WAHTN

Consumer and Community Involvement Program

CCIPROGRAM ANNUAL REPORT

2025 - 2026

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Acknowledgement of Country

The Western Australian Health Translation Network (WAHTN) Consumer and Community Involvement Program (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.

Acknowledgement of Lived Experience

We acknowledge the importance and expertise of the lived experience voice of health consumers, carers and communities. We recognise their involvement in making a difference in informing and supporting health research and impacting the health and wellbeing of our communities.

Foreword

Dr Debbie Turner
General Manager WAHTN

This year has seen the CCIProgram strengthen its reach across the Western Australian Health Translation Network (WAHTN), with more Partner organisations drawing on its expertise, training and support to build meaningful consumer and community involvement (CCI) into their research.

It is particularly encouraging to see this capability extending across the network, from individual researchers and projects through to health services and research organisations developing their own approaches to CCI. This reflects both the growing maturity of consumer involvement in WA and the value of the shared CCIProgram resource available to all WAHTN Partners.

I am pleased to share the achievements of our Partners, consumers, researchers and CCIProgram team during 2025–26.

Deb Langridge
Lead, WAHTN CCIProgram

This has been an exciting year for consumer and community involvement in health and medical research. After many years contributing to national conversations about how CCI can be strengthened, it has been rewarding to see major developments such as the new NHMRC CHF Statement on Consumer and Community Involvement in Health and Medical Research and Australia's first National Health and Medical Research Strategy 2026–2036 come into place.

The Consumer and Community Involvement Program (CCIProgram) has been actively involved in this changing national landscape, contributing WA experience and expertise while continuing to support researchers, consumers and organisations here in WA. For our team, the real excitement is seeing these changes move from national direction into practice, and helping our partners understand what strengthened expectations for meaningful involvement mean for their own research and organisations.

I look forward to building on this momentum in the year ahead.

About us

The WAHTN CCIProgram works across Western Australia's health and medical research sector to strengthen meaningful consumer and community involvement (CCI) in research.

Working with consumers, researchers, research teams, health services, universities, medical research institutes and other organisations, the CCIProgram provides support ranging from tailored guidance for individual projects to capacity building for researchers and consumers, and strategic support for organisations strengthening CCI within their research systems and approaches.

A key focus this year has been strengthening the way the CCIProgram works across the WAHTN partnership, with greater access to CCI expertise, training and support for Partner organisations and their researchers. This has included widening complimentary access to the CCIProgram Masterclass Series, alongside more tailored support for organisations seeking to build their own CCI capability and approaches.

Demand for CCIProgram support has also continued to grow, with 262 individual projects supported, compared with 220 in the previous year. To support this growing breadth of work, the CCIProgram strengthened its staffing capacity including the introduction of a Senior CCI Coordinator role and the appointment of two CCI Coordinators. Alongside the team, we were also pleased to host two McCusker Centre for Citizenship interns, Shanelle Houpapa and Nevin Blessingh.

2025 - 2026 at a glance

The infographic below highlights key CCIProgram activity and milestones during 2025–26, capturing our support for CCI-focused events, capacity building, research projects and grant applications across WAHTN Partners and the wider WA research sector.

19

Institutions and organisations directly supported

eCourses

1,120 **Enrolments** in 2025-26

5,176 **All-time enrolments** across both eCourses

62

Involvement opportunities

262

Individual **projects** supported

6,500+

Members of the CCIProgram

1,534

Total **registrations and applications** for events and involvement opportunities

$21,500,354

Awarded to grants receiving tailored support in 2024-25

63

Research **grant applications** supported

1,800

Event **attendees**

4,530

Followers across the CCIProgram newsletter, Facebook, Instagram and LinkedIn.

National Initiatives and representation

The national environment for CCI in health and medical research has shifted significantly over the past year. Australia's first National Health and Medical Research Strategy 2026–2036 (National Strategy) and the new Statement on Consumer and Community Involvement in Health and Medical Research, released jointly by NHMRC and the Consumers Health Forum of Australia (CHF) (the Consumer Statement) strengthened expectations for CCI across the research system.

Together, these developments signal an important progression. Involvement of lived experience voices in informing research is increasingly recognised across different types and stages of research, including research priority setting and translation. The national conversation is moving beyond whether consumers and communities should be involved in research towards how meaningful involvement is embedded and supported across research organisations, funding systems and research practice. The Consumer Statement describes involvement as essential to high-quality health and medical research and, importantly, sets out responsibilities not only for researchers and consumers, but for research institutions and funders.

Contributing WA experience to national direction

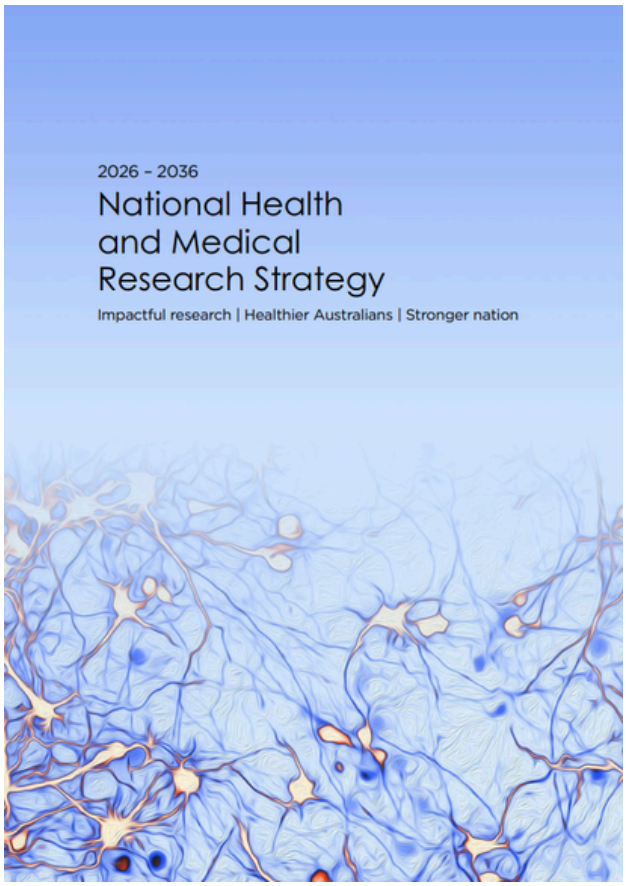
During the reporting period, the CCIProgram provided mechanisms for the experience and perspectives of WA consumers, researchers and organisations to contribute to these national developments.

National consultation opportunities were promoted across WAHTN Partners and the CCIProgram network. WAHTN and the WA CCI Community of Practice contributed submissions to consultation on the draft Consumer Statement, and the CCIProgram contributed a submission to the draft National Health and Medical Research Strategy. Representation of the CCIProgram within NHMRC, MRFF and Australian Health Research Alliance (AHRA) structures and committees provided further opportunities for WA experience to inform national discussions and directives.

The CCIProgram was also included as an example within the National Strategy, recognising the strong foundations developed through more than two decades of CCI in WA. Resources accompanying the new Consumer Statement similarly include CCIProgram work alongside examples of CCI practice from across Australia. This recognition reflects the collective contribution of WA consumers, researchers, WAHTN Partners and the broader CCI sector.

From national direction to implementation

With the National Strategy and Consumer Statement now in place, the focus has shifted towards implementation. The challenge for the research sector is increasingly how these expectations are translated into organisational systems, research practice and meaningful opportunities for consumers and communities to influence and inform research.



Through AHRA, WAHTN is also contributing to the development of CCI capability across Australia's Research Translation Centres. During the year, the AHRA CCI Advisory Committee evolved towards a national community of practice, providing a mechanism for Research Translation Centres to share experience, address common challenges and support one another to strengthen CCI. This has included the CCIProgram sharing its established expertise and providing guidance to emerging Research Translation Centres developing their own approaches to CCI.

Work undertaken over the past year positions WAHTN to remain closely connected to this next phase. Through the CCIProgram, WAHTN is represented on the NHMRC Research Committee, the NHMRC Targeted Calls for Research (TCR) Prioritisation Working Committee and the NHMRC-MRFF Consumer Advisory Group and chairs the AHRA CCI Advisory Committee. These roles provide pathways to continue contributing WA experience nationally while bringing emerging developments and opportunities back to WAHTN Partners.

This national involvement has also extended into practical implementation. The CCIProgram contributed expertise to NHMRC work supporting CCI in Clinical Trials and Cohort Studies funding review and the 2025 funding program, including mentoring, training and assessment processes for Consumer and Community Reviewers. Deb Langridge, CCIProgram Lead, has also worked with the NHMRC CEO to showcase the Consumer Statement and what meaningful involvement looks like in practice through national webinars and events.

Supporting national CCI implementation through the Health Research Hub

The national Health Research Hub is becoming an increasingly important part of the infrastructure supporting this next phase. In partnership with AHRA and powered by Monash University, the Hub brings together practical CCI guidance, resources, training and examples of good practice in one national platform. The CCIProgram contributes to its ongoing development and operation.

HEALTH RESEARCH HUB

Powered by MONASH University In partnership with AHRA

Following its development and launch on 1 December 2025, the Hub has now moved into an ongoing implementation phase, with a focus on maintaining and growing its role as a central, accessible source of practical CCI support for the research sector. With the release of the Consumer Statement in May 2026, the Hub is linked and positioned as a 'one-stop shop' to support implementation, helping researchers, consumers and organisations move from principles and responsibilities of consumer and community involvement in research to practical application. Resources from the Hub align directly to the NHMRC's Supporting Resources for the Consumer Statement.

Positioning WA for what comes next

The significance of the work undertaken by the CCIProgram in 2025–26 therefore extends beyond contributing to national policy. Through their collective investment in the CCIProgram, WAHTN Partners are connected to national CCI developments and have access to established expertise, networks and practical resources as the sector moves into implementation.

The opportunity now is to build on these foundations by continuing to contribute WA experience nationally while supporting WAHTN Partners to translate strengthened expectations for meaningful consumer and community involvement into practice within their own organisations.

State-wide Initiatives and representation

Across WA, growing recognition of the value of consumer and community involvement is reflected in the increasing number of WAHTN Partners seeking support to strengthen CCI within their organisations.

The CCIProgram continued its established partnerships with **UWA, UNDA, Murdoch University** and the **Harry Perkins Institute of Medical Research**, providing ongoing CCI expertise and support across their research communities. Alongside these established collaborations, support expanded across a growing range of organisational priorities within the wider WAHTN partnership, including research and innovation planning, research priority setting, development of CCI frameworks and approaches, and building internal CCI capability. This included work with **WA Country Health Service (WACHS)**, **Ramsay Health Care's Joondalup Health Campus, Sir Charles Gairdner Osborne Park Health Care Group,** the **Child and Adolescent Health Service (CAHS)** and **ECU's Nutrition and Health Innovation Research Institute (NHIRI)**.

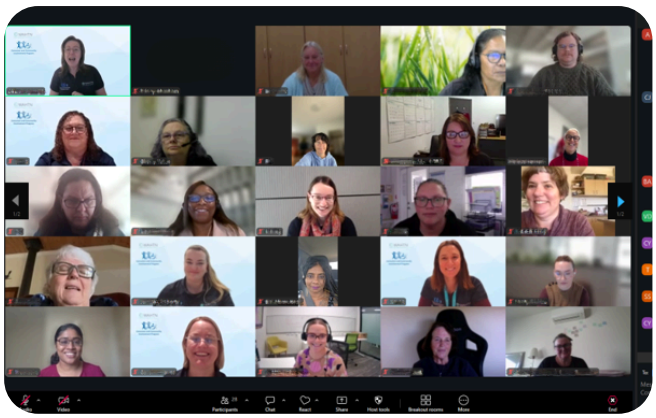
The CCIProgram also broadened the support available across the WAHTN partnership, including the introduction of an annual tailored CCI seminar for Partner organisations, designed around the learning needs of their staff and researchers.

Women from Culturally and Linguistically Diverse (CaLD) communities attending the UNDA Micro Community Conversation: Talking to your GP about cancer screening

The CCIProgram also contributed to the **WA Grants and Innovation Service (WAGES)**, a FHRI Fund supported initiative strengthening WA's capability and competitiveness in national funding schemes, directed by AUScelerate. Through membership of the WAGES Steering Committee and delivery of CCI content within its workshops, consumer involvement is being embedded within broader efforts to strengthen research and innovation capability across WA.

Co-presentation at the WAGES Workshop

The **WA CCI Community of Practice** continued to provide an important mechanism for collaboration across the state. During 2025–26, members worked collectively around the development of the revised Consumer Statement, including reviewing the draft Statement and contributing to the submission process. This collaboration enabled experience and perspectives from across WA's CCI sector to contribute to national developments, while also supporting shared understanding of what the strengthened expectations for CCI will mean in practice.



Rural, regional and remote community members attending the online WA Country Health Services Community Conversation

Tailored CCI Support

62
Involvement Opportunities

63
Grants supported

Researchers continued to access tailored CCI support across different stages of the research process, from early planning and project design through to grant development, consumer recruitment, advisory structures and ongoing involvement.

CCI Coordinators worked with research teams to identify whose lived experience was most relevant, consider the most appropriate approach to involvement and support consumers and researchers to establish effective working relationships. This individualised approach allows CCI to be adapted to the needs of each research project rather than applying a single model across different areas of research.

Connecting researchers with lived experience

Tailored CCI support looks different for each research project. For some researchers, the most appropriate approach may be finding a research buddy to work closely with the team. For others, it may involve establishing a Consumer Advisory Group, holding a Community Conversation, or combining different approaches as the research develops.

CCI Coordinators work with researchers to consider whose lived experience is most relevant, how consumers can meaningfully contribute and what approach will best fit the research. Where recruitment is needed, the CCIProgram supports the process of promoting opportunities, interviewing interested consumers and establishing the initial connection with research teams. During 2025–26, the CCIProgram supported 40 researchers across 62 involvement opportunities, connecting them with 160 consumers with relevant lived experience.

Promotion for Consumer Advisory Group members for the Molecular Therapy Laboratory

Impact Case Study:
Rare genetic disease therapy

The CCIProgram's longstanding work with Murdoch University's Molecular Therapy Laboratory demonstrated how this support can evolve over time. Early involvement included a Community Conversation and research buddies, followed by ongoing CCI guidance and support with grant applications as the research developed.

Funding through the Stan Perron Charitable Foundation enabled the team to expand its work and deepen consumer involvement through another Community Conversation. This work helped strengthen the research program as it progressed to subsequent MRFF funding, with the CCIProgram supporting the establishment of an ongoing Consumer Advisory Group during 2025–26.

This reflects the value of an approach that can grow with the research, providing different forms of support as the needs of the project, research team and consumers change over time.

30.6%

applications supported in 2024-2025 funded

$21,500,354

awarded in 2024-2025

Grant support and funding outcomes

Grant development continued to be an important area of tailored support, with the CCIProgram supporting **63** research grant applications during 2025–26 and providing guidance on how consumer and community involvement could be meaningfully incorporated into proposed research. Grant outcomes are tracked according to the year in which CCIProgram support was provided, as assessment processes for major national schemes can extend well beyond the year of submission.

Looking across grant applications supported in the previous three years, a consistent pattern of strong funding outcomes is evident, with around **one in three** going on to receive funding.

Most recently, 30 of the 98 applications supported during 2024–25 were funded, representing a success rate of **30.6%** and **$21.5 million** in research funding.

This sustained level of success is notable within a highly competitive funding environment. While funding rates vary considerably between schemes and are not directly comparable, the MRFF reported an average funded rate of 21.5% across competitive funding between 2022 and 2024, while the 2025 NHMRC Ideas Grant round funded 8.1% of applications.

Across applications supported by the CCIProgram since 2022–23, **69** have now gone on to secure more than **$58.5 million** in research funding. This includes 6 applications supported during 2025–26, with many funding outcomes from this reporting year still pending.

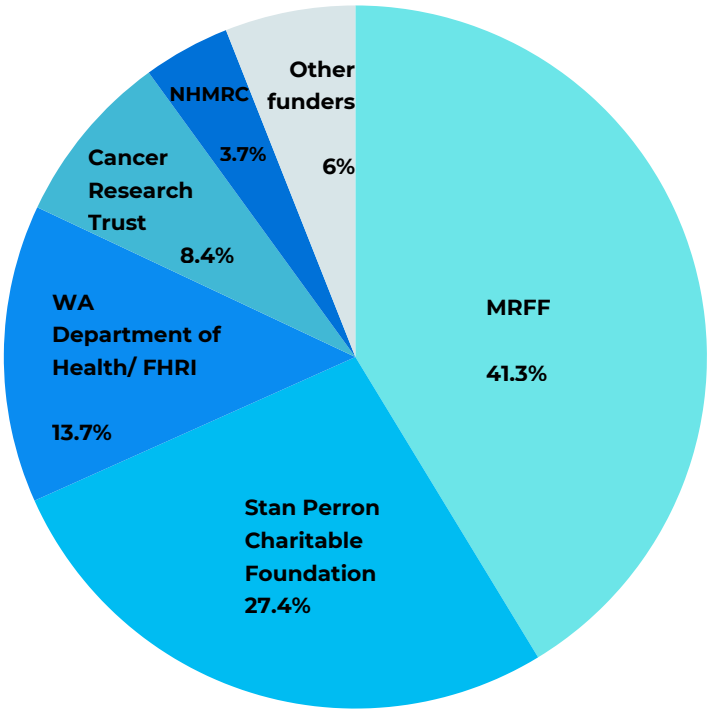


Figure 1: Sources of funding for successful applications supported by the CCIProgram, 2022–23 to 2025–26

$7,515,724*

in funding outcomes to date from applications supported in 2025–26

**Includes MRAIS funding as an in-principle funding commitment conditional on the associated MRFF/NHMRC application being successful. It does not represent confirmed funding at the time of reporting.*

Capacity Building and Resources

75
Capacity Building Events

1,800
Attendees

Capacity building and engagement activity grew substantially, with the CCIProgram delivering 75 events attended by 1,800 people. Compared with the previous year, the number of events increased by **60%** and attendance almost **doubled**. Activities included Community Conversations and Micro Community Conversations, Masterclasses, tailored training, presentations, webinars, forums and panels, providing opportunities for consumers to inform research and for researchers and consumers to build their knowledge and capability in CCI.

Community Conversations

The CCIProgram delivered **26** Community Conversations during 2025–26, including 15 standard Community Conversations and 11 Micro Community Conversations, involving **299** consumer attendees. This represents growth from the previous year, when 11 Community Conversations were held with 194 attendees.

Community Conversations continued to provide researchers with a way to hear directly from people with relevant lived experience, often early in the research process when community perspectives can have the greatest influence on informing research priorities, questions and approaches.

Co-designed resource created through discussions started at the UWA Community Conversation Dads: Let's talk Periods

Impact Case Study:
Dads, let's talk periods

Improving menstrual health requires understanding more than the experiences of people who menstruate. Social support can also shape how young people experience and manage their periods, yet the role of fathers has received relatively little attention.

Dr Dani Barrington and her research team at The University of Western Australia worked with the CCIProgram to bring together 16 fathers of young people who menstruate. The Community Conversation explored how fathers currently support their children, what they need to do this better and how more fathers could be engaged in menstrual health.

The conversations identified fathers as an important but often overlooked source of support. While many were already providing practical help, they wanted greater confidence in talking about periods and providing emotional support. They also identified a need for trustworthy, accessible information developed specifically for fathers.

These insights directly changed the next steps for the research. A practical 'Dad-proof' resource, originally envisaged as a later research output, was brought forward and is now being co-designed with fathers. The emerging research program will also bring together the perspectives of fathers and young people who menstruate to better understand how support can be strengthened.

The project demonstrates the value of thinking broadly about whose lived experience can inform research. By involving people who influence the experience of a health issue, not only those who experience it directly, CCI can reveal new opportunities for research, resources and practical change.

Table 2: Community Conversations hosted during 2025-2026

COMMUNITY CONVERSATION	PARTNER ORGANISATION	RESEARCHER
Help shape future medical research at Sir Charles Gairdner Hospital and Osborne Park Hospital	Sir Charles Gairdner Osborne Park Health Care Group (SCGOPHCG)	SCGOPHCG Research Office
Have your say on the future of country health research	WA Country Health Service (WACHS)	WACHS Strategy, Change and Innovation Directorate
Dads, let's talk periods: supportive fatherhood for improving adolescent menstrual experiences	UWA	Dani Barrington
Dental care at the Oral Health Centre WA (OHCWA)	UWA	Mohammed Junaid
Consumer Lead Medication Reviews (PROMPT)	UWA	Amy Page
HealthSpan – Supporting healthy living – What matters?	UWA	Daniel Green
Living with Bone and Joint Conditions	HPI	Bo He and Kai Chen
Living Longer vs Living Better	HPI	Alexey Terskikh
Partnering with Your GP to Prevent Long-Term Health Problems: A SMART GP	UNDA	Charlotte Hespe
Boola Kep Boola Koort Water Roundtable	Murdoch	Roz Walker
Development of personalised medicines for individuals living with inherited high cholesterol	Murdoch	Kelly Martinovich
Brain Health at Home: Shaping the Future of Cognitive Care	Murdoch	Fairuz (Mohd) Shiratuddin
Exercise for people living with multiple sclerosis and anxiety	Murdoch	Yvonne Learmonth
Heart-healthy eating: What support does the South West WA need?	ECU	Lauren Blekkenhorst
Heart-healthy eating: What support does Bunbury need?	ECU	Lauren Blekkenhorst

Table 3: Micro Community Conversations hosted during 2025-2026

MICRO COMMUNITY CONVERSATION	PARTNER ORGANISATION	RESEARCHER
Heart-healthy eating: Micro Community Conversation Series (Donnybrook, Busselton, Bridgetown, Manjimup and Nannup)	ECU	Lauren Blekkenhorst
Skin Cancer in Rural WA	UWA	Lena Kranold
Pregnancy perspectives of bacterial infections, screening and treatment	UWA	Lucy Furfaro
Insights into SIDS & SUDC	UWA	Melanie Andrew
Talking to your GP about cancer screening - would it help? with cultural communities (Men)	UNDA	Diane Arnold-Reed and Caroline Bulsara
Talking to your GP about cancer screening - would it help? with cultural communities (Women)	UNDA	Diane Arnold-Reed and Caroline Bulsara
Exploring Barriers to exercise during cancer treatment: Photovoice and Micro Community Conversation	ECU	Mary Kennedy

Impact Case Study:
Heart Healthy Eating: Listening Locally

What supports healthy eating in one regional community may not work in another. Dr Lauren Blekkenhorst from ECU's Nutrition and Health Innovation Research Institute (NHIRI) wanted to understand these differences before determining the next direction for her research.

Working with the CCIProgram, the research team went directly to communities across the South West, holding Community Conversations in Bunbury, Busselton, Donnybrook, Manjimup, Bridgetown and Nannup. This place-based approach revealed important differences in the barriers and opportunities people experienced, from food affordability and availability to transport, health services and community support.

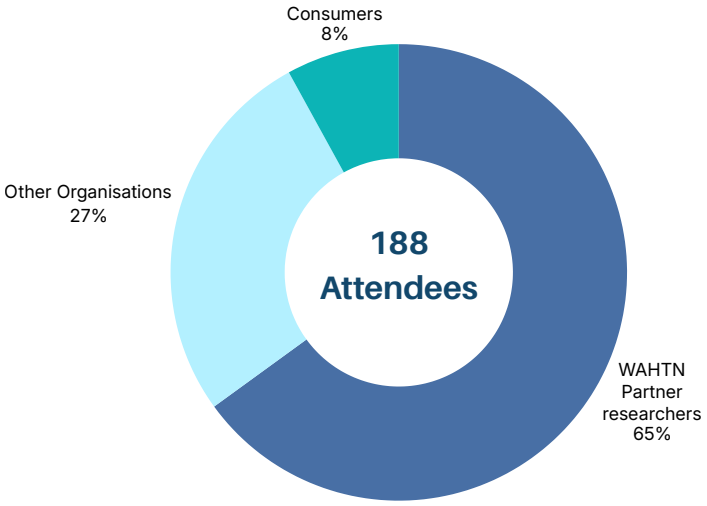
Crucially, communities were involved early, before future research directions or interventions had been determined. Their insights provided a much richer understanding of how local environments shape what is realistic and relevant for people living there and were followed up with further exploration of potential solutions through an online discussion.

By going town to town and listening first, the project demonstrates both why regional communities cannot be treated as identical and the value of involving communities before deciding what the research response should be.

Donnybrook Micro Community Conversation

Masterclass Series

The CCIProgram delivered **11** Masterclasses to **188** attendees during 2025–26, a substantial increase from 106 attendees in the previous year. This included 122 researchers from 13 WAHTN Partner organisations, 50 attendees from organisations outside the WAHTN partnership, and 16 consumers.



Of these, three additional Masterclasses were delivered through partnerships with the **Child and Adolescent Health Service (CAHS)** and the **Bone Health Foundation/ANZ Bone and Mineral Society**. These partnerships extended the reach of the Masterclass Series to researchers and organisations across Australia.

It was pleasing to see that with complimentary access to Masterclasses extended to all WAHTN partners from 1 January 2026, attendance broadened beyond **UWA**, **Murdoch University**, **CAHS, UNDA** and **HPI** to also include **Curtin University, ECU, EMHS, NMHS, Ear Science Institute, Lions Eye Institute** and **SMHS.**

Masterclass Researcher Co-Presenter Bo He with CCIProgram team member

The focus for 2026–27 will be on increasing awareness and encouraging researchers from across WAHTN to take advantage of this capacity-building opportunity.

Our Masterclasses supported researchers and consumers to take the theory of CCI and put it into practice through these hands on sessions. Each Masterclass provided examples in practice, co-presented with our guest consumers and researchers from **UWA, Murdoch University, Curtin University, UNDA** and ECU.

CCI and Successful Grant Writing Masterclass

Table 4: Masterclass Series held during 2025-2026

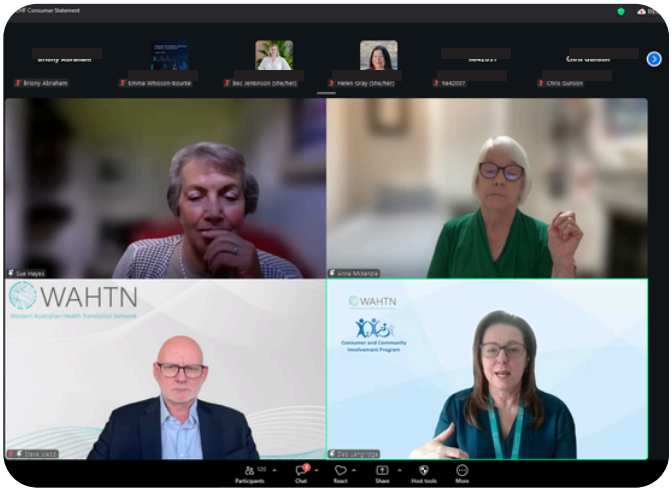
MASTERCLASS	SESSIONS	ATTENDEES
Introduction to CCI	5	115
Writing in Plain Language	3	21
CCI and Successful Grant Writing	3	52

Tailored Trainings, Presentations, Webinars, Forums & Panels

Beyond the established Masterclass Series, the CCIProgram delivered **38** tailored training sessions, presentations, webinars, forums and panels, reaching **1,313** attendees, which was a significant increase when compared with 29 activities and 622 attendees in the previous year.

CAHS CCI Seminar:
Delivered by the CCIProgram

A key focus was supporting the sector to respond to the new Consumer Statement. A WAHTN-wide webinar attended by **206** people introduced the Statement and its implications, followed by Putting the New Consumer Statement into Practice tailored training sessions to help researchers understand what the strengthened expectations mean for CCI in practice.



NHMRC CHF New Consumer Statement Webinar

Other activities reached researchers and consumers across universities, research institutes and health services, with highlights including the Western Australian Psychological Science Conference, NHIRI Research Symposium and Fiona Wood Foundation Consumer Breakfast.

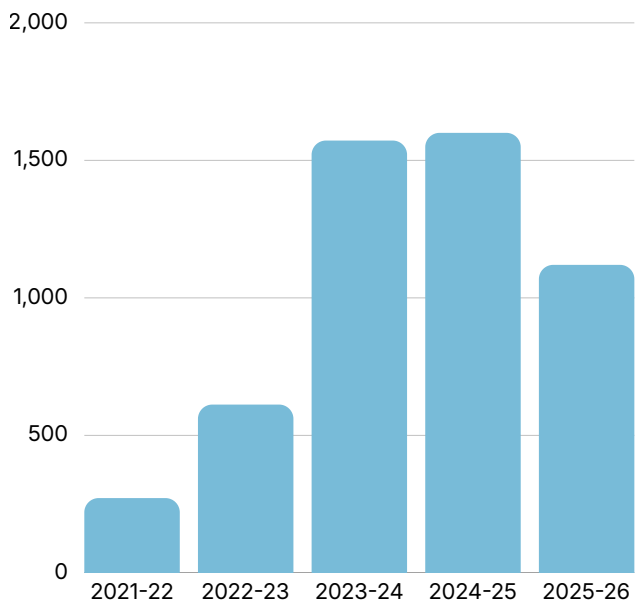
eCourses

The CCIProgram eCourses continued to provide accessible, foundational CCI learning across WA and nationally, recording **1,120** enrolments from 130 organisations during 2025–26. While overall enrolments were lower than in the previous year, the learner profile continued to shift. WAHTN Partner organisations accounted for 63% of enrolments, with a further 7% from WA users outside the partnership and 30% from interstate. Learners were represented across every Australian state and territory.

Importantly, representation of students and people earlier in their research careers continued to increase. The proportion of enrolments from people with 0–5 years of research experience increased from 35% to 45%, while student representation increased from 12% in 2022–23 to 29% in 2025–26. This growing representation of students and early-career researchers supports the development of CCI knowledge and practice from an early stage of their research careers.

The foundational Consumer and Community Involvement in Health Research eCourse accounted for 72% of enrolments, with 28% completing CCI and Grant Writing.

eCourse enrolments over the last 5 years



Strategic Partnerships and System-Level Impact

An increasing part of the CCIProgram's work is supporting organisations to strengthen the structures, relationships and approaches that enable meaningful consumer and community involvement beyond individual research projects. This includes building internal CCI capability, supporting organisational planning and priority setting, supporting Aboriginal-led research, and embedding lived experience within health services research.

Growing CCI capability

At **Edith Cowan University**, NHIRI continued implementation of its CCI Roadmap, including the appointment of a dedicated CCI Coordinator to support researchers across the Institute. The CCIProgram has provided ongoing mentoring and support to the new role, helping to build CCI capability within NHIRI.

Prof Josh Lewis presenting at WA CCI CoP on the NHIRI CCI Roadmap

Working together, NHIRI and the CCIProgram have also established an institute-wide Consumer Advisory Group, providing an ongoing mechanism for consumer perspectives to inform the strategic development of CCI across the Institute.

CAHS continued its partnership with the CCIProgram through the CCI Scholarship Program, supporting clinician researchers to strengthen their CCI knowledge and apply it in practice. Scholarship recipients filled 52 places across the CCIProgram Masterclass Series, while the Program promoted 10 CAHS consumer involvement opportunities directly linked to research scholarship holder projects. These opportunities generated 57 expressions of interest and supported 27 consumer interviews.

Supporting Aboriginal-led Research

This year saw the launch of the Yarning about Aboriginal Health Research Data in Boorloo (Perth) Community Report, detailing key findings and recommendations grounded in the views of Aboriginal community members. The project was led, designed, analysed and controlled by Aboriginal people, with collaborators from **Wungening Aboriginal Corporation**, **ECU**, **The Kids Research Institute** and **Murdoch University**.

Initiated in 2023 by Professor Bep Uink, the project commenced with a community yarning event supported by the CCIProgram team. Building on this foundation, the study team established an ongoing Community Group to bring a cultural and community lens to the research and explore Aboriginal Data Sovereignty.

Yarning about Aboriginal Health Research Data in Boorloo (Perth) Community Report

Supporting Aboriginal-led Research

The CCIProgram was also pleased to play a supporting role in Boola Kep, Boola Koort: Many Waters, Many Hearts, a Water Roundtable hosted at **Murdoch University** and led by Dr Mara West, Professor Roz Walker and WAHTN Board member Professor Rhonda Marriott AM.

Dr Mara West, Prof Rhonda Marriott and Prof Roz Walker

Impact Case Study:
Bringing community voice to the table

Boola Kep, Boola Koort: Many Waters, Many Hearts brought Aboriginal community representatives from across Western Australia together to speak directly about an issue fundamental to the health and wellbeing of their communities: access to safe, reliable water.

Community voices were deliberately heard first. Elders, homeland leaders and community representatives shared the realities of poor water quality, infrastructure failures and the health, cultural and intergenerational consequences for their communities. Importantly, they were able to bring these experiences directly to Water Corporation, researchers, government and other stakeholders with a role in creating change.

The Roundtable created an opportunity not only to be heard, but to work together on what needs to happen next. Community knowledge and priorities informed discussions about service delivery, research, policy and practical solutions, strengthening the foundations for ongoing action and partnership.

The CCIProgram supported the Aboriginal-led Roundtable and subsequent reporting, helping to ensure the knowledge and priorities shared by communities were captured and could continue to inform action.

Boola Kep, Boola Koort: Many Waters, Many Hearts Water Roundtable

Strengthening Consumer Involvement in Health Services Research

The CCIProgram's work with WAHTN Partner health services has increasingly extended beyond support for individual research projects into broader research planning, priority setting and organisational approaches to consumer involvement.

Working with the Research Department of **Sir Charles Gairdner Osborne Park Health Care Group**, the CCIProgram supported a Community Conversation exploring how consumers, carers and family members want to be involved in informing research across the health service. The findings are now informing the Research Department's broader approach to strengthening consumer involvement across the research lifecycle.

SCGH and OPH Community Conversation

The CCIProgram also worked with **WA Country Health Service (WACHS)** as it develops its Research and Innovation Framework for regional, rural and remote Western Australia. Through an online Community Conversation, people living across country WA shared their experiences of healthcare and identified what matters to them as WACHS considers its emerging research priorities. These perspectives will contribute directly to the ongoing development and refinement of the Framework.

These perspectives may also inform the **West Australian Rural Research and Innovation Alliance (WARRIA)** in their initial impact and CCI planning as it works towards NHMRC accreditation as a Research Translation Centre.

Together, these partnerships reflect a growing focus on embedding lived-experience perspectives within health services research and ensuring research priorities remain connected to the needs of the people and communities that healthcare services are designed to serve.

This focus has extended into primary care and the education of our future health workforce. The CCIProgram has worked with researchers exploring how primary care can better respond to patient needs, including consumer input into preventive care in general practice and culturally appropriate approaches to cancer screening. The Program has also supported UWA and Curtin University to seek community perspectives on the selection of future medical students, including the experiences of people from culturally and linguistically diverse communities, people experiencing financial barriers to healthcare, and people with lived experience of mental health challenges.

Impact Case Study: Keeping the patient at the centre of healthcare

For Dr Piers Truter, consumer involvement is not a one-off activity. During 2025–26, this ongoing partnership continued to shape research into urgent care for musculoskeletal injuries at Rockingham General Hospital, building on work developed over previous years.

Working closely with consumers has broadened the focus of the research from a clinical question about safely diverting people from Emergency Department physician care to a wider consideration of what good injury care looks like from the patient perspective. Consumer insights have influenced research priorities, service delivery models and the outcomes being measured, while also highlighting equity and the need to recognise that one model of care will not work for everyone.

A Community Conversation provided further direction, with consumers identifying practical opportunities including more direct access to the diversion pathway, better connections between urgent and follow-up care, and community-based options.

The work was recognised with the 2024 WA Health Excellence Award for Excellence in Person-Centred Care. As Piers describes his approach: "This is not a transaction. It's a relationship."

CCIProgram Membership

The CCIProgram's membership is more than a network of people interested in health research. Throughout the year, members had opportunities to contribute their lived experience to research, take part in conversations about emerging health priorities, and build their own knowledge and skills in CCI.

Across the year, **62** consumer involvement opportunities were promoted to CCIProgram members through the Matching Service. These attracted 304 expressions of interest, with 205 consumers interviewed for opportunities to work alongside research teams.

Members were also invited to contribute to and inform research through Community Conversations and other consumer involvement events. Across 26 Community and Micro Community Conversations, **299** consumers took part in discussions helping to shape research questions, priorities and approaches.

Further opportunities included the Fiona Wood Foundation Consumer Breakfast, the WA Psychological Science Conference, NHIRI's An Appetite for Consumer-Driven Research Symposium, and the WAHTN webinar introducing the new Consumer Statement.

Consumers continued to build their confidence and capability to contribute to research, with **30** attending consumer-focused training opportunities. These included CCI Masterclasses, ANZBMS/BHF CCI webinars, the Consumer Grant Review Panel Workshop, and Speaking as One: Integrating Consumer Insights into Research Proposals tailored training.

Impact Case Study:
When lived experience leads to discovery

Some of the strongest impacts of CCI emerge over time. Over seven years, the Inclusion Body Myositis (IBM) Consumer Advisory Group has evolved from a group responding to researcher-led questions into a genuine research partnership. Consumers now help identify research priorities, challenge assumptions and shape new avenues of investigation, with some progressing to lead research themselves as honorary research fellows.

The value of this relationship is evident in what the team has discovered. When consumers repeatedly raised symptoms that were not traditionally associated with IBM, researchers listened. Continence and lymphoedema have emerged as areas for further investigation, while consumer experiences of pain have also challenged assumptions about the condition and influenced subsequent research.

In one striking example, consumers questioned the accepted view that continence issues were unrelated to IBM and initiated work to investigate the connection. The findings have opened further avenues of research into how IBM may affect areas of the body previously not associated with the disease. With researchers, clinicians and consumers working closely together, emerging knowledge can also feed directly back into clinical care and support.

This is CCI at its most powerful: lived experience not simply informing research, but generating questions, challenging established thinking and contributing to new knowledge about the disease itself.

62
Involvement Opportunities

304
Expressions of Interest

205
Consumers Interviewed

299
Consumers at 26 Community Conversations

30
Consumers attending Training

Looking Forward

The year ahead presents an opportunity to build on the momentum of 2025–26. With strengthened national expectations for consumer and community involvement now in place, the CCIProgram will continue working with WAHTN Partners to translate these expectations into meaningful and sustainable CCI practice.

An increasing focus will be supporting Partner organisations to strengthen CCI at an organisational level. Building on work already underway across the network, this will include continuing to work with the Research Department at Sir Charles Gairdner Osborne Park Health Care Group as it develops its CCI framework, and collaborating with Ramsay Health Care's Joondalup Health Campus on a Research Priority Mapping workshop focused on mental health.

Building CCI capability across the wider WAHTN partnership will also remain a priority. The CCIProgram will continue to expand access to tailored CCI seminars, working with Partners including **Lions Eye Institute** and the **Child and Adolescent Health Service**, and seeking opportunities to deliver tailored sessions across all WAHTN Partner organisations. Alongside the Masterclass Series, eCourses and individual project support, these sessions provide another way of bringing practical CCI knowledge and expertise directly into Partner organisations and their research communities.

A major focus for 2026–27 will be planning for the WA CCI in Research Showcase, to be held in April 2027. Envisaged as a collaborative event across the WAHTN partnership, the Showcase will bring together consumers, researchers and organisations to celebrate and share the breadth of exceptional CCI practice taking place across Western Australia. It will provide an opportunity to showcase CCI across health services, universities, medical research institutes and other research settings, and across the breadth of health and medical research, from discovery and basic science through to clinical, health services, implementation and translational research.

CCIProgram Lead and CCI Coordinators

More than a celebration of what has been achieved, the Showcase will provide an opportunity for the WA research community to learn from one another, strengthen connections and share approaches that can support meaningful CCI across different research settings. It reflects the CCIProgram's broader direction for the year ahead: building capability across the WAHTN partnership, strengthening organisational approaches to CCI, and creating opportunities for the considerable experience and expertise already present across Western Australia to be shared and built upon.

As this work continues, the CCIProgram will remain connected to national developments, contributing WA experience and expertise while bringing emerging guidance, resources and opportunities back to WAHTN Partners. At the centre of these activities will remain the consumers and communities whose lived experience helps ensure that research is relevant, responsive and capable of making a meaningful difference.

Appendix 1 - Glossary

Carer
In this document, the term carer refers to an individual who provides ongoing personal care, support, advocacy and/or assistance to a person living with a medical condition or illness.

Community Conversation
A facilitated group discussion where up to 30 people with lived experience share insights to guide research on a specific topic.

Consumer
A person with lived experience of a health issue and/or accessing health care and health systems. This includes patients and potential patients, and their families, friends, carers, and other members of the public. Consumers can also include people who represent consumer organisations or individual patients. Some people prefer to use another term instead of consumer. These include person with lived experience, person with disability, and lived experience expert.

Consumer and community involvement (involvement)
When consumers and communities actively work with researchers and research institutions to shape decisions about priorities, policy, and practice related to health and medical research.

Future Health Research Innovation (FHRI) Fund
A WA Government fund supporting health and medical research, innovation, and commercialisation to improve community health, grow the economy, and strengthen the health system.

Involvement Opportunities
Occasions where a consumer is invited to take on a defined role within a specific research project — such as joining an advisory group, acting as a research buddy, or reviewing grants and documents.

Lived or Living Experience
Knowledge and perspectives that someone gains through their own experiences. These may include health issues, accessing health care and health systems, and being part of a community.

Lived or living experience of caring/being a carer
A current or previous experience of being an unpaid carer or support person for someone experiencing a medical condition, medical ill-health, trauma or distress.

Medical Research Future Fund (MRFF)
An Australian Government fund supporting health and medical research through a $20 billion long-term investment aimed at improving lives, driving innovation, and strengthening the health system.

Micro Community Conversation
A small, focused discussion (4–6 people) used at early research stages to test ideas and identify priorities.

National Health and Medical Research Council (NHMRC)
Australia's lead agency for funding health and medical research, developing health advice, and setting ethical standards for research and healthcare.

Research Buddy
A consumer who works alongside a researcher or team throughout a project, offering lived experience input via regular conversations, document review, and feedback.

CCIProgram Partners and Collaborators

WAHTN Partners

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