inquiring approach. Having an epidemiologist as a treasurer is really good!

Darlene Cox
Executive Director

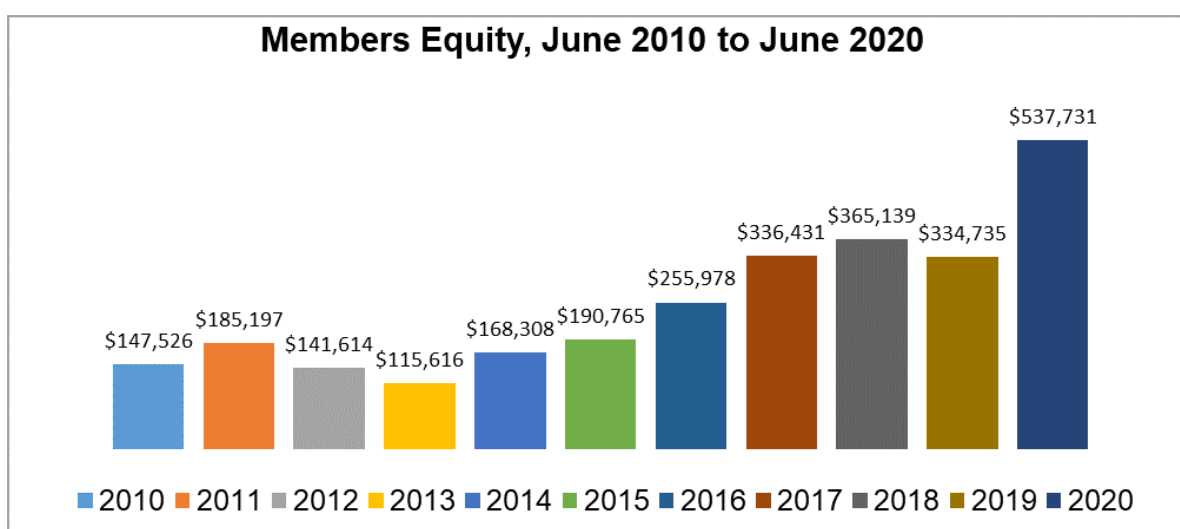
Treasurer's Report

HCCA ended the 2019-20 financial year with a surplus of \$148,437 after the auditor's adjustments for depreciation, 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 \$537,731 at 30 June 2020. 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.



Indra Gajanayake



The Association is in a very strong financial position and, in the unlikely event of being wound up, has sufficient reserves to settle all debts and obligations. Apart from office equipment, the Association's assets are held as cash with \$430,510 in operating accounts and \$393,853 in term deposits.

Total income for the 2019-20 year was \$1,223,640, which was \$286,166 more than the income received in 2018-19.

The Service Funding Agreement with the ACT Health Directorate (core funding) remains HCCA's main source of income, comprising around 58% of total income.

In addition, HCCA received additional funding from the ACT Health Directorate on a number of projects: Community Health Literacy, Advance Care Planning, Kids' Interstate Shared Care, Digital Health Record Tender Evaluation, and Consumer Experiences of Women Affected by Transvaginal Mesh Procedures. Of these projects, Community Health Literacy was the largest, with funding of \$197,055.

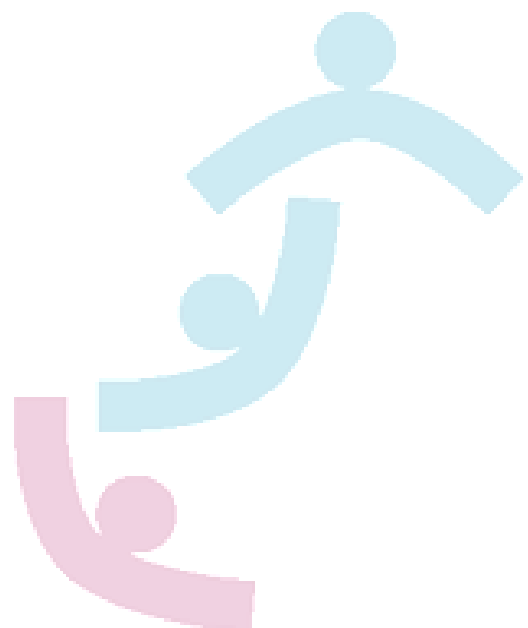
HCCA also worked with Major Projects Canberra to provide consultancy services to the Canberra Hospital Expansion Project (\$86,274).

Due to the COVID-19 pandemic, HCCA received the Federal Government's stimulus payment and rent relief from the ACT Government. These generated an additional income of \$70,156.

Wages and related staff costs remain the Association's main expense. The total staff costs across all programs during the year was \$880,903, equivalent to 72% of the total income. The staff costs went up from \$836,905 in 2018-19. This increase was due to new positions created to service the additional research and project funding agreements.

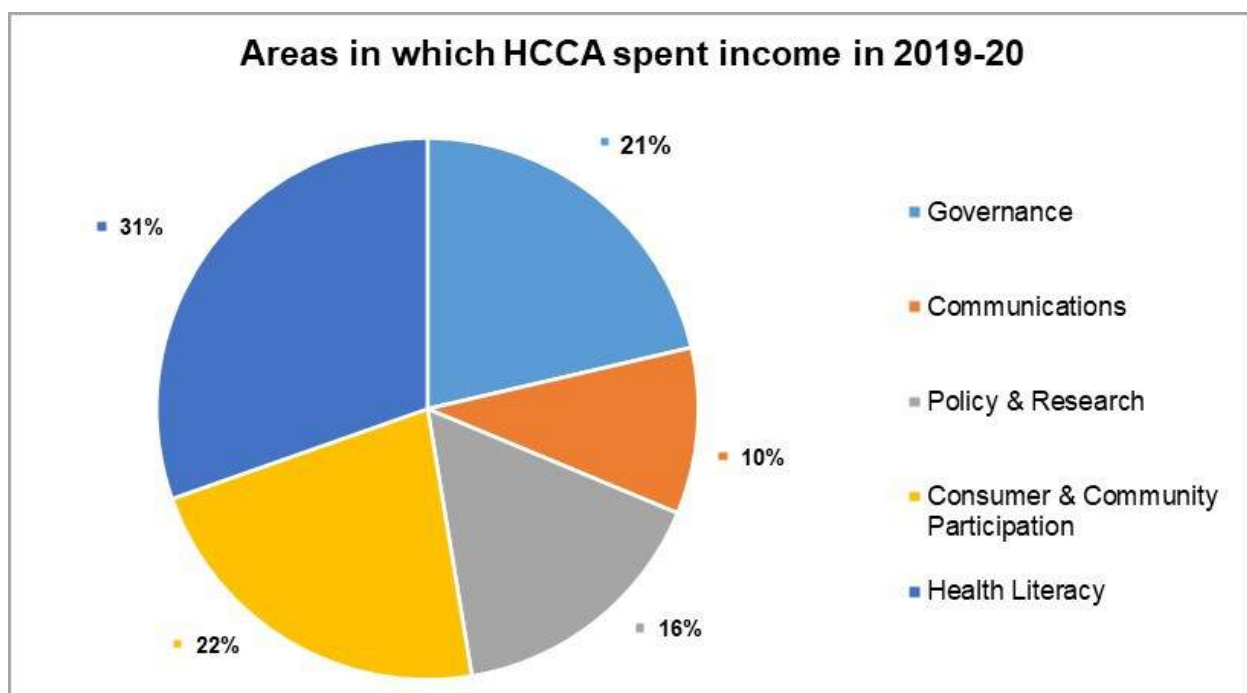
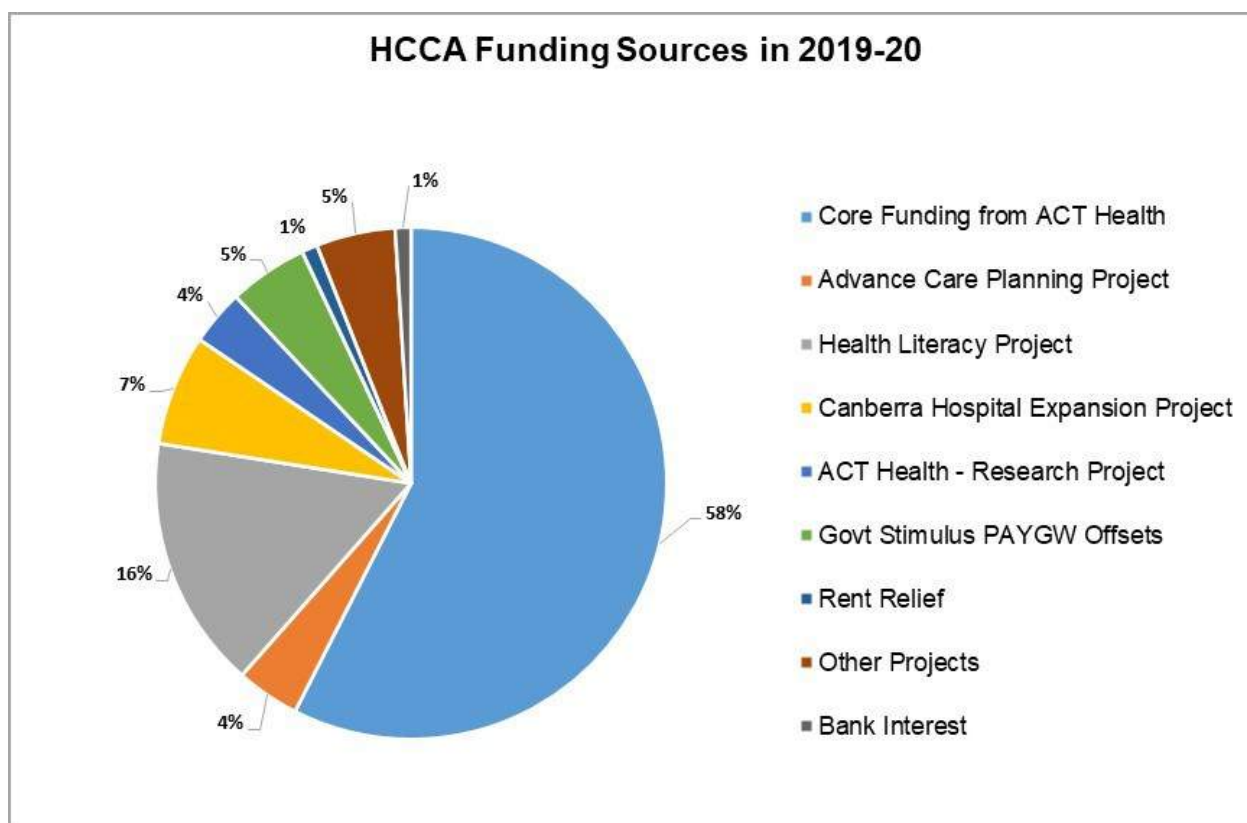
I wish to thank our Executive Director Darlene Cox, contract bookkeeper Lesley Porroj and Office Manager Sandra Avila for their support in my role as Treasurer during the year.

