AutismCRC

Community Forum Guidance:
Engaging with Aboriginal and Torres Strait Islander autistic peoples, autistic individuals with high and complex support needs, and their families/supporters

Supporting information

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Copyright and disclaimer

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Autism CRC

Autism CRC is the independent national source of evidence for best practice in relation to autism across the lifespan and the spectrum.

We provide the national capacity to develop and deliver evidence-based outcomes through our unique collaboration with autistic people, families, professionals, services providers, researchers, and government. Together, we are addressing agreed needs and co-producing outputs with these stakeholders for the benefit of the community.

Autism CRC was established in 2013 as the world's first national, cooperative research effort focused on autism under the Australian Government's Cooperative Research Centres (CRC) Program. We receive funding from a number of sources, including the Australian Government. Autism CRC is no longer part of, or associated with, the CRC Program.

autismcrc.com.au

A note on terminology

We recognise that when referring to individuals on the autism spectrum, there is no one term that suits all people. In our published material and other work, we use the terms 'autistic person', 'person on the autism spectrum' or 'person on the spectrum'. The term 'autistic person' uses identity first language, which reflects the belief that being autistic is a core part of a person's identity.

Autism Spectrum Disorder (ASD) is diagnostic terminology used by the healthcare sector and is used in the context of a person being 'diagnosed with Autism Spectrum Disorder'.

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1. Introduction

1.1 Purpose of this document

The purpose of this document is to outline the administrative aspects of the project, describe the methods used, and provide an overview of the outcomes of the research activities conducted. It has been developed to provide a clear and transparent account of the approach taken. Accordingly, it is relevant to anyone wanting to understand this information, and/or apply methods and findings in future endeavours.

1.2 Overview of chapters

This document comprises the following chapters:

1. **project overview:** this chapter provides information about the broader project logic, purpose and the objectives and intended outcomes
2. **administration:** this chapter provides information about broader project governance, organisation, and coordination
3. **methodology and outcomes:** this chapter provides an overview of methodologies used to develop key elements and summaries of research activity outcomes.

2. Project overview

This chapter provides information about the research questions, purpose, objectives and foundations of the project. It includes an overview of the intended outcomes of the project as originally conceived, followed by outlines of specific adaptations.

2.1 Research questions

Across the broader project, evidence was gathered to answer the following core research questions. These were adapted accordingly across the research activities conducted. The questions were:

1. what principles/key considerations should guide co-production with autistic individuals with high and complex support needs and Aboriginal and Torres Strait Islander autistic peoples (including their families and supporters)?
2. how should co-production with Aboriginal and Torres Strait Islander peoples/individuals with high and complex support needs (including their families and supporters) be conducted?
3. what is the likely appropriateness, acceptability, feasibility, and effectiveness of the implementation resources (training and tool) being developed for the National Framework for assessing children's functional strengths and support needs (the Framework)?

2.2 Purpose

The purpose was to develop, establish and engage with community forums relating to two identified priority communities: (1) Aboriginal and Torres Strait Islander autistic people and (2) autistic individuals with high and complex support needs, including their respective families/supporters. Each community forum would be led by a convenor who had lived experience relevant to each community and the information gathered used to inform a *Community Forum Guidance Document* for future engagement with members of each community.

Autistic individuals with high and complex support needs was defined as those who require substantial assistance with self-care and other activities of daily living on a consistent basis across life contexts (e.g., require 24/7 care and supervision due to health, mental health, behavioural, cognitive and/or communication challenges) and are likely to have significant needs that require management within the community by families, carers, and/or disability support services.

2.3 Objectives

The project had the following objectives.

1. Establish two community forums comprised of members from the identified priority communities and other key stakeholders that each foster deep, inclusive and ongoing collaboration and practice development activities.
2. Engage with the community forums to support implementation of the Framework, including associated resources, in ways that are responsive to the needs of each identified priority community.
3. Deliver a written document which outlines outcomes from the environmental scan, methods for establishing and working with the forums, and recommendations for how to

facilitate continued engagement with members of each community to inform future work conducted with the forums.

2.4 Foundations

The project stemmed from Autism CRC's commitment to community consultation, collaboration, and co-production. Since its establishment, Autism CRC has supported community consultation activities that have informed the development, delivery, and implementation of national guidelines, strategies, and frameworks. As part of its ongoing commitment, Autism CRC sought to establish community forums to expand and deepen consultation with groups known to experience barriers to participation in traditional consultation and subsequently under-represented in research and practice development activities. This under-representation often translates to inappropriate support and service provision and contributes to poor outcomes and compounding impacts upon wellbeing. It sought to address this by (a) creating a mechanism for on-going consultation with individuals from these groups and organisations that represent them, (b) fostering deep, ongoing, and inclusive collaboration, and (c) the long-term building of partnerships.

2.5 Intended outcomes

This project was intended to facilitate Autism CRC in fostering collaboration with members of the identified communities through the establishment of the community forums and development of the *Community Forum Guidance Document* for engaging with members of each community. The forums would then support Autism CRC's longer-term program, having a view across all activities, rather than being engaged on an individual project basis. Doing so would facilitate increased accessibility and engagement, reduce participant burden, and maximise efficiency when engaging in consultation and co-production with members of each priority community.

Each forum was originally intended to have a convenor and up to 20 members from across the country who would provide ideas and views regarding Autism CRC initiatives. Convenors were to have experience with this type of project, as well as lived and/or professional experience relevant to each forum community. As such, the project team would directly approach and engage two convenors who bring these sets of knowledge, skills, and experience. The convenor would work with the project team and Autism CRC to establish the forum, including working out how it would work, who would be involved in the first instance, and the Terms of Reference.

The process for inviting members would be worked out through consultation with each forum convenor and differ depending on their needs. However, the approaches were expected to engage a diverse group of people who could bring a range of personal and professional views, ideas, and experiences to each forum. We anticipated that in the first year, a 'purposive' approach to inviting members would be used. This meant that we could be sure that people who were invited had knowledge, skills, and/or experience relevant to each forum, and at the same time reflect the diversity we were seeking. However, an intended key responsibility for the convenors in the first year was to work with members, the project team, and Autism CRC to establish procedures for inviting, engaging, and then transitioning members that will then be put in place moving forward to ensure open, transparent, and sustainable membership moving forward.

Members of each forum would engage would ways that aim to maximise accessibility and a positive and respectful experience. To the greatest extent possible, modes would be tailored to individual

members and may include, for example, online and in-person options, individual and small group meetings, a variety of approaches (e.g., yarning, individual and group discussions, surveys), and support for a range of communication modes such as augmentative communication, artwork, and spoken language.

2.6 Adaptations

Extended wait times for ethical approvals, delays in recruitment inherent to co-production with each of the target populations, and operational challenges necessitated revision of Objective 1. Rather than establishing community forums as was originally conceived, each with 20 members comprising of community members, professionals, and representatives from relevant organisations that would be maintained beyond the life of the project, a revised project plan was developed in partnership with Autism CRC.

A small number of specific individuals known to the forum convenors and individuals within Autism CRC's existing networks were then purposively recruited to participate in co-production activities within the bounds of the project timeline. These individuals participated in individualised engagement activities that reflected an iterative process of co-production to inform a *Community Forum Guidance Document* that is specific to engaging with autistic individuals and their families/supporters from each community.

Given the various practical and ethical challenges experienced in establishing the community forums that could be maintained outside the bounds of the current project, the development of the *Community Forum Guidance Document* was intended to provide Autism CRC with the knowledge and tools to establish an internal mechanism for on-going engagement with members of these priority groups within the organisation. In turn, this was intended to facilitate increased accessibility, reduce participant burden, and maximise efficiency when engaging in consultation and co-production activities with members of each community.

3. Project administration

This chapter provides information about the project team, governance, organisation, and coordination.

3.1 Project team

The project team included people with diverse knowledge, skills, experience, and perspectives and comprised professionals with diverse lived experience and professional experience, including in relation to professional disciplines, neurodivergence, cultural and linguistic diversity, human-centred and empathetic design, and co-produced framework and guideline development.

Teena Caithness (Organisation consultation and research support)

Teena is a speech pathologist who has worked in a range of settings including government, non-government and private practice. Teena has experience as a research assistant, has contributed chapters in books and co-developed the Australian Key Word Sign Vocabulary (Auslan version). A former Board member of Speech Pathology Australia, Teena also has experience with clinical guideline development and was involved in development of the *National Framework for assessing children's functional strengths and support needs* (Fitzpatrick et al., 2024).

Libby Groves (Project Co-ordinator and research support)

Libby is a speech pathologist who brings clinical experience working with people with communication support needs. She also lectures on multi-modal communication within the Master of Speech Pathology Program at Griffith University. Libby worked as a research assistant for the development of the *National Guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia* (Trembath et al., 2022), the update of the *National Guideline for the assessment and diagnosis of autism in Australia* (Goodall et al., 2023) and the *National Framework for assessing children's functional strengths and support needs* (Fitzpatrick et al., 2024).

Emma Hinze (Community Forum Convenor/Research support)

Emma is a PhD candidate and research assistant at Griffith University, with a Bachelor of Psychology with Honours. As a parent of an autistic son and an individual with a physical disability, she brings a unique dual perspective to her research. Emma brings experience in researching neurodivergence, lived experience of disability and family member experience of disability, and guideline development. Her PhD research focuses on understanding depression in autistic adults, aiming to improve identification and diagnostic processes. Emma's personal and professional experiences fuel her drive to enhance mental health outcomes within the autistic community. She is a member of the Autism QLD Advisory Committee and has contributed to the updating of the *National Guideline for the assessment and diagnosis of autism in Australia* (Goodall et al., 2023) and the development of *National Framework for assessing children's functional strengths and support needs* (Fitzpatrick et al., 2024).

Tara Lewis (Community Forum Convenor/Aboriginal and Torres Strait Islander advisor)

Tara is an Iman woman with connections to Taroom Country in Western Queensland. She grew up on Yuggera and Turrbal Country in Meanjin where she completed her Bachelor of Speech Pathology. Tara is the Knowledge Translation Lead at Indigenous Allied Health Australia (IAHA), where she is responsible for leading and managing the implementation of IAHA's research strategy and IAHA's engagement with impactful research initiatives. Tara also works alongside Aboriginal and Torres Strait Islander communities in establishing and maintaining research governance that enables Aboriginal and Torres Strait Islander peoples to self-determine research priorities and outcomes that will directly impact their communities. Tara represented IAHA within the project team that developed the *National Framework for assessing children's functional strengths and support needs* (Fitzpatrick et al., 2024) and led the Aboriginal and Torres Strait Islander consultation.

Zheng Yen Ng (Research co-ordination and support)

Zheng Yen Ng is a Research Fellow in the School of Allied Health, Sport and Social Work at Griffith University with a background in applied linguistics and experience in cultural responsiveness and early childhood health service provision for communities with communication difficulties. He brings experience in conducting qualitative research, engagement with families and service providers around allied health service provision, specifically for families with diverse language and cultural backgrounds. Zheng was involved in developing the *National Framework for assessing children's functional strengths and support needs* (Fitzpatrick et al., 2024).

David Trembath (Program Lead/research advisor)

David Trembath is Senior Principal Research Fellow at CliniKids, The Kids Research Institute Australia. His human rights-based research is focused on optimising the learning, participation, and wellbeing of children with neurodevelopmental disability through the delivery of safe, effective, and desirable services and supports. David brings over 20 years of clinical-research experience working with children with neurodevelopmental conditions. He co-chaired the development of the *National Guideline for supporting the learning, participation, and wellbeing of autistic children and their families in Australia* (Trembath et al., 2022), the update of the *National Guideline for assessment and diagnosis of autism in Australia* (Goodall et al., 2023) and the *National Framework for assessing children's functional strengths and support needs* (Fitzpatrick et al., 2024).

Rachelle Wicks (Project Lead)

Rachelle Wicks is a multiply neurodivergent (AuDHD) Research Fellow at Griffith University, Honorary Research Fellow within the Autism Research Team at The Kids Research Institute Australia, and Chair of the Autism QLD Advisory Committee. She has a background in psychology and early childhood education and development and brings lived experience to her role and advocates for neurodiversity-affirming practice and research that is co-designed and co-produced with the communities that it aims to benefit. Rachelle was a member of the development and working groups that developed the NHMRC approved Autism CRC update of the *National Guideline for the assessment and diagnosis of autism in Australia* (Goodall et al., 2023) and played leading roles within the project team that developed the *National Framework for assessing children's functional strengths and support needs* (Fitzpatrick et al., 2024), including lead for the project extension.

3.2 Project partners

Indigenous Allied Health Australia (IAHA)

IAHA is a national, member-based Aboriginal and Torres Strait Islander allied health organisation. IAHA leads workforce development and support in the sector to improve the health and wellbeing of Aboriginal and Torres Strait Islander peoples. IAHA also supports the broader allied health workforce, individuals, and organisations by providing expertise, interest, and commitment. Within this project, IAHA is a project partner in co-developing the Aboriginal and Torres Strait Islander Community Forum, providing input in the research design, recruitment, data collection, write-up, and deliverables of findings, and involved in the Organisation Consultation, providing input and expertise and advice in community consultation.

