



Participatory and Inclusive Autism Research Practice Guides



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Participatory and Inclusive Autism Research Practice Guides

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Foreword from Autism CRC Chair

It is testament to the positive shift in the autism research landscape that I am able to introduce a third iteration of these important guides, focussed on participatory and inclusive autism research practices.

While there is much work to be done, Autism CRC has been proud to be part of that shift by adopting and promoting more inclusive and participatory research practices with autistic people, their families and their supporters. Our vision is to see autistic people empowered to use their diverse strengths and interests. By understanding, recognising and valuing the lived experience of end-users, we can ensure end-user driven research that delivers practical outcomes and resources that benefit the community and achieve our vision.

Autism CRC first released inclusive research practice guides and checklists for autism research in late 2014. The resources formed part of our commitment to build the research capacity within the autism research community and also to enhance the co-production skills of our researchers.

Since then we have continued to review and revise our own internal practices by evaluating the nature and extent of autistic and broader autism community involvement in Autism CRC projects and initiatives. The **Participatory and Inclusive Autism Research Practice Guides** have benefited from people's perspectives of such involvement, both the potential benefits and challenges, situated within the context of Autism CRC's journey of engaging end-user organisations and inclusive research practices.

We believe these earlier guides have already provided a practical resource for researchers throughout our networks. Our aim now is to further enhance the uptake and quality of participatory and inclusive research practices nationally and internationally.

Thank you to all those who have given their time and expertise to these guides. No resource such as this comes about without the efforts of many. This version has benefited from the work of previous contributors, and has been further enhanced by more recent research, practice and the learnings of our latest contributor, Dr Jac den Houting.

We hope you join us as we strive towards true participatory and inclusive practices in all our projects; where research is driven by the needs of the community, and researchers, practitioners and the community, share power and responsibility from the inception of a project through to the dissemination of findings and outputs.



Producing research with autistic people and other community members

Autism CRC's vision is to see autistic people empowered to use their diverse strengths and interests. Our mission is to motivate, facilitate, and translate collaborative autism research, across the life span and the spectrum, underpinned by inclusive practices. We are committed to inclusive research practices and co-production with autistic people and their supporters, to ensure our research provides practical and tangible outputs that benefit the community.

Autism CRC is dedicated to working with autistic people and other community members throughout the research process, from the development of research ideas and priorities, through stages of planning, implementation, dissemination, evaluation, and utilisation of research. Autism CRC has introduced a range of initiatives to support academics, autistic people, and other community members in working together to produce quality research. In addition to these Participatory and Inclusive Autism Research Practice Guides, such initiatives include the:

- ▶ Sylvia Rodger Academy Research Program, which upskills autistic adults and autism researchers to work together as research co-producers;
- ▶ Co-production Partner Initiative, which recognises organisations that have demonstrated a commitment to sustainable research co-production;
- ▶ autistic review of all project proposals, ensuring that Autism CRC research investments are relevant to, and respectful of, the autistic and broader autism communities;
- ▶ Autism CRC Awards for Achievement in Autism Spectrum Research, which recognise and celebrate achievements in inclusive research practice and the translation of research into practice;
- ▶ Australasian Autism Research Council (AARC), established to review and define national priorities for autism research, as identified by the autistic and broader autism communities.

Perhaps most importantly, Autism CRC continues to work towards establishing a culture in which autistic people are recognised as experts by experience, with valuable knowledge and skills to contribute to autism research and practice. The following inclusive research principles outline how we will keep working to nurture and grow this culture, and to empower autistic people through our research.



Inclusive research principles

1 **Our research will be conducted in partnership with autistic people and their supporters**

Autistic people and their supporters will, wherever possible, be involved in the production of Autism CRC research. Where practical, this involvement will occur at the level of co-production or higher. Autism CRC has developed and implemented a number of initiatives to support research co-production, including the Autism CRC Research Co-Production Partner Initiative, the Sylvia Rodger Academy Research Program, and these Participatory and Inclusive Autism Research Practice Guides.

2 **We will produce high quality research that addresses the needs and priorities of autistic people and their supporters**

Autism CRC research will address the issues that are important to autistic people and their supporters. In 2018, the Australian Autism Research Council (AARC) was established under the auspices of the Autism CRC, to review and define national priorities for autism research. In 2019, the AARC published a report outlining the results of a consultation with over 1,000 Australian autistic and autism community members. From this consultation, 10 key research priorities were identified: built environment; choice in living and housing; communication; education; employment; family and carer support; gender, diversity, and inclusion; health and disability service delivery; health and wellbeing; and, justice (AARC, 2019). In 2021, further consultation was conducted to identify more specific research priorities in five of these areas (AARC, 2021). In 2022, the AARC became known as the Australasian Autism Research Council as it expanded to include members from both Australia and New Zealand.

3 **Our research will have real life, real world benefits for autistic people and their supporters. Our research will contribute to greater acceptance and inclusion of autistic people in the community.**

Historically, autism research has been disproportionately skewed towards basic scientific research, including genetic and biological research (den Houting & Pellicano, 2019; Office of Autism Research Coordination, 2019). Although we acknowledge the value of basic scientific research, we seek to establish a more appropriate balance between basic and applied research, with greater emphasis on research that will produce tangible benefits for autistic people. Our research will include that which focuses on strategies for supporting, accommodating, and empowering autistic people.

4 **We will produce research that can be efficiently translated into practice. We will develop tools and resources that autistic people and their supporters can use easily and affordably.**

Autism CRC has developed a range of free and low-cost resources to ensure that autistic people and their supporters can utilise our research outputs. Examples include the myWAY Employability smart web platform, the inclusionED professional learning community, the StepWrite assistive writing app, and The Integrated Employment Success Tool. We will continue working to translate our research outputs into practical resources for the autistic and autism communities.

5 Our research will focus on autistic people's diverse strengths and interests, as well as exploring support needs and the impact of context.

Our research will be strengths-based, while at the same time acknowledging autistic people's support needs. We will take into account the impact of context, recognising that an autistic person's abilities and support needs may vary widely across contexts.

6 Our research tools, processes and outputs will be accessible for autistic people and their supporters.

Our research will be accessible for autistic people as participants, as co-producers, and as an audience to research outputs. We will work to ensure that our research materials and processes meet the needs of autistic people with varying abilities and support needs. Our research outputs will, as much as possible, be freely or affordably available to autistic people and their supporters.

7 Our research will reflect and respect the diversity of the autistic community.

Autism CRC recognises that autistic people are a diverse community, with a broad range of strengths, interests, and support needs. We aim to meet the needs of autistic people across the lifespan, by investing in work spanning three programs of research: Early Years, School Years, and Adulthood. In addition, we acknowledge that there are many specific groups within the autistic community with unique needs, including autistic people with high and complex support needs; those with co-occurring conditions; autistic girls and women; members of the LGBTQIA+ community; First Nations people and members of racial, ethnic, and cultural minority groups; and various other marginalised and intersectional communities.

8 Autistic people's contributions to our research will be acknowledged and valued.

Autistic people add value to Autism CRC research in a broad range of capacities. We are committed to fairly compensating and acknowledging these contributions. Autistic people who produce, co-produce, or consult on Autism CRC research will receive appropriate payment for their work. They will have opportunities for authorship and/or acknowledgement in written publications and other dissemination of research. Where possible, autistic research participants will also receive compensation and acknowledgement for their contributions.

9 We will build research capacity within the autistic community.

Autism CRC has established initiatives to provide research training to autistic adults. Through the Sylvia Rodger Academy Research Program, autistic adults are upskilled to act as co-producers and leaders of research. Through PhD scholarships and postdoctoral positions, autistic researchers have been supported to pursue and establish careers in autism research. We will continue to work with the autistic community in developing research skills and experience, to facilitate greater community control in autism research.

10 We will work towards addressing power inequities between academia and community members. We will build trusting and meaningful relationships between the academic and autistic communities, so they may work together in true co-production.

An imbalance of power is inherent in collaborations between academics and community members. These power inequities may be exacerbated when community members are autistic, or members of another marginalised group. Through our research and other initiatives, Autism CRC will continue working to empower autistic people, and to facilitate equitable and trusting collaborative relationships between academics and community members.

Key concepts in participatory research

What is participatory research?

Participatory research includes community members throughout the research process, rather than just as research participants (Cargo & Mercer, 2008). Participatory research is sometimes also called “community engagement” or “patient and public involvement”. In autism research, participatory research means that autistic people and their supporters have a say in what research is done, how the research is done, and how the research findings are used. When we talk about “community members” in autism research, first and foremost we are talking about autistic people. When it’s relevant, “community members” can also refer to supporters of autistic people, like their family members and friends, service providers, educators, policy makers, and other relevant people or organisations.