Dr Indra Gajanayake
Treasurer



Financial Resources

HCCA is mainly funded by the ACT Health Directorate. A detailed audited report for 2019-2020 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 2019-2020 and the areas in which this income was invested.



HCCA Members

In 2019-20 HCCA had 144 individual members of whom 51% were actively engaged with the programs and activities run by the organisation. We also had 23 organisational members.

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

- ACT Council of Social Service Inc. (ACTCOSS)
- ACT Lymphoedema Support Group
- ACT ME/Chronic Fatigue Syndrome Society
- Alcohol, Tobacco and Other Drugs Association of the ACT
- Alzheimer's Australia ACT
- Asthma Foundation ACT
- Bosom Buddies ACT Inc
- Canberra & Queanbeyan ADD Support Group Inc
- Canberra Ash Incorporated
- Canberra Lung Life Support Group
- Canberra Multicultural Community Forum Inc. (CMCF)
- Canberra Region Kidney Support Group
- Carers ACT
- Community Medics Australia Ltd
- Council on the Ageing (COTA) ACT
- Heart Support Australia
- Hepatitis ACT
- Meridian (formerly the AIDS Action Council of ACT)
- National Health Co-op
- Palliative Care ACT
- Parkinson's ACT
- People With Disabilities ACT Inc
- RSI and Overuse Injury Association of the ACT
- Shelter ACT
- Sleep Apnoea Association Inc
- Women's Health Matters
- Women With Disabilities ACT
- Youth Coalition of the ACT

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/>



UPDATE FROM THE OFFICE

National Careers Week from 11 - 17 October 2020 is an opportunity to recognise, celebrate and share awareness about the diversity of careers and their caring roles. Everyone can get involved in Careers Week, not just careers. The following ideas could inspire you to think of ways to become involved - from attending an event, spreading awareness on social media or sharing your story as a career. You can also get in touch with CareersACT to find out more locally in Careers Week.

HCCA recognises and appreciates the careers and the essential (but sometimes unseen) work that they do every day to keep the people they care for well. We value the work of [CareersACT](#) - the main body for careers in the ACT, whose role is to support, connect and empower careers to maintain that caring role and personal wellbeing. If you need some information or support in your caring role, contact CareersACT on 0295 5450 or through [their website](#).

Our newsletter, Consumer Bites, is the main form of communication with our membership and networks. HCCA published 28 issues. From 27 March to 28 May 2020, we published weekly instead of fortnightly newsletters as information and services about the COVID-19 pandemic were changing rapidly.

Website www.hcca.org.au

20,219 page views compared to 14,373 in 2018-2019

10,972 sessions compared to 6,860 in 2018-2019

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

HCCA posted 10 blog posts during this reporting period compared to 14 blog posts in 2018-19

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

843 followers compared to 778 in 2018-2019

748 likes compared to 702 in 2018-2019

Twitter <https://twitter.com/healthcanberra>

1,029 followers compared to 1001 in 2018-2019

Feedback from Consumer Bites's subscribers:

'Please pass on my congratulations on a fantastic Consumer Bites, I know the amount of work that goes into informing members and especially with such a complex range of information'.

'Would you please pass on my congratulations, thanks and appreciation to the team that produces Consumer Bites? In fact I suppose that all HCCA workers play a part, so please pass on my message as appropriate. Consumer Bites shows that Bulletins can be well written, readable and interesting, which in my opinion is as rare as feathers on an elephant!'

'Thanks for the latest issue of Consumer Bites. Really informative and a reliable knowledge source in this awful time'.

'I just wanted to say thank you to HCCA for your excellent newsletter. It is so comprehensive and full of good information'.

'Thanks, HCCA - Love reading your newsletters!'

thank you for sending out Consumer Bites. I found the information about where to access more information about the Covid-19 tracking app especially helpful'.

Health Policy Highlights

HCCA Position Statements

During 2019-20, the Health Policy and Research Advisory Committee developed and published position statements on:

- *Consumer Participation in Research* - supporting consumers to participate at all stages and at all levels of research, to help ensure that consumer priorities are better understood by researchers, decision-makers and the public.
- *Co-design* - involving consumers or service users as equal partners in the planning or design of services, policies, programs and initiatives

HCCA's position statements can be found on our website: <https://www.hcca.org.au/about/position-statements/>

COVID-19 Information Survey

During March and April 2020, early in the COVID-19 pandemic in Australia, we conducted a series of surveys to help us, and our health system, provide consumers in the ACT and surrounds with the information needed during the Coronavirus pandemic.

Each week, for four weeks, our weekly survey report was shared with a range of stakeholders to help improve information for, and communication to, consumers. All reports, including analysis for three subgroups (people aged 65+yrs, women and people with disabilities) can be found on the HCCA website.

A big thanks to HCCA's Health Policy and Research Advisory Committee for their support for this work. The committee was invaluable in assisting with analysis and helping us make these reports available quickly to everyone. These reports can be found on our website: <https://www.hcca.org.au/policy/consumer-information-about-covid-19/>

COVID-19 Issues Register

HCCA maintained a COVID-19 Issues Register between March and June 2020. The Register allowed HCCA to track the questions and issues consumers raised with us, and our actions. We published regular Issues Summaries, initially weekly then fortnightly as the number of issues decreased.

The Issues Summaries give a snapshot of consumer questions and concerns as the COVID-19 situation evolved.

- Many questions related to staying well and preventing COVID-19 transmission. Some of these questions reflected uncertainty about what was permitted under current social distancing requirements, and what do if people weren't following guidelines.
- Over the reporting period, concern about a lack of trustworthy COVID-19 information reduced. This may have reflected growing familiarity with information sources, and an improvement in the quality of public information. Lack of access

to translated information remained a concern. Toward the end of the reporting period we received more questions about COVID-19 misinformation and how to counteract it.

- Questions about where to go for health services, what services were available, and the health impacts of delaying or deferring treatments were consistent themes. The negative impacts of isolation on mental health was an emerging theme later in the reporting period.

