

National Roundtable Executive Summary

NHMRC Draft Statement on Consumer and Community Involvement in Health and Medical Research

Overview

Between July and September 2025, a national consultation series comprising 25 Roundtables was delivered across all Australian states and territories to inform the NHMRC Draft Statement on Consumer and Community Involvement in Health and Medical Research (The Draft Statement). The process engaged 497 attendees, including consumers, community representatives, researchers, clinicians, policy makers, funders, and Aboriginal and Torres Strait Islander leaders.

Sessions were conducted both in-person (18) and virtually (7) to maximise accessibility and representation. Each Roundtable followed a consistent World Café (abridged) format, with Yarning Circle terminology respectfully adopted for Aboriginal and Torres Strait Islander session. A joint National Health and Medical Research Council (NHMRC)/Consumers Health Forum (CHF) introductory video was used to ensure national alignment and consistency.



Adelaide Roundtable, 6 August 2025

Governance and Delivery

The project was led by The Kids Research Institute Australia (The Kids) with NHMRC and CHF oversight. A Project Advisory Group comprising 12 Project Partners – Association of Australian Medical Research Institutes (AAMRI), Flinders University, Health Care Consumers of the ACT Inc., Health Consumers



Council, WA Inc., University of Tasmania, The George Institute for Global Health, The University of Queensland, Translational Research Institute Pty Ltd, University of New South Wales, Victorian Comprehensive Cancer Centre Alliance, and Advocacy Consultants Mr John Stubbs AM and Ms Anne McKenzie AM, provided regional engagement and delivery support. The Kids Kulunga Aboriginal Unit contributed essential cultural advisory input. A further 200+ people were involved in the delivery of the Roundtables as facilitators and scribes.

In managing and delivering the Roundtables, The Kids committed to accessibility; providing interpreters, honorariums, and inclusive venues, including Virtual Roundtables with selection criteria that prioritised regional and remote participants. Roundtable summaries were completed using a standardised template and were shared with NHMRC.

Scope of Outputs

The consultation deliverables include (attached):

- **Roundtable Summaries** – individual Roundtable feedback (shared through TEAMS Channel).
- **Roundtable Summary Overview** – thematic synthesis of national feedback.
- **Demographics Summary** – analysis of participant profiles and reach.
- **Attendee Evaluation Summary** – quantitative and qualitative participant reflections.
- **Project Partner Delivery Team Evaluation Summary** – analysis of Roundtable delivery.

Key Insights and Themes

Participants expressed strong support for NHMRC's national leadership in embedding consumer and community involvement across the research lifecycle. The Draft Statement was broadly welcomed as a significant step toward cultural and systemic change. However, participants consistently emphasised that authentic implementation requires clear mandates, accountability mechanisms, and sustainable resourcing.

As one participant noted:

"To support effective implementation, you need resources, structures, and skills development for both consumers and researchers. Otherwise, it remains aspirational."

Conclusion

The Roundtables underscored a shared national commitment to meaningful consumer and community involvement in health and medical research. Participants called for the NHMRC to maintain its leadership role by ensuring that the final Statement is supported by an implementation plan providing practical guidance, measurable outcomes, and dedicated investment to move consumer and community involvement from aspiration to action.

Submitted by The Kids Research Institute Australia

Overview of Roundtable Summaries

The overview is based on summaries from twenty-five Roundtables held across Australia, attended by 497 people. Below are the most common points raised about the NHMRC Statement:

- The importance, purpose and value of consumer and community involvement needs to be clearly stated.
- A decision to not mandate consumer and community involvement as a funding pre-requisite means that it will continue to be considered optional rather than a fundamental part of research.
- Language needs to be consistent and unambiguous and should be strengthened by using an active voice and remove words such as 'can', 'may', 'should' and replace with must and require.
- The use of 'them' needs to be changed to consumers and community members.
- The audience the Statement is intended for needs to be clear.
- Funding to support training, guidance and capacity building for researchers, consumers and community members is needed.
- The definition of consumers needs to be more inclusive.
- The difference between involvement and participation needs to be clarified.
- The full diversity of the community needs to be reflected by expanding the list of priority populations and including the importance of specific cultural/safety requirements and issues.
- Accessibility needs to be improved by providing a plain language version that uses infographics, visuals and includes the research cycle.
- The Values need to be clearer, reduced in number, and linked to the Principles (eg the use of the word "our" is unclear).
- More needs to be included on roles and responsibilities to address any power imbalances and ensure there is accountability for funders, research organisations and researchers to ensure effective involvement is implemented.
- An implementation plan is needed that includes outcome measures and evaluation strategies in order to drive system-wide structural changes.
- A national policy on remuneration for consumers and community members is needed as it is currently a significant barrier to effective consumer and community involvement.

NHMRC Roundtables

25

Roundtables held in every State and Territory across Australia

7

Sessions held virtually



180

People online

497

People attended the Roundtables

18

Sessions in person



317

People face-to-face

Location



ONLINE - 180

Other regional - 9+

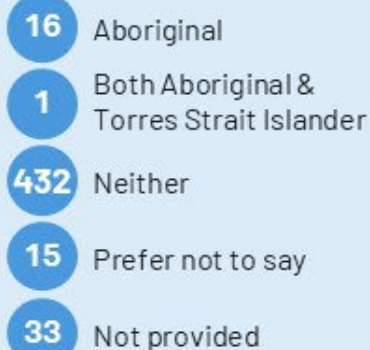
Nationality



Gender



Aboriginality



Perspective



Draft Statement Roundtables

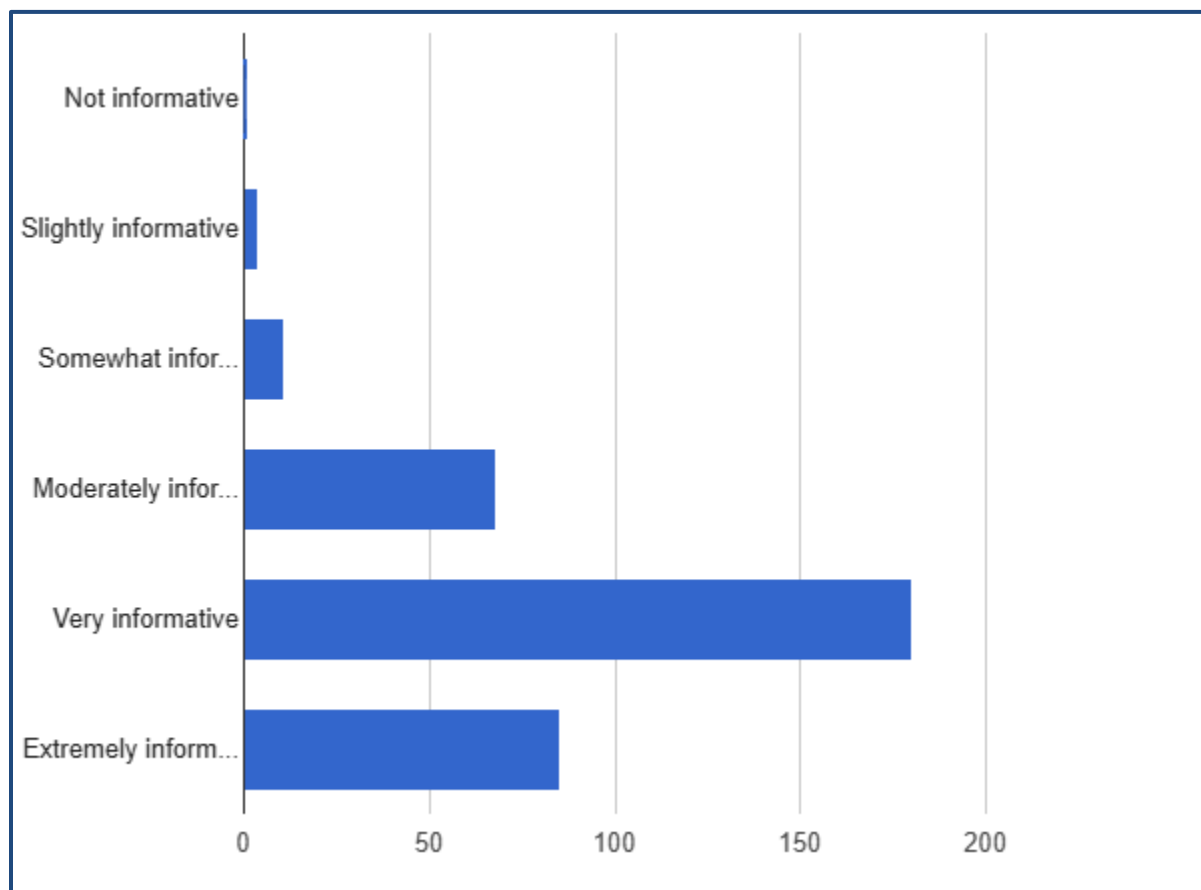
Attendee Evaluation Summary

Attendees N=497

Evaluation Responses N=350 (70%)

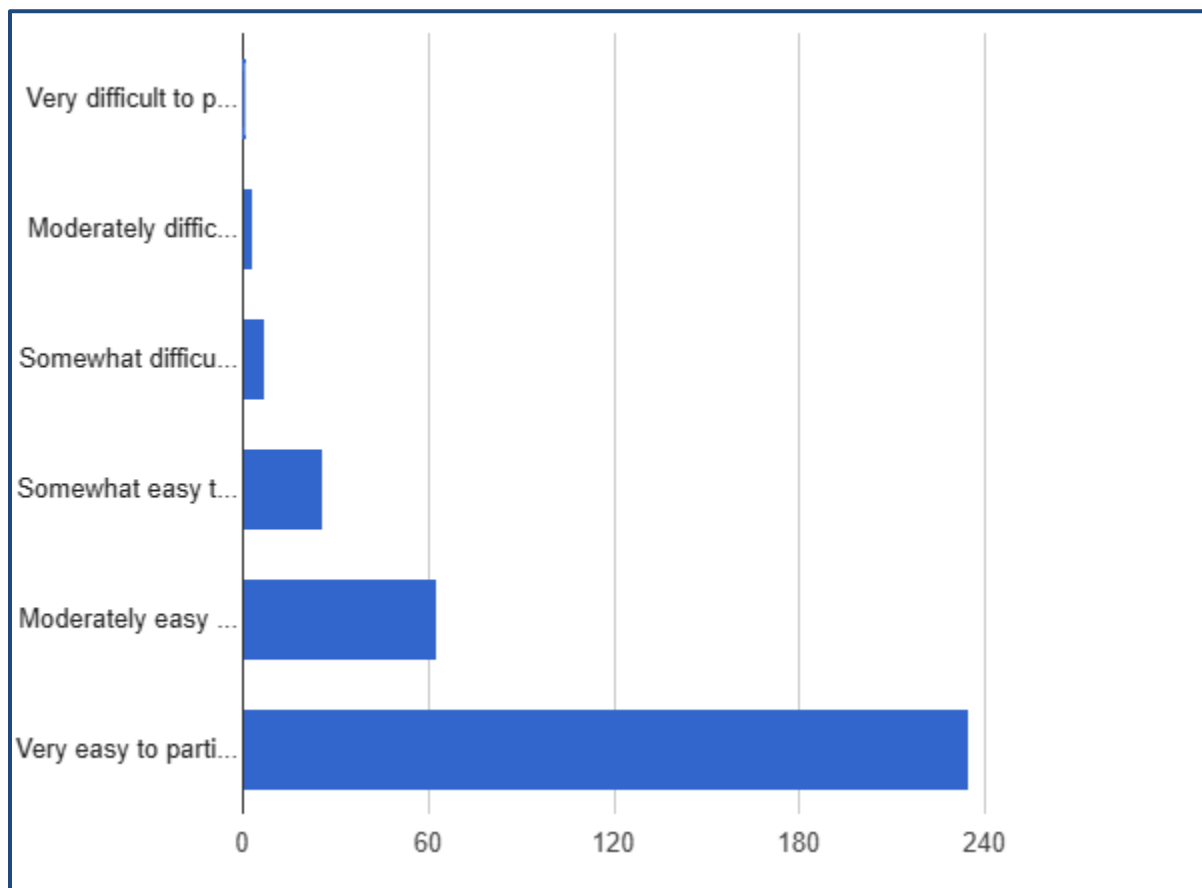
Question 1a: The Roundtable was:

Not informative (1, 0.3%), Slightly informative (4, 1.1%), Somewhat informative (11, 3.2%),
Moderately informative (68, 19.5%), Very informative (180, 51.6%), Extremely informative (85, 24.4%)



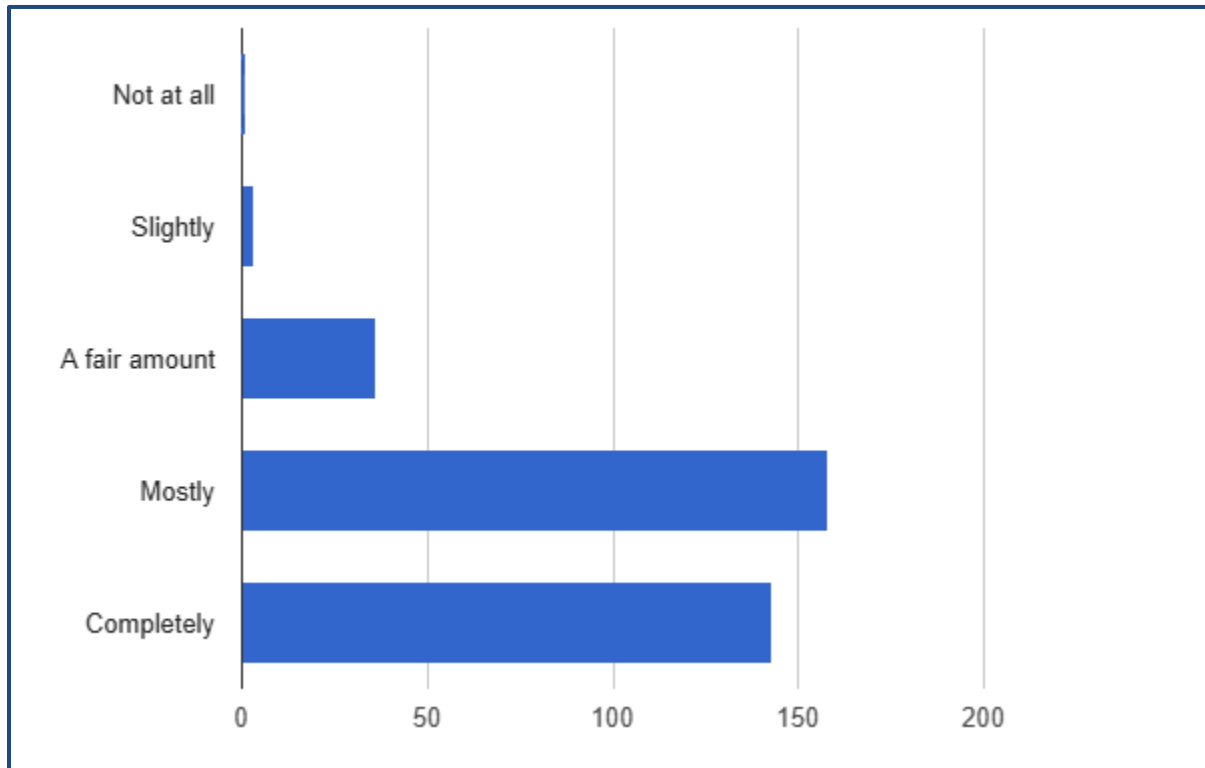
Question 1b: The Roundtable was:

Very difficult to participate in (1, 0.3%), Moderately difficult to participate in (3, 0.9%), Somewhat difficult to participate in (7, 2.1%), Somewhat easy to participate in (26, 7.8%), Moderately easy to participate in (63, 18.8%), Very easy to participate in (235, 70.1%)



Question 2: Did the Roundtable meet your expectations?

Not at all (1, 0.3%), Slightly (3, 0.9%), A fair amount (36, 10.6%), Mostly (158, 46.3%), Completely (143, 41.9%)

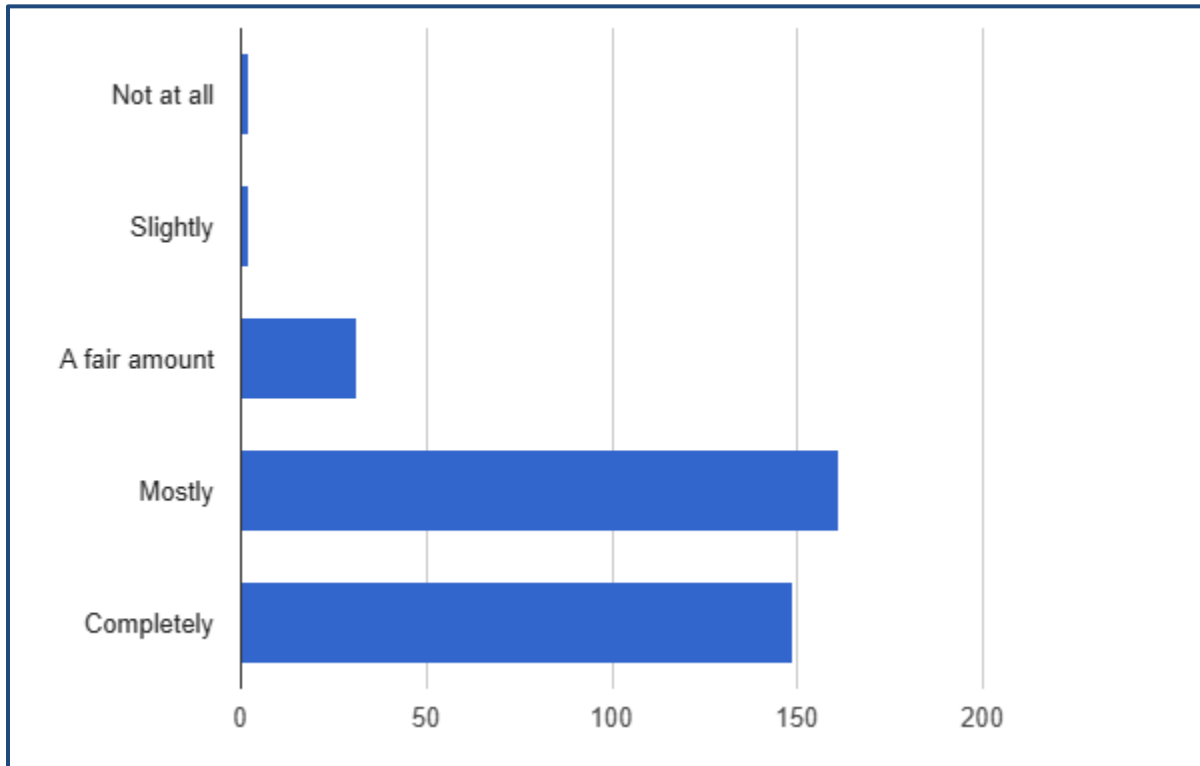


What was different from your expectations? (N = 5)

- ✓ "I thought that my fellow consumers would have read the statement & be ready to contribute."
- ✓ "I was expecting more questions"
- ✓ "Insufficient time for all to input and consider responses"
- ✓ "Overwhelmed"
- ✓ "There were a lot more people involved, and I was shocked to hear how many round tables are being held for this - it seems like over-kill for a short document that will only ever be moderately adhered to."

Question 3: Did the Roundtable discussion cover the areas that were important to you?

Not at all (2, 0.6%), Slightly (2, 0.6%), A fair amount (31, 9.0%), Mostly (161, 46.7%), Completely (149, 43.2%)

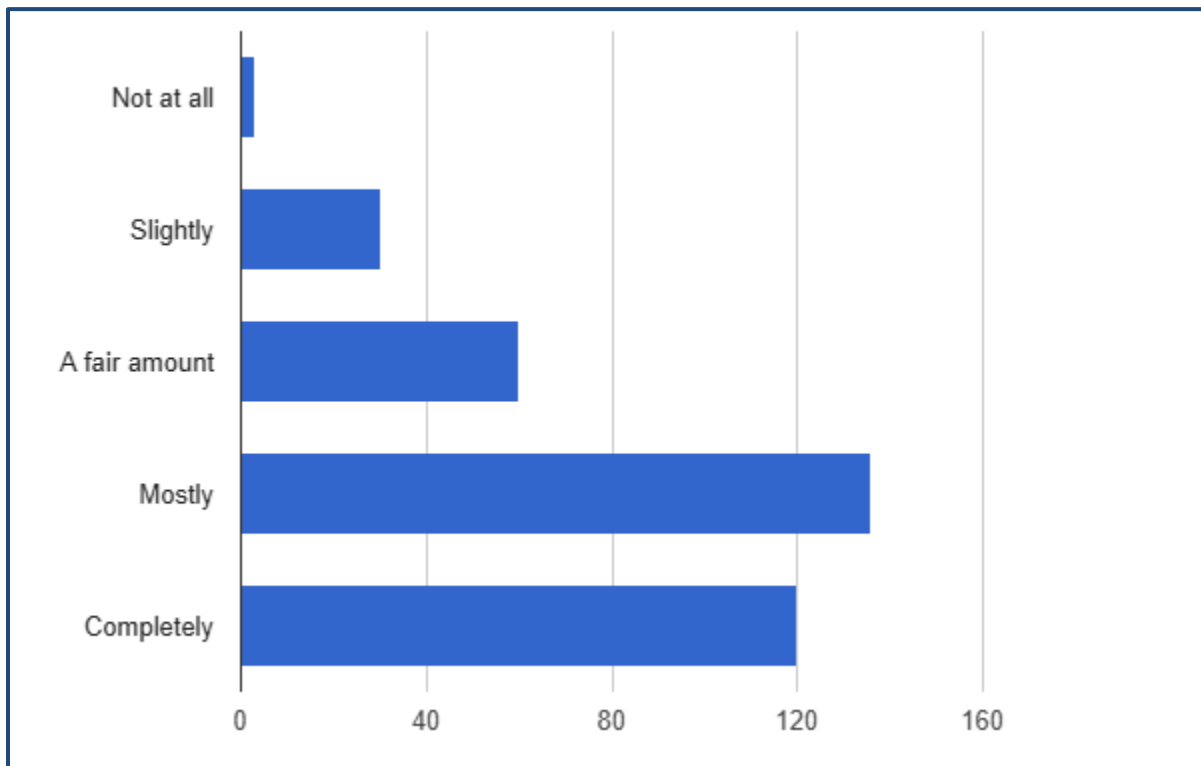


What topics would you have liked to see included in the discussion/what other question(s) should have been asked? (N = 5)

- ✓ "Implementation"
- ✓ "Inclusion and diversity"
- ✓ "Make up of panel, what areas should be represented, how members are selected, criteria/database"
- ✓ "Role and responsibility of NHMRC in CCI participation."
- ✓ "Who was involved in the draft"

Question 4: I feel my participation in the Roundtable will have a positive impact on The Statement.

Not at all (3, 0.9%), Slightly (30, 8.6%), A fair amount (60, 17.2%), Mostly (136, 39.0%), Completely (120, 34.4%)



Additional comments (optional). (N = 89)

The Roundtable was widely valued as a well-run, collaborative event, but participants expressed significant uncertainty about whether their contributions would meaningfully shape the final Statement. The main improvement areas highlighted were greater transparency, clearer communication of impact, more inclusive engagement, and stronger follow-through on feedback integration.

Positive Experiences

- Many participants praised the event as well-facilitated, engaging, and inclusive, with skilled facilitators and valuable networking opportunities.
 - The diversity of attendees (consumers, researchers, institutions) was appreciated for generating broad perspectives.
 - The facilities and organisation were generally commended, with several attendees noting they felt heard, valued, and able to contribute.
- ✓ "Great engaging facilitators. Powerful conversations. Great to network with other consumers and researchers who are passionate about this space."
- ✓ "Fabulous session, well done!"

- ✓ *"Thoroughly enjoyed the discussion and felt it was very well organised and everyone's voices were heard."*
- ✓ *"I felt heard and appreciated. I enjoyed the sharing of the group. The diversity in the attendees was really valuable in garnering broad perspectives."*

Uncertainty About Impact

- A strong theme was doubt about whether feedback would actually influence the final Statement.
- Many participants said it was unclear how input would be used, whether feedback would be actioned, and how outcomes would be communicated back.
- Several questioned if the process was a "box-ticking exercise", particularly given perceptions that the draft was already close to final.