Participatory research has existed for more than 50 years (Arnstein, 1969). Academics in many different fields (including agriculture, mental health, public health, and indigenous cultures) use participatory approaches in their research. Historically, autism research has mostly been controlled by non-autistic researchers and professionals, with some input from parents of autistic children, but very little input from autistic people (Jivraj et al., 2014). This has started to change, and participatory autism research is becoming more common.

Participatory research is a framework, or a way of thinking about research (Cargo & Mercer, 2008). It is not a research method or methodology. Almost any research project could be conducted using a participatory framework. There are no specific rules for how participatory research should work, but there are some key concepts that make participatory research different from other research. The most important concept in participatory research is the idea of sharing power.

Power

Power is a person or group’s ability to have influence or control (Roper et al., 2018). In research, academics usually have most or all of the power, and the people who participate in research usually have very little or no power. This is called a power imbalance.

Researchers usually have control over decisions like:

- ▶ which research questions are asked, and which research projects are conducted

- ▶ which methods will be used to answer research questions
- ▶ who the participants in a research project will be
- ▶ what participants will be asked to do
- ▶ how research findings will be interpreted
- ▶ how research findings will be published or shared
- ▶ how research funding will be spent.

In participatory research, the aim is to share power more evenly between researchers and community members (Cornwall & Jewkes, 1995). Ideally, community members should have as much power as researchers, or even more.

When first starting out in participatory research, it can be difficult to figure out how to share power. Academics might be used to having lots of control and making all the decisions in research, and it might be hard for them to give up control. Community members might find research confusing or intimidating, and have trouble speaking up or lack the confidence to take on more control.

Autistic people in particular might not be used to having power. They might be used to living in circumstances that meet other people’s needs, but not their own. They might be used to having other people make decisions for them, or speak for them, even when they don’t want this to happen. This might be especially true for autistic people who are non-speaking or have an intellectual disability. Because of this, in undertaking participatory research you may want to try to give autistic people even more power than everyone else, to make sure that autistic people’s voices are heard (Nicolaidis et al., 2011).

In participatory research, it is very important that researchers and community members work together to reduce power imbalances. Each research team will need to use different strategies to share power, to meet different people’s needs and preferences. Here are some simple strategies that might help to lessen power imbalances between researchers and community members:

- ▶ researchers using their first name instead of ‘Dr’ or ‘Professor’
- ▶ researchers wearing casual clothes (instead of business clothes) to meetings
- ▶ holding meetings at a location that suits the community members instead of the researchers (for example, a low-sensory environment instead of a university campus)

- ▶ holding meetings in a way that suits the community members instead of the researchers (for example, text-based meetings through online chat, rather than Zoom or face-to-face)
- ▶ writing documents in plain English as well as, or instead of, academic language
- ▶ making decisions by voting, or using another strategy that ensures everyone has a say in the decision
- ▶ paying community members fairly for their time.

Although the above strategies might help to reduce power imbalances, they are unlikely to be enough on their own to achieve an equal balance of power between researchers and community members. To achieve an equal balance of power, researchers and community members will usually need to work together over time, trying a range of different strategies to figure out which ones work best for them (Roper et al., 2018).

Building and maintaining trusting relationships

To enable effective participatory research, it is important to establish strong working relationships between everyone involved in the research process. Different team members need to feel like they can trust each other. When everyone in the team trusts each other, they will be able to work together more effectively (Jagosh et al., 2015). This might include:

- ▶ trusting other team members to do tasks on their own
- ▶ feeling comfortable to share opinions openly

- ▶ feeling safe asking for support or accommodations
- ▶ being able to disagree with other team members without worrying about consequences.

Trusting relationships can help to make power-sharing easier. When academics trust the community members they work with, they will feel more comfortable sharing control of the research process with those community members. When community members trust the academics they work with, they will feel more comfortable about speaking up and taking control.

For autistic people, it might be particularly difficult to trust researchers. In the past, some researchers treated autistic people very badly, and as a result many members of the autistic community are distrustful of researchers (Raymaker, 2019). Even today, some researchers treat autistic participants poorly, and some autistic people have had bad experiences with research (e.g., Lory, 2019; Pellicano et al., 2014). This means that researchers may need to work even harder to earn autistic people's trust.

Some strategies that might be useful for building trust between team members include:

- ▶ team-building exercises
- ▶ activities to identify shared goals
- ▶ actively listening and treating each other with respect
- ▶ making sure to follow through on team decisions
- ▶ keeping in regular contact
- ▶ having fun together
- ▶ regularly evaluating the collaboration and taking steps to improve.



The best way to develop a trusting relationship is to establish and maintain a working relationship over time (Cargo & Mercer, 2008; Nicolaidis et al., 2019). Often, researchers who want to work with autistic people will design a research project, get funding for the project, start running the project, and then ask autistic people to join in. For example, they might advertise for autistic people to be members of an advisory group. This can work for some research projects, but it isn't always the best approach for good participatory research, as shown in Figure 1.

A better approach is for researchers and community members to get to know each other first, before any work happens on a research project (Cargo & Mercer, 2008). Then, they can work together throughout the whole research project, as shown in Figure 2.