Wherever possible HCCA provided information to help people answer the questions they raised with us. HCCA also shared information in the Issues Summaries to inform the ACT Government's COVID-19 response. The Registers are online at: <https://www.hcca.org.au/policy/consumer-information-about-covid-19/>

ACT Health COVID-19 Ethical Framework

Since the COVID-19 pandemic began in early 2020, Kate Gorman and Darlene Cox have been involved in the development of an ACT Health Ethical Framework. This pandemic-related work was quickly put in train by Canberra Health Services in late March 2020 as it became apparent from the experiences of other countries worldwide that health systems were being overwhelmed by the demand for care, and in particular intensive care resources. The intention of the Ethical Framework is to ensure that there is a fair, equitable and evidence based system for consumer access to health care should the demand for care outstrip the capacity of the system to respond.

This work includes the approach to end of life care. The Framework also includes arrangements for visitors for patients who are COVID-19 positive.

The Clinical Ethics Committee (Canberra Health Services) began the work by preparing advice for Canberra Health Services. A team of researchers at the Australian National University then took carriage of the work, with Canberra Health Services, to develop the ACT Ethical Framework. The final draft is yet to be finalised, however this is likely to be endorsed in November 2020 as it is recognised by clinicians that there is still a risk of major outbreak of COVID-19 in Canberra. HCCA continues to advise on the development of the framework and community participation in this work and has organised, encouraged and supported consumer and community organisations in the ACT to participate in the consultation process.



Health Policy Submissions

National

Australian Commission on Safety and Quality in Health Care

- ACSQHC - Draft Consumer Guide to 2nd edition Australian Charter of Healthcare Rights (Dec 2019)

Australian Digital Health Agency

- Feedback about My Health Record - Issues around Advanced Care Plans, Representatives and Compliance with National Health Act (Feb 2020)
- National Child Health Record Consultation (May 2020)

Australian Medical Council

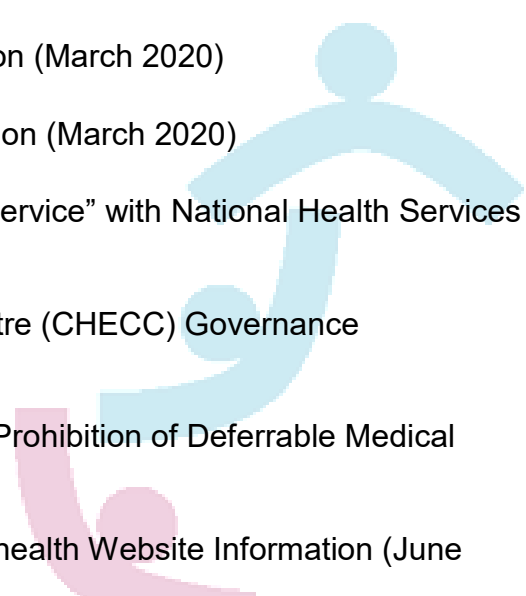
- Assessment of RANZCR & RANZCO (July 2019)
- Review of National Framework for Internship (August 2019)

Therapeutic Goods Administration

- Consultation: Increased Online Access to Ingredient Information (Oct 2019)

Local Policy Submissions

ACT Health Directorate

- Clinical Systems Evaluation (Sept 2019)
 - Policy Process Consultation (Dec 2019)
 - Territory Wide Health Service Plan - Follow up on YourSay survey (Jan 2020)
 - Consumer Participation Guideline Consultation (March 2020)
 - Mutual Rights and Responsibilities Consultation (March 2020)
 - Replacement of ACT Health “Find a Health Service” with National Health Services Directory (NHSD) Widget (March 2020)
 - Clinical Health Emergency Coordination Centre (CHECC) Governance Framework (May 2020)
 - ACT Government Project on Options for the Prohibition of Deferrable Medical Interventions on Intersex People (June 2020)
 - Feedback to ACT Health Directorate on Telehealth Website Information (June 2020)
- 

- Input to Proposal to Develop a Local Cancer Genomic Testing Service in the ACT/ Region (Aug 2019)

ACT Legislative Assembly Inquiry

- Inquiry into Planning for the Surgical Procedures, Interventional Radiology and Emergency Centre (SPIRE) and the Canberra Hospital Campus and Immediate Surrounds (Feb/March 2020)

Canberra Health Services

- Multiple Chemical Sensitivity/Idiopathic Environmental Intolerance Procedure (Feb 2020)
- Consultation on Consumer Feedback Management Policy and Procedure (Feb 2020)
- Challenging Behaviour Guideline Consultation (Feb 2020)
- Consent and Treatment Policy Consultation (Mar 2020)
- Communication Plan Telehealth Prescribing (May 2020)
- CHS Risk Register for COVID-19 (May 2020)
- Review Telehealth Draft Guideline (May 2020)
- Exceptional Care Governance Frameworks (May 2020)



Kathryn Briant meeting with Daniel Lalor, the Director of Pharmacy at Canberra Health Services

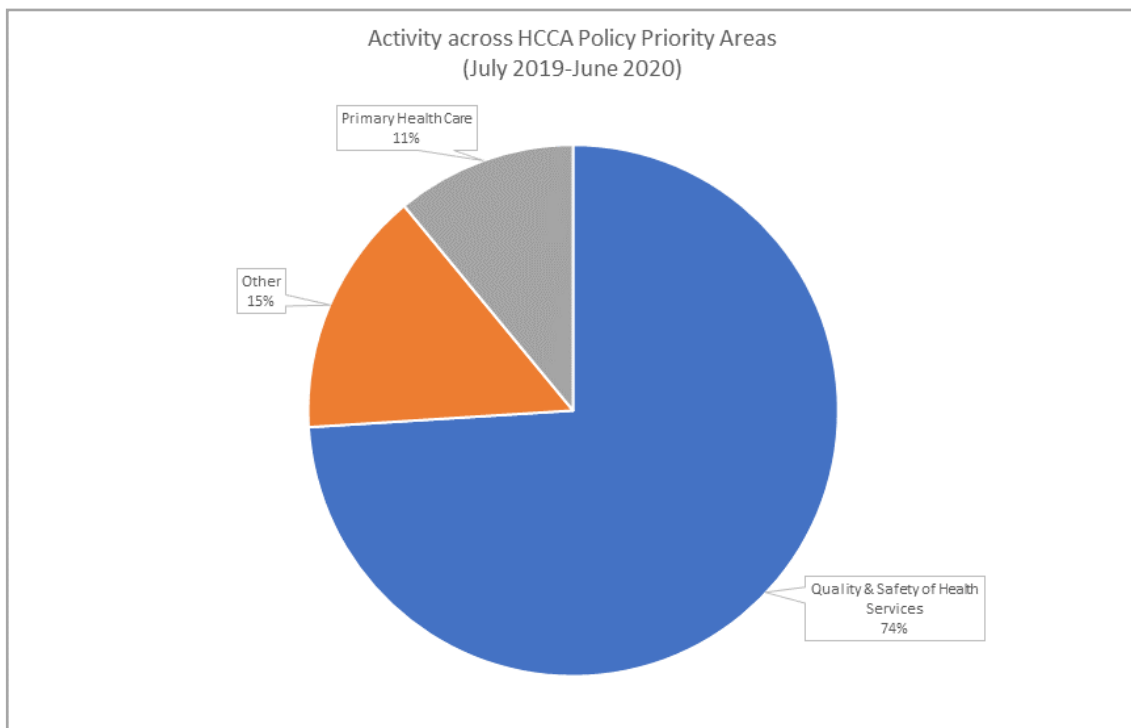
Policy Priority Areas

Each year the Executive Committee sets Policy Priority Areas to guide the work of the organisation. In 2019-20, the Policy Priority Areas were:

1. Quality and Safety in Health Care
2. Health of Older People
3. Primary Health Care
4. Mental Health
5. Cost of Health Care

The diagram below demonstrates how our policy activity is split across our priority areas.

Activity Across HCCA Policy Priority Areas



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 eHealth, Health of Older People, Quality and Safety, Access & Design and Maternity Services.

Health of Older People Consumer Reference Group

This Consumer Reference Group is chaired by Adele Stevens and met four times during this reporting period. Due to the COVID-19 pandemic this group was unable to meet from March to June 2020. This Consumer Reference Group aims to:

- Inform the ACT Health Directorate, Canberra Health Services and Capital Health Network about the needs of older people, and
- Provide a reference point for the development of patient-centred care in terms of the needs and experiences of older people.



Members of Health of Older People Consumer Reference Group:
Kaye Powell, Sue Schreiner and Wendy Robson - Oct 2019

Vale Sue Schreiner: Sue had an amazing intellect, a kind heart and a strong sense of service. Many of us were privileged to call her a friend. Sue was a lawyer and had been a magistrate and coroner. She was very involved with the HCCA Health of Older People Consumer Reference Group and helped us with important policy issues around consent, advance care planning and clinical ethics. Her contribution is valued and she will be missed.

