WAHTN
Western Australian Health Translation Network

Consumer and Community Involvement Program

UNDERSTANDING COMMUNITY PERSPECTIVES ON BLOOD TESTS FOR ALZHEIMER'S DISEASE

MICRO COMMUNITY CONVERSATION SUMMARY REPORT

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Murdoch University

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ACKNOWLEDGEMENTS

Acknowledgement of Country

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.

This event was held on Wardandi Noongar Country at Donnybrook Library. We acknowledge the Wardandi people as the Traditional Custodians of this land and pay our respects to Elders past and present. We recognise their continuing connection to Country, culture and community.

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.

We extend our heartfelt gratitude to the South-West Community members for sharing their thoughts and experiences surrounding alzheimers, dementia and healthy ageing.

BACKGROUND

Alzheimer's disease is the most common cause of dementia. Changes in the brain linked to Alzheimer's disease can begin many years before a person develops symptoms such as memory loss. Researchers are interested in finding ways to identify these changes earlier and to better understand whether healthy lifestyle behaviours, such as physical activity, healthy eating and social connection, may influence a person's risk.

Recent advances have led to the development of blood tests that can detect biomarkers (biological markers) associated with Alzheimer's disease. These blood tests are less expensive and more accessible than brain scans. However, they cannot diagnose Alzheimer's disease or predict whether someone will develop dementia. Instead, they provide information about biological changes that may be associated with Alzheimer's disease.

To help inform this area of research, the CCIProgram facilitated a Micro Community Conversation in Donnybrook, Western Australia. Community members shared their views on research into Alzheimer's disease blood biomarkers, whether people should be offered their individual blood test results, and what would make participation in this type of research more accessible and worthwhile. The findings in this report will help researchers understand community perspectives and inform the design of future research.

This work is supported by the WA 2025 Early-Mid Career Research (EMCR) Fellowships: Preventive Health for Priority Populations Program, which is a co-funding partnership program of the Western Australian Future Health Research and Innovation (FHRI) Fund and The Hospital Research Foundation Group (THRF).

THE CONSUMER AND COMMUNITY INVOLVEMENT PROGRAM

The Consumer and Community Involvement Program (CCIProgram) is dedicated to embedding the voices of consumers and community members in health research. Established as part of the Western Australian Health Translation Network (WAHTN), the program works to ensure that research is shaped by lived experience and addresses real-world health challenges.

At the heart of the CCIProgram is a team committed to building connections between researchers, consumers, and organisations. This team provides tailored support, guidance, and resources to ensure consumer involvement is an integral part of research design, implementation, and translation.

By championing consumer and community involvement at local, state, and national levels, the CCIProgram continues to evolve, ensuring that health research is informed, shaped and guided by those with lived experience.

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THE RESEARCHER

Dr Kelsey Sewell PhD

Research Fellow and Lecturer

Dr Kelsey Sewell is an early career researcher in the Centre for Healthy Ageing at Murdoch University whose research focuses on dementia prevention and healthy brain ageing. Her work explores how modifiable lifestyle factors, particularly physical activity, influence cognitive health and biological markers associated with Alzheimer's disease.

Dr Sewell is leading the *Small Steps* research program, which aims to support older adults living in regional Western Australia to become more physically active through a remotely delivered, co-designed online program.

The study will investigate whether increasing physical activity can improve memory and thinking, while also examining changes in blood biomarkers associated with Alzheimer's disease risk. The project includes collaboration with researchers from Murdoch University, Adelaide University and international partners and has been supported through a WA Government Future Health Research and Innovation Fund Early-to-Mid Career Research Fellowship in partnership with The Hospital Research Foundation Group.

Dr Sewell presented the background information for this Community Conversation, introducing attendees to current research on Alzheimer's disease biomarkers, the emerging role of blood tests, and the opportunities and limitations of using these tests in dementia prevention research.

WHAT IS A COMMUNITY CONVERSATION?

