National Centre of Excellence in **Intellectual Disability Health**

# What's Important to Us in Health Research? Establishing National Health Research Priorities Through a Co-Design Process

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## Acknowledgement of Country

We acknowledge the Traditional Custodians of Country throughout Australia, and their continuing connection to land, sea and community. We pay our respects to them and their cultures, and to elders both past and present.

We pay our respects to all First Nations people with intellectual disability and acknowledge the higher prevalence of intellectual disability among First Nations people and the distinct challenges they face, along with the contributions they make to society.

## Acknowledgement

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## Cover Artwork

Amongst the Bush, Holly Walton, 2025.

## National Centre of Excellence in Intellectual Disability Health

The establishment of the National Centre of Excellence in Intellectual Disability Health was in response to the significant health disadvantage experienced by people with intellectual disability. The Centre supports the delivery of the Australian government's National Roadmap for Improving the Health of People with Intellectual Disability.

The Centre builds on the work of 3DN and the Centre's nine Consortium organisations – First Peoples Disability Network, Council for Intellectual Disability, Down Syndrome Australia, The Kids Research Institute Australia, Queensland Centre of Excellence in Autism and Intellectual Disability Health, Queenslanders with Disability Network, Centre for Disability Studies, University of Melbourne and UNSW.

Our vision is that every person with intellectual disability in Australia gets high quality health care.

Our mission is to work together with people with intellectual disability to make their health as good as it can be.

## Our values

- We support the leadership of people with intellectual disability in their own lives and in the Centre.
- We are leaders in accessible communication and other inclusive practices.
- We respect family members and other advocates.
- We include people from diverse backgrounds.
- We listen to each other and value all perspectives.
- We are honest and open.
- We are accountable to people with intellectual disability and each other for what we do.

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# Research Insights

**AJ**

## Introduction

For a long time, research about disability was controlled by people who didn't have disabilities. This meant the researchers made all the decisions and often ignored what was important to the people the research was focused on.

Research in Australia has included people with intellectual disability. Some of this research included people with intellectual disability as researchers or advisors. However, the research hasn't always focused on topics that people with intellectual disability thought were important in their lives.

This project was about working together as an inclusive research team.

We wanted to find out what matters to people with intellectual disability in health research.

## Our team

AJ and other researchers DC, GG & MO'D all work at the Centre for Disability Studies (CDS), PF worked at the University of New South Wales and the project was a project of the National Centre of Excellence in Intellectual Disability Health.

Our team included people with many different backgrounds and experiences. AJ wrote this summary. She is a researcher on our team with intellectual disability. She works to make sure people with disabilities have the same rights as everyone else. She is passionate about good healthcare, fair jobs and easy to read information. She is also involved in the performing arts.

## Our research

We did the research in two parts. The first part was interviewing researchers with lived experience to hear their experiences about the importance of health. The second part was running an art competition for people with lived experience to showcase what health issues matter to them.

We collaborated as a team. Everyone contributed in their own way and had a role in all parts of the research. We made sure the research included everyone.

## What matters

We found that what matters to the researchers and artists with intellectual disability were eight different areas of health. We did not rank them in order of importance. They are shown as equally important.

Three of the areas we called 'overarching'. This means they sit over all the themes and need to be thought about and included in all health research with and for people with intellectual disability. These ideas are:

- **Lived experience, Narrative and Identity**
  Valuing personal experiences of health
- **Person-centred Care, Autonomy and Self-determination**
  Empowerment and control over health decisions
- **We are only just scratching the surface**
  Understanding there is a lot more to know about the unmet needs of people with intellectual disability

The other important areas for health research are:

- **Well-being**
  Mental health moves beyond illness to focus on well-being, including spending time with other people and in nature and doing activities that are meaningful to the person
- **Communication and Health Literacy**
  Good communication and easy to read information in a variety of accessible formats
- **Accessible and Inclusive Health Systems and Practice**
  Challenging barriers to health systems and improving the skills of health workers
- **Health Promotion and Medical Conditions**
  Promoting better health and learning more about different medical conditions
- **Arts-based Research**
  Using creative ways to do research through art and storytelling

## What we did well

This is a summary of what AJ thought worked well in the project. Our project worked well because:

- We included the voices of people with lived experience in both the interviews and the art competition
- Different people were able to communicate in different ways
- Participants enjoyed expressing themselves during the art competition and feeling valued as artists
- The art project was so successful it could lead to being a yearly art competition
- Both the interviews and art competition were great ways for people with lived experience to express themselves through storytelling and creativity so everyone can share their ideas
- Our team had lived experience team members from different backgrounds
- All research team members contributed to the research planning, recruitment, data collection, analysis, writing, presenting and promotion
- Our research team member with lived experience had a voice and purpose during the project rather than just being on the team for show and not doing the work

- We used creative ways to do the data analysis
- We showed that people with and without disability can work well together as a team
- We showed that people with intellectual disability know what they want in health
- The government should listen to what people with intellectual disability have said is important to them.
- What we learned can also help the rest of Australia. It shows other researchers different ways to do research. It shows the government and people working in health which parts of health and the health system are most important to people with intellectual disabilities.

## Conclusion

In summary, this project showed the deep and creative ideas of 49 people with intellectual disabilities through 60 different artworks. We also talked to 16 researchers with intellectual disability. This is a brand-new way of doing health research in Australia. This helped us learn more about how to do research in a way that respects and includes everyone. What matters is people with intellectual disability having a voice in health research.

# Background

Emancipatory research seeks to address the power imbalance that has historically dominated disability research [1]. The focus is on prioritising the voices of people with disability in the direction, design and implementation of research which is relevant and directly impacts on their lives. It is underpinned by the social model of disability and identifies how research has been used as an abuse of power by researchers who pursue their own goals and priorities to suit academic interests, and as such acknowledges systemic oppression of people with disability [1].

Previous national research agenda setting exercises in Australia have been inclusive of but not focused on the health research priorities of people with intellectual disability specifically [2]. In mapping the disability research landscape based on published literature, Smith-Merry and team identified that most funding (22%) went to intellectual disability research. It is unclear however, the extent to which people with intellectual disability determined the research agenda of these published studies [3, 4].

A recent audit of intellectual disability health research that has been funded in Australia in the five-year period, 2019-2024, highlights that most research funding has been awarded to the areas of general health and congenital disorders. The authors also note that inclusion of people with lived experience of intellectual disability in research is indicatively increasing yet remains inconsistent. There is no indication that the research receiving funding are priority areas for people with intellectual disability as decided by people with intellectual disability [5].

Despite existing agenda and priority setting initiatives nationally and internationally, the current work is the first national project that used inclusive methods, is co-designed with people with intellectual disability and prioritises the voices of people with intellectual disability through using a mixed and creative approach to capture these voices.

This collaborative and inclusive project sought to gather perspectives from people with intellectual disability about their priorities for research which would contribute to better health. The work has a broader scope also to inform the wider research agenda in Australia to reflect the areas of health and health systems that are important to people with intellectual disability.

To reflect the diversity of the population of people with intellectual disability in Australia and to ensure a diversity of voices could be captured, the team co-designed a qualitative, multi-modal methodology.

This qualitative research used Arts Based Research (ABR) and qualitative interviews to understand “What health issues matter most” to people with intellectual disability. The aim was to use these insights to frame and propose a set of research priorities for health research with and for people with intellectual disability in Australia. Research priorities in this project are understood as areas of health research that are important to people with intellectual disability. A prioritisation exercise where areas of importance are ranked from most to least important was not completed. Therefore, any one issue or thematic area identified should not be interpreted as more important than another. A full traditional prioritisation exercise would take more time and resourcing, and further creative and adaptive methodologies which was not feasible within the 12-month timeline. However, it could potentially be a future project. Nonetheless, the issues raised are areas of importance for people with intellectual disability and the value in identifying these should not be underestimated.

# Research Approach

A qualitative, multi modal approach was used in this research using an ABR and narrative framed qualitative interviews. The research team were from a range of disciplines and lived experiences. Some were experienced academic researchers; others were emerging academic and community researchers, with one member of the research team identifying as a person with intellectual disability, one as a parent of children with disabilities, one as a sibling of a family member with intellectual disability and another with family and carer lived experience of family members with disabilities.

This team had a strong commitment to inclusive research principles and practices where people with intellectual disability "play an active part" in the research [6], and actively shape how the research is done [7]. Extending beyond the immediate research team, people with intellectual disability were positioned as co-creators of knowledge in the ABR, and as key informants in the qualitative interviews where their experiential knowledge of undertaking research was drawn on. Further in the ABR component, others with lived experience as supporters, family members, partners, allies, carers and artist judges of the art competition, also played an active part.

Planning the research was undertaken as a collaborative team using co-design approaches for the overarching research design, and design and development of research approaches and tools. The team held inclusive meetings and employed broader inclusive ways of working to move from research idea to implementation. An overview of the collaborative and inclusive approaches used for data collection and analysis is provided in the following sections.

The two parts of the research were conducted over nine months, beginning with the qualitative interviewing from July 2025 until February 2026. The Arts Competition had a longer lead in time and required recruitment of a specialist arts-based researcher. It was conducted from August 2025 to March 2026.

## Positionality

AJ is a researcher with lived experience of intellectual disability. She is an advocate for the rights of people with disabilities with a strong passion for inclusive health and employment and easy read translation. She also works as a singer, dancer and actor in the performing arts industry.

DC is an educator, arts practitioner and researcher whose work explores disability and inclusive creative environments. She is a parent of children with disability and runs a nature immersion business working with children, young people and families, particularly those with disability. She is of Irish and Danish heritage and lives and works in Australia.

GG is a clinician, health professions educator and inclusive researcher. She is from a cultural and linguistic diverse background and identifies as a woman of colour. She is a co-conspirator in disability rights and conducts disability research in the global south and in Australia.

MOD is a disability and inclusive researcher. She has worked in Ireland, Europe and Australia. She has a younger brother with intellectual disability and is an advocate and ally for better inclusive practices, equity and disability rights.

PF is a disability and inclusion researcher focusing on inclusive and collaborative research alongside people with lived experiences of disability. She has lived and worked in Australia and New Zealand/ Aotearoa. She has carer lived experience and family members with disabilities.

RDA is an inclusive researcher. His work focuses on digital inclusion, inclusive employment, and co-designed research with people with intellectual disability.

We would like to take this opportunity to acknowledge Sian Anderson (SA) who was involved in the initial design and pilot interviews.

# Ethics

This research project was approved by the human research ethics committee of the University of Sydney reference 2025/HE000244. Easy Read documentation, such as flyers, participant information statements (PIS), consent forms, and Terms and Conditions for the arts competition were used for advertising and recruiting participants.

## Consent

The consent process differed for each of the participant groups. Art competition participants gave consent during the digital submission process via an online portal, which included a copy of the PIS and consent forms and was explained in the Terms and Conditions of the competition. Interview participants gave their written consent directly to the lead researcher via email. Both groups were advised during these processes that they could withdraw their consent at any time during the process.

## Privacy and Confidentiality

Recordings of interviews were deleted after they were transcribed. Transcripts have been stored with anonymous tags on an encrypted hard drive. All transcripts will be destroyed 15 years after the conclusion of the project in accordance with the National Statement.

Digital copies of artworks and artists statements are currently displayed in an online exhibition where participants gave consent for this (as described below). They will remain online for a period of 5 years after the research project is complete unless participants request the digital copy of their artwork be removed (as explained in the PIS and consent form). All personal information, including phone numbers and email addresses (only collected to be able to contact participants) were destroyed after the art competition finished.

# Part 1 – Art competition

ABR is an established research approach in qualitative research [8, 9], and is an emerging method in inclusive research, primarily through Inclusive Arts with people with intellectual disability [10]. There are several reasons for using ABR in our research about 'What health issues matter' for people with intellectual disability including; its accessibility to the intended participants, transformative potential for knowledge building and dissemination, and that, based on artistic expression, it can open up what Leavy [9] suggests is a "...unique, transdisciplinary way of knowing and communicating" (p. 24). Within inclusive research the emphasis in ABR on 'expression' is key. Jude Kelly, the Artistic Director of the Southbank Centre in the United Kingdom, a collaborating organisation in Inclusive Art notes, "I think to understand other people's lives through forms of expression ...often end up being artistic, because they're the ones that cross barriers" [10] (p. 63). Similarly, the emphasis on 'voice' in ABR aligns strongly with the aim of inclusive research to bring otherwise silent or silenced voices into research which is 'about them'.

In this research those voices have been heard through the artists' art statements and through their art works. The art competition, described in detail below, also served a 'research aim' that aligns in ABR and inclusive research; to directly communicate what the artists were expressing – and let the 'audience' interpret meaning through what they saw and experienced – to be 'subjectively' engaged with, giving ultimate 'voice' to the artists.

## Co-design of the competition

Two research team members co-led the development of the art competition (DC & AJ). Both researchers are arts practitioners who have strong networks in the performing arts and creative arts fields. Through her art and self-advocacy work, AJ has strong experience, and many connections, in these fields. DC has extensive experience as a creative producer, specialising in large-scale, inclusive art projects. When it was decided that the research would be including an arts competition AJ & DC began meeting weekly via online meetings as they live in different States of Australia. They worked with the broader team on the research ethics application which included developing clear statements about the purpose of the competition in plain English, approaches for recruitment, wording of promotional materials and wording of the PIS and consent forms in Easy Read. AJ pilot tested the Easy Read documents and made revisions to improve accessibility of this information for participants. AJ and DC co-developed and designed the promotional video, with AJ using their theatrical background in the design and delivery of the video.

The positionality of AJ and DC and their co-design of the competition fostered inclusion in the broader arts community. The competition was purposeful and an opportunity to promote and celebrate work of artists beyond the research context it was situated in. It valued artists with intellectual disability as valuable contributors to the Australian art community and is one of very few art competitions of its kind to promote the art of people with intellectual disability in Australia. It was conceived as not just a creative activity; but a purposeful one that centred the artist's aesthetic, artistic merit, intrinsic value of the artworks and a commitment to the artworks having critical consideration.

To this end, the competition followed the National Association for the Visual Arts (NAVA)'s good practice recommendations for awards, prizes and competitions. This included consideration of legal requirements, responsibilities of organisers (including terms and conditions, entry processes, selection process, judging, selling, transparency, and cultural safety)[1] and responsibilities of artists accessibility, artist fees and intellectual property (including copyright, licensing, moral rights and ownership). Unfortunately, the project budget did not allow for artist loan fees to be given to the finalists.

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1 Cultural safety in this context includes groups such as First Nations, d/Deaf, Disabled or other underrepresented artists or collectives

A commitment to centring participants identity as an “artist” in the broader Arts community was also reflected in the professional curation of the art exhibition, the importance given to the artist statements, the high quality of the prizes and the decision to have a longer period for the online exhibition (approximately five months). Also central to this aim was the convening of an expert judging panel using the networks of AJ & DC. All judges were paid according to NAVA’s payment standards [11].

## Co-Judging the artworks – collaboration and inclusion

The artist judging panel included two high profile lived experience artists, two artists without lived experience of intellectual disability who are experienced art workers from the arts industry and leaders in disability art, and one neurodivergent artist who also works as a researcher and community development practitioner in arts-in-health and socially engaged practice. Our judging panel selection exceeded NAVA's best practice recommendation to include at least one member of the minority community for which a competition is aimed.

Rigorous judging criteria were applied in line with other art competitions, such as artistic merit, impact, adherence to the theme, creativity and originality. DC developed a scoring system based on these criteria using Jotform® and Excel (Microsoft 365, Excel 2021). Judges critically engaged with both the artworks and the artist statements. AJ & DC worked closely with the judging panel to ensure accessibility and inclusion were embedded in the judging process. Documents for the judging panel were written in Easy Read and plain English. These included the Terms and Conditions, the judging panel brief, judges score card instructions and judges' score cards which were both pilot tested by AJ. (See Appendix A, B, C, D and E)

DC met with members of the judging panel online on four occasions via Zoom® for the briefing, to check in regarding the accessibility of the judging materials and the process and to finalise prize winners. Judges with lived experience of disability had access to in-person support from other judging panel members if needed. The judging panel could contact DC at any time during the process for clarification of the process or other support. The judging took place at a busy time of the year over the summer holiday break (Jan-Feb 2026). However, the whole panel remained engaged and completed their judging within the short timeframe. They were a cohesive group that shared ideas for adapting the awards that included inclusion of a shortlist that was shared publicly before completion of the judging and the inclusion of five Highly Commended awards to celebrate the high quality of artwork submissions. The judges wrote comments about the artworks of four prize winners and five highly commended artists. These comments were published in the online exhibition and presented at the Prize Ceremony described below. There was also inclusion of a 'People's Choice' award that attracted 993 nominations. Members of the wider community voted for their favourite artwork and submitted their vote via the online platform Jotform®, which AJ pilot tested (See Appendix F).

## Online Exhibition – collaboration and inclusion

The online exhibition was launched on 6th February 2026 using Kunstmatrix, a “leading digital platform designed for creating, curating, and sharing immersive 3D virtual art exhibitions”. This platform was chosen collaboratively by the research team because of its relatively user-friendly functionality compared to other platforms that were explored. The platform included possibility for text-based and audio-based options for contextual information, voice over functionality, simplified layout “exhibition rooms” and self-guided tour options. Self-guided tour options meant visitors would be able to navigate the exhibition immersion automatically without needing to physically touch a computer. Visitors could also choose to download a PDF of the catalogue to look at the exhibition without 3D immersion.

DC curated the exhibition using typical curator techniques such as exhibition theme, visual aesthetic, spatial design, cohesive narrative and visitor experience. AJ pilot tested the navigation and visual aesthetic, giving feedback on accessibility.

## Prize ceremony – collaboration and inclusion

The prize ceremony was held in person in Sydney and via live streaming on 25 February 2026. AJ and MA collaboratively MC-ed the event, each writing their own script for the presentation. One of the lived experience judges was invited to represent the judging panel and present the awards. Prize winners were given the option to attend in person, via livestream or via video. Five award winners attended in person, while three attended the live stream. One award winner sent a video, which was presented at the ceremony.

## Arts competition participants

The online art competition was opened to amateur artists who were over 18 years old, identified as having intellectual disability, live in Australia and have an interest in creative expression through various art mediums. To recruit a wide range of participants, art was defined as expressing ideas or emotions through a medium of the artist's choice, including but not limited to painting, drawing, sculpture, music, dance, writing, digital art and more. All artists were required to submit their artworks in a digital format. The artists were informed their artwork should address the question 'What health issues matter most to you'.

## Recruitment

A promotional campaign was developed including a promotional flyer (see Appendix G) that was posted on the Centre for Disability Studies (CDS) website, the National Centre of Excellence in Intellectual Disability Health (NCEIDH- the Centre) website and shared on social media posts and via email. A video was also shared via CDS and NCEIDH social media platforms. The emails were targeted to networks within the Centre, to organisations that work in the arts with people with intellectual disability and sent via the research team email to a broader group. Emails were also sent to broader arts organisations across Australia utilising DC networks in the arts industry. The Centre Consortia organisations were also requested to promote the competition by sharing the opportunity with people with intellectual disability connected to their organisations and networks.

Artists were directed to one of the art competition leads on the research team (DC) to find out more about the competition and to register their intention to submit an artwork. Through this connection artists were able to ask any questions they had about the opportunity, including to clarify their eligibility, the 'fit' of their intended artwork with the competition theme, technical questions about submitting the artworks and other general questions. This was an important part of the recruitment process that enabled the artists to connect positively and confidently with the competition. Easy Read PIS and consent forms were also able to be discussed, and any questions that artists had were addressed at the recruitment stage. The Terms and Conditions (provided in Easy Read) of the competition required participants to read the PIS and consent form when submitting their artwork and statement. It stated that artist statements submitted to this competition would be used for research purposes. It also explained that artists could withdraw their consent at any time and that artists will be contacted throughout the process to recheck for consent.

## Data collection

The competition saw 49 participant artists submit 60 artworks in a wide range of mediums. Artists were located across Australia, including 27 artists from New South Wales, one artist from Australian Capital Territory, three artists from Queensland, five artists from South Australia, one artist from Tasmania, 12 artists from Victoria and three artists from Western Australia. 31 artists identified as female, 17 as male and one artist specified “unknown”.

Art submissions were initially planned to be open for 12 weeks (1st October 2025 – 16 January) to account for the submission period falling at a busy time of year. Due to the time required to attain ethics approval the submission window was reduced to two months from 1st November 2025 until 16th January 2026.

## Inclusion and accessibility in the data collection

The research team considered various submission methods to prioritise accessibility and decided to develop a customised form on the online platform Jotform® given the potential complexity of managing varied and large file sizes and the need for consistency across submissions (See Appendix H).

AJ and three other lived experience researchers from CDS pilot tested the customised submission form for accessibility, while Artists were encouraged and supported by the research team to have support people as involved as they wanted and needed throughout the process. DC was also available to assist artists with art submissions via phone if needed.

Participant artists were asked to provide digital files (photographs or video recording) of their artwork, the artwork title and an artist statement (written or video) which expressed participant's priorities for research about health and health services in Australia for people with intellectual disability. Information about the artwork's creation date and dimensions (height x width), material used as well as a small amount of basic demographic data were also collected. This included: name of artists, gender, and State or Territory where the artist was based. Participants were able to opt-in to consent to whether they wished for their name, artwork and artist statement to be exhibited online and at the launch event. Contact information (email and phone number) were also collected so we could contact participants in relation to the logistics of the art competition if needed. Consent for participating in the research was obtained via the Terms and Conditions, which was linked to, and accessed via the customised JotForm.

Artist statements were the focus for data collection for the purposes of data analysis. According to NAVA, artist statements are a "crucial element" for audiences to be able to understand artists and their practice; they serve as a bridge between the artist and their artwork, providing important context, intention and ideas so that viewers can construct meaning in their engagement with an artwork. Creţiu,[12] explains the main purpose of the artist statement is to act as the artist's "verbal self", giving voice to the artist's 'basic philosophy of creation, personal aesthetics, own technique, sources of inspiration' (p.7)

The submission form explained that an artist statement was required so artists could "tell us about [their] artwork" and give contextual information about how their artwork connects to the art competition's theme "Health Matters" as per standard art competition protocols. The form gave the artists three question prompts to write their artist statement (the same core three questions developed for the semi-structured interviews):

- What health issues matter most to you?
- Are there any health issues people with intellectual disability experience that you wish health professionals understood better?
- Why did you choose to make this artwork about health?

These questions were discussed, revised and adapted by AJ and research team to support accessibility and clarity for artists in being able to create their artist statements.

While the online form gave artists the option to submit either a text-based or audio-based artist statement, artists were supported and encouraged to use a range of different types of communication methods to best meet their needs to construct their artist statement. Some artists used scribes to write their artist statement from their spoken description, while others engaged in supported decision making to co-write a statement with their caregiver or support worker. One artist used personalised Artificial Intelligence (AI) for their artwork and artist statement. Personalised Artificial Intelligence is where a customised GPT has been designed and trained specifically to perform functions and tasks for its user. One statement also included a statement from a parent. Another artist submitted a video of a conversation with their support worker.

All artworks and artist statements were collated by DC and shared with the research team for the purposes of data analysis. The approach used for the data analysis is described below, drawing on the underlying inclusive research principles that were used to frame this phase of work.

## Data analysis

A Reflexive Thematic Analysis (RTA) approach [13, 14] was used to analyse the artist's statements, with a focus on 'understanding' what the key ideas were that were expressed through the artwork and then contextualised in artist statements. In this way, we considered the artists statement to be the 'voice' of the artist [12]. Rather than directly looking for answers and listing these as themes, the artworks and artist statements were engaged with to see what insights they offered – visual, auditory, sensory, and what messages and stories were shared through them about health experiences in the lives of people with intellectual disability. This reflects an important principle of RTA, that, "...themes are conceptualised as meaning-based, interpretive stories" [14], (p.2). The researchers 'noticed' and 'reflected on' these ideas and messages and used them to inform 'our' interpretation of 'What health issues matter most' to people with intellectual disability. Later in the report we share how these 'meanings' can be articulated as areas of research deemed important by people with intellectual disability, to shape future research with, for, by and about health in the lives of people with intellectual disability.

The broader research team met and agreed that three researchers (AJ, DC & PF) would analyse the artist statements, and 'talk about them' asking themselves, 'What do you think the artist is saying about their work and how did we think that links to our question about 'What health issues matter most to people with intellectual disability? Their approach is outlined below.

The written statements and artwork titles were used as the starting point. The authors used ChatGPT to assist with data formatting including sorting the artist statement themes that had been generated by the analysis team.  All final data interpretation, data analysis, and conclusions were developed solely by the authors. PF read these on her own and DC & AJ read them together. Given the relational and contextual connection between an artists' work and artist statement, the researchers also engaged with the artworks alongside the artist statements – (primarily visually, but for some by listening) to better understand what was being expressed by the artists. DC & AJ did this as a pair, with PF doing it solo. The three researchers came together twice in online meetings to talk through what they had shared about each artwork and artist statement on the Excel spreadsheet (Microsoft 365, Excel 2021) that was used to document the ideas that this engagement with the statements and artworks evoked. This sense of 'ideas evoked' rather than 'coding for' themes, is also reflective of approaches to RTA described in research 'with' people with intellectual disability [15], and in inclusive disability art research [10, 16]. These approaches and ours reflect what Braun & Clarke [14] refer to as 'Big Q' research where the approaches to analysis are "artfully interpretive' rather than positivist or 'answer' driven [14].

The three researchers share their approach in more detail in **Box 1.**

## Our co-design approach for data analysis

1. **Planning meeting – active participation, inclusion, relationship-driven**
   - We discussed the idea of doing two separate sets of analysis
   - AJ said she wanted to talk about what she was seeing in the artworks and artist statement – that doing this verbally, with someone else who read the statement would work
   - We decided DC and AJ would work together as they already had a good working relationship; PF would work solo

2. **Data Analysis Meeting #1 – flexible ways of working together**
   - We met over Zoom and read the artist statement out loud together
   - We talked about how important it was to look at the artwork, title and statement as a cohesive unit even though we were analysing the statement itself for the research
   - We then summarised the artist statement and artwork title
   - We both talked about what came to mind after hearing the statement and looking at the artworks.
   - Sometimes this was clearer than other times, for example if the artist wrote directly what their artwork was about but sometimes it was not so clear and it took longer to talk about the ideas coming from the artist statement and artwork.
   - DC took notes and wrote them in the Excel Spreadsheet which also had a column to note quotes from the artist statement that helped with understanding the meaning.

3. **Data Analysis Meeting #2 – shared responsibility and purpose**
   - We met with PF who had done the same thing on her own and compared what we had written down.
   - We didn't change anything because we felt like we had similar ideas – where they were different, they were just different words – not ideas
   - PF cut and pasted the ideas into a word document then used ChatGPT to sort them into groups. That document was used to develop Power point slides that had one 'big idea' and a summary of what it meant on each slide
   - We discussed how some ideas were connected, highlighted some key words on the slides and moved them around to develop the 'story'
   - After this discussion we agreed that there were two 'big ideas'/ 'themes' that sat around or over the rest like an umbrella, that some of the others 'touched or overlapped' with each other and others sat on their own (see **Figure 1**)

4. **Data Analysis – Knowledge Translation and creative processes**
   - DC developed the diagram – Figure 1.
   - We met again with the bigger research group and talked through the diagram.
   - AJ gave feedback on the diagram and suggested some changes to make it easier to understand and read
   - DC created a second draft of the diagram

Artworks are evocative and artist statements are more than a description of the artwork. They touch on artists' feelings, experiences, perspectives, intentionality, motivation, reflections and identity. There is a crucial connective bridge between artworks and artist statement which required a deeply reflective approach to the analysis for the researchers. In the practice of 'doing the analysis' the researchers 'spoke' their reflections out loud and talked about how the 'reactions' to the artworks and artist statements resonated for each of them – with clear references to our positionalities. The RTA we engaged in required that we 'owned our perspectives' [14] which encompassed not only our identities – gender, disability, age for example, but also our principles and approaches to researching inclusively. For AJ this is as a person with intellectual disability, artist and self-advocate, for DC as an arts-based researcher, artist and nature-based educator and for PF an academic researcher committed to transformative rights-based research. RTA as Braun and Clarke note requires, "... depth of engagement, thinking creatively and reflexively about the data, an intensive and organic...process [so as to] move beyond the most obvious or superficial meanings in the data" [17] (p. 3). In our broader team analysis meeting, we were able to share that the themes that we presented from our deeply reflexive thematic analysis had definitely 'moved beyond' what the first 'look' at the artworks had considered would be the key themes. These themes are discussed below. All quotes are verbatim as written in the artist statements and remain unedited for grammar or spelling. This reinforces the authentic voice of the artists.

## Findings - Art competition Key Themes

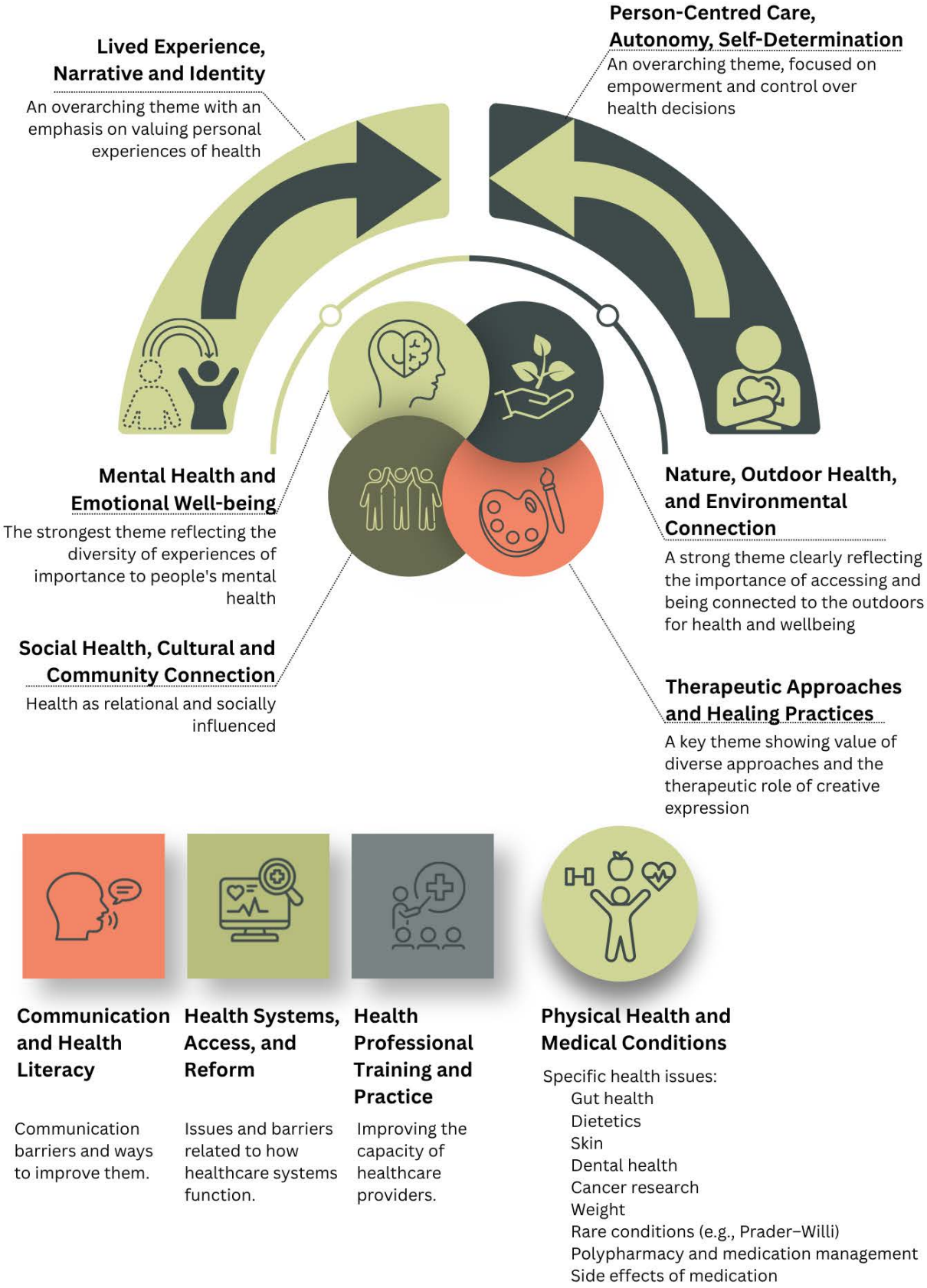


**Figure 1:** Overarching themes and other themes

## Overarching themes

Artists expressed key messages about the way they want and need to be positioned in relation to their health and health care. These messages formed two overarching key themes; Lived experience, narrative and identity; and Person-Centred care, autonomy and self-determination. These are framed as overarching themes because they are linked by being 'principles and values based'. The two themes are depicted in the diagram as forming a semi-circle with two arrows meeting in the centre to symbolise the need for both these ideas to converge equally.

Framing these themes in this way reflects the need for research about health in the lives of people with intellectual disability to engage with these themes as research questions or topics, and to do research in a way that reflects these principles in 'theory' and in research practice. This would include doing research that is inclusive of people with lived experience as 'active participants' in the research. Reflecting inclusive research practice, active participation can involve people with lived experience as researchers and advisors. Such research seeks to centre lived experience through narrative and creative methods and uses flexible communication to support diverse needs. It would also include framing research within a theoretical context that seeks to transform health systems and health services practice. In doing this it should reflect the inclusive research principle of changing systems and practices to improve outcomes for people with intellectual disability.

## Overarching theme: Lived Experience, Narrative and Identity

A key idea that was expressed by the artists was the need to value personal experiences by 'hearing and seeing' these in people's stories told by them – their narratives as the dominant narrative. This included hearing the stories of complex health journeys people experienced, and how they are interwoven and intersect with disability (impairment) and other 'identities', including culture. Importantly, the works and statements reflected a lack of a 'diagnostic' embodiment of disability – positioning disability experience instead as embedded in their holistic lived experiences, where sometimes 'disability' is overshadowed by them and by systems.

*Health issues make me live away from my family and community. This artwork brings me closer to them and my culture (P2)*

*Sometimes, people treat me differently, like an alien from outer space and not as an adult. This can make me feel unimportant. This picture is how I would like people to see me (P5)*

*I am the reason research exists. I am the evidence health research begins with people like me... I have a voice! (P22)*

*This artwork showcase[s] how disability and health come in all shapes and sizes. It shows how some aspects are visibly challenging, and other challenges go unseen (P25)*

*This work challenges the idea that silence equals absence and argues that lived experience is a form of evidence (P44)*

*I have chosen to use my own face in this artwork to express my own journey; Mental health matters most to me because I want people with intellectual disabilities to be better understood (P4)*

## Overarching theme: Person centred care, autonomy, self determination

People expressed that they are 'turning up' in health encounters and health care as a whole person and want to be seen as 'their whole person'. This 'wholeness' was expressed in different ways by artists and linked to ideas of autonomy, self-determination and agency.

*This piece invites the health sector to listen differently and to recognise people with disability as authorities on their own lives. (P44)*

*Health, to me, is not found in forms or frameworks, but in recognition — being seen and respected as a whole person rather than managed as a problem. (P44)*

*We are people first, not doing anything or not having the ability to show off their skills feels like a perpetual holiday where in reality all we want is to [be] seen and be able to do the same. (P17)*

*People with intellectual disabilities should be invited to attend doctor's staff meetings and conferences so they can share their views and experiences directly. (P31)*

Some of the art spoke to the relational context of 'self-determination' and 'autonomy' which is sometimes expressed as supported or relational autonomy and autonomy support [18]. This is about 'standing beside' people who are asserting their autonomy.

*I want to have my supporters with me, but I want to be listened to as well. I don't want doctors to only talk to my supporters. (P3).*

Research that explores the place and role of autonomy support would offer an opportunity to understand this nuanced role and how it can be strengthened in healthcare.

Our analysis would suggest that true person-centred approaches need to be based on deep understanding of 'the person' as outlined in the earlier 'lived experience' theme. This requires that research 'about' health in the lives of people with intellectual disability is undertaken in a way that both seeks to 'find out' about the person in meaningful ways, for example using ABR, and its outcomes speak to ways the health system can 'understand' who people are. These overarching themes that focus on understanding diverse lived experiences and developing person centredness based on a deep understanding of the person 'as told by them' influence how the remaining themes are understood and how they can translate to research priorities. Each of the remaining themes are linked back to these two overarching themes.

## Wellbeing: A cluster of interconnected themes

Our analysis resulted in a representation of the following set of themes as overlapping and intersecting. Rather than a list of 'themes'. Figure1 depicts these intersections.

This 'cluster' includes the following groups of themes: a. Mental health and emotional wellbeing; b. Nature, outdoor health and environmental connection; c. Social health, cultural and community connections; d. Therapeutic approaches and healing practices. The themes Mental health and emotional wellbeing and Nature, outdoor health and environmental connection, were directly referenced more often by the artists. These are seen as complimentary to each other and anchored to the overarching themes. An example of this is the artwork *Sunshine Smiles –Sad Storms*, a photographic collage, where the artist speaks to the holistic nature of health where physical, nature-based, social health, leisure and creative expression are reflected as 'what health issues matters' to the artist.

## Mental health and emotional wellbeing

The key message within this theme is the need to understand that mental health and emotional wellbeing is not necessarily or primarily about mental illness and treatment of mental illness. Some artists spoke about diagnosed mental illnesses including anxiety, but equally the messages expressed were about what is important to the artists for good mental health and emotional wellbeing in their daily lives.

*Through this artwork, I want to share what mental health means to me and how important it is to care for our hearts every day. (P33)*

*Mental health matters most to me because I want people with intellectual disabilities to be better understood. (P4)*

*Whenever I see this picture, it reminds me of all the good things about me and I feel better about myself when I pour myself into my artwork. (P5)*

Mental health was expressed as being central to quality of life, and a strong message was the importance of self-chosen practices to support mental health that people had built into their lives. These included mindfulness and art and doing things that gave people 'joy and comfort'.

*Art is like my therapy it brings me so much joy and satisfaction just to see each new painting come together (P15)*

One artist in their work 'Melbourne Central Clock' commented,

*When I feel sad, I go see the clock and it makes me happy (P23)*

Another artist uses music to support his mental health and wellbeing. His work 'Playing Guitars, Crying' shows how experiences and people affect their emotional regulation and health. His support worker comments:

*When he is playing or listening to guitar he smiles and is calm. (P12)*

Another artist – in their work 'Over the Rainbow' – also spoke about the importance of art-making to manage their emotional well-being in relation to grief and loss.

*I created this piece with a rainbow over a sunset, showing how my mum is waiting on the other side for me now. (P48)*

The importance of inclusive and accessible counselling and therapy was also expressed, along with the need for a supportive group of people around the artist. The following part of an artists' statement written by supporters of the artist reflects this.

*[Artists] family, friends, therapists and the community are incredibly proud of [artist] and her willingness to share her experience to help all of us to understand how she deals with the uncertainty of her life. Her health is paramount (P17).*

Mental health and emotional wellbeing are strongly connected to the following theme about being in nature and environmental connection.

## Nature, outdoor health and environmental connection

Many of the artworks were situated 'within' nature and reflected on the 'healing' experienced while spending time in the outdoors doing activities like swimming and walking.

*[Name of artist] does daily walking taking the same route each time. This helps [them] to maintain both her physical and psychological health. (P37)*

*I chose this because when I'm in the water I feel free, my body relaxes and I can move my body more than ever. (P7)*

*Being in the water helps my mental health. It makes me feel relaxed and happy. (P41)*

The artists highlighted 'intentional' engagement with nature and their relational connection to outdoor environments. People reflected why they spent time in nature, their relationship to nature and the outcomes of this for them. In their work 'Amongst the Bush', one artist describes their connection to regional Victoria where they grew up:

*When my health matters and i feeling stressed and overwhelmed from working in the city life I escape back into country victoria were im originally from and i go back into the bush were all the stress and feeling over overwhelmed brushes away as im in the bush amoung the eucalptus and nature im at peace (P20)*

Two other artists spoke directly about their personal connection to nature in their artworks 'House and Garden' and 'Sunshine', respectively:

*Having a healthy relationship with myself and with animals and nature is very important to us. Helps people stay happy and well. (P40)*

*I did this artwork the sunshine cause the sun makes me feel better and healthy. it's very important to look after yourself in the fresh air and enjoy life outdoors, and have fun, Go wild! (P26)*

## Social Health, Cultural and Community Connection

This theme reflects how artists were expressing the relational context of their health and how health was influenced by their social and community connections. Including within families, with friends and within their culture and community.

*My artwork is about social health and keeping yourself healthy with good boundaries with your friends (P49)*

*the peoples around me that are my wellbeing and heath with my art and with my story around my life (P8.1)*

It also spoke to the social determinants of health where people reflected on the need for things like housing security and safety in their daily lives and how this impacted their capacity to 'be healthy'.

*A healthy life means to have a safe & happy place to live- surrounded by trees to help us breath fresh air (P40)*

## Therapeutic Approaches and Healing Practices

A key theme in the interconnected cluster showed the value of diverse therapeutic approaches and the therapeutic role of creative expression. Some artists spoke about how art making is an important communication strategy to support health, emotional regulation and well-being.

*Together [art mentor and Name of artist] have developed a drawing language and trust that has allowed [Name of artist] to be more confident and independent to manage her health and moods. (P16)*

This artist also speaks to how crucial art-making has been in developing agency in the lead up to ongoing medical procedures related to several intersecting chronic health issues such as bronchiectasis and epilepsy:

*Working with a speech therapist and several artists... has allowed [Name of artist] to have agency over her situation. This method of working has been supported by a highly skilled team to produce significant change for [Name of artist] in her behaviour as she develops her independence and matures into the young woman she is today (P16)*

Other artists spoke about how creative expression supports their mental health through directly regulating, and communicating about their sensory or emotional needs.

*[Name of artist]'s creative output is strongly linked to his sensory needs (P19)*

*I can express [my] emotions through the colours and the calmness of the water (P15)*

*I colour in to help me unwind and feel in control, sometimes my mind wanders, choosing what I color in and what it means to me makes me feel happy and calm. (P46)*

The need to better understand the benefits of animal assisted therapy was another important and valuable therapeutic approach for some artists.

*I find love and companionship with my dogs... [I] think pet therapy in the Health Care System is very beneficial... Therefore, more programs and training is needed, so pet therapy can continue. [Pet therapy] good for my overall health (P35)*

*When engaged in animal therapy programs she expresses her happiness through her vocalisations, signing and engagement - lots of smiles and cuddles! (P13)*

## Accessible and responsive: health systems and practices

Artists that expressed these health system and practice areas as 'Health Matters' for them did so quite descriptively – indicating changes they wanted to systems and practices and/or experiences that reflected the barriers they experienced. They 'sit under' the overarching themes and are supplementary to the cluster of 'wellbeing' themes.

Physical health and medical conditions are depicted as a 'standalone' theme only in as much as 'the list' of conditions is to some extent endless and very much dependent on individual health conditions. Therefore, the list is not exhaustive but reflective of the conditions experienced by the artists who submitted work. We address this first because of this difference from the other themes in this section.

## Physical Health and Medical Conditions

Some artists spoke about specific physical health issues that impacted their lives as people with intellectual disability. The physical health and medical conditions discussed by the artists include gut health, dietetics, skin, dental health, cancer research, weight, rare conditions (e.g., Prader–Willi), polypharmacy and medication management, and the side effects of medication. These health and/or disability related conditions were referred to primarily in relation to wellbeing, indicating the strong connection between these themes and the cluster of wellbeing themes.

One artist, expressed the interconnectedness and spiralling issue of polypharmacy, reflecting on the lack of control that can come with complex mental health, it's treatment - particularly medication, and the competing need and desire to be physically healthy.

*I'd like to be able to do more art, walk with the dog, and yet my body just wants more sleep and to eat unhealthy food that gives me a quick energy boost, before crashing even more (P38)*

Others depicted their main health issue explicitly in the title of their artwork. For example, 'Health Gut', is an anthropomorphic stomach painting; The artist says:

*If your gut weekly it means that you are not healthy so kindly keep your gut weekly once at least clean all the toxic out of the body (P18)*

In a similar way the artwork 'The hunger never stops' is a drawing by an artist who shares their experiences of living with Prader Willi Syndrome

*I want health professionals to help us especially with obesity and helping our brain. to know we can't help it (P21).*

Another artist – in their mix-media self-portrait 'Me' – reflects the need for health professionals to look beyond what they 'see' to understand the intersecting complexities that are the health experiences of many people with intellectual disability. The artist comments:

*This artwork showcases how disability and health come in all shapes and sizes, It shows how some aspects are visibly challenging, and others challenges go unseen (P25)*

Their artist statement includes a list of health issues including dermatitis, physical health, and their disability identity as a First Nations person with Down Syndrome and cultural identity as a person who notes Aboriginal health as important to them. This is a powerful expression of the need for a holistic approach to understanding and responding to the health needs of people with intellectual disability.

## Practices and system reform

The following three themes are depicted as being next to each other in Figure 1 – three broad themes of interest and importance in health research and intellectual disability that are or seem to be 'ever present' and regularly researched. These are a. communication and health literacy, b. health systems, access and reform, c. health professional training and practice.

## Communication and Health Literacy

The need for flexible communication for accessing health information and in healthcare interactions, and for navigating health issues, services and systems was expressed by the artists in their work, and shown in the diverse ways they submitted their entries.

As explained in previous sections, the artists had a broad range of communication styles and methods that they used during the submission process to create artist statements. Supported communication methods included the use of scribes, audio, video, AI and supported decision-making with support worker/carer. One support worker explained,

*[Name of artist] has limited verbal communication and uses a communication diary, signs and known words to express himself. As such staff have discussed the below artwork with [name of artist] and supported him with [his] submission (P25)*

One artist's parent spoke about the importance of AI in the lives of people with intellectual disability in relation to communication around health and well-being.

*AI has been life changing for [Name of artist] participation and contribution (P1)*

Many artists clearly described communication methods that support them to engage with health practitioners in their artworks and artist statements. One artist's work 'My Voice Takes Time' expresses how the artist communicates and processes information:

*My voice takes time. I use lots of ways to communicate, like my iPad, signs, photos, and my face. Give me time to share my voice (P9)*

One artist submitted a short film 'These are the Sounds I make', which documents the many ways they communicate.

*[Name of artist] communicates through the 'sounds she makes' signing, miming, using conversation cards and technology/ipad.*

This young filmmaker used supported decision-making to creatively produce her film. Her support worker speaks to the importance of these communication methods:

*Inclusive communication and supported decision-making improve health and wellbeing (P39)*

Artists expressed frustration about the communication barriers people with intellectual disability experienced and described ways to improve them. One artist – speaking about their work 'Speak' shared,

*I want to have my supporters with me, but I want to be listened to as well. I don't want doctors to only talk to my supporters (P3)*

Health literacy was not directly referenced by the artists but was how we interpreted what we saw and heard through some of the art works and art statements. The following artist of the piece 'Maladaptive dreaming' shares,

*The reason why I choose to make this artwork about Maladaptive daydreaming is because I wanted to show the emotion of what it is like to experience it.*

Their reference to the 'emotion of it' suggests the need for information to be co-designed with people with intellectual disability using creative methods so 'more than the facts' are included in health information.

## Health Systems, Access and Reforms

Barriers related to how healthcare systems function is another theme that was reflected and expressed by many of the artists. Artists reflected on cultural and language barriers, including for First Nations people with intellectual disability. The following statement is a stark and beautiful articulation of the reality of displacement experienced by First Nations people with disabilities from remote communities and the importance of ongoing connection to family and culture that healthcare services need to support.

*Health issues make me live away from my family and community. This artwork brings me closer to them and my culture (P2)*

*As a young Aboriginal man with Down Syndrome and multiple health conditions [Name of artist] has overcome many challenges throughout his life. [his] artwork... shows how some aspects [of his health and disability] are visibly challenging, and other challenges go unseen.*

Some artists spoke about the compounding experiences (time, cost, frustration) of 'health up-keep' for people with intellectual disability.

*My dream is for a clinic where everything is under one roof, so all the tests and assessments, all the specialist appointments and therapies are accessible and in the same place (P27)*

Further, and reflecting the overarching themes of person centredness and understanding of lived experiences, there were some messages about the importance of people with intellectual disability being at the centre of health system reform.

*People with intellectual disabilities should be invited to attend doctor's staff meetings and conferences so they can share their views and experiences directly (P31)*

The abstract painting, 'Messed up Health System', serves as a strong metaphor for a health system that fails to meet the needs of people with intellectual disability. As the artist explains:

*Doctors use big words that we don't understand, and we get pushed away. That is what the painting means in how our health System is treating us. Treat us like anyone else but explain it so that we can understand the reasons why it is important for people with intellectual disability to be healthy.*
*SO FIX THE HEALTH SYSTEM UP FOR US TO UNDERSTAND.*
*OTHERWISE YOU WILL BE LIKE THIS PAINTING AND BE MESSED UP and be Pushed away! (P31)*

Artists also highlighted the importance of improving health assessment and funding for people with intellectual disability. One artist submitted a satirical performance art piece, 'Reasonable and Necessary: The Great Feather Redistribution Scheme', that comments on the funding allocation in NDIS planning and assessment. In their work, the artist destroys a pillow releasing its feathers across a room, commenting,

*What you are witnessing is not mess — it is policy in motion, no feathers were lost, they were reframed (P1)*

The artist uses key words from NDIS funding processes ("reasonable and necessary") to share a satirical metaphor for his perspective of a broken system. His work speaks to the need for a human right's approach to health system reform and how the expectation of change shouldn't just be on the person with intellectual disability.

*If support is truly reasonable and necessary, why must it remain inside the object it came from (P1)*

## Health Professional Training and Practice

As noted above, people reflected on their place in reforming health systems and practices by being at the centre of education and drawing on their lived experiences to 'educate', 'challenge' and ultimately change practice. The overarching aim being to improve the capacity of healthcare providers – to inform inclusive, accessible and respectful practice.

*I rely on support workers to help me with this but if Health professionals explained health information to me in a way I understand, I may not need this support. (P41)*

*Doctors need to know how to speak to people with a disability and to the carer as well. Find out more about their conditions, just don't shrug them off (P31)*

*Treat us like anyone else but explain it so that we can understand the reasons why it is important for people with intellectual disability to be healthy (P31)*

# Part 2 – Online semi-structured interviews

## Participants

Purposive [19] and snowball [20] sampling techniques were used to identify people with intellectual disability who have been or are lived experience researchers and others with an interest in research about the health of people with intellectual disability. To be included in the study participants needed to be 18 years or older, self-identify as a person with intellectual disability and have been or are lived experience researchers and others with an interest in research about the health of people with intellectual disability. The decision to interview people with intellectual disability with experience as researchers or aligned with research, centred on the core focus of this project on identifying areas of importance for future research. It was anticipated that this group would have access to the language of research, insight into the research process and knowledge of specific research projects already completed.

The dual identity of researcher and person with intellectual disability is a powerful and unique perspective. Often the voices of researchers with intellectual disability do not get to determine the focus of research, despite being involved in other aspects of the research process. Coupled with the inclusion of artists with disabilities above, this project demonstrates ways to include the varied voices, roles and diversity of people with intellectual disability and highlights the benefits of multi-modal research approaches.

## Recruitment

An email with information about the project was sent to all known inclusive research groups across Australia. Organisations with lived experience researchers were also approached. As well as leaders and facilitators of intellectual disability research projects which include lived experience researchers. Those who expressed interest received a copy of the PIS and consent form. Participants contacted the lead researcher directly to express interest in taking part in an interview. Written consent was received via email.

## Data collection

The interview process was prepared with inclusivity. Before the first interview, the two researchers, AJ and RDA (except for first two interviews where it was SA with AJ and one interview where it was PF with AJ) conducted a practice run-through with the interview questions, maintaining that AJ was comfortable with the interview format, with a focus on adapting the questions from a lived experience viewpoint. AJ and RDA practiced asking questions in turns and opening the interviews, with AJ's preference for verbal communication tailoring a conservational and accessible approach to the interviews.

Interviews were conducted online via Zoom® by two researchers together. AJ's lived and research experience influenced interview interactions in impactful ways. Participants were given the opportunity to relate to AJ as someone with similar experiences, while AJ could draw on their own experiences to foster trust, establish a connection while asking follow-up questions that aligned with a shared understanding of the topics being discussed. During the interviews, AJ highlighted their own experiences with accessible information, health services, and communication obstacles, which participants reacted and related to with recognition and openness.

If participants consented, the interview was recorded and transcribed. A co-developed semi-structured interview guide asked participants information about their experience of health research and their opinions on research priorities in intellectual disability health (see Appendix I). A small amount of basic demographic data about the geographic location, age and gender of participants was also collected. Members of the research team confirmed or re-negotiated consent with participants through a process of regular checking. This process occurred before, during and after the interviews where appropriate. All members of the research team had extensive experience working with people with intellectual disability in research and in human service practice and understand the additional time it takes to gain consent from people who may need assistance to understand information.

## Data analysis

Following the completion of the interviews, a co-analysis of the transcripts was undertaken, discussing them collaboratively. RTA was used to analyse the interview transcripts [14]. In alignment with the first part of this report, this approach was chosen for its ability to generate robust, conceptual-researcher interpreted themes from qualitative data [14]. This approach grounds researcher subjectivity as a resource instead of a limitation, positing that 'the researcher is positioned as active in the research process; themes do not just 'emerge' [14]. That is, themes are not identified as patterns that passively 'emerge' from the data, rather they are actively interpreted and constructed through the researcher's ongoing theoretical and lived experience position, disciplinary knowledge and reflexive engagement, instead of assuming meaning is intrinsic or obvious within participants' accounts [14]

Three members of the research team participated in the data analysis, RDA and AJ worked as a pair as they had worked together exclusively on the interviews, while DC conducted an independent analysis of the same transcripts. The analysis followed the six-stage process outlined by Braun and Clarke[14].

The first stage, familiarisation with the data was undertaken through repeated reading and discussion of transcripts that were documented on a shared Excel spreadsheet (Microsoft 365, Excel 2021). Secondly, initial codes were generated inductively across the dataset to identify significant information that mirrored participant experiences and health priorities. These codes were designed as the building foundation for future interpretation.

Thirdly, theme development was undertaken by grouping related codes into focused organisational concepts, entailing recurring patterns and shared meanings. Codes regarding participants' experiences towards medical jargon, the absence of accessible documents such as easy read, and the burden of having to educate health professionals about their own disability were, for example, coupled together under a single interpretive theme instead of being seen as different topics.

Fourthly, these themes were reviewed and refined during online meetings. Where there was significant overlap within the two sets of analysis, this reinforced confidence in the themes constructed. If they diverged, this allowed the researchers to discuss the differences and deepen their understanding of the data. Finally, refining these themes required filtering and defining different groupings into names that highlighted the interpretative account each theme represented.

Additionally, AJ's lived experience allowed them to be further connected to dimensions of data that would have been possibly discounted. These dimensions include identifying a participant's narrative of being 'too shy to speak up' mirroring a systemic obstacle instead of an individual deficit, or when an account of 'positive' health experiences concealed underlying access problems. This led to further questioning in the interview and further reflection in analysis about the 'meanings' being shared. This highlights how the inclusive approach taken to the interviewing flowed on to the co-analysis.

Corresponding with RTA, theme names were constructed as a meaning-based interpretative account instead of topic summaries [14]. A data analysis table was created through the analysis of participant accounts, and transcript quotes, consolidating into three main themes. Quotes are 'as said' by the participants and have not been edited in this report, reinforcing the commitment in this research to 'hearing' the voice of the participants directly.

The three main themes are depicted in Figure 2. The process for developing this diagram mirrored the process used in the first part of this research – the Art Competition. As such, the co-development of Figure 2 by DC and AJ was the same process as Figure 1, iterative, collaborative and conversational with an aim of creating an accessible knowledge translation piece. While the co-development process again drew on DC's strength in design skills and AJ's clarity around accessibility, it also emphasised AJ's role as the key interviewer. The conversations therefore focussed on AJ's suggestions for how to visually 'capture' the interview findings and AJ's preferences for layout. Additionally, AJ wrote the theme summaries, while DC scribed, provided conversational input to unpack some of the nuances of the theme complexities and ensured key elements of the diagram were consistent with the previous diagram. The diagram was then sent to the broader research team and discussed at a team meeting before finalising.

## Part 2 Interview findings

Sixteen lived experience researchers participated in the interviews. They were located across Australia, including New South Wales, Victoria, Queensland and Tasmania. Their research roles varied from being part of advisory committees to collecting or analysing data. The length of time that they had been involved in research also varied. The interviewers asked participants to speak to their 'researcher' experience. While participants had held a range of roles it was interesting to note that in most cases the research projects they had worked on, the research topics were not chosen and informed by people with intellectual disability directly. Some participants noted that they are currently employed as research assistants while others noted they are working as advocates. All lived experience researchers were verbal and able to communicate without assistance or support. On average interviews lasted 21 minutes with a range of 15 – 33 minutes.

Participants described research in different ways:

*Learning about facts learning things and putting it all together. (P008)*

*Research is where you're getting information. From different things set to help. To help you understand better. Better information about what's out there for different people with disabilities or, like, other things (P012).*

## Interview research themes

Together the themes presented below provide an interpretive narrative of how people with intellectual disability view and experience contemporary health systems. They reflect that people experience health services as spaces where medical information is structurally inaccessible, where disclosing a disability changed how people are treated, and how the relationship between health and intellectual disability remains under- acknowledged both in health practices and in health systems. Figure 2 depicts each of the three key themes and their sub-themes.

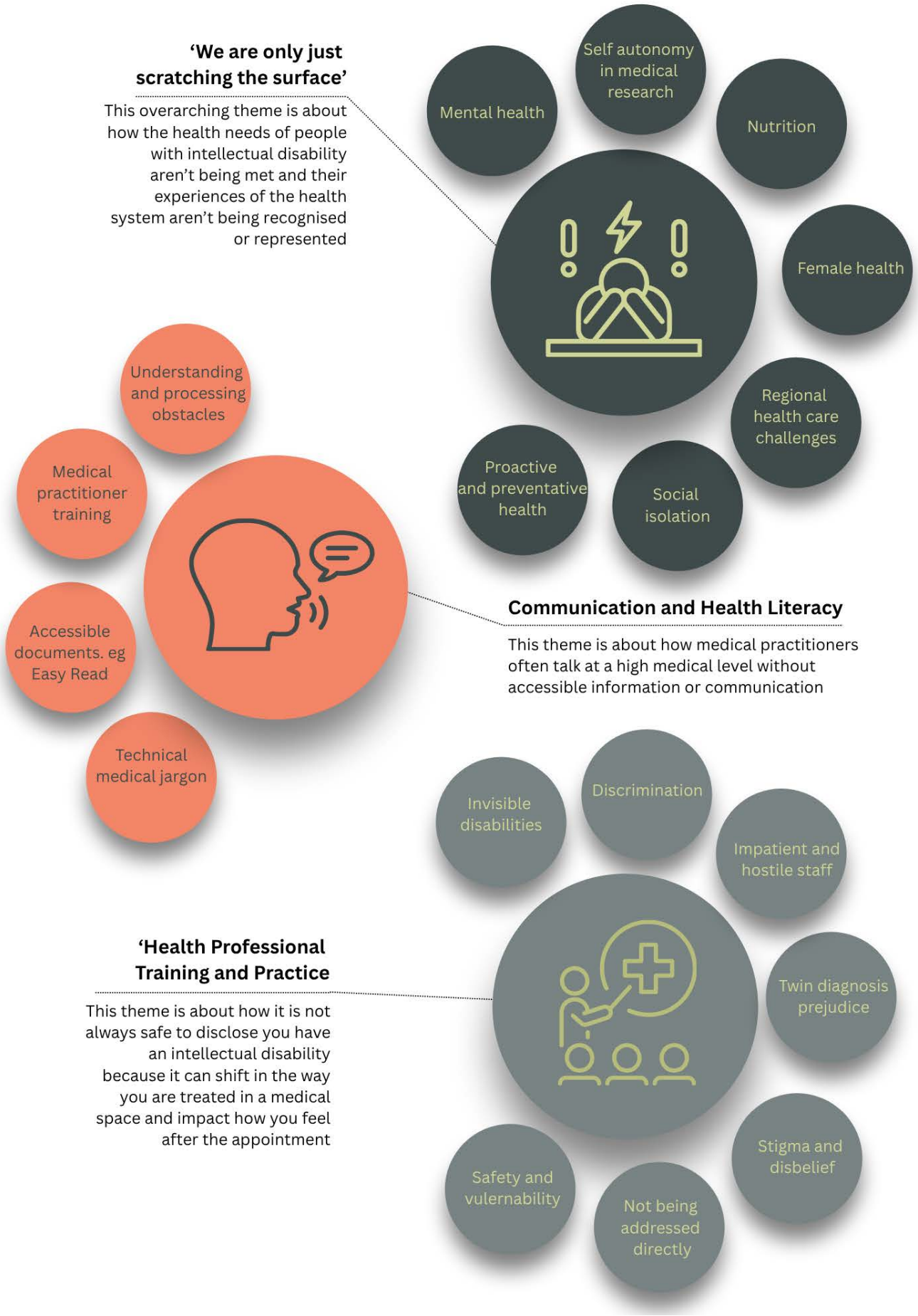


**Figure 2:** Interview themes and sub themes

## Overview of themes

The three themes from the semi-structured interviews are; 'We are only just scratching the surface'; Communication and Health Literacy: 'They talk to you like you have been to Medical School', Health Professional Training and Practice: 'The attitude in the room just changed'. Definitions of these themes are provided in Table 1.

