Consumer and Community Involvement Program

WAHTN
Western Australian Health Translation Network

IMPROVING MENTAL HEALTH IN MULTIPLE SCLEROSIS

May 2026

COMMUNITY CONVERSATION SUMMARY REPORT

Prepared By

Assoc Prof Yvonne Learmonth
Emily Wood - PhD candidate
Assoc Prof Brook Galna
Prof Yasmine Probst
Karen Djumas - CCI Program
Caroline Jones - CCIProgram

Murdoch University

MS Research Australia — Advocacy Cure

UNSW Sydney

perron institute

CONTENTS

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.

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.

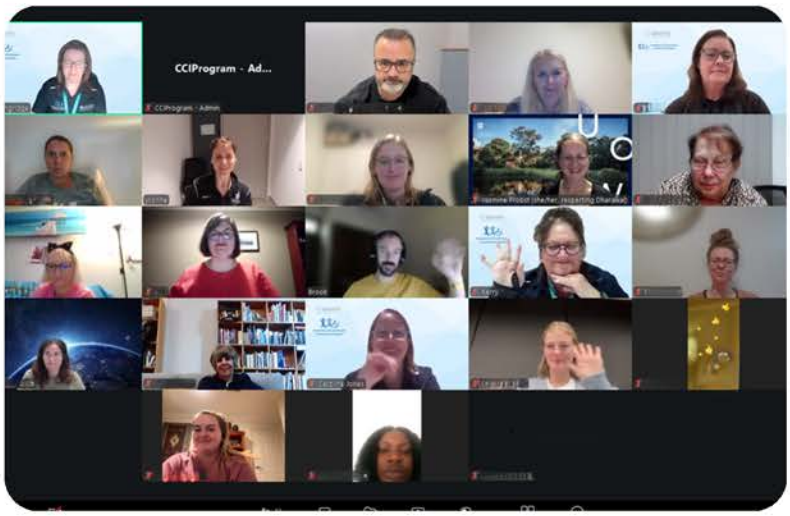
We extend our heartfelt gratitude to the consumers and community members who shared their lived experiences of Multiple Sclerosis.

BACKGROUND

Multiple sclerosis (MS) is a chronic neurological condition that affects every person differently and can have a significant impact on physical, emotional and social wellbeing. Alongside the physical symptoms of MS, anxiety is common, with around one in three Australians living with MS experiencing clinical anxiety. Anxiety can influence many aspects of daily life, including confidence, independence, participation in meaningful activities and overall quality of life.

Research shows that physical activity can improve both physical and mental wellbeing for many people living with MS. However, anxiety, fatigue, uncertainty about symptoms and concerns about exercising safely can make it difficult for people to start or maintain regular physical activity. While exercise is widely recommended as part of MS management, there is limited understanding of how existing programs can better support people who experience anxiety or reduce barriers to participation.

To help address this gap, researchers from Murdoch University and the University of New South Wales partnered with the Consumer and Community Involvement Program (CCIProgram) to seek guidance from people with lived experience before commencing a future research study. During the Community Conversation, attendees were invited to discuss an early concept for a 16-week home-based physical activity support program that would combine individually tailored activity, online support from physiotherapists, occupational therapists or exercise physiologists, regular video check-ins, simple activity tracking and motivational resources. Importantly, the discussion was not about evaluating a final program. Instead, researchers sought advice on whether the concept addressed the real-world needs of people living with MS and anxiety, and how it could be improved before the study design was finalised.



ABOUT THE RESEARCH TEAM

The project brings together researchers from Murdoch University, the University of Wollongong and the University of New South Wales with expertise in multiple sclerosis, neurological rehabilitation, exercise science, physiotherapy and implementation research. The team partnered with the Consumer and Community Involvement Program (CCIProgram) to ensure people with lived experience could contribute to shaping the research from an early stage.

The project is led by Associate Professor Yvonne Learmonth, a nationally recognised researcher with extensive experience working alongside people living with multiple sclerosis. Her research focuses on improving health, wellbeing and quality of life through evidence-based approaches that reflect the priorities and experiences of the MS community.

Emily Wood, a PhD candidate at Murdoch University, is undertaking doctoral research exploring walking-based activities for people living with MS and contributed to the development and delivery of the project. Associate Professor Brook Galna brings expertise in movement, physical activity and healthy ageing, with a research focus on understanding how movement can support health and wellbeing across neurological conditions. Professor Yasmine Probst contributed expertise in multiple sclerosis research and disability inclusion as a collaborator on the project.

The Community Conversation formed an important early stage of the research, providing the team with practical insights from people with lived experience before finalising the proposed study design.

Assoc Prof Yvonne Learmonth

Assoc Prof Brook Galna

Prof Yasmine Probst

PhD Candidate Emily Wood

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.