A Community Conversation is an event using an abridged version of the Word Café Method[1] and allows for the facilitation of informal, open conversations around a specific topic of importance. This method allows researchers to informally obtain a range of communal ideas from a group of people with lived experience around a particular topic specified prior to the event.[2],[3] Additionally, a Community Conversation provides an opportunity for attendees to reflect upon their own relevant experiences and contribute in meaningful discussions within a safe and comfortable space.

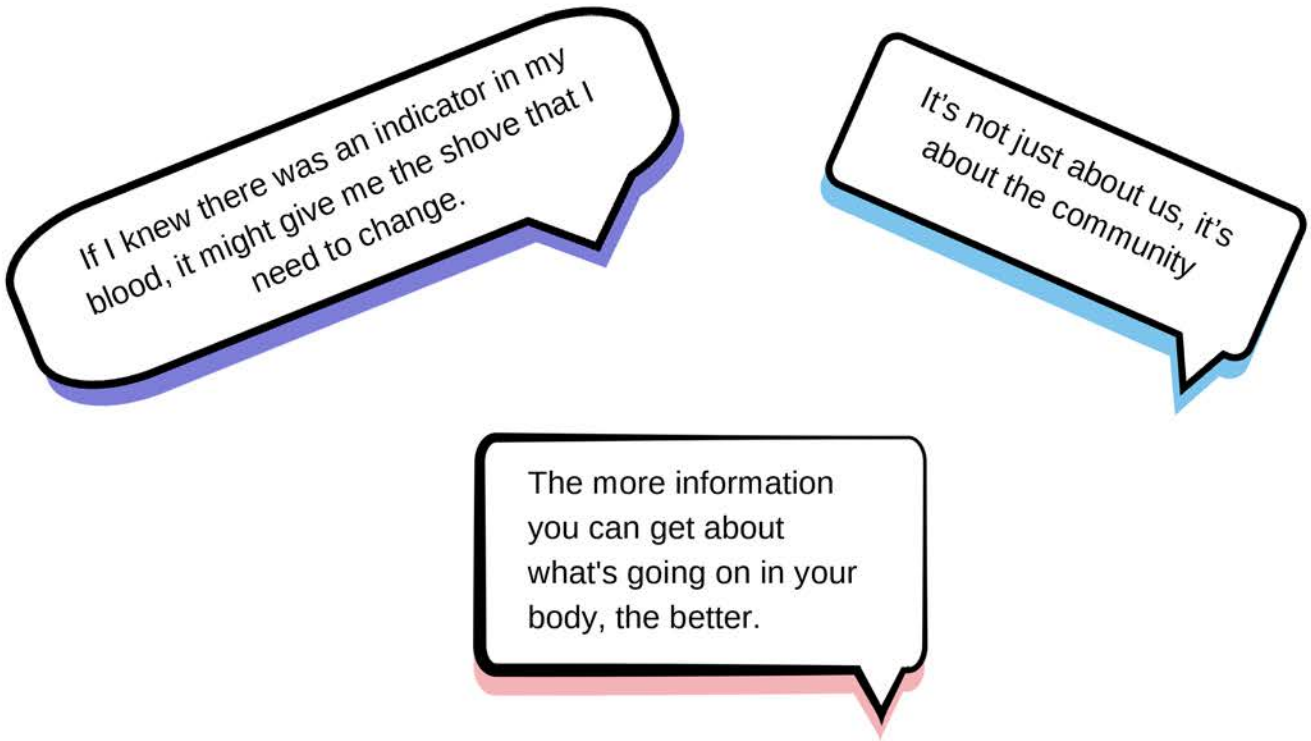
[1] Brown, J., & Isaacs, D. (2005). The World Cafe ́: Shaping our futures through conversations that matter. Barrett-Koehler
[2] Chieh-Ling Yang, Delphine Labbé, Brodie M. Sakakibara, Janneke Vissers & Marie-Louise Bird (2022) World Café- a community conversation: a Canadian perspective on stroke survivors needs for community integration, Topics in Stroke Rehabilitation, 29:5, 392- 400.
[3] Carter, E. W., Schutz, M. A., Gajjar, S. A., Maves, E. A., Bumble, J. L., & McMillan, E. D. (2021). Using Community Conversations to Inform Transition Education in Rural Communities. The Journal of Special Education, 55(3), 131–142.

