



Consumer and Community
Involvement Program



WAHTN
Western Australian Health Translation Network

HELP SHAPE FUTURE MEDICAL RESEARCH AT SIR CHARLES GAIRDNER AND OSBORNE PARK HOSPITAL

COMMUNITY CONVERSATION SUMMARY REPORT



Prepared By

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June
2026



Government of **Western Australia**
North Metropolitan Health Service
Sir Charles Gairdner Osborne Park Health Care Group

S H I N E T H I S I S I S S U E

02.

Acknowledgements

03.

Background

04.

The Research Department Team

05.

About the Community Conversation

06.

Structure and Process

07.

Key Insights of the Community Conversation

08.

Key Themes of the Community Conversation

09.

Questions 1

12.

Questions 2

16.

Questions 3

ACKNOWLEDGEMENTS

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.



BACKGROUND

The Sir Charles Gairdner Osborne Park Health Care Group (SCGOPHCG) is one of Western Australia's leading health research organisations, supporting more than 500 active research studies across a broad range of clinical specialties, from laboratory-based discovery science through to clinical trials. The Department of Research provides leadership, governance and support to researchers, with a strong focus on generating research that improves patient care and health outcomes.

As part of its ongoing commitment to strengthening consumer involvement in research, the SCGOPHCG Research Department partnered with the Consumer and Community Involvement Program (CCIPProgram) to better understand how consumers, carers and family members would like to be involved in informing research. The Community Conversation formed part of a broader project that included a pre-event consumer survey, enabling attendees to build on survey findings and explore priorities in greater depth through facilitated discussion.



THE RESEARCH DEPARTMENT TEAM

The Community Conversation formed part of a broader initiative led by the SCGOPHCG Research Department to strengthen consumer involvement across the research lifecycle. The project was initiated under the leadership of Samantha Bowyer, Acting Director of Research, and progressed by the Research Department team. In the lead up to the Community Conversation, project leadership transitioned to Dr Nabil Siddique, who introduced the event and continues to lead the next stage of the project.

The Community Conversation was coordinated by Dr Ondine Gordon, Research Grants and Partnerships Coordinator, and Adjunct Associate Professor Karen Taylor, Research Manager. Together they worked closely with the CCIP Program to design the engagement process, develop the pre-event survey, recruit consumers and translate the findings into practical outcomes for the Research Department.

Three members of the Research Department were table scribes throughout the event, capturing discussion and listening directly to consumer perspectives. This approach allowed the Research Department team to hear first-hand the experiences, expectations and ideas shared by attendees.

Research Department Team

Dr Nabil Siddique

Director of Research, SCGOPHCG

Adj A/Prof Karen Taylor

Research Manager, SCGOPHCG

Dr Ondine Gordon

Research Grants and Partnerships

Coordinator, SCGOPHCG

Research Team Scribes

- Dr Rose McDowell
- Suhela Kazi
- Nicky Maxwell

ABOUT THE COMMUNITY CONVERSATION

A Community Conversation provides an opportunity for people with lived experience to take part in informal, facilitated discussion about a topic of importance, sharing their experiences, perspectives and ideas in a safe and comfortable environment.

The SCGH and OPH Community Conversation was held on 10 June 2026 at the Harry Perkins Institute of Medical Research. It brought together 26 consumers, carers and family members with lived experience of receiving care through Sir Charles Gairdner Hospital and Osborne Park Hospital. The Research Department worked with the CCIP Program to recruit members of the WA community with lived experience of receiving care through SCGH or OPH. The opportunity was promoted through relevant consumer, health service and community networks, supported by flyers and social media.

The event was jointly facilitated by the CCIP Program and the SCGOPHCG Research Department. Dr Nabil Siddique introduced the project and its purpose, while members of the Research Department participated as scribes, providing an opportunity to hear first-hand the experiences, expectations and ideas shared by attendees.



JOIN A COMMUNITY CONVERSATION ABOUT HEALTH RESEARCH

Sir Charles Gairdner Hospital and Osborne Park Hospital are working to strengthen how patients, carers and families are involved in health and medical research.