Hobart Roundtable, 26 July 2025

- ✓ *"Hard to know if our participation will be impactful until we see the final statement."*
- ✓ *"I don't have a lot of faith that our feedback will be well utilised."*
- ✓ *"I think the CEO video ... highlighted the reluctance for any suggestions to be incorporated. It hinted that it is possibly a box ticking exercise and lowered expectations."*
- ✓ *"Who knows? Often comments / contributions get pulled into a middle generic type of statement."*

Calls for Transparency and Follow-Up

- Participants wanted clarity on next steps, timelines, and visibility of how feedback will be integrated.
 - Requests included: sharing outputs/notes from the session, updates on revisions, and opportunities for continued involvement.
 - Concerns were raised about NHMRC's responsiveness, past feedback being overlooked, and whether consumer voices will genuinely shape the document.
- ✓ *"I am keen to understand how our feedback will inform the final Statement, and if consumers and the community will be involved in determining what feedback will be included."*
 - ✓ *"Only expectation not met was - left meeting with not being clear on when the outcome of the consult will be known or if we will be contacted again to let us know the final version of the Statement is live."*
 - ✓ *"I would like to see any outputs from the consultation process that can be publicly shared."*
 - ✓ *"It's a bit unclear how the input from the Roundtable will be integrated into the statement."*

Suggestions for Improvement

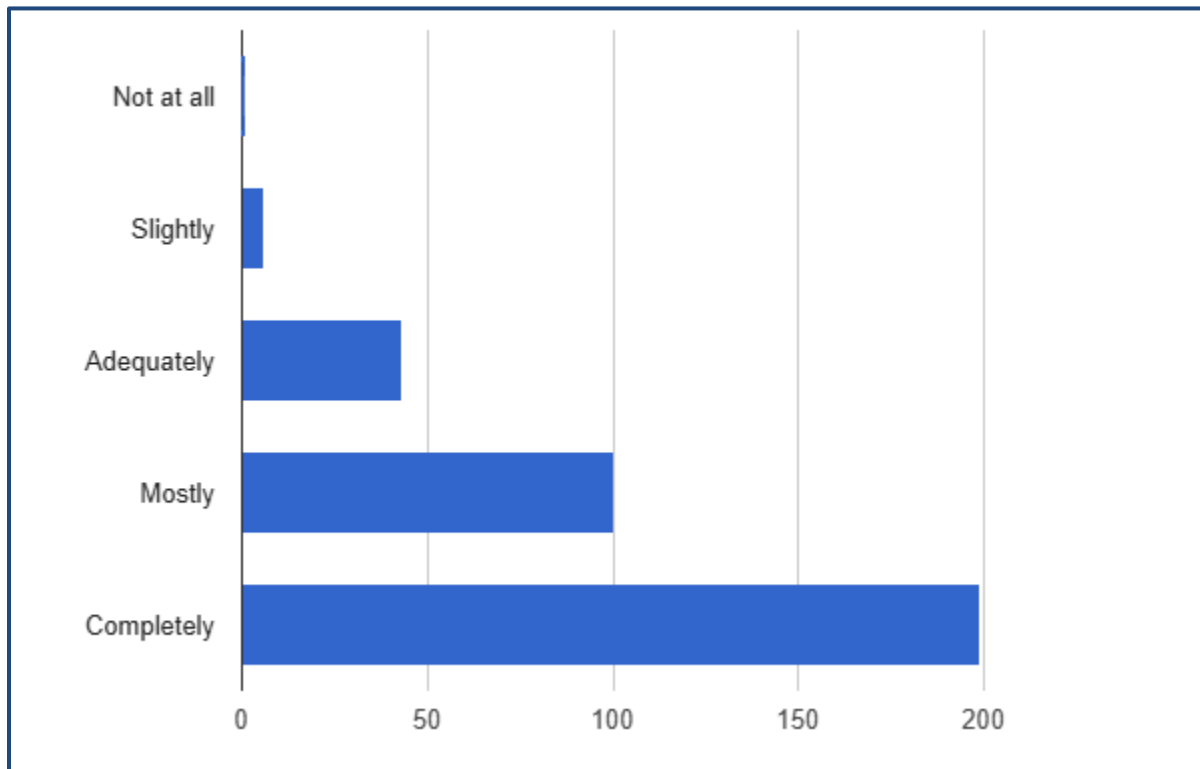
- Ensure mixed representation at tables (consumers, researchers, institutions).
 - Provide clearer purpose and audience for the Statement, and improve accessibility (less government-speak, more consumer-friendly).
 - Incorporate visual aids (slides, walk-throughs of the draft) during sessions.
 - Include rural, remote, and CALD communities in future engagement.
 - Improve scribing accuracy and avoid potential conflicts (e.g., NHMRC staff as scribes).
- ✓ *"Ensure that consumers and research and institution are mixed on tables."*
- ✓ *"Would be good to have an overview of what is intended by the document. ie what they want to convey, vs what they have conveyed."*
- ✓ *"It might have been helpful to have a powerpoint and provide more visuals/go through the draft as we went and comment as a group."*
- ✓ *"Were consumers and communities in rural and remote areas and CALD communities without English proficiency consulted at any point regarding this statement?"*

Practical Issues

- Some participants noted logistical or technical challenges (hearing loop issues, noise, parking, disengaged breakout group members with cameras off).
 - A few expressed frustrations that participation levels varied and that some group members did not contribute.
- ✓ *"A number of participants had not read the statement."*
- ✓ *"About half of the participants in my breakout group did not turn their camera on or contribute. I hope they will not be paid and that money donated to a good cause instead!"*
- ✓ *"Hearing loop doesn't work – made it difficult to understand all the discussions."*
- ✓ *"Lovely environment, however very noisy to interact with table members when discussing questions due to ambience of the room."*

Question 5: Did the welcome and information provided in the opening session meet your needs?

Not at all (1, 0.3%), Slightly (6, 1.7%), Adequately (43, 12.3%), Mostly (100, 28.7%), Completely (199, 57.0%)



Additional comments (optional). (N = 28)

Overall, participants found the welcome and opening session professional, friendly, and helpful, with advance materials enabling meaningful engagement. However, some felt more clarity on the statement's purpose, revisions, and the role of CCI was needed, and a few perceived the introduction as patronising or more focused on endorsement than genuine input. While the session met most participants' needs, improvements in context, transparency, and opportunities for connection would strengthen future sessions.

Overall Impressions

- Many participants felt welcomed and satisfied with the opening session, describing it as *clear, professional, friendly, well-organised, and accommodating*.
- Several people appreciated receiving the draft document and guiding questions in advance, which allowed them to prepare and engage more meaningfully.
- Accessibility and practical support were noted positively (e.g., help with seating and mobility needs).

Areas Needing Improvement

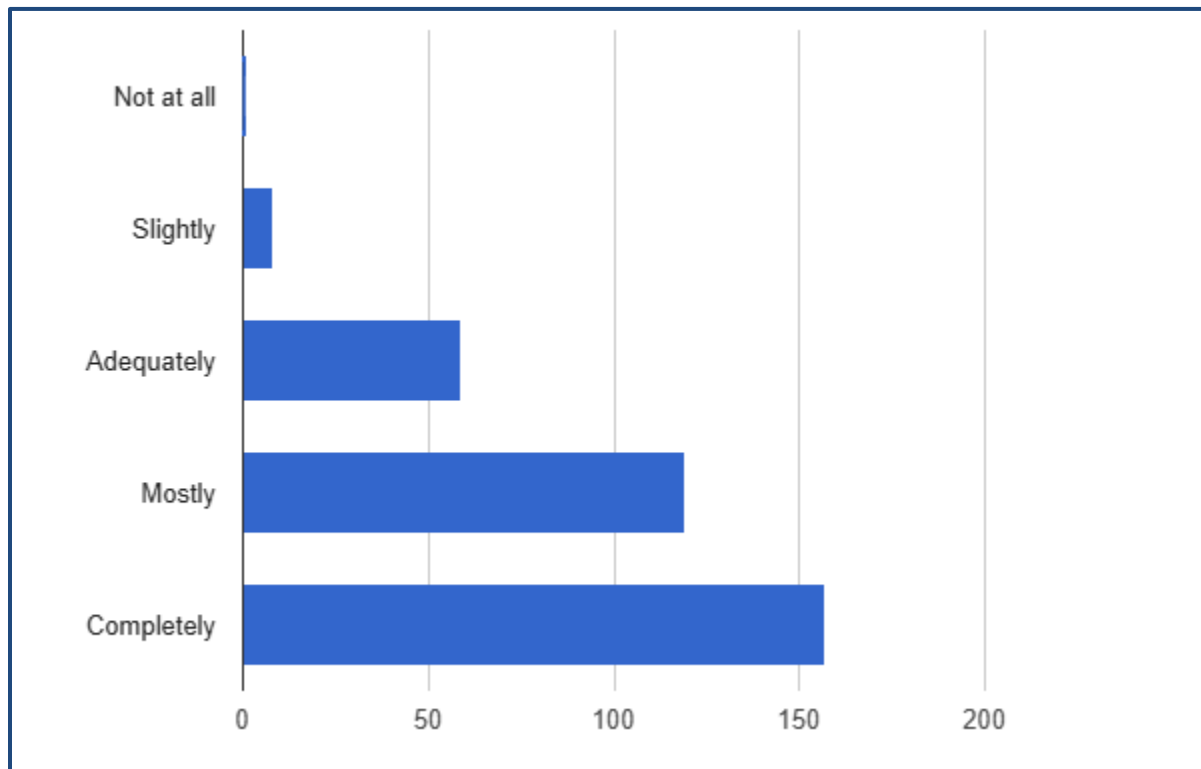
- Some participants found aspects of the introduction unclear or insufficiently detailed:
 - Confusion about what was meant by “the statement” (a sentence/paragraph vs. the full document).
 - A need for more context and history of how the statement had been developed or revised.
 - Requests for a summary of what had been amended or removed from the original statement.
- A few felt that the tone of parts of the introduction was patronising or that the video suggested the process was about endorsement rather than genuine input.

Participation and Engagement

- Some wanted more time to meet others at the table before moving into discussion.
- A returning participant appreciated the chance to re-join after technical issues in an earlier session.
- There was interest in continued engagement opportunities beyond finalising the Statement.
- ✓ *“Yes – the welcome and opening session met my needs. The overview provided was clear and set the tone for the session.”*
- ✓ *“I would have liked to see a document that summarised what has been removed and amended in the original statement.”*
- ✓ *“Excellent commentary and feedback from sectors of the community who are traditionally left out by the mainstream research approach supported by many research active institutions”*
- ✓ *“It seemed that NHMRC was really only looking for endorsement, not genuine input.”*
- ✓ *“They were fantastic. They accommodated my seating requirements.”*

Question 6: How well were your questions answered?

Not at all (1, 0.3%), Slightly (8, 2.3%), Adequately (59, 17.2%), Mostly (119, 34.6%), Completely (157, 45.6%)



Additional comments (optional) (N = 20)

Overall Themes

- **Positive experiences:** Several participants noted that facilitators and scribes were excellent, respectful, and provided good responses. Some questions were thoughtfully addressed, and participants appreciated having multiple ways to share their reflections (e.g., chat and verbally).
 - **Partial or mixed experiences:** A few respondents felt that while facilitators tried their best, some questions couldn't be fully answered due to lack of knowledge, context, or the nature of the session. Some noted that their questions were acknowledged but not always resolved.
 - **Unanswered or unclear experiences:** A number of participants indicated that the forum didn't feel designed for answering questions, that there wasn't enough time, or that their questions weren't addressed (e.g., follow-up on scribe notes, broader strategic questions).
 - **No questions / not applicable:** Several people mentioned they didn't have questions, or their questions weren't relevant in the session's context.
- ✓ "Didn't have a lot of questions on the day but questions before the event were answered well"
- ✓ "Actually did not have many questions. Not sure that the intent of the session was to give answers as such anyway."