Figure 1

Community engagement in a traditional research process

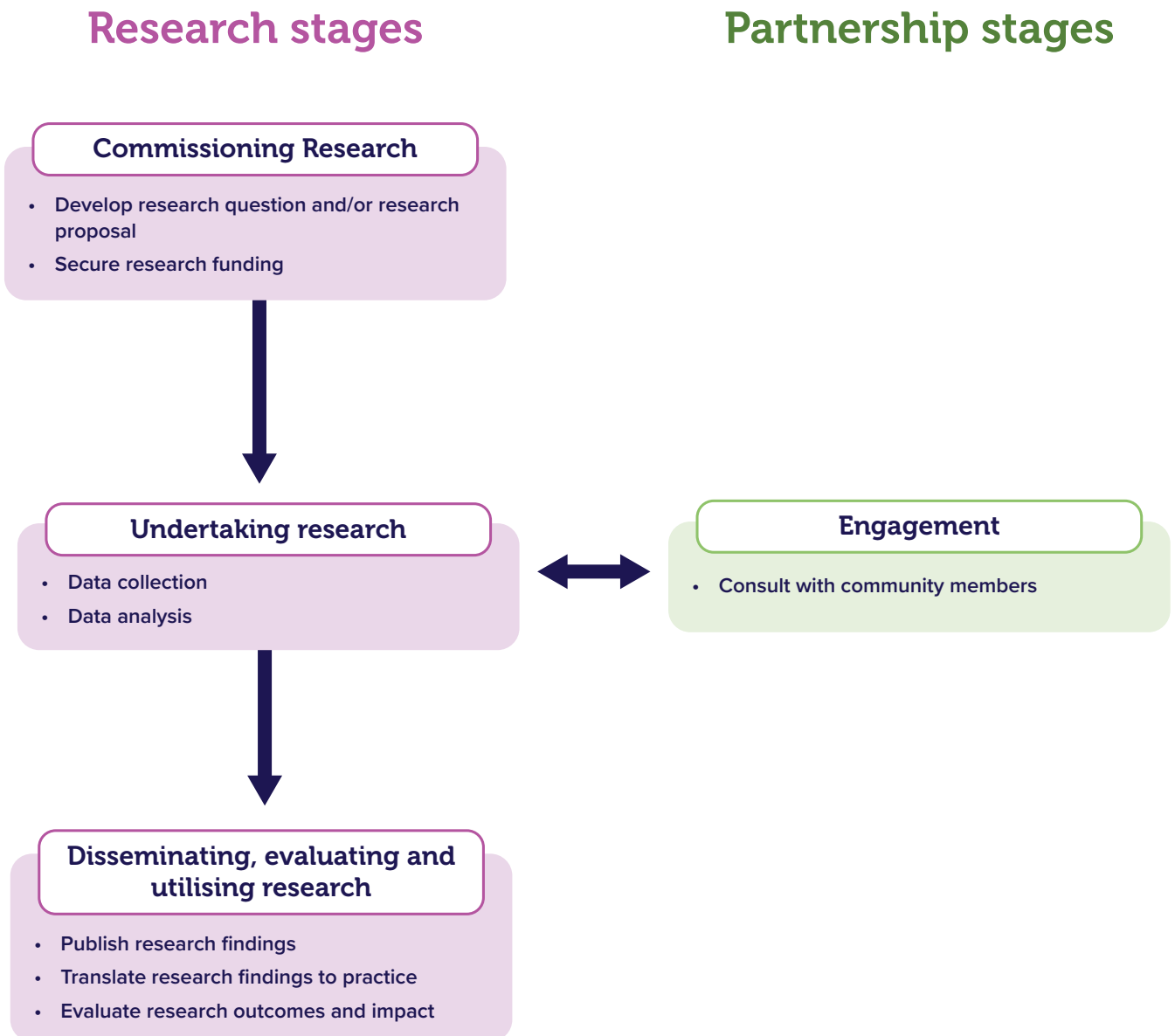
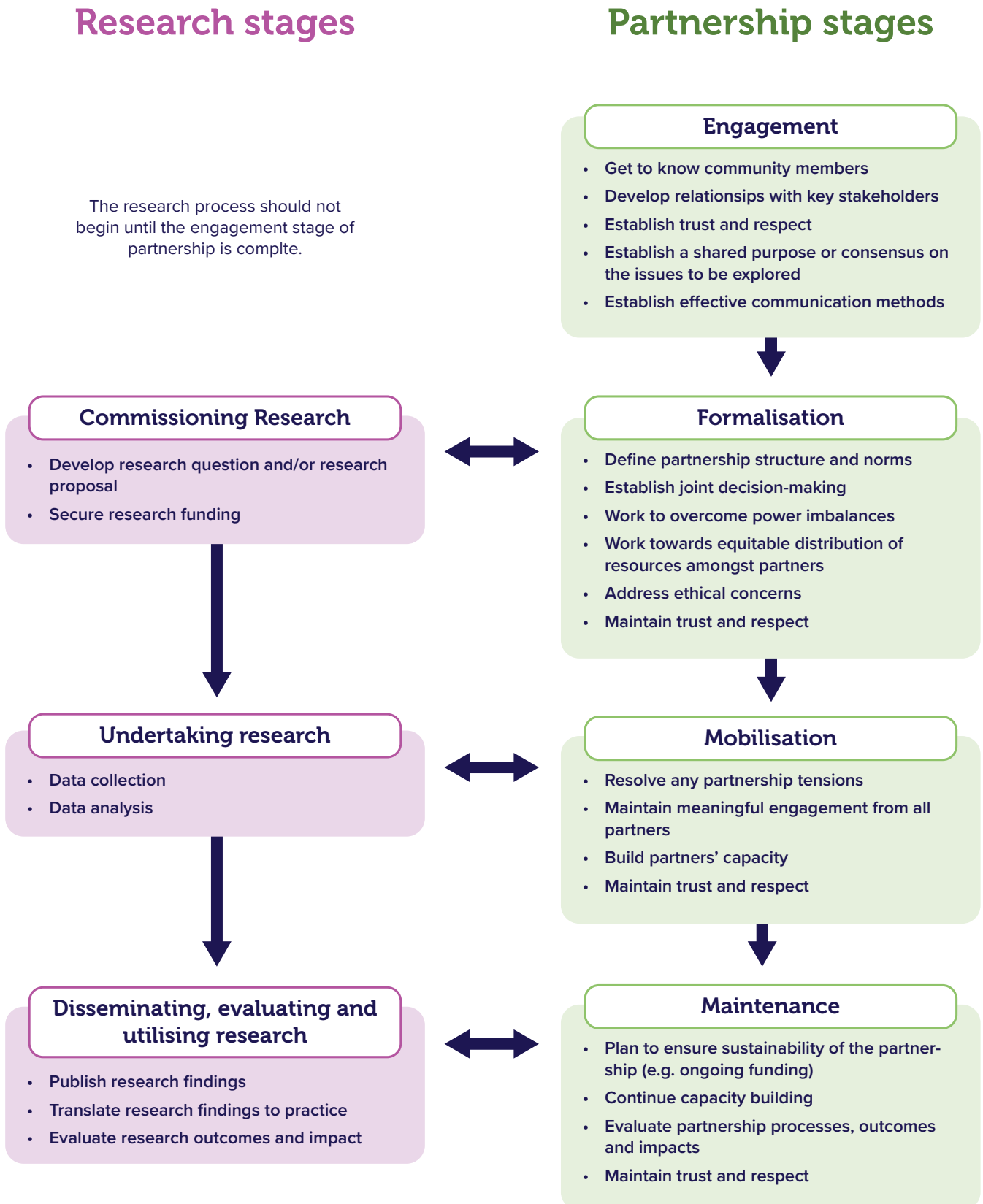


Figure 2

Community engagement in a participatory research process



Stakeholders' roles

Different people have different roles in participatory research. Each person's role will depend on their individual knowledge, skills, and experience (Tritter & McCallum, 2006). Usually, a researcher's role is to provide research expertise. This might include:

- ▶ knowing how to apply for research funding
- ▶ understanding the relevant evidence base
- ▶ knowing how to apply for ethical approval
- ▶ making sure a research project is scientifically sound
- ▶ knowing how to collect and analyse data
- ▶ knowing how to publish research findings.

Usually, a community member's role is to provide lived expertise and connection to the relevant community (Pellicano & Stears, 2011). This might include:

- ▶ knowing which research topics are important to the community
- ▶ making sure a research project is relevant to, and respectful of, the community
- ▶ making sure the research tools (like surveys or interview questions) are accessible to the community
- ▶ promoting the research within the community
- ▶ communicating research findings to the community.

There are a range of different stakeholders in the autism community who might act as community members in participatory research. Community members can be individual people, or representatives of an organisation. The foremost stakeholders in the autism community are autistic people, and representatives of autistic-led organisations. Other relevant community members include parents, friends, and family members of autistic people; service providers and other non-academic professionals; government agencies; policy-makers; and corporate organisations.

It can be helpful for community members to understand the research process and have some research skills, but this isn't essential for participatory research. Sometimes, a lay opinion might be more useful than an academic opinion – for example, to make sure research is accessible to a wide audience. It is important that everyone in the research team understands what knowledge, skills, and experience each person brings to the research project. The team can then work together to decide what each person's

role will be. Establishing clear roles at the beginning of a research project can help to make sure that the project is carried out as planned, and help each person understand and respect each team member's contribution to the project (Nicolaidis et al., 2019).

How do I engage community members?

The role that community members have in participatory research is very different from the role of research participants, and so there should be different standards for recruitment. When academics are recruiting research participants, they may try to gather a random or representative sample of the population. When academics are choosing other researchers to collaborate with, though, they don't choose a random sample from the whole population of researchers. Instead, they choose people who have the knowledge, skills, and experience needed for their project (Nicolaidis et al., 2019). Often, researchers will choose collaborators who they already know and get along with, because they recognise that good working relationships with other researchers are important.

When engaging community members in research, it is best to work together with community representatives to collaboratively decide which stakeholder groups should be engaged in the research project, and who should represent those groups. Decisions about who is involved should be based on the knowledge, skills, and experience that they will bring to the project, the time and energy they are able to commit, and any existing working relationships.

Because a community member's role is to provide lived expertise, we should engage with community members who have lived experience that is relevant to the research topic. Sometimes there may be more than one group of community members with relevant lived experience, and it can be useful to engage representatives of all these groups. For example, in a research project examining home-schooling for autistic students, a range of community members might be relevant: autistic students; parents of autistic students; educators of autistic students; autistic adults who were home-schooled; and education policy-makers. In contrast, in a research project examining autistic women's identities and self-esteem, autistic women might be the only relevant community members, and it may be inappropriate to engage with other groups.

Some researchers may be new to the autism community, and/or may not have any established relationships with autistic people and other community

members. Some strategies for beginning to build relationships with community members include:

- ▶ contacting Autism CRC's Sylvia Rodger Academy to be put in touch with alumni from the Research Program, Future Leaders Program, and Governance Program
- ▶ contacting autistic led-organisations like the Autistic Self-Advocacy Network of Australia and New Zealand (ASAN-AuNZ) and the I CAN Network
- ▶ contacting autism-specific organisations and service providers, including the various state-based autism peak bodies
- ▶ posting on social media using hashtags like #AskingAutistics, #Autistic, #Autism, and #Neurodiversity.

What about autistic academics?

Autistic researchers who conduct autism research can be considered insider-researchers – that is, researchers who are members of the group that they

are studying (Greene, 2014). Some of the key issues associated with insider research are similar to those in participatory research - for example, navigating power dynamics.

In participatory research, though, an important part of a community member's role is to provide a lay (i.e., non-academic) perspective on the research. An autistic researcher who has academic training will be able to provide an autistic perspective on a research project, but their perspective is likely to be influenced by their academic knowledge. This means that an autistic researcher might not be well-placed to perform some of the key roles of a community member, such as making sure that the research is accessible to the autistic community.

Because of this, it is important to involve lay autistic people in participatory research, and not to rely only on autistic academics to act as community members. Autistic academics can be valuable members of participatory research teams, but they should be involved as well as – not instead of – lay autistic people.

