



CCI in Research: Current practices and themes across Research Institutions

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Welcome!



ACKNOWLEDGEMENT OF COUNTRY

The WAHTN CCIP Program acknowledges the Aboriginal people of the many traditional lands and language groups of Western Australia.

We acknowledge the wisdom of Aboriginal Elders both past and present and pay respect to Aboriginal communities of today.



ACKNOWLEDGEMENT OF LIVED EXPERIENCE

We acknowledge the importance and expertise of the lived experience voice of health consumers and carers.

We recognise their involvement in making a difference in supporting health research and impacting the health and wellbeing of our communities.

CCIProgram supports consumers, community members and researchers to work in partnership to inform decisions about health research priorities, policy and practice.

- *We improve lives by ensuring the community's voice is heard and understood in health research.*
- *We enable involvement in health research by supporting and connecting community with researchers, partners and policy makers.*

CONSUMER AND COMMUNITY INVOLVEMENT PROGRAM (CCIProgram)

A platform of the WAHTN



Other platforms of the WAHTN

- Clinical Trials & Data Management (CTEP-WA)
- Research Education & Training Program (RETProgram)
- Allied Health Enabling Platform
- Australian National Phenome Centre (ANPC)
- Biobanking
- Health Economics

How the CCI Program works

- ✓ Provide CCI support and services in WA plus interstate and national projects;
- ✓ Membership of over 6,200 consumers and people with lived experience;
- ✓ Partner with WA Universities, Medical Research Institutes, State Government and all WA Health Service Providers;
- ✓ Member of Australian Health Research Alliance (AHRA) and part of National CCI Projects with 3 other Health Translation Networks and CHF.

Current areas of focus

- ✓ Building capacity of researchers and consumers;
- ✓ Policy and Governance to shape and embed CCI in research;
- ✓ Collaborations at State level to enhance and make visible the translation and impact of lived experience in research outcomes and health services;

At Present

- General understanding and embracing CCI in all forms of research by Universities, Medical Research Institutes, Health Services and WA Government as per 2016 Consumer Statement;

“the primary guidance for institutions and researchers in responsible research practices, states:

Appropriate consumer involvement in research should be encouraged and facilitated by research institutions and researchers.

whereby researchers are encouraged to consider the benefits of actively engaging consumers in their proposed research” p11

At Present

- Awareness by researchers and their institutions that CCI is becoming more than just a 'nice thing' to do;
- Growth in capacity of consumers and researchers in their understanding and acknowledgement of CCI as an essential part of best practice research;
- Recognition of CCI as a point of 'success' for grant submissions;
- Concept of 'co-design' brings fear and loss of control.

Areas of continuing growth and things to consider

- Policy on CCI in research processes and standard practice;
- CCI Criteria for funding and grant schemes;
- Reporting of CCI in research methods, processes, and outcomes;
- Agreement on CCI in Health Research Ethics Committees (HREC's);
- Measurement of CCI Impact and Return on Investment (RIO).

Areas of continuing growth and things to consider

- Statement of roles and responsibilities of 'Institutions' re CCI;
- Embed CCI and ensure visibility of CCI in research regarding
 - State and National Research Strategies;
 - Vision and Mission Statements across sector;
 - Funding and Grant Schemes.
- National Standards and/or Principles of CCI.

'Our'role

- Celebrate and share the successes.....and challenges;
- Collaborate for the benefit of CCI nationally;
- Communicate within and across sectors;
- Be bold in being strategic.



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