WAHTN
Western Australian Health Translation Network

Consumer and Community Involvement Program

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.

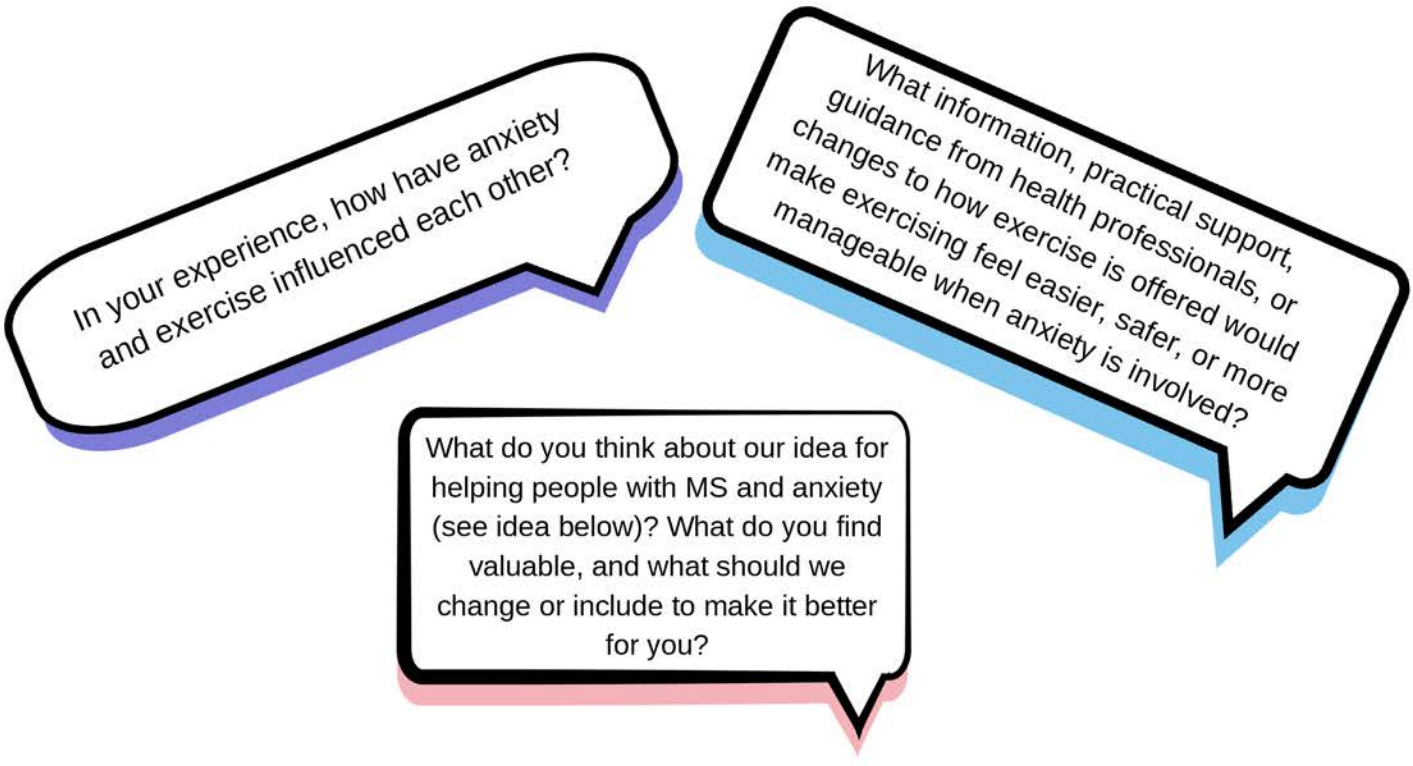
[1] Brown, J., & Isaacs, D. (2005). The World Cafe ́: Shaping our futures through conversations that matter. Barrett-Koehler
[2] Chieh-Ling Yang, Delphine Labbé, Brodie M. Sakakibara, Janneke Vissers & Marie-Louise Bird (2022) World Café- a community conversation: a Canadian perspective on stroke survivors 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 COMMUNITY CONVERSATION

The Community Conversation was held online on Wednesday 27 May 2026 and brought together 12 people from across Australia with lived experience relevant to the project. Attendees included people living with multiple sclerosis (MS) who experience anxiety, along with carers and health professionals who support people living with MS. Participants joined from Western Australia, New South Wales and Victoria, providing perspectives from a range of communities and health service settings.