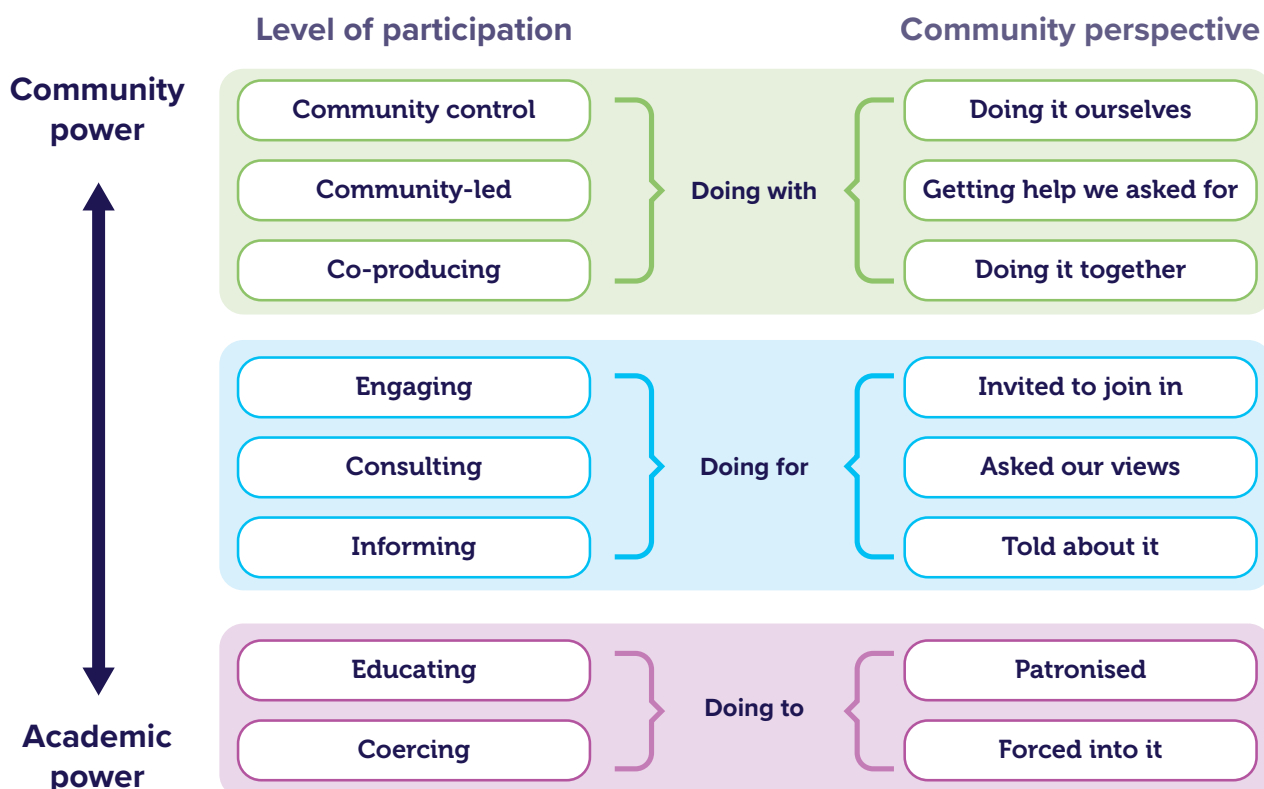


Levels of community participation in research

Community members can be involved in research at a range of different levels. The different levels of community participation describe how much involvement a community member has, and how much power they have in the research process (Arnstein, 1969). Figure 3 shows the different levels of community participation in research.

Figure 3

Levels of community participation in research.



Coercion

The lowest level of community participation is coercion. This is when community members are forced to participate in research or convinced to participate when they don't want to. An example of coercion might be a service provider conducting research to test how effective their services are, and telling clients that they won't be able to access services any more if they don't participate in the research. Coercion is unethical and research at this level is never appropriate.

Educating

The next level of participation is educating. At this level, researchers believe that the community needs their help, and try to teach, 'fix', or 'cure' the

community members. An example of educating might be a group of non-autistic researchers who develop and test an intervention program designed to teach autistic children not to stim (i.e. rocking, hand-flapping, and other repetitive behaviours). Research at this level is rarely appropriate, as it is focused on the researchers' priorities rather than the community's priorities.

Informing

At the informing level, researchers believe that the community could be interested in research, so they tell the community about their research to help them understand. Researchers might explain what their research is, why they're doing it, how they're doing it and what the outcomes of the research are. An example of informing might be a researcher who

visits a local community group to give a presentation on their research. Research at this level might be appropriate when the community is interested in the research, but does not have the time or capacity to be involved in producing it.

Consulting

The next level of participation is consulting. At this level, researchers invite the community to give feedback and suggestions for the research. Researchers are still in control of the research, and they can choose whether to take on the suggestions or not. An example of consulting might be a researcher who sets up an advisory group of autistic adults to give feedback on a research project. The researcher may make some changes to the project based on the advisory group's feedback but ignores other suggestions. Research at this level might be appropriate when a researcher is just getting started in participatory research, when community members don't have much experience in research or when community members don't have a lot of time to be involved in the project.

Engaging

At the engaging level, researchers initiate the research project and invite the community to work with them to do the research. Once the community has joined the project, researchers and community members work together, sharing power and control of the research. An example of engaging might be a non-autistic researcher who wants to understand autistic adults' social experiences. The researcher conducts background research, writes a research proposal, and gets funding to run the project. They then invite three autistic adults to join the research team, and all four team members work together to design a survey, analyse the data, and write reports. Research at this level might be appropriate when a researcher needs to get funding before they can pay community members for their time.

Co-producing

In co-production, researchers and community members work together as equal partners from the beginning of the research process. Researchers and community members jointly agree on a research question to answer, and together they design and conduct the research project. Researchers and community members share power and control all throughout the research process. An example of co-production might be a non-autistic researcher and an autistic person who know each other, and are both interested in understanding the differences between autistic and non-autistic social skills. Together they

come up with an idea for a research project, write a proposal, and get funding for their project. They work together to produce the research, making all the important decisions jointly. Research at this level might be appropriate when the researcher has some previous experience of participatory research, and the community members want to be very involved in the research.

Community-Led

The next level is community-led research. In community-led research, the community comes up with an idea for a research project and invites researchers to help them produce the research. The community might need lots of help from researchers, all throughout the research process; or they might just need help occasionally with certain tasks. An example of community-led research might be an all-autistic organisation that runs educational workshops for autistic people and wants to find out if their events are beneficial. They ask a researcher for advice on the best way to investigate this. The researcher helps the organisation to design a study, and they work together to get funding and ethical approval for the study. The organisation gathers data and the researcher gives advice on how to analyse the data. The organisation writes and publishes a report on their findings. The organisation makes all the decisions about the research, taking into account the researcher's advice. Research at this level might be appropriate when it is important for the community to have lots of power, but the community doesn't have enough research experience to run the project by themselves.

Community Control

The highest level of participatory research is community-controlled research. In community-controlled research, the community comes up with an idea for a research project and produce the research by themselves. People who aren't community members aren't involved in the research process at all, except maybe as participants. An example of community-controlled research might be, as above, an all-autistic organisation that runs educational workshops for autistic people and wants to find out if their events are beneficial. Using their own funds, the organisation designs a research project and gets ethical approval for the study. They gather and analyse the data themselves, and write and publish a report on the findings. The organisation independently makes all the decisions about the research. Research at this level might be appropriate when the community members who will run the project have lots of research skills and experience.

Participatory research in practice

The phrase participatory research usually refers to research at the “consulting” level or higher. At the bottom three levels – coercion, educating and informing – community members are not involved in producing the research, so these levels do not fit the definition of participatory research (as shown in Figure 4).

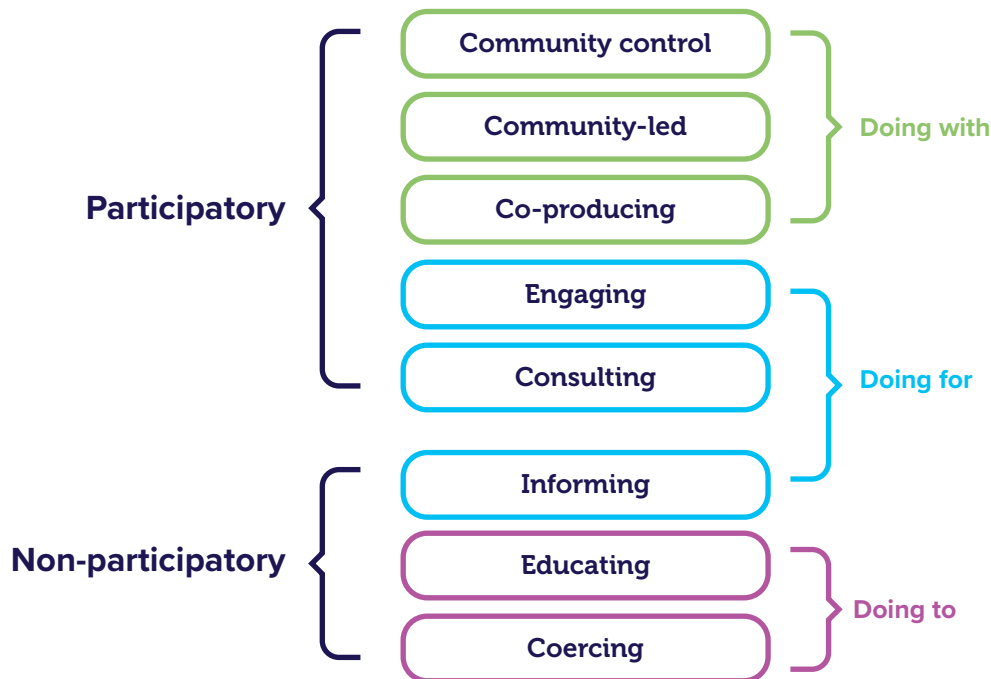
In a participatory research project, we should aim for the highest level of community participation that is realistic and achievable for our project. This will be different for different research projects.