ABOUT THE MICRO COMMUNITY CONVERSATION

A Micro Community Conversation is a small, structured discussion designed to gather insights from a highly targeted small group of individuals (typically 4-8 participants) with specific lived experiences. The format is designed to be intimate, flexible, and highly focused, making it particularly useful for discussing niche, sensitive, or emerging health research areas.

For this Micro Community Conversation, the researchers wanted to hear from individuals over the age of 60 that **had not** received a diagnosis for Alzheimer's or Dementia but had an interest in ageing well. The aim was to understand whether a blood test to measure levels of biomarkers for these diseases and the impact of lifestyle factors was useful and feasible for the community.

The Community Conversation was held on Monday, 13th of July 2026 and included 8 consumers from rural South-West Australia. The conversation was led by Caroline Jones, CCI Coordinator at the Consumer and Community Involvement Program.



PROMOTION

The Research Team worked closely with the CCIProgram to recruit members of South-West region in Western Australia who were over 60 years of age and did not have a diagnosis of Dementia or Alzheimer's disease, but an interest in either disease or in healthy ageing. We shared promotional communications across multiple channels.

Flyers and social media posts (Facebook, Instagram and LinkedIn) were posted and circulated around relevant networks, including the CCIProgram Newsletter.

AGENDA

10.45am	**Registration, refreshments**	**All**
11.00am	**Welcome** • Acknowledgement of Country & Acknowledgement of Lived Experience • Welcome to the workshop • Introductions	**Caroline Jones**
11.10am	**Presentation**	**Kelsey Sewell**
11.25am	**Process of the morning**	**Caroline**
11.30am	**Question 1**: Researchers are exploring whether lifestyle changes, such as physical activity, healthy eating and social connection, could influence biomarkers linked to Alzheimer's disease that can be measured through a blood test. **What are your first thoughts about this research, and how important do you think it is? Why?**	**All**
11.50am	**Question 2**: Researchers are considering whether people who take part in studies like this should be offered the option of receiving their own blood test results. These results may come months or years later and may provide information about biological changes associated with Alzheimer's disease risk, but they cannot say for certain whether someone will or will not develop Alzheimer's disease or dementia. **What are your thoughts about offering people this choice? If researchers offer this option, what would they need to do to help people feel informed and supported when making that decision?**	**All**
12.10pm	**Question 3**: As part of this research, people may be asked to travel twice to a larger town, such as Bunbury, for blood tests. **How do you think this will affect whether people are willing to take part? What could researchers put in place to make this easier, more acceptable, or more worthwhile for people?**	**All**
12.30pm	**Next Steps**	**All**
12.45pm	**Evaluation & Honorarium information**	**All**
1.00pm	**Close**	

STRUCTURE AND PROCESS

Attendees joined the Community Conversation on Monday July 13th 2026 at Donnybrook Community Library. The Micro Community Conversation was facilitated by Caroline Jones, CCI Coordinator from the CCIProgram, who guided attendees through structured discussion questions. The context for the discussion was provided by Dr Kelsey Sewell from Murdoch University.

Three tailored questions were posed to attendees, with 20 minutes per question allocated for discussion:

1. Researchers are exploring whether lifestyle changes, such as physical activity, healthy eating and social connection, could influence biomarkers linked to Alzheimer's disease that can be measured through a blood test. **What are your first thoughts about this research, and how important do you think it is? Why?**
2. Researchers are considering whether people who take part in studies like this should be offered the option of receiving their own blood test results. **What are your thoughts about offering people this choice? If researchers offer this option, what would they need to do to help people feel informed and supported when making that decision?**
3. As part of this research, people may be asked to travel twice to a larger town, such as Bunbury, for blood tests. **How do you think this will affect whether people are willing to take part? What could researchers put in place to make this easier, more acceptable, or more worthwhile for people?**

The comments, feedback and suggestions were all captured by Dr Kelsey Sewell who acted as scribe for the day, and are presented in the following pages of this report.