The session began with an overview of the project and the research team's proposed study. Researchers shared an early concept for a 16-week home-based physical activity support program designed to improve mental health and wellbeing for people living with MS and anxiety. The proposed program included individually tailored physical activity supported by physiotherapists, occupational therapists or exercise physiologists, regular video check-ins, simple activity tracking, motivational resources and in-person assessments at the beginning and end of the program. The researchers emphasised that the concept was intended as a starting point for discussion and would be refined based on consumer feedback.

Attendees were invited to reflect on their own experiences of MS, anxiety and physical activity, discuss what they believed would make a program like this useful and achievable in everyday life, and identify opportunities to strengthen the proposed research before it progresses to the next stage.



PROMOTION

The Research Team worked closely with the CCIProgram to recruit members of the Australian community who had lived experience of Multiple Scelrosis (MS) and anxiety to hear their thoughts on exercising with anxiety and MS. We shared promotional communications across multiple channels.

Flyers and social media posts (Twitter, Facebook, Instagram and LinkedIn) were posted and circulated around relevant networks, including consumer and/or related health service provider networks and community groups.

AGENDA

Improving mental health in multiple sclerosis

Wednesday, 15 April 2026

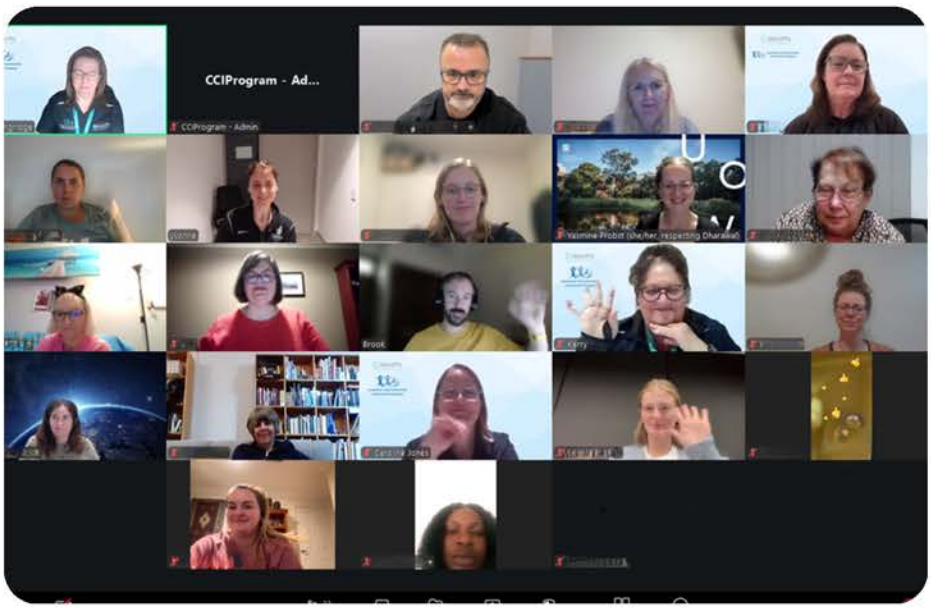
4pm - 6pm (AWST)/ 6pm to 8pm (AEDT)

Agenda

3.45pm	**Registrations**	**All**
4.00pm	**Welcome** • Acknowledgement of Country & Acknowledgement of Lived Experience • Welcome to the workshop • Introductions	**Deb Langridge**
4.10pm	**Presentation**	**Yvonne Learmonth**
4.20pm	**Process of the evening**	**Deb Langridge**
4.25pm	**Question 1**: In your experience, how have anxiety and exercise influenced each other?	**All**
4.45pm	**Question 2**: What information, practical support, guidance from health professionals, or changes to how exercise is offered would make exercising feel easier, safer, or more manageable when anxiety is involved?	**All**
5.00pm	**5 minute stretch break**	**All**
5.05pm	**Question 3**: What do you think about our idea for helping people with MS and anxiety? What do you find valuable, and what should we change or include to make it better for you?	**All**
5.20pm	**Question 4:** Is there anything important we haven't asked about today that you think we should know? How would you like to be involved from here, and how can we share results in ways that are most useful to you?	**All**
5.35pm	**Table facilitator feedback**	**Table facilitators**
5.50pm	**Next Steps**	**All**
5.55pm	**Evaluation & Honorarium information**	**All**
6.00pm	**Close**	

STRUCTURE AND PROCESS

Attendees joined the Community Conversation online, where they were welcomed by the Consumer and Community Involvement Program (CCIProgram) facilitation team and introduced to the research team and the purpose of the project. Following this introduction, attendees were allocated to one of three facilitated breakout rooms.



Each breakout room was led by a trained CCIProgram facilitator, whose role was to guide the discussion, encourage all attendees to contribute and ensure everyone had an opportunity to share their experiences and perspectives. A member of the research team was also present in each room as a scribe, recording attendees' comments, ideas and suggestions throughout the discussions.