Table 1: Overview of themes and subthemes.

| Theme | Core Meaning | Sub-themes |
|---|---|---|
| 'We are only just scratching the surface' | Participants recounted experiences that illustrated a broader picture of unfulfilled health needs that expand beyond healthcare encounters into environments that contemporary systems barely recognise. | • Mental health<br>• Social isolation<br>• Proactive and preventative health<br>• Nutrition<br>• Regional healthcare challenges<br>• Female health<br>• Self-autonomy in medical research |
| Communication and Health Literacy: 'They talk to you like you have been to Medical School' | Medical experiences fundamentally fail to assist how people with intellectual disability receive, process and clarify information, producing a compounding strain that falls onto the individual. | • Technical medical jargon during conversations<br>• No accessible documents such as easy read to read or take home<br>• Needing to educate health care professional about disabilities<br>• Understanding and processing obstacles |
| Health Professional Training and Practice: 'The attitude in the room just changed' | Announcing an intellectual disability or other health conditions in medical spaces stimulates shifts in how people with intellectual disabilities are treated, with repercussions still being felt after the appointment. | • Discrimination, stigma and disbelief<br>• Twin diagnosis prejudice Invisible disabilities, Impatient and hostile staff, safety<br>• Vulnerability<br>• Not being addressed directly. |

### ‘We are only just scratching the surface’

People spoke about a sense of sweeping unmet health needs and issues that they felt they and their peers had clearly articulated in the research they had been involved in, however, they reflected that these remained predominantly invisible to the systems around them. They acknowledged that health issues impacting most on people with lived experience stretch far beyond individual engagement with health practitioners or services into spheres that contemporary systems barely recognise including self-autonomy in research ‘about them’, social isolation, issues in regional and remote areas, proactive and preventive health, and health issues for population groups including women.

Mental health was the most frequently expressed priority across participants – this health issue is present across the interview data where participants indicated the escalating challenge of managing numerous mental health and mental health related conditions alongside the issues they experienced that related more directly to intellectual disability. Within this context, the importance noted was not the discrimination encountered by them, but the absence of services and resources to support them and their complex and intersecting health and disability needs.

P015, who currently works as a health ambassador, declared bluntly:

*there's hardly anything around intellectual disability and mental health.'(P015).*

P004 connected this absence to life expectancy, reporting that

*people with disabilities are more likely to die early if we don't get the help we need (P004).*

P013 highlighted that mental health stretched past medical settings into socialising, friendships, and community participation *(P013).*

P014 characterised anxiety-related blackouts that others need to understand *(P014),* while their support person reiterated the social isolation that accompanied finishing school in a small regional town where *'there's not necessarily a lot of external groups' (P014)*.

Social connection and isolation was another significant theme. P003 reflected on their experiences with the COVID-19 pandemic to highlight how restrictions made people with intellectual disability feel they *'were going back to when institutions were around,' (P003)*, and stressed the importance of friendships, relationships, and social media as instruments of connection.

P009 introduced bullying in online and offline contexts as a health issue that propels people towards feeling *'socially isolated and feel as if they don't matter' (P009)*. P003 advocated for further 'storytelling in health' where anyone could recount personal experiences and find supportive connection, describing that 'a lot of people don't know how to put it into words' (P003).

Proactive health for general wellbeing was introduced by some participants as a key issue for research. P010 urged for better nutritional mindfulness while P011 talked at length about diet, exercise, and the circumvention of long-term health conditions such as diabetes. P015 underscored this with a reflection on their preventive health approaches for reducing one's sugar intake, while increasing exercise and fitness goals.

P002 advocated for more proactive and preventive health campaigns around the significance of attending regular medical appointments. P010, a competitive basketball player, reported wishing to *'be the best version I can of myself' (P010)*, seeing being healthy as a realistic ambition, not just problem management.

Women's health was also referred to as another area that has been neglected in research with people with intellectual disability. For example, P003 highlighted menopause as a concern for people with intellectual disability where women have never been given education about what it is and with support staff minimising symptoms: *'oh yeah, you're fine, it's just hot in here' (P003)*. P006 reinforced this, reporting that *'I don't think a lot of women get believed' (P006)*, and identified menopause as a topic that had surfaced in their own research projects where they work as a professional research assistant. P008 raised historical issues around health decisions for women for disability, particularly with regards to reproductive rights particularly where surgical choices like sterilisation have been made by others. They highlighted that despite improvements in understanding autonomy and the rights of women with disabilities, attitudes around the relationship between disability and women's health still carry that legacy (P008). P003 stated this powerfully: *'they just saw us as a thing, not as a human being... we get all the same things that anyone else gets' (P003)*.

Furthermore, participants highlighted practical barriers such as structural and geographic challenges towards accessing health services. P012 depicted experiencing a three-to-four-month wait list for specialists and the strain of having limited care plan visits necessitating constant returns to the GP *(P012)*.

P014's support person stressed the immense challenge of finding suitable services in regional Tasmania, where *'mum and dad doing Googling'* was the foremost way towards finding out what was available (P014). P016 echoed this point through describing their search for local specialists as their biggest health challenge *(P016)*. P004 introduced the rising cost of healthcare as a barrier, noting that *'I don't know how they're going to live, and I don't know how they're going to afford to go to a doctor, because everything's gone up' (P004).*

P008 found emergency departments as especially difficult for people with intellectual disability due to experiencing levels of heightened anxiety, stress and long waits. Their solution recommended teaching breathing exercises to patients and further educating front-line emergency department staff in supporting stress management *(P008)*.

Finally, perhaps the most fundamental issue expressed by several participants voiced their desire for self-determination in health research. P010 remarked that people with lived experiences should be *'telling the government what we* want' instead of having research priorities placed on them (P010). P013 asked for equal access to health services and information: *'treat us as normal individuals... treat us equally and give us access to information' (P013).*

P002 called for a national survey of people with intellectual disability to voice their own opinions towards what health research should be. P003's account discussed how health research must adopt co-designed approaches and that *'there's no one better than someone that's going through that health issue presenting at a conference' (P003)*.

Lastly, P015 reasoned that health reforms must begin with a disability-centred approach, reflecting that disability reforms often *'get streamlined on to other people as well' (P015)*. These statements position people with intellectual disability as not merely being passive recipients within health services, but as direct consultants of their own health priorities.

### Communication and Health Literacy: 'They talk to you like you have been to Medical School'

This theme illustrates how participants had experiences with medical information being provided in ways that were inaccessible, overwhelming, or presumed a degree of cognitive engagement that did not align with their lived experiences. These presumptions did not merely include use of challenging words but also signal deeper structural failures towards acknowledging different communication styles and adjustments to create an inclusive communication environment. Without such adjustment, the consequences of not being understood further increases.

A key example of this would be complex medical jargon. Participants recounted clinicians conversing with them in the likeness of engaging a colleague. P011, described how their gastroenterology physician, in their appointment, used terminology she could not understand, necessitating her to Google terms on her phone mid-consultation:

*they sometimes start rattling off like you're one of their colleagues, and it can be really overwhelming... it's hard enough to try and process information some days, and then you've got all these big words (P011).*

One participant reported hearing medical terminology that left him thinking *'what are you talking about?' (P007)* and asked for plain English or simplified terms. Another participant commented that people with intellectual disability find it challenging to comprehend unfamiliar words and called for doctors to instead *'explain it with a similar word.' (P016)*.

P003 recommended medical professionals reduce their 'doctor talk' and embrace co-constructed approaches while communicating with patients, specifically those with intellectual disabilities *(P003)*. One of the participants solutions to the excessive use of medical jargon amongst health care professionals was for them to *'speak slower'* and *'have enough time for me, have enough patience,'* positing these not as favours but as required clinical processes *(P015)*.

P014 reinforced this point with their personal experiences conversing with a cardiologist that slowed down his language, allowing them to *'understand things way better that way' (P014),* emphasising that this conversational barrier conversing with people with intellectual disability was a systemic failure, not intrinsic.

Furthermore, what distinguished this theme from simply being communication feedback, difficulties or complaints, was the compounding effects participants reported. P011 described having to continuously call medical practices after appointments because they usually felt overwhelmed during their appointments and only felt *'more clarity after'* when that feeling subsided, and that they needed accessible follow-up documents and summaries *(P011)*. P009, undergoing treatments for cancer, highlighted receiving hospital booklets that were *'quite confusing'* with *'a lot to read and go over,'* with no easy read options provided *(P009)*. P015 mirrored this by highlighting hospital admission forms that required details like previously used medications that can be '*very complicated for people with intellectual disabilities (P015).*

The lack of Easy Read health information was another crucial element highlighted by participants within this theme. P013, who works as a professional research assistant that creates accessible easy read materials, emphasised not knowing such documents existed until their 30s:

*I'm in my 30s now, and I never knew about easy read documents before I started working at the centre... it's pretty surprising and shocking and sad (P013)*

P006 also pinpointed implementing easy read as the number one change necessary in healthcare, restating how they *'can't speak highly enough' of it (P006)*. However, despite its recognised value, participants recorded that easy read documents were rarely presented in practice, even by general practitioners they had worked with for years *(P013)*.

Finally, perhaps the most cogent of this theme was the strain placed on people with intellectual disability to fill the gap between medical knowledge and intellectual disability. P011 reported their frustration with having to assume the role of *'the teacher'*, educating medical professionals about intellectual disabilities while concurrently attempting to secure care (P011). P003 reiterated that people with intellectual disability should be the ones speaking at health conferences, *'instead of having just doctors talk, doctor talk' (P003).*

Taken together, these narratives indicate not only a need for research into inaccessible health communication but also to the critical urgency for implementation and action research that propels socio-structural change. This includes research that is framed as health literacy research with people with intellectual disability to investigate the impact of easy read health documents in medical spaces, accessible follow-up summaries after appointments, and training modules that prepare health-care professionals to tailor their communication strategies for people with lived experiences, conducted by people with intellectual disability. In a sense, participants were not asking for the problem to be studied further; they were highlighting and providing solutions that require testing, implementation, and entrenchment within routine practice.

### Health professional training and practice: 'The attitude in the room just changed'

This theme highlights participant experiences concerning discrimination, stigma, disbelief and the need for attitudinal shifts in health spaces. In particular, this theme highlights the downward cascading consequences of these experiences for current healthcare interactions. Across the research narratives, participant accounts detailed how their medical experiences were not only negative in nature but were triggered by the 'announcement' of their disability itself.

P011's narrative is at vivid account of this. They described attending a consultation with their general physician with the aim of receiving a disability support referral letter. During the appointment, P011 indicated their bipolar diagnosis in addition to their intellectual disability and remarked how the appointment immediately shifted:

*As soon as I mentioned the bipolar, it just went to, like, the DSM... it went from a GP appointment to, like, a psychiatric evaluation. It was so demeaning (P011)*

The general physician proceeded spending the entire appointment questioning P011 on their mental health, leaving them unable to receive their needed referral which necessitated a second consultation. From this experience, P011 highlighted not only being inconvenienced and frustrated but how it also prompted them to stop visiting that general practitioner for four months, despite being in a period where they required continuous treatments *(P011).*

Furthermore, P011 indicated being aware of others experiencing similar experiences such as their friend who was physically constrained in a psychiatric ward who now declines any mental health support in general. They observed how *'the way you're treated can determine your future care' (P011)* and forms the essential basis for what this theme illuminates: negative treatment does not merely entail short-term harm, it pushes people away from healthcare environments completely.

This experience of being limited to a singular label was not distinctive to P011. Numerous participants highlighted the obstacles of traversing health systems with other medical conditions in addition to having an intellectual disability. P011 recounted this as a *'dual diagnosis kind of thing'* wherein having an additional condition made traversing medical systems *'quite tricky'* (P011). Similarly, P009, navigating anxiety, cancer and their intellectual disability concurrently stated that *'a lot of doctors don't understand disabilities within cancer'* and advocated for more understanding and awareness.

*P003 highlighted being disparaged for years, having been told they were 'just complaining or lazy', before being diagnosed with ADHD (P003).*

Another prominent experience reported was the pattern of disbelief and discrimination that unfolded across clinical and non-clinical contexts. P008 remarked having spent four to five years attempting to get their disability pension recognised as they had numerous issues with Centrelink staff being hesitant or suspicious of them having a disability based on their appearance *(P008)*. P003's fiancé experienced a comparable struggle for the Disability Support Pension over a three-year period after they had suffered a stroke as disability evaluators *'only saw the outside of his stroke and that was it. They didn't see his mental health, how his memories affected how his day-to-day is' (P003).*

P012 recounted conversing with chemist staff who 'don't believe you're on the pension when presenting scripts' (P012). P016's account described how a health professional denounced their stuttering as *'not a problem,'* forcing them to pursue another provider that was not as dismissive *(P016)*. These accounts emphasise a broader theme wherein intellectual disabilities are described by many participants to be an 'invisible disability', that solicits scepticism. According to P013, *'I present very well, so people sometimes forget I have an intellectual disability" (P013)*. While P011 *reported their lived experience as an 'invisible disability' stating 'people look at you and you look fine, but in your brain, you're not functioning the same' (P011).*

Lastly, various participants highlighted medical professionals steering conversations towards support people instead of speaking directly to them. P007 exemplified this as a critical problem as '*doctors quite often ask the actual support person instead of the person with the disability' (P007).* P001 reported similar experiences in pharmacies and group home environments, where workers or staff always opted to speak with support workers instead of the client.

Several participants (P001, P004, P005, P007, P011, P014, P016) recounted needing to bring a support person to consultations or appointments with the express aim of helping process non-accessible information, only to experience the medical professional addressing their support person in lieu of them. P012 shared a personal experience of an X-Ray technician becoming hostile because they were not obeying instructions *'the right way,'* which sparked a panic attack *(P012)*. P009, currently undergoing cancer treatment, depicted certain medical staff as *'quite harsh' (P009)* while P004 raised the concern that people with disabilities can be *'manipulated or gaslit'* by medical professionals making pre-conceived assumptions *(P004)*.

The analysis of these accounts not only offers a visible portrayal of 'negative experiences' but a structural pattern of discrimination where the announcement of a disability or having additional medical conditions triggers judgement and changed the terms of the engagement with the health service. This further degraded participants' trust towards future healthcare-seeking. P003 puts this succinctly: 'they just saw us as a thing, not as a human being' (P003).

P015 posited their solution within a systemic and attitudinal shift, with better training for medical students in universities, and attitudinal change predicated on the principle that *'if we focus on disability first... it gets streamlined on to other people as well' (P015)*. Additionally, P013, who had previously worked on co-creating a capability framework promoting change within health curriculums on a university level verified how *'a lot of the doctors don't know... we're trying to advocate and change that' (P013).*

## Integration

Some common threads were found across the two research approaches. These are depicted in Figure 3 and discussed in this section. Lived experience, narrative and identity, and Person-Centred care, autonomy and self-determination were found in the Arts Competition research to be overarching themes that provided a framing for the other themes from that research. In integrating the findings from the Art Competition research and the interview research we found a convergence through the theme 'We have barely scratched the surface', a theme from the interview research that speaks to broad and underlying principles and topics for future research centred on the voices and experiences of people with intellectual disability. These themes can be viewed as framing for future research and research practice. If these overarching ideas are not recognised and observed in health research and health research approaches, it is likely that health research relating to the health of people with intellectual disability will perpetuate rather than dismantle the current structural and systemic ableism in health.

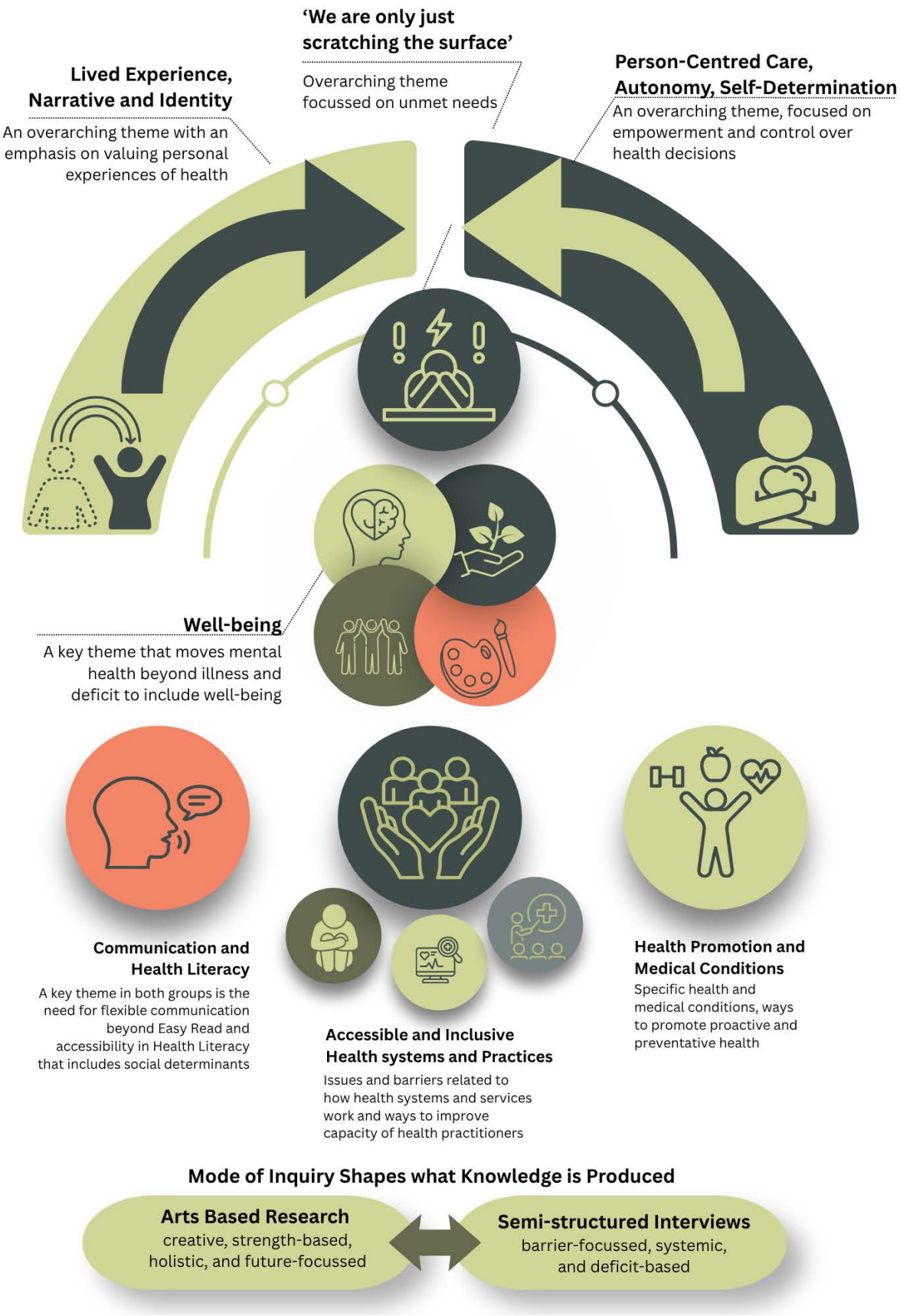


**Figure 3:** Integration of findings from the art competition and interviews

## Modes of inquiry – shaping 'the knowledge'

At the base of the diagram we have included the two research approaches with an interconnecting arrow that depicts how together they provided distinct but also overlapping ideas. Artists positioned themselves clearly as wanting and needing person-centred care, autonomy and self-determination and spoke clearly about the importance of a lived experience perspective, giving strong, complex narratives about their health journeys as 'whole' people. Lived experienced researchers, on the other hand, provided a reflection of the barriers existing within the research context. Even when they shared personal anecdotes from their own health journeys, they spoke from a position, and identity, as a 'researcher' and are therefore 'inside' and within the system. While artists were largely future focussed and suggested ideas for change, lived experience researchers tended to use deficit language more in line with the medical model of disability and focused on negative aspects such as discrimination stigma and feeling unsafe. This could reflect the bias of research in focusing on 'problems' and understanding experiences that can be negative, rather than a solution-focused, implementation and system change approach. This finding is bolstered by the observation that for most of the lived experience researchers interviewed, the research topics they had been involved in were chosen by others. Various participants questioned how their involvement usually began after the research question had already been established, situating them as contributors to an agenda set by researchers without disabilities instead of designers of the research itself.

This diverges with the art competition, wherein participants were presented with an open question: 'what health issues matter most?' and conversely replied with breadth, nuance, and a problem-solving mindset through creative expression. This distinction highlights that how people with intellectual disability are 'invited into research', fundamentally influences what knowledge is generated.

Lived experience researchers tended to focus on health care and services, doctors, medical conditions while artists had a holistic view of health. This was also partly due to the scope of ABR compared to semi-structured interviews. Within the community context of an art competition, the identity of 'artist' seemed to allow for richer, nuanced and complex understandings of health to be creatively expressed through their own health journey compared to the interview setting.

## Understanding and addressing wellbeing

A dominant theme across both artists and researchers with intellectual disability was well-being and mental health. Lived experience researchers mainly described mental health as illness and the importance of treatment and pushed against this as the focus. Some interviewees did highlight the importance of social inclusion and its impact on wellbeing, and artists expressed the importance of managing one's own well-being through healing experiences with art and nature. The Arts Competition research showed how people with intellectual disability understand their health and wellbeing, manage their overall health to impact positively on mental health, and have a strong sense of what helps them and how they wish to be treated. Thus, reinforcing the importance of self-determination and for health practitioners to see the individual rather than the disability label. This was echoed in the interview research where people spoke of the 'attitude in the room changing' when complex and intersecting experiences of health and intellectual disability were shared.

## Finding out if communication is accessible and meaningful

Communication and Health Literacy was a key theme in both groups. Artists spoke about the need for a range of communication methods and demonstrated these methods in the submission of their artworks and artist statements, whereas lived experience researchers spoke mostly about Easy Read. They described these as a norm and a “must”. The main reason why they were introduced or knew about Easy Read was from their role as lived experience researchers. Easy Read is a crucial accessibility tool, but as depicted by the artists other modes of communication are important for true inclusion for Video, visuals, art, supported-decision making. Besides making health information accessible, a crucial question that must be addressed is how people can apply information meaningfully in their personal life contexts.

For lived experience researchers the focus was on individual literacy and how to understand the information. One researcher reflected on how they only became aware of Easy Read while being involved in research and now has an expectation for the health system to provide the same. Thus, illustrating how the opportunity for capacity building in one area, has informed rights in another. Artists depicted health literacy from a broader perspective. As highlighted by Mauro et al [21], health literacy needs to see beyond and focus on social components such as housing, leisure and living environment (culture) which were elements depicted by the artists. Further, the interview research reflected that promoting the use of information and communication methods that are available, like Easy Read and other pictorial and audio/visual methods is only one part of what is needed – they highlighted that research needs to find out if these approaches are working and inform how they evolve.

## Reforming health systems and heath care practices

Accessible and inclusive health systems and practices was another health research issue common in both groups. The diagram depicts three areas that converged - health professional training, health system access and reform and inclusive practices. Artists describe about the need for doctors to do better; interviewees highlighted the need for more training and referred to health care providers lack of knowledge. Also expressed across the research was the need for people with intellectual disability to be central to the development and delivery of health professional training, and to be central and agentic in health care interactions as an educative tool. This speaks to the need for research that looks beyond training about things like the ways health professionals communicate with people with intellectual disability, to looking at the 'environments' of health care services, both the physical and social aspects and applying what is known about 'inclusion' to these environments.

Principles of Universal Design could be applied to this kind of research, along with an intersectionality understanding of inclusion – with a particular lens of diverse cultures, gender and sexualities and ages. Issues for LGBTIQA+ people with intellectual disability who were ageing were raised in the interview research. In the Art Competition research from an Aboriginal and Torres Strait Islander perspective was given, along with culturally and linguistically diverse (CALD) and rural perspectives.

Capacity building around inclusion is a critical issue and research to understand the impact of work on inclusion through training and environmental and attitudinal changes on the health experiences of people with intellectual disability is needed.

## An endless list of health and medical conditions – prevention and treatment

Both groups talked about specific health and medical conditions. Most of those related to their specific experiences living with particular conditions, but some focussed on health promotion: oral and sexual health, nutrition. Proactive health promotion and preventative health measures were referred to in the research – again with a focus on people with intellectual disability at the centre of this work. Both artists and interview participants stressed the significance of preventative approaches, however, these persist as areas where people with lived experience described restricted access and opportunity.

Importantly the research reminds us that the 'full range' of health and medical conditions that can be experienced across society and within certain populations might be experienced by people with intellectual disability. We heard about gut health, diabetics, hearing and seeing, menopause, dementia, obesity, mobility issues, mental and psychiatric health, reproductive choices, dermatitis, dental health, cancer, rare conditions and others. This is a strong reminder that health research that is addressing prevention, treatment for all of these conditions and health promotion across the broad range of 'health' needs to include the experiences of people with intellectual disability. They are 'part of' not separate from the community of people who should be benefiting from all health research.

# Discussion

True emancipatory research is led by people with disability, focuses on issues important to people with disability, and seeks to influence systemic and structural change across all parts of society[22]. Though the current research is more aligned with inclusive research with people with intellectual disability which uses participatory co-design approaches, the principles of emancipatory research align with these approaches and provide powerful goals with which future research can be judged. Impact driven research which prioritises the voices of people with intellectual disability as leaders and directors of that research is less frequently evidenced compared with research which involves people with intellectual disability as advisors, co-researchers or co-designers of aspects like Easy Read outputs. Each approach has value and there is no single approach to inclusive research[23]. People with intellectual disability should be able to determine how they wish to be involved and in which aspect of the research process. The primary focus of this current research was to provide an opportunity for people with intellectual disability across Australia to share what they felt were important issues for future health research. The study was designed to ensure inclusion of a broad range of voices and experiences of people with intellectual disability – framed in this research as 'artists' and 'researchers'. They brought different, distinct and converging perspectives 'told' in different ways. They also reflected diverse lived experiences of gender, sexualities, age and cultural diversity and diverse geographic positioning across Australia.

Lived experience of intellectual disability does not translate into expertise in research necessarily. Research is a specific skill. Lack of research skill and knowledge does not mean that people with intellectual disability cannot and should not determine where research funding and resourcing is spent or be involved in the research that is 'about them'. Further, there are people with intellectual disability who have acquired research skills over many years and are experienced researchers. The inclusive arts-based approach was successful in prioritising the perspectives of a broad group of people with intellectual disability, who had diverse communication approaches. The artists expressed rich, complex and nuanced responses to the question "what health issues matter most" to people with intellectual disability. The messages they shared through their art and their artist statement reinforces the importance for using 'holistic' concepts of health in health research with people with intellectual disability. The ARB approach to the research and the rich, talented art works also speaks to the importance of using creative methods in health research with people with intellectual disability.

The targeted semi-structured interview phase recognised the lived experience researcher expertise who had insider knowledge of research themes and processes. In contrast to the arts-based responses the interview narratives focused strongly on barriers and problems in the health system. The issues raised highlight areas that research should aim to improve, such as the interactions with health professionals, access to accessible information. It implies a need for greater implementation science and action research approaches where there is a focus on clear system change. The focus on barriers in the interviews is not surprising, given that research often focuses on identifying problems and gaps. However, the lived experience narratives clearly seek a solution that is based on perspectives and insights of people with intellectual disability to translate into effective system change.

Overwhelmingly, the desire for self-determination and autonomy over their health, with respect for multiple identities and being treated as a holistic person, rather than reduced to a diagnosis, ignored or overlooked in favour of support workers or family members in health interactions came out strongly in the art and interview data. A person-centred health system is one that acknowledges the diversity of the population, responds to individual needs and values multiple identities. People with intellectual disability who participated in this study highlighted these elements of person-centred care as fundamental to a better experience with the health system. The experiences highlighted by participants also pinpoint deeper issues transcending attitudinal obstacles alone. Across the dataset, participants narrated being doubted, dismissed, or having their credibility and reputation undermined upon divulging a disability, implying they were being wronged not only as patients but as empowered patients with lived experiences. Correspondingly, the inaccessibility of health information and the escalating strain of browsing systems not devised for them meant that participants were often incapable of fully making sense of or acting on their own health experiences. Acknowledging these dynamics reconceptualises the issue from one of individual medical encounters to one of structural justice and situates people with intellectual disability as reliable experts on their own health, a standard that should be established as the foundation for future research design.

Research about the health experiences of people with intellectual disability has historically focused on the issues of health system accessibility and responsiveness predominantly. What access means, in terms of services and practices has been conceptualised by researchers including Levesque, Harris & Russell [24]. Their research conceptualises the dimensions of access to health care across different populations. This well-known and utilised framework outlines five dimensions of accessibility; Approachability, Acceptability, Availability and Accommodation; Affordability and Appropriateness. Levesque, Harris, Russell [24] also outline five corresponding abilities of 'the person' who seeks access to health care, these are; Ability to perceive -this is connected to health literacy, health beliefs, trust and expectations; Ability to seek – which connects to personal and social values, culture, gender and autonomy; Ability to reach – which relates to living environments, transport, mobility and social support; Ability to pay – which relates to income, assets, Social Capital, Health insurance; and Ability to engage – empowerment, information, adherence, care giver support. This conceptual framework is well placed to frame research about the health access and response themes such as addressing priority health and medical conditions of specific concern to people with intellectual disability; embedding flexible and accessible communication across the health system and ensuring access to supported decision making in health. Supported decision making is key to a person-centred health system which respects the self-determination and autonomous lives of people with intellectual disability.

Having access to information in a way that is accessible and appropriate to the person's preferred communication style is a critical aspect of supported decision making. Participants spoke how there was often an expectation for them to bridge the gap for health professionals with expectations for people with intellectual disability to understand medical jargon. Information was rarely provided in Easy Read or other accessible formats. Of note, one participant spoke to how being involved in research raised awareness of Easy Read. While there is a body of research on health literacy for people with intellectual disability[25,26], we are not aware of any that uses creative methods to understand how people feel about their exclusion from or challenges with accessing, applying and appraising health information and how these insights could inform more accessible health information to build health literacy.

Overall, our research calls for engaging 'deeply' with lived experience expertise and using and promoting the voices of people with intellectual disability in health system and health practices reform.

There is also a need to address persistent issues in health and the health system – they might be seen as the 'wicked problems' [27] of healthcare for people with intellectual disability. 'Wicked' because they are complex and have no definitive and objective answers [27].

For many people with intellectual disability who engaged with this study, health was understood more broadly than a health condition or health system issue. Overall, well-being describes a fundamental clustering of issues that matter to people with intellectual disability – emotional well-being and mental health, social health, environment, nature and connection.

Participants stressed the importance of understanding mental health from a broader well-being lens and not from a diagnostic or treatment perspective. Art itself was used by many to support their well-being and better mental health. Participants connected mental health with nature and the environment also, and spending time in the outdoors engaging with nature was another way of supporting better mental and emotional well-being.

Connecting with the environment and community were healing experiences for participants. However, there is a lack of research about the ways people with intellectual disability connect with nature, the environment and outdoor health, and its mental health and emotional wellbeing outcomes. While there is a body of work about approaches like forest therapy [28,29] and nature bathing for adults with disability, the research has not focused on people with intellectual disability. Any research that has included people with intellectual disability has a 'therapy' focus – where it is used as a planned intervention rather than looking at how 'self-determined' time in nature, the outdoors and environmental connection works for people with intellectual disability [30]. The ABR, in particular, highlighted how people with intellectual disability are 'self-managing' their health through choosing things like being in nature and outdoor health and non-Western therapies and approaches. These and the centrality of community and cultural connections to promote what we have called 'social health' have been highlighted as important to people with intellectual disability warranting attention in future research.

Connection to community and the broader social determinants of health were also expressed through artistic narratives of friends, family and community as well as the need for safe and healthy places to live. The social determinants of health are known to account for the largest proportion of inequities in health, yet research addressing these social determinants to improve the health outcomes of people with intellectual disability is under-developed [31]. Much literature exists on housing, education and employment for people with intellectual disability yet, very few studies make the connection to health equity and health outcomes. The evidence that does exist shows a direct link to health experiences, for example, with use of emergency departments [32]. Addressing the social determinants of health is essential for better health and overall quality of life for all people with disability including people with intellectual disability [33].

## Implications

Our findings show strong implications for funding agencies, researchers, health and disability practitioners alongside people with intellectual disability. They offer clear guidance for inclusive research approaches and principles for health practice across these groups. The findings also highlight that the research topics that matter to people with intellectual disability include areas where there is currently little or no research. Giving voice to people with intellectual disability, and centring them as active leaders, is therefore crucial if research agendas are to meaningfully improve the health of people with intellectual disability. A detailed ranking of the research areas identified from our findings will involve further inclusive processes that are beyond the scope of this current project.

Inclusive research, particularly ABR, is inherently applied, connecting research directly to the people it aims to benefit. There was a clear message from participants that the art competition itself should be continued as an ongoing annual project. This will ensure we can continue centring the voices of people with intellectual disability in creative ways for the ongoing development of a research agenda on health in the lives of people with intellectual disability. It will also progress future inclusive research work, promote purposeful, creative activities that position people with intellectual disability as artists in the broader arts community, and provide a crucial space for lived experience voices to be included in diverse ways that will capture their evolving and ongoing needs.

People with intellectual disability from across Australia have given generously of their time through a range of mediums to share what is important to them in terms of health. There are clear areas of the health experience which require further focus in terms of research, and in particular translational research, which improves the interaction with and outcomes from the health system. Future research funding should ensure that the issues identified here by people with intellectual disability shape the focus and design of research.

The diverse voices of people with intellectual disability should shape the research agenda but also the implementation and translation into system and policy reform. The richness of the data and the breadth of issues identified serve to acknowledge the complexity of the health system. There are lessons for policy reform as persistent, 'wicked' problems in the health system continue to lead to inequities and harmful outcomes for people with intellectual disability.

Methodological implications are also relevant. This work demonstrates the strength of collaborating inclusively and designing a study which incorporates multi-modal approaches to gather the perspectives of people with intellectual disability.

Furthermore, based on the results from the integrated findings, several key areas for future health research were pinpointed. These key areas included wellbeing, health communication and its accessibility and impact, inclusion of the experiences of people with intellectual disability in health and medical condition research, understanding what inclusion 'is' and how to achieve it in health services and health care and socio- cultural factors impacting health in the lives of people with intellectual disability. Some perhaps new insights highlighted the importance of exploration of holistic nature-based practices as they are experienced and undertaken by people with intellectual disability, linked to a fuller understanding of how people 'manage' their health through choice of approaches to health care and 'activities' that promote their wellbeing. Crucially, each of these areas should be conducted through inclusive and co-designed methodologies that situate people with intellectual disability as leaders and decision-makers throughout the research process.

## Strengths and limitations

The study had a number of strengths:

- This is the first known study in Australia to be co-designed with people with intellectual disability to identify the health issues and research priorities for people with intellectual disability at a national level.
- The multi-modal research design supported the inclusion of a diverse group of people with intellectual disability from across Australia. It enabled the expression of health issues and health priorities in various forms – spoken word, sculpting, painting, poetry, video, digital media and photography
- Ethically approved and implemented adhering to best practice principles of inclusive research and arts competition standards.
- Despite the short time frame available, there was an overwhelming response to the art competition with 60 artworks submitted. This is indicative of the importance of health and health research to people with intellectual disability as well as the value in inclusive arts-based approaches to support expression of the issues that are relevant.
- Reflexive, collaborative approach to analysis was taken and is outlined above. The integration of interview data and artist statements provides a powerful narrative on what matters to people with intellectual disability when it comes to their health and future health research in Australia.

There were some limitations to the project:

- A one-year time period was given to complete this work. This is an extremely restrictive timeline for an ambitious, inclusive and multi-modal project. Such timelines typically enforced by funding agencies are prohibitive of inclusive and co-design practices. However, due to the experience of the project team in inclusive and arts-based work and the networks of relationships in place, the project was co-designed, ethically approved, implemented and reported on within a 12-month time period.
- Research interviews and artists statements were analysed using a reflexive thematic analytic approach. The works of art were alluded to but a separate deep analysis of the art works was not feasible in the time available. There is potential to further analyse the data in particular the art works to explore further insights that can be garnered.
- The semi-structured interviews contrasted in depth and richness. Some participants provided intricate, critical reflections while other participants presented broader response. These differences highlight the varied communication approaches and research experience among participants and was facilitated by the analytic approach. However, such differences emphasised that some voices were more noticeably featured in the thematic constructions than others.
- Future work could include specific groups like children and young people, as their voices are not represented; or specific target groups such as First Nations, CALD or LGBTIQA+ to further explore their intersection with disability.
- Time restrictions meant a thorough priority setting process, specifically a ranking of most to least important from the perspective of people with intellectual disability and based on the research findings could not be completed.

## Conclusion

In summary the art competition has shared deep, creative, meaningful insights through 60 art works from 49 people with intellectual disability which is a unique contribution to health research in Australia. The intention of the ARB method was to be accessible, to be positioned within a purposeful and meaningful 'real world' context, to reach a diverse range of people with intellectual disability across Australia and to centre the voices and experiences of people with intellectual disability in shaping future research relating to their health. It achieved this. This was complemented by an inclusive team-based approach to semi-structured interviewing and analysis, of researchers with intellectual disability across Australia, of which, 16 people participated. Our deeply reflective, inclusive, diverse and diversely experienced research team and the methods we used also contribute to understandings about how health research can be conducted.

Our findings reflected a strong, inclusive methodology for hearing different voices in different ways. We were able to develop a range of research areas of importance, but detailed ranking of these priorities will require further work beyond the scope of this current report, particularly given the crucial need for rigorous, inclusive processes. Our findings can, however, immediately help inform research that the Centre funds (seed funding), project work developed by the Centre and contribute to a broader research agenda aimed at improving the health of people with intellectual disability.

# Appendices

A. Terms and Conditions
B. Judging Panel Brief
C. Instructions for Judges Scorecard
D. Judges Scorecard PDF version
E. Judges Scorecard JotForm
F. People's Choice JotForm
G. Health Matters Art Competition Flyer
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# Appendix A Terms and Conditions

# Terms and Conditions

**About the Competition**

Health Matters! is an art competition presented by the Centre for Disability Studies and the National Centre of Excellence in Intellectual Disability Health. It is part of a research project for engaging people with intellectual disability in thinking about what matters most in health research. The artworks and information will be used in the research process to help identify the national health research priorities of people with intellectual disabilities.

**Eligibility**

This art competition is free to enter and is open to Australia residents over 18 years of age who identify as having an intellectual disability. Participants must be amateur artists. Artworks must be the original work of the artist

**Art Works**

The artworks can be created in a medium of the artist's choice, including but not limited to poetry, painting, drawing, sculpture, music, dance, writing, digital art and more.

**Competition Theme**

The theme of the competition is *"Health Matters!"*

Artists are invited to make artworks that show what health issues matter most to them.

When planning artworks, artists might like to think about:

a. What health issues you want to show or talk about in your artwork

b. If there are health problems that you think doctors should understand better.

c. What health issues matter most to you and how you can show them in your artwork.

Artwork will help researchers learn what really matters in health for people with intellectual disabilities.

**Submission of Entries**

Entries open on 10th November 2025 and close 15th January 2026. To enter upload a digital copy of your artwork to our website.

Entries must be submitted before midnight (AEST) 15th January 2026 to be eligible.

Digital files can be one of four types: A document (DOCX, PDF, TXT), an image (JPG, PNG, GIF), an audio file (MP3, WAV) or a video (MP4, MOV).

Artists must include an artist statement with their artwork. Artist statement can be 1 of 2 file types: A document (DOCX, PDF, TXT) or a video (MP4, MOV)

Judging will be based on digital copies of the artist's artwork only.

Artworks can't include company logos, brands, or characters from movies, TV, games, or other licensed material.

Entries must not include anything offensive, harmful, or inappropriate. The organisers reserve the right to disqualify any work that contains hate speech, discrimination, violence, or explicit material.

The organisers are not responsible for lost, late, incomplete, or incorrectly submitted entries. Proof of sending does not count as proof of entry.

**Warranties**

The artist warrants that the work is their original work and does not infringe on the rights of others.

AI-generated art, or art that relies on AI tools to create the main content, is not allowed. By entering, you confirm your work is original and not made by AI.

**Costs of Artwork**

Artists are responsible for the costs of creating their artwork. CDS will provide art supplies for those who request support, but any other costs remain the responsibility of the artist.

**Judging Process**

Judging will be between 15th January and 30th January 2026.

A judging panel (lived experience and non-lived experience) will determine winners.

The judging panel will be selected by the Centre for Disability Studies and the National Centre of Excellence in Intellectual Disability Health and announced at the beginning of the judging period.

Entries will be judged primarily on their artistic merit, as well as how well they address the competition theme, the overall impact of the work, creativity, and originality. Only eligible entries will be considered, and the judges' decision is final. The organisers reserve the right not to award a prize if no entry meets the standard.

**Prizes**

There are four prize categories:

- **1st Prize** – $1000 gift voucher for art supplies or materials
- **2nd Prize** – $500 gift voucher for art supplies or materials
- **3rd Prize** – $500 gift voucher for art supplies or materials
- **People's Choice** – $500 gift voucher for art supplies or materials

Jury prize winners will be notified by 4th February 2026 via phone call or email and announced at the Sydney Launch event in February and via social media.

**People's Choice Award**

The People's Choice prize will be awarded to the entry that receives the most votes from the public during their visit to the online exhibition. Votes must be submitted via the online form. Only eligible entries will be considered, and the organisers' count of votes is final.

Voting for the People's Choice prize will be open during 5-13th February 2026 and will be announced at the Sydney Launch event in February 2026 (TBC) and via social media.

**Online Exhibition**

Artworks will be showcased in an online exhibition, which will be launched at an event in February 2026 (TBC). Participants and their families will be invited to attend the event where prizes will be awarded to winners.

**Sydney Launch Event**

Winners of the art competition will be announced and receive their prizes at a launch event in Sydney in February 2026 (TBC). CDS will arrange flights and one night's accommodation for each winner and one support person, if needed, to attend the event.

**Copyright and Attribution**

All artwork remains the creative work of the original artist. By entering the competition, artists grant the organisers a non-exclusive, worldwide licence to use images of their work for promotional, marketing, and exhibition purposes in any media (online or print) for a period of five years.

The organisers may make reasonable edits to digital copies of artwork (such as resizing, cropping, or adjusting colours) for these purposes, but will not alter the content or meaning

of the artwork. All artwork will be credited to the original artist unless the artist chooses to remain anonymous.

**Decisions and Disqualification**

All decisions made by the organisers and judges are final. The organisers reserve the right to disqualify any entry and may provide a reason. Examples of reasons include, but are not limited to:

- The entry contains offensive or inappropriate content.
- The entry violates the originality or AI rules.
- The entry is incomplete, late, or incorrectly submitted.
- The entry does not meet eligibility requirements.

**Research and Data collection**

All artwork and artist statements will be anonymised for any data analysis during the research process, so individual artists cannot be identified.

**Personal Information and Privacy**

Any personal information collected for the competition will be used only for the purposes of running the competition, contacting winners, and promoting the event or artwork. Artists are responsible for keeping their contact information up to date before, during, and after the competition period. Personal information will be stored securely and handled in accordance with privacy laws. It will not be shared with third parties without the artist's consent.

**Artist Statements and Research Participation**

Artist statements submitted to this competition will be used for research purposes. Artists must read the participant information statement and sign a consent form when submitting their artwork and statement. Artists can withdraw their consent at any time; the researchers will provide a way to do this and will check in with the artist after submissions are collected if they wish to withdraw.

**What's Important to Us in Health Research? Establishing National Health Research Priorities Through a Co-Design Process.**

Terms and Condition

# Appendix B Judging Panel Brief

# Judging Panel Brief for Health Matters!

**Welcome** to the **judging panel for Health Matters!** We're excited and honoured that you are part of this important project. This document will give you all the **key information** you need about the **competition and the judging process**.

If you have **any questions,** please **contact Dan on** danielle.carey@sydney.edu.au

## About the Competition

***Health Matters!*** is an online competition presented by the **Centre for Disability Studies (CDS)** and the **National Centre of Excellence in Intellectual Disability Health (NCEIDH)**.

The competition invites people with intellectual disability to create artwork that expresses what health issues matter to them.

Artworks can be created in any **medium the artist chooses**, for example, **poetry, painting, drawing, sculpture, music, dance, writing, digital art and more**.

## Who Can Enter?

The competition is **free to enter** and open to **Australia residents** who are

- over **18 years of age**,
- **identify as having an intellectual disability** and
- are **non-professional artists**.

## Why We're Running the Competition

This art competition is part of a **research project** that looks at what **health issues** matter most to **people with intellectual disability**. The artworks will help our research team identify the **national health research priorities** of **people with intellectual disabilities**.

## How the Competition will work

- The competition will run online
- Participants will submit a **digital copy of their artwork** via the CDS website.

- All artworks will be showcased in an **online exhibition**, which will be launched at an event in Sydney in February 2026.

## Terms and Conditions

The **Terms and Conditions** are **available on the website** in both Easy Read and Plain English. A **copy will be emailed** to all judges.

## Judging Overview

Judges will be chosen by **CDS** and the NCEIDH and announced at the beginning of the judging period.

The **judging panel** will **determine the winners**.

## Judging Process

- The **judging period** will take place online in **January or February 2026 (TBC)**.
- Judges will receive **scoring sheet**s and **digital access** to all eligible entries.
- Each entry will also include a **short artist statement** to give **context** to the **artwork**.
- Judges will be asked to **review and score the artworks** using a **simple scoring guide** that outlines the judging criteria.
- The panel will meet **online via zoom** to discuss **final selections** and **determine winners**.
- All **final decision**s will be **confirmed collectively** and **approved** by the research team.

## Judging Panel

The panel will include **lived experience artists**, **arts workers**, **disability advocates**, and **researchers**. CDS will ensure the judging process is **fair, inclusive, and accessible**.

## Judging Criteria

CDS will provide judges with a **judging sheet and scoring criteria**.

Entries will be judged on:

- **Artistic merit** - The technical skill and overall quality of the artwork

- **Competition theme** - How well the artwork shows what health issues matter to the artist
- **Impact** - The emotional or cognitive response the artwork creates in the viewer
- **Creativity** - How interesting or imaginative the artist's use of materials, ideas and methods is
- **Originalit**y - The originality or uniqueness of the idea or concept

Only **eligible entries will be considered**, and the **judges' decision is final**. The organisers reserve the right not to award a prize if no entry meets the standard.

## Prizes

There will be **four prizes**. Each prize will be a **gift voucher (art supplies or materials)**.

- 1st Prize - to the value of $1000
- 2nd Prize - to the value of $500
- 3rd Prize - to the value of $500
- People's Choice to the value of $500

## Online Exhibition

Digital copies of participant's artworks will be **showcased in an online exhibition**.

## Launch Event

**Winners** of the Health Matters! art competition will be **announced and presented** with their prizes at a **launch event** in **Sydney in February 2026**.

Judges are **warmly invited** to attend at their **own expense**. Attendance is **optional**, but provides an **opportunity to meet the artists**, **speak with the research team** and **hear about the research findings** for the research project.

## Confidentiality

Judges must **maintain integrity and confidentiality** at all times. They **must not discuss** any entries or personal details outside of their role as judge

Judges **must not publicly discuss, share or announce** artworks or winners before the **official announcement**

Judges must **inform Dan Carey** if they **personally know** one of the competition participants so we can manage any **conflicts of interests** mindfully.

## Payment

CDS will **pay judges** according to the **National Association for Visual Art (NAVA)'s Code of Practice** for Visual Arts, Craft and Design.

Payment will be **$287.87**. This assumes a **half day of work**, which includes **three hours** of reviewing time and **one hour in a zoom meeting** with the panel to discuss and finalise winners

## Contact Information

Please contact **Dan Carey** for any **questions or support needs** during the judging process.

Dan Carey
Research and Inclusion Officer
Centre for Disability Studies
danielle.carey@sydney.edu.au

# Appendix C Instructions for Judges Scorecard

## Welcome!

This scoring sheet helps judges choose winners for the Health Matters art competition.
It shows what to look for in each artwork and helps keep judging fair for everyone.

### What we judge

You will use **five things** to judge each artwork :

1. **Artistic merit** – How well the artwork is made. This includes skill and overall quality
2. **Competition theme** – How well the artwork connects to the theme "Health Matters!"
3. **Impact** – How the artwork makes the viewer think and feel
4. **Creativity** – How interesting or creative the artwork is
5. **Originality** – How new or original the ideas are

## How to use the scoring card:

1. Write down the artist's name and artwork
2. Look at the artwork and read the artist statement
3. Choose one option for each section
    a. Excellent
    b. Good
    c. Poor
4. Write your name at the bottom of the sheet
5. Optional: Write comments to explain your score

## Scoring

- Excellent = 10 points
- Good = 5 points
- Poor = 1 point

Judges fill out the scoring card.

CDS staff will then add up the scores.

## Questions?

Please contact **Dan Carey** at danielle.carey@sydney.edu.au

# Appendix D Judges Scorecard PDF version

# JUDGING SCORECARD

Artist's Name_____

Artwork_____

## 1 Artistic Merit

How well is the artwork made?

| | | |
|---|---|---|
| ☐ **EXCELLENT** Very good skill and overall quality | ☐ **GOOD** Some skill and overall quality | ☐ **POOR** Limited skill and overall quality |

## 2 Competition Theme

How well does the artwork connect to the theme "Health Matters"

| | | |
|---|---|---|
| ☐ **EXCELLENT** Very clear connection to the theme | ☐ **GOOD** Some connection to the theme | ☐ **POOR** Little or no connection to the theme |

## 3 Impact

How does the artwork make you think and feel?

| | | |
|---|---|---|
| ☐ **EXCELLENT** Makes you think and feel a lot | ☐ **GOOD** Makes you think and feel a little bit | ☐ **POOR** Does not make you think or feel |

## 4 Creativity

How interesting or creative is the artwork?

| | | |
|---|---|---|
| ☐ **EXCELLENT** Very creative and interesting | ☐ **GOOD** A little interesting and creative | ☐ **POOR** Not interesting or creative |

## 5 Originality

Does the artwork feel new or original?

| | | |
|---|---|---|
| ☐ **EXCELLENT** Very new or original ideas | ☐ **GOOD** Some new or original ideas | ☐ **POOR** Not new or original |

Judge's Name_____

Comments about artwork (if you want)

Total Score (CDS Staff will do this):_____

# Appendix E Judges Scorecard JotForm version

All fields marked with * are required and must be filled.

Judge's Full Name *

First Name

Second Name

Artwork *

## 1. Artistic Merit

How well is the artwork made?

Choose one option *

- EXCELLENT - Very good skill and overall quality
- GOOD - Some skill and overall quality
- POOR - Limited skill and overall quality

## 5. Originality

Does the artwork feel new or original?

Choose one option *

- EXCELLENT - Very new or original ideas
- GOOD - Some new or original ideas
- POOR - Not new or original

Comments about artwork (if you want to)

Submit Scores

Powered by Jotform

# Appendix F People's Choice JotForm

Choose your **favourite artwork** in the Health Matters Art Competition.

The artist with the most votes will win the **People's Choice Award**.

You can **vote once** per one email address.

The winner will be given a **$500 voucher** to spend on art materials or art classes.

### How to find the artist and the name of the artwork

1. Click on the link to look at the list of artworks
2. You can find the artist and artwork names below each artwork image

This is the link to the list of artworks

https://artspaces.kunstmatrix.com/en/exhibition/15090737/catalog

### How to vote

1. Enter your Email Address
2. Click on your favourite artist and their artwork
3. Click the Submit Vote button

Your Email Address *

example@example.com

Click on your favourite artist and their artwork to vote *

- Axel Andersen - Reasonable and Necessary
- Ben Chew - Over the rainbow
- Brett Roberts - Snake River
- Brianna George - My bubble #1

# Appendix G Health Matters Art Competition Flyer

2025 ART COMPETITION

# HEALTH MATTERS!

# CALL FOR ENTRIES

The Centre for Disability Studies is calling for artworks on the theme of health issues for people with intellectual disability.

**Free to enter**
**Judging panel**
**Prizes**
**Online exhibition**

National Centre of Excellence in Intellectual Disability Health | CDS Centre for Disability Studies | cid Council for Intellectual Disability | Down Syndrome Australia | First Peoples Disability Network Australia | Queensland Centre of Excellence | QDN | The KIDS Research Institute Australia | The University of Melbourne | UNSW Sydney

**ENTRIES CLOSE 16TH JANUARY 2026**

# HOW TO ENTER

1. Create an artwork in a medium of your choice on the theme of health matters
2. Write or record a short description of your artwork (250 words max)
3. Submit a digital version of your artwork and description on our website cds.org.au/art-competition by **16th January 2026**

# ELIGIBILITY

- 18+ Be 18 years or older
- ID Identify as having intellectual disability
- Live in Australia

## QUESTIONS?

**Contact danielle.carey@sydney.edu.au to ask for support or if you need art materials**

This art competition is part of a research project led by the Centre of Disability Studies (cds.org.au) as part of the National Centre of Excellence in Intellectual Disability Health aiming to understand what people with intellectual disabilities think is important in health research.

THE UNIVERSITY OF SYDNEY 2025/HE000244 V2 10 Oct 25

# Appendix H Artwork Submission JotForm

CDS
Centre for Disability Studies

National Centre of Excellence in Intellectual Disability Health

Welcome to **Health Matters!**

This is an online art competition run by the **Centre for Disability Studies** as part of the **National Centre of Excellence in Intellectual Disability Health**.

This art competition is part of a **larger research project** we are doing.

Your art works will help our **research team** look at what **people with intellectual disability** think matters most in **health research** for people with intellectual disability.

You can **read more** about the competition here.

If you **need help** to submit your artwork or if you have any questions, you can **contact Dan Carey** at danielle.carey@sydney.edu.au

## Information about you

The next questions are about you.

We ask these questions to make sure you can enter the competition

We also use this information to contact you if you win the competition.

Name *

First Name

Last Name

E-mail *

ex: myname@example.com

example@example.com

Phone Number *

0000-000-000

Please enter a valid phone number so we can contact you in you're a winner.

Gender *

Please Select

Male, Female, Non-binary or other

Which state or territory do you live in?

Please Select

QLD, NSW, VIC, TAS, SA, WA, NT, ACT

I am 18 year old or over *

◯ Yes

## Eligibility

You can enter this competition if you:

- are 18 years old or older
- live in Australia
- have an intellectual disability

Please tick YES to the following sentences to show that this is true for you

I live in Australia *

◯ Yes

I am a person with an intellectual disability *

◯ Yes

How did you hear about this competition?

☐ Social Media

☐ Centre for Disability Studies website

☐ A friend or family

☐ Other (please explain)

## Your Artwork

The next questions are about your artwork.

We ask these questions to make sure you created the artwork yourself.

Please tick YES to the next questions to show that these are true for you.

I made this artwork myself *

◯ YES

I did NOT use AI to help make my artwork. *

◯ Yes

## Uploading your Artwork

In this section, you will upload your artwork.

We also need some information about your artwork for the exhibition.

Title of Artwork *

Type of artwork *

eg. Drawing, Sculpture, Painting, Textile, Mixed Media, Dance, Digital Art, Theatre, Movement, Poetry.

Size of your artwork (how long and how wide it is)

Artwork Image 1 - Please upload your best image/video here - this will be used in the online art exhibition *

**Upload a File**

Drag and drop files here

A document (DOCX, PDF, TXT), an image (JPG, PNG, GIF), an audio file (MP3, WAV) or a video (MP4, MOV)

Artwork Image 2 - If you'd like to show a different angle of your artwork, you can add another photo here (optional).

**Upload a File**

Drag and drop files here

Artwork Image 3 - If you'd like to show a different angle of your artwork, you can add another photo here (optional).

**Upload a File**

Drag and drop files here

## Artist Statement

This is where you **tell us about your artwork**.

Please explain what your artwork has to do with the art competition's theme "Health Matters."

You can **write it down** or **record your voice**.

Some questions to **help you make your artist statement**:

a. What health issues matter most to you?

b. Are there any health issues people with intellectual disability experience that you wish health professionals understood better?

c. Why did you choose to make this artwork about health?

If you want to talk about your artwork instead of write, type "I will record my voice" in the box below and then click the record button to record your voice.

Write about your art work *

Type here...

0/250

Tell us about your art work

Record 0:00/3:00

## Terms and Conditions

You **need to read** the **Terms and Conditions before you submit** your artwork.

You can find the Terms and Conditions in **Plain English** here, or in **Easy Read** here.

Please tick YES to the next question to show this is true for you.

I have read the terms and conditions for Health Matters! online art competition *

- ◯ YES

## Online Exhibition

Your artwork will be shown online from 5th February 2026.

We need to know how you want your artwork to be displayed.

Please click Yes or No for each sentence.

I give permission for my name to be shown in the online exhibition. *

- ☐ YES
- ☐ NO

I give permission for my artwork to be shown in the online exhibition *

- ☐ YES
- ☐ NO

I give permission for my artist statement to be shown online exhibition *

- ☐ YES
- ☐ NO

You have reached the end of the submission form

You need to press "Submit" to complete your entry.

Save Submit

Powered by Jotform

# Appendix I Semi-Structured Interview Guide

**What's Important to Us in Health Research? Establishing National Health Research Priorities Through a Co-Design Process.**

**Semi-structured interview prompts and questions**

**This project is going to make a report to the National Centre of Excellence for Intellectual Disability Health and it's going to tell them what people with intellectual disabilities think they should be researching. We want to hear your ideas for projects about health.**

**About the interviewee's experience:**

What is research?

You have previously worked as a Lived Experience researcher - can you tell us about the project or projects you have worked on?

What happened in the project?

What work did you do in the project?

Were there other people working on the project too? What work were they doing? Did you work together?

How did the people in the team decide what they were going to do?

Did the people in the team choose the parts of the project they were going to work on?

Did you work on the parts of the project you wanted to work on?

If there were disagreements about the work, how were they resolved?

**This project is about health research and collecting information about what people with intellectual disabilities think is important in health research.**

Do you know about any health research projects? (Prompt talk about the work done by mainstream health researchers, with examples. Work done **by** researchers **about** people with intellectual disabilities in hospital, for example La Trobe University study. Projects with **lived experience researcher** input for example swallowing campaign by NSW Council for Intellectual Disability)

**What's Important to Us in Health Research? Establishing National Health Research Priorities Through a Co-Design Process.**

**Semi-structured interview prompts and questions**

If you think about the health of people with intellectual disabilities, what do you think we need to know more about? (Prompt: are there health problems that you or other people you know with intellectual disabilities experience that doctors should understand better?

Are there problems with health services – hospitals, doctors, allied health professional that we need to know more about?)

**(Repeat)** This project is going to make a report to the National Centre of Excellence for Intellectual Disability Health and it's going to tell them what people with intellectual disabilities think they should be researching. We want to hear your ideas for projects about health.

What is the most important health issue for people with intellectual disability that we need to know more about?

Health Services

What other health issues are important to you at the moment?

Is there anything else you'd like to tell us about?

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