Consumer and Community Involvement Program

WAHTN
Western Australian Health Translation Network

THE DEVELOPMENT OF PERSONALISED MEDICINES FOR RARE GENETIC CONDITIONS

Community Conversation

SUMMARY REPORT

April 2025

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Personalised Medicine Centre

Murdoch University | perron institute

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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.

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 rare genetic conditions.

We also thank the research team from the Molecular Therapy Laboratory at Murdoch University, for their commitment to involving consumers in shaping the future of personalised medicines for rare genetic conditions.

BACKGROUND

Rare genetic diseases affect fewer than five in 10,000 people, yet collectively they represent a significant health challenge. These conditions are typically caused by errors in the genetic code, disrupting the production of essential proteins and leading to severe and often life-limiting symptoms. Historically, treatment has been limited to managing symptoms rather than addressing the underlying cause, leaving families with few options and uncertain futures.

In recent years, however, advances in molecular therapy and personalised medicine have transformed the landscape. By targeting the smallest building blocks of the body, genes and proteins, new treatments can address the root cause of disease. This shift away from a one-size-fits-all approach has already produced life-altering therapies for some conditions, offering improved quality of life and, in some cases, slowing disease progression.

At the forefront of this work in Western Australia is the **Molecular Therapy Laboratory, part of the Personalised Medicine Centre at Murdoch University.** The team, led by leading researchers in the field, is developing and testing therapies designed to correct genetic errors and restore function. Their work has already contributed to approved treatments that have changed lives, and ongoing research aims to expand these breakthroughs to more rare conditions, bringing hope to individuals and families across Australia and beyond.

THE RESEARCH TEAM

Dr Jessica Cale

Dr Jessica Cale is a Research Fellow at the Molecular Therapy Laboratory, where she undertakes innovative work in genetic medicine. Jessica earned her PhD from Murdoch University in 2021, with a focus on antisense therapies for Marfan syndrome, a rare and complex connective tissue disorder. Jessica has provided her expertise in several industry-funded, commercial-in-confidence research projects, advancing antisense technologies for healthy aging and cancer applications. Jessica's current research focuses on developing disease models and therapeutic strategies for children affected by rare genetic conditions, with the goal of bringing treatments to those who currently have none.

Dr May Aung-Htut

Dr Aung-Htut is the Co-Head of the Molecular Therapy Laboratory. A PhD graduate from the University of New South Wales, May previously held postdoctoral positions at the UNSW and University of South Australia working on cellular aging and transcriptional regulation of programmed cell death. Her current research focuses on therapeutic antisense oligonucleotides for various diseases, including multiple sclerosis, congenital muscular dystrophy and Pompe's disease. Her ultimate goal is to extend this research to other diseases, including rare inherited diseases and cardiovascular disease.

Dr Kelly Martinovich

Dr Martinovich is a Research Fellow at the Molecular Therapy Laboratory. Kelly completed her PhD in 2021 at the University of Western Australia investigating oligo based therapeutics for people with rare Cystic Fibrosis variants. As a highly skilled Lab-based researcher, she has advanced the understanding of many cell and molecular biology methodologies, contributing to novel discoveries in Airway Diseases, Infectious Diseases, Cardiovascular Diseases and oligo-based therapeutics. She is focused on developing novel therapeutics and bridging the gap between academia and industry.

Thankyou to our Research Team Scribes:

Dr Karina Yui Eto, Kristin Ham and Isabella Trew for their assistance in scribing the conversation with the attending community members.

THE CONSUMER AND COMMUNITY INVOLVEMENT PROGRAM

Established as part of the Western Australian Health Translation Network (WAHTN), the Consumer and Community Involvement Program (CCIProgram) is dedicated to embedding the voices of consumers and community in health research. The Program works to ensure that research is shaped and informed 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.

Top Row Left to Right: Anna Gee, Donelle Toussaint, Caroline Jones, Kerry Mace
Bottom Row Left to Right: Briony Abraham, Deb Langridge, Ingrid Laing

WHAT IS A COMMUNITY CONVERSATION?

A Community Conversation is an event using an abridged version of the World 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

While scientific progress is accelerating, the lived experience of people with rare genetic diseases remains complex and deeply challenging. Families often face delays in diagnosis, limited therapies, and fragmented care. These experiences shape daily life, affecting education, employment, and social participation. Beyond the clinical aspects, rare conditions affect education, employment, and social participation, shaping every part of daily life. These realities must be understood and addressed if research is to be truly meaningful.

The Community Conversation provides an opportunity for consumers, families, and supporters to share their perspectives directly with researchers and clinicians. Their insights will guide the priorities of the Molecular Therapy Laboratory, ensuring that future therapies, trials, and support systems are grounded in the needs of those most affected. By placing lived experience alongside scientific expertise, the discussion will help shape research pathways that are equitable, responsive, and capable of delivering real-world impact.

PROMOTION

The Personalised Medicine Centre Research Team partnered with the WAHTN Consumer and Community Involvement Program (CCIProgram) to recruit members of the Australian community with lived experience of disease and family health history. The aim was to ensure that diverse consumer perspectives were included in discussions about precision health and personalised medicine.

Recruitment was supported through targeted communications across multiple channels. Flyers and social media posts (Twitter, Facebook, Instagram, and LinkedIn) were developed and shared widely through relevant networks, including consumer organisations, health service providers, and community groups. Rare Voices Australia supported the promotion, helping to extend the reach and engagement with the rare disease community.

The development of personalised medicines for rare genetic conditions - Community Conversation

Wednesday 9 April 2025 – 6 to 8pm
Murdoch University (Boola Katitjin 360.4.031)

Agenda

5.00pm	**Tour of The Molecular Therapy Laboratory**	
5.45pm	**Registrations & Refreshments**	**All**
6.00pm	**Welcome** • Acknowledgement of Country & Acknowledgement of Lived Experience • Welcome to the Community Conversation • Introductions	**Caroline Jones**
6.10pm	**Presentation**	**Dr Jessica Cale**
6.20pm	**Process of the evening**	**Caroline Jones**
6.25pm	**Question 1:** When you (or the person you care for) were diagnosed with a genetic condition, where did you seek information about the condition and how could this information have been more accessible and available to you?	**All**
6.50pm	**Question 2:** Do you feel adequately informed of all available treatments for the diagnosed condition?	**All**
7.10pm	**Question 3:** What would you need to make an informed decision about being involved in the development of a personalised medicine specifically for you?	**All**
7.30pm	**Table facilitator feedback**	**Table facilitators**
7.45pm	**Next Steps and opportunities for involvement**	**Caroline, May and Jessica**
7.55pm	**Evaluation**	**All**
8.00pm	**Close**	**All**

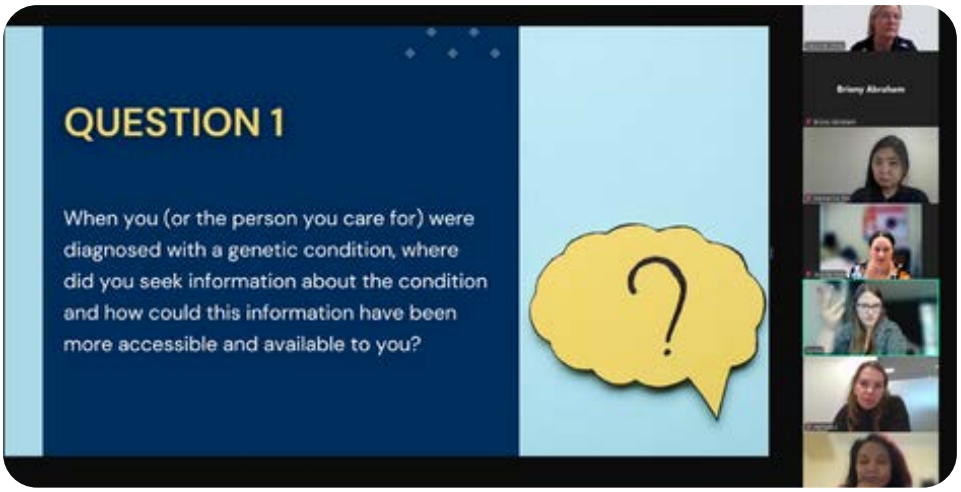
STRUCTURE AND PROCESS

Held at Murdoch University, the event began with the option of an earlier start for attendees interested in a guided tour of the laboratory facilities, led by one of the key researchers, Dr Jessica Cale. Following the tours and the arrival of all attendees, the session formally commenced with a welcome and Acknowledgement of Country delivered by Caroline Jones, CCI Coordinator with the CCIProgram. An overview of the session agenda was then provided to orient attendees.