It is important to note that one research project might have different community members involved at different levels, or at different times during the project.

For example, a project could be co-produced by an autistic person and a non-autistic researcher, and also have an advisory group of autistic people who consult on the project. The same project might also have autistic participants who aren’t involved in producing the research but are informed about the project. This is okay, as it is not always practical for everyone in a research project to be involved at a high level, and different people will have differing preferences about how much they want to be involved in research (Tritter & McCallum, 2006).

Figure 4

Participatory and non-participatory levels of community engagement in research.



Participatory methodologies

Participatory research is a framework, not a research methodology or method. Almost any research project, methodology or method can be conducted in a participatory way. It might be more difficult to involve community members in some types of research, like biomedical research, but it is still possible, important, and beneficial. For example, participatory research is becoming increasingly common in clinical trials (including randomised controlled trials) in health research (Crocker et al., 2018).

There are, however, a number of specific methodologies that are inherently participatory. Research using these methodologies must involve community members. Two of the most common participatory methodologies are Participatory Action Research and Community-Based Participatory Research.

Participatory Action Research (PAR)

PAR is a research methodology that involves cycles of planning, acting, observing and evaluating, with the goal of learning about and improving practice (McTaggart, 1991). There are a small number of examples of PAR used in autism research, primarily in educational settings (see Bevan-Brown et al., 2008; Lam et al., 2020; Ostmeyer & Scarpa, 2012; Vincent et al., 2016). PAR is informed by the following key principles:

1. PAR is participatory, involving community members in most aspects of the research and action
2. PAR is cooperative, with community members and researchers both contributing their expertise to a collaborative process
3. PAR is a co-learning process, through which both community members and researchers develop knowledge
4. PAR is a method for developing competency and capacity within an existing system or community
5. PAR is an empowering process, through which community members gain increased control over their own lives
6. PAR achieves a balance between research and action (Israel et al., 1992; Minkler, 2000).

Community-Based Participatory Research (CBPR)

CBPR is used mostly in research with marginalised and minority communities. There are a small number of examples of CBPR in autism research, most conducted by the Academic Autism Spectrum Partnership in Research and Education (AASPIRE; see Nicolaidis et al., 2016; Nicolaidis et al., 2015; Nicolaidis, Schneider, et al., 2020; Nicolaidis, Zhen, et al., 2020; Raymaker et al., 2019; Raymaker et al., 2020). CBPR is informed by ten key principles:

1. CBPR recognises community as a unit of identity
2. CBPR builds on strengths and resources within the community
3. CBPR facilitates collaborative, equitable partnership in all research phases and involves an empowering and power-sharing process that attends to social inequalities
4. CBPR promotes co-learning and capacity building among all partners
5. CBPR integrates and achieves a balance between research and action for the mutual benefit of all partners
6. CBPR emphasises public health problems of local relevance and ecological perspectives that attend to the multiple determinants of health and disease
7. CBPR involves systems development through a cyclical and iterative process
8. CBPR disseminates findings and knowledge gained to all partners and involves all partners in the dissemination process
9. CBPR requires a long-term process and commitment to sustainability
10. CBPR addresses issues of race, ethnicity, racism, and social class and embraces 'cultural humility' (Israel et al., 2018, pp 32-34).

Less common participatory methodologies include: empowerment evaluation; cooperative inquiry; appreciative inquiry; decolonising methodologies; and, emancipatory methodologies.

Why is participatory research important?

Participatory research has lots of important benefits. However, there are also challenges that can make it difficult to do high-quality participatory research. Some of these benefits and challenges are explained below.

Benefits

- ▶ It is morally and ethically right. Like the disability advocacy slogan says, there should be “nothing about us, without us!” Participatory research gives the people who will be most affected by research a chance to shape the research that is done about them (Cargo & Mercer, 2008).
- ▶ It produces research that is more relevant and beneficial to the community. Participatory research tends to answer the research questions that are most important to the community and produces outcomes that are more helpful to the community (Brett et al., 2014; Forsythe et al., 2019).
- ▶ It improves participant recruitment. When research is designed together with the community, it tends to be easier to recruit community members to join the research as participants (Crocker et al., 2018).
- ▶ It is capacity-building for the community, meaning that it allows community members to gain skills and learn something new (Roper et al., 2018). They might learn broad research skills, like how to design a research project, and also more specific skills such as how to use a particular computer program. Over time, community members may gain enough skills to undertake community-led or community-controlled research.

Challenges

- ▶ It is almost always more time-consuming. Building relationships between community members and researchers is a very important part of participatory research, but it can take a long time. Participatory research might also involve more people and more steps than non-participatory research - for example, sending documents to an advisory group for feedback is an extra step that takes time (Blackburn et al., 2018; den Houting et al., 2021).
- ▶ It is almost always more expensive. Involving community members in research means that those community members should be paid for their time. This is an extra expense that non-participatory research does not have (Blackburn et al., 2018; den Houting et al., 2021).
- ▶ It does not fit within current research systems. The way that most research organisations (like universities) think about research does not take participatory research into account. This means it can be difficult to explain participatory research to ethics committees (Nicolaidis et al., 2019) and it can be difficult to get funding for participatory research projects.
- ▶ There is a risk of tokenism (Nicolaidis et al., 2019). Because participatory research is becoming more popular, there is a risk that some researchers might set up ‘advisory groups’ so they can claim that they did participatory research, but not listen to the advisory group’s input.
- ▶ Some community groups might be underrepresented. It is possible to make participatory research accessible for just about everyone, but some groups are easier to include than others (Ocloo & Matthews, 2016). For example, researchers might need to make lots of changes to how they work in order to involve non-speaking autistic people and autistic people with intellectual disability in participatory research.

Which level of participation is right for my project?

There are a lot of factors to consider when deciding what level of community participation might be right for a particular research project. Some of these factors are discussed below.

1. **Your own status as autistic or non-autistic.** If you are an autistic researcher or community member, you may be able to conduct community-led or community-controlled research. If you are a non-autistic researcher, it is likely that co-production will be the highest level of participation you can achieve (unless you are asked to help with community-led research).
2. **Your previous experience with participatory research.** If you have never conducted participatory research before, consultation can be a good way to gain experience working with community members. If you have had some experience conducting participatory research, consider building on that experience by aiming for a higher level of community involvement.
3. **Your connection to the autistic community.** Depending on your personal and professional background, your level of involvement with the autistic community will vary. If your connection to the autistic community is limited, consultation can be a good way to meet autistic people and start to develop relationships with community members. If you have established networks within the autistic community, consider building on those relationships to form co-production partnerships. If you have well-established, equitable and trusting relationships with one or more autistic colleagues, you are ideally placed to co-produce research.
4. **Project status.** To achieve the highest levels of community participation, it is important to work with community members as early as possible in the research process. If you don't yet have a research idea or plan, you could co-produce by developing an idea together with community members. If you are already planning a project or in the very early stages of research, you could invite community members to engage in the research. If you have progressed past the early stages of the research project, consultation is likely the highest level of participation that you can achieve.
5. **Community members' capacity.** Community members will have different levels of capacity for involvement depending on their interest in the project, their availability, their skill set and so on. It is important to discuss expectations regarding level of participation with each community member and jointly agree on the most appropriate level of involvement for each person.
6. **Your level of comfort with co-production principles.** Some elements of co-production can be challenging, particularly when you are new to participatory research. If you are used to having a lot of power and control in research, sharing power with community members may feel very uncomfortable. This is normal! As long as you are willing to work through any discomfort that you may feel during the research process, you can consider co-production. Alternatively, you can consider consulting until you become more comfortable working together with community members.
7. **Timeframe and budget.** Very tight timeframes and/or budgets can make it challenging to achieve a high level of community engagement. In these cases, consultation may be more appropriate. When timeframes and/or budgets are more flexible, consider aiming for higher levels of participation. If you are early in project planning and do not yet have a set timeframe and/or budget, consider co-producing the research and factor in any additional time or budgetary costs associated with co-production in your planning going forward.
8. **Systemic factors.** You may encounter systemic factors that influence the level of community participation you can achieve. For example, some funding bodies and/or Human Research Ethics Committees may not allow community members to be named as Chief Investigators/ Principal Investigators in relevant applications. To achieve equitable co-production, you may need to consider implementing strategies within your team to counteract any power imbalance imposed by systemic factors.

Participatory Guides and Inclusive Guides

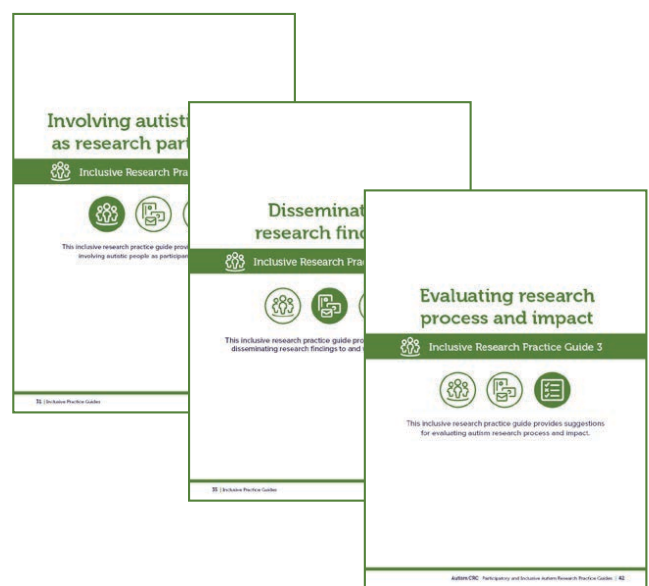
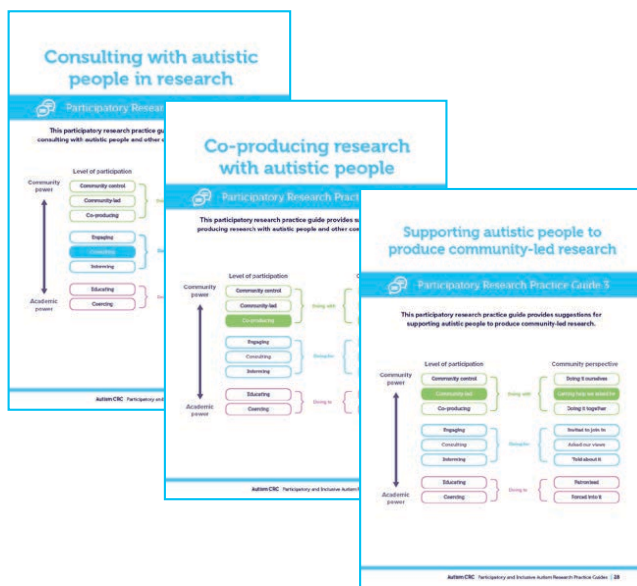
The following sections of this document contain two different types of guidelines: **Participatory Research Practice Guides, and Inclusive Research Practice Guides.**

The **Participatory Research Practice Guides** provide information and advice about producing research together with autistic people and other community members. There are three Participatory Research Practice Guides:

1. Consulting with autistic people in research
2. Co-producing research with autistic people
3. Supporting autistic people to produce community-led research

The **Inclusive Research Practice Guides** provide information and advice about conducting research that is inclusive of and accessible to autistic people and other community members. There are three Inclusive Research Practice Guides:

1. Involving autistic people as research participants
2. Disseminating research findings
3. Evaluating research process and impact



Currently, there are no Participatory Research Practice Guides for the “engaging” and “community-controlled” levels of research, because there is little existing research on these levels. For research at the engaging level, the information in the “Co-producing research with autistic people” guide may be useful. For community-controlled research, the information in the “Supporting autistic people to produce community-led research” guide may be useful.

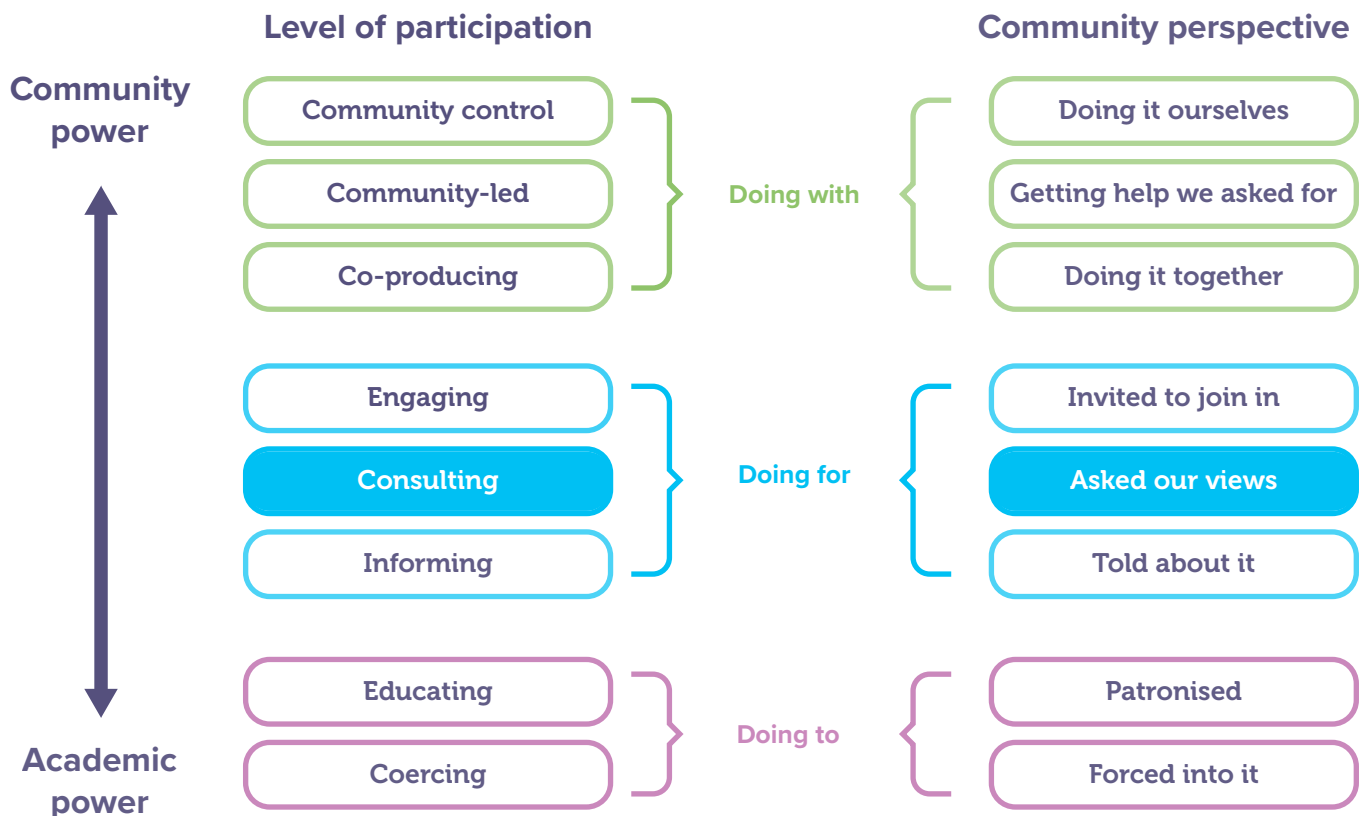
You may choose to read all of the guides, or just some. Each guide contains different information, so you may find the Inclusive Research Practice Guides useful even if you are conducting participatory research, or vice-versa.

Consulting with autistic people in research



Participatory Research Practice Guide 1

This participatory research practice guide provides suggestions for consulting with autistic people and other community members in research.



What is consultation?

Consultation is the lowest level of participation that involves community members in producing the research. At this level, researchers invite the community to give feedback and suggestions for the research. Researchers are in control of the research, and they can choose whether to take on the suggestions or not. An example of consulting might be a researcher who sets up an advisory group of autistic adults to give feedback on a research project. The researcher

may make some changes to the project based on the advisory group's feedback, but might ignore other suggestions. Research at this level might be appropriate when a researcher is just getting started in participatory research, when community members don't have much experience in research, or when community members don't have a lot of time to be involved in the project. To date, most participatory autism research has happened at the consultation level.

Methods of consultation

Some common ways that researchers can involve community members in research at the consultation level include:

- ▶ setting up an advisory group to give one-off or ongoing input
- ▶ asking an individual community member to give one-off or ongoing input
- ▶ asking an autistic-led organisation to give one-off or ongoing input
- ▶ hiring an autistic person (or other community member) to work as a research assistant.

Involving autistic people or other community members as participants in qualitative research, such as focus groups or interviews, is not the same as consultation. If you are collecting, analysing, and reporting on data from autistic people, then those autistic people are acting as research participants, not consultants. Qualitative research is useful for highlighting autistic

people's experiences and perspectives, but it is not the same as participatory research.

Some common research tasks that might benefit from community consultation include:

- ▶ identifying the research topic/question
- ▶ selecting the research methodology and/or methods
- ▶ choosing and/or adapting surveys, interviews, and other data collection tools
- ▶ writing recruitment materials and participant information and consent forms
- ▶ sharing recruitment materials with potential participants
- ▶ interpreting research findings
- ▶ disseminating research findings
- ▶ evaluating the research project.

Practical strategies for consultation

The list below is an example of some steps that you might follow in a community consultation process. You can use this list as a guide for conducting your own community consultation. You might choose to follow all the steps in this order, or just use some of these strategies, or you might create a totally different process. There is no "right" process for community consultation, so you should use the approach that works best for your project.

1. Discuss the research project with key community representatives to decide on the best methods for consultation.
2. Invite relevant community members to consult on the project and/or advertise for consultants.
3. Together with the consultants, collectively agree on processes for consultation. Important decisions to make might include:
 - ▶ will you hold group meetings? Where, how often, and for how long?
 - ▶ how else will you communicate (e.g., email)?
 - ▶ will there be a group leader/chair?
 - ▶ will consultants need to reach consensus/make decisions?
 - ▶ how will consultants be reimbursed for their time?

4. Create a Terms of Reference document that lists all of the consultation processes you have agreed on. This might not be needed for one-off or informal consultations, but it can be useful when consultation is ongoing.
5. Keep a record of consultants' input and feedback. Record whether and how the consultants' suggestions were actioned. If suggestions were not actioned, explain why not. Share the record with consultants regularly (e.g., after each meeting).
6. Keep the consultants updated on how the project is progressing, for example by sending update emails between meetings.
7. Offer the consultants opportunities to author written publications and/or to co-present research findings.
8. Acknowledge consultants' input in any written publications or other outputs.
9. Evaluate how effective your consultation process was. Ideally, you should incorporate evaluation all throughout the consultation process. See **Inclusive Research Practice Guide 3** for more information about evaluation.
10. After the project, work to maintain and/or build on the relationships established with the consultants. This may include seeking future opportunities to capitalise on these relationships through a co-production partnership.

Example recruitment poster

Interested in Autism Research?

Join our advisory group!

What are we doing?

We are conducting a research project to evaluate how successfully the Autism CRC has been able to engage the autism community (including Autistic people, their families, and service providers) in participatory autism research.

This project will run over two years, and has two stages:

Stage One will ask participants about their experiences of participatory research with the Autism CRC, using an online survey and interviews.

Stage Two will develop and test a framework for evaluating participatory autism research.

Why are we contacting you?

We are establishing an Autistic advisory group to provide input on this research project. We are looking for 4 – 5 Autistic graduates of the Autism CRC's Research Academy to participate in our advisory group.

If you join the advisory group, we will ask you to:

- Commit to be part of the group for two years;
- Attend approximately six online meetings, up to 2 hours duration each, over the two years;

- Spend up to two hours preparing before each meeting, for example by reading documents sent by the research team;
- Give your opinion and feedback on different aspects of the research project; this might include (for example) feedback on the survey and interview questions, advice on interpreting data, and/or input in developing the evaluation framework.

Advisory group members will receive payment of \$160 per meeting.

Interested?




Please submit a brief statement outlining your background, why you are interested in joining the advisory group, and any previous experience you have had in autism research and/or practice.

Statements can be submitted as either a written document (maximum of 300 words), **OR** a video (maximum of 2 minutes), and must be received by **5pm on 9th July 2018**.

To submit statements, and for more information, contact:

Contact

For more information




autismcrc.com.au
[@autismcrc](https://twitter.com/autismcrc)

1. Roles and responsibilities of the group

The Advisory Group was established on *[date]* as part of *[name]* project.

The role of the Advisory Group is to:

- provide advice and input to the research team at relevant stages of the research project
- ensure the autistic perspective is represented in the research project
- collaborate with the research team to create high-quality co-produced research outputs.

Members of the Advisory Group commit to:

- attend all scheduled Advisory Group meetings
- undertake necessary preparation for meetings
- complete agreed-upon tasks in between meetings, if required
- where appropriate, liaise with the broader autistic community regarding the work of the Advisory Group.

Members of the Advisory Group will expect:

- to be provided with all relevant information and documentation for each Advisory Group meeting in a timely manner
- to be given reasonable time to process information, make decisions and communicate to the group
- reasonable accommodations for sensory, social, communicative, and other needs, if required
- open and honest discussions
- contributions to be heard, respected, and actioned where appropriate.

2. Term

This Terms of Reference (ToR) is effective from *[date]*, and continues until the completion of the research project on *[date]*, or until termination by agreement between the parties.

3. Membership

Membership of the Advisory Group will be open to autistic adults with an interest in autism research. The Advisory Group will comprise a maximum of *[number]* members at any given time. Each member commits to membership in the Advisory Group for the full term of this ToR. If a member is unable to fulfil their commitment to the Advisory Group for the full term of this ToR for any reason, a replacement member may be recruited at the discretion of remaining Advisory Group members and the research team.

At the commencement of this ToR, the Advisory Group will include as members:

- Member 1
- Member 2
- Member 3
- Member 4
- Member 5

4. Meetings

It is anticipated that *[number]* Advisory Group meetings will be held over the term of the project. Meetings will be held through online video-conferencing using Zoom or a similar platform. Each meeting will run for approximately *[number]* hours. Scheduling of meetings will be determined based on project progression and will be coordinated by the research team.

Advisory group members will receive a minimum of *[number]* weeks' notice of meeting dates/times, with a Doodle Poll (or similar) to be circulated to all members approximately *[number]* weeks prior to proposed meeting dates to determine members' availability. Members will receive a minimum of *[number]* weeks to review relevant documents before each meeting. Relevant documents and meeting agendas will be compiled by the research team and sent to Advisory Group members by email. Meetings will, where possible, be chaired by the Project Leader.

5. Ways of working

The research team is committed to co-producing autism research together with members of the autistic community. The research team and members of the Advisory Group acknowledge that inherent power imbalances exist when academics and community members come together to co-produce research. In recognition of this, preferred ways of working (including methods of communication; discussion formats; decision making processes; degree of involvement in the research project; etc.) will be at the discretion of the Advisory Group and research team, with priority given to the needs and preferences of autistic Advisory Group members.

6. Confidentiality and Intellectual Property

Over the course of the research project, Advisory Group members may become privy to confidential information or intellectual property which is generated as a result of the research. Advisory Group members agree not to disclose any confidential information or the details of any intellectual property shared with them through their participation in the Advisory Group.

7. Remuneration

Advisory Group members will be paid at a rate of \$*[amount]* for each meeting they attend (\$ *[amount]* p/h for a *[number]*-hour meeting plus *[number]* hours' preparation time). Payment will be provided as either (the member's choice of) a bank deposit to the member's nominated account, or gift vouchers from a major retailer.

8. Amendment, Modification, or Variation

This ToR may be amended, modified, or varied in writing with the agreement of Advisory Group members and the research team.

Meeting 1: DD/MM/YYYY

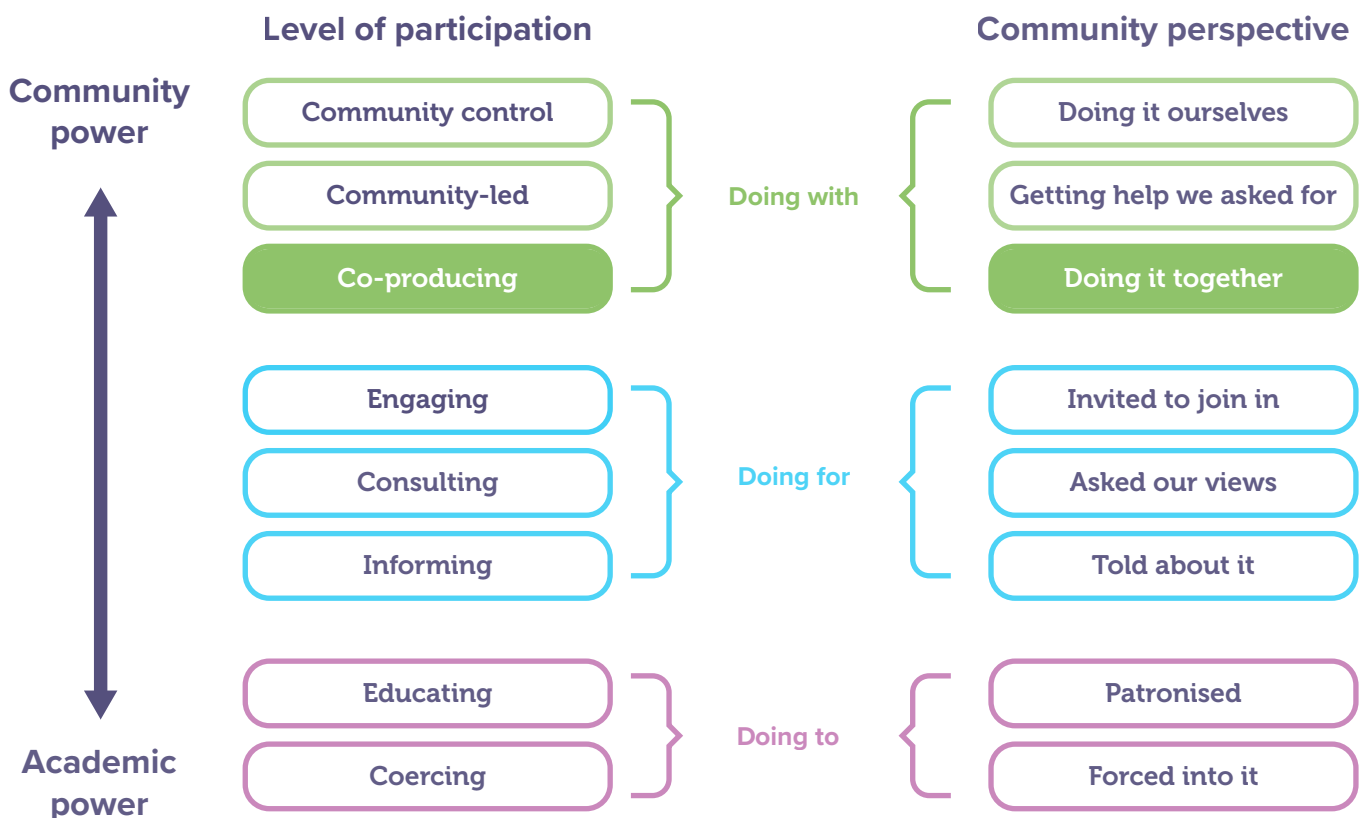
Topic	Issue	Suggested action	Actioned?	Comments
Terms of Reference	Proposed time frames for notification of meeting dates and reading documents too short	Minimum time frame for notification of meeting dates to be extended to 4 – 5 weeks; minimum time frame for reading documents to be 3 weeks.	Yes	
	Some formatting issues noted in ToR document	Rectify formatting issues	Yes	
Interview template	Some questions are very vague	Make questions more specific	Yes	Questions in template are only a guide – they will be adapted to each individual interview including specific detail where appropriate
	Autistic participants may benefit from seeing interview questions ahead of time	Give participants a copy of interview template prior to interview	To be actioned	This will be actioned during the interview process
	Autistic participants may benefit from examples for some questions, e.g. examples of what may constitute “participatory research”	Add examples to appropriate questions	Yes	
	Confusion regarding whether interview and survey responses need to relate to same project	Clarify which project/s responses should relate to	Yes	Survey responses and interview responses do not necessarily need to relate to the same project. This has been added to the interview template.
Information and consent forms	Participants can't indicate whether they want to receive a summary of results	Add an extra consent option where people can indicate interest in receiving results	No	This isn't possible as responses will be anonymous – we won't know who has requested results. Instead, a statement has been added to the end of the survey telling participants they can email the researchers if they want to receive results.
	Stating there are no benefits to participants ignores altruistic benefits	Add sentence regarding benefits to indicate they will be contributing to research.	Yes	
	Confidentiality phrasing – “except as required by law” may be intimidating	Change phrasing if possible	No	After researching this, it appears that this particular phrasing is a standard requirement of research so best not to change it.
	Payment for interview participants	Consensus that autistic participants / participants who are not being paid for their time during the interview should receive payment from this project.	Yes	Selected participants will receive a \$20 gift card for participating in the interview (roughly 1 hour).

Co-producing research with autistic people



Participatory Research Practice Guide 2

This participatory research practice guide provides suggestions for co-producing research with autistic people and other community members.



What is co-production?

In co-production, researchers and community members work together as equal partners from the beginning of the research process. Researchers and community members jointly agree on a research question to answer, and together they design and conduct the research project. Researchers and community members share power and control all throughout the research process. An example of co-production might be a non-autistic researcher and an autistic person who know each other, and are both

interested in understanding the differences between autistic and non-autistic social skills. Together, they come up with an idea for a research project, write a proposal, and get funding for their project. They work together to produce the research, making all the important decisions jointly. Research at this level might be appropriate when the researcher has some previous experience of participatory research, and the community members want to be very involved in the research.

Principles of co-production

All co-produced research projects should follow the important principles explained below (Social Care Institute for Excellence, 2015; Strnadova et al., 2020).

1. Power-sharing

Team members should share responsibility for and ownership of the project. It is important to acknowledge any power imbalances and inequities within the team and take action to manage these. Different people will play different roles in the team and different people might have more or less power at different stages, but key decisions should be made collectively.

2. Diversity

Any team that is co-producing research will include people with different perspectives and skills. All of these perspectives and contributions can be useful and need to be heard. It is important that academic expertise and community expertise are recognised as being equally valuable. Ideally, the team should represent all the relevant academic and community groups and viewpoints on the research topic.

3. Accessibility

Everyone involved in co-producing the research must have an equitable opportunity to contribute to the team. This means addressing any barriers that might discourage or prevent a team member from contributing. Consider, for example, the physical and sensory accessibility of research spaces; the accessibility of project information; and the time frames for project commitments.

4. Reciprocity

Everyone involved in a co-produced research project should gain some type of benefit from taking part. Benefits for all team members might include building relationships, learning from each other, developing skills, and contributing to social good. Academic team members might value outcomes like publications and research grants. Community team members might also value those outcomes, or may find more value in other benefits like receiving payment, opportunities for capacity building, and helping their community.

5. Flexibility

There is no one “right” way to co-produce research, or a strict process that needs to be followed. Different co-produced projects might use very different research processes. When co-producing research, consider which strategies are most appropriate for the specific context you are working in and the community you are working with, and which strategies will meet each individual team member’s needs.

6. Transparency

Everyone in the team should share an understanding of the research goals, context, process, each person’s role, and the expected outcomes of the project. To achieve this, it is important that the team establishes open communication and trusting relationships. Each team member will bring different knowledge, beliefs, and preconceptions to the project. Acknowledging and reflecting on these biases is key to maintaining transparency.

Guidelines for including autistic adults as co-researchers

The Academic Autism Spectrum Partnership in Research and Education (AASPIRE) has developed a set of guidelines that can be used to guide participatory autism research, particularly research co-production (Nicolaidis et al., 2019). These guidelines give practical suggestions for actions that non-autistic researchers and autistic adults can take to help them work effectively as a team throughout the research process. A summary of the guidelines is included here.

1. Be transparent about partnership goals and choose an appropriate approach to match those goals.
2. Clearly define community partner roles, consider who needs to be included on the team, and partner with people who are likely to help the project succeed.
3. Create processes for effective communication and power-sharing.
4. Regularly focus on building and maintaining trust.
5. Collaboratively disseminate findings.
6. Encourage community capacity building..
7. Fairly compensate community partners for their work

(Nicolaidis et al., 2019, p. 4).

Practical strategies for co-production

Different strategies will be useful at different stages of a co-production partnership. There are six stages that will be relevant to most research partnerships (Cornish et al., 2017). In this section, we explain the six stages and suggest some activities and strategies that might be useful during each stage.

1. **Understanding the context.** This stage involves building an understanding of the context that your partnership will exist in, and how the context might impact on the partnership (and vice versa). The team might:
 - ▶ identify the key people and/or organisations who exist in the context and understand how they relate to each other
 - ▶ learn what “research” means to the different stakeholders in the context, what previous experience they have had with research, and what their research priorities are
 - ▶ understand what “good” research looks like for the different stakeholders in the context.
2. **Establishing the partnership.** This stage involves initiating a partnership between academics and community members, and figuring out how the different team members will work together. The team might:
 - ▶ discuss each team member’s motivation for joining the research partnership and what their goals for the partnership are
 - ▶ have a conversation about the knowledge, skills, and experience that each team member brings to the partnership
 - ▶ work together to allocate roles and responsibilities to each team member, making sure that everyone understands and is comfortable with what is expected of them
 - ▶ collectively decide on a process for decision-making that will allow all team members to have a say in important decisions about the research
 - ▶ discuss the power dynamics within the partnership. Which team members have the most power and which have the least? What actions can the team take to address power imbalances?
3. **Sustaining the partnership.** This stage focuses on the ongoing work that team members need to do to make sure that the partnership works effectively over time. This stage will usually occur at the same time as stages 4 and 5, and sometimes also stage 6. The team might:
 - ▶ reflect on the methods of communication that the team uses, and consider whether and how communication could be improved
 - ▶ think about strategies for managing conