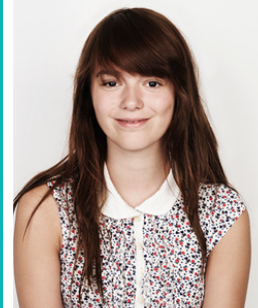




Consumer and Community
Involvement Program

2019 – 2020 Year in Review Activity Report



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A MESSAGE FROM THE EXECUTIVE DIRECTOR

It gives me great pride and pleasure to share the Consumer and Community Involvement Program (CCIProgram) Activity Report 2019-2020. Consumer and community involvement (CCI) in medical research has been seen as increasingly important for many years with the CCIProgram and its earlier iterations front and centre at this change in Western Australia (WA).

This report shows the increasing reach and importance of CCI within the WA medical research sector over the past year. Among the highlights are the WA Department of Health's Research Innovation Office formalising ties and the CCIProgram's involvement and recognition in the recently released WA Future Health Research and Innovation Fund Strategy 2020-2022. Details of projects supported, workshop attendances and matching services show the wide range of activities and services CCIProgram provides.

The strength of CCI in Western Australia has also allowed the Western Australian Health Translation Network to co-lead a nationwide CCI initiative along with other translation centres.

All good ideas sell themselves and it has been pleasing to see researchers who perhaps were a little dubious about the benefits of involving consumers and community come to embrace CCI as the benefits to their research become obvious. Involvement of consumers and community leads to better research. Better research leads to better health outcomes.



Prof Gary Geelhoed

A MESSAGE FROM THE HEAD OF CCIPROGRAM

2019-2020 has been a period of growth, change and challenges for the Consumer and Community Involvement Program . We have embraced the national conversation on the significance of the work we do by changing our name to the CCIProgram – Your Voice in Health Research, and have been building our presence at a state and national level. Our passion to support best practice research in Western Australia is supported by our vision to improve lives by ensuring the community’s voice is heard and understood in health research, and to be the connecting network that bring researchers, partners, policy makers and people with lived experience together.

I am excited about the opportunities that have been developed in the past year with our strengthening partnership with the WA Department of Health’s Research Innovation Office, and our involvement in the recently released WA Future Health Research and Innovation Fund Strategy 2020-2022. The Strategy sets before us an exciting future in the health research and innovation space with consumer and community involvement being a key component of the actions and initiatives.

We have enjoyed the launch of our video series that captures the voices of people with lived experience, the partners and researchers we work with and the CCIProgram team. They all share the significant and impact of involvement in research and innovation in WA. COVID-19 changed and accelerated the way in which we support and build the capacity of our community members, researchers and partners and we look forward to continuing to be innovative in the way we train and develop those we work with.

We hope you find the CCIProgram: Year in Review an informative read, and look forward to continuing to work with amazing people from communities and the health research and innovation sector to enhance best practice research outcomes throughout WA.



