



Australian Autism Research Council: 2020-21 Research Priority Update

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Under the auspice of the Autism CRC

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Autism CRC

Autism CRC is the world's first national, cooperative research effort focused on autism. Taking a whole-of-life approach to autism focusing on diagnosis, education and adult life, Autism CRC researchers are working with end-users to provide evidence-based outcomes which can be translated into practical solutions for governments, service providers, education and health professionals, families and people on the autism spectrum.

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, when speaking of adults 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 About the Australian Autism Research Council

The Australian Autism Research Council (AARC), under the auspices of the Autism CRC, provides a regular and organised mechanism to:

- consult on the state of autism research in Australia;
- identify priorities for autism research in an Australian context;
- report on priorities for autism research in Australia; and
- inform funding strategies for autism research in Australia.

Its overarching goal is to ensure that the delivery of these objectives is community-led – that is, by autistic people, their families, and allies who provide services and support – for the benefit of those communities and for the broader Australian community.

The full objectives and mechanisms for the AARC can be found in its Terms of Reference via the AARC webpage (Australian Autism Research Council. 2021). The membership of the AARC includes representatives of the autistic and broader autism communities, including autistic people, family members, a service provider, health and education professionals, a relevant federal government employee, and researchers.

At the time of writing, the members of the AARC are Charlotte Brownlow, Shelly Dival, Melanie Heyworth, Katie Koullas, Wenn Lawson (co-chair), Pam Macrossan, Malcolm Mayfield, Liz Pellicano (co-chair), Rebecca Poulsen, Geraldine Robertson, Travis Saunders, Lizzie Smith, and Samarra Toby.

Katharine Annear and Renata Morello were also members of the AARC for part of the period in which the focus groups have been conducted but resigned in late 2020. We thank them for their contributions.

1.1.1 Guiding principles

The following guiding principles of the AARC inform its conduct:

Autistic People at the Centre

The priorities should be focused on assisting autistic people to discover what they want for their own lives and supporting them to achieve their goals.

Inclusive of all Autistic People

The priorities should reflect the full diversity of the autism spectrum, including autistic people living without formal diagnosis. Priorities should focus on challenges, issues and positive models of care being inclusive of: age, gender, LGBTQIA+, geography, ethnicity, co-occurring disability, socio-economic disadvantage, and Aboriginal and Torres Strait Islander individuals and families.

Impact

The research priorities should target areas that will create the most meaningful impact for autistic individuals and their families.

2. Involving the Autistic and Autism Communities in Setting Research Priorities

In 2019, the AARC conducted the first community consultation to identify priorities for Australian autism research. This consultation reached more than 1,100 community members from across Australia using an online survey and written submission process. Following the publication of the resulting Research Priorities Report, the AARC recommended that further community consultation was necessary to identify more detailed research questions under these broad areas.

This is an important contribution to a major shift in the way in which autism research is conducted not just here in Australia, but globally.

Autism research has benefited from a significant increase in public investment across the world in recent years. This investment means that there are now billions of dollars spent on autism research and thousands of academic journal articles published every year on autism. Yet research

has repeatedly shown that the vast majority of this research focuses on basic science – the underlying biology and causes of autism – rather than on research that is prioritised by autistic people, family members and those who support them, which focuses instead on people’s more immediate, practical concerns.

The establishment of the Autism CRC in 2013, whose stated mission is “to motivate, facilitate, and translate collaborative autism research across the life span and the spectrum, underpinned by inclusive practices” (Autism CRC, 2021), has helped to shift the funding landscape for autism research in Australia. In the last 5 years, there has been a significant shift towards funding research that focuses more closely on the everyday experiences of autistic people and their families (den Houting & Pellicano, 2019).

A gap still nevertheless exists between what is researched, and the research that the autistic and autism communities feel is most important to them to be undertaken. There is still much work to be done to narrow this gap. Priority-setting exercises are one way of narrowing this gap. They bring together community members to shape the research agenda, by identifying and prioritising the top areas in a research field. And they ensure that researchers and research funders are aware of the issues that matter most to the people being researched.

Investigations into the research priorities of autistic people and the broader autism community are an essential means to reach that goal.

From the first 2019 community consultation, the AARC have identified the top ten research priority areas for autism research in Australia. These are shown in alphabetical order in Figure 1 below:

Figure 1: AARC 2019 Research Priorities



In the remainder of this report, we synthesise the findings from the following in-depth community consultation. We begin by describing the methods of this targeted consultation, including the steps we took to appoint the vendor. We then summarise the findings of the consultation, including their limitations and the opportunities they offer.

This report is intended to be read alongside the ORIMA report (ORIMA Research, 2021a) which describes the process in more detail, including the full list of fifty research topics which were developed through this process.

3.2020 Focus Groups

3.1 Methods and Findings

The key objective of the in-depth 2020 AARC community consultation was to identify and prioritise specific research questions for five of the top ten broad research areas. These five areas included Education, Health and Wellbeing, Employment, Justice, and Communication. These were five of the six highest rated priorities, including the more highly rated of the two health-focused priorities.

The AARC's call for proposals had suggested that an online, multi-round Delphi-style process might be an appropriate methodology for this consultation. The Delphi technique is a structured

decision-making process in which a panel of experts meets multiple times, with the goal of coming to a consensus on a topic. This technique is commonly used for consulting community members on research priorities.

In April 2020, proposals were sought from potential researchers to undertake the 2020 AARC community consultation. Critically – and in line with the guiding principles of the AARC – the AARC expected that the design and delivery of the community consultation would be co-produced with autistic people. The extent of co-production in proposals was one of the key assessment criteria, together with research quality, alignment with the AARC guiding principles, and feasibility.

In early July 2020, ORIMA Research, a research, evaluation and data services company with a dedicated team focused on disability services research (ORIMA Research, 2021b), were contracted as the successful applicant for the 2020 AARC community consultation.

Given the AARC's strong community focus, an Expression of Interest (EOI) process was used to recruit and select focus group members from the broader community including autistic people, family members, and professionals. Focus group members were selected by AARC members with support from the Autism CRC to coordinate the process. The EOI process sought to ensure diversity of experience – critical to community priority-setting exercises – with balanced inclusion of autistic people, family members and professionals with a range of relevant perspectives. Selected members – 'experts' – were instructed to draw on their own professional, personal and / or lived experience to help inform a list of research topics and questions most relevant to each research priority.

For all five Priority Areas, EOIs were particularly encouraged from autistic individuals who predominantly communicate in a non-traditional way (e.g., Augmented and Alternative Communication or sign), individuals living in regional or remote areas, and Aboriginal and/or Torres Strait Islander people. There was also specific expertise prioritised for each group to help ensure a diverse range of perspectives (see Appendix A). Each group had to include at least three autistic people, two parents, carers or family members, and two relevant professionals (see Appendix B for the relevant professions which were represented in each group).

A total of 70 EOIs were received from which 57 people were offered a position on a focus group (the AARC could offer up to 12 places for each group). Fifty-five of these positions were accepted, although three people did not go on to participate in the development or prioritisation of the research topics. In addition, three individuals who did not submit an EOI were also appointed by direct invitation (this only occurred where the AARC felt an important form of professional expertise

was not represented in any of the EOIs received)¹. More than half of the EOIs received were from autistic people, and more than half of these individuals were also the parent or carer of another autistic person. The percentage of people who expressed a preference for each group varied from 19% for the Justice group to 76% for the Education group².

As ORIMA's report outlines (ORIMA, 2021a), they worked with 55 experts across the five Priority Areas, with up to 12 members for each area. For each Priority Area, the experts took part in a ten-day online discussion board, which allowed for rich discussion of the current strengths and challenges of autism research and the kinds of research they would like to see prioritised in the Priority Area. Experts were polled half-way through the discussion process (at day five) and asked to select up to five topics that they felt were most important. The results of this poll were then shared with the other experts within each Priority Area to generate discussion to further refine the questions and to identify any notable gaps in their expressed thoughts.

At the conclusion of the discussion boards, participants from all the discussion boards were invited to complete a final prioritisation poll for all the topics. A total of 45 participants completed this final poll.

The research also included a literature scan to help guide the research.

This process resulted in 50 research questions of various levels of depth and precision, outlined in the ORIMA report (ORIMA, 2021a). Refreshingly, many of these were clearly questions that are not yet being thoroughly examined in academic practice but would resonate with many autistic people and their families, and autistic communities. In each of the five Priority Areas – Communication, Education, Employment, Health and Wellbeing, Justice – questions were identified that directly related both to improving the subjective experience of autistic people and to pursuing the identification of tangible changes to a social environment that is currently poorly designed to serve autistic people's needs.

3.2 Analysis

What was particularly informative about this community consultation was the broad overarching themes that emerged across experts' discussions and the key shifts in the way that autism is

¹ This resulted in a 13th individual being offered a place in the Employment group.

² Applicants could express interest in up to three groups. No applicant was offered a place in multiple groups.

understood and responded to within research and society more broadly. ORIMA helpfully highlighted these themes in their report (ORIMA, 2021a, Figure 8, p. 52).

Key among these themes, as indicated above, were efforts to shift away from the traditional medical model in autism research. This model dominates autism research and is based on a belief that the difficulties associated with being autistic can be explained on the basis of disordered biological processes – that is, processes that reside wholly within the individual. There is no room within the traditional medical model for the social dimensions of being autistic. There is increasing recognition within autism research, however, that such a model is insufficient, and that consideration must be made to the broader social influences and the need for society's and other people's role in creating disability. The ORIMA process indicated how deeply dissatisfied autistic people and their allies were with the continued use of the medical model within autism research.

Although clearly of significant importance, there were, of course, limitations to this research.

One of these limitations relates to the number of people involved in identifying the research questions within each Priority Area. These numbers were nothing like those that had taken part in the 2019 AARC community consultation, which exceeded 1,100 people (Australian Autism Research Council, 2019). What made this community consultation different was that (1) the individuals within each Priority Area were specifically selected for their experiential and professional expertise (i.e., they were considered 'experts') and (2) significant time was devoted to discussing thoroughly the relevant issues, generating rich information.

While this sort of community consultation helps to identify research questions that one group of experts considers important, it is possible that a different group of experts may have come up with a somewhat different set of research questions. Indeed, the existence of a consensus within each topic area does not necessarily mean that these are the 'right' research questions on which to focus. That said, during the discussion process, the ORIMA team conducted polling for the top priorities with experts within each Priority Area and across all members (n=55) of the five Priority Areas. The fact that there was significant convergence in the polling of research questions between those experts who were involved in identifying the research questions for a particular Priority Area, and those who were not, warrants confidence in the resulting research questions.

Priority-setting exercises of this kind also often involve an 'evidence checking' step in which the list of proposed research questions is checked against the existing scholarly evidence. That way, any questions that have already been answered by existing research can be removed and replaced with others that have not yet been answered. The ORIMA team included a literature scan as an evidence-checking step in their approach.

The limited time and resources dedicated to this project meant, however, that the depth and breadth of ORIMA's search for existing evidence was necessarily limited. Thus, researchers and funders who go on to deploy these priorities in their own work will need to ensure that they do the requisite comprehensive searches on their research question of choice to ensure that they are addressing an uncertainty in the literature.

4. Deploying the Priorities in Practice

Now that the questions are identified, it is crucial that we develop a program to help researchers know what to do with these prioritised questions so that the whole process can best fulfil its potential.

This point brings us directly to the issue of *how* research is conducted as well as what the research questions are.

All stages of the AARC's community consultation have reinforced our sense that autistic people and their allies want to be involved in decisions around research. There is no reason to assume that this enthusiasm ends with the identification of the research questions. Instead, it is likely that a shift towards involvement of this kind would also be enthusiastically greeted with regards to the design, conduct, and dissemination of resulting research itself.

This genuine "co-production", and not just "co-design", of research is not straightforward, of course. It requires a further move towards sharing power and responsibility between academic and non-academic autistic partners (den Houting, Higgins & Isaacs et al, 2021). It also involves greater education and training of autism research stakeholders – non-autistic researchers *and* autistic community members – in the '*how to*' of co-production (den Houting, Higgins & Isaacs et al, 2021). But the potential positive effects on researchers, community partners and on the research itself are manifold.

Involving community members in the conduct of research has the potential to make the research more relevant to community members, more tailored to their everyday lives, and more consistent with their values (Brett, Staniszewska & Mockford et al, 2014). Community involvement can also lead to better, more rigorous research, including identifying ways to minimise bias, increasing the generalisability of participant samples (i.e., including the full diversity of the autism spectrum and making efforts to include multiply marginalised people including those of different age, gender, sexuality, geography, ethnicity, co-occurring disability, socio-economic background and cultural and linguistic background) and enhancing data quality. Researchers can gain fresh insight into

issues, identify barriers to research implementation and generate more effective dissemination. Because participation can take many forms – from consultants, to collaborations and partnerships – researchers are encouraged to develop relationships with those with whom they might not otherwise deeply connect and to include people who use non-traditional forms of communication.

Not only might this way of deploying the Research Priorities enhance the quality of research, but it might also begin to build trust between researchers and the broader community. At present, autistic people and family members sometimes report negative experiences of participating in research. They have reported poor management of expectations of the research process and receive little-to-no feedback on the research process or its outcomes. These negative experiences with researchers have made them feel undervalued and marginalised from the research process (Pellicano, Dinsmore & Charman, 2014). ORIMA’s research highlighted that many experts in the community consultation expressed a desire for researchers to be more transparent with their study participants, and to be thoroughly supportive during the research process, accommodating people’s preferences and needs. Moving towards a more fully “co-productive” approach could well assist redressing this balance (Fletcher-Watson, Adams & Brook et al., 2019; Nicolaidis, 2019; Nicolaidis, Raymaker & Kapp et al, 2019; Pellicano, Dinsmore & Charman, 2013).

This appeal aligns with the Autism CRC’s guidance for inclusive research (Autism CRC, 2016) and also follows recent best-practice approaches for conducting more relational autism research (Cascio, Weiss & Racine, 2020). Specifically, researchers are encouraged to:

- i. **Respect holistic personhood** – to design the research process using a strengths-based approach, accounting for potential participants’ needs, preferences or priorities.
- ii. **Acknowledgement of lived world** – to reflect on their own beliefs and values and consider how they might influence the research, while at the same time understanding and respecting the cultural and social factors that influence participants’ lives.
- iii. **Individualisation** – to respond to each participant’s unique preferences and needs during study participation.
- iv. **Focus on researcher-participant relationships** – to build relationships with participants, acknowledge and address potential power imbalances, and ensure that communication is open and transparent throughout the research process, including when the study is over.

-
- v. **Empowerment in decision-making** – to focus on enhancing the agency of participants by ensuring that the structures (e.g., consent processes) and environments provide better opportunities for participants to make informed decisions.

These principles should stand researchers in very good stead in developing a more genuinely co-productive approach.

4.1 Next Steps

The AARC has recommended that community consultation and engagement around autism research priorities should be an ongoing and iterative process. Members of the AARC will discuss what the next steps should be.

One possibility is whether a similar in-depth community consultation should be conducted on the remaining five Priority Areas – that is, in ‘Built Environment’, ‘Choice in Living and Housing’, ‘Family and Carer Support’, ‘Gender, Diversity and Inclusion’, and ‘Health and Disability Services Delivery’.

Another possibility is for the AARC to examine the most effective strategies for the 50 research priorities identified in this project to influence decisions about which research projects get developed and funded. These strategies could include:

- Working with funders to shape their research agenda;
- Working with researchers to build their capacity to respond to these research questions, to promote cooperation and collaboration, especially with members of the autistic and autism communities;
- Working with members of the autistic and autism communities to grow their capability and confidence in research and research-related skills; and
- Identifying research that has been completed in response to this in-depth community consultation and make it publicly available.

Each of these strategies offers the possibility of further deepening the work already conducted and thereby significantly shifting conventional approaches to autism research for the benefit of autistic people and the research community alike.

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Appendix A

Priority Perspectives

Up to three priority perspectives were included for each group as a way to encourage Expressions of Interest from particular groups and help ensure a diverse range of perspectives.

Table 1: Priority Perspectives

Priority Perspectives	
Communication	<ul style="list-style-type: none">• Autistic people (or their family members) who have experienced challenges due to a lack of communication supports or misunderstandings in this area• Autistic people (or their family members) from non-English speaking backgrounds• Professionals working with members of the autistic community in relevant fields
Education	<ul style="list-style-type: none">• Perspectives relevant to different stages of the education journey• Perspectives relevant to different models of education• Autistic people (or their family members) who have experienced school refusal and/or accessed an alternative form of education
Employment	<ul style="list-style-type: none">• Autistic people (or their family members) who have worked or are working in different kinds of employment• Autistic people (or their family members) who have been unsuccessful in finding sustainable employment or who are underemployed• Employers who currently employ at least 1 autistic staff member and professionals working to assist autistic people to obtain and/or maintain employment
Health & Wellbeing	<ul style="list-style-type: none">• Autistic people (or their family members) with 1 or more co-occurring health conditions, including mental health conditions• Professionals who have worked with members of the autistic community in relevant fields
Justice	<ul style="list-style-type: none">• Autistic people (or their family member) who have had previous contact with police and/or the justice system• Professionals with experience working in the justice field

Appendix B

Relevant Professionals

Below are the relevant professional perspectives which were part of each group. Note these professions are listed in the singular but may refer to multiple individuals. For example, there were four current or former teachers in the Education group. Some professional participants were autistic and/or the family member of an autistic person.

Table 2: Relevant Professional Perspectives by Focus Group

Professional Perspectives	
Communication	Speech pathologist, teacher, journalist
Education	Teacher, speech pathologist
Employment	Job coach, support coordinator, employer
Health & Wellbeing	Nurse, psychologist, social worker
Justice	Psychologist, social worker, police officer, lawyer

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Our values

**Inclusion**

Working together with those with the lived experience of autism in all we do

**Innovation**

New solutions for long term challenges

**Independence**

Guided by evidence based research, integrity and peer review

**Cooperation**

Bringing benefits to our partners; capturing opportunities they cannot capture alone



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