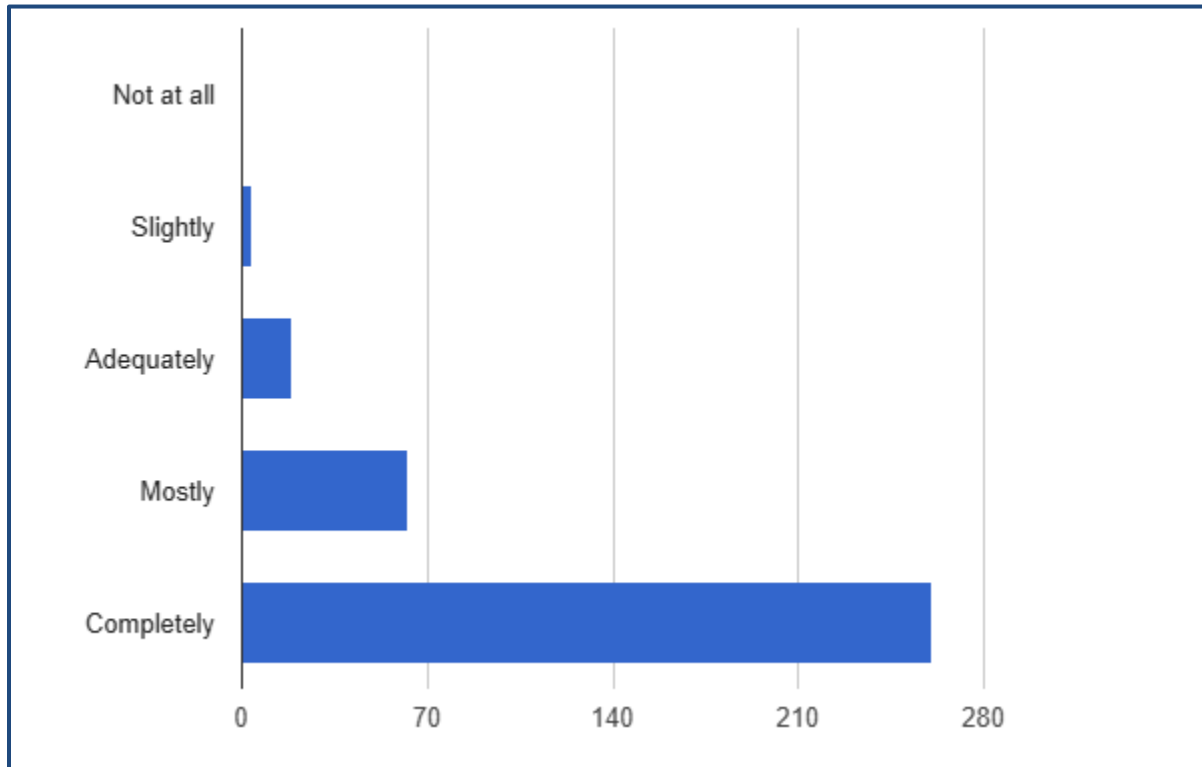
- ✓ "facilitator & scribe were excellent"
- ✓ "Facilitators didn't have knowledge of how the statement had been developed"
- ✓ "I think my facilitator tried her best but some answers were unknown - knowing the intended audience for a document, and in what context they will be reading it, is essential to figuring out if it's fit for purpose."
- ✓ "I was left wondering why the statement 'strongly suggests' rather than mandates"
- ✓ "My question is only adequate as it is external, hence there is no answer (how will this document work in synergy with the draft NHMRC strategy which omits references to consumers in many section



Bendigo Roundtable, 23 July 2025

Question 7: Did you have an opportunity to provide your comments and input?

Not at all (0, 0.0%), Slightly (4, 1.2%), Adequately (19, 5.5%), Mostly (63, 18.2%), Completely (260, 75.1%)



Additional comments (optional) (N = 25)

Participants largely felt included and able to contribute, though time limits, dominant voices, and environmental challenges occasionally constrained fuller participation.

Overall Positives

- Many participants felt they had ample opportunities to contribute, with facilitators actively checking in and creating a supportive, inclusive environment.
 - Breakout groups were praised for encouraging contributions, and some participants valued being able to supplement verbal input with written reflections in the chat.
 - Several highlighted excellent facilitation and scribing, noting their contributions were captured and appreciated.
 - Participants enjoyed the diversity of voices and perspectives shared, describing discussions as robust, valuable, and well-run.
- ✓ "Very inclusive session. Plenty of opportunities to make comments and provide input."
- ✓ "Yes – I had multiple opportunities to provide my comments and input. The facilitator was proactive in checking in with all participants several times throughout the discussion, ensuring everyone had space to contribute."
- ✓ "Great variability in voices at the table. Allowed for multiple perspectives."

Barriers and Challenges

- Time constraints were a recurring theme: some felt discussions were cut short, limiting the ability to expand on points or ensure all voices were heard.
 - Dominant voices or interruptions sometimes intimidated quieter participants, making it harder for them to contribute.
 - Environmental factors (e.g., noisy or crowded rooms, online participants joining from public spaces, difficulty hearing across multiple tables) hindered participation.
 - Some participants suggested better use of chat to allow more equitable contributions without requiring airtime.
- ✓ *"Insufficient time often meant that additional points were unable to be raised or expanded upon."*
- ✓ *"It felt difficult to get my voice across as there was a person, who was opinionated and I did not feel confident enough to speak."*
- ✓ *"I worry I talked too much!... I wonder if the opportunity/encouragement to put more stuff in the chat... might have worked better to engage more people."*

Question 8: Is there anything else you would like to add? (N = 124)

Participants were highly supportive of the initiative and eager to see it lead to practical, equitable, and well-supported consumer involvement in research. While the concept and process were valued, there is strong demand for clearer implementation strategies, better recognition of consumer contributions, and ongoing communication about progress.

Overall Experience

- The roundtable was widely seen as well-organised, inclusive, and valuable, with excellent facilitation, preparation, and opportunities for discussion and networking.
 - Many participants enjoyed the diversity of perspectives and appreciated the safe, open space for sharing.
 - Some concerns were raised about seating arrangements (consumers and researchers being separated) and inconsistencies in facilitation quality across tables.
- ✓ *"Great event well organised"*
- ✓ *"Very inclusive open conversations that delved deep into the subject matter"*
- ✓ *"Great to participate and being involved in this Roundtable."*
- ✓ *"Today was fantastic. Thank you so much for creating such a safe and welcoming space."*
- ✓ *"The facilitation was excellent."*

Positive Aspects

- Strong praise for facilitation, structure, and organisation.
 - Valuable opportunity for consumer voices to be heard and to engage with leaders, researchers, and community members.
 - Participants felt respected and valued, with gratitude expressed to facilitators and organisers.
 - The event enabled networking and collaboration.
- ✓ *"Excellent preparation for Roundtable provided and facilitated"*
- ✓ *"Great facilitation – management of timing etc."*

- ✓ *"Thank you making me feel valued and my feedback included"*
- ✓ *"The discussions were quite educative and great"*
- ✓ *"Great way of gaining feedback and facilitation was great."*

Key Issues & Areas for Improvement

- **Payment & Resources**
 - Concern that \$50 for 2 hours may be inadequate.
 - Suggestions to better allocate funds (e.g., reduce catering waste, increase participant compensation).
 - **Implementation & Impact of the Statement**
 - Many asked how feedback will be reviewed, prioritised, and applied.
 - Desire for clearer roadmap, follow-up guidelines, and practical implementation plans.
 - Interest in evaluation mechanisms to measure the impact of consumer involvement.
 - Requests for tools, guides, and training resources to avoid tokenism and support genuine co-design.
 - **Content of the Statement**
 - Calls for alignment with NHMRC Translational Research principles and international standards (e.g., WHO, UK policies).
 - Greater clarity needed around roles of government, institutions, researchers, and consumers.
 - Suggestions to include multicultural groups, regional voices, mental health peak bodies, and trauma-informed frameworks.
 - **Facilitation & Engagement**
 - Most facilitation was praised, though some tables experienced weaker moderation or poor representation of feedback.
 - Suggestions for polling, interactive activities, or broader questions beyond the structured three.
- ✓ *"To support effective implementation... you need resources, structures to make it work like skills development which is research literacy, meeting participation for both consumers and community members."*
 - ✓ *"Would love more understanding on how all feedback in all sessions is going to be reviewed and decisions made around prioritising what needs to be implemented."*
 - ✓ *"Trauma informed framework for the lived experience roles is essential in the Statement."*
 - ✓ *"I think the round table went well overall. The facilitator did well to involve all participants."*
 - ✓ *"Our facilitator seemed a little nervous/unsure about managing our discussion... Please hype her up because she seems lovely and competent."*

Question 9: The best thing about the Roundtable discussion was? (N = 225)

Attendees stated the best aspects of the Roundtable were the diverse perspectives, the inclusive and respectful environment, the effective use of breakout groups with skilled facilitation, the opportunity to connect and collaborate, and the chance to learn from one another.

Diversity of Perspectives and Ideas

Participants valued hearing a wide range of views, experiences, and insights. The diversity of backgrounds (consumers, researchers, clinicians, administrators, and community members) was seen as enriching, with many noting that differing perspectives sparked deeper, more meaningful conversations.

- ✓ "Diverse perspectives, safe environment."
- ✓ "Hearing that others have similar experiences is validating and breaks down the isolation."
- ✓ "The best thing... was hearing different perspectives and real experiences, and seeing how everyone's ideas could help shape the future of health and medical research."

Inclusion and Opportunity to Contribute

Many felt included, listened to, and given equal opportunity to participate. Smaller breakout groups were especially praised for enabling everyone to speak, share openly, and feel heard.

- ✓ "Being able to have my say and hopefully improve and increase consumer engagement research and studies."
- ✓ "Everyone was given an equal opportunity to participate."
- ✓ "Feeling very included, also hearing all perspectives and ideas."

Breakout Groups and Facilitation

The structure of the event, especially the breakout rooms—was a highlight. Participants appreciated the skilled facilitators and scribes, who ensured discussions stayed on track and captured ideas accurately.

- ✓ "Breakouts - really terrific way of doing this consultation."
- ✓ "The breakout session facilitator did a great job in making sure everyone had their say and felt welcome."
- ✓ "Fantastic facilitators managing to capture all inputs."

Collaboration and Connection

Networking and building connections with like-minded, passionate people was highly valued. Many participants highlighted the respectful, cooperative environment that allowed for trust and meaningful dialogue.



Melbourne Roundtable, 17 July 2025

- ✓ *"Connectivity with like minded expertise and passionate people."*
- ✓ *"Great participants. We quickly built rapport and were able to build constructive discussion."*
- ✓ *"Meeting other people with similar interests, ability to contribute."*

Learning and Knowledge Sharing

The roundtable was seen as an opportunity to learn from others, expand understanding of consumer engagement, and gain insights into research processes.

- ✓ *"Listening and learning from others – always enlightening."*
- ✓ *"I learned a lot from my fellow participants."*
- ✓ *"It was informative about the additional steps behind the roles of consumers and links to researchers."*

Organisation and Environment

Participants praised the organisation, time management, and supportive atmosphere. The professional facilitation and smooth process created a sense of safety and respect, enabling open sharing.

- ✓ *"Great discussion. Very respectful of everyone's opinion and extremely great time management!"*
- ✓ *"Well facilitated, scribed and the small group discussion ran well."*
- ✓ *"The openness and transparency shown was important. It's important to feel safe and comfortable."*



Hobart Roundtable, 26 July 2025

Question 10: The worst thing about the Roundtable discussion was? (N = 168)

The most common challenges were *time constraints, uneven participation, accessibility and venue issues, and lack of diversity or clarity on how feedback would be used*. Despite these, many participants had no negative feedback at all.

Mixed Views on Session Length

- Several participants felt there was *not enough time* to properly contribute, cover topics in depth, or allow scribes to capture points fully.
- Comments included: *"Not enough time," "Time limited discussions left issues open,"* and *"Could have been longer meetings – 2.5 hours would have been optimal."*
- Some also noted sessions felt *a bit rushed* or that time allocations across questions weren't balanced.
- While some wanted *longer sessions* or breaks, others felt it was already *too long* or exhausting.
- A few mentioned late evening timing and difficulty balancing family or health needs.

Participation & Dynamics

- Concerns were raised about *dominating participants* taking too much air time, making it difficult for others to contribute.
- Others noted *lack of engagement* (e.g., cameras off, not responding), which reduced collaboration.
- One participant mentioned difficulty when breakout rooms included people who didn't engage or went off topic.

Accessibility & Venue Issues

- Hearing difficulties were mentioned several times: *"Hearing loop problems," "It was very noisy and hard to hear in the room,"* and *"Not a round table – hard to see and hear."*
- The physical setup, acoustics, and lighting were problematic for some, particularly those with sensory challenges or chronic pain: *"It was quite a long session which is difficult for consumers with chronic pain. A break in the middle would be appreciated."*
- Parking, travel into the city, and late timing were additional barriers.

Diversity & Representation

- Several comments highlighted *lack of diversity* in the participant group (gender, CALD, disability, youth).
- Some noted separation of groups (e.g., researchers vs. consumers, young people apart from others) as unhelpful: *"Young people being separated from others. I think that can be useful for some but it should be optional."* *"Researchers and consumers were separated."*
- Concerns were expressed about *systemically white approaches* impacting marginalised participants: *"Watching 2 culturally & racially marginalised participants be impacted by systemically white ways of doing things. NHMRC & AAMRI, please do better!"*

Structure & Process

- Some participants struggled with unclear framing of questions or summaries not accurately reflecting input: *"People were not clear with the expectations and so each group had different interpretations."*
- Requests for *more structure* (e.g., clearer prompts, visuals, polls, or breaks) came up.
- There was concern that group feedback was "whittled down" to too few points, losing nuance.
- Several were unsure how their contributions would influence the draft, with comments like *"No information on how feedback will be reviewed or prioritised."*

Minor / Practical Issues

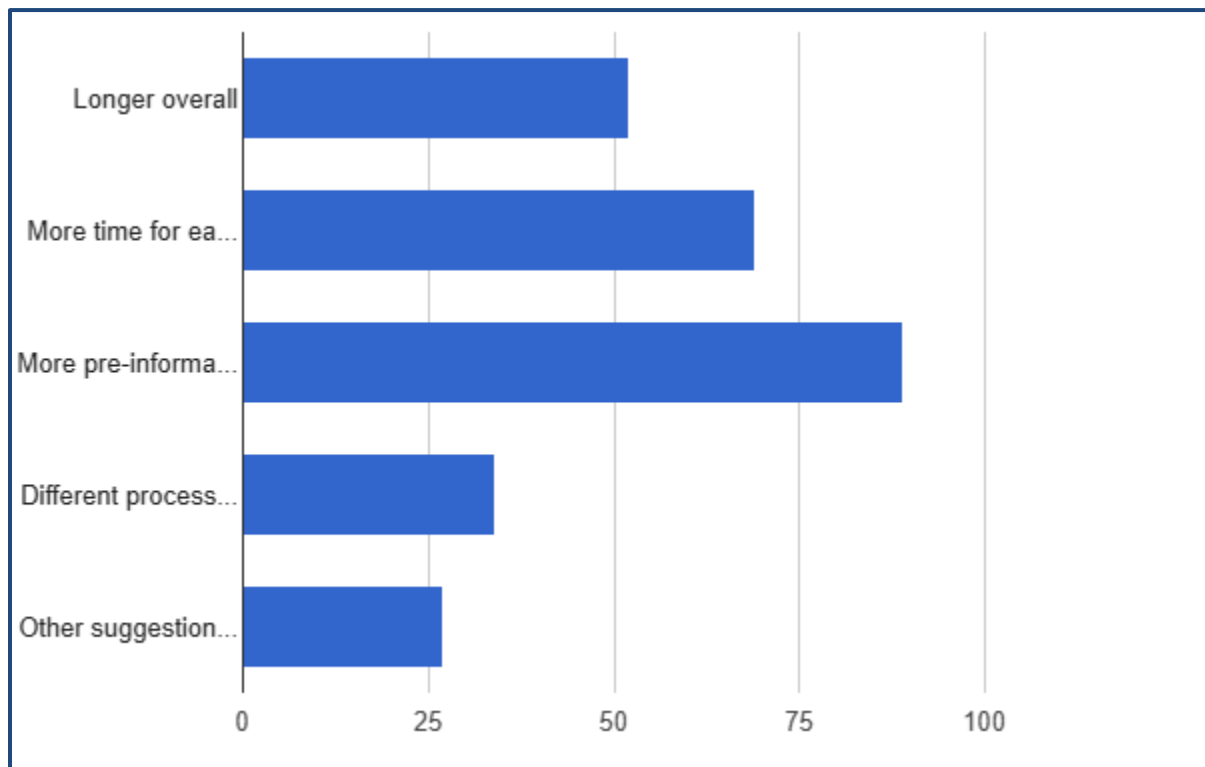
- Coffee didn't arrive, no tea or toilet break, rain during the event, and parking challenges were noted.
- A few mentioned personal factors (e.g., *"my inexperience," "I hadn't read the document"*) as their own "worst thing."

Positive Outliers

- A large number of respondents wrote *"Nothing"* or *"No worst thing"*, showing many participants were satisfied overall.

Question 11: Do you have any suggestions about how we might improve future roundtables?

Longer overall (54, 26.2%), More time for each question (71, 34.5%), More pre-information (92, 44.7%), Different process for seeking feedback from the community (please share ideas below) (34, 16.5%), Other suggestions (please specify) (29, 14.1%)



Please share your ideas for seeking feedback from the community. (N = 25)

Participants want a mix of structured surveys, flexible community-led approaches, and accessible formats, alongside incentives and follow-up communication to ensure their feedback is valued and acted on.

Pre-Roundtable Input

- Many participants valued receiving questions in advance and suggested expanding this further.
- Ideas included pre-round questionnaires or surveys to focus discussion, avoid confusion, and allow feedback on additional issues beyond the set questions.
- Suggestions for quantifiable scales (e.g., rating sections 1–10) and success scores before discussions to better frame improvement conversations.

Alternative Feedback Mechanisms

- Use of surveys, polls, email, online forums, and website submission for those unable to attend in person.
- Adding fun polls or word visualisations to keep sessions engaging.
- Options for shorter sessions (e.g., 90 minutes) to make participation easier.

Community-Specific Engagement

- Targeted consultations with specific groups (e.g., trans & gender diverse people, condition-specific, language-specific).
- Approaches like yarning circles, community-specific interviews, and co-delivery by trusted community members to build trust and inclusivity.
- Collaborating with consumer peak bodies such as Lived Experience Australia and mental health carers' groups.

Inclusion & Accessibility

- Calls for more accessible information (videos, diagrams, easy English, translated material, interpreters).
- Reduce reliance on text and make sessions more visual.
- Ensure opportunities for hard-to-reach groups

Practical Supports

- Suggestions to appoint consumer champions to lead local roundtables.
- Advertising sessions through flyers in waiting rooms to reach community members.
- Offering incentives (e.g., gift cards) for completing surveys.

Follow-Up & Representation

- Desire for broader representation of community voices in discussions.
- Suggestion of smaller, mixed groups from earlier rounds for future discussions.
- Clear follow-up communication about outcomes and final products.
- Allowing participants to vote on key questions or propose their own, shaping group discussions.

Please share your suggestions to improve future Roundtables. (N = 29)

Session Format and Accessibility

- **Length and structure:** Three hours was considered long; suggestions included shorter or more condensed sessions, or spreading questions across multiple shorter online sessions.
- **Accessibility:** Calls for more inclusive practices (support for people with cognitive difficulties, clearer preparation instructions, accessible in-person venues). Breakout rooms were valued but need stronger facilitation to keep discussions balanced. Some suggested rotating groups mid-way.

Participation and Inclusivity

- **Diversity:** Participants noted limited representation (gender, CALD, ATSI, disability) and encouraged more inclusive engagement strategies.
- **Expectations:** Clearer guidance before sessions (e.g., reminding people to read materials, setting expectations for camera use, providing space for networking).
- **Follow-up contributions:** Desire for ways to share ideas after sessions if time runs out.

Facilitation and Process

- **Stronger facilitation:** Facilitators should gently redirect conversations if dominated or off track. Adding a co-facilitator with lived experience was suggested.
- **True co-design:** Interest in more collaborative approaches, such as workshops with follow-up sessions after revisions. *"Maybe opportunity to workshop the doc as a true co-design process? If this is the case, a follow up session would be held after changes have been made to check the changes have covered all relevant points."*

Communication and Feedback

- **Clarity:** Participants wanted background on different versions of documents, clearer explanation of changes, and less emphasis on the CEO video. *"Not sure how helpful the video from the CEO was. It would have been better to understand clearly what has changed from the previous statement to this current draft."*
- **Notes and feedback loops:** Requests for copies of discussion notes and transparency on how input is collated, combined, and used in final decisions.

Tools and Innovation

- **Technology:** Suggestions to use shared documents or digital tools (Menti, Miro, Padlet) for broader participation and capturing input in real time. *"You could explore using a shared document that everyone can contribute to during the session, as well as tools such as Menti, Miro or Padlet, to enable different ways of participation."*
- **AI scribes:** Proposed as a way to ensure all views are recorded, not only those noted by human scribes.

Recognition and Communication

- **Remuneration:** Calls for better recognition and compensation for consumer representatives' time and expertise.
- **Ongoing engagement:** A dedicated website or email newsletter to notify people about future opportunities and updates



Darwin Roundtable, 13 August 2025

Draft Statement Roundtables

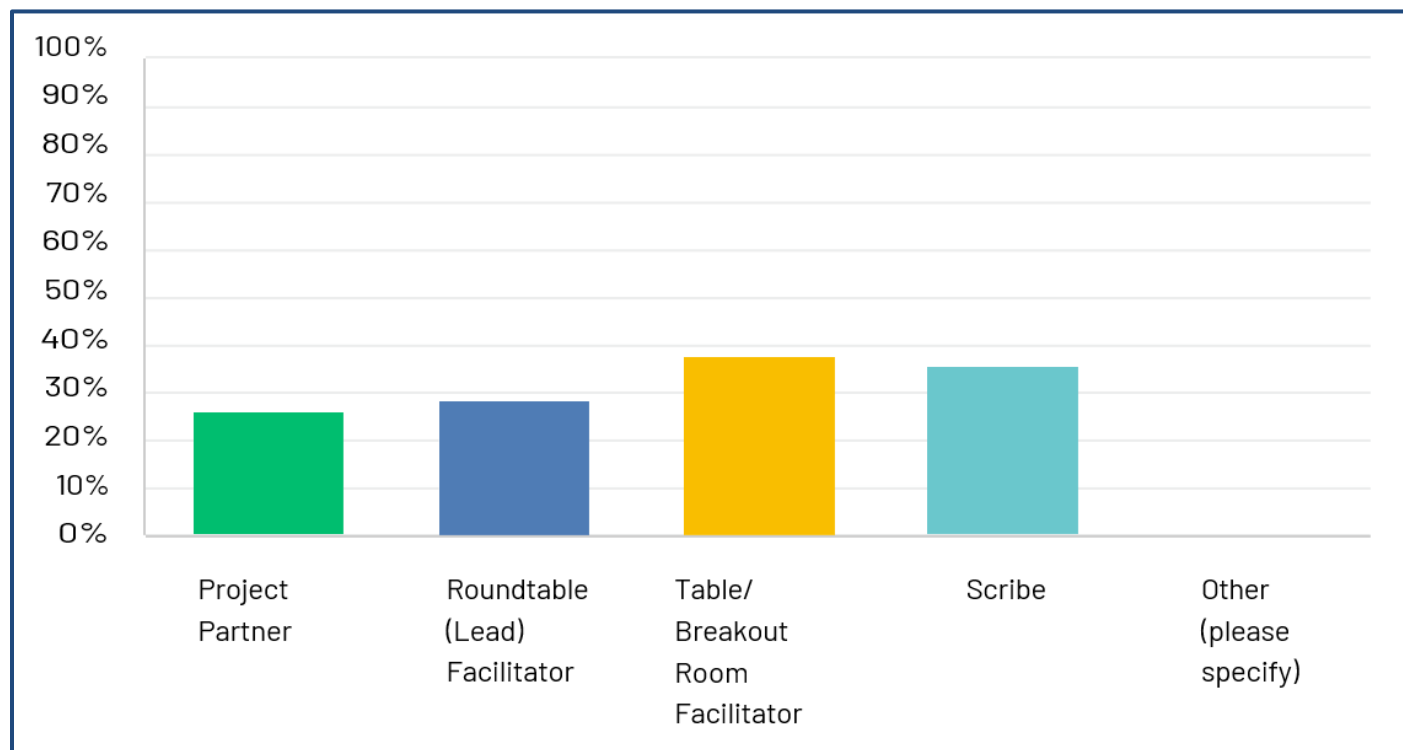
Partners, Facilitators and Scribes Evaluation Summary

Roundtable Support Team Members: 200+

Evaluation Responses N=43 (appx. 22%)

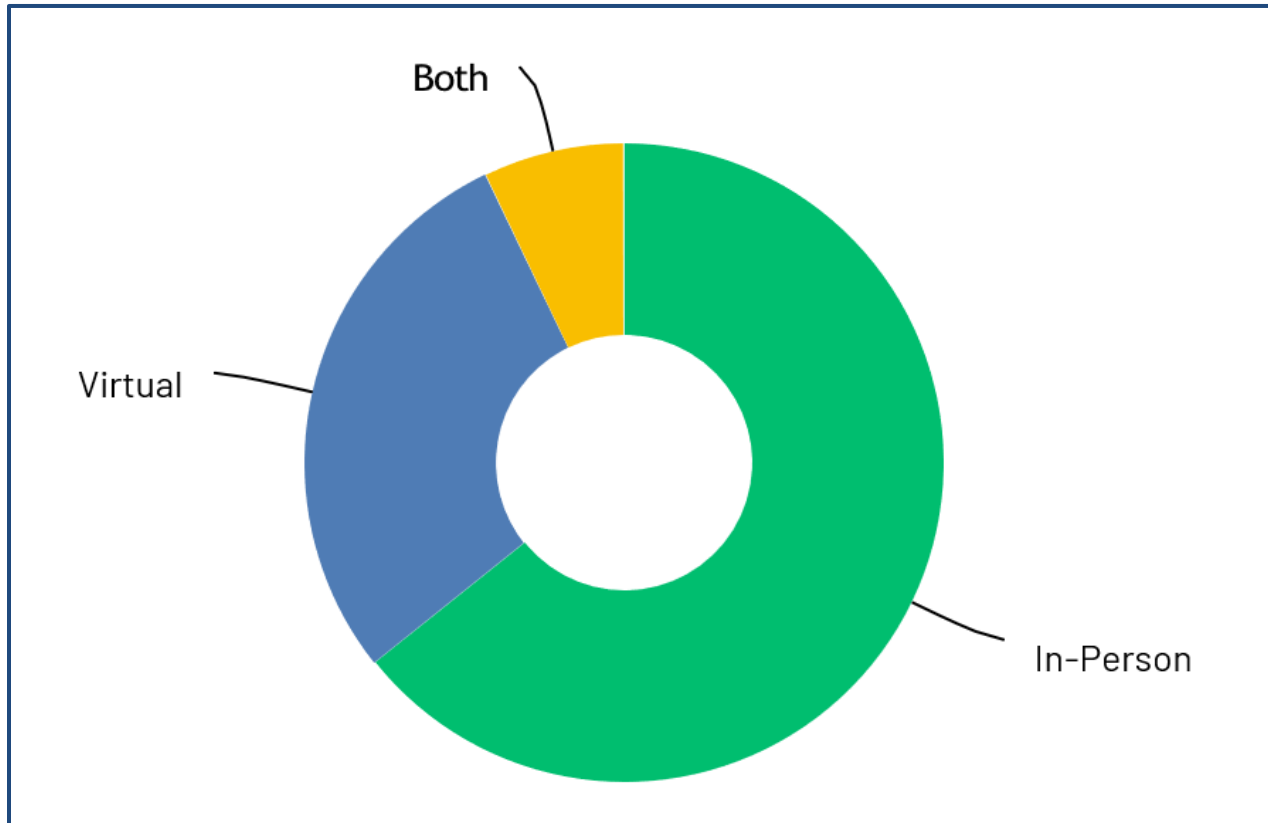
Question 1: What was your role? (Select all that apply)

Project Partner (11, 26.2%), Roundtable (Lead) Facilitator (12, 28.6%), Table/Breakout Room Facilitator (16, 38.1%), Scribe (15, 35.7%), Other (please specify) (0, 0%)



Question 2: Which type of Roundtable did you support?

In-Person (27, 64.3%), Virtual (12, 28.6%), Both (3, 7.14%)



Question 3: On a scale of 1-5, with 1 being “Not at all” and 5 being “Completely” how did you feel about the following?

I felt the briefing provided by The Kids Research Institute Australia prepared me for my role:

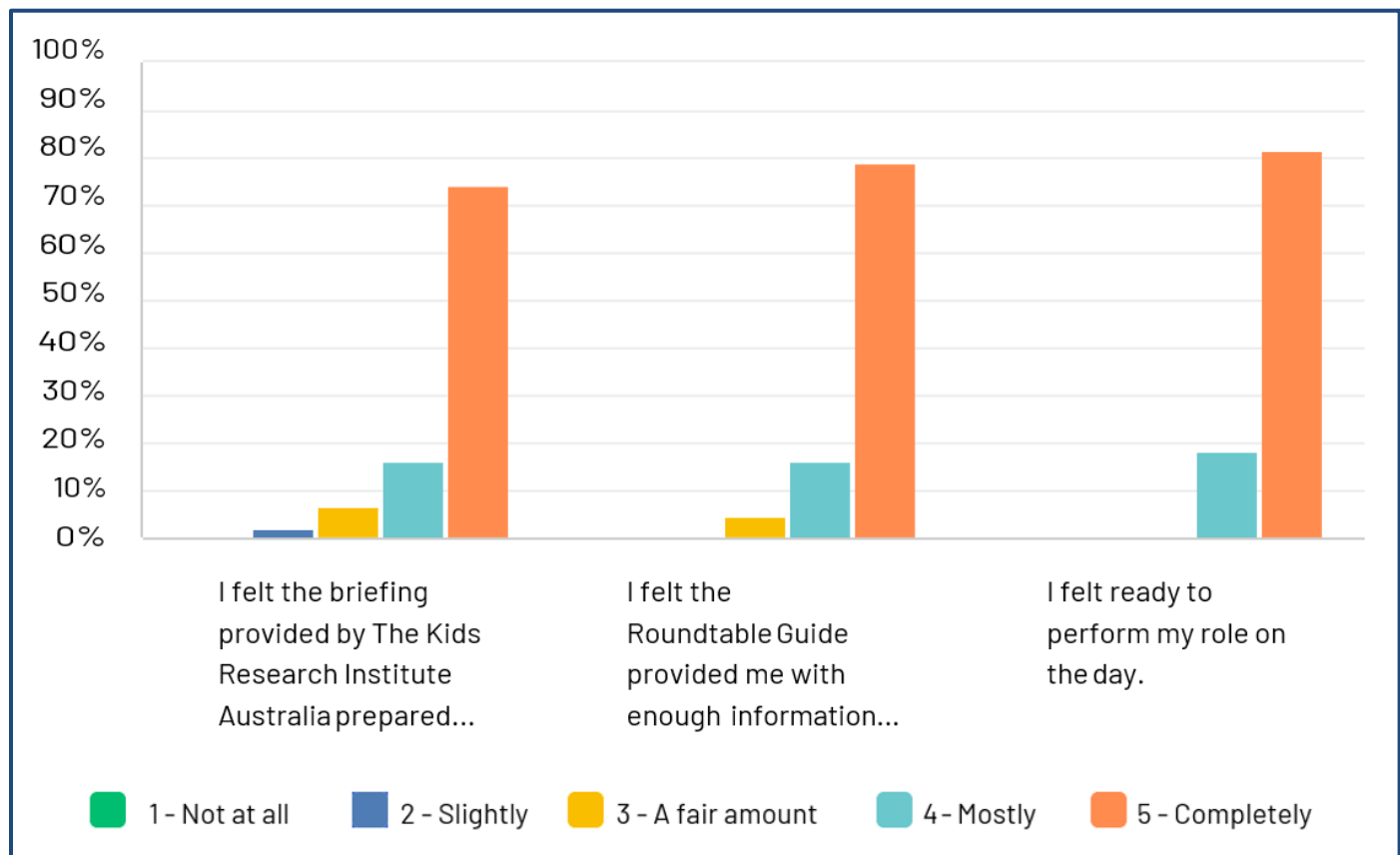
Not at all (0, 0%), Slightly (1, 2.3%), A fair amount (3, 7.0%), Mostly (7, 16.3%), Completely (32, 74.4%)

I felt the Roundtable Guide provided me with enough information to perform my role at the Roundtable:

Not at all (0, 0%), Slightly (0, 0%), A fair amount (2, 4.7%), Mostly (7, 16.3%), Completely (34, 79.1%)

I felt ready to perform my role on the day:

Not at all (0, 0%), Slightly (0, 0%), A fair amount (0, 0%), Mostly (8, 18.6%), Completely (35, 81.4%)



Question 4: Additional comments on the preparation materials, e.g. what worked well; opportunities for improvement in preparation practices, etc. (N=19)

The feedback showed that the preparation was well-received and highly effective, with materials and videos standing out as strengths. Improvements could focus on providing clearer context, strengthening logistics, and improving data and resource management.

Overall strengths:

- Preparation materials, templates, and briefing documents were consistently described as *clear, well-organised, and very helpful*.
- The briefing video was particularly valued and described as “brilliant” and “amazing” for setting expectations and providing tips.
- Receiving reading materials in advance supported participants to follow discussions effectively.
- The involvement of facilitators and scribes, supported by clear guidance, was seen as a strong approach.
- Planning meetings with partners and pre-briefings helped build understanding, relationships, and readiness.
- Roundtables were well-structured, with a good balance of consumer voices.
- ✓ *“I thought the roundtables were organised well with a good mix of consumer stakeholders to spark discussion and feedback. The number of consumers on each table was also appropriate to allow all to have their say. Having a facilitator and separate scribe was also a good idea.”*
- ✓ *“It was so well organised, materials were great, post-it notes were a good idea and well used. It was enjoyable”*
- ✓ *“Getting the reading materials beforehand helped tremendously when keeping up with the conversations and knowing what section is referenced in the discussion. I also think the YouTube video was AMAZING in preparing me for what to expect and shared helpful tips.”*

Opportunities for improvement:

- Two respondents wanted more background/context on how the draft statement had been developed and how feedback would be used.
- Suggestions for additional practical support included roleplay/demonstration examples for handling situations, more support for inexperienced scribes, and finer logistical coordination (avoiding duplicate invites, improving data handling of EoIs).
- One person felt the pace and amount of information at times was overwhelming.
- One person requested opportunity for input into tender bid/costing processes in the future, as underestimation led to heavier in-kind partner contributions.
- ✓ *“An example such as a demonstration (dialogue/roleplay) of how to manage different situations might have been useful.”*
- ✓ *“Aside from doubling up of resourcing/calendar invites, etc I felt that The Kids did an outstanding job coordinating and facilitating these roundtables.”*
- ✓ *“I feel the briefing may have been helpful for staff/people/orgs who didn't have very much workshop facilitation/host experience, but as i have considerable experience, parts with direction around facilitation and how to host workshops wasn't very useful. I would have appreciated more information on the background context of the work perhaps.”*

Question 5: On a scale of 1-5, with 1 being “Not at all” and 5 being “Completely” how did you feel about the following?

I was able to perform my role at the Roundtable(s):

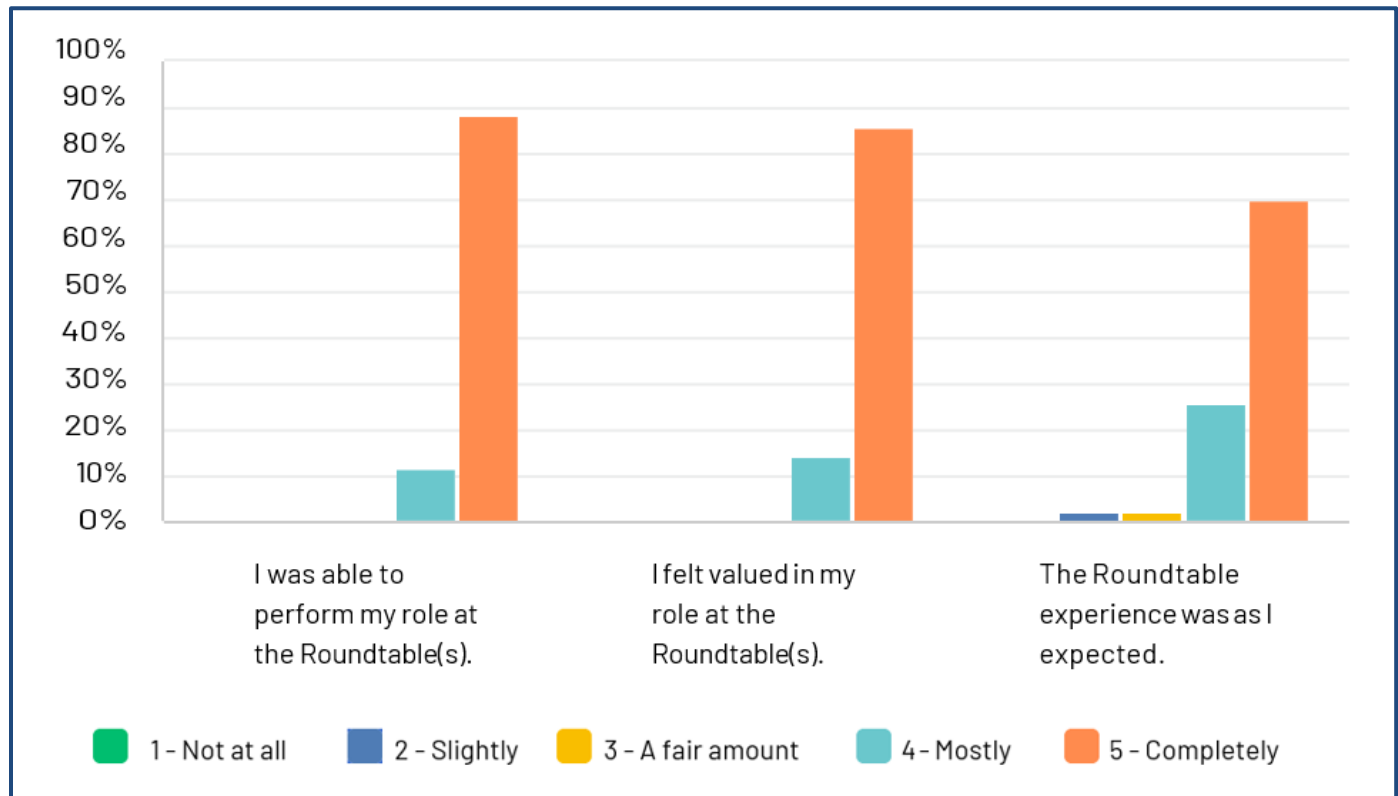
Not at all (0, 0%), Slightly (0, 0%), A fair amount (0, 0%), Mostly (5, 11.6%), Completely (38, 88.4%)

I felt valued in my role at the Roundtable(s):

Not at all (0, 0%), Slightly (0, 0%), A fair amount (0, 0%), Mostly (6, 14.0%), Completely (37, 86.0%)

The Roundtable experience was as I expected:

Not at all (0, 0%), Slightly (1, 2.3%), A fair amount (1, 2.3%), Mostly (11, 25.6%), Completely (30, 69.8%)



Question 6: Additional comments about performing your role, e.g. what you enjoyed, what was challenging, what could be improved, etc. (N=23)

Overall, the roundtables were perceived as a smooth, effective process, providing meaningful opportunities to shape CCI in health and medical research, while also highlighting areas for refinement in participant engagement, discussion management, and materials design.

Overall strengths:

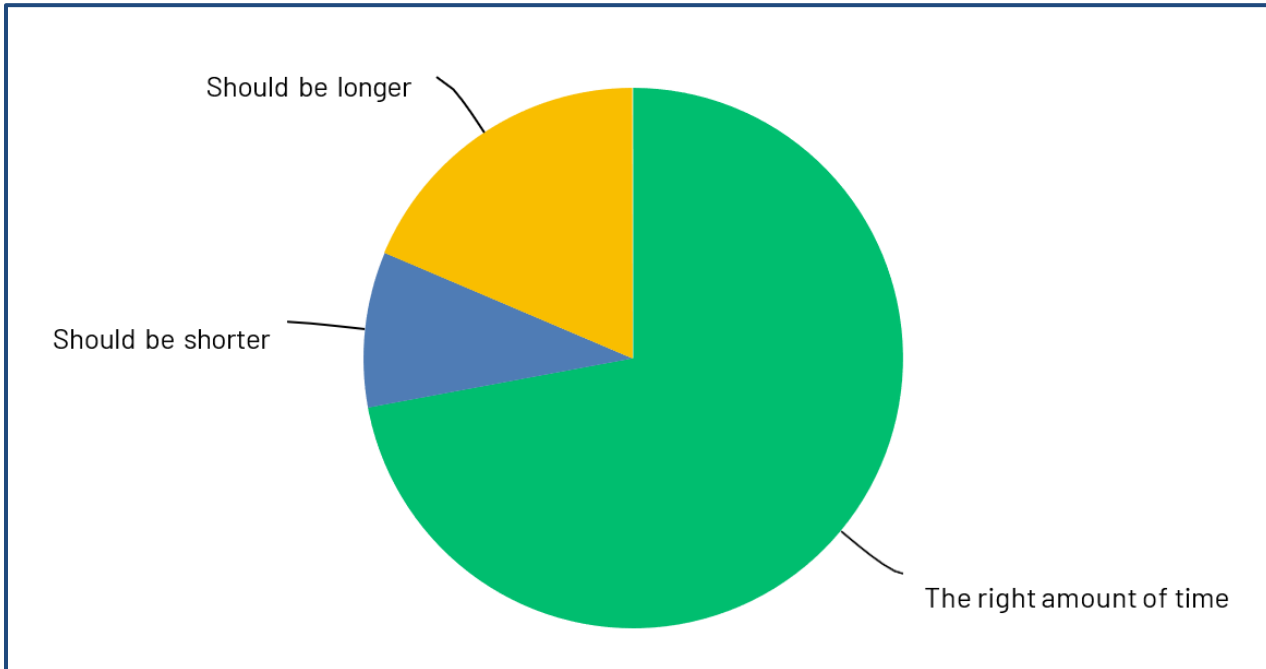
- Roundtables were engaging, well-organized, and valuable experiences.
 - Collaborative environment with respectful, positive group dynamics.
 - Participants appreciated hearing diverse perspectives and networking opportunities.
 - Facilitation and support materials (slides, templates, structured processes) helped facilitators and scribes feel well-prepared, confident, and valued in shaping discussions.
- ✓ *"I enjoyed coming together as a group and all working together to help improve CCI in the health and medical research sector - I hope we can do more of this in future! Even when there were differences of opinion, everyone was respectful and there was an understanding that everyone had the best intentions. It really was a great group to be a part of. I also enjoyed facilitating and received positive feedback on our session."*
- ✓ *"I felt well prepared for my role, because all the materials were supplied and the knowledge that the full partnership were carrying out the roundtables in the same manner - this consistency provided me with confidence in the process and was able to articulate that to the attendees. I enjoyed having multiple voices in the one room, passionate about Consumer and community involvement in research and all wanting the statement to be the best it can be."*
- ✓ *"I enjoyed hearing diverse perspectives, and feeling that my role was important in lifting up the voices of diverse stakeholders in shaping the final Statement."*
- ✓ *"It is always a valuable experience to hear from consumers. It was a good workshop, I enjoyed them."*
- ✓ *"Extremely well run. I really enjoyed the experience."*

Challenges and suggestions for improvement:

- Managing discussions when participants jumped between topics or became sidetracked, ensuring all participants could contribute equally, and scribing context accurately was challenging at times.
 - Questions could be more open-ended to better elicit broad feedback and stakeholder engagement could be improved through more rigorous attendee screening and targeted messaging.
- ✓ *"Keeping up with the discussion as a scribe was tricky, but noting time is limited, I worked to keep up with what I was able to. The sticky notes were great for questions/comments that weren't necessarily fitting for what was being discussed."*
- ✓ *"It was challenging writing on butcher's paper. It would have been easier to use a laptop, but I can understand the challenge of attendees viewing a small screen."*
- ✓ *"Some of the roundtable attendees were clearly only there to collect their fee and did not participate at all (no video, no voice chat). There were some additional challenges in getting some participants to join in and offer comments. Would suggest a more rigorous screening process to enable more involved participants."*
- ✓ *"The communication for each stakeholder group could have been improved by targeted messaging - i.e., consumers were confused at times, and rural areas were difficult to engage. A targeted approach with local people would be better next time."*

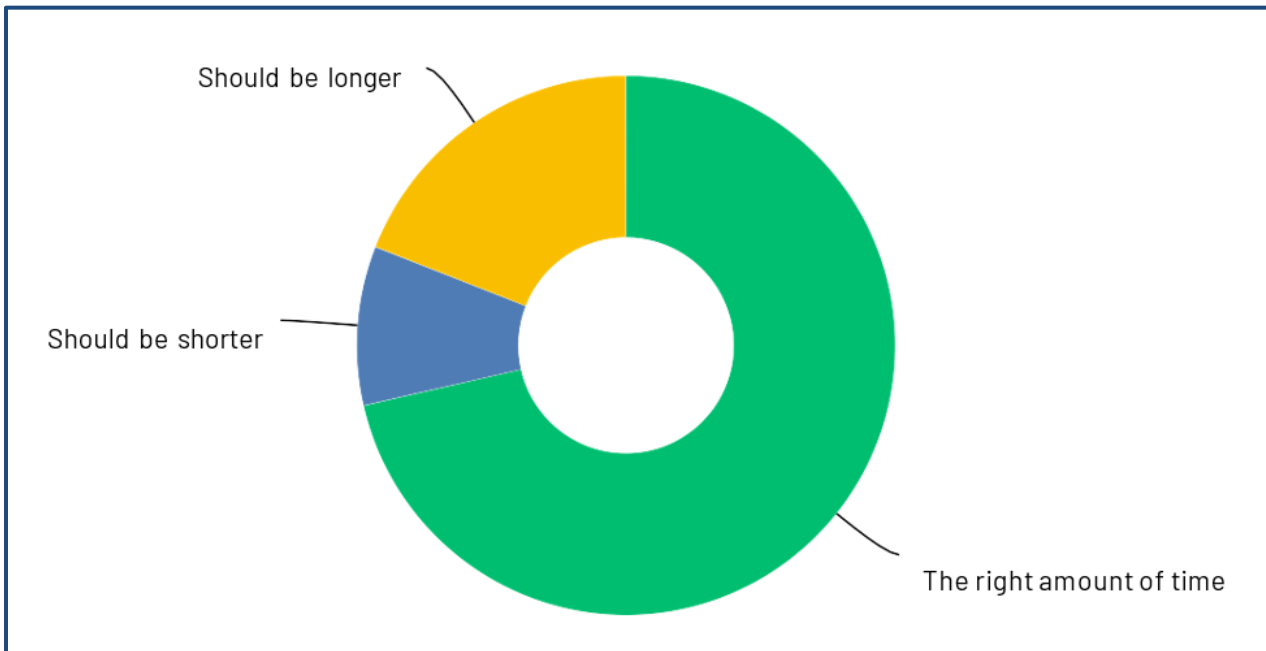
Question 7: I felt the timing of the Roundtable (2 hour session) was:

The right amount of time (31, 72.1%), Should be longer (8, 18.6%), Should be shorter (4, 9.3%)



Question 8: I felt the timing for the questions (30 minutes per question) was:

The right amount of time (30, 71.4%), Should be longer (8, 19.1%), Should be shorter (4, 9.5%)



Question 9: Additional comments on the timing and setup of the Roundtable, e.g. reflections on the environment, setup, working with the attendees, etc. (N=18)

Overall, participants felt the timing and setup of the Roundtable were well-planned and effective. The 2-hour session generally allowed for meaningful discussion and questions, and Zoom participation worked smoothly. Facilitators were praised for keeping discussions on track and helping participants feel heard. The collaboration with partner organizations was viewed positively, enabling resource efficiency and co-located events. The venue, location, and setup, including catering, registration, and room layout—were highly appreciated and considered appropriate for facilitating small-group conversations.