We are inviting people with lived experience of receiving care at either hospital, or as a carer of a person to join a facilitated Community Conversation.

Your experiences and perspectives will help us:

- understand what matters most to patients, carers and families in research
- identify how consumers can be involved meaningfully in research
- help shape future approaches to consumer involvement in research at SCGH and OPH

WORKSHOP DETAILS:

DATE:	Wednesday, 10 June 2026
TIME:	10am - 12pm
LOCATION:	Harry Perkins Institute, Nedlands

A \$80 honorarium is offered to attendees and light refreshments will be provided.

Register here:
<https://bit.ly/4nbJlde>

SCAN ME



STRUCTURE AND PROCESS

The Community Conversation used the CCIProgram's facilitated Community Conversation methodology, based on an adapted World Café approach. Attendees were seated across three small discussion tables, each supported by an experienced CCIProgram facilitator and a member of the SCGOPHCG Research Department acting as a scribe.



The discussion explored three questions designed to understand:

- the most important actions SCGH and OPH could take to support greater consumer involvement in informing research;
- the best ways for researchers to connect with and involve consumers, carers and family members; and
- what would make involvement in research a positive and worthwhile experience.

Each question was discussed in turn before attendees rotated to the next discussion. Scribes captured key discussion points throughout the event, enabling the themes presented in this report to be developed from the collective discussion across all three tables.

KEY INSIGHTS OF THE COMMUNITY CONVERSATION

Raising awareness and improving access

Attendees highlighted the need to increase awareness of research opportunities through a range of communication channels, including clinics, GP practices, waiting rooms, appointment letters, social media and community organisations. Information should clearly explain what research is, why it is important, how consumers can contribute, and what level of commitment is involved. Attendees also emphasised reaching underrepresented groups, including culturally and linguistically diverse (CALD) communities, carers and family members.

Making involvement accessible and inclusive

Consumers identified several practical barriers to involvement and recommended flexible meeting times, accessible venues, parking support, interpreters, technical assistance and a dedicated contact person. They also supported offering multiple ways to be involved, such as online options and translated resources, recognising that no single engagement approach suits everyone.

Building relationships and engaging early

Attendees stressed that consumer involvement should begin at the earliest stages of research, rather than after key decisions have already been made. Researchers should build ongoing, trusted relationships with consumers by engaging through familiar settings such as clinics, community organisations and disease-specific groups, and by maintaining regular communication throughout the research process.

Clear communication and support

Consumers consistently called for information to be presented in plain English, with minimal jargon and unnecessary paperwork. They wanted clear expectations about the purpose of the research, their role, time commitment and how communication would occur. Avoiding excessive documentation and unrealistic deadlines was also seen as important to creating a positive experience.

Demonstrating meaningful impact

Attendees emphasised the importance of ensuring that consumer involvement is genuine rather than tokenistic. Attendees wanted evidence that their feedback influenced decisions and led to changes in the research. They also valued receiving updates throughout the project and learning about the final outcomes, implementation and impact, so they could see how their contribution had made a difference.

KEY THEMES OF THE COMMUNITY CONVERSATION

Theme	Consumer Comments
Make research visible and accessible	"Improve how the community is informed of opportunities." "If SCGH and OPH could improve one thing, it would be awareness [of research opportunities]."
Build genuine partnerships, not token involvement	"I have just been a 'guinea pig', not been involved in the entire process." "You want a chair not a high chair. You want to be a true participant. Don't want to feel like a token."
Communicate clearly and keep consumers informed	"Communication should be lined up with the phases. Updates at the end of each stage is important so we know it is progresses." "Getting updates. [Tell us] what happens next."
Build relationships through trust, respect and empathy	"What is the research equivalent of good bedside manner?" "I don't want to feel like I am just a number." "A personal interaction with the researcher is important. I want to be reassured that my personal info is looked after."
Meet people where they are and tailor opportunities	"Community conversations like this is number 1!" "Checking in at a centre you are attending is a good way to approach a person."
Create inclusive and accessible opportunities	"There are entire communities that are not accessed about research. E.g. migrants and CALD groups." "People who are not tech savvy need to be considered."
Respect consumers' time, circumstances and contribution	"If I get a load of papers the day before, that is too much. I have my life to live. Too much to read the day before is a lack of respect for my time." "Paying me for my time is important." "When I am getting involved, I would like to know the entire commitment required. You don't want to get involved and then have to withdraw."
Show that consumer involvement leads to meaningful outcomes	"I want to know that I am making a difference." "I want to gain meaning and purpose by making a difference."

QUESTION 1

IN THE SURVEY YOU COMPLETED PRIOR TO ATTENDING TODAY'S COMMUNITY CONVERSATION, PEOPLE IDENTIFIED BARRIERS TO INVOLVEMENT IN INFORMING RESEARCH SUCH AS TIME, WORK COMMITMENTS, TRANSPORT, PARKING, HEALTH ISSUES AND NOT KNOWING ABOUT OPPORTUNITIES.

PEOPLE ALSO IDENTIFIED THINGS THAT HELP, SUCH AS FLEXIBILITY, CLEAR COMMUNICATION AND BEING ABLE TO CONTRIBUTE IN DIFFERENT WAYS.

WHAT ACTIONS DO YOU THINK ARE THE MOST IMPORTANT OR URGENT FOR SCGH AND OPH TO TAKE TO HELP MORE CONSUMERS BECOME INVOLVED IN INFORMING RESEARCH?

PROMPTS:

- What should happen first?
- What would make the biggest difference?
- What support is most important?
- What would help involve a broader range of people?
- If SCGH and OPH could improve just one thing, what should it be?

Attendees identified a range of practical and cultural changes that they believed would make it easier for consumers to become involved in informing research. The discussion focussed on the importance of making research more visible, building trust, supporting meaningful involvement and ensuring opportunities are accessible to a broader range of consumers.

Research is too invisible.

Increase awareness of research and opportunities to become involved

The strongest and most consistent message from attendees was that research opportunities need to be much more visible. Many people described not knowing what research was taking place within the hospitals, how to become involved, or even that consumers could play a role in informing research. Several attendees also wanted greater visibility of the research already taking place within SCGH and OPH so consumers could better understand current activities and identify where they may be able to contribute.

QUESTION 1 (Continued)

Attendees suggested promoting opportunities through multiple channels rather than relying on one method. Ideas included information provided during appointments by doctors, nurses or specialists, posters and digital screens in waiting areas, information included with appointment letters, GP clinics, pharmacies, disease-specific organisations, community groups, local newspapers, radio, social media and existing consumer networks. Several attendees also suggested including questions about research involvement in patient surveys completed following hospital appointments. Many attendees felt that improving awareness would have the greatest impact if SCGH and OPH could focus on just one priority.

Communicate clearly and help people understand research

Attendees discussed the importance of using clear, simple language when communicating about research and consumer involvement. They wanted information that explained what research is, why it matters, how consumers can contribute and what difference their involvement could make.

People also wanted to understand the expectations before agreeing to become involved, including the level of commitment required, the different ways they could contribute and whether involvement was for a single project or over a longer period. Several attendees noted that not everyone wishes to become an ongoing consumer and that people should be able to choose opportunities that align with their interests.

Attendees wanted honest communication, regular updates and meaningful feedback throughout the research process. Building trust was seen as an important part of this, with attendees discussing the value of receiving information from trusted health professionals and understanding how they would be supported throughout their involvement.

Create genuine, supported partnerships with consumers

Attendees wanted consumers to be involved as genuine partners throughout the research process rather than being consulted only after key decisions had already been made. Several people spoke about wanting researchers to ask consumers what topics should be researched and to involve them from the beginning through to the completion of projects.

There was strong support for approaches that demonstrated researchers were listening and valuing consumer input. Suggestions included establishing or strengthening consumer groups and advisory panels, working with existing consumer councils, maintaining relationships with engaged consumers, creating opportunities for co-design and using consumer roadmaps to help identify research priorities.

Attendees also wanted to know that their input would genuinely influence research, supported by regular feedback and updates demonstrating how consumer contributions had shaped decisions. One attendee reflected on a previous experience, saying they felt they had "just been a guinea pig" rather than involved throughout the research process. Another commented that consumers wanted "to be a true participant" and not feel like "a token."

QUESTION 1 (Continued)

Improve inclusion by reaching a broader and more diverse community

Attendees felt that greater effort was needed to involve people from communities that are often underrepresented in research. Particular emphasis was placed on engaging CALD and migrant communities through culturally appropriate approaches, partnerships with community organisations and communication in different languages.

Attendees also discussed the importance of involving carers and family members alongside patients, recognising that they often have valuable lived experience and perspectives.

Suggestions included working with charities, NGOs, disease-specific organisations and existing community networks to broaden awareness and involvement.

Several attendees also raised cultural safety, inclusive research design and ensuring people understand the support available to enable their involvement.

Reduce practical barriers and provide appropriate support

Attendees recognised that many practical barriers influence whether people are able to become involved in research. They discussed the importance of flexible meeting times, including evening and weekend sessions, to accommodate both working people and retirees.

Many attendees also highlighted the need for practical supports such as parking, accessible venues, interpreters, hearing assistance, wheelchair access and technical support where required. Some noted that these supports may already exist but people are often unaware they are available, resulting in individuals choosing not to be involved.

Several attendees suggested providing a dedicated contact person or research team member to support consumers throughout their involvement and help them access any assistance they require.

Some attendees also offered additional ideas to support consumer involvement, including using research ambassadors, reviewing existing consumer feedback, improving the readability of consumer-facing materials, providing clear identifiers for research staff, considering different approaches to honorarium payments, and exploring other ways to promote research opportunities and consumer involvement.



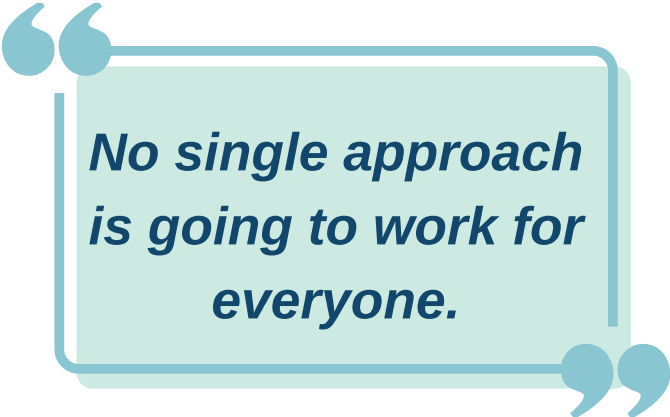
QUESTION 2

RESEARCHERS AT SCGH AND OPH WANT TO INVOLVE CONSUMERS, CARERS AND FAMILY MEMBERS MORE OFTEN AND EARLIER IN INFORMING AND BEING INVOLVED IN THEIR RESEARCH.

FROM YOUR EXPERIENCE, WHAT ARE THE BEST WAYS FOR RESEARCHERS TO CONNECT WITH AND INVOLVE PEOPLE IN INFORMING RESEARCH?

PROMPTS:

- How should researchers find and approach people?
- What works well?
- What doesn't work well?
- How can we target particular groups of people who are often missed?
- What can researchers do make it easier for people to say yes?
- What would make you join a consumer register?
- What concerns might you have?



***No single approach
is going to work for
everyone.***

Consumers recommended a range of practical approaches researchers could use to connect with consumers, carers and family members earlier and more effectively. The discussion emphasised the importance of meeting people where they are, building trusted relationships, using a variety of engagement approaches and maintaining communication throughout the research journey. While attendees discussed a range of recruitment approaches, there was broad agreement that no single method would suit everyone. Several suggestions generated mixed views, reinforcing the message of offering multiple opportunities for people to engage in ways that best suited their circumstances and preferences.

QUESTION 2 (Continued)

Meet people where they already are

Attendees consistently discussed the importance of approaching people in places they already attend or trust, rather than expecting them to seek out research opportunities. Suggestions included discussing research during clinical appointments, providing information with outpatient appointment letters, engaging through GPs and primary health care providers, community organisations, libraries, community events and disease-specific organisations.



Attendees also suggested researchers connect with existing organisations and networks that already have trusted relationships with consumers, carers and communities. Examples included carer organisations, NDIS providers, Aboriginal organisations, charities, community resource centres and community groups.

Researchers meet a committee at a café to update us on progress of grant application and research.

Build relationships through trusted, ongoing communication

Attendees emphasised that meaningful involvement relies on building relationships rather than making one-off requests. They valued opportunities to meet researchers, hear directly about research projects and receive updates throughout the research process, including when projects were delayed or funding outcomes were still pending.

Several attendees felt that researchers returning to communities to share outcomes demonstrated respect for people's contributions and helped avoid research feeling exploitative. Attendees valued opportunities to hear directly from researchers, ask questions and develop relationships through community presentations, discussion forums and ongoing engagement with groups connected to the research topic.

QUESTION 2 (Continued)

Make it easy for people to understand and respond

Many attendees discussed the importance of making research information accessible and easy to engage with. They wanted clear, plain language with minimal jargon or acronyms, visual communication where appropriate, and simple ways to obtain further information, such as QR codes, contact details and opportunities to speak directly with someone involved in the research. Some attendees also discussed reducing the amount of written information provided at first contact, noting that lengthy documents could discourage people from engaging.

Provide flexible and inclusive ways to become involved

Attendees recognised that different people require different approaches to support their involvement. They discussed the importance of interpreters, translated information, cultural safety, accessibility supports and considering people who are less confident using technology.

There was also discussion about offering opportunities for online involvement, which could make research more accessible for people living in regional and remote areas or those unable to travel. Where possible, attendees also suggested reducing financial barriers by assisting with costs associated with consumer involvement.

Include carers and family members throughout the research journey

Attendees consistently highlighted the important role of carers and family members in supporting people to be involved in research. They felt carers should be included in discussions about research opportunities and, where appropriate, have the option of being listed as a contact person.

Several attendees also noted that involving carers from the beginning could help support ongoing involvement throughout a research project.



QUESTION 2 (Continued)

Offer opportunities at the right time

Several attendees reflected the importance of timing when approaching people about research. Some felt existing healthcare interactions, such as clinical appointments or hospital visits, created natural opportunities to discuss research without requiring an additional visit.

There was also discussion about consumer registers. Some attendees supported routinely asking people whether they would like to hear about future research opportunities, while others felt this should not be a once-only question, recognising that people's interest and circumstances may change over time.

Several attendees felt that a consumer register would be more meaningful if people could express interest in particular research topics rather than simply registering a general willingness to be contacted.

Attendees also shared a range of additional ideas to strengthen researcher connections with consumers, including using research buddies or ambassadors, volunteer information points, researcher presentations for community groups, interactive activities in waiting areas, dedicated apps, expanding recruitment into other public settings, and creating opportunities for consumers to suggest future research topics.



QUESTION 3

IMAGINE THAT SCGH AND OPH RESEARCHERS HAVE SUCCESSFULLY CONNECTED WITH YOU AND INVITED YOU TO BE INVOLVED IN RESEARCH.

WHAT WOULD MAKE THAT A POSITIVE AND WORTHWHILE EXPERIENCE FOR YOU?

PROMPTS:

- What would help you feel comfortable contributing?
- What information would you want upfront?
- How much communication would you expect?
- What would make you feel that your contribution was valued?
- What would encourage you to stay involved?
- What would make you decide not to participate again?

The discussion highlighted that a positive consumer experience is shaped as much by how researchers engage with people as by the research itself. Attendees consistently described the importance of respectful relationships, clear expectations, ongoing communication and demonstrating that consumer contributions genuinely influenced research. While practical supports such as parking, technology and honorariums were recognised as important, attendees consistently described respectful relationships, genuine partnership and ongoing communication as the factors most likely to determine whether involvement was a positive experience.

What is the research equivalent of good bedside manner?

Build respectful and supportive relationships

Attendees consistently described the importance of feeling respected, welcomed and genuinely valued throughout their involvement in research. They valued personal interactions with researchers, opportunities to ask questions and having a consistent contact person who could provide reassurance and guidance when needed.

Many attendees felt researchers should approach consumer involvement with warmth, empathy and genuine interest, taking time to build rapport and recognise the expertise that consumers bring through their lived experience. Respect for consumers' wellbeing, privacy and psychological safety was also seen as fundamental to creating a positive experience.

QUESTION 3 (Continued)

Set clear expectations and maintain communication throughout the research journey

Attendees wanted clear information from the outset about the purpose of the research, what would be expected of them, the likely time commitment and how they would be kept informed throughout the project.

There was strong support for regular communication, including updates on research progress, delays, outcomes and implementation. Attendees felt communication should be planned from the beginning and continue throughout the project, with updates aligned to key milestones. Many felt even brief updates reassured them that the research was progressing and demonstrated respect for their contribution.

Attendees also wanted communication to be proportionate, avoiding lengthy documents, excessive paperwork and requests with unrealistic timeframes that placed unnecessary demands on consumers. Several attendees suggested providing an onboarding resource that explained the purpose of the research, common terminology, expectations and key contacts, helping consumers feel confident from the outset.

Demonstrate that consumer contributions make a difference

Attendees consistently expressed that their involvement needed to feel meaningful. They wanted to understand how their feedback had influenced the research and to see the outcomes of projects they had contributed to, including any changes to practice, policy or future research.

Several attendees described the importance of researchers listening to consumer perspectives and acting on their suggestions where appropriate. Feeling that contributions had been acknowledged and genuinely considered encouraged ongoing involvement, whereas involvement that felt tokenistic was seen as discouraging. Attendees also wanted to understand what happened after the research concluded, including how findings had been implemented and whether their contribution had influenced change.



QUESTION 3 (Continued)

Respect individual circumstances and preferences

Attendees discussed the importance of researchers recognising that consumers have different needs, responsibilities and preferred ways of engaging. They emphasised providing realistic timeframes for feedback, offering flexibility in how people could be involved and recognising that different people preferred different methods of communication and involvement. There was support for a range of involvement options, including online and face-to-face involvement, telehealth for regional and remote consumers, printed materials where preferred and support with technology when required. Attendees also highlighted the importance of accommodating different learning styles, disabilities and neurodiverse needs to make involvement accessible to a broader range of consumers.

Support consumers to be involved confidently and safely

Attendees wanted to feel confident that they would be supported throughout their involvement. They discussed the importance of knowing their personal information would be protected, having confidence that confidentiality would be maintained and understanding who to contact if questions or concerns arose during the research. Several attendees also valued opportunities to discuss concerns, ask questions and receive reassurance where needed. This included support to understand research terminology, opportunities to debrief where appropriate and confidence that researchers would respond appropriately if issues arose during the research process.

Involve consumers as valued members of the research team

Attendees described positive experiences where consumers were treated as active members of the research team rather than being consulted only at isolated points throughout a project. They valued opportunities to contribute to research design, review documents, provide ongoing input and be included in regular project communication. Attendees also recognised that consumers contribute more than lived experience alone, bringing a wide range of skills and experiences that can strengthen research. They valued opportunities to contribute in different ways throughout the research process, including reviewing documents, helping develop resources and providing ongoing advice. Some attendees also discussed the importance of appropriately recognising consumer contributions, including opportunities for co-authorship where appropriate.

Attendees also shared a range of additional ideas to strengthen the consumer experience, including connecting new consumers with people who have previous research experience, providing information in multiple formats, supporting different learning styles and abilities, and ensuring consumers receive information about research findings and outcomes once projects are complete.

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