Deb Langridge

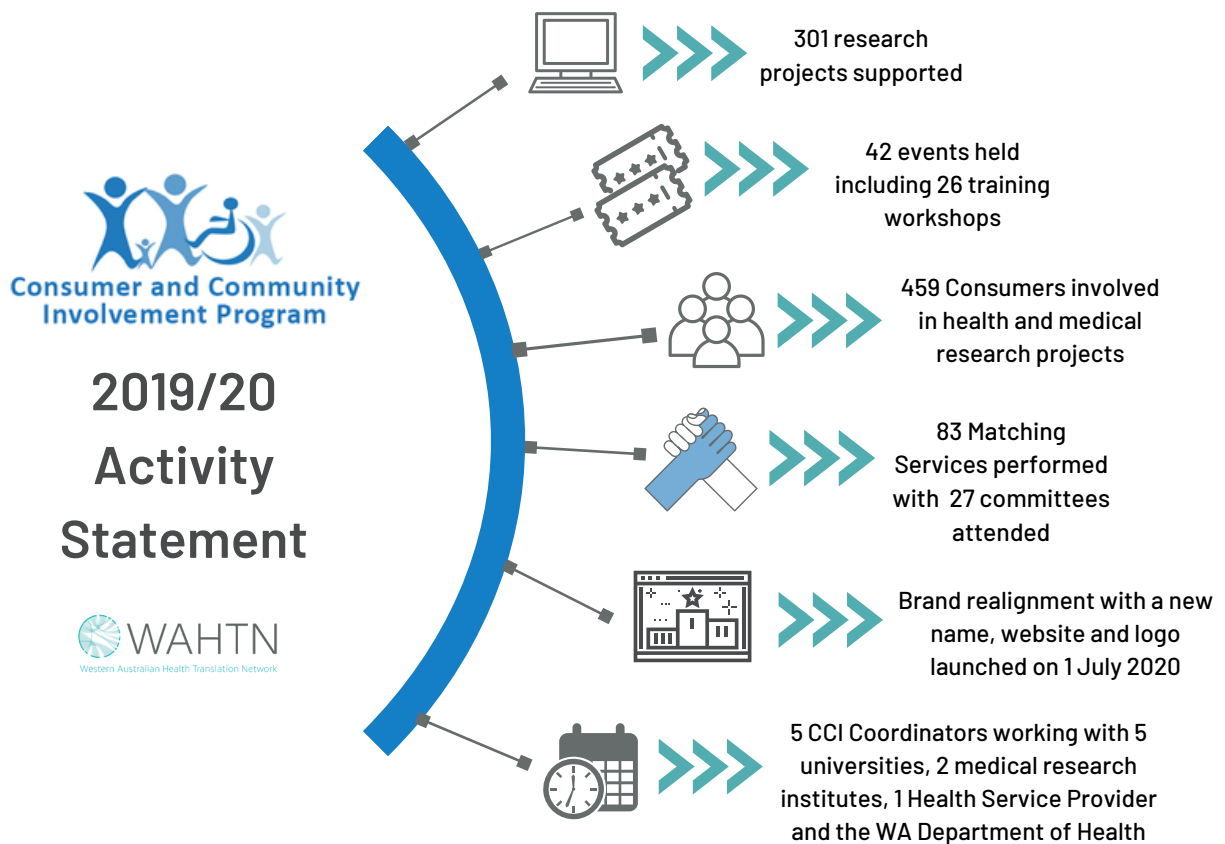
EXECUTIVE SUMMARY

From 1 July 2019 to 30 June 2020, the Consumer and Community Involvement Program (CCIProgram) previously known as the Consumer and Community Health Research Network (CCHRN) has continued to support and resource partner organisations, researchers, consumers and community members with effective ways to be involved in health and medical research.

This past year has been unprecedented, with the COVID-19 pandemic casting uncertainty on many parts of our community and requiring us to interact and work in different ways. While this has challenged us at times, the CCIProgram has directed its focus towards the opportunities created by COVID-19 and has embraced new ways of working.

The CCIProgram has implemented new methods of serving researchers and the community in the digital space, and has embraced the opportunity to involve consumers and community members in COVID-related research across WA.

Despite its challenges, the past year has been tremendously productive. The CCIProgram has supported and facilitated events, training for researchers and consumers, community conversations in both face-to-face and digital forums and recruitment of consumer and community members for involvement in research projects across WA Universities and health services. Details of the CCI support provided is highlighted below:

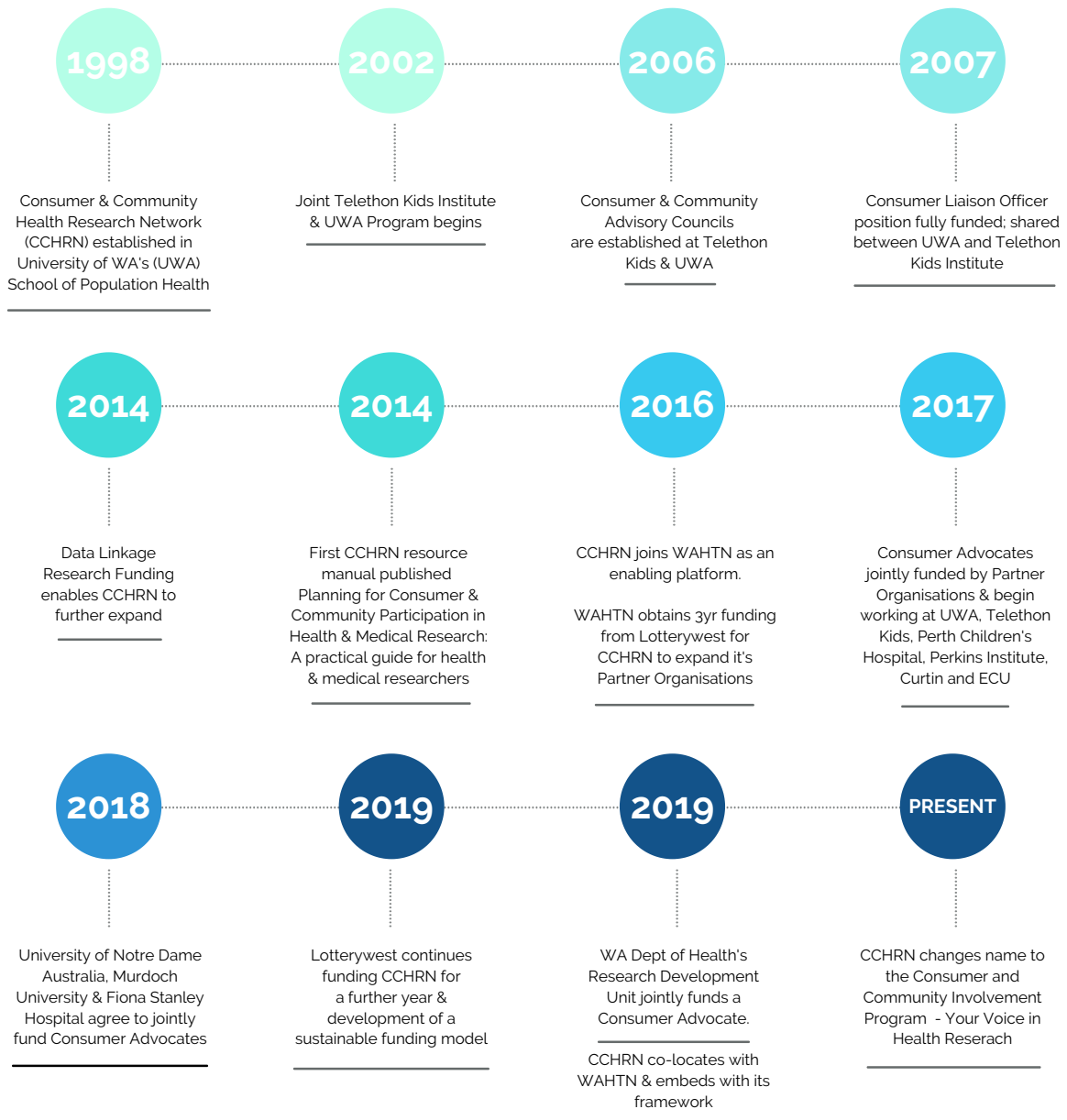


The projects, resourcing and growth highlighted in this Year in Review indicate the continued and ever-growing value of CCI in health and medical research. Our future remains strong, and we look forward to working with our partners and the Western Australian community.

ABOUT US

The CCI Program is an enabling platform of the WA Health Translation Network (WAHTN) and supports researchers and partner organisations across WA to involve consumers and community members across all stages of the health and medical research process. Consumer and Community Involvement in research is about consumers, community members and researchers working together to shape decisions about research priorities, practice and policies, so that CCI can become standard practice in health research.

Established in 1998 through the University of Western Australia's School of Population Health and the Telethon Kids Institute (founding partners), the initiative has evolved into a state-wide platform that is recognised nationally and internationally as a best practice model. The timeline below outlines the growth of the CCI Program:



The WAHTN has invested in the CCI Program over the last three years, culminating with the co-location of the CCI Program and WAHTN teams at the Harry Perkins Institute for Medical Research in the final quarter of 2019.

The amalgamation with WAHTN has strengthened the team and capacity for CCI, and has further enabled the development and expansion of the CCI Program from its founding stages to become a state-wide, internationally recognised, 'Best Practice' CCI platform.