KEY INSIGHTS OF THE COMMUNITY CONVERSATION

Consumers want choice, supported by clear and trustworthy information

Consumers strongly supported having the option to receive their individual blood test results, recognising that people differ in how much information they want. Clear, plain language information, opportunities to ask questions and support before and after receiving results were considered essential for informed decision-making.

The value of blood testing depends on whether the information can be acted upon

Consumers saw value in blood tests if they could motivate lifestyle changes, support future planning or help identify opportunities for treatment as research progresses. At the same time, attendees questioned the usefulness of knowing their risk if there were no effective actions, treatments or clear explanation of what the results meant.

Practical, accessible research design encourages participation

Consumers felt travelling for research was acceptable for many people when participation was flexible, well communicated and supported through practical measures such as travel assistance or appointment options. Understanding how the research could benefit both individuals and future generations was seen as an important motivator for participation.

KEY THEMES OF THE COMMUNITY CONVERSATION

Theme	Consumer Comments
Knowledge and informed choice	• "The more information you can get about what's going on in your body, the better." • "Knowledge is power."
Planning for the future	• "I would rather know now and put things in place… right now I am constantly thinking about it." • "Knowing all of this, if we knew, what plans can we put into place as to how we are going to be looked after?" • "Importance of preparing your family and not letting fear stop that."
Clear communication and support	• "Should be in terms where anyone can understand it." • "DO NOT want a letter in the mail – I want to speak to someone." • "Definitely need support, before and after receiving the results."
Trust, privacy and personal control	• "The information should be used for us, not against us." • "We have to keep commercial interests away from this information." • "As long as we are treated as a number, not a name."
Knowledge should lead to action	• "If I knew there was an indicator in my blood it might give me the shove that I need to change." • "If there was a blood test that I could see changed my risk, I would do anything."
Making participation accessible	• "Send out the form and let them get it done when they want, give them the choice of time and place." • "Depends on the distance – about an hour is the threshold." • "Reimbursement would be welcomed."
Contributing to future research and the community	• "It's not just about us, it's about the community, if we found a cure for dementia this is really important for the community." • "They need to understand they are doing something for the future." • "Anything that helps the next generation."

COMMUNITY CONVERSATION QUESTIONS AND RESPONSES

ATTENDEE INSIGHTS

The following pages contain the responses and thoughts shared by attendees at the Community Conversation.

QUESTION 1

RESEARCHERS ARE EXPLORING WHETHER LIFESTYLE CHANGES, SUCH AS PHYSICAL ACTIVITY, HEALTHY EATING AND SOCIAL CONNECTION, COULD INFLUENCE BIOMARKERS LINKED TO ALZHEIMER'S DISEASE THAT CAN BE MEASURED THROUGH A BLOOD TEST.

WHAT ARE YOUR FIRST THOUGHTS ABOUT THIS RESEARCH, AND HOW IMPORTANT DO YOU THINK IT IS? WHY?

PROMPTS:

- Hopes and concerns
- Personal relevance / impact on family
- Potential benefits / risks
- Prevention
- Lifestyle changes
- Motivation for lifestyle change
- Usefulness of this information / what would you want to know?
- Trust in the results
- Privacy and use of information
- Access / equity issues

Consumers described a mix of hope, uncertainty and concern when discussing research into whether lifestyle behaviours could influence blood biomarkers linked to Alzheimer's disease. Many recognised the potential value of the research, particularly if it could help people better understand their risk, prepare for the future or motivate healthy lifestyle changes. At the same time, attendees questioned how useful this information would be in the absence of effective treatments or certainty about whether lifestyle changes could alter outcomes.

The discussion also highlighted that views about receiving information were highly personal. While some people felt knowing their risk would allow them to plan ahead and make informed choices, others felt the uncertainty could create unnecessary anxiety, particularly if there were limited options to prevent or treat the disease.

COMMUNITY CONVERSATION QUESTION 1 RESPONSES (CONT.)