Facilitators guided attendees through four discussion questions with approximately 15 minutes was allocated to each discussion question, providing attendees with time to reflect on their own experiences while also building on the ideas shared by others. This approach encouraged rich discussion and the exploration of diverse perspectives.

Feedback from each breakout room was captured by the research team scribes and subsequently collated and analysed by the CCIProgram. The themes, insights and consumer comments presented throughout this report reflect the collective views and experiences shared during these facilitated discussions.

KEY INSIGHTS OF THE COMMUNITY CONVERSATION

Anxiety and exercise have a complex, two-way relationship.

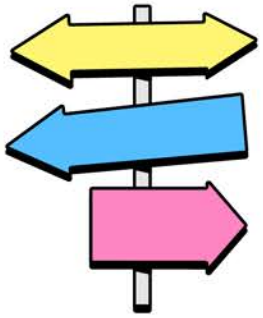
People with lived experience described exercise as beneficial for anxiety, mood, confidence and overall wellbeing. However, anxiety also made exercise harder, particularly when consumers were worried about falling, fatigue, symptom flare ups, heat sensitivity, being judged, or not knowing how their body would respond. The relationship was not always direct, with broader life stresses, medical appointments, caring responsibilities, concerns about potential impact to National Disability Insurance Scheme (NDIS) funding support and uncertainty about MS also influencing whether exercise felt possible.

Exercise support needs to be personalised, flexible and responsive to changing symptoms.

Consumers repeatedly emphasised that MS affects people differently and can change quickly. Generic programs, fixed expectations or “one size fits all” approaches were seen as less useful and potentially anxiety-provoking. Flexibility to modify, pause, restart, reduce intensity or do “whatever you can” was considered essential, particularly across a 16-week program where relapse, fatigue or other health changes may occur.

Trust, human connection and MS-knowledgeable support are central to reducing anxiety.

Attendees valued health professionals who understood MS, built rapport, listened, adjusted programs and involved them in decisions. Several consumers described the anxiety of having to explain MS, symptoms and limitations to professionals who did not understand their experience. Peer support, family or carer involvement and exercising with others were also seen as potentially motivating, provided they remained optional and matched individual preferences.



Real-life barriers will shape whether a program is feasible.

Cost, time, transport, technology required for online, access to suitable spaces, equipment needs and competing responsibilities were all raised as factors that would influence participation. Home-based and telehealth options were appealing for many, particularly those who do not drive, live regionally or experience fatigue and anxiety with travel. However, some consumers found leaving the house more motivating, highlighting the need for choice rather than a single delivery model.

KEY THEMES OF THE COMMUNITY CONVERSATION

Theme	Consumer Comments
Exercise can improve anxiety, mood and wellbeing	• "Always feel better when I go, even when I don't feel physically great." • "I feel like I've had a dose of medication." • "Feel totally carefree when leaving studio, on a high, all worries are gone."
Anxiety can stop people from exercising	• "Fear of it [exercise] that can stop me from doing it." • "I'm able to do it [exercise] in the moment and push it. But sometimes I don't know how, and the response is I don't do it [exercise] at all."
MS is unpredictable and exercise needs can change	• "The relationship [between anxiety and exercise] isn't always direct." • "The uncertainty of MS is always there." • "flexibility is required, if a relapse happens, you never know what's coming."
Programs need to be individualised and flexible	• "Needs to be individualised, what's safe for us, and manageable." • "Make it flexible, be individual for each person." • "Doing whatever you can, even if it's nothing, that's okay and part of the plan."
Trust and human connection matter	• "If I know they care about me as me, it goes a long way and eases anxiety." • "It is their personal connection that keeps me there." • "No app will fix it."
MS, loss and isolation	• "MS a disease of incremental loss." • "Feel like I'm slowly disappearing from life." • "Hard to walk in our shoes with some of the things we face."
MS-knowledgeable support is important	• "My MS and my anxiety is worse if I have to explain to them what I'm talking about." • "Would want to know their [coaches] experience with MS." • "Positive that there are therapists that understand what they are doing and understand MS."

KEY THEMES OF THE COMMUNITY CONVERSATION

Theme	Consumer Comments
Practical access barriers affect participation	• "I don't drive, it's hard to get places." • "I have difficulty getting into/out of a car, the world isn't disability friendly." • "In all honesty - first thought cost, who pays, is it free, does it affect my NDIS?"
Home-based and telehealth options are useful but not enough on their own	• "The home-based aspect is probably one of the strongest parts of the idea." • "I like the convenience of it being at home, but I think my husband would worry I won't remember the right technique." • "I would require a paper pictorial or similar to guide correct movements."
Peer, family and carer support can motivate engagement	• "Peer support is invaluable." • "Would be great to have a peer group option, not good for everyone but for some could be really motivating." • "Family member, relative or carer to do it with you."
Information, navigation and follow-up are needed	• "I don't know what I don't know." • "How can we get this information, find out about this?" • "Education for neuros to make referrals to these sorts of [exercise designed for people with MS and anxiety] programs at diagnosis rather than waiting until function declines."
Research needs to lead somewhere	• "A lot of research is done, but doesn't necessarily follow-through. It would be nice if this is progressing." • "Will it be implemented and at what stage?" • "Answers [that anxiety can be improved through exercise for people with MS] need to really matter."
Ongoing involvement should be built in	• "I'd like to give my opinion on how the programme will be delivered, and the process." • "And I'm a big advocate for paying people with lived experience for their time with longer engagements." • "[Have] lived experience co-investigator/s."

COMMUNITY CONVERSATION QUESTIONS AND RESPONSES

ATTENDEE INSIGHTS

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

QUESTION 1

IN YOUR EXPERIENCE, HOW HAVE ANXIETY AND EXERCISE INFLUENCED EACH OTHER?

> ***I always feel better when I go [gym], even when I don't feel physically great or am anxious.***

People with lived experience described a complex and often bidirectional relationship between anxiety and exercise. Experiences varied depending on symptoms, life circumstances and stage of disease. While anxiety was frequently described as a barrier to exercise, many attendees also spoke about the significant benefits exercise provided for their mental wellbeing, confidence and ability to manage symptoms. Attendees highlighted that this relationship changed over time and was influenced by factors including fatigue, fear of symptom worsening, environment, social support and finding forms of movement that were enjoyable and sustainable.

Anxiety can be a barrier to exercise

Attendees described that anxiety may be a barrier to exercise. Anxiety related to fear of falling, uncertainty about fatigue and symptom flares, overdoing exercise, lack of confidence, being judged by others, standing out in group settings, and unpredictability associated with MS. Some attendees described avoiding exercise altogether when unsure how their body would respond. Others spoke about competing life pressures, caring responsibilities and other medical concerns taking priority over exercise.

Some consumers described anxiety around exercising incorrectly and concerns about whether exercise advice was appropriate. One attendee reported previous experiences with MS physiotherapists who they felt lacked knowledge, which increased both anxiety and fatigue. Another reflected that "fear of it can stop me from doing it".

QUESTION 1 (Continued)

Exercise was widely described as beneficial for anxiety and mood

Exercise was widely described as having a positive impact on anxiety, mood and emotional wellbeing. Some consumers described feeling "sorted for the week", "carefree" and "on a high", while another remarked that exercising felt like "having a dose of medication". Several attendees reported that exercise reduced anxiety in other areas of their life and helped them manage emotions. Some noted that when they stopped exercising, anxiety and low mood increased.

The relationship between anxiety and exercise was complex and changed over time.

Consumers explained that the relationship between anxiety and exercise was not always direct, with one attendee observing that "the relationship isn't always direct". Anxiety could arise from other aspects of life, such as medical appointments, household responsibilities, caring roles or decision making, and this could affect motivation or ability to exercise. Several attendees noted that priorities changed over time, with exercise becoming more important following relapses or changes in mobility. Others described learning to change their mindset, avoid pushing too hard and accept that their exercise needs changed over time.

Fear of fatigue and symptom worsening influenced exercise decisions

Many consumers described anxiety about doing too much and triggering fatigue or worsening symptoms. Uncertainty and difficulty finding the right balance, particularly on bad days or during periods of increased symptoms, were common themes. Some described fear about how they would feel later in the day or the following day. Heat sensitivity was also raised as affecting exercise choices.

Enjoyment and meaningful activities supported ongoing exercise

Attendees described the importance of doing activities they enjoyed rather than following prescribed exercises indefinitely. Pilates, yoga, dance and other enjoyable forms of movement were discussed. Several attendees stated that if they enjoyed an activity it was easier to maintain, and that exercise had become a hobby or an important part of their routine. One attendee reflected that "it's a privilege to move". Building consistency and making exercise a habit were also raised.

Environment and social support influenced anxiety and confidence

Consumers described how settings and support influenced their anxiety and confidence. Some preferred smaller groups or specialised environments such as small group instructor led classes e.g., pilates, while others found gyms intimidating or difficult to access. Concerns about being judged or standing out were raised. Attendees valued exercising with knowledgeable professionals and supportive people. Several noted that being around others who understood MS, or exercising in supportive environments, increased confidence and reduced anxiety. Some carers highlighted the need for better understanding of MS among exercise professionals and more accessible local exercise options.