With the advancement of involvement in research in WA communities, the CCI Program has been in step with the parallel growth at a national level with the National Health and Medical Research Council (NHMRC), implementation of their Statement on Consumer and Community Participation in Health and Medical Research.

This supports an aim of increasing translation of research evidence to improve health outcomes and enables the CCI Program to offer its CCI services at an increasingly wide range of research organisations.

Governments, funding bodies and research organisations across the world are increasingly recognising the importance of including the lived experiences, values and priorities of consumers and community members in research policies and practice.

The CCI Program is continuing to collaborate with WAHTN Partners and other organisations about ways to support CCI in research. These Partnerships make visible to others in the health sector the benefits of CCI in research and ways in which organisational capacity can be built.

[1] National Health and Medical Research Council, Statement on Consumer and Community Involvement in Health and Medical Research, September, 2016, <https://www.nhmrc.gov.au/about-us/publications/statement-consumer-and-community-involvement-health-and-medical-research>

2019-2020 YEAR IN REVIEW HIGHLIGHTS

During 2019 and 2020 the CCIProgram has provided dedicated support for CCI across health and medical research organisations and universities, including:



- Harry Perkins Institute of Medical Research
- University of Western Australia
- University of Notre Dame Australia
- Curtin University
- Edith Cowan University
- Murdoch University
- Australian National Phenome Centre
- Child and Adolescent Health Service
- Telethon Kids Institute
- WA Research and Innovation Office

We continued to work in collaboration with the Health Consumers Council of Western Australia and have partnered together in many endeavours to advocate and support consumers and the community.

CCIPROGRAM TEAM

We have grown our team to eleven members and have commenced a partnership with the WA Department of Health's Research Innovation Office. This has been a very exciting expansion of our CCI Coordinator service model, enabling us to work directly with the Department on research policy, protocol and practices internally.



PROGRAM NAME CHANGE AND UPGRADE OF THE CCIPROGRAM WEBSITE

In July 2020, the CCIProgram changed its name from the Consumer and Community Health Research Network to the Consumer and Community Involvement Program and upgraded its website to provide greater accessibility for researchers and consumers.



The name change and tag line highlights the most critical part of our work at the CCIProgram – “Your voice in health research”. CCIProgram also reflects the changes occurring in the research sector at a State and National level, where CCI is not only gaining momentum and interest, but is also being incorporated into best practice models of health and medical research.

VOICES ON INVOLVEMENT

The CCIProgram developed a suite of video resources which tell the story of CCI, using voices from people with lived experience, researchers, Partners and CCIProgram staff.

The 'voices on involvement' videos capture the experiences of people who live day to day with illnesses, those who have a unique community perspective, and the researchers sharing how they conduct involvement in their research, and have been a useful addition to the CCIProgram website and training sessions.

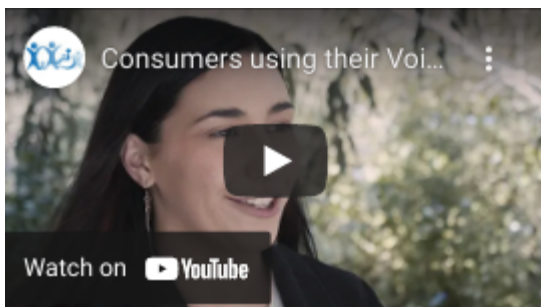


CCIProgram - What we do



 <https://youtu.be/kpsPr94afug>

Consumer Involvement



 <https://youtu.be/D17PIhZRylg>

Researcher Services

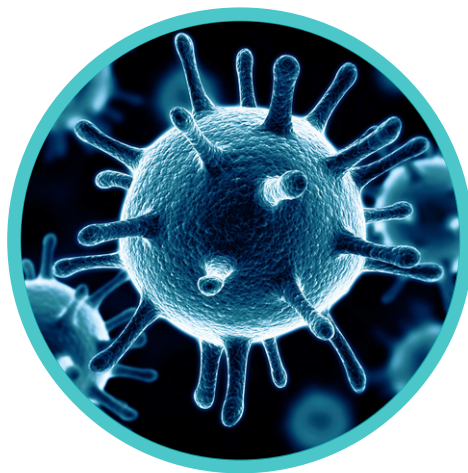


 <https://youtu.be/X4T0TgRmbWU>

WAHTN LED COVID-19 RESEARCH COLLABORATION

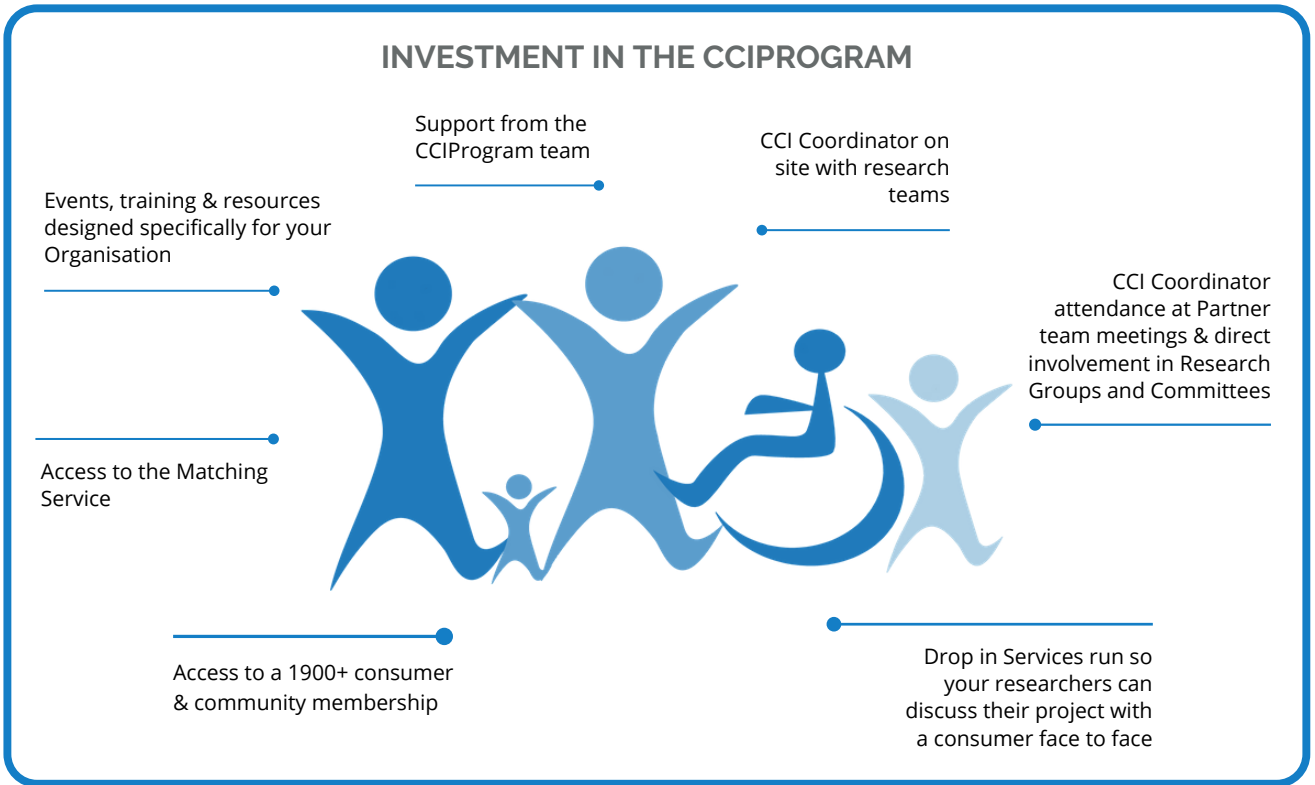
WAHTN was asked by the Minister for Health to lead the WA COVID-19 Research response and formed a Research Collaboration of over forty WA stakeholders, including the CCI Program. The CCI Program has been directly supporting researchers with regards to the Ministers directive to ensure CCI is embedded within the research process.

This includes providing individualised support for researcher applications to the WA Department of Health COVID-19 Research Grants, development of the first COVID-19 Community Representative Pool, and delivery of a COVID-19 Community Research Consent Survey to inform clinicians, health services and researchers of community voices with regards to COVID-19 treatment and research. This has provided an exciting opportunity for cross-sector collaboration and capacity building for CCI in the research space.



CONSUMER INVOLVEMENT

The CCIProgram offers various methods of CCI support to Partner Organisations.



This represents a substantial amount of CCI facilitated by the CCIProgram, and has contributed to a growing consumer and community representative base.

Matched Consumers to 83 Research Opportunities

Supported 157 existing research projects

Involved 450 consumers in research projects across WA

Supported 144 new Research Projects

Provided ongoing strategic input to 27 organisational research committees

CCI Coordinator's work closely with researchers to determine and facilitate the most suitable forms of consumer and community involvement. We then connect researchers with appropriate consumers and community members for involvement in research using our 'matching service', a unique service that has been recognised as an attributing element to the CCIProgram's 'international best practice' standing and is a key reason why our Partner Organisations invest in our services.

THE MATCHING SERVICE

Our international best practice process of involving consumers in health and medical research

RESEARCHERS & CCI COORDINATORS WORKING TOGETHER

The CCI Coordinator and researcher meet to decide on the type of CCI required, the budget and timeline for desired delivery is discussed



ADVERTISING & PROCESSING

Once published the Matching Service request is monitored by staff and the advertising strategy is adjusted as necessary. Once the application closing date has passed the vacancy team speaks directly with all applicants to start the recruitment and acceptance process

CCIPROGRAM TEAM SUPPORT

Once the Matching Service request has been submitted the admin, marketing and vacancy team get to work



RESEARCHERS CHOICE

A short list of the suitable applicant profiles are discussed with and sent to the researcher (or research team) for final selection. They are provided with critical information about the consumers including the way the consumer conducts themselves during meetings, how they deliver information and their ability to listen and discuss

RESEARCHERS & CONSUMERS CONNECT

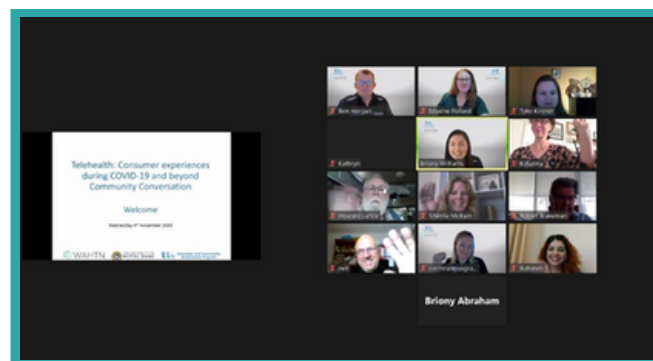
The CCI Coordinator provides support to the researcher and team including connecting the researchers and consumers. The research team is supported until they feel confident to conduct the meetings and other activities on their own



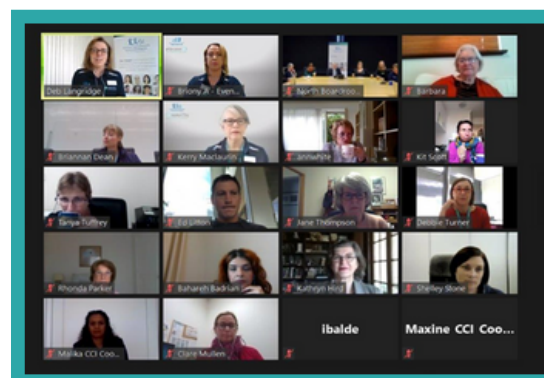
DEVELOPMENT AND DELIVERY OF ONLINE SERVICES, TRAINING AND EVENTS

The CCIProgram's core services have been integrated and converted into online formats to ensure we are able to continue to support researchers and consumers and community members during the COVID-19 pandemic. The CCIProgram's signature Drop in Services have become more individualised with some Partners having the service as a recurring weekly option rather than being specific to grant submission dates.

Consumer and researcher training has been piloted via an online delivery platform and accommodate individualised focus areas or teams, and generalised training and support. Community Conversations can also be delivered in an online format, which allows for community members to participate regardless of location and venue. Finally, we are in the process of using external funds to develop an online CCI module that will provide Partners with new options for capacity building with their research community.



Telehealth Community Conversation



'Show us Your Mug' Morning Tea

In addition to this, the CCIP Program continued to facilitate face-to-face events and training where possible, with a total of 42 events and training sessions delivered to researchers and consumers over 2019-2020, which were delivered both in person and online via Zoom.



Antibiotic Allergies Community Conversation



Familial Hypercholesterolaemia Community Conversation

CCI PROGRAM PARTNER HIGHLIGHTS

The CCI Program is fortunate to work with and support its partner organisations on projects embedding consumer and community involvement further into organisational structures and the research process. Some key highlights from our partners are detailed below.

100 Families WA Project, University of Western Australia

The 100 Families WA Project is a collective action research project aiming to tackle entrenched disadvantage in WA families. After the establishment of a Community Advisory Group in 2018, activities have included: the development of resources, influencing the way the project is delivered, and assisting with communicating project findings to the public, including speaking at conferences and to government bodies and social service agencies, and appearances on Podcasts, radio and in newspaper articles. A member of the CAG is co-leading a working group to measure the impact of the project.

Curtin Autism Research Group (CARG) Voice, Curtin University

Curtin Autism Research Group (CARG) is a multi-disciplinary team of autistic individuals and their families, researchers, students, and volunteers affiliated with Curtin University, with an extensive network of industry and research partners throughout Australia and internationally. CARG also includes a large number of researchers affiliated with the Autism Cooperative Research Centre (CRC). The team is dedicated to finding evidence-based, innovative and effective approaches to supporting autistic individuals and their families, at all stages in life.

Over the past 12 months, our Consumer and Community Involvement Coordinator has supported five CARG projects co-produced with 22 autistic individuals. One of the highlights of the year was the release of a Photo Voice Gallery that was part of a PhD project, and funded by the Autism CRC, portraying factors important to the quality of life in autistic adults.

Depth of Field: Exploring Hearts, Minds & Voices UWA School of Allied Health

UWA's Dr Gabrielle Brand approached the CCI Program in 2017 for advice on involving consumers in the development of a tool to be used with health professionals education, to assist in gaining a better understanding of mental health. We were able to link Gabrielle with Carli Sheers, a Consumer Representative, who initially provided advice on a grant application to Healthway which received funding in 2018.

"Carli continued to advise on all aspects of the project, including co-design of the tool itself. The final tool consisted of a series of powerful visual narratives that recounts the reality of what it's like to live and recover from mental health issues. The tool was launched at an exhibition at the Perth Town Hall during WA Mental Health Week 2019" - Dr Gabrielle Brand

Carli continues to work on the project. Both Gabrielle and Carli talk about their experiences project in one of our CCI Program Videos here: <https://youtu.be/X4T0TgRmbWU>

Multiple Sclerosis Research Priority Workshop, Edith Cowan University

A Multiple Sclerosis Research Priority Workshop was held at Perth Zoo in February 2020.

Consumers with a variety of neurologically based conditions came together for an all-day event with researchers from Edith Cowan University to identify and prioritise the best ways to personalise treatments for people living with a neurological condition.

This research was funded in partnership with MSWA and aims to develop a systematic profile of people with MS, stroke, Huntington's disease and Parkinson's disease, and was informed by the 21 consumers with lived experience that attended the priority workshop.

School of Medicine Community Reference Group, University of Notre Dame Australia

A forum with the Deans from eight faculties and other key staff at the University of Notre Dame Australia (UNDA) was organised in early July. The purpose of this forum was to identify health research synergies for the University and how they might overlap, support and enable collaboration with community members and consumers.

One exciting outcome was the recommendation that up to eight Consumer Reference Groups (CRG) be formed to represent the various Faculties and Schools at UNDA. The CRG's include people with lived experience of acute and chronic illnesses and work with researchers to guide the direction, development and manner of their research and clinical work.