The potential value of earlier knowledge and planning
A recurring message was that understanding a person's risk could help individuals prepare for the future. Consumers discussed planning for their own care, making decisions while they still had capacity, and reducing the burden on family members. Several attendees spoke about the importance of putting plans in place rather than avoiding the possibility of a future diagnosis.

Others described the emotional complexity of this knowledge. Some felt that knowing earlier would allow them to prepare, while others questioned whether learning about a possible risk many years in advance would simply increase worry without changing the outcome.

The usefulness of information depends on whether it can lead to action
Many attendees linked the value of the research to whether there were meaningful actions people could take. Several questioned how useful blood biomarkers would be if lifestyle changes ultimately made little difference or if effective treatments were not available. Conversely, others felt the research would become increasingly valuable if future medications or other interventions became available, allowing people to identify when they might benefit from treatment.

Lifestyle change as both motivation and uncertainty
Consumers discussed whether blood test information could encourage healthier behaviours. Some believed seeing evidence of increased risk could motivate people to improve their physical activity, diet or social connection.

However, attendees also recognised uncertainty around the relationship between lifestyle and Alzheimer's disease. Examples were shared of people who had lived healthy lifestyles but still developed dementia, leading some to question how much influence lifestyle behaviours have compared with other factors.

Balancing hope with the emotional impact of knowing
The discussion reflected differing views about whether people would want this information. Some attendees described living with ongoing concern because of a family history of Alzheimer's disease and felt that knowing more would help them regain a sense of control. Others preferred not to know, expressing concern that early knowledge could increase anxiety without providing certainty.

These differing perspectives highlighted that there was no single view about whether knowing one's potential risk would be beneficial.

COMMUNITY CONVERSATION QUESTION 1 RESPONSES (CONT.)

Trust, privacy and control of personal information

Consumers emphasised the importance of protecting personal health information. There were concerns about how blood test information could be accessed or used by commercial organisations, including insurers and pharmaceutical companies.

Several attendees stressed that personal health information should remain under the individual's control, with some expressing the view that people should decide if and when to share information with family members. Discussions also reflected that many supported contributing de-identified information to research where it could benefit future generations.

Monitoring over time and contributing to future research

Some attendees saw value in blood biomarkers as a way of monitoring changes over time, particularly if lifestyle changes or future treatments could influence results. Consumers described blood testing as a potential reference point that could help people track changes and make informed decisions about their health.

Alongside personal benefit, several attendees discussed the broader value of contributing to research that may improve understanding of Alzheimer's disease and support future generations.

Other thoughts

Additional discussion explored individual differences in Alzheimer's disease risk, including questions about why some people develop dementia despite healthy lifestyles and whether emerging technologies such as artificial intelligence may help explain these differences. Consumers also discussed advance care planning, family involvement in health decisions, and the importance of maintaining personal autonomy.

QUESTION 2

RESEARCHERS ARE CONSIDERING WHETHER PEOPLE WHO TAKE PART IN STUDIES LIKE THIS SHOULD BE OFFERED THE OPTION OF RECEIVING THEIR OWN BLOOD TEST RESULTS.

THESE RESULTS MAY COME MONTHS OR YEARS LATER AND MAY PROVIDE INFORMATION ABOUT BIOLOGICAL CHANGES ASSOCIATED WITH ALZHEIMER'S DISEASE RISK, BUT THEY CANNOT SAY FOR CERTAIN WHETHER SOMEONE WILL OR WILL NOT DEVELOP ALZHEIMER'S DISEASE OR DEMENTIA.

WHAT ARE YOUR THOUGHTS ABOUT OFFERING PEOPLE THIS CHOICE? IF RESEARCHERS OFFER THIS OPTION, WHAT WOULD THEY NEED TO DO TO HELP PEOPLE FEEL INFORMED AND SUPPORTED WHEN MAKING THAT DECISION?

PROMPTS:

- Benefits / concerns
- Information needed
- Explaining uncertainty
- Timing of results
- How results are shared
- Support before and after
- Impact on family
- Building trust

Consumers strongly supported giving people the choice to receive their individual blood test results. A consistent message across the discussion was that this decision should remain with the individual and be accompanied by clear information and appropriate support. While attendees acknowledged that the results could not predict whether someone would develop Alzheimer's disease or dementia, many still valued having access to information about their own health.

The discussion highlighted that the way results are communicated is just as important as the results themselves. Consumers emphasised the need for information that is easy to understand, opportunities to ask questions, and reassurance about how personal health information would be used.

Consumers wanted the choice to receive their results

The strongest message was that people should be able to decide whether they receive their individual blood test results. Many attendees felt they would personally want to know, describing health information as empowering and valuable even when uncertainty remained.

COMMUNITY CONVERSATION QUESTION 2 RESPONSES (CONT.)

At the same time, consumers recognised that not everyone would make the same decision. The discussion acknowledged that individuals differ in how much information they want to receive and that having a genuine choice was important.

Clear explanations are essential for informed decision-making
Consumers consistently emphasised the importance of receiving clear, plain language information before deciding whether to receive their results. They wanted to understand what the blood test measured, what the results could and could not tell them, and whether there were any actions they could take in response.

Several attendees questioned the value of receiving results if there was no explanation of what they meant or whether anything could be done about them. Information that enabled people to make an informed decision before participating in the research was seen as essential.

Results should be delivered with opportunities for discussion and support
A recurring theme was that results should be communicated personally rather than through a letter alone. Consumers wanted the opportunity to speak with someone who could explain the findings, answer questions and provide reassurance.

Attendees discussed several possible sources of support, including general practitioners, specialists, the research team and Alzheimer's support organisations. While views differed about who should provide this support, there was broad agreement that support should be available both before and after people received their results.

Uncertainty should be communicated openly
Consumers recognised that blood biomarkers cannot provide a diagnosis or predict with certainty whether someone will develop Alzheimer's disease. Many felt this uncertainty should be explained clearly so people understood the limitations of the results.
Some attendees also wanted results to include context, such as what would be considered a normal range or how their results compared over time, to help make the information more meaningful.

COMMUNITY CONVERSATION QUESTION 2 RESPONSES (CONT.)

Protecting privacy and maintaining trust

Trust in how personal information would be managed was another consistent theme. Consumers wanted reassurance that their results would remain confidential and would not be used by commercial organisations or in ways that could disadvantage them.

The discussion highlighted that confidence in how information would be stored, shared and protected would influence people's willingness to receive their results.

Ongoing access to information and follow-up

Consumers discussed the importance of being able to revisit information after receiving their results. Suggestions included having somewhere to access reliable information, opportunities to ask further questions, and the option of additional blood tests where appropriate.

Some attendees also questioned why results might take months or years to be returned and felt researchers should explain expected timeframes so people understood what to expect.

Other thoughts

Additional discussion explored whether blood testing should become more widely available through general practice and the challenges this may present, including GP knowledge, consultation time and the costs of specialist care. Consumers also reflected on the importance of receiving an accurate diagnosis and maintaining quality of life following a dementia diagnosis. While these issues provided valuable context, the dominant messages focused on ensuring people have a genuine choice, receive clear information, and are supported throughout the process of receiving their results.

QUESTION 3

AS PART OF THIS RESEARCH, PEOPLE MAY BE ASKED TO TRAVEL TWICE TO A LARGER TOWN, SUCH AS BUNBURY, FOR BLOOD TESTS.

HOW DO YOU THINK THIS WILL AFFECT WHETHER PEOPLE ARE WILLING TO TAKE PART? WHAT COULD RESEARCHERS PUT IN PLACE TO MAKE THIS EASIER, MORE ACCEPTABLE, OR MORE WORTHWHILE FOR PEOPLE?

PROMPTS:

- Distance from Bunbury
- Usual travel patterns
- Communities most affected
- Transport options
- Cost reimbursement
- Appointment timing
- Seasonal considerations
- Making it feel worthwhile
- Who might miss out?

Consumers generally felt that travelling to a larger regional centre twice for blood tests would be acceptable for many people, provided the travel requirements were reasonable and well communicated. However, attendees recognised that travel would not affect everyone equally. Distance, age, health, personal circumstances and where people lived were all seen as influencing whether participation was practical.

The discussion focused on making participation as flexible and accessible as possible. Consumers emphasised that practical arrangements, clear communication and helping people understand the purpose and value of the research would all contribute to participation.

Flexibility would make participation easier

A recurring message was that flexibility would reduce barriers to participation. Consumers suggested providing options around where and when blood tests could be completed, including allowing appointments over a broader time window or enabling tests to be completed closer to home where possible.

Attendees also felt it was important to explain from the outset what participation would involve, including the need to travel and why the blood tests could not necessarily be conducted at any pathology provider.

COMMUNITY CONVERSATION QUESTION 3 RESPONSES (CONT.)

Distance affects people differently
Consumers recognised that willingness to travel depended on individual circumstances rather than distance alone. While many felt travelling to a regional centre would not be a significant barrier, others suggested that travel beyond approximately one hour could become difficult.

The discussion highlighted that age, health, work commitments, seasonal conditions and weather could all influence people's ability to travel. Attendees noted that what was manageable for one person may not be practical for another.

Some groups may face greater barriers to participation
Several attendees identified communities who may experience additional challenges participating in this type of research. These included people living in remote areas, people with disability, Aboriginal people living in remote communities, people living in residential aged care, and some culturally diverse communities.

Consumers highlighted the importance of considering these groups during study planning to help ensure opportunities to participate were as inclusive as possible.

Practical support could reduce barriers
Consumers discussed a range of practical supports that could make participation easier. These included reimbursement for travel costs, carpooling, and making use of existing travel assistance programs where appropriate.

Some attendees also suggested outreach approaches, such as a travelling service, while others supported greater use of existing local pathology services if this was feasible.

Understanding the purpose and value of the research motivates participation
A strong theme throughout the discussion was that people were more likely to participate when they understood why the research mattered. Consumers wanted clear information about how the study would contribute to future knowledge, what outcomes researchers hoped to achieve, and how individual participation would make a difference.
Several attendees also felt it was important to be open about what was already known, what remained uncertain, and how the research fitted into the broader effort to better understand Alzheimer's disease.

COMMUNITY CONVERSATION QUESTION 3 RESPONSES (CONT.)

Personal benefit also influences willingness to participate
Alongside contributing to research, consumers discussed the personal value of participating. Some felt they would be motivated by receiving information about their own health, particularly if future blood tests could demonstrate changes in their personal risk or the impact of lifestyle changes.

Others reflected that learning more about dementia and connecting with people who had lived experience also made participation feel worthwhile.

Other thoughts
Additional discussion explored the importance of establishing a person's baseline health and recognising that lifestyle, diet and physical ability change over time. Consumers also reflected on individual differences in motivation to change behaviours later in life. While these ideas provided useful context, the dominant messages centred on reducing practical barriers, providing flexibility, and clearly communicating both the personal and broader value of participating in research.

EVENT SUMMARY

The CCIProgram facilitated a Micro Community Conversation at Donnybrook Library to explore community perspectives on emerging blood tests for Alzheimer's disease. Consumers discussed the potential role of lifestyle factors in influencing Alzheimer's disease biomarkers, whether people should be offered their individual blood test results, and what would make participation in future research more accessible.

The conversation highlighted strong support for informed choice, clear communication and appropriate support when sharing individual results. Consumers also emphasised the importance of protecting privacy, reducing barriers to participation and ensuring research is designed in partnership with the communities it aims to benefit.

WHAT'S NEXT FOR THIS PROJECT?

The findings from this Community Conversation will help inform the next stages of Dr Kelsey Sewell's research into Alzheimer's disease blood biomarkers and lifestyle interventions.

Consumer insights will support the development of research processes that are responsive to community priorities, including how information is communicated, whether individual results are shared, and how participation can be made more accessible for regional communities.

The project team will continue to involve consumers as the research progresses, using these insights to strengthen participant information, support informed decision-making and improve the overall research experience. This ongoing partnership will help ensure the research remains consumer-informed and reflects the needs and expectations of the communities it is intended to benefit.

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