ACT Accessibility and Design Consumer Reference Group

This Consumer Reference Group is chaired by Darlene Cox and met four times during this reporting period. The Accessibility and Design Consumer Reference Group expanded to include the consumer representatives on reference groups for SPIRE

(Canberra Hospital Expansion Project). Regular updates and discussion on SPIRE, transport, parking, outpatients and now telehealth are a significant part of the work of this group.

Questions discussed this year included how the closure of Hospital Road will affect access, how to provide more parking options with adequate time periods at Canberra Hospital and how to ensure safety and signage for consumers crossing significant roads around the Canberra Hospital and to the Walk-in Centres. CHS staff often attend this group to present on topical issues or to ask the group for their ideas on health service changes. While moving the meetings online has diminished our face to face time, staff and consumers continue to engage in robust discussion to address accessibility and design issues.

e-Health Consumer Reference Group

The EHCRG is chaired by Russell McGowan. The group met four times during this reporting period. The e-Health Consumer Reference Group aims to:

- Provide informed advice to the ACT Health Directorate, Canberra Health Services, Calvary Public Hospital and Capital Health Network, as well as to health consumer representatives, about e-Health proposals and projects, and
- Act as a reference group for the ACT Health Directorate and other health organisations, who are seeking consumer input or comment on e-Health information initiatives.

HCCA continued to contribute to the implementation of the ACT Digital Health Strategy (2019-2029), ensuring that benefits to consumer and health outcomes are maximised.

One of the major elements of the Digital Health Strategy is the ACT Digital Health Record. The plan for this record is to provide a holistic view of the patient throughout hospital and community care. A consumer portal is part of the ongoing plans as this work develops. The aim of the Digital Health Record is to improve access to information for clinical decision making, for better care and health outcomes. Consumer and organisational representatives were involved in the tender assessment process for the Digital Health Record and continue to be involved in the development of this work.

Through a number of consumer and organisational representatives on various project and program boards, HCCA provided input to a range of e-Health projects, including:

- Digital Patient Journey Boards – development and implementation at Canberra Health Services
- Clinical Systems Program implementation at Canberra Health Services and Calvary Public Hospital, including Electronic Medicines Management and Patientrack
- My Health Record consumer advocacy, including through Capital Health Network and the Australian Digital Health Agency
- Telehealth services in the ACT, as use has increased during COVID-19, particularly through primary care and outpatient services.

Quality and Safety Consumer Reference Group

The Quality and Safety Consumer Reference Group is chaired by Sue Andrews and met five times during this reporting 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 COVID-19 restrictions, the group has continued to meet online for shorter periods of time.



Members of the e-Health Consumer Reference Group - 27 November 2019

Topics and input opportunities have included:

- A presentation about the second edition of the National Standards for Quality and Safety In Health Care, and the work being done at Canberra Health Services in response to this
- A report on the State of Patient Safety and Quality In Australian Hospitals
- The work of consumer representatives locally in contributing to the accreditation of private hospitals
- Work being done at Canberra Health Services to improve policies and procedures around informed consent
- The topic of telehealth, which has been an important part of health services' response to restrictions imposed by COVID-19. Many consumers have found the opportunity to have their health appointments by telehealth has improved their access to health care.

ACT Maternity Consumer Reference Group

This Consumer Reference Group provides informed input to health services from the perspective of mothers of babies and young children. The group is primarily a resource for the ACT Health Directorate, Canberra Health Services and national bodies. These organisations can seek consumer input on documents, policies, new initiatives or proposals.

Research Projects Highlights

The Kids Interstate Shared Care Project

As part of the new plan for children's health services, the ACT Health Directorate engaged HCCA to undertake consumer consultation with children and families who are, or have been, subject to interstate care arrangements. Overcoming the challenges presented by the fires and COVID-19, the project interviewed 16 participants, 12 families and four organisations, covering a wide range of conditions and care experiences, including but not limited to: leukaemia, osteosarcoma (bone cancer), brain cancer, craniofacial abnormalities, cystic fibrosis, epilepsy, genetic conditions, Down Syndrome, musculoskeletal issues and severe gastrointestinal disease.

Some children were born with conditions, some conditions had diagnosis significantly delayed, and others had their first episode of ill-health when they were two or three years old but continued to have treatment and recurrences over many years. Some of the participants' children recovered, after a long period of ill-health, some continued to be chronically ill and were expected to need health care for the rest of their lives and unfortunately, some had died.

The results of this in-depth consultation were collated in *The Consumer and Family Experiences and Expectations of Accessing Interstate Specialist Care: The Kids Interstate Shared Care Project Final report*. The report made 17 recommendations across a range of issues including improving care coordination, access to information, improving patient and family experiences of care and supporting families and children. The report was released by the ACT Government on 9 September 2020 (<https://www.health.act.gov.au/about-our-health-system/planning-future/territory-wide-health-services/new-plan-childrens-health>) and was recognised as foundational work in the process of improving the situation of families managing these kinds of health care arrangements.

Experiences of Women Affected by Transvaginal Mesh

In December 2019, HCCA finalised and submitted the report on the research we had completed on *Experiences of Women Affected by Transvaginal Mesh*. The purpose of this research was to document the lived experience of women to inform the development of a new multidisciplinary service at Canberra Health Services to support women affected by transvaginal mesh implants. HCCA continues to have a staff representative on the steering group for the design of the new mesh service. It was intended that HCCA would hold a workshop to provide design input from women who had been affected by mesh implants into the new transvaginal mesh support service at Canberra Health Services. This had been planned for March 2020, but unfortunately, was cancelled due to COVID-19 restrictions. HCCA continues to provide guidance in the development of the service. The service opened to support consumers in July 2020.

Community Health Literacy in the ACT

The Community Health Literacy Project is a three year project funded by the ACT Government. In 2019, the first year of this project, HCCA identified initiatives that would meet priority health literacy needs in ACT communities. In 2020, we began work on these new projects, with advice from a Steering Group that brings together consumer representatives – HCCA members Karin Calford and Shelley McInnis – and representatives of the Capital Health Network, Calvary Public Hospital, ACT Health Directorate, ACT Office for Mental Health and Wellbeing, Canberra Health Services and Carers' ACT.

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. The Network launch planned for April 2020 was deferred due to COVID-19. The rescheduled launch was held as a webinar in August 2020 attracting over 100 participants to hear Rachel Stephen-Smith MLA, Minister for Health, launch the Network and to listen to keynote speaker Professor Kirsten McCaffery, on why health literacy matters, and what health and community professionals can do about it.



Kate Gorman, Rachel Stephen-Smith MLA, Minister for Health and Prof Kirsten McCaffery from the Sydney Health Literacy Lab at Uni of Sydney at the launch of the Canberra Health Literacy Network - 26 August 2020

Canberra Health Literacy Website

The new Canberra Health Literacy website shares practical resources and information to support health and community professionals, and consumers and carers. This year we have been busy identifying and collating relevant resources and information, and writing content for these diverse audiences, which we will continue to add to over the life of the project. We are proud that the website meets the requirements of international best practice website accessibility guidelines (Web Content Accessibility Guidelines 2.0).

Guide to Health Care Complaints

One of the resources we have been working on this year is a Consumer Guide to Health Care Complaints. Thank you to the HCCA members who have provided advice and feedback on this resource this year. We are also grateful to the Canberra Mental Health Forum and Mental Health Consumer Network for their advice on the project, and to People with Disabilities ACT who have generously permitted us to adapt a consumer resource they have developed, to include in this project. We also value the advice that ACT Health Services Commissioner Karen Toohey and her Office have provided.

Looking After Your Health With a Long-Term Condition

This research project was redesigned to take into account the impact of COVID-19 on how people look after their health when they have a long-term condition. This year we ran a consumer and carer survey that had close to 100 respondents, and conducted semi-structured conversations with consumers who have a variety of long-term conditions. The project will end in late 2020.

Health Literacy Training for Community Workers

HCCA has worked with consultant Susan Abbott, to develop and pilot the Community Workers' Guide to Health Care in the ACT. This is a series of seven discussion-based workshops that introduce community workers to the concept of health literacy, encourage them to reflect on how they support health literacy, and introduce resources and strategies to help workers and service users build confidence, knowledge and skills related to health literacy. This includes identifying trustworthy health information, asking questions, and tips on staying safe when using health care. The sessions were piloted in three workshops (one in person, two online) and we are looking forward to finalising the training package this year. This project is guided by a Project Advisory Group that brings together a consumer representative (HCCA member Chris Bowman) and community services professionals representing Toora Women, Meridian (formerly AIDS Action Council), ACTCOSS and Woden Community Service.

Sarah Spiller

Coordinator Health Literacy Program

Health Literacy Program

Increasing health literacy in the community is a key goal for HCCA. We do this through providing information directly to consumers, and to the health system to support navigation for consumers and will provide health literacy training directly to community sector workers in 2020-21.

Increasing Health Literacy Among Consumers

HCCA delivered 15 information sessions to over 289 people, which included multicultural communities, seniors and people with chronic conditions.

The health literacy information sessions are either requested directly by community groups or are advertised to the general public. We also organise guest speakers on general health issues such as foot care or gut health for the Chronic Conditions Seminar Series. These sessions are held at night or on weekends for workers who may have chronic conditions.

Two highlights this year were the information session, Staying Healthy in a Changing Climate (35 people attended) and delivering a Dying to Know event with other organisations (75 people attended). Both were held at the COTA ACT hall in Hughes and were very well received.

Staff also engaged in meaningful conversations about the health system with over 50 people at the ACT Deafness Resource Centre Hearing and Health Expo.

Due to COVID-19 many information sessions and attendance at expos were cancelled. We are increasingly delivering information online.

Increasing Health Literacy in the Health Environment

HCCA has continued to work with health staff so that all the elements of wayfinding across Canberra Health Services (CHS) are consistent and coherent. These include the CHS website, staff messages, letters to patients about appointments and wayfinding kiosks. Most of our activity centres on signage, transport, parking and handouts such as referral forms. Two planned workshops with volunteers and staff to identify what is working well and actions to improve the health literacy environment have been delayed due to the pandemic.

First Impressions projects were conducted at the University of Canberra Hospital and the Phillip Health Centre. These projects identify how easy it is to get to and around health facilities using the fresh eyes of consumers who have never attended. Consumers always have interesting insights but due to health budgets and priorities not all suggestions can be put into place. HCCA staff are working with CHS staff to identify the impact of the First Impressions projects across 18 health service areas in the last three years.

Due to COVID-19 much of our activity with the health system was focused on health literate information for outpatients and visitors to the hospitals.

Claudia Cresswell
Health Literacy Officer

Health Infrastructure Update

In September 2019, HCCA entered a service agreement with Major Projects Canberra (MPC) to provide consultancy services to the Surgical Procedures, Interventional Radiology and Emergency Centre (SPIRE) Project. This project was renamed the Canberra Hospital Expansion (CHE) Project in August 2020. The SPIRE project is a new emergency, surgical and critical healthcare facility to be built at the Canberra Hospital. Under this agreement, HCCA provides consultancy services including provision of advice and support for consumers to effectively participate in the SPIRE Consumer Reference Group (CRG) and participate in the review/development of Models of Care. The SPIRE CRG, comprising consumer and/or staff representatives from key community stakeholder groups was established in October 2019. The CRG is an advisory body providing guidance, advice and health service consumer insights on matters of design, accessibility, safety (including cultural safety) and amenity in relation to the SPIRE Project's building expansion design and construction.

The CRG meets monthly and is chaired by Dr Alan Thomas, President of HCCA. In this capacity, Alan also attended the SPIRE Project Control Groups for Main and Enabling Works. HCCA is also represented on the CRG by consumer representatives, Louise Bannister and Gev Khambata and two HCCA staff members, Anne Meuronen and Yelin Hung.

HCCA consumer and staff representatives participated in clinical user groups developing the SPIRE Models of Care, Functional Briefs and the 30% Preliminary Sketch Plans. They participated in the Early Contractor Involvement (ECI) Expression of Interest and Request for Tender processes by commenting on proposals for consumer engagement outlined in the tenders. HCCA also supported the work of the CRG by:

- Hosting an orientation session, in conjunction with MPC, for CRG consumer representatives on health infrastructure terms and processes
- Developing resources, including a paper on "What is important for consumers in health infrastructure"; a list of health infrastructure acronyms and terms; and consumer principles for the SPIRE Models of Care and infrastructure design.

In February 2020, HCCA lodged a [submission](#) to the ACT Legislative Assembly *Inquiry into Planning for the Surgical Procedures, Interventional Radiology and Emergency Centre (SPIRE) and the Canberra Hospital campus and immediate surrounds* and was invited to appear at a public hearing, before it was cancelled due to COVID-19. In addition to the SPIRE Project, HCCA has continued its involvement in other key health infrastructure projects including:

- Working with Canberra Health Services and Carers ACT to conduct a consultation process on Residential Accommodation Services at the Canberra Hospital
- Nominating and supporting a consumer representative for the Centenary Hospital Expansion Project Control Group and a staff representative for the Paediatric Working Group
- The Weston Creek and Dickson nurse-led Walk-in Centres.

Anne Meuronen

Consumer Participation Coordinator – Health Infrastructure

From the Multicultural Corner

HCCA continued to provide information sessions to multicultural communities. HCCA facilitated workshops for the community to promote mental health and wellbeing, health literacy, how to navigate the health system, advance care planning and aged care services. During this period we have delivered 11 community education sessions to 155 people.

We ran sessions on Managing your Medicines and Blood Test Preparation. There is the need for consumers to have a better understanding on how to prepare for a blood test especially if fasting or if diabetic; bringing medicines from overseas including prescribed medicines; the visa status for health care cards, and the high price of some PBS medications. Many members stated their use of Webster Packs to manage their medications was very useful.

We also presented a session about Navigating the Health System to Moments of Experiencing Life Together group which provides multicultural women with a network for support and mentoring. Members of this group stated they wished they had known about the services presented. What is important about the work we do is to provide a bridge to new migrants overcoming the challenges upon arrival here. It can be very daunting to start out in a new country, not knowing anyone, not understanding the health system, having no local experience when applying for jobs and no social networks.

A highlight was the consumers walkthrough of Canberra Hospital Food Services. It provided a journey through the food preparation, and the processes and tasting of various meals from the menu. We provided feedback to the food services manager, chef and other staff.



HCCA consumers and Canberra Hospital Food Services staff at the walkthrough to Canberra Hospital Food Services - 21 November 2019

On 25 January 2020, HCCA was recognised and awarded a Certificate of Acknowledgement by the Indian Australian Association of Canberra (IAAC) at its award night. This award was for the work we do with our Culturally and Linguistically Diverse (CALD) Communities delivering workshops and information sessions that help people navigate the health system to become better informed.

COVID-19 has limited face to face information sessions. It has been a learning journey to communicate using online platforms. This is still a work in progress as there are many barriers stopping people from CALD backgrounds accessing technology. The

various barriers include language, access to internet, equipment, and lack of knowledge and confidence when using online platforms. We have been working with Canberra Multicultural Community Forum (CMCF) to build capacity for people to learn how to connect online and continue our health literacy community sessions gradually.

For the first half of 2020, we made sure that information for COVID-19 reached the hard to reach communities especially in those less common languages. A highlight was the resilience of our multicultural communities, and following guidelines and restrictions. The radio stations assisted greatly in helping to provide this information to people in their languages. This work was recognised at the ACT Multicultural Awards 2020.

We have worked closely with our friends at CMCF and thank them for their support

Yelin Hung

Multicultural Liaison Officer



Yelin Hung receiving Indian Australian Association of Canberra Certificate of Appreciation - 25 January 2020



Yelin Hung with Tamil Seniors Association ACT talking about Advance Care Planning - 15 February 2020

Advance Care Planning Program

With funding from the ACT Health Directorate we continued to provide information to the ACT and region about Advance Care Planning. We delivered ten information sessions to 215 people including multicultural groups, members of the LGBTIQ+ community, LIONS club, university occupational therapy students and the general public. While the subject material is difficult at times, the key message - to plan for your end of life care and live well today - has been well received by participants. One participant said *'realising he had no-one to ask to be his Enduring Power of Attorney alerted him to the need to deepen his friendships as well as plan for end of life care'*.

When the pandemic started in March 2020, we could not deliver face to face presentations.

Culturally and linguistically diverse groups for whom HCCA presented tailored presentations included:

- Two presentations to Canberra Multicultural Community Forum groups
- One presentation for Filipino seniors
- One presentation for Tamil seniors

HCCA was also tasked with convening a forum for a range of Advance Care Planning providers and health services to discuss the gaps and the future directions of advance care planning in the ACT. This forum was held on 25 September 2019.



Advance Care Planning Forum - 25 September 2019

HCCA staff collaborated with colleagues from Canberra Health Services to create a community event for Dying to Know Day on 8 August 2019. The intention was to allow participants to have facilitated conversations about topics around death that were important to them. They were also supported with information provided by a range of service providers related to end of life and palliative care. The day was considered extremely successful with about 75 participants gathering to hold lively and interesting discussions. Feedback indicated that they had been able to find information and discuss topics important to them. As a result of the success of the first Dying To Know Day event, HCCA was invited to partner with the (then) AIDS Action Council staff to provide a smaller, modified version of this day specifically intended for LGBTIQ+ community members. This event was also very successful with around 15 participants hearing information and sharing stories with a range of service providers and health professionals in the end of life field. This event was held on 21 November 2019.

Getting Out and About

During 2019-2020 HCCA held two community stalls. The purpose of having these stalls is to display material with information about ACT Health services and talk to consumers and the community about the various services available, how to navigate the health system and how to access care they need. We also talked to consumers about the work HCCA does and the different ways we can become active health consumer advocates to improve the quality and safety of health care. These stalls help our Health Literacy Program, which promotes better understanding and knowledge in different parts of the community when it comes to using health services.

We had stalls at the Deafness Resource Centre Hearing and Health Expo and the National Multicultural Festival at the beginning of 2020.



Madhumita Iyengar, Yelin Hung, Mary Petterson, and Manaswini Iyengar - February 2020

HCCA Committees 2019 - 2020

Consumer Participation Committee

This Committee provides oversight of the implementation and evaluation of the HCCA Consumer and Community Participation Framework, provides input and consumer expertise to consumer and community participation activities, and endorses consumer representatives for non strategic committees. The Committee met five times during this reporting period.

Members of the Consumer Participation Committee are:

- Alan Thomas (Chair)
- Louise Bannister
- C Moore
- Sue Andrews
- Christine Bowman
(resigned December 2019)

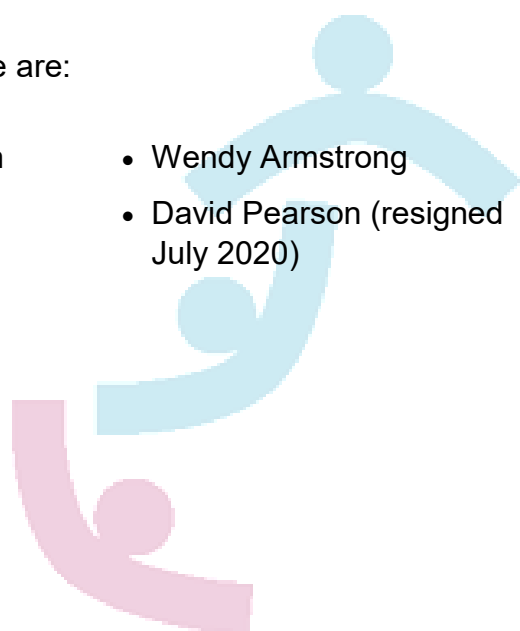
The Health Policy and Research Advisory Committee

HCCA's Health Policy and Research Advisory Committee provides an integral role to our policy and research work. The Committee met five times during this reporting period. Functions of the committee include to:

- Provide advice about HCCA input into draft policies and documents released for consultation by the ACT Health Directorate and others organisations.
- Identify and contribute to policy, research proposals and activities relevant to the HCCA Strategic Plan and expertise of committee members.
- Evaluate the quality of HCCA's submissions, and monitor implementation progress where HCCA has provided input.

Members of the Health Policy Advisory Committee are:

- Linda Trompf (Chair)
- Fiona Tito-Wheatland
- Margaret Norington
- Marion Reilly
- Wendy Armstrong
- David Pearson (resigned July 2020)



Consumer and Community Participation Highlights

- In this period (July 2019-June 2020) HCCA supported 35 consumer representatives in 96 consumer representative roles and eight organisational representatives (staff members) in 81 committee roles across the ACT Health Directorate, Canberra Health Services, Calvary Public Hospital, and other ACT and national bodies.
- HCCA made 43 endorsements of consumer and organisational representatives to committees, of which 30 were consumer appointments, and 13 were organisational appointments.
- 37 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 add an additional consumer representative to a committee.
- Of the 37 endorsements to new committees, 17 were made to Canberra Health Services committees, 6 were made to ACT Health Directorate committees, one to Calvary Public Hospital committees, seven to Major Projects Canberra, three to other local bodies, one to a national body, and one to a Capital Health Network committee.
- Consumer and organisational representatives spent around 1207 hours preparing for meetings, and around 1179 hours attending meetings. This does not include travel time.
- Committees where activity increased included those related to COVID-19, the Canberra Hospital Expansion infrastructure project and Canberra Health Services committees relating to end of life.
- HCCA met with the Minister for Health and Shadow Minister for Health in the ACT six times to discuss issues of interest to consumers.
- HCCA Consumer Participation Training was delivered in September 2019.
- Members Forums (previously known as the Consumer Representatives Forum) were held in August and November 2019 and March and May 2020.



Gev Khambata and Claudia Cresswell



Fiona Tito Wheatland and Kate Gorman

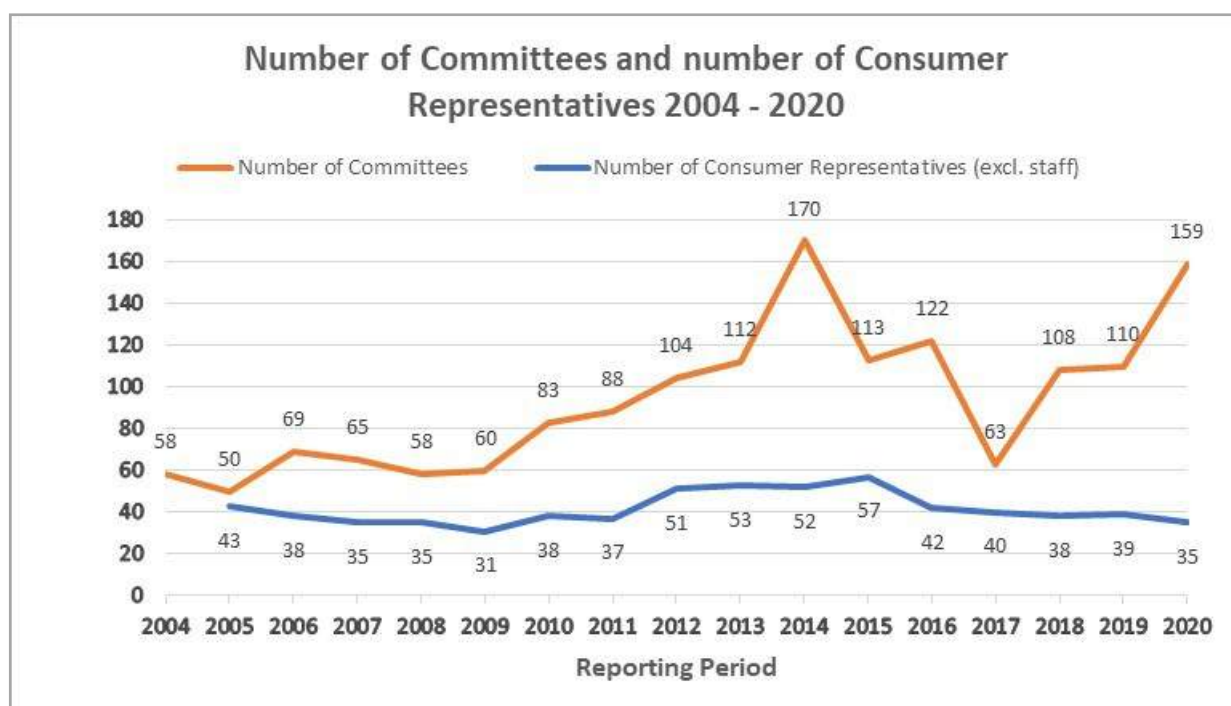
Consumer and Community Participation Program

Consumer Representation

It has not been possible to carry out many of the consumer participation activities HCCA would have facilitated in the second half of this period due to COVID-19. We are adapting our participation mechanisms, which usually include face to face consultations and meetings, to accommodate the restrictions imposed to manage COVID-19.

The consumer representative program continued to endorse and support consumer representatives on committees during this reporting period. Some committees paused work or delayed their formation during the period due to COVID-19. Other committees were formed to address health service needs around COVID-19. Other areas of increased activity included the Canberra Hospital Expansion infrastructure project and Canberra Health Services committees relating to end of life.

In this period (July 2019-June 2020) HCCA supported 35 consumer representatives in 96 consumer representative roles and eight organisational representatives (staff members) in 81 committee roles across the ACT Health Directorate, Canberra Health Services, Calvary Public Hospital, and other ACT and national bodies. In all, representation was provided on 159 committees (some committees had more than one HCCA member over time or at the same time).



Organisation	Numbers of Committees
ACT Health Directorate	24
Australian National University	6
Calvary Public Hospital	7
Canberra Health Services	84
Capital Health Network	4
Community Services Directorate	1
Major Projects Canberra	5
Local Organisations	12
National Organisations	13
Private Health Services	1
University of Canberra	2
TOTAL	159

Focus groups and consultations

Health services have continued to seek HCCA's help in gathering input from consumers on a one-off basis to inform specific projects.

- A focus group was convened by HCCA in February 2020 (the second of two) to provide input about community needs into the ACT Ambulance Service (ACTAS). A diverse range of community organisation representatives attended. HCCA will continue to work with ACTAS to embed consumer partnerships in service design and delivery.
- Canberra Health Services partnered with HCCA to run a focus group which provided input into the Paediatric Diabetes and Endocrinology Service. Several families who use this service convened to provide input into a review of the model of care for the Paediatric Diabetes and Endocrinology Service (6 February 2020).
- HCCA held a consumer workshop to review the Canberra Health Services Consumer and Carer Participation Guideline (11 February 2020).

Consumer Participation Training

This year HCCA has delivered:

- Consumer Participation Training on 7 and 14 September 2019 (one course, open to all community members)
- A consumer orientation presentation for consumers working in infrastructure design for the (then) SPIRE project, on 6 December 2019.

Health services staff training

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

- A condensed version of HCCA Training to consumer representatives (2) and staff (12) at Calvary Private Hospital on 5 March 2020.
- A workshop for the Australian Diabetes Educators Association on *Becoming A Consumer Centred Organisation* on 30 July 2019.

- A session for health staff in partnership with Canberra Health Services on *Working With Consumer Representatives* on 17 October 2019.
- A presentation to consumers and health staff (together) to mark World Cancer Day at the Canberra Region Cancer Centre on *Getting what you need/ helping consumers get what they need from a health service* on 4 February 2020.

With these exceptions, HCCA staff have not delivered other training to health services staff during this period due to the disruption of our normal activities by COVID-19. We have spent time adapting our training offerings to online delivery and anticipate that it will be available to health service staff in the next reporting period.

Presenting Consumer Perspectives

HCCA staff have spoken at the following events during this year to give consumer perspectives on health care:

- Canberra Health Services Innovation and Improvement Forum, 25 September 2019 (Kate Gorman).
- Quality Improvement Symposium in Wellington, New Zealand, 11 October 2019 (Darlene Cox).
- ADACAS Annual General Meeting, 29 October 2019 (Kate Gorman).
- Conference of the International Society to Improve the Use of Medicines (ISIUM) in Bangkok, 26-28 January 2020 (Kathryn Briant).

Kate Gorman

Manager Consumer and Community Participation



Kathryn Briant and Mary Murray (member of ISIUM organising committee - 26-28 January 2020)

Consumer Representatives

Adele Lewin	Helen Cotter	Marion Reilly
Adele Stevens	Helen Dyrw	Michelle Banfield
Adina Jordan	Indra Gajanayake	Miriam Pavic
Alan Thomas	Jenny Berrill	Pat Branford
Beatrice Vann	Jo Bothroyd	Priyanka Rai
David Baxter	Joanne Baumgartner	Russell McGowan
David Pearson	Karin Calford	Shelley McInnis
Dean Hewson	Kate Moore	Sue Andrews
Don McFeat	Kathryn Dwan	Sue Schreiner
Eliza Moloney	Katrina Muir	Terri Warner
Fiona Tito Wheatland	Kaye Powell	Trish Lord
Fran Parker	Kerry Snell	Wendy Armstrong
Geri Badham	Leia Earnshaw	
Gev Khambata	Linda Trompf	
Heather Warfield	Louise Bannister	

Organisational Representatives

Anne Meuronen	Kate Gorman	Jessica Lamb
Claudia Cresswell	Kathryn Briant	Sarah Spiller
Darlene Cox	Kristal Coe	Yelin Hung

Sponsored Conference Attendance

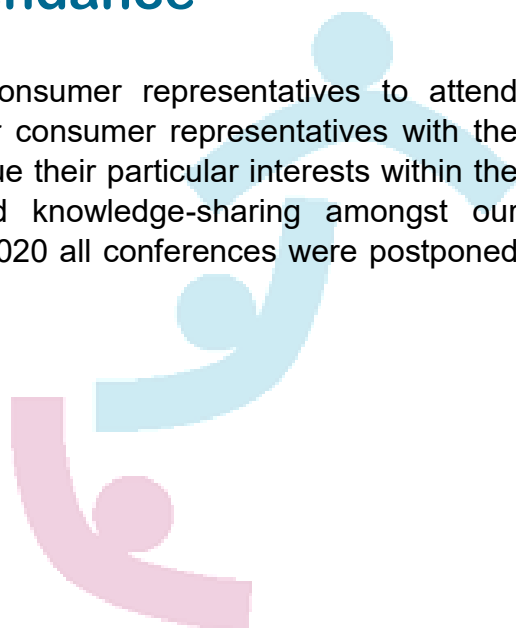
HCCA is proud to continue to sponsor our consumer representatives to attend conferences and other events. This provides our consumer representatives with the opportunity to increase their knowledge and pursue their particular interests within the area of health, and facilitates discussion and knowledge-sharing amongst our members after the event. Between March-June 2020 all conferences were postponed due to the COVID-19 pandemic.

December 2019

Preventing Overdiagnosis Conference

Karin Calford

Russell McGowan



List of Consumer and Organisational Representative Positions 2019-2020

ACT Health Directorate

ACT Child and Adolescent Clinical Services Plan Steering Committee

Fiona Tito Wheatland

ACT Health and Wellbeing Partnership Board

*Darlene Cox**

ACT Multicultural Health Reference Group

*Yelin Hung**

ACT Nursing and Midwifery Leaders Network

*Kristal Coe**

ACT Public Health System Data Governance Steering Committee

Fiona Tito Wheatland

*Darlene Cox**

Centre for Care Closer to Home Committee/ Hospital in the Home Expansion

Sue Andrews

Adele Stevens

Clinical Health Emergency Coordination Centre (CHECC) Committee

*Darlene Cox**

Clinical Leadership Forum

Shelley McInnis

Clinical Systems Program Board

*Kathryn Briant**

Critical Systems and Infrastructure Governance Committee

*Kathryn Briant**

Culture Review Oversight Group

*Darlene Cox**

Digital Health Record Program Board

*Darlene Cox**

Digital Patient Flow Program Board

Dean Hewson

Drug Strategy Action Plan Advisory Group

Wendy Armstrong

LGBTIQ+ Health Reference Group

*Darlene Cox**

Medicines Advisory Committee

*Kathryn Briant**

NGO Leadership Group

*Darlene Cox**

Nursing and Midwifery -Towards a Safer Culture Advisory Group

Miriam Pavic

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**

Health Technology Advisory Committee

Russell McGowan

Technology Strategic Steering Committee

*Darlene Cox**

Russell McGowan as proxy

Territory-wide Health Service Plan Steering Committee

*Darlene Cox**

* Organisational Representative

List of Consumer and Organisational Representative Positions 2019-2020

Australian National University

ANU Medical School for the Future

Taskforce

Indra Gajanayake

Bushfire and Maternal Health Research Project

*Kate Gorman**

Canberra Clinical Genomics Advisory Board

*Darlene Cox**

HealthANSWERS Implementation Working Group

Indra Gajanayake

Medical School Advisory Board

*Kate Gorman**

Our Health In Our Hands Health Experience Board

*Kate Gorman**

Calvary Public Hospital

Communicating for Safety Committee

Heather Warfield

Calvary Medication Safety Committee

Trish Lord

Clare Holland House Quality, Risk and Safety Committee

Fran Parker

Clare Holland House Self-Assessment of Compliance with the Palliative Care Standards

Fran Parker

Clinical Governance Committee

Jenny Berrill

GRACE Steering Committee

Shelley McInnis

Partnering with Consumers Committee

*Kate Gorman**

Canberra Health Services

Aboriginal and Torres Strait Islander Steering Group

Wendy Armstrong

ACT Equipment Loans Scheme Advisory Committee

Marion Reilly

ACT Food Services Quality Committee

*Yelin Hung**

ACT Maternal Services Advisory Network

Adina Jordan

ACT Palliative Care Forum

Adele Stevens

Allied Health Leadership Committee

Adele Lewin

Allied Health Professional Lead Committee

Adele Lewin

Ambulatory Care Administration Standards and Governance Committee

*Claudia Cresswell**

Arts in Health Advisory Group

Geri Badham

Bariatric Surgery Advisory Committee

Russell McGowan

Sue Schreiner

* Organisational Representative

List of Consumer and Organisational Representative Positions 2019-2020

Blood Management (NSQHS Standard)

Linda Trompf

Breast Screen ACT Reference Group

Louise Bannister

Breast Screen Consumer Reference Group

Linda Trompf

Breast Screen Quality Committee

Louise Bannister

Cancer and Ambulatory Support Clinical Governance Committee

Indra Gajanayake

Centenary Hospital for Women and Children Expansion Project Control Group

Miriam Pavic

Centenary Hospital for Women and Children Pediatric Reference Group

*Anne Meuronen**

Choosing Wisely and Low Value Care Steering Committee

*Darlene Cox**

Chronic Disease Management Clinical Network

Trish Lord

CHS Expansion Maternity Assessment Unit/Gynaecology Procedures Suite and Post Natal Working Group

*Jessica Lamb**

Clinical Ethics Committee

Sue Schreiner

Terri Warner

Clinical Ethics Committee COVID-19 Working Group

*Kate Gorman**

Clinical Governance Committee

Jo Bothroyd

Clinical Governance Standards Committee (NSQHS Standard)

Darlene Cox (resigned June 2019)*

*Kate Gorman**

Clinical Handover Working Group (NSQHS Standard)

*Kate Gorman**

Clinical Review Committee

Fiona Tito Wheatland

Cognitive Impairment and Delirium Working Group (NSQHS Standard)

Beatrice Vann

Communicating for Safety Standard Committee (NSQHS Standard)

Russell McGowan

Karin Calford

Community Care Clinical Governance Committee

Indra Gajanayake

Joanne Baumgartner

Comprehensive Care Standard Committee (NSQHS Standard)

Indra Gajanayake

Consent Working Group (NSQHS Standard)

Fiona Tito Wheatland

Consumer Handout Committee (NSQHS Standard)

Helen Dyriw

Kerry Snell

* Organisational Representative

List of Consumer and Organisational Representative Positions 2019-2020

*Kathryn Dwan**

Consumer Participation Working Group
(NSQHS Standard)

*Kate Gorman**

COVID-19 Decision Making Framework
Steering Group

*Darlene Cox**

COVID19 Taskforce

*Darlene Cox**

Critical Care Executive Committee

Jo Bothroyd

Diabetes Service Reference Group

Kaye Powell

Dickson Walk-in Centre Working Group

*Claudia Cresswell**

Dickson Walk-in Centre/CHC Project
Control Group

*Claudia Cresswell**

Diversity Training Day Committee

*Yelin Hung**

Division of Allied Health Quality and
Safety Committee

Adele Lewin

Division of Medicine Quality and Safety
Governance Committee

Indra Gajanayake

Domiciliary Oxygen and Respiratory
Support Scheme (DORSS)

Helen Cotter

End of Life Care Research Collaboration
Committee

Shelley McInnis

Adele Stevens

End of Life Care Working Group (NSQHS
Standard)

*Yelin Hung**

Adele Stevens

Facility Wide University of Canberra
Hospital Operational Committee

Don McFeat

CHS Governance Committee

*Darlene Cox**

Health Services Executive Committee

*Darlene Cox**

Health Services Executive Committee
(Quality and Safety)

*Kate Gorman**

Interpreter Working Group (NSQHS
Standard)

*Yelin Hung**

Maternity and Gynaecology Safety and
Quality Committee

Leia Earnshaw

Medical and Dental Appointments
Advisory Committee

Alan Thomas

Medication Safety Committee (NSQHS
Standard)

*Kathryn Briant**

Mental Health Consumer and Carer
Advisory Committee

Adele Lewin

*Yelin Hung**

Mental Health Justice Health Alcohol and
Drug Service Corporate Governance
Committee

* Organisational Representative

List of Consumer and Organisational Representative Positions 2019-2020

David Baxter

National Standards Governance
Committee (NSQHS Standard)

*Kate Gorman**

Occupational Violence and Aggression
Consultancy Working Group

*Kate Gorman**

Occupational Violence and Aggression
Working Group

Shelley McInnis

Occupational Violence Prevention and
Management Committee

Heather Warfield

Organisation Wide Screening and
Comprehensive Care Planning Working
Group (NSQHS Standard)

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 Working Group

*Claudia Cresswell**

Partnering with Consumers (NSQHS
Standard)

*Kate Gorman**

*Yelin Hung**

Policy Committee

Terri Warner

Preventing and Controlling Healthcare-
associated Infections (NSQHS Standard)

Jenny Berrill

Quality Report Working Group

Fiona Tito Wheatland

RACC Quality and Safety Committee

Louise Bannister

Recognising and Responding to Acute
Deterioration Committee (NSQHS
Standard)

Adele Lewin

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

*Kate Gorman**

*Claudia Cresswell**

Terminal Sedation Working Group

Adele Stevens

The Canberra Hospital Bed Replacement
Program

*Kate Gorman**

Timely Care Steering Committee

Wendy Armstrong

Transfusion Information Working Group
(NSQHS Standard)

Linda Trompf

* Organisational Representative

List of Consumer and Organisational Representative Positions 2019-2020

Transitional Therapy and Care Program
Executive Management Committee

Trish Lord

Transvaginal Mesh Review Committee

*Kate Gorman**

Walk-in Centre Executive Steering
Committee

*Kate Gorman**

Weston Creek Walk in Centre Project
Control Group

*Claudia Cresswell**

Women Youth and Children's Community
Health Programs Quality & Safety

Committee

*Kate Gorman**

Women Youth and Children's Quality and
Safety Committee

Priyanka Rai

Capital Health Network

Community Advisory Council

Kate Moore

Parkinson's Nurse Program Advisory
Group

Katrina Muir

Pharmacy in Residential Aged Care
Facilities Program Governance Committee

Trish Lord

ACT Health Pathways Governance
Committee

*Darlene Cox**

Community Services Directorate

Carer's Strategy Governance Group

*Kate Gorman**

Major Projects Canberra

Emergency Department Model of Care
Working Group

*Kate Gorman**

Intensive Care Model of Care Working
Group for SPIRE

Jo Bothroyd

SPIRE Project Consumer Reference
Group

Alan Thomas

*Anne Meuronen**

Gev Khambata

Kerry Snell

Louise Bannister

*Yelin Hung**

SPIRE Project Control Groups

Alan Thomas

Surgical Model of Care Working Group for
SPIRE

Karin Calford

Local Organisations

Canberra CALD Women's Forum
Committee

*Yelin Hung**

* Organisational Representative

List of Consumer and Organisational Representative Positions 2019-2020

Canberra Multicultural Community Forum Committee
*Yelin Hung**

Canberra Region Medical Education Council
Fiona Tito Wheatland

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

Community Development Network Steering Committee
*Yelin Hung**

COTA Elder Abuse Prevention Network
*Kate Gorman**

Humanitarian Settlement Program Network Meeting
*Yelin Hung**

Canberra Multicultural Community Forum Multicultural Matters Meeting
*Yelin Hung**

Northern Region Networking Interagency
*Yelin Hung**

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

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

ACT Housing Tenant Consultative Group
*Yelin Hung**

National Organisations

AHPRA Community Reference Group
*Darlene Cox**

APHRA Aboriginal and Torres Strait Islander Health Strategy Group
*Darlene Cox**

Australian Council on Healthcare State Advisory Committee
Russell McGowan

Australian Pharmacy Standards Review Reference Group
Fiona Tito Wheatland

NPS MedicineWise Consumer Advisory Group
Karin Calford

Partnering with Consumers Committee (ACQSHC)
*Darlene Cox**

Mitchell Institute Self-Care Policy Options Expert Working Groups
*Darlene Cox**

NPS MedicineWise Clinical Intervention Advisory Committee
*Darlene Cox**

Private Health Services

John James Private Hospital Clinical Risk and Audit Committee
Marion Reilly

* Organisational Representative

List of Consumer and Organisational Representative Positions 2019-2020

University of Canberra

Ageo Evaluation Committee – SmartCare
in Aged Care

Beatrice Vann

Pharmacy Course Advisory Group
Committee

Pat Branford



HCCA members at the Annual General Meeting - 30 October 2019

HCCA Organisational Chart 2019- 2020