3.3 Involvement of Aboriginal and Torres Strait Islander peoples

A number of individuals and organisations from Aboriginal and Torres Strait Islander communities were centrally involved in the development of guidance for engaging with Aboriginal and Torres Strait Islander people. Two organisations - IAHA and the Institute for Urban Indigenous Health - were represented in the organisation consultation. Tara Lewis, Iman woman and speech pathologist, was a member of the project team and convenor of the Aboriginal and Torres Strait Islander community forum. As forum convenor, Tara led the development of a research methodology to support engagement with Aboriginal and Torres Strait Islander peoples through yarning sessions with Aboriginal and Torres Strait Islander autistic people and parents of autistic children. She also contributed to various other research activities within the broader project as IAHA's representative. We acknowledge that this document may not cover the perspectives of all Aboriginal and Torres Strait Islander Peoples and communities.

3.4 Involvement of the autistic and autism communities

Involvement of the autistic and autism communities was embedded within the project, including within the project team, research activities, and development of final outputs. The broader project team was led by an autistic researcher and included individuals with lived experience of autism, other neurodivergence, and disability more broadly across personal and professional contexts. Autistic adults and family members of autistic children and young people from each prioritised community provided input into the content and development of the *Community Forum Guidance Document* and feedback on the full draft. Organisation representatives comprised people with lived experience, including those with personal experience of neurodivergence, family members of people with lived experience of autism, and those with professional experience.

3.5 Project governance

Project team roles are described in the previous section (Project Team). The project lead liaised and collaborated with Autism CRC's Research and Community Engagement Manager and an autistic Project Officer in the recruitment of autistic individuals to participate in the community forum (i.e., individual consultation). The project lead also collaborated with team members responsible for convening consultation with each group (Emma Hinze and Tara Lewis).

3.6 Ethics protocols

Ethical approval for research activities were provided by the Griffith University Human Research Ethics Committee:

- organisation consultation: GU Ref No: 2025/413.
- engaging with Aboriginal and Torres Strait Islander autistic people and their families: GU Ref No: 2025/497.
- engaging with autistic individuals with high and complex support needs and their families: GU Ref No: 2025/451.

3.7 Risk assessment

A risk assessment was conducted and approved through Griffith University GSafe+ (Risk Assessment number: 24405). An outline of this document is provided in Appendix 1.0.

4. Methodology and outcomes

This chapter provides a summary of the methodology used.

4.1 Overview of research activities

Several research activities were conducted to inform the development of the *Community Forum Guidance Document*. These included:

- an environmental scan of research and grey literature related to research co-production that was specific to each group each group
- individual consultation with community members
- organisation consultation with representatives from community-based and professional organisations.

The methods used varied according to the unique characteristics and needs of each group to ensure that information gathered was specific, relevant and appropriate with autistic individuals with high and complex support needs, Aboriginal and Torres Strait Islander autistic people, and their respective families/supporters. The approach to combine evidence from these multiple research activities within a systematic process was chosen to maximise opportunities for multiple converging perspectives and sources of evidence to come together to address the research questions.

4.2 Environmental scans

Environmental scan methodology was selected for its adaptability and its capacity to draw on diverse data sources and viewpoints to meet the project goals and research questions. The method also supports genuine community engagement and co-production, as demonstrated in recent National Framework for assessing children's functional strengths and support needs (Fitzpatrick et al., 2024) and Autism CRC National Guidelines (Goodall et al., 2023; Trembath et al., 2022).

Coding frameworks and outcomes of each environmental scan were further used to inform the individual and organisation consultations. The resulting guiding principles and best practice points were used to scaffold engagement with those who participated in the individual consultation and gather their perspectives. The coding framework was further utilised to analyse data from the individual consultation sessions and interviews conducted with organisation representatives.

4.2.1 Individuals with high and complex support needs

4.2.1.1 Aim

The aim of this environmental scan was to identify existing co-production guidelines, information, and resources related to co-production with autistic individuals with high and complex support needs. Co-production was broadly defined as research involving different levels of community engagement, from consultation to co-design and co-production.

4.2.1.2 Research questions

The environmental scan gathered evidence to address the following research questions.

1. What principles/key considerations should guide co-design and/or co-production with individuals with high and complex support needs?
2. How should co-design and/or co-production with individuals with high and complex support needs be conducted in terms of:
   a) What engagement approaches should be used?
   b) What knowledge is required?
   c) What methodologies should be used?
   d) How outcomes should be evaluated?

4.2.1.3 Method

A search of the research and grey literature was carried out using a systematic protocol, similar to the one successfully employed in the Autism CRC National Framework for assessing children's functional strengths and support needs in 2024. For this project, "grey literature" included publicly accessible sources from government and non-government organisations' websites, such as government departments and agencies, professional associations and societies, community organisations, and research institutions. Since a recent systematic review found no research studies involving co-production with autistic individuals with an intellectual disability (Gibbs et al., 2024), a broad search strategy and scope were used instead of the more restrictive approach typical of traditional systematic reviews.

4.2.1.4 Eligibility

Literature from research and grey sources were included in the review if they met all the following criteria:

- the topic was a health- or disability-related area
- the article/report/guideline/framework reported on elements of co-production and/or co-design specific to individuals with high or complex support needs and their families, including:
  - primary studies using co-design methods that provide explicit insight into optimal approaches to co-production/co-design
  - primary studies that evaluate the use of co-production/co-design methods
  - methodological papers, government reports and guidelines/toolkits/frameworks with a primary focus on co-production/co-design in policy, practice, and service provision.
- the article was applicable, but not limited to, the health and disability sectors and individuals with high or complex support needs and their families
- the article described and/or evaluated co-design policy, practice, and service provision methodology
- information was presented in English
- the article was available in pdf format.

Articles were excluded if they:

- did not have a substantive focus or insight into optimal approaches to co-design with individuals with high or complex support needs and their families.

4.2.1.5 Search strategy

Systematic searches were conducted between March and May 2025 using Google search engine, Google Scholar, and backward snowballing (i.e., using references from included articles) relevant to autistic people with high and complex support needs and individuals with disability more broadly. Discussions were held among team members about the scope and the inclusion of document types.

Given the diverse nature of high and complex support needs, as well as the limited research specifically related to co-production with autistic people with an intellectual disability (Gibbs et al., 2024), complex communication needs and other profound or multiple disabilities, search terms were broadened to include specific conditions that often co-occur with autism and contribute to the high and complex support requirements of the target group. This approach was taken to ensure a comprehensive search and maximise the information gathered. The search terms used are listed in Table 1.

4.2.1.6 Study selection

The environmental scan was carried out in two stages. In the first stage, three members of the project team performed searches across each modality. The results were reviewed, and the relevance of each was assessed for potential eligibility. Each reviewer then judged whether the linked document was appropriate, recorded the URL of each relevant search result on a recording sheet, and downloaded the document for full-text review.

Ninety-three identified documents were divided between two reviewers for full-text screening. Each reviewer then independently read their assigned documents and reached consensus-based judgments on inclusion according to the eligibility criteria. Based on the full-text screening, 34 articles were excluded (see Appendix 1.1), leaving 59 documents for extraction (see Appendix 1.2).

4.2.1.7 Data extraction

For each identified article, reviewers extracted specific information relevant to addressing each research question in a standardised data extraction form in Microsoft Excel. Data was extracted by two members of the project team, with consensus checks conducted on the extracted data and any disagreements resolved via consensus.

Table 1: Individuals with high and complex support needs environmental scan search terms

Search terms used in research database searches in the environmental scan for individuals with high and complex support needs.

Stages	Search strategy
Initial search	co-production OR coproduction OR “co-production” OR co-design OR codesign OR “co design” OR “participatory action research” OR “community-led” OR “consumer involvement” OR “consumer engagement” AND autis* OR health OR disability
Detailed search	co-production OR coproduction OR “co production” OR co-design OR codesign OR “co design” OR “participatory action research” OR community-led OR “consumer involvement” OR “consumer engagement” AND “support need* OR “complex need*” OR “intellectual disabilit*” OR “high need*” Or “high support needs” OR “severe disability” OR “profound disability” OR “complex disability*” OR non-speaking OR non-verbal OR nonverbal OR “non speaking” OR disab* OR “complex communication need*” OR “severe impairment*” OR “severe physical disabilit*” OR “significant care need*” OR “significant need*” OR “significant support need*” OR “multiple disabilit*” OR “multiple care need*” OR “multiple support need*” OR “intensive support need*” OR “intensive care need*”

Stages	Search strategy
Detailed search adding autism terms	co-production OR coproduction OR “co production” OR co-design OR codesign OR “co design” OR “participatory action research” OR community-led OR “consumer involvement” OR “consumer engagement” AND autis* OR ASD OR “autism spectrum disorder” AND “support need* OR “complex need*” OR “intellectual disabilit*” OR “high need*” Or “high support needs” OR “severe disability” OR “profound disability” OR “complex disability*” OR non-speaking OR non-verbal OR nonverbal OR “non speaking” OR disab* OR “complex communication need*” OR “severe impairment*” OR “severe physical disabilit*” OR “significant care need*” OR “significant need*” OR “significant support need*” OR “multiple disabilit*” OR “multiple care need*” OR “multiple support need*” OR “intensive support need*” OR “intensive care need*”
Refined search	coproduction AND autis* OR disability AND “high support needs”
Government-specific search	coproduction AND autis* OR disability AND “high support needs” AND government
Added co-occurring conditions	coproduction AND autis* OR “high support needs” OR “intellectual disability” OR “complex communication needs” OR “mental health” OR “physical disability”

4.2.1.8 Analysis

Following the Framework method of analysis (Gale et al., 2013), a coding framework was created for analysing all data related to the principles and best practices for conducting co-production with autistic individuals with high and complex support needs and their families. This included research activities such as individual and organisation consultations carried out during the development of the *Community Forum Guidance Document*. For guiding principles (RQ1), an initial set of categories was developed based on the guiding principles in Autism CRC’s *Participatory and Inclusive Autism Research Practice Guides* (den Houting, 2021). Additional categories were then identified based on characteristics and patterns identified in the relevant data extracted from the included documents. These categories were later refined into a smaller set that represented each final guiding principle. Subcategories were added to provide detail and context for each principle, which were then condensed into a series of best practice points based on the principles (see Appendix 1.3).

The categories for knowledge, methodologies, engagement approaches, and outcomes (RQ2a/b/c/d) were solely based on characteristics and patterns identified within relevant extracted data. Subcategories were added to provide more detail and context (see Appendix 1.4 to 1.7). Each coding framework was cross-checked between two members of the project team, with disagreements resolved through consensus.

Data related to each research question was then sorted and analysed using a coding framework through directed content analysis (Hsieh & Shannon, 2005). This process was carried out with the assistance of Copilot via Griffith University. Specific instructions for the AI were developed and tested before the analysis. AI outputs were cross verified by project team members for accuracy.

A narrative summary and key points from extracted data on guiding principles for co-production with autistic individuals with high and complex support needs, and their families, were generated using the AI tool (Copilot). Two team members cross-checked the summary and key points against the environmental scan data to verify that it was comprehensive and accurate.

For each remaining sub-element of RQ2 (engagement approaches, knowledge, methodologies, and outcomes), key points were developed solely based on the characteristics and patterns identified within relevant data extracted using a strict set of instructions in Copilot. These key points were then expanded into narrative summaries with practical examples drawn only from the data provided to the AI tool. Two project team members cross-checked each narrative summary and key points against the extracted data to ensure accuracy and completeness. Information from the narrative

summaries was then integrated with data from other research activities within the *Community Forum Guidance Document* and the key points presented in this document for brevity.

4.2.1.9 Outcomes

The following provides an overview of the outcomes of the environmental scan related to co-production with autistic people with high and complex support needs, per the research question.

RQ1: What principles/key considerations should guide co-design and/or co-production with individuals with high and complex support needs

Outcomes of the coding analysis of data related to principles and key considerations indicated that co-production with autistic people with high and complex support needs should be guided by these eight principles and associated best practice points. These research-based principles and best practice points were shared during individual consultation engagements and refined through an iterative feedback process. Additional details on coding outcomes are available in Appendix 1.5. For the final set of principles and best practice points, see the *Community Forum Guidance Document*.

Principle 1: Power-sharing and equity

Co-production should actively rebalance power. Autistic people with high and complex support needs, and, where relevant, their families and supporters, should be supported to have meaningful influence at every stage where appropriate. While roles and levels of decision-making power may vary, efforts should be made to ensure that no decisions are made without those directly involved.

When someone cannot self-advocate, respectful family advocacy can support or amplify their preferences and rights. This involves recognising the expertise (that comes from lived experience and daily connection) of those who support non-speaking or highly supported people, while ensuring all contributions are resourced, respected, and included in shared decision-making. Family input does not replace the autistic voice but can help uphold it when direct input is unavailable.

Best practice points:

- creating structures for shared decision-making
- recognising and addressing power imbalances across roles and institutions
- supporting different ways and levels of participation
- including family and supporter input when needed
- valuing all contributions equally, regardless of role or title
- sharing ownership of knowledge and decisions
- reviewing how power is held and used over time
- avoiding tokenism by ensuring real influence.

Principle 2: Accessibility and flexibility

Co-production should be accessible and flexible at every stage to ensure that autistic people with high and complex support needs, and, where relevant, their families and supporters, can engage in ways that work for them.

This includes both universal and individual access, flexibility in timing and format, and the proactive removal of barriers. Accessibility should be ongoing and responsive, adapting to changing needs and contexts over time. Families who advocate on behalf of those unable to contribute directly should also be supported to participate meaningfully.

Best practice points:

- offering multiple modes of engagement
- ensuring environmental, sensory, and communication accessibility
- being flexible with timing, format, and input
- meeting people where they are (e.g., informal or online options)
- proactively identifying and removing barriers
- allocating time, funding, and support to enable access
- supporting family or supporter input where appropriate
- adapting strategies to reflect changing capacities and needs.

Principle 3: Recognition, reciprocity, and capacity-building

Co-production should respect and value all contributions, including lived and relational expertise. Autistic people with high and complex support needs, and, where relevant, their families and supporters, should be genuine partners and/or contributors, not token participants. This includes fair recognition, shared learning, and support to build capacity over time.

Families who advocate for those unable to contribute directly should have their role acknowledged as valid and meaningful. Building capacity requires adapting to diverse communication styles, learning needs, and abilities, with training and support that facilitate active participation.

Reciprocity means everyone contributes, and everyone benefits.

Best practice points:

- valuing lived, relational, and practice-based knowledge
- recognising family advocacy where autistic people cannot contribute directly
- providing flexible recognition (e.g., payment, authorship, credentials)
- offering training and support tailored to different needs
- supporting growth in confidence and capability over time (recognising that progress may not always be linear)
- embedding two-way learning and co-reflection
- avoiding extractive practices — all input must be acted upon
- enabling continued growth and leadership beyond the project.

Principle 4: Diversity, inclusion, and authentic voice

Co-production should, as much as possible, ensure that all relevant perspectives, identities, and lived experiences are present, valued, and empowered to contribute meaningfully. Inclusion is not passive, it requires intentional actions to involve those who are often excluded, including autistic people with high and complex support needs and, where relevant, their families and supporters.

All contributions should be treated with respect, and all forms of knowledge, academic, community-based, and lived, valued equally. Authentic voice should be supported through accessible, alternative, or supported communication. Intersectionality should be recognised, particularly for autistic people with intellectual disability and/or multiple additional diagnoses, whose perspectives and support needs may differ.

Best practice points:

- proactively seeking diverse participants
- respecting all communication styles
- creating safe, inclusive spaces for contribution
- supporting family or relational advocacy where needed
- addressing intersectionality and diverse experiences
- avoiding tokenism by integrating feedback into decisions
- explaining when input is not used and why.

Principle 5: Respect, trust, and safety

Co-production should be built on mutual respect, emotional and physical safety, and genuine trust. Autistic people with high and complex support needs, and, where relevant, their families and supporters, should feel welcome, valued, and safe to participate without fear of harm, exclusion, or retaliation.

This includes recognising trauma, creating consistent and supportive relationships, and consulting before decisions are made. Safety should be actively maintained and not assumed. Families who advocate for those unable to participate directly must also feel safe, heard, and respected.

Best practice points:

- valuing all forms of expertise and contribution
- promoting psychological and cultural safety
- recognising and responding to trauma and past harm
- prioritising consistency, trust, and relationship-building
- designing inclusive, non-retaliatory feedback processes
- co-creating safer and braver spaces over time
- consulting before, not after, decisions are made
- supporting family members who advocate on others' behalf.

Principle 6: Transparency and accountability

Co-production should ensure that everyone shares a clear understanding of the project's purpose, goals, roles, and expected outcomes. Communication should be open and ongoing, with all contributions acknowledged and discussed. Transparency includes recognising differing forms of expertise and ensuring decisions are made and shared fairly.

Accountability means closing the loop, explaining how feedback is used, what happens next, and why some suggestions may not be taken up. It also means building in time for reflection and shared oversight across the project.

Both transparency and accountability are essential in building trust and relationships over time, and will increase the chances of future participation)

Best practice points:

- clearly sharing goals, roles, scope, and processes
- communicating openly and honestly throughout
- recognising different types of knowledge and assumptions
- explaining how input is used or, if not, why
- including time for collective reflection and feedback
- ensuring all voices are heard and credited appropriately

Principle 7: Collective action, relationships, and wellbeing

Co-production should intentionally support positive relationships, shared purpose, and environments that promote wellbeing. Autistic people with high and complex support needs, and those who support them, should feel safe, included, and able to contribute in ways that align with their strengths and values.

This means fostering trust over time, building supportive networks, and valuing community knowledge. Genuine collaboration requires conditions that enable creative, respectful participation, including space for emotion, vulnerability, and hope. Engagement should enhance both individual and collective capacity to participate meaningfully.

Best practice points:

- prioritising relationships built on mutual trust and shared purpose
- designing inclusive, welcoming environments
- encouraging creative input and shared leadership
- using community and peer networks to strengthen involvement
- supporting resilience, self-expression, and emotional safety
- promoting personal and collective wellbeing throughout.

Principle 8: Rights, ethics, and reflexivity

Co-production should be guided by a rights-based, ethical approach that prioritises participant safety, informed consent, and meaningful choice. Autistic people with high and complex support needs, and their families or supporters where relevant, should be respected as contributors and decision-makers throughout the process.

Ethical reflexivity is essential. This includes anticipating potential risks, protecting people from harm and tokenism, and adapting processes to support informed participation. Confidentiality should be upheld at all times, and contributions must be handled with care and integrity.

Best practice points:

- embedding a human rights approach into all co-production activities
- prioritising informed, voluntary, and ongoing consent
- actively identifying and addressing tokenism
- exploring issues that matter most to autistic people and families
- supporting decision-making through reflective, inclusive processes
- respecting confidentiality and privacy across all stages.

RQ2a: What engagement approaches should be used

The following provides a summary of data relevant to engagement approaches related to co-production with autistic individuals with high and complex support needs that was extracted from the articles included in the environmental scan. For more detailed information, please refer to the *Community Forum Guidance Document*.

1. **Foundational principles for engagement:**
    - **build mutual respect and trust** through relationship-building and shared purpose
    - **prioritise safety and psychological security**, using trauma-informed approaches
    - **meet people where they are at**, acknowledging diverse needs and capacities
    - **close the loop** by showing how contributions influence outcomes
    - **take responsibility** for inclusive and ethical engagement.

2. **Inclusive and accessible practices:**
    - use **Easy Read formats**, visual aids, and multimodal communication (e.g., cards, videos)
    - ensure **physical and digital accessibility** (e.g., sensory rooms, screen reader-friendly documents)
    - offer **multiple modes of participation**: online/in-person, synchronous/asynchronous, verbal/non-verbal
    - provide **support people**, interpreters, and assistive technologies as needed
    - tailor engagement to **individual preferences**, including pronouns and communication styles.

3. **Co-design and co-production strategies:**
    - start co-design **early** (priority setting, planning) and continue through evaluation
    - use **arts-based and generative methods** (e.g., storyboards, poetry, games) to foster creativity and expression
    - incorporate **supported decision-making** principles and engage families/guardians when needed
    - ensure **shared decision-making and ownership** of knowledge and outcomes.

4. **Engagement methods and tools:**
    - use diverse methods: workshops, focus groups, surveys, interviews, living labs
    - employ reflective practices (e.g., diaries, team reflections) to learn from the process
    - use prompts and structured activities to guide discussions and support expression
    - apply frameworks like IAP2 Spectrum and Ladder of Participation to define levels of involvement (Inform → Empower).

5. **Facilitator and team considerations:**
    - build **rapport and team cohesion** through check-ins, social time, and shared rituals
    - ensure **skilled facilitation**, especially for engaging autistic people or those with intellectual disabilities
    - address **power dynamics** explicitly and foster **reciprocity** and respect
    - provide **training and mentorship** to build capacity for co-production.

6. **Practical supports:**
    - offer **transport, refreshments, breaks**, and flexible scheduling

- provide **remuneration** or recognition for contributions
- plan for **fatigue management** and emotional support
- use **feedback loops** to adapt and improve engagement processes.

7. Challenges and solutions:

- anticipate **communication barriers** and gatekeeper influence (e.g., carers, staff)
- address **institutional constraints** (e.g., rigid protocols, ethics processes)
- be transparent about **scope, limitations, and expectations**
- avoid **tokenism** by ensuring meaningful involvement and influence.

RQ2b: What knowledge is required

The following provides a summary of data relevant to the knowledge required for co-production related to autistic individuals with high and complex support needs that was extracted from the articles included in the environmental scan. For more detailed information, please refer to the *Community Forum Guidance Document*.

Core principles and frameworks:

- **participatory research:** understand that it is a framework for involving community members throughout the research process, not just as participants
- **co-production definition:** collaboration and collective decision-making that changes traditional researcher–participant relationships; equal but different contributions
- **equity and inclusion:** ground all approaches in principles of equity, inclusion, and active collaboration.

Essential knowledge areas

Power dynamics:

- strategies for sharing power and addressing imbalances
- techniques for creating safe spaces where all voices are heard.

Relationship building:

- importance of trust and transparency
- long-term engagement to maintain trust
- understanding cultural and contextual factors.

Roles and responsibilities:

- **academic researchers:** Identify gaps in the literature, maintain networks, value lived experience
- **co-researchers:** Shape questions from lived experience, negotiate boundaries, model collaborative relationships.

Consent and ethics:

- design accessible consent materials with lived experience input
- knowledge of institutional ethics systems and HRPP requirements
- awareness of emotional labour and potential trauma in sharing lived experiences.

Communication and language:

- **avoid jargon;** use common, accessible language
- clarify terms like “outcomes” and “evidence” early.

Co-design processes:

- **principles and phases:** discovery, sense-making, prototyping
- familiarity with frameworks like IAP2 Spectrum of Public Participation that is designed to assist with the selection of the level of participation that defines the public's role in any public participation process
- skills in divergent and convergent thinking.

Capacity building:

- training and support for people with lived experience
- informal pastoral care to prevent distress and failure.

Facilitation skills:

- active listening, inclusive engagement, managing diverse views
- ability to reconcile contrasting perspectives and reach consensus.

Knowledge types:

- **experiential knowledge:** recognise and integrate lived experience narratives
- **expert knowledge:** understand assumptions about knowledge distribution and challenge them.

Contextual preparation:

- prepare methods and tools to respect and accommodate participant needs
- consider intersectionality and diversity within disability communities.

RQ2c: What methodologies should be used

The following provides a summary of data relevant to methodologies related to co-production with autistic individuals with high and complex support needs that was extracted from the articles included in the environmental scan. For more detailed information, please refer to the *Community Forum Guidance Document*.

1. Core participatory methodologies

Participatory Action Research (PAR):

- **cyclical process:** planning, acting, observing, evaluating
- **principles:** cooperative, empowering, collaborative learning.

Community-Based Participatory Research (CBPR):

- emphasises equitable partnerships across all research phases
- promotes co-learning, capacity building, and power-sharing.

Other participatory approaches:

- empowerment evaluation, cooperative inquiry, appreciative inquiry, decolonising methodologies, emancipatory methodologies.

2. Co-design and co-production frameworks

Experience-Based Co-Design (EBCD):

- **phases:** setting up, discovery/analysis, co-design
- uses qualitative enquiry and participatory methods to understand experiences and collaboratively design solutions.

User-centred design & informant design:

- iterative design based on user feedback
- includes lived experience experts to help avoid normative assumptions.

Substantive co-design research cycle (gold standard):

- co-planning, co-defining research design, co-conducting, and co-disseminating findings with lived experience researchers.

3. Practical steps for co-production

Six phases of research with co-production:

- initiating → planning → doing → sense-making → sharing → reflecting
- co-researchers involved in instrument design, data collection, interpretation, and dissemination.

Running co-design groups:

- **planning:** budget for access needs, honorariums, define scope, recruit diverse stakeholders
- **meeting preparation:** accessible formats, flexible participation options, agenda sharing
- **hosting:** active facilitation, inclusive discussion
- **follow-up:** feedback loops, acknowledgment, reimbursement.

4. Capacity building and training

- training in research skills for both academic and co-researchers
- building competencies across **Knowing, Doing, Being** dimensions (history, inclusion practices, openness).

5. Inclusive data collection and analysis

- **methods:** submissions in the way that works for the individual, be it surveys, community forums, interviews, focus groups, prototyping, creative design-driven approaches
- Inclusive analysis techniques:
  - use of visual aids, Easy Read materials, collaborative coding sessions, thematic mapping with co-researchers, workshopping.

6. Ethical and governance considerations

- flexible research design to accommodate iterative co-production
- strategies:
  - clearly articulate rationale for co-production
  - allow time for accessible ethics applications
  - address power dynamics and capacity concerns
  - involving a consumer advisory committee to support development of research materials.

7. Levels and dimensions of co-production

- **decision-making power**: shared or ceded to participants
- **stages of involvement:** from consultative to collaborative across project phases
- **modes of interaction:** in-person, remote, hybrid; individual or group formats
- **tools:** conventional qualitative methods + creative approaches (e.g., design workshops).

RQ2d: How should outcomes be evaluated

The following provides a summary of data relevant to outcomes of co-production related to autistic individuals with high and complex support needs that was extracted from the articles included in the environmental scan. For more detailed information, please refer to the *Community Forum Guidance Document*.

1. Impact of co-production

- two levels of impact:
  - **intrinsic value**: promotes power-sharing, collective control, and cultural change within organisations
  - **research outcomes**: improves relevance, reach, and applicability of research findings.
- **requires additional time and resources**, making impact assessment essential for justification and improvement
- impact shown by data, not only authors' opinion
- questions to ask:
  - what does evaluating research mean
  - what to evaluate
  - when to evaluate
  - why evaluate
  - how to evaluate
  - evaluating community engagement.

2. Individual-level outcomes

- **learning about research methods**: builds capacity and addresses power imbalances between academic researchers and co-researchers with disability (critical reflection, exchange, and mutual learning)
- **personal growth and empowerment**: participants report transformative experiences and increased confidence
- **knowledge translation**: extends beyond project boundaries, inform and influence service delivery models.

3. Community-level outcomes

- strengthens **community responsibility, connection, ownership, and pride**
- facilitates **leadership roles for disabled people,** enabling systemic scrutiny and cultural change in policy processes
- supports **universal design** through diverse perspectives.

4. Quality and evaluation challenges

- lack of **evidence-informed indicators** and **evaluation frameworks** for co-produced research
- quality involves:

  - depth and breadth of **power-sharing and transparency**
  - **stakeholder satisfaction,** adaptability, and sustainability
- **continuous evaluation** and **post-project reflection** are critical for improvement.

5. Feedback and reflection

- accessible feedback mechanisms (written, verbal, video, interviews) throughout and at project end
- reflection activities (e.g., with the help of video-recordings) help identify benefits, challenges, and areas for improvement
- structured processes like **"you said, we did"** enhance accountability.

6. Capacity building and measurement

- develop **data collection tools** to measure impact and outcomes
- success indicators include:
  - improved understanding of disability inclusion and co-design processes
  - increased skills and awareness among participants and government engagement employees
- develop a monitoring framework to track impact and report to stakeholders.

7. Broader outcomes

- co-production can lead to:
  - **innovative outputs** (e.g., toolkits, frameworks, guidelines)
  - **catalytic validity**: Active participation facilitates change beyond research settings
- outcomes often transcend design outputs to include **capacity building and cultural shifts**.

4.2.2 Aboriginal and Torres Strait Islander peoples

4.2.2.1 Aim

The aim of this environmental scan was to identify best practice for co-design and/or co-production with Aboriginal and Torres Strait Islander peoples in health- and disability-related areas.

4.2.2.2 Research questions

The environmental scan gathered evidence to address the following research questions:

1. What principles/key considerations should guide co-design and/or co-production with Aboriginal and Torres Strait Islander peoples?
2. How should co-design and/or co-production Aboriginal and Torres Strait Islander peoples be conducted in terms of:
    a. What engagement approaches should be used?
    b. What knowledge is required?
    c. What methodologies should be used?
    d. How outcomes should be evaluated?

4.2.2.3 Method

Internet searches were conducted as per the methods described for the environmental scan for autistic individuals with high and complex support needs. In addition, the environmental scan for Aboriginal and Torres Strait Islander peoples also included replication of the research database searches outlined in Butler et al. (2022) given recent publication of a systematic review of best practice for co-design in health with Aboriginal and Torres Strait Islander Peoples (Butler et al., 2022) and associated development of key principles and best practices for co-design in health with Aboriginal and Torres Strait Islander Australians (Anderson et al., 2023). This was done to capture any relevant research that had been published since the review searches were conducted.

4.2.2.4 Search strategy

Internet searches were conducted between March and May 2025 as described for the environmental scan for autistic individuals with high and complex support needs. The following simplified set of key search terms used by Butler et al. (2022) were applied:

co-production OR co production OR co-design OR codesign OR co design AND "First Nation" OR Indigenous OR aboriginal OR "Torres Strait Islander" AND health OR disability

Research database searches were conducted in May 2025 using PsycINFO, Medline (via PubMed), PubMed, CINAHL and Embase. As per Butler et al., the search terms listed in Table 2 were used per database, with the period limited to 2022 to 2025.

Table 2: Aboriginal and Torres Strait Islander environmental scan search terms as per Butler et al. (2022)

Search terms used in research database searches in the environmental scan for Aboriginal and Torres Strait Islander peoples.

Database	Search terms
PsycINFO	Aborigin* OR Indigenous OR "Torres Strait Islander*" OR "First Nation*" AND "Co-design" OR Codesign OR "Co design" OR "Participatory action research" OR "Indigenous research methodology*" OR "Community-led" OR "Consumer involvement" OR "Consumer engagement" OR "Patient and public involvement" OR "Co-design" OR Codesign OR "Co design" OR "Participatory action research" OR "Indigenous research methodology*" OR "Community-led" OR "Consumer involvement" OR "Consumer engagement" OR "Patient and public involvement"
Medline	Aboriginal OR Indigenous OR "Torres Strait Islander" OR "First Nation" OR Aboriginal OR Indigenous OR "Torres Strait Islander" OR "First Nation" AND "Co-design" OR Codesign OR "Co design" OR "Participatory action research" OR "Indigenous research methodology" OR "Community-led" OR "Consumer involvement" OR "Consumer engagement" OR "Patient and public involvement" OR "Co-design" OR Codesign OR "Co design" OR "Participatory action research" OR "Indigenous research methodology" OR "Community-led" OR "Consumer involvement" OR "Consumer engagement" OR "Patient and public involvement"
CINAHL	Aborigin* OR Indigenous OR "Torres Strait Islander*" OR "First Nation*" AND "Co-design" OR Codesign OR "Co design" OR "Participatory action research" OR "Indigenous research methodology*" OR "Community-led" OR "Consumer involvement" OR "Consumer engagement" OR "Patient and public involvement"
Embase	Aboriginal OR Indigenous OR 'Torres Strait Islander' OR 'First Nation' AND 'co-design' OR codesign OR 'co design' OR 'participatory action research' OR 'indigenous research methodology' OR 'community-led' OR 'consumer involvement' OR 'consumer engagement' OR 'patient and public involvement'

4.2.2.5 Eligibility

Articles were included in the environmental scan if they met all the following criteria:

- the topic was a health- or disability-related area
- the article/report/guideline/framework reported on elements of co-production and/or co-design specific to Aboriginal and Torres Strait Islander Australians, including:
  - primary studies using co-design methods that provide explicit insight into optimal approaches to co-production/co-design
  - primary studies that evaluate the use of co-production/co-design methods
  - methodological papers, government reports and guidelines/toolkits/frameworks with a primary focus on co-production/co-design in policy, practice, and service provision
- the article is applicable, but not limited to, the health and disability sectors and Aboriginal and Torres Strait Islander Australians
- the article describes and/or evaluates co-design policy, practice, and service provision methodology
- information was presented in English
- the article was available in PDF format.

Articles were excluded if they:

- did not have a substantive focus or insight into optimal approaches to co-design with Aboriginal and Torres Strait Islander Australians.

4.2.2.6 Selection

The environmental scan search was conducted across two stages. At stage one, three members of the project team conducted internet searches; one team member conducted the research database searches. Results from each search mode were reviewed and the relevance of each one screened for potential eligibility. Each reviewer then made a judgement regarding the appropriateness of the linked document, recorded the URL of each relevant search result in a recording sheet, and downloaded the document for full-text investigation.

Fifty-two identified documents from the internet and research database searches were then divided across two reviewers for full text screening and extraction. Reviewers then independently read each document allocated to them and made consensus-based judgments for inclusion against the eligibility criteria. Based on full-text screening, 15 articles were excluded (see Appendix 1.6), resulting in 38 documents being included for extraction (see Appendix 1.7).

4.2.2.7 Data extraction

For each identified article, reviewers extracted specific information relevant to addressing each of the research questions into a standardised data extraction form in Microsoft Excel. Data were extracted by two members of the project team, with consensus checks conducted on the extracted data and any disagreements resolved via consensus.

4.2.2.8 Analysis

As per the method outlined for the individuals with high and complex support needs environmental scan, a coding framework was developed for analysis of all data relevant to the principles and best practices for conducting co-production with Aboriginal and Torres Strait Islander peoples across the research activities (individual and organisation consultations) undertaken in the development of the Community Forum Guidance Document. Initial categories for the Guiding Principles (RQ1) and principle-based best practice points were based respectively on the principles and associated best practices distilled from Butler et al.'s (2022) systematic review as reported in Anderson et al. (2023).

To develop the Guiding Principles, additional categories were then developed based on characteristics and patterns found within data relevant to RQ1 extracted from the included documents. These categories were then condensed to form a smaller final set that reflected each principle, with final codes aligning with the six principles reported by Anderson et al. (2023). Data relevant to engagement approaches (RQ2a) was then coded against Anderson et al.'s 27 principle-based best practices for co-production with Aboriginal and Torres Strait Islander peoples. Each coding framework was cross-checked between two members of the project team, with disagreements resolved through consensus. Extracted data per research question was then sorted into meaning units and analysed against this coding framework, using directed content analysis (Hsieh & Shannon, 2005). This process was completed using Copilot via Griffith University. Specific instructions for the AI were developed and tested prior to analysis.

For each remaining sub-element of RQ 2 (engagement approaches, knowledge, methodologies, and outcomes), key points were developed based solely on characteristics and patterns found within relevant data extracted using a set of strict instructions in Copilot. These key points were then expanded into narrative summaries with practical examples drawn solely from the data provided to the AI tool. Two project team members cross-checked each narrative summary and associated key points against the extracted data to confirm accuracy and completeness. Summaries were then

shared with the Aboriginal and Torres Strait Islander forum convenor for their feedback. In respecting their lived expertise and wishes, summaries of the research literature are presented in this document, so the voices of community members are highlighted and prioritised in the *Community Forum Guidance Document*. To avoid repetition, the key points have not been included.

4.2.2.9 Outcomes

The following provides an overview of the outcomes of the environmental scan on co-production with Aboriginal and Torres Strait Islander peoples in health-related research per research question.

RQ1: What principles/key considerations should guide co-design and/or co-production with Aboriginal and Torres Strait Islander peoples

In line with Anderson et al. (2023), outcomes from the environmental scan indicated that co-production with Aboriginal and Torres Strait Islander peoples should be underpinned by the following six Guiding Principles and 27 associated principle-based best practices. Tables with further information on the occurrence of the principles and best practice points within the extracted articles are presented in Appendix 2.2 and 2.3 respectively.

Principle 1: Inclusive partnerships/relationships

Fostering and maintaining equitable and collaborative relationships between all participants is central in driving effective co-design projects. Establishing appropriate communication channels and conflict resolution processes, formulated by and with community, that maintains trust and supports authentic partnerships is imperative.

Best Practice Points

- sustained collaboration that fosters two-way learning is developed and maintained
- self-determination of Aboriginal and Torres Strait Islander Australians is supported by the project
- achieving equity for Aboriginal and Torres Strait Islander Australians is prioritised
- regular and sustained culturally appropriate communication channels are maintained
- conflict resolution protocols are formalised to manage disagreement.

Principle 2: Respect

The expertise, experience and time of Aboriginal and Torres Strait Islander people and organisations must be respected and recompensed to ensure equity for all involved in the co-design process. Approaches must incorporate flexibility and must be familiar and engaging for Aboriginal and Torres Strait Islander Australians to feel comfortable and welcome to lead and participate in the process.

Best Practice Points:

- expectations of Aboriginal and Torres Strait Islander people and organisations are fair and reasonable
- provision of remuneration to Aboriginal and Torres Strait Islander people and organisations equitably compensates their time and knowledge
- adequate time and resources are provisioned to successfully complete the project objectives
- flexible and iterative processes are embedded and facilitated
- culturally appropriate language, branding and design is used throughout the project.

Principle 3: Culturally grounded approach

The strength and diversity of Aboriginal and Torres Strait Islander culture must be reflected in the co-design project and approach. A continuous process of striving for cultural competency and self-reflection by non-Indigenous people involved in the project is essential.

Best Practice Points:

- continuous striving for cultural competency is reflected in the processes
- diversity among Aboriginal and Torres Strait Islander Australians and cultures is acknowledged and responded to by the project
- Aboriginal and Torres Strait Islander worldview underpins all components of the project
- strengths of Aboriginal and Torres Strait Islander cultures, knowledges and peoples are recognised and applied throughout the project
- continuing impacts of colonisation are acknowledged and mitigated.

Principle 4: Aboriginal and Torres Strait Islander leadership

Authentic and appropriate Aboriginal and Torres Strait Islander leadership must be embedded within the co-design approach. The nature and function of this leadership must be determined with the community and should reflect the community's structure and interests. Aboriginal and Torres Strait Islander leadership needs to begin during the conception stages of the project and extend beyond the completion of the project.

Best Practice Points:

- Aboriginal and Torres Strait Islander leadership directs all levels and components of the project
- priorities and processes are determined by Aboriginal and Torres Strait Islander communities
- capabilities that support Aboriginal and Torres Strait Islander leadership are nurtured and strengthened
- governance structures are determined by the community and reflect community interests
- appropriate cultural and community approvals are obtained.

Principle 5: Benefit to community

Co-design projects must aim to serve Aboriginal and Torres Strait Islander Australians and communities above all else. The project conception, design, processes and outcomes must provide timely, tangible and sustainable benefits that are valued by the community.

Best Practice Points:

- the community sets the agenda for the project or contribute to these
- the outcomes of the project offer tangible and sustainable benefits that are valued by the community
- Aboriginal and Torres Strait Islander people and communities own the data and the knowledge resulting from the project
- capabilities valued and prioritised by Aboriginal and Torres Strait Islander people are fostered and strengthened.

Principle 6: Transparency and evaluation

Transparency in all aspects of the co-design project is essential. Accountability to Aboriginal and Torres Strait Islander leaders must be formalised and embedded into co-design projects. Embedding monitoring and evaluation throughout the co-design process using agreed performance indicators that facilitate transparency and accountability to community is essential.

Best Practice Points:

- transparency in decision making and benefits to stakeholders is ensured to enable accountability
- monitoring and evaluation processes are built into the project
- project outcomes are not pre-determined and are authentically co-designed.

RQ2a: What engagement approaches should be used

The following provides a summary of data relevant to engagement approaches for co-production with Aboriginal and Torres Strait Islander peoples that was extracted from the articles included in the environmental scan. For more detailed information gathered through yarns with community members, please refer to the *Community Forum Guidance Document*.

Effective co-production with Aboriginal and Torres Strait Islander communities begins with a foundation of Aboriginal and Torres Strait Islander leadership. Priorities, processes, and decision-making must be determined by the communities themselves (Indigenous voices representation). Governance structures should empower Aboriginal and Torres Strait Islander voices, and leadership must be supported at every stage to uphold self-determination. This could be done by employing Aboriginal and Torres Strait Islander staff, form a committee, seek involvement from Aboriginal and Torres Strait Islander organisations, local stakeholders, and aiming for diverse leadership (diverse peoples and knowledge) and distributed leadership (people leading different areas of work).

Equally critical is adopting a culturally grounded approach. Engagement must centre on an Aboriginal and Torres Strait Islander worldview, acknowledging and addressing the ongoing impacts of colonisation. Decolonising methodologies and cultural rigour are essential to ensure that research and service design reflect Indigenous ways of knowing, being, and doing. It is important to recognise our own lenses and challenging our knowledge systems.

The principle of respect underpins all engagement activities. Cultural safety must be actively practiced, and processes should be flexible, iterative, and responsive to community needs. Adequate time and resources are vital for appropriate engagement, research proposal discussion, governance, and methodologies. Respect also means recognising diversity across Aboriginal and Torres Strait Islander communities, obtaining appropriate ethical and community approvals, and maintaining culturally appropriate communication throughout the project. Fair remuneration and the use of Aboriginal and Torres Strait Islander branding further demonstrate respect and reciprocity.

Engagement must deliver benefit to the community, as defined by the community itself. Tangible, sustainable outcomes should be prioritised, alongside formal recognition of knowledge ownership and sovereignty (intellectual property and copyright). Building local capacity, capabilities (e.g., research capabilities), and partnerships (e.g., policy) ensures that benefits endure beyond the life of the project.

Strong, inclusive partnerships are the cornerstone of successful co-production. These partnerships should foster collaboration, equity, and two-way/mutual learning with meaningful engagement. It is

important to create shared spaces (Third Space) where power is balanced and decisions are transparent, approaches are adapted to community feedback, each voice is heard equally, and research integrity upheld. Partnerships should include empowering and involving community members and peak bodies, while the intercultural interactions can be meaningful and powerful. Relationships must be cultivated well before project commencement and sustained long after its completion, recognising that trust takes time and cannot be fast-tracked.

A scale of intensity of engagement of community members involves stages to: Inform (understanding the project), Consult (obtain community feedback), Involve (two-way exchange of information that encourages meaningful discussion and opportunity to influence outcomes), Collaborate (enabling all parties to provide input), Empower (research partners, participating group and/or community make decisions).

Practical engagement approaches include meeting in culturally safe spaces, including on Country, in homes, or community centres, and using culturally appropriate methods such as Yarning together (Duguula Gayirray), walking together (Yandaarray), sharing together (Duguula Nguraljili), working together (Djama Rramba), storytelling, and deep listening (Dadirri). Employing Aboriginal and Torres Strait Islander staff in key roles and ensuring cultural responsiveness training for all team members reinforces cultural safety and accountability.

Shared decision-making is central to ethical engagement. Formal agreements should clarify roles, responsibilities, and conflict resolution processes, while consent must be free, prior, and informed—and renegotiated as needed. Flexibility in timelines is essential to accommodate cultural obligations such as Sorry Business (time of mourning to allow for cultural activities and ceremonies) and competing community priorities.

Finally, engagement should be guided by evidence-based practice that include decision-making, rigour, that privileges Indigenous knowledge systems over Western biomedical constructs, and monitoring and evaluation processes should be co-designed to ensure relevance and accountability.

In essence, co-production with Aboriginal and Torres Strait Islander peoples is a relational process that requires humility, patience, and a commitment to power-sharing. By embedding cultural safety, respecting Indigenous sovereignty, and prioritising community-defined benefits, researchers and practitioners can create partnerships that are authentic, equitable, and transformative.

RQ2b: What knowledge is required

The following provides a summary of data relevant to knowledge required for co-production with Aboriginal and Torres Strait Islander peoples that was extracted from the articles included in the environmental scan. For more detailed information regarding the knowledge required to engage with Aboriginal and Torres Strait Islander peoples in culturally responsive ways, please refer to the *Community Forum Guidance Document*.

Effective co-production with Aboriginal and Torres Strait Islander peoples begins with a deep understanding that this process is not simply a method, but a relationship-driven journey grounded in respect, reciprocity, and cultural integrity. At its core, co-production must privilege Aboriginal and Torres Strait Islander knowledge systems, cultural values, and worldviews. This means moving beyond Western biomedical and biopsychosocial models or health policy frameworks to embrace holistic concepts of health and wellbeing that encompass social, emotional, spiritual, and cultural

dimensions of life. Recognising the ongoing impacts of colonisation, systemic racism, and power imbalances is essential to creating authentic and equitable partnerships.

Ethical engagement is essential. Researchers and practitioners must be familiar with key governance frameworks such as the AIATSIS Code of Ethics and related guidelines, which emphasise collective rights, cultural continuity, and proportionate ethical review. These frameworks require that risk and benefit assessments be contextualised within Indigenous rights to land, water, culture, and history. Indigenous research governance structures, such as local protocols and Indigenous Reference Groups, must be respected and integrated into all stages of the process.

Cultural responsiveness is another cornerstone. Those involved in co-production need training and experience to understand and respect cultural differences, coupled with self-awareness of their own positionality and privilege. Cultural humility, acknowledging that Western models may not fit Indigenous contexts, is critical for building trust and sustaining relationships.

The process is underpinned by six foundational values: spirit and integrity, cultural continuity, equity, reciprocity, respect, and responsibility. These values guide actions such as ensuring mutual benefit, protecting cultural distinctiveness, valuing Indigenous knowledge, and maintaining accountability to communities. Responsibility includes doing no harm and establishing processes that safeguard participants' rights and cultural heritage.

Knowledge of intellectual and cultural property rights is vital. Researchers must understand the limitations of Western intellectual property law and ensure agreements protect communal, oral, and sensitive knowledge in ways that align with Indigenous conceptions of ownership.

Practically, co-design requires time, flexibility, and authentic engagement. It is a process, not a one-off workshop, that involves sustained dialogue engagement and shared decision-making. Indigenous leadership and concepts such as Yarning (dialogue), Dadirri (deep listening), and Ganma (knowledge sharing) should shape the approach. Creating a "Third Space" for inclusive collaboration helps redress power differentials and fosters genuine partnership.

Finally, operational knowledge includes the ability to negotiate research agreements, apply participatory and strength-based methodologies, and embed Indigenous worldviews in evaluation frameworks. Language matters too—using culturally specific terms and respecting evolving preferences ensures communication is meaningful and inclusive.

In essence, co-production with Aboriginal and Torres Strait Islander peoples demands more than technical skill; it requires a commitment to cultural safety, ethical integrity, and shared power, decision-making, understanding, and accountability authority. It is a transformative process that challenges dominant paradigms and invites all participants to learn, reflect, and act in ways that uphold the sovereignty and expertise of Aboriginal and Torres Strait Islander communities.

RQ2c: What methodologies should be used

The following provides a summary of data relevant to methodologies for co-production with Aboriginal and Torres Strait Islander peoples that was extracted from the articles included in the environmental scan:

Co-production with Aboriginal and Torres Strait Islander peoples requires a methodology that is deeply respectful, culturally grounded, and led by Indigenous voices. At its core, the process must be Aboriginal and Torres Strait Islander-led, ensuring agency and control across all stages, from conception and design to process (delivery, analysis, and dissemination) and evaluation.

Governance structures such as advisory or reference groups should be established early, with clear Terms of Reference and Aboriginal and Torres Strait Islander leadership in chairing roles to uphold community priorities and minimising power imbalances. The involvement of stakeholders could include recruitment of community members from urban, regional, and remote areas, with diverse backgrounds and experiences, functioning for the project as project officers, or part of a governance, a reference or an advisory group.

The approach must be culturally grounded, privileging Aboriginal and Torres Strait Islander worldviews, knowledge systems, and collectivist values. This means embedding Indigenous epistemologies and using decolonising methodologies. Strengths-based frameworks are essential to counter deficit narratives and celebrate resilience and capability. Methods such as Yarning, Dadirri (deep listening), and Ganma (two-way knowledge sharing) are central to this process. Yarning is a particularly culturally safe conversational method that facilitates relationship building, data collection, and collaborative analysis. Its forms—social, research topic, collaborative, and therapeutic yarning—enable trust, shared understanding, and emotional safety. Furthermore, language is an important part of our understanding, perspectives, and knowledge of connections with the world.

Inclusive partnerships underpin successful co-production. These partnerships must foster reciprocal relationships between professionals and community stakeholders, equity, mutual respect, and shared decision-making, creating shared spaces or “third spaces” for two-way learning and intercultural dialogue. Participatory Action Research and Aboriginal Participatory Action Research provide iterative cycles of planning, action, and reflection, ensuring flexibility and responsiveness to community needs. Demonstrating cultural continuity and equity, respect, spirit and integrity, responsibility is important.

Flexibility and iteration are defining features of co-production methodologies. Timelines, resources, and processes must adapt to cultural protocols, community priorities, and events such as Sorry Business. Continuous feedback loops and collaborative analysis, such as Collaborative Yarning Methodology, ensure findings align with Aboriginal and Torres Strait Islander values and priorities. Cultural rigour is achieved by adhering to local protocols, creating culturally safe spaces, and respecting norms such as appropriate facilitator gender.

Ethical integrity is non-negotiable. Projects must secure community and ethical approvals early, uphold data sovereignty, and formalise agreements on knowledge ownership. Transparency and accountability in roles, expectations, and outcomes are critical. Monitoring and evaluation processes should be co-designed with communities, embedding culturally relevant indicators and storytelling as evaluative tools [relevant to/suitable in evaluation outcomes].

Finally, while privileging Indigenous methodologies, projects must maintain evidence-based rigour, combining cultural responsiveness with scientific integrity. This includes embedding continuous quality improvement, ethical protocols, and iterative evaluation to ensure that co-production leads to tangible, sustainable benefits for Aboriginal and Torres Strait Islander communities.

RQ2d: How should outcomes be evaluated

The following provides a summary of data relevant to outcomes of co-production with Aboriginal and Torres Strait Islander peoples that was extracted from the articles included in the environmental scan:

Effective co-production with Aboriginal and Torres Strait Islander peoples requires outcomes that are genuinely co-designed rather than predetermined. This means creating processes that are flexible, reflexive, and participatory, allowing communities to set priorities and shape the agenda. The principle of "handing over the stick" underscores the importance of enabling Aboriginal and Torres Strait Islander communities to drive both the process and the outcomes, ensuring they reflect local needs and aspirations rather than external interests.

Ethical considerations are central to this approach. The rights and interests of Indigenous knowledge holders must be recognised and protected, including through agreements on intellectual property and data ownership. Best practice involves equal recognition of Indigenous collaborators as inventors and promoting joint ownership of research outputs. These measures safeguard cultural integrity and ensure that knowledge sharing occurs on equitable terms.

Co-production should deliver tangible benefits for communities, such as job creation, policy implementation, and capacity building. Outcomes should be communicated in clear, accessible language, and engagement should continue beyond the life of the project to maintain trust and support future collaboration. Ongoing attribution and acknowledgment of Indigenous contributions are essential for sustaining respectful partnerships.

Evaluation plays a critical role in ensuring accountability and cultural relevance. Monitoring and evaluation frameworks should adopt decolonising approaches that prioritise Aboriginal and Torres Strait Islander leadership and culturally safe practices. These frameworks should assess not only whether intended outcomes were achieved but also the quality of collaboration, shifts in power dynamics, and empowerment indicators such as community voice and critical thinking. Importantly, evaluations should allow for unexpected outcomes and recognise that meaningful change often requires long-term commitment.

Knowledge sharing should extend beyond conventional academic formats to include oral, visual, and experiential forms that reflect Indigenous ways of knowing. Transparent reporting, guided by tools such as GRIPP2 and CONSIDER, can help address gaps in documenting co-design processes and their impact on equity.

The strengths of co-design lie in its ability to build trust, foster mutual understanding, and support cultural revitalisation. By embracing two-way learning and valuing Indigenous ontologies, co-production can generate transformative outcomes that challenge existing norms and create sustainable, culturally grounded solutions.

4.3 Individual consultations

As indicated in the Project Overview section, extended wait times inherent to co-production with each of the target communities and operational challenges regarding the longevity of the forums beyond the project necessitated changes to Objective 1. This process resulted in a revised conceptualisation of the community forums as individual consultations and the development of an associated plan for recruitment in partnership with Autism CRC. Rather than establishing larger groups comprised of community members, professionals, and organisation representatives, and engaging in an ongoing series of consultation points as originally conceived, the revised plan centred on relationship-focused engagements with a small number of individuals from each community. These individuals were purposively recruited through a joint process established between the forum convenors, project lead, and Autism CRC's Research and Community Engagement Manager, to participate in co-production activities within the bounds of the project timeline. Each group comprised family members of autistic individuals known to the forum convenors, as well as autistic individuals identified and invited through Autism CRC's existing networks. These individuals participated in individualised engagement activities that formed an iterative co-production process to develop the *Community Forum Guidance Document* for engaging with autistic individuals and their families/supporters from each priority community.

4.3.1 Individuals with high and complex support needs

4.3.1.1 Aim

The aim of these individual consultations was to involve autistic people who require high and complex supports, along with their families or supporters, in tailored discussions that could help develop a *Community Forum Guidance Document* for Autism CRC. The consultations aimed to identify barriers and facilitators to engagement, preferred consultation methods, and practical needs for the safe, respectful, and sustainable participation of autistic people with high and complex supports and their families in future consultation, co-design, and co-production activities.

4.3.1.2 Participants

The individual consultations involved three autistic people requiring high and complex supports and three family members or primary carers. Participants included adolescents and adults, all of whom had a formal autism diagnosis. Two autistic participants were formally recruited to take part in individual consultations. A third autistic person, who was a family member in one participating household, joined several of that parent's consultation sessions and contributed observations and experiences. They were identified through the forum convenor's community contacts, the project lead's professional networks, and Autism CRC's existing networks and project team contacts. Recruitment intentionally included autistic people and families with previous experience of consultation or engagement with Autism CRC, as well as those with no prior involvement in any formal consultation activities.

Autistic participants had a range of communication profiles, such as reliance on augmentative and alternative communication and a history of childhood apraxia of speech. All autistic participants required high and complex supports and had co-occurring conditions, such as intellectual disability and psychosocial conditions, including anxiety, depression and post-traumatic stress disorder.

Family participants were all parents and primary carers of autistic people requiring high and complex supports.

4.3.1.3 Methods

The consultation design prioritised relationship-building, flexibility, and accessibility, recognising the diverse communication and support needs of all participants. All consultations were conducted as individual sessions via Microsoft Teams video conferencing, enabling video, audio and automated transcription, and supporting participation from home environments. Two autistic participants met independently with the convener; one autistic participant chose to participate with a parent present, and family participants completed separate caregiver-only sessions.

Participants received written information about the project before meeting with the convener. Each consultation process began with a brief online meet-and-greet (approximately 10 to 20 minutes) to get to know each other, clarify the project aims and discuss whether and how participants wished to be involved. During this initial contact, the convener invited participants to identify any communication, sensory, technological, or scheduling supports that would assist them in participating comfortably and offered practical assistance with Microsoft Teams where required.

Consultations were conversational and strongly participant-led, rather than formally structured interviews. For autistic participants, the convener adapted the process to individual communication profiles and cognitive needs and used a deliberately relationship-focused style. With one autistic participant with intellectual disability, the guiding principles were explored indirectly through shared discussion of both the participant's and the convener's interests, routines and preferred activities. This reciprocal sharing of experiences supported rapport and mutual engagement, while allowing the convener to link naturally occurring topics back to the draft principles in specific, personalised ways. For the autistic participant using augmentative and alternative communication, the convener and participant similarly engaged in a two-way exchange of stories and examples, with the participant responding via their preferred communication system and the convener adjusting pacing and turn-taking to allow extended processing time.

Across all consultations, the emphasis was on creating a relaxed, low-pressure environment that felt more like an extended conversation than an interview. Participants were invited to guide the direction and depth of the discussion, and the convener followed their cues on which issues to elaborate, when to pause, and when to conclude. The convener introduced the guiding principles and core topics as anchors but allowed participants to approach them in their own words and through issues that were most salient to them.

For family participants, the consultation process involved a series of five engagement points conducted approximately monthly between August and December 2026. Each engagement point focused on a broad target area related to the emerging *Community Forum Guidance Document*, while leaving substantial scope for families to raise issues and examples that were most important to them at the time. Between sessions, families were at times provided with brief, tailored activities designed to elicit further input for the guidance document in indirect and accessible ways. These activities included, for example, reflecting on preferred modalities for information (such as Easy Read materials, visual resources or videos) and describing specific examples of helpful and unhelpful engagement. In the final stages of consultation, families were provided with the full draft of the *Community Forum Guidance Document* to review at their own pace and identify points of agreement, concern or suggested revisions.

At the beginning of subsequent sessions, the convener provided a brief synthesis of the previous discussion and showed how elements of families' feedback had been incorporated into revised versions of the guidance document. This included, where appropriate, integrating families' own wording as brief "sound bites" within the text. This feedback loop supported transparency about how input was being interpreted and invited correction, refinement, and further elaboration. The remainder of each session focused on collaboratively working through the next set of principles or practical scenarios, using open questions to explore how these would operate in families' everyday contexts and what changes would be required for the guidance to feel accurate, workable and genuinely supportive.

4.3.1.4 Ethics

The ethics application process began with planning meetings among the project lead, convenor and project team to refine the consultation design and procedures. Given the involvement of autistic people who require high and complex supports and their families, the project underwent a full higher-risk review by the Griffith University Human Research Ethics Committee (HREC). The application addressed capacity and supported decision-making, potential distress, cumulative care burden, privacy, data security, and reimbursement, and specified safeguards such as flexible consent and assent procedures, clear withdrawal options, and protocols for responding to distress or disclosures of risk. Emma Hinze drafted the application, which Rachelle Wicks and Zheng Ng reviewed, and subsequently revised in response to HREC feedback, resulting in full approval (2025/451).

4.3.1.5 Consent/assent

Informed consent procedures were adapted to reflect variations in communication, decision-making capacity and legal guardianship arrangements. Written information about the project was provided in accessible formats, including plain-language and Easy Read summaries. For autistic participants with decision-making capacity, informed consent was obtained directly, with additional time and explanations provided as required. For autistic participants who could not provide fully informed consent in a legal sense, consent was obtained from a parent or legally authorised guardian, alongside active assent from the autistic person wherever possible. Assent procedures incorporated visual scales, simple language explanations and opportunities to indicate comfort or discomfort throughout the session. Participants were reminded that they could stop the consultation at any time and could decline to answer any questions without needing to provide a reason.

4.3.1.6 Data analysis

Data analysis was carried out in two stages. First, a framework analysis approach (Gale et al., 2013) was employed to develop preliminary, research-based guiding principles and best practice points from the literature and national policy documents, as described in the Method section above. These principles formed the initial analytical framework for interpreting consultation data.

In the second stage, data from consultations with autistic individuals requiring high and complex supports, their families, and organisation representatives were analysed using directed content analysis. Consultation notes and transcripts were entered into a matrix where each contribution was mapped against existing principles and proposed engagement processes, such as preferred formats, modalities, supports, and conditions for participation, to determine whether they aligned with, refined, extended, or challenged them. New codes were added to address gaps or issues not

covered in the initial framework, as identified through feedback. Through repeated iterative cycles, the guiding principles, associated “what this means in practice” statements, and engagement process recommendations were reworded, reordered, or expanded to reflect participants’ input.

At each iteration, proposed revisions were reviewed across autistic, family, and organisational contributions to ensure that no group’s perspectives were overlooked and that differences were acknowledged rather than averaged out. When a suggestion could not be implemented in the original form, the convener discussed the constraints with participants and collaborated with them to identify alternative wording or structural adjustments that still reflected the underlying concern wherever possible. This iterative negotiated process ensured that the final guiding principles, engagement processes, and practice points were grounded in both the research evidence and the lived and practice-based knowledge shared through the consultations.

4.3.1.7 Outcomes

Synthesising findings from the environmental scan, consultations with autistic people who require high and complex supports and their families, and input from key organisation representatives, the project developed specific recommendations that directly informed the *Community Forum Guidance Document*. Key outcomes included (a) clarifying why precise and inclusive definitions of this group are essential for representation and fair engagement; (b) emphasising engagement built on genuine connection and ongoing rapport, with autistic people and families treated as central members whose perspectives can influence priorities, wording, and decisions, rather than as participants in a one-off checklist exercise; and (c) highlighting the need to recognise and respond to diverse forms of communication and support needs, using creative, individually tailored approaches to engagement that go beyond standard consultation formats. Across consultations, contributors stressed the importance of transparent feedback loops, including being shown how their input was interpreted and used to revise the guidance, and this approach was incorporated into the *Community Forum Guidance Document* to support future consultation and co-production activities that are practical, grounded in lived experience, and supported by clear, ongoing communication. For further details, refer to the *Community Forum Guidance Document*.

4.3.2 Aboriginal and Torres Strait Islander peoples

4.3.2.1 Aim

The aim was to engage Aboriginal and Torres Strait Islander family members of autistic people and autistic adults in yarning sessions conducted in partnership with IAHA. The purpose of these yarning sessions was to inform the development of a *Community Forum Guidance Document* for Autism CRC that are aimed to be culturally responsive and provide recommendations about how to best engage with Aboriginal and Torres Strait Islander peoples in future in consultation, co-design, and co-production activities. The research activity followed a participatory action research approach, ensuring that Aboriginal and Torres Strait Islander perspectives and cultural knowledge are central to the research process. The six core principles of Aboriginal and Torres Strait Islander research - spirit and integrity, cultural continuity, equity, reciprocity, respect, and responsibility - were applied throughout the design, development, and execution of the consultation and broader project to ensure cultural appropriateness and alignment with the values of the communities involved.

This project also responded to long-standing concerns from Aboriginal and Torres Strait Islander autistic people and families regarding deficit-based and extractive research practices. By embedding yarning and community-led guidance, the project aimed not only to inform Autism CRC processes, but to strengthen relational trust and ensure the research life-cycle centred Aboriginal and Torres Strait Islander knowledge, sovereignty, and relational accountability.

4.3.2.2 Participants

As noted previously, individuals who participated in the yarning sessions were purposively recruited through a joint process established between Tara Lewis (forum convenor and IAHA representative within the project team), the project lead, and Autism CRC. IAHA distributed an Expression of Interest (EOI) to its membership, inviting Aboriginal and Torres Strait Islander autistic adults and families of autistic children and young people to participate. In addition, emails were sent to Aboriginal and Torres Strait Islander autistic people and families who had previously taken part in Autism CRC yarning activities or research, offering an opportunity to continue contributing to the ongoing project through this culturally grounded process.

Invitations to contribute were sent via email to three Aboriginal and Torres Strait Islander autistic adults identified by the Autism CRC research manager and several family members of autistic children/young people/adults known to the forum convenor via IAHA's networks. Of those who were invited, final participants included four family members and one autistic adult.

The cohort was intentionally small, relationally connected, and grounded in trust. In Aboriginal and Torres Strait Islander research, depth of narrative, context, and relational meaning are prioritised over numerical representation, and this approach allowed participants to speak from lived experience, cultural authority, and kinship knowledge (Bishop, 2024).

4.3.2.3 Methods

Five yarning sessions in total were conducted by Tara Lewis. These sessions collected insights from participants about their lived experiences and stories, guided by broad, open-ended questions that were based on the project research questions. This ensured that the process was culturally safe and adhered to Aboriginal and Torres Strait Islander research principles, including data sovereignty and ICIP (Indigenous Cultural and Intellectual Property). Yarning was not a transactional interview, but a

culturally recognised form of knowledge exchange that prioritised respect, relationship, and the pace of the storyteller (Besarab & Ng'andu, 2010). Participants determined the depth and direction of their contributions, and the researcher's role was to listen, facilitate, and uphold relational integrity (Besarah & Ng'andu, 2010; Geia, 2013; Kennedy, 2022).

The sessions were facilitated by an Aboriginal researcher, and de-identified data were analysed and used to shape the Guiding Principles and associated best practice recommendations for the Community Forum Guidance Document. A member of the research team (Taryn Jones) co-facilitated sessions that focused on yarning about the tool being developed within Part B of the broader project.

4.3.2.4 Ethics

The ethics application process began with team meetings between Tara Lewis and the research team to discuss the design, process, and expected outcomes. Since the research involved Aboriginal and Torres Strait Islander Peoples, a full ethics application was submitted through the Griffith University Human Research Ethics Application (HREA). Key resources, including Booklet 30 of the Griffith University Research Ethics Manual, AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research (AIATSIS, 2020), and Aboriginal Participatory Action Research: An Indigenous Research Methodology Strengthening Decolonisation and Social and Emotional Wellbeing (Dudgeon et al., 2020), were used to incorporate the six core principles of Indigenous research throughout the project. Emma Hinze drafted the application, which was then proofread and reviewed by Rachelle Wicks. After addressing feedback from the Griffith University Ethics Committee, Emma Hinze resubmitted the application, leading to full approval (2025/497). This collaborative process ensured the research adhered to both institutional and cultural ethical standards.

4.3.2.5 Consent

Informed consent was obtained either during initial contact or at the beginning of the yarning sessions. Participants were informed of their rights, including their ability to withdraw at any time, and provided the option to allow their stories to be attributed to them if they choose.

4.3.2.6 Data analysis

Data analysis followed an Aboriginal-led qualitative approach grounded in relational accountability, storytelling integrity, and cultural sovereignty. Audio recordings and detailed notes from the yarning sessions were transcribed verbatim and checked for accuracy by the Aboriginal member of the research team. Rather than coding or fragmenting stories into discrete "themes," analysis centred on identifying culturally meaningful patterns that reflected how participants understood autism, connection, identity, responsibility, and interactions with systems (Bishop, 2024; Simonds & Christoper, 2013).

The analysis process unfolded iteratively and relationally. Each yarn was reviewed multiple times to preserve tone, context, and the deeper meanings embedded in narrative, humour, pauses, and emotion. Key insights were discussed with participants to ensure accuracy, cultural integrity, and that interpretations reflected participants' intended meanings, with reflections guided by the six core Indigenous research principles: spirit and integrity, cultural continuity, equity, reciprocity, respect, and responsibility. This ensured that themes did not emerge from researcher-imposed frameworks, but from the relationships, stories, and lived experiences shared by participants.

Where similarities across yarns emerged naturally, such as community strength, exhaustion in navigating systems, Aboriginal and Torres Strait Islander leadership as advocacy, or Country as healing these were treated as collective knowledges rather than aggregated “findings.” Participants’ own words were prioritised in identifying key principles and practical recommendations, particularly when insights challenged deficit discourse or reframed the role of autistic children, adults, and families through cultural lenses.

Throughout the process, Indigenous Cultural and Intellectual Property (ICIP) was upheld. Participants retained sovereignty over their stories, and the research team ensured no cultural or personal knowledge was extracted, decontextualised, or interpreted without respect. Draft summaries were reviewed by participants themselves to confirm that interpretation aligned with the intent of participants’ contributions and avoided deficit framing or pathologizing narratives. These relationally derived insights informed the Guiding Principles and recommendations for the *Community Forum Guidance Document*.

4.3.2.7 Outcomes

Community Forum Guidance Document, focusing on improving culturally responsive engagement with Aboriginal and Torres Strait Islander autistic people and their families/supporters. These recommendations were integrated into the final Guidance Document, with the aim to support Aboriginal and Torres Strait Islander autistic people and their families to participate in consultation activities and have their needs, priorities, and preferences represented and acted upon. For further details, refer to the *Community Forum Guidance Document.*

The lived experiences did not simply inform language or procedural steps; they reshaped how Autism CRC approaches engagement with Aboriginal and Torres Strait Islander peoples, shifting consultation from transactional input to shared responsibility, relational continuity, and Aboriginal and Torres Strait Islander leadership across the project lifecycle.

4.3.3 Organisation consultation

4.3.3.1 Aim

To optimise information that could be used to inform the *Community Forum Guidance Document*, a separate organisation consultation was conducted. The aim of the organisation consultation was to draw on the experience and expertise of community and professional organisations acknowledged as key stakeholders. Forty organisations were invited to nominate a representative to participate in the consultation based on their involvement co-producing the Framework, engagement with Autism CRC on previous projects, and/or peak representation/advocacy for Aboriginal and Torres Strait Islander peoples or autistic people with high and complex support needs and their families/supporters. An invitation email and accompanying demographics and consent survey were sent to identified organisation CEOs. Individuals who represented their organisation in the Framework Reference Group but had since left the organisation were also invited to contribute. All participating representatives provided consent to participate.

4.3.3.2 Participants

Thirty organisations accepted the invitation, 21 of which had previous representatives who participated in the Framework Reference Group. Organisation representatives comprised people with lived experience, family members of people with lived experience, and professional experience (see Table 2). The project team acknowledge that there is an extensive community of organisations not included in this list, that are highly relevant and important to the health, learning, participation, and wellbeing of children and their families, including autistic children with high and complex support needs, Aboriginal and Torres Strait Islander peoples, and their families/supporters.

Table 3: Organisations and participating representatives

Organisations and representatives involved in the project's consultation.

Organisation	Representative
Indigenous Allied Health Australia	Tara Lewis
National Rural Health Alliance	Susi Tegan
Carers Australia	Cathy O'Toole
Australasian Society for Developmental Pediatrics	Louise Butler
Australian Multicultural Health Collaborative	Priyanka Rai
Occupational Therapy Australia	Catherine Daley
Speech Pathology Australia	Erin West
Australian Psychological Society	Linda De George-Walker
Australian Physiotherapy Association	Kristy Nicola
Optometry Australia	Ursula White
Audiology Australia	Eleanor Hoskins
Australia Dental Association	Mihiri Silva
Australian Association of Social Workers	Angela Scarfe
Australian Association of Special Education	Sally Howell
Royal Australian College of General Practitioners	Tim Jones

Organisation	Representative
Australian College of Nurse Practitioners*	Ella van de Velde Fidock Rebecca Sedgman
Royal Australian & New Zealand College of Psychiatrists	Valsa Eapen
Australian Association Psychologists Inc	Amanda Curran
Allied Health Professionals Australia	Amanda Curran
Children and Young People with Disability Australia*	Shae Hunter Lauren Riessen
Queensland Centre for Intellectual Disability, UQ**	Katie Brooker
Australian Primary Health Care Nurses Association**	Teresa Tay
Institute for Urban Indigenous Health**	Julie Nicholson
AllMeansAll**	Stephanie Gotlib
AEIOU Foundation**	Joy Xiang
AGOSCI**	Sheridan Forster
The Royal Australasian College of Physicians Pediatrics and Child Health Division**	Paul Hotton
Autism Awareness Australia**	Nicole Rogerson
Australasian Society for Autism Research**	Iliana Magiati

* Indicates the role was shared with another representative of the same organisation.

** Indicates organisations that that have previously partnered with Autism CRC but did not participate in the Framework Reference Group or had not previously contributed to Autism CRC projects.

4.3.3.3 Interviews

A semi-structured interview was held with each participating organisation representative/s. Interviews were conducted by a member of the project team (Teena Caithness) via Microsoft Teams and lasted ~60 minutes each. Each interview was video recorded and transcribed for data analysis purposes. Representatives received a copy of the interview questions within the invitation email and again prior to the interview.

Interview questions

Organisation representatives were asked the following research questions.

1. What does high and complex support needs mean to you?
2. What methods are helpful and/or unhelpful when it comes to community consultation with, and/or in relation to, autistic individuals with high/complex support needs and their families?
3. What methods are helpful and/or unhelpful when it comes to community consultation with, and/or in relation to, Aboriginal and Torres Strait Islander peoples?

4.3.3.4 Analysis

All interview transcripts were downloaded and data sorted into separate files per research question by a member of the project team. Data for research questions 2 and 3 were then separately analysed using the principles and best practices coding frameworks developed using information extracted in each respective environmental scan to check for consistency.

In addition, Copilot was used to identify key themes emerging from the interview responses. These themes were then used to generate a narrative summary of all representatives' responses per interview question. A project team member cross-checked each summary against the interview transcripts per interview question for accuracy and completeness. It was also compared with the previously identified themes to confirm that it accurately reflected the organisations' views. Outcomes were used to inform the *Community Forum Guidance Document* and ensure that the evidence-base included all key stakeholder perspectives.

4.3.3.5 Outcomes

RQ1: What high and complex support needs means to you

The following provides a summary of organisation representative responses to RQ1.

Across the diverse set of interviews, organisation representatives offered rich and varied definitions of high and complex support needs. Despite differences in terminology and emphasis, there was a shared understanding around the multifaceted nature of these needs. Representatives consistently described high and complex support needs as multifactorial in nature, emphasising that it cannot be defined by a single diagnosis. Instead, it encompasses a combination of factors, including co-occurring intellectual disability, other neurodevelopmental differences, physical and medical conditions, mental health conditions, and environmental challenges, that interact with both environmental and systemic barriers. Across definitions, there was a shared focus on functional impact and inability to independently perform activities of daily living, such as personal care, mobility, communication, and safety, which necessitates ongoing and often intensive support and care.

Communication challenges were frequently cited as a defining feature of individuals with high and complex support needs, particularly for those with limited or no spoken language. Many rely on augmentative and alternative communication (AAC), behavioural interpretation, or trusted carers/supporters to communicate their thoughts, needs, and preferences. Families and carers were broadly recognised as central to advocacy, care coordination, and the interpretation of needs, particularly when individuals are unable to self-advocate. However, many noted that the burden on families is often compounded by systemic barriers, including racism, poverty, fragmented services, and a lack of culturally appropriate services, which intensify support needs and complicate access to resources.

Alongside this, there was broad agreement that support needs must be understood as individualised, context-dependent, and dynamic over time. Static or fixed labels were regarded as insufficient to capture the fluctuating nature of support needs; support should be tailored not only to the person but also to their life contexts and evolving circumstances.

Despite these commonalities, notable differences emerged in how high and complex support needs was defined by the organisation representatives. Terminology preferences varied, with some representatives preferencing clinical descriptors such as "Level 3 autism" or "profound autism," while others opposed deficit-based language and advocated for strength-based or rights-based terminology. The focus of complexity also differed; some emphasised co-occurring conditions and clinical presentations, such as intellectual disability, obsessive-compulsive disorder, epilepsy, or trauma, whereas others highlighted environmental and systemic contributors, including housing stress and cultural exclusion. The scope of the definitions across representatives ranged from narrow interpretations, such as those limited to individuals requiring 24-hour care, PEG feeding, or

with severe intellectual disability, to broader understandings that incorporate psychosocial and relational dimensions, including trauma from systemic failure and lack of community inclusion.

Age also played a role in shaping the definition shared by representatives. Some applied the concept of high and complex support needs exclusively to children, while others extended it across the lifespan. Views on the use of labels were also mixed. While some regarded terms such as “high support needs” as necessary for service access and clarity, others argued that such labels are stigmatising and should be replaced with more humanising alternatives.

Overall, the definitions of high and complex support needs provided by representatives reflected their varied roles, experiences, and values. The following five distinct definitions emerged:

1. Clinical definition (diagnosis-based)

High and complex support needs refer to individuals, often diagnosed with Level 3 autism or “profound autism”, who present with multiple co-occurring conditions such as intellectual disability, severe communication impairments, physical disabilities (e.g., PEG feeding, mobility limitations), and/or chronic health issues**.** These individuals require intensive, multidisciplinary support across all domains of daily living, including personal care, communication, mobility, and safety.

2. Functional definition (needs-based)

High and complex support needs describe individuals whose ability to independently perform daily activities is significantly impaired due to a combination of developmental, cognitive, physical, or psychosocial factors. Support needs may include assistance with communication, decision-making, emotional regulation, and accessing education, employment, or community life. The complexity arises from the intensity, diversity, and duration of supports required.

3. Social model definition (contextual/environmental)

High and complex support needs are not solely determined by an individual's impairments but by the interaction between those impairments and environmental barriers. These may include systemic racism, poverty, trauma, inaccessible services, or lack of culturally appropriate care. Complexity is shaped by the context in which the person lives, and support needs reflect the adaptations required to ensure equitable participation.

4. Relational definition (family and carer-centred)

High and complex support needs refer to individuals whose support needs extend beyond what a single caregiver or family can sustainably provide without external assistance. This includes children or adults who rely on carers for communication, advocacy, and navigating systems. Complexity is dynamic and influenced by family capacity, burnout risk, and the availability of trusted relationships and support networks.

5. Inclusive definition (rights-based and person-centred)

High and complex support needs describe individuals who require tailored, long-term support to exercise their rights as citizens and participate meaningfully in society. This includes those with limited spoken communication, high sensory sensitivity, or behavioural expressions of distress. The definition emphasises dignity, autonomy, and the need for inclusive, trauma-informed, and accessible systems that adapt to the person, not the other way around.

RQ2: Methods that are helpful and/or unhelpful for community consultation with autistic individuals with high/complex support needs and their families

The following provides a summary of organisation representative responses to RQ2:

Engaging autistic individuals with high and complex support needs and their families requires more than a standard approach to consultation and engagement. Insights from the interviews with organisation representatives consistently highlighted that effective engagement needs to be flexible, inclusive, culturally responsive, and built on trust. It must also acknowledge the diversity, complexity, and systemic barriers that shape the lived experiences of community members.

Start with trust and relationships

Representatives emphasised that trust cannot be built through one-off engagements with autistic individuals with high and complex support needs and their family members. They highlighted the importance of ongoing relationships, embedding co-design from the outset, and that representation of lived experience in consultation teams can signal authenticity and respect. They broadly noted that successful engagement begins with building rapport, and families and individuals must feel safe and respected. Engagement should feel relational, not transactional, and people's stories should be "held gently" with respect and care. Avoiding rushed, tokenistic consultations was recommended, and researchers were encouraged to instead allow time for relationships to develop. Strategies that can help create a sense of security were suggested, such as building in lead time prior to engagement officially starts to get to know participants on an individual basis, and adopting relational approaches like yarning, side-by-side conversations, and informal check-ins.

Offer real value and reciprocity

Representatives broadly noted that autistic individuals with high and complex support needs and their families are more likely to engage when they understand the purpose and benefit of consultation to themselves. Recognition of lived experience as expertise by offering renumeration was broadly mentioned, whether through payments or gift card, and many cautioned against methods in which participants give their time and lived expertise but receive nothing in return. Researchers were encouraged to explain clearly to community members how their input will shape any outcomes and share progress updates across time, including check-ins to ensure their contributions had been interpreted as they intended and clarify any misunderstandings.

Safety and trust must be prioritised

Representatives broadly noted that face-to-face engagement should occur in safe environments where participants feel comfortable and at ease, such as at home, in a park, or familiar community spaces, rather than clinical or organisational settings which may feel intimidating or inaccessible. If engagement occurs in more professional settings, sensory-friendly environments and sensory considerations more broadly (e.g., lighting, noise, smells, and minimising distractions) were viewed as being essential to creating a sense of safety and comfort. Some noted that group settings can be overwhelming for some individuals, both in-person and online, and that small group sessions or one-on-one formats often work better. Representatives also highlighted that community members should be asked what environment they prefer to meet their needs, and their autonomy respected, and that support persons or familiar communication partners should be involved (where relevant) to reduce anxiety and promote comfort. Transparency about expectations, processes, and mandatory reporting requirements and how this is critical to reduce fear and build trust was discussed.

Communication is the foundation

Representatives emphasised that communication must be clear, respectful, and tailored to individual capacity and preferences. Examples of clear communication strategies included using plain language, avoiding jargon, and offering materials in multiple formats, such as visuals, audio and easy-read documents, and providing translated resources. Some noted that it is essential to ensure access to relevant vocabulary for those using augmentative and alternative communication (AAC) and to prepare interpreters in advance with conceptually aligned materials for individuals from culturally and linguistically diverse backgrounds (CALD). Some highlighted that researchers need to always assume competence and speak with directly with individuals, not around them, even if a support person assists.

Literal communication styles should be respected by avoiding ambiguous or abstract questions, with one representative noting that overly promotional or vague language can erode trust. Representatives reflected that written questions provided ahead of time can reduce anxiety and support processing, and that communication must be clear and consistent across time and people to avoid confusion. Any technical terms should be explained in accessible ways that meet individual needs.

Accessibility and flexibility are key

Organisation representatives highlighted that accessibility goes beyond physical spaces. It also includes easy-read materials, closed captions, Auslan and other interpreters, and ensuring compatibility with screen readers. For CALD communities, it was recommended that resources are translated into languages other than English and interpreters are pre-briefed to ensure concepts are conveyed accurately. Representatives broadly recognised that traditional recruitment often misses this group and recommended that recruitment strategies should be creative, community based and accessible to those who use assistive technologies (e.g., screen readers). Suggestions for alternate recruitment strategies included QR codes placed in clinics and waiting rooms, social media outreach via Facebook, Instagram, and TikTok, and engagement through community leaders and networks to reach families who may not respond to mainstream channels. Some recommended using functional descriptions in recruitment materials rather than labels like “high support needs,” which in their experience many autistic people do not identify with and perceive as disrespectful.

Representatives further noted that rigid consultation formats are inappropriate and ineffective for this group given individuals and families often face fatigue, time constraints, and fluctuating capacity. This can be addressed by offering multiple modalities for participation, such as surveys, voice-to-text, video recordings, drawings, comic strips, and asynchronous interviews, which allow people to engage in ways that suit them best.

If engagement is conducted via face-to-face or online meetings (one-to-one or in a group), some noted that silence and an overall slower pace should be welcomed. Group dynamics should also be considered, with some representatives noting that group consultations can disadvantage individuals with slower communication and/or processing speed and those who use minimal or no spoken communication, which results in dominant perspectives potentially overshadowing others. Meetings should also be structured in a way that allows for extended processing time, breaks, and/or multiple short sessions (e.g., small “breakout” groups in Teams) and follow-up opportunities should be built into the engagement process. For those individuals in regional and remote contexts, providing the

option for online participation was seen to help increase access, though it was noted that connectivity issues need to be considered.

Barriers to participation are real

Representatives discussed the various barriers to engaging in consultation faced by autistic individuals with high and complex support needs and their families. Several highlighted that families managing complex care responsibilities often lack the capacity to engage, and that the emotional and logistical burden on families, especially ageing caregivers, must be acknowledged. Representatives reflected that traditional recruitment methods, such as surveys, newsletters, and social media, were frequently ineffective in reaching individuals with high and complex support needs and their families and could be perceived as scams. Some noted that forms sent home or via email are often ignored due to stress and competing priorities and emphasised that engagement should be designed to minimise disruption and accommodate caregiving responsibilities. Incentives like remuneration, childcare, and practical benefits were suggested as helpful ways to encourage engagement and reduce burden; however, clarity about the purpose and outcomes of engagement was viewed as being essential. Families may act as gatekeepers, preferring to speak on behalf of the individual. This must be respected, while also seeking ways to hear directly from the person where possible.

RQ3: Methods that are helpful and/or unhelpful for community consultation with Aboriginal and Torres Strait Islander peoples

The following provides a summary of organisation representative responses to RQ3.

Effective community consultation with Aboriginal and Torres Strait Islander people requires a foundation of respect, cultural safety, trust, and genuine partnership. Understanding the cultural and historical context is also critical. Across the interviews, representatives consistently emphasised that consultation should be community-led rather than externally imposed; it should originate from, or be endorsed by, the community itself to ensure that language, messaging, and processes signal safety and relevance. This is particularly important given historical and ongoing trauma and various other lasting impacts of colonisation and past experiences with professionals that engender mistrust surrounding research and service provision.

Partnering with local communities and adopting a collaborative approach helps build trust and avoids repeating harmful patterns. The starting point is to ask, *“Whose priority is this?”* If the purpose is driven by external research or organisational agendas, the process risks being tokenistic and culturally unsafe. In contrast, when communities’ initiate consultation, the benefits flow directly to them, and the process respects their governance and aspirations. Transparency about obligations, such as mandatory reporting, was considered essential to creating spaces that are genuinely safe, not just perceived as safe.

Building trust is not a quick exercise; it demands time, continuity, and reciprocity. Representatives highlighted that Aboriginal and Torres Strait Islander communities value relationships deeply, and trust cannot be established through one-off engagements or rushed timelines. Quick, transactional consultations, such as those designed to meet deadlines or tick compliance boxes, undermine this trust and perpetuate harm. Instead, sustained partnerships and respect for cultural protocols are essential for achieving authentic and impactful outcomes.

Communities have repeatedly voiced their fatigue with being “over-researched, over-questioned, and tired of it.” Engagement must feel genuine, not tokenistic, and should avoid hierarchical

approaches that “do to” communities rather than “be with” them. Consultation should involve elders and respected community members, recognise and respect their authority, and abide by cultural protocols. Representation within consultation teams is also critical as having Aboriginal and Torres Strait Islander professionals embedded in leadership roles signals safety and authenticity. This representation must include individuals with genuine cultural authority and lived experience, not disconnected representatives who lack community ties.

Several helpful methods emerged, with the most effective methods being those that reflect cultural practices. Yarning circles and storytelling were repeatedly identified as preferred culturally appropriate approaches that create safe spaces, foster open dialogue and relational engagement, and allow participants to share experiences in culturally familiar ways. Face-to-face engagement, particularly on Country in rural and remote areas, were seen as essential for building relationships, understanding local context, and fostering meaningful interaction, while flexibility in timing and format was strongly recommended. Digital tools can play a role, but they should complement, personal interaction but they should complement rather than replace, and they must be simple and accessible. This is particularly important in rural and remote areas where connectivity is limited, and technology can create barriers.

Across the interviews, representatives consistently emphasised that flexibility is key to effective engagement. Communities should be asked how they prefer to be consulted, rather than being presented with rigid structures or deadlines, and processes should adapt to their preferences. This includes timing, location, and format. Practical supports such as transport assistance, childcare, or gift cards help to remove barriers and show respect for people’s time and expertise. Communication should be simple, visual, and, where possible, translated into Aboriginal languages to demonstrate respect and inclusivity. Collaboration with Aboriginal Community Controlled Organisations - such as NACCHO, IAHA, and First Peoples Disability Network - was considered best practice, alongside co-design principles that allow communities to shape objectives, methods, and outcomes.

Representatives also noted various additional considerations that extend beyond logistics. Many families face intersectional challenges, including disability, autism, mental health, FASD, domestic violence, and poverty. As such, engagement strategies need to account for these layers and avoid siloed approaches. Concepts like “disability” may differ from Western perceptions and not translate directly into Aboriginal languages, so communication should be clear and use plain language, visual aids, and interpreters where needed. Jargon and institutional language need to be avoided to ensure cultural sensitivity in framing questions. Workforce realities also matter, with some representatives noting that there are very few Aboriginal and Torres Strait Islander professionals in some fields, creating a cultural load on those individuals.

Representative also spoke about certain practices they saw as deeply unhelpful. These practices include tokenistic engagement, large impersonal forums that silence quieter voices, and imposing external agendas without community input. Representatives warned against the fatigue caused by repeated engagement in research that fails to deliver tangible benefits, describing communities as “over-researched and tired.” Over-reliance on digital tools was also noted as problematic, given connectivity issues and varying levels of technological literacy. Approaches that impose external agendas or treat communities as homogeneous groups were viewed negatively as they fail to acknowledge the diversity of Aboriginal and Torres Strait Islander Peoples and perpetuate systemic inequities. “Fly-in, fly-out” engagement models were perceived as fuelling research fatigue and undermining trust, while ignoring cultural protocols or failing to follow through on commitments were mentioned as signals of disrespect. Underlying these challenges are systemic and historical

factors that continue to impact upon Aboriginal and Torres Strait Islander peoples today. Distrust of government and research institutions persists due to past experiences of harm, including fear of child removal and misuse of personal information. Intersectional complexities add further layers of difficulty, compounded by resource limitations and the cultural load placed on the small number of Aboriginal and Torres Strait Islander professionals available.

To overcome these challenges, researchers and organisations should commit to power-sharing and sustainability. This means embedding cultural governance, employing Aboriginal and Torres Strait Islander people as paid team members, and planning for continuity beyond project timelines; engagement should not end abruptly when funding ceases. Longer lead times, stable structures, consistent personnel, and providing remuneration to individuals for participation to acknowledge their expertise and time are essential for maintaining trust. Establishing steering committees and advisory panels with equal voting rights, using culturally responsive frameworks, and co-designing research projects with communities were also cited as effective models and approaches.

Representatives highlighted that underlying all these practices is a commitment to “Nothing about us without us.” Aboriginal and Torres Strait Islander voices must lead every stage, from planning and design to implementation and evaluation. Their lived experience is a form of evidence and should be valued alongside scientific data. Engagement should focus on strengths and aspirations, not deficits, and should aim to create tangible outcomes that matter to communities.

Ultimately, representatives emphasised that successful engagement with Aboriginal and Torres Strait Islander peoples is a relationship, not a checklist. It is about listening deeply, respecting cultural protocols, and walking alongside communities rather than ahead of them. By embedding respect, reciprocity, cultural responsiveness, and community leadership and addressing special considerations such as timing, intersectionality, identity diversity, and sustainability, research with Aboriginal and Torres Strait Islander peoples can move beyond tokenism and create pathways that are meaningful, inclusive, and capable of delivering lasting change.