Learning pacing and self-management reduced anxiety

Consumers described developing strategies over time to manage anxiety around exercise. These included pacing activities, seeking advice from physiotherapists or exercise physiologists, deep breathing, mindfulness, journalling and talking with trusted people. Several attendees noted that they had learned not to push themselves as hard and that understanding their own limits improved confidence and reduced anxiety.

QUESTION 2

WHAT INFORMATION, PRACTICAL SUPPORT, GUIDANCE FROM HEALTH PROFESSIONALS, OR CHANGES TO HOW EXERCISE IS OFFERED WOULD MAKE EXERCISING FEEL EASIER, SAFER, OR MORE MANAGEABLE WHEN ANXIETY IS INVOLVED?

People with lived experience emphasised that making exercise easier was less about a particular program or technology and more about having exercise that was individualised, adaptable and delivered by knowledgeable and supportive health professionals. Consumers highlighted the importance of trust, human connection, clear information and feeling involved in decisions. Practical considerations, financial barriers and the need for flexibility were also raised.

Individualised and tailored approaches were strongly valued

Consumers consistently emphasised that exercise programs should be individualised, meaningful and based on a person's capabilities, interests and goals. Many highlighted that everyone experiences MS differently and that "one size fits all" approaches could increase anxiety.
Several attendees described wanting programs that considered what they enjoyed doing, their physical abilities and how exercise could fit into everyday life. One carer noted that generic exercise sheets felt like a "set and forget" approach and were not motivating. Others highlighted the importance of graded programs that evolve over time and are linked to real-world activities.

Human connection and trust were viewed as more important than technology

Many attendees spoke about the importance of relationships with health professionals. Trust in physiotherapists and exercise physiologists was considered important, but several consumers explained that it was the personal connection that kept them engaged. One attendee reflected that "it is their personal connection that keeps me there" and that "no app will fix it".

> ***If I know they care about me as me, it goes a long way and eases anxiety.***

Consumers valued feeling known as an individual and appreciated health professionals who built rapport, celebrated small gains and involved them in decisions rather than simply providing instructions. Visible agreement and head nodding from other attendees reinforced the importance of these relationships.

Support with fatigue, flare-ups and pacing was important

Consumers described the importance of ongoing adjustment and pacing when managing fatigue, pain and symptom fluctuations. Several highlighted the need for health professionals to understand these changes and provide reassurance that modifying activities was acceptable.
Planning ahead, monitoring symptoms, reducing activity early and having personalised safety plans were identified as strategies that made exercise feel more manageable. One attendee reflected on the importance of "being honest with yourself and the plan", while another noted the tendency to want to "[I'll] show you, MS" and push beyond what was sustainable.

QUESTION 2 (Continued)

Knowledgeable and understanding health professionals increased confidence

Consumers highlighted the importance of health professionals understanding MS and having the skills to adapt exercise safely. Some preferred one-to-one sessions because they felt safer and trusted that knowledgeable clinicians would know how to manage falls or adjust exercises appropriately.
Several attendees emphasised that health professionals needed to explain the relationship between symptoms, fatigue and exercise, and provide reassurance when modifications were needed.
Positive feedback and regular follow-up were seen as important for maintaining confidence and reducing anxiety.
Some consumers expressed frustration with approaches they perceived as patronising, with broad agreement among attendees that communication should be respectful and collaborative.

Clear information and flexibility reduced anxiety

Consumers described wanting practical information upfront, including whether exercise was safe, whether modifications were needed, how exercise should be approached during relapses and how fatigue would be managed. Several attendees noted that uncertainty increased anxiety.
Attendees valued knowing that exercise plans could be modified and that stopping, slowing down or adjusting activities did not represent failure. One consumer explained that "doing whatever you can, even if it's nothing, that's okay and part of the plan".
Quiet environments, flexibility within sessions and clear expectations were also identified as important.

Social connection and feeling safe influenced participation

Several attendees valued opportunities to connect with others and described exercise as one of the few opportunities to leave the house and interact socially. Others highlighted the importance of exercising with people who understood their capabilities and limitations.
At the same time, some consumers found it confronting to exercise alongside people who were more severely affected by MS, while others preferred not to disclose their diagnosis or be treated differently. Small groups and supportive environments were generally preferred.

Cost and access to support were barriers for some consumers

Some attendees described limited access to [financial or personal] support, particularly for those who were not eligible for NDIS funding and did not have the financial means to access fee-for-service supports. **Consumers highlighted the value of group activities and accessible services that could provide support [financial or personal] before their condition progressed further.**

QUESTION 3

THINKING ABOUT THIS PROPOSED EXERCISE SUPPORT IDEA (SEE BELOW), WHICH ASPECTS FEEL USEFUL OR REALISTIC, WHICH PARTS MAY NOT WORK FOR YOU, AND WHAT WOULD NEED TO CHANGE TO FOR IT TO WORK IN REAL LIFE?

People with lived experience viewed the proposed exercise support program positively and considered it realistic, provided it was flexible, personalised and delivered by health professionals with MS knowledge. Consumers highlighted the importance of fitting the program into everyday life and ensuring that participation did not create additional stress or anxiety. Practical considerations including cost, accessibility, technology, peer support and the ability to pause and restart were identified as important factors that would influence participation.

Flexibility and individualisation were considered essential

Consumers consistently emphasised that flexibility would be critical, particularly for a program extending over 16 weeks. Several attendees highlighted that symptom fluctuations and relapses are unpredictable, making it important that participants could pause and re-engage without feeling they had failed. A carer noted that without flexibility for stopping and starting, participation would be difficult. Many described the importance of programs being individualised and adaptable to each person's needs. Several attendees commented that flexibility would help reduce anxiety and support ongoing engagement.

QUESTION 3 (Continued)

The program needed to fit into everyday life

Consumers highlighted that practical considerations would influence whether the program was realistic. Time, competing responsibilities and how exercise would fit into existing routines were commonly discussed. Some questioned whether adding another commitment would create stress rather than reduce it.
Several attendees described wanting flexibility around scheduling, while others noted that two 30-minute sessions per week felt manageable. Structured programs that provided a clear pathway and enabled consumers to mentally plan ahead were viewed positively.

Cost and funding concerns influenced acceptability

For some consumers, cost was the first consideration. Questions were raised about who would pay for the program, whether there was a risk that participation in the program could jeopardise their access to NDIS supports. Concerns about affordability and access to supports outside the NDIS were also raised.
One attendee referred to the "sinister reality" of funding uncertainty and another described concern after seeing a friend lose supports. Several consumers reflected that broader life stresses and anxieties would influence whether they could engage with the program.

Home-based and online delivery were viewed positively

Many attendees viewed home-based and telehealth delivery favourably because they reduced travel, preparation and accessibility barriers. This was considered particularly important for people living in regional areas, those unable to drive and those who experienced difficulties with transport or accessing venues.
Some consumers appreciated the convenience of exercising at home, while others noted that leaving the house was motivating and provided an opportunity for social connection. In-person sessions were still preferred by some attendees, particularly those who found exercising outside the home more motivating.
Technology-related barriers were also identified, with concerns raised about screen positioning during video sessions and telehealth being anxiety-inducing for some people.

Peer support and shared experiences were viewed positively

Many consumers saw value in peer support, with some suggesting peer groups, joint sessions or opportunities to connect with others participating in the program. Peer support was described as "invaluable", with broad agreement from others.
At the same time, consumers noted that peer support should remain optional, recognising that different people would prefer different levels of connection.

QUESTION 3 (Continued)

MS knowledge and continuity with existing supports were important

Consumers valued the inclusion of health professionals with experience and understanding of MS. Several attendees explained that having to repeatedly explain their symptoms increased anxiety and wanted confidence that coaches or therapists understood the condition.
Many also highlighted the importance of connecting the program with existing supports. Some expressed a preference for involving their own exercise physiologist or other health professionals who already knew their capabilities and needs.

> ***My MS and my anxiety is worse if I have to explain to them what I'm talking about.***

Practical supports would make participation easier

Attendees identified several practical supports that would improve participation. These included reminders, support with setting up technology, information about equipment requirements, paper-based resources, pictorial exercise guides and apps that could record activities and bring information together in one place. One attendee remarked that "one app that does everything would be bloody amazing". Others however noted that an app wouldn't replace, or be as supportive, as human interaction with a health care provider.
Consumers also valued accountability and support during exercise sessions. Some preferred exercising alongside another person, while others felt they would benefit from having someone present virtually to exercise with them.

Ongoing feedback and monitoring were valued

Consumers highlighted the value of check-ins and opportunities to monitor progress. Several attendees liked the idea of recording activities and being able to review what they had achieved over time. Video support was viewed positively because it provided reassurance, helped maintain motivation and enabled exercises to be adjusted in response to changing symptoms.
Questions were also raised about what would happen after the program finished, with some attendees expressing interest in ongoing support or peer connections beyond the formal program.

QUESTION 4

IS THERE ANYTHING IMPORTANT WE HAVEN'T ASKED ABOUT TODAY THAT YOU THINK WE SHOULD KNOW?

HOW WOULD YOU LIKE TO BE INVOLVED FROM HERE, AND HOW CAN WE SHARE RESULTS IN WAYS THAT ARE MOST USEFUL TO YOU?

People with lived experience highlighted a range of broader considerations beyond the proposed intervention itself. Consumers emphasised the importance of understanding the changing nature of MS, maintaining feedback loops with the research team and ensuring that research leads to meaningful outcomes. Attendees expressed strong interest in ongoing involvement, clear communication and ensuring information and support reached people at different stages of their MS journey.

MS changes over time and affects more than physical function

Consumers highlighted that MS is progressive and unpredictable, and that it can be hard to predict having stable health over a long period of time. Several attendees noted that an exercise program of 16 weeks could be a long time when symptoms and circumstances can change rapidly. Other medical conditions and health concerns were also identified as factors that could affect participation and exercise.

One attendee reflected on the impact of isolation and loneliness, describing how MS can lead to feeling less connected to social activities and experiencing a gradual loss of confidence and stamina. They shared that they felt "like I'm slowly disappearing from life", which affected both mental wellbeing and motivation to do things that would be beneficial physically.

Access to information and "navigation" support were important

Consumers highlighted the importance of knowing what services and supports are available, particularly following diagnosis. Some attendees described not having a health team or being unsure how to access information and support. Others emphasised the importance of referrals occurring earlier and ensuring information reached people before significant declines in function. Several consumers described the value of someone to help navigate the different services [a navigator role] to help people understand and access services.

One attendee remarked, "I don't know what I don't know", while another described the benefits of a health care system navigator who helped connect people with available supports.

> ***I don't know what I don't know.***

QUESTION 4 (Continued)

MS, loss and uncertainty influence participation

Several consumers reflected that anxiety associated with finances, NDIS reviews and concerns about incremental losses associated with MS can influence participation, regardless of the quality of a program. One attendee described MS as "a disease of incremental loss", while others highlighted that life priorities and competing demands could affect whether exercise remained a focus. Consumers also noted that even well-designed programs still require people to prioritise participation within the context of their broader lives.

Consumers wanted greater clarity about the research

Attendees expressed interest in understanding the purpose of the research and how outcomes would be measured. Several questioned whether the focus was on exercise, anxiety, motivation or something broader, noting that the benefits of exercise for mental health were already widely understood. Consumers emphasised that answers needed to matter and wanted to understand how the research would contribute to improving care and support.

There was strong interest in ongoing involvement and co-design

Consumers expressed strong interest in remaining involved throughout the research process. Many attendees wanted opportunities to provide feedback on program delivery, future stages of the study and implementation. Interest in co-design was widespread, with attendees supporting the involvement of people with lived experience on committees and throughout the project.
Flexibility in opportunities for involvement was considered important, with suggestions including surveys, advisory groups and providing feedback at different stages. One attendee highlighted the importance of paying people with lived experience for their time during longer-term engagement.

Feedback loops and plain language communication were highly valued

Consumers wanted research findings and updates to be shared in simple and accessible ways. Written information, emails and concise summaries were preferred, with attendees emphasising the importance of plain language. Several described wanting information they could read, pause and revisit later.
There was strong support for ongoing communication, including updates about future stages of the project and clear information if the project was not progressing. Consumers wanted to know that research would lead to action rather than ending without follow-through.Attendees indicated that the terms "exercise" and "anxiety" were generally acceptable. However, some consumers noted that terminology should be checked with individuals during the program and adjusted where needed. Clear explanations and plain language were considered important to support understanding.

Families, clinicians and organisations should be involved

Consumers highlighted that information should reach not only people with MS, but also carers, family members and clinicians. Neurologists were seen as important stakeholders and several attendees felt their neurologist should know when they were participating in research and have access to information about the project.
Consumers also suggested involving organisations and networks that could help disseminate information more broadly. Some attendees noted that the approach may also be relevant for people with other neurological conditions.

EVENT SUMMARY

The Community Conversation provided the research team with valuable insights into the experiences of people living with MS and anxiety, and the factors that influence participation in physical activity. Attendees shared practical suggestions to strengthen the proposed research, highlighting the importance of flexibility, personalised support and recognising the realities of living with MS.

The research team valued the opportunity to hear directly from people with lived experience at an early stage of the project. The discussion reinforced the importance of consumer involvement in shaping research that is relevant, acceptable and responsive to the needs of the MS community.

WHAT'S NEXT FOR THIS PROJECT?

The insights and recommendations captured through this Community Conversation will be used to refine the proposed research and the design of the planned 16-week support program.

Once funding is secured, the research team will continue to work with people with lived experience as the project develops, ensuring consumer perspectives remain central to the design, delivery and translation of the research.

Contact us

Phone :
+61 8 6151 1071

Address :
6 Verdun St
Nedlands WA 6009

Website :
www.cciprogram.org

Follow us on social media

@cciprogram

@cciprogram

@CCI_Program

Consumer and Community Involvement Program

WAHTN
Western Australian Health Translation Network

Consumer and Community Involvement Program