Dr Cale provided background on personalised medicines, explaining how molecular therapies target genetic errors at the root cause of disease rather than just managing symptoms. Using simple illustrations, she showed how small genetic changes disrupt protein production and highlighted examples of approved therapies that have already transformed the lives of people with rare conditions. This overview helped establish a shared understanding for the group discussions.

Participants were then divided into two breakout tables, each facilitated by a CCIProgram CCI Coordinator and supported by a Murdoch University scribe to capture feedback. Facilitators posed three questions in total, with 20 minutes allocated to each, and all comments, feedback, and suggestions were recorded and are presented in the following pages of this report.

In recognition of interest from individuals unable to attend in person, a follow-up online session was also offered. Two additional consumer perspectives were gathered in this format, responding to the same three discussion questions, and these insights have been integrated into the findings of this report.



KEY INSIGHTS OF THE COMMUNITY CONVERSATION

Information gaps undermine trust and increase patient burden

Participants consistently described being left without adequate, reliable information at diagnosis and throughout their journey. They were forced to turn to Google, social media, and international sources to understand their condition and available treatments. This lack of guidance from clinicians created mistrust and emotional distress, leaving families to become “their own researchers.” Researchers must prioritise translating their findings into plain language, accessible resources, and clinical guidance to reduce this burden.

Continuity of care and equitable access remain major system failures

Consumers highlighted a critical breakdown in the transition from paediatric to adult services, leaving patients unsupported and “falling through the cracks.” Access to trials and treatments in Western Australia was described as limited, with Australia often lagging behind international progress. Equity concerns were raised around age, geography, and socioeconomic status. Research programs should therefore integrate system-level solutions that address these barriers ensuring innovations in personalised medicine do not deepen existing inequalities.

Informed decision-making requires transparency, support, and consumer partnership

Participants emphasised the need for clear, honest information on risks, side effects, expected outcomes, costs, and long-term availability of therapies. They called for researchers to meet patients, demonstrate knowledge of their condition, and co-design materials that could also inform GPs and pharmacists. Strong support systems, including mental health care and on-call networks, were seen as essential for safe trial participation. Researchers must embed consumer voices early and maintain transparency to build trust and enable meaningful decision-making.

Personalised medicine is seen as both inclusive and holistic — not just genetic

The term personalised medicine resonated powerfully with attendees, making them feel recognised and included within a fragmented system. Importantly, they viewed it not only as gene-targeted therapy but as a broader approach that integrates social, emotional, and holistic care. For attendees, personalised medicine represents a chance to link patients to specialists, ensure continuity, and create person-centred pathways. Research that embraces this broader definition combining clinical innovation with equity, psychosocial support, and consumer partnership will have the most impact.

KEY SUMMARY RESPONSES AND DISCUSSION POINTS

Theme	Consumer Comments
Information gaps and reliance on self-research	• "Patients felt forced to turn to it [Google] when left without adequate help." • "Lack of reliable sources; overwhelming to navigate and hard to filter." • "Social media can be a double-edged sword." • "Become own researcher—lack of data and information." • "Often left with unanswered questions about specifics of their condition and what to expect, only given broad responses or brushed off."
Clinician knowledge and dismissive experiences	• "Lack of knowledge and advice given by the doctors." • "Some doctors were somewhat dismissive of their condition since there is no treatment available and no support was given afterwards." • "Often GPs are not guided by the right information (since they also don't know where to access the correct information)." • "Even specialists were only able to give quick information within their 15 minutes appointment."
Access barriers and inequities	• "One attendee attended a symposium for rare conditions in the Eastern States and highlighted how WA is isolated in comparison. This isolation poses barriers to connect with specialists and others living with rare conditions or caring someone who does." • "There are only few communities dedicated to the rare genetic conditions and perhaps more could be achieved if they were united, one community for rare conditions in general." • "Lack of care translation from childhood to adulthood (model at PCH is great but doesn't follow a patient into adulthood, leaving patient lost in the adult system)." • "Most did not have access to a relevant specialist, especially within WA."
Emotional and mental health impacts of rare conditions	• "Emotional impact: Many described the process as isolating, overwhelming, and frightening. Mental health suffered due to the lack of support and clarity." • "Participants highlighted that there is no mental health support for those dealing with rare conditions." • "Knowing that you're not alone is so important."
Need for transparent, plain-language information to support decision-making	• "Information should be written in plain English/lay language." • "Want to be asked to participate and have what they say taken onboard." • "Guidelines stating what to expect (e.g., symptoms progression, where to find further information) from their condition would be well-received."
Systemic improvements and infrastructure	• "Rare disease register: Underutilized, potential for improvement." • "De-centralisation of research and funding access across Australia (less of each state having their own peak bodies that fund small groups of researchers instead of investing in common efforts)." • "Establish a centralised, umbrella foundation (akin to Wikipedia) that people can easily find and navigate to the appropriate resources." • "Continuity of care through the transition period from child to adult (16–18 years old)."

Community Conversation
Detailed Responses and Themes

ATTENDEE INSIGHTS

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

QUESTION 1

WHEN YOU (OR THE PERSON YOU CARE FOR) WERE DIAGNOSED WITH A GENETIC CONDITION, WHERE DID YOU SEEK INFORMATION ABOUT THE CONDITION AND HOW COULD THIS INFORMATION HAVE BEEN MORE ACCESSIBLE AND AVAILABLE TO YOU?

Prompts:

- Who were the people that you spoke to?
- Were there organisations that you came into contact with
- Where did you find the information (where online, in physically?)
- What formats was this information available in (webpages, pamphlets/ brochures, journal articles, video)?

Key insights included:

- Participants described drawing on a wide range of sources for information following diagnosis. Common first steps included Google searches, international organisations, and the websites and social media pages of communities dedicated to their specific genetic condition. Clinicians, specialists, and hospital-based genetic services were also consulted, though attendees noted limitations in the advice provided. Family members, peers with the same condition, and support groups (often accessed through Facebook and other online platforms) were mentioned as important, though experiences of these groups were mixed, providing both valuable support and, at times, experienced as competitive or comparative.

> ***Social media can be a double-edged sword.***

- Some attendees sought more formal sources such as research articles, university materials, and scientific conferences, though access to journal articles was sometimes restricted. The group reinforced the importance of access to these publications and open source journals. One consumer described attending a symposium for rare conditions in the Eastern States, highlighting Western Australia's isolation and the resulting barriers to specialist access and peer connection. Another noted that advice from a friend with direct experience of the same condition was a significant support.

Question 1 (cont)

Key insights (continued)

- Across all accounts, attendees described turning to international sources such as Johns Hopkins, NIH, or COORD databases due to the limited availability of Australian-based resources. Several also emphasised that they were forced to become their own experts, relying heavily on online searches and scientific articles, even when difficult to interpret. Some reflected that if tools such as ChatGPT had been available at the time, it may have eased their struggle to understand complex information.

Challenges

Participants consistently reported gaps in the healthcare system as a major challenge. Many described doctors, including general practitioners, as dismissive, particularly when no treatment was available. They noted that initial appointments often provided only brief, general advice, without guidance on where to find more detailed or trustworthy information. Specialists were also described as limited in their time, often restricted to short appointments without the capacity to explain the underlying genetic mutation or expected progression of symptoms. Paediatric patients were more likely to be referred to specialist services (e.g. PCH), but attendees highlighted a lack of transition into adult care, leaving patients unsupported later in life.

Key challenges raised included:

- Lack of informed healthcare providers.
- Reliance on self-research, with 100% of attendees using Google and online forums, and some also turning to Reddit.
- Limited access to relevant specialists, particularly in WA.
- Barriers to understanding and assessing the reliability of online information.
- Emotional impacts, with many describing the process as overwhelming, isolating, and frightening.

Question 1 (cont)

Suggestions for improvement

Participants identified several ways information could be made more accessible and useful:

> ***Want to see more compassion in the system.***

- Better translation of research findings into information for clinicians, ensuring that knowledge is passed on to patients.
- Clinicians acknowledging when they do not have all the answers and providing direction to reliable external sources.
- Development of condition-specific guidelines outlining expected symptoms, progression, and where to find further information.
- Increased visibility and promotion of rare disease research.
- Greater collaboration across states, rather than fragmented peak bodies and decentralised research funding.
- Improved use of rare disease registers to connect patients and share knowledge.
- More inclusive support that extends beyond childhood and adolescence, ensuring adults with rare genetic conditions also have access to information and care.

Question 2

DO YOU FEEL ADEQUATELY INFORMED OF ALL AVAILABLE TREATMENTS FOR THE DIAGNOSED CONDITION?

Prompts

- Are you concerned that there are available treatments that you are not aware of?
- What would you need to feel more fully informed?

> ***No, we do not feel informed.***

Attendee insights

The consensus across attendees was clear: no, they do not feel adequately informed. For many rare genetic conditions, there are no approved treatments available. Where treatments do exist, not everyone is eligible to access them, and patients often have to be the ones informing clinicians about trial opportunities or emerging options. Most attendees were aware only of symptomatic management strategies. The highly variable presentation of rare conditions further complicates understanding what treatments may apply, and families described feeling left without clear guidance.

Participants noted that clinicians often failed to explain connections between symptoms and treatment, and when clinicians lacked knowledge, families felt their concerns were dismissed rather than investigated further. Families described “good clinicians” as those who asked questions, acknowledged gaps in their own knowledge, and showed a willingness to learn from the patient experience.

The lack of information placed significant mental and emotional strain on attendees. They described feeling fatigued by the need to self-advocate, research clinical trials independently, and educate their own doctors. Mental health support for people living with rare conditions and their carers was highlighted as almost entirely absent.

Social media and online communities were again raised as sources of information, offering connection, news, and shared experiences. However, they could also be discouraging when attendees encountered poor prognoses or accounts of deaths from similar conditions.

Question 2 (cont)

Challenges

Participants identified several recurring challenges:

- Lack of Australian resources, with most trial and treatment information coming from international sources.
- Slow access to treatments in Australia, with approval and information lagging behind other countries.
- System barriers, including confusing referral pathways, long waits to see specialists, and clashes between NDIS processes and medical advice.
- Self-advocacy required: patients often had to chase information, confirm drug availability with pharmacies, explore off-label or supplements, or bring research findings to their clinicians themselves.
- Dismissive experiences with clinicians who were unaware of rare conditions and uninterested in investigating further.
- Inequities in access based on age, gender, location, and socioeconomic status.
- Lack of mental health support for both patients and carers.

> ***Knowing that you're not alone is so important.***

Suggestions for improvement

Participants suggested several ways to address these gaps:

- Establish a centralised, umbrella foundation or organisation (likened to a "Wikipedia" model) to connect people with resources across all rare conditions. This could:
  - Provide a directory of specialists, researchers, and support organisations.
  - Link directly to trials, treatments, and support groups.
  - Enable patients to input their own experiences, ensuring collective knowledge is shared.
- Share research wins and ensure more visible collaboration between researchers, universities, and consumers. This would give families reassurance that progress is being made.
- Provide psychological support, validation, and opportunities to connect with others in similar situations. Participants emphasised the importance of "knowing that you're not alone" and having "some form of hope."
- Extend support beyond condition-specific groups to create broader networks of people with similar challenges, reducing isolation and broadening peer support.

Question 3

WHAT WOULD YOU NEED TO MAKE AN INFORMED DECISION ABOUT BEING INVOLVED IN THE DEVELOPMENT OF A PERSONALISED MEDICINE SPECIFICALLY FOR YOU?

Prompts:

- Possible side effects
- Costs
- Risks to health

Attendee insights

Participants emphasised the importance of clear, transparent, and honest information to guide decisions about involvement in personalised medicine. They wanted to be asked directly to participate, have their perspectives taken seriously, and know that researchers had a strong understanding of their specific condition and individual circumstances.

Information sheets were considered essential, outlining the pros and cons of proposed medicines, potential side effects, and drug–drug interactions. These should be written in plain English and made available not only to patients but also to their general practitioners and pharmacists, helping ensure that healthcare providers are informed and able to support them. Participants also wanted technical information available where needed, and clarity about which gene mutations were being tested and how this could affect treatment.

Beyond written information, attendees wanted researchers to engage directly with people living with rare conditions. Meeting face-to-face was seen as critical to building trust and ensuring that treatment development reflects patient priorities.

Question 3 (cont)

Challenges and considerations

Participants raised practical and emotional concerns that would need to be addressed to support decision-making:

- Uncertainty about whether medicines would be available after a trial ends, and if so, at what cost.
- Concerns about affordability and the need for government subsidies or support from the health department.
- Questions about when treatments would be most appropriate (for example, only at younger ages) and what the expected outcomes would be.
- Lack of accessible information about clinical trials in WA and the need for a centralised registry.
- Poor continuity of care between paediatric and adult services, and the need for better handover.
- Emergency departments being ill-equipped to manage rare conditions or recognise patients receiving personalised therapies.

Participants also reflected that willingness to accept risks from treatments often increases with the severity of symptoms, highlighting the need for transparent risk–benefit information.

> ***Information should be clear and honest***

Suggestions for improvement

To enable informed decision-making, attendees suggested:

- Developing plain-language information sheets with clear details on risks, side effects, gene targets, and expected outcomes.
- Provide clear, plain-language materials for patients, along with technical information for healthcare providers, including GPs and pharmacists.
- Ensuring strong support systems are available if complications arise, including mental health, insurance, and housing support.
- Government and health department involvement in community engagement and oversight of trials, giving families confidence that trials are legitimate and accessible.
- Improved public–private integration to reduce delays in access to therapies.
- Establishing a centralised rare disease innovation hub in WA, with online and physical presence, to coordinate care, trial information, and support.
- Using diverse channels to notify patients of local and national trial opportunities (e.g. social media, newsletters, peer groups, newspapers).

Additional Recommendations and Observations

Participants highlighted broader recommendations that go beyond individual decision-making, pointing to systemic changes needed to ensure equitable, person-centred personalised medicine pathways:

- Enhance and strengthen current rare disease support initiatives and portals (e.g., Rare Voices Australia, Rare Portal).
- Encourage co-design and patient participation in developing personalised medicine pathways.
- Integrate social and emotional support as a standard part of care, rather than an optional extra.
- Ensure personalised medicine initiatives do not further marginalise those already disadvantaged by the system.
- Improve continuity of care during the transition from childhood to adult services (particularly ages 16–18).
- Increase access to information sources, including webinars from patient organisations and resources provided through national portals.

Additional Recommendations and Observations (cont)

Information needs identified for decision-making

Participants emphasised that the following details would be critical in making informed choices about personalised medicine:

- Has the treatment been thoroughly tested and researched?
- How does personalised medicine compare to currently available treatments?
- How might treatment outcomes differ across age groups (juvenile, adolescent, young adult, adult)?
- What are the potential side effects and long-term effects?
- How would personalised medicine interact with other existing conditions or treatments?
- What costs would be involved, and would the government or insurers provide coverage?

Systemic frustrations

Participants described frustration at the lack of accessible information on diagnosis and clinical trials when they needed it. Some reported having no access to their own genetic test results, limiting their ability to share vital information with future care providers. Others felt there was no link or coordination between childhood and adult care, leaving them to fall through the cracks.

Reflections on personalised medicine

The term personalised medicine resonated strongly with attendees. For many, it represented not only genetics but also a holistic, connected model of care that acknowledges their individuality, links patients to appropriate specialists, and prevents them from being forgotten. They saw the concept as a way of fostering inclusion in a system that often overlooks rare conditions. Participants stressed the importance of involving consumers in research and suggested that young people could act as advocates to facilitate communication and improve accessibility of information about personalised medicine.

EVENT SUMMARY

The Community Conversation at Murdoch University successfully brought together consumers, families, and community members with lived experience of rare genetic disease to engage directly with the Personalised Medicine Centre Research Team.

Attendees were provided with background on the team's research and the opportunity to contribute their perspectives through structured breakout discussions. Both in-person and online sessions ensured broad involvement opportunities, and all feedback was carefully recorded to inform the next stages of research.

The event created a valuable forum for shared learning, mutual understanding, and building stronger partnerships between researchers and the rare disease community.

NEXT STEPS

The Personalised Medicine Centre Research Team has secured research funding through the Stan Perron Foundation, providing continuity and growth for this research program.

The insights gathered through the Community Conversation will be applied immediately to guide the development of the project, ensuring that consumer perspectives remain at the centre of the work.

As the research progresses, the team will continue to expand opportunities for consumer involvement, offering new ways for people with rare genetic diseases and their families to engage with and shape advances in personalised medicine.

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Information and new updates for the Personalised Medicine Centre can be found online. Scan the QR code to learn more.

WANT TO KNOW MORE?

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