

Consumer and Community Involvement Program

NUTRITION & HEALTH INNOVATION RESEARCH INSTITUTE (NHIRI)

CCI ROADMAP WORKSHOP REPORT



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Acknowledgements

The WAHTN CCIProgram 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.

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.

Introduction



Deb Langridge, Head CCIProgram
WA Health Translation Network

Edith Cowan University's Nutrition and Health Innovation Research Institute's (NHIRI) has been a leader of consumer and community involvement (CCI) within health research for many years, championing the voice of people with lived experience being heard throughout the research process.

With a growing reputation of leading in consumer involvement, NHIRI commenced a three-year CCI strategy in 2023, working in partnership with the CCIProgram, to embed CCI practices across the Institute, supported by governance and processes.

Having achieved the Year 1 CCI plan milestones, NHIRI's team have taken the opportunity to audit and analyse the Institute's internal CCI-related policies and practices. Identifying these key internal actions together with the remaining milestones of the original CCI plan, the CCIProgram and NHIRI have worked to outline an overarching CCI Roadmap for the Institute.

This report captures key insights and outcomes from the CCI audit and analysis process with a resulting 'roadmap' of short-term actions, and future goals and actions to work towards for consideration.

The NHIRI CCI Roadmap shows the way forward for the integration of consumer involvement practices within research at the Institute, ensuring this 'best practice' and visible approach by all at NHIRI delivers excellence in relevant and translatable research outcomes.

Our team has been excited to work with NHIRI to develop this 'next step' in their CCI journey and strongly believe it will continue to guide the strong commitment of the NHIRI Board, academic staff and students in including the lived experience voice in best practice research.

Deb Langridge, CCIProgram

Background

Edith Cowan University's School of Medical and Health Sciences Nutrition & Health Innovation Research Institute (NHIRI) is a team of world-leading, multi-disciplinary researchers, aligned through a common purpose of discovering and sharing real-world solutions to improve health and quality of life.

NHIRI is committed to research innovation and excellence with consumer and community involvement. NHIRI's commitment to Consumer and Community Involvement (CCI) has resulted in a growing reputation as a leading CCI organisation, reflecting our researchers' expertise and alignment with national best practice research principles.

Consumer involvement in NHIRI research has:

- increased the relevance and responsiveness of research to health needs
- improved the quality of research and its impact on health outcomes
- strengthened the effective translation of research into policy and practice
- built public confidence in the research
- increased opportunities for research funding

Working in partnership with the WA Health Translation Network (WAHTN) CCIProgram, NHIRI instigated a three-year commitment to further develop and enhance NHIRI's CCI capabilities, building the capacity of NHIRI members to implement CCI effectively across all research projects.





NHIRI's CCI STRATEGY - Initial Stages

In November 2022, the NHIRI Board approved the implementation of a CCI strategy supported by governance and processes, driven by the goal to embed CCI visibly within the institute. In partnership with the CCIProgram, a clear three-year CCI development plan was designed to build the necessary internal capacity. Milestones outlined included;

Year 1

- Research Priority Mapping Workshop
- Upskill staff and students
- Development of KPI process
- Onboarding strategy

Year 2

- Establish Consumer Advisory Group
- Institute specific CCI support, resources and reporting
- Establish Involvement Bank with EOI process

Year 3

- Review impact and measurement
- NHIRI-specific Masterclass Series
- Progress report re: CCI outcomes and future planning
- Communication of NHIRI CCI outcomes and success

Progress so far

In January 2023, NHIRI commenced the 3-year partnership with the CCIProgram with the aim to embed consumer and community involvement across the entire program of work at NHIRI.

One of the major activities planned for Year 1 of the implementation project was to run a Research Priority Mapping Workshop (the Workshop). The purpose of the Workshop was to collate potential future research focus areas, guided by the wider community and prioritise with a lived-experience lens.

As part of the research priority mapping process, a pre-workshop survey was shared with a total of two-hundred and sixty-one ideas and thoughts received from eighty-seven consumers/carers with a lived experience of one or more identified heart health condition/s. Following thematic analysis, the workshop was hosted in August 2023, involving eleven consumers in a full day process to discuss and finalise key research priorities. A full report of the identified Future Research Priorities for NHIRI can be accessed here.



Consumer-informed research priorities can now guide the Institute's work into the future. Extending this consumer involvement opportunity in June 2024, NHIRI was allocated an ECU Community Conversation event, enabling a deeper dive into one of the identified research priority areas with involvement from 32 people with a lived experience of a heart health condition.

Upskilling of staff and students was set as an expectation through the introduction of a CCI professional development KPI. As a result, 22 NHIRI members have completed the Introduction to CCI eCourse and 35 Masterclass session have been attended.



Now mid-way through the implementation plan, the NHIRI team has identified the need to develop a roadmap to support the audit and analysis of internal CCI-related practices and identify necessary key actions. In conjunction with the rest of the CCI plan, this will embed CCI practices within the Institute.

An internal CCI Workshop was undertaken in September 2024, documenting NHIRI's strengths, and identifying common challenges. This workshop provided the base for the resulting CCI Roadmap development. Key insights and findings from the workshop can be read here.

NHIRI's CCI Roadmap Development

The CCI Workshop insights and findings have been incorporated into a CCI framework with three pillars. These pillars align to core areas where CCI can be embedded within the Institute.



CAPACITY BUILDING & RESOURCES

How researchers will equip themselves with the knowledge and capability to undertake best practice CCI.



GOVERNANCE POLICY
& STRATEGIC
DIRECTION

Leadershipwhich enables organisational CCI practices through strategic management, governance and accountability.



LIVED EXPERIENCE INVOLVEMENT

How researchers go about applying CCI within their organisation.

Governance, Policy & Strategic Direction



AUDIT INSIGHTS	IMMEDIATE ACTIONS	FUTURE GOALS AND ACTIONS
NHIRI leadership has endorsed CCI at an organisational level Direction for actions to embed CCI within the Institute can be guided by the CCI Roadmap Resourcing required to achieve this will need NHIRI Board support	ACTION 1) Advisory Board informed and updated on the planned approach to CCI Roadmap to embed CCI at NHIRI developed and taken to Advisory Board. Level of resourcing support needed will be determined through the approval process.	5-year goal - Plan allows for a transition period, some CCI supported internally at NHIRI and some through CCIProgram.
As a strategic priority, CCI practices will be integrated within the planning of the Institute -Strategic Plan could reflect the Institute's CCI goals -Research Priority mapping has been undertaken -Operational plans should reflect CCI plans and resourcing Relevant policies should reflect CCI practices	ACTION 1) Continued CCI Roadmap to feed into strategic planning day agenda Build into strategic plan with progress milestones	 10-year goal - Proactive priority setting in the community 'don't know what we don't know' - targeted outreach to ensure connection to those who are more difficult to reach. Outreach informs the research priority mapping CCI Mission Statement Ensure research mapping priorities are integrated into research planning Ensure operational plan development incorporates budget and provision of necessary human resources Use the CCIProgram Policy Checklist to review existing NHIRI policies to incorporate CCI or develop as a standalone CCI policy (examples - consumer recruitment strategy, Honorarium policy)
CCI needs to be accounted for in organisational responsibilities and accountabilities such as financial and human resourcing; 1. Institute budgets provide for CCI costs • Costs for Institute-wide CCI approaches (CAG) • Costs for 'pre-award' CCI 2. Project budgets allow for full costs of CCI, including human resources 3. Staff resourcing allows for Institute-wide CCI activities and project-specific CCI activities	have a specified FTE percentage which funds a CCI person to support both the project and CCI at NHIRI overall NHIRI/ CCIProgram agreement provides support for CCI development from 2023-2025. The agreement allows for the setting up of Institute wide CCI approaches such as the Consumer Advisory Group (CAG) and pre-award Involvement Bank.	 10-year goal - Dedicated CCI person who supports, co-ordinates and builds capacity. Stays on top of changes at a sector level. External source? Build internal CCI capacity to grow to an overarching CAG in mid/ end of 2025 (within current CCIProgram agreement by Sem 2 2025) Operational budgets to reflect ongoing honorarium and associated costs of CAG and Involvement Bank once established CCI within HR's professional development strategy - demonstrate in portfolio, included in performance appraisal, KPI, incorporated into orientation process (receive an info pack and sets KPI's) Not as constrained by University processes
Development of CCI reporting and evaluating processes so CCI activities are measurable and reportable to the Institute's leadership A KPI relating to researchers completing CCI professional development currently exists	ACTION 1) Continued Embed CCI in regular reports and annual reports KPI completion is being mapped so that this can be tracked for completion	CCI report on website as demonstration of ongoing commitment Operationalise the KPI/expectation



Capacity Building & Resources

AUDIT INSIGHTS	IMMEDIATE ACTIONS	FUTURE GOALS AND ACTIONS
Knowledge and information access Researchers would benefit from more explicit guidance to build their capacity Guidance material tailored to fit NHIRI practices is needed Guidelines are needed for recruitment of consumers, involvement methods, remuneration, guidelines/template for CCI budget development in projects.	ACTION 3) Creating an info pack (researcher focus/lens) that is a step-by-step guide with examples CCIProgram to provide available guidance/ information resources.	Guidance materials will be customised to fit NHIRI such as the CCIProgram Honorarium Guidelines.
Training and skills development Researchers have access to CCIProgram eCourse and Masterclasses. There's a desire for more workshops, education and training. CCI training is set as a KPI for NHIRI members but currently not monitored.	ACTION 1) Continued Map the 'current state' of the experience and training of NHIRI staff/members – track the eCourse completion and Masterclass attendance KPI.	Build an ongoing process to capture this metric through logging certificates of completion and an annual check to follow up on those not meeting KPI.
Leadership and Mentoring NHIRI has a strong CCI culture and is 'ahead of the game' NHIRI members have been building their CCI knowledge and experience, guided by a few key researchers with well-developed CCI expertise. Their knowledge is mostly tacit and being accessed by other NHIRI members on an 'as needed' individual basis. Accessing this knowledge through a more structured approach would build capacity.	ACTION 4) Develop a schedule of Journal Club CCI mentoring .	10-year goal - Reward for NHIRI staff engaged/involved in CCI practices Build capacity of students to support CCI - hand over these responsibilities with each rotation, growing knowledge and capacity over time (onboarding idea). This would be professional development for honours students and ECRs.
Processes and Systems A core strength of NHIRI is the numerous consumers (10-12+) involved in projects as well as some established consumer groups (project specific). Currently there isn't a structure enabling co-ordinated access to consumers for involvement (consumer register/database). Some processes are established but need improvement while others are not yet created/documented.	ACTION 5) Capturing and harnessing NHIRI's existing consumers and groups using a consumer registry/membership database.	Creation/documentation of CCI processes (process for recruitment strategy/EOI process and promotion of these opportunities) and improvements to existing processes (honorarium process) Membership - research buddies/consumer investigators, CAG, document reviewers, priority setting mapping, translation.



Lived Experience Involvement

AUDIT INSIGHTS	IMMEDIATE ACTIONS	FUTURE GOALS AND ACTIONS
Involvement Methods and Structures A NHIRI CAG is planned to enable all researchers to access consumers with relevant lived experience, using an effective model for both the consumers and NHIRI Consumer groups have formed on a project-by-project basis, so some researchers have access to consumer involvement while others don't. Similarly, some researchers have individual consumers involved as research buddies/ consumer investigators.	ACTION 7) Currently the formation of the NHIRI Consumer Advisory Group is on hold so processes/infrastructure can be developed/implemented. The CCIProgram can support NHIRI to review existing consumer involvement structures. An approach will be developed enabling Institute-wide access to an overarching CAG that is well integrated with project specific consumer groups and consumers in research buddy/consumer investigator roles. CCIProgram will support the creation of Institute-wide CCI through the formation of the NHIRI CAG and Involvement Bank in 2025.	
Consumer/ Researcher Relationship Support The relationship between researchers and consumers could be further supported through guidance material and operational processes; Consumers and researchers to have clearly communicated, shared expectations. These would support each to understand their respective roles and responsibilities Consumers have their involvement recognised through honorariums, but the process could be improved and recognised in additional ways Consumers and researchers could have additional support for phases of relationship management including onboarding, induction, maintaining and concluding Consumers and researchers have effective communication and feedback processes which could be enhanced through feedback mechanisms	ACTION 6) Creating an Info pack (Consumer focus/lens). NHIRI to adapt the CCIProgram Involvement Agreement which covers Roles/Responsibilities, Code of Conduct and Confidentiality. Operational processes to be developed to include support recruitment, induction and onboarding processes.	10-year goal - Evaluation by consumers re research outcomes "Uber review" • Creating a consumer feedback mechanism • Perceptions/expectation mapping of the consumer role • Consumer involvement in NHIRI research symposium/conference presentations/ outward facing events • CCI champions • Pitch your project • Improvement of the remuneration process to pay honorariums, through the ECU finance structures • Recognition process to be developed

Roadmap of CCI Actions

	ACTIONS	STEPS TO ACHEIVE	
1	Roadmap developed and approved	Bring ADR into the process Map/audit NHIRI's CCI core members and students. Identify the current state Create a roadmap Establish the desired state Ensure embedded within strategic planning, including research priorities, overarching vision/mission statement, goal to link to KPIs	
2	There is a desire to have a 'CCI person' at NHIRI. To achieve building the funding for this role, grant applications will have a specified FTE percentage which funds a CCI person to support both the project and overall consumer involvement at NHIRI.	1. Category one applications must have a 0.1 FTE for CCI support - \$ value and budget line 2. Template created 3. Demonstrate value to build the business case for ongoing role over time Provide a process for costing of CCI components.	
3	Creating the info pack (researcher focus/lens) that is a step-by-step guide with examples.	1. Identify existing resources 2. Modify for NHIRI use 3. Support through Journal Club mentoring to ensure it is utilised	
4	Journal Club mentoring	(5 skills to learn at Journal Club, create a curriculum) Content to support broad knowledge and capacity building (i.e. applicability for epidemiology etc).	
5	A consumer registry/membership database to capture and harness NHIRI's existing consumer assets.	A registry will capture consumer information and nature of involvement with NHIRI research including relationship ownership Define the Institute's approach to sharing consumers (Selection bias/integrity/diversity) A mechanism/process will be needed to enable the consumers have control over increasing or reducing their involvement to manage their workloads and to give permission to share their information with other NHIRI researchers	
6	Creating an Info pack (Consumer focus/lens).	Identify existing resources Documents for 'what we are looking for fellowships' are adapted Modify for NHIRI use	
7	Formation of the NHIRI CAG and creation of the Involvement Bank .	Work with CCIProgram to review NHIRI's existing consumer involvement structures and develop an approach that will enable Institute-wide access to an overarching CAG that is well integrated with project specific consumer groups and consumers in research buddy/consumer investigator roles.	
8	Review and refresh CCI Roadmap.		

WANT TO KNOW MORE?

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