The CRG members provide advice on a range of activities including:

- Providing insights into and reviewing documents.
- Providing advice on the best way to recruit participants for studies.
- Helping with the translation of research findings and informing the wider community about the School of Medicine's research projects.

The first CRG met in 2020 to represent the School of Medicine, with the establishment of additional CRG's during 2021.

Child Health Symposium Consumer Involvement Sessions (2019), Child and Adolescent Health Service

The Child Health Symposium held at Perth Children's Hospital in November 2019 and 2020 saw a collaboration between the Child and Adolescent Health Service and the CCIP Program to deliver Consumer Involvement Sessions, including an interactive breakfast session by the CCIP Program.

This brought together researchers, consumers and community members, and representatives from child and adolescent health to discuss the practical processes, outcomes and ideas of involving consumers and community members in research and how to obtain great outcomes for all.

Australian National Phenome Centre, Murdoch University

The Australian National Phenome Centre (ANPC) was officially launched on 4 October 2019. The ANPC is one of the most significant research collaborations in Western Australia, bringing together the five WA universities and a variety of research institutes. The Centre aims to transform and optimise disease prevention, diagnosis and personalised health and the CCIP Program has worked closely to involve community from its inception.

With the support of the Executive Director of the Centre, Prof Jeremy Nicholson, a Community Board Member will sit on the Scientific Board and will be involved in setting the strategic direction of the Centre to ensure the community's voice is represented.

A Community Advisory Board comprising eight members representing consumers with specific conditions including diabetes, autism and cancer and featuring representation from the Aboriginal and Torres Strait Islander communities will make recommendations to the Board. Recruitment and appointment of the Community Board Members and the Community Advisory Group was undertaken in 2020 to inform all research projects at the ANPC.

Harry Perkins Institute

In early 2020, the CCIP Program brought together people with a lived experience of liver cancer with researchers from the Harry Perkins Institute and the WA Liver Cancer Collaborative.

The community consultation explored the experience of individuals with a diagnosis of liver cancer, close relatives and carers to explore the concepts behind a major funding proposal. We were excited to hear that the project was awarded \$10 million in funding in mid-2020.

FUTURE PLANS

Our current partnerships demonstrate a passion and an ongoing commitment to continue to work with the research and community sector across WA and to build the capacity and integrity of research projects and their outcomes.

Involvement in new projects, such as the Australian Research Health Alliance's (AHRA) National CCI Project has enhanced our capacity to undertake high-level strategic work, and we look forward to continuing our involvement in these projects into the next financial year.

As part of the WAHTN organisation we will continue to advocate and promote the involvement of consumers and community and the translation of research outcomes which contributes significantly to the health and wellbeing of West Australians. Further to this, our future plans include:

- Support the implementation of the WA Future Health and Innovation Research (FHRI) Fund Strategy 2020 - 2023 and building the capacity of researchers and consumers in CCI.
- Formation of a WAHTN CCIP Program Stakeholder Advisory Group to guide and assess future initiatives of the CCIP Program and WA FHRI Fund Strategy.
- Offering a fee-for-service CCI model on a state and national basis, to make our services widely accessible.
- Development of a guidance package for involving Aboriginal and Torres Strait Islander Peoples in health and medical research in a culturally secure manner, which will be directly informed by consumer and community consultation.
- Collaborate with key stakeholders across the state such as the Health Consumers Council WA to build the membership and capacity of people with lived experience involved in research and innovation.

SUMMARY & RECOGNITION

Our current and future plans and Partnerships demonstrate a passion and an ongoing commitment to continue to work with the research and community sector across WA, and to build the capacity and integrity of research projects and their outcomes.

As part of the WAHTN organisation, the CCIP Program will continue to advocate and promote the involvement of consumers and community members and the translation of research outcomes which contributes significantly to the health and wellbeing of Western Australians.

The CCIP Program would like to recognise and thank the Partners that we have worked collaboratively with over the past year, and we look forward to strengthening these relationships in 2021.

HOW TO CONNECT WITH US

If you would like to find out more about what we do, or are interested in being involved in research or involving consumers and community members in your research process:

Please visit our website cciprogram.org.
Email us at admin@cciprogram.org,
or by phone (08) 6151-1071.

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