Overall strengths:

- Timing allowed for questions and discussions without feeling overly rushed.
 - Facilitators effectively managed discussions and maintained focus.
 - Venue location, setup, and catering contributed to a positive experience.
 - Small-group sizes supported robust conversations with diverse perspectives.
 - Collaboration with partner organizations was efficient and beneficial.
- ✓ *"Working together with a partner organisation was really good. We were able to stretch the dollar further by co-locating our roundtables. Holding the event close to public transport and at a hotel was a good decision. The setup was perfect - with catering and registration outside of the room and a decent amount of space for round tables and front lectern & screen."*
- ✓ *"Zoom worked really well."*
- ✓ *"I thought the setup worked well and the group sizes facilitated robust conversations with different perspectives."*
- ✓ *"The roundtables were well organised and everyone understood their role. The food and venue were amazing. The venue and setup were appropriate to facilitate conversations in small groups."*
- ✓ *"The people - all of them- were fantastic. It made the experience worthwhile"*

Challenges and suggestions for improvement:

- Some questions, particularly 2a and 2b, were difficult to fully address within the time allocated.
 - A short mid-session break could help maintain energy and focus.
 - Slightly more time per section (10–15 minutes) could reduce rushed discussions and allow better idea consolidation.
 - Some tight table spacing and room acoustics sometimes made it hard to hear discussions.
 - Smaller breakout groups may require adjusted timing as they progress through questions faster.
 - End-of-session sharing could use a bit more time for participants to consolidate and present ideas.
- ✓ *"Question 2 was hard to keep to time given there were two parts. In a 2 hour session you need to include a break. It was a lot to cover, but would not suggest a longer time. People would have preferred more time at the end to share with the room."*
- ✓ *"Tables were very close together so it made it quite hard to hear and listen to feedback."*
- ✓ *"Could give specific time in between for debrief of ideas"*
- ✓ *"I think having a bit of extra time for each section, even by 10–15mins, would have helped discussions feel less rushed (less like everyone has to rush to get their point across), and allowed for better consolidation/weigh-up of ideas."*

Question 10: Please share any other reflections or feedback on your experience supporting the Roundtables. (N=12)

Participants shared generally positive reflections on their experience supporting the Roundtables, highlighting both the strengths of the event and areas where improvements could be made. Many appreciated the professional coordination and partnership approach, the networking opportunities, and the opportunity to contribute to a national consultation process. At the same time, several practical and structural challenges were noted, particularly regarding participant preparation, inclusivity, and follow-up clarity.

Overall strengths and positive experiences:

- Many respondents enjoyed the experience and found it insightful, especially for students and those engaging with diverse stakeholders.
 - The Kids Team received recognition for excellent organisation, attention to detail, and support in managing a large-scale national consultation.
 - The Roundtables facilitated valuable connections between consumers, researchers, and supporting organizations.
 - Participants valued the sharing of experience and problem-solving approaches among multiple organizations across Australia.
 - Both table facilitators and head facilitators were praised for professionalism and organisation.
- ✓ *"There was clearly a lot of coordination done by The Kids Team and as a partner, I was really appreciative of that, bc we don't yet have the capacity to do that level of activity on our own. So a big thankyou to The Kids for the time and effort you put in and for supporting a fantastic partnership to deliver on this national consultation!"*
- ✓ *"A good networking opportunity between consumers, researchers and those who support these working relationships. People connected and focused on what they think NHMRC should do. It was a privilege to be involved."*
- ✓ *"It was invaluable working with all the other organisations across Australia. Everyone contributed their experience, provided support and regular updates on what was working well or not and the solutions they were putting in place."*
- ✓ *"From my external perspective, this appeared to be an enormous task to arrange, but The Kids delivered it brilliantly, professionally and with plenty of detail and coordination."*
- ✓ *"I thought it was a great event! I'm really glad I was able to be a part of this."*

Challenges and suggestions for improvement:

- One person noted that many attendees had not read the draft statement in advance, resulting in rushed discussions.
 - Participants expressed uncertainty about how their feedback would be used and whether it would meaningfully influence NHMRC decisions, with some perceiving the process as a potential "tick-box" exercise.
 - Other reflections and suggestions are shown in the quotes below:
- ✓ *"I'm not sure why these weren't set up as recorded sessions as so much information will have been lost. The depth to feedback that you capture from qualitative discussions has been minimised to a few points on paper. The structure and promotion of this also limited attendance of people with disability. I had requested information around accessibility but never received it so did not want to share with my network. The structure, such as the space and timing, would have made it largely impossible to include the voice of linguistically diverse attendees or someone with a sensory disability for example. There was a lack of consideration of younger people as consumers. Most attendees were middle aged or older. I'm not sure what will actually happen from the round tables so it would be good to get clarity around that. People in my group felt that this was a bit of a tick box activity."*



- ✓ *"It was overall a good experience, and hopefully all feedback can make its way to NHMRC and be implemented meaningfully. There were many in our Roundtable that thought researchers/professionals should be COMBINED with consumers (i.e. sat at the same table rather than separated), to encourage fluid thinking and dynamic discussions. Or perhaps it would have been beneficial for participants to hear the rationale of why they were placed on separate tables (e.g., did the consultation want to group feedback by sector?)."*
- ✓ *"Holding the virtual roundtables brought with it some unexpected guests. The team however dealt with this exceptionally well."*

NOTE: Questions 11 and 12 were for Project Partners only to answer.

Question 11: Please rate the following on a scale of 1-5, with 1 being "Not at all" and 5 being "Completely."

My experience of being a Roundtable Partner was as expected:

Not at all (0, 0%), Slightly (1, 4.8%), A fair amount (0, 0%), Mostly (7, 33.3%), Completely (13, 61.9%)

I enjoyed being a Roundtable Partner:

Not at all (0, 0%), Slightly (0, 0%), A fair amount (2, 9.5%), Mostly (2, 9.5%), Completely (17, 81.0%)

I felt my contributions as a Roundtable Partner were valued:

Not at all (0, 0%), Slightly (1, 4.76%), A fair amount (0, 0%), Mostly (4, 19.1%), Completely (16, 76.2%)

The attendee recruitment process went smoothly:

Not at all (0, 0%), Slightly (3, 14.3%), A fair amount (2, 9.5%), Mostly (9, 42.9%), Completely (7, 33.3%)

I felt confident in convening our Roundtable(s):

Not at all (0, 0%), Slightly (0, 0%), A fair amount (0, 0%), Mostly (5, 23.8%), Completely (16, 76.2%)

I felt the Roundtable setup and process worked well:

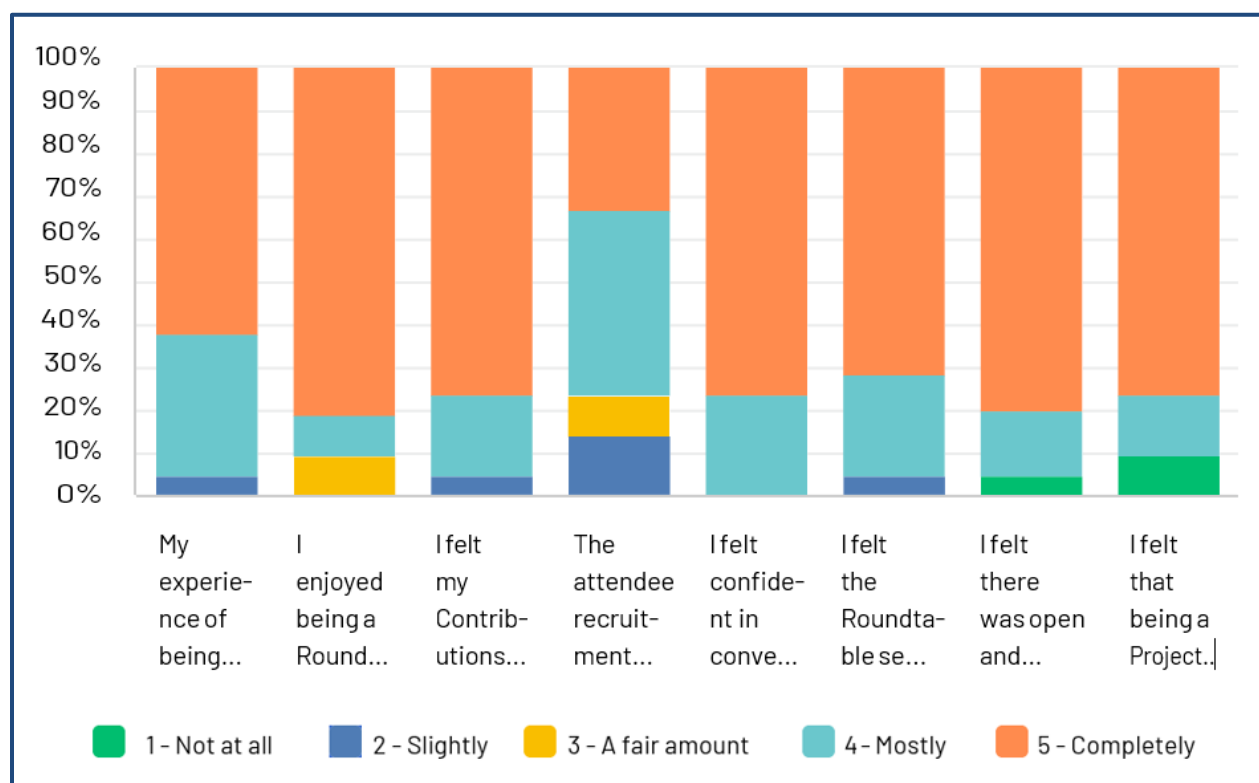
Not at all (0, 0%), Slightly (1, 4.8%), A fair amount (0, 0%), Mostly (5, 23.8%), Completely (15, 71.4%)

I felt there was open and transparent communication between The Kids and the Partners throughout the project:

Not at all (1, 5.0%), Slightly (0, 0%), A fair amount (0, 0%), Mostly (3, 15.0%), Completely (16, 80.0%)

I felt that being a Project Partner offered the opportunity to develop new or strengthen existing relationships with community/stakeholders:

Not at all (2, 9.5%), Slightly (0, 0%), A fair amount (0, 0%), Mostly (3, 14.3%), Completely (16, 76.2%)



Question 12: Additional comments (optional) e.g. what worked well, challenges, areas for improvement, etc. (N=10)

Overall, participants expressed a highly positive experience engaging with the roundtables while also offering constructive feedback on areas for improvement. The feedback highlights strengths in team coordination and participant engagement, alongside opportunities to refine processes, resource allocation, and collaboration practices.

Overall strengths and positive experiences:

- ✓ "Thank you the Kids for bring this team of amazing organisations and people together. I learnt so much and have made many valuable connections. Great work!"
- ✓ "A really positive and fun experience."
- ✓ "Thank you for doing a great job! It was such a pleasure working with you all :)"
- ✓ "I felt it was highly beneficial to have the NHMRC staff involved in the process, as they were able to offer further information and insight into the DRAFT that assisted groups with convening information."
- ✓ "It was all very smooth."

Challenges and suggestions for improvement:

- ✓ "The Kids are an incredible team to work with. It is hard when you are managing multiple stakeholders and they did a great job keeping us on track. Considerations for the future - resource more staff to support the team deliver >25 roundtables, trust the State / Territory partners to prepare their local facilitators and scribes, and look for efficiencies in the recruitment process."
- ✓ "Not all NHMRC scribes were impartial with some views shared at times. I don't think this would have impacted the results in a big way, but may have quietened some voices for fear of being challenged."
- ✓ "Not sure that the process for determining who could attend the round table discussions worked. There were several emails trying to backfill positions around the table (real and virtual) in the latter part of the consultation period."
- ✓ "I would like to see all partners approach future work, grants, and projects as equal collaborators. There is a real opportunity to galvanise the momentum from this exercise to meaningfully advance consumer engagement. However, the repetitive nature of consultation is becoming a barrier to progress. We need to provide that feedback clearly. Consumers and community members want to see tangible changes now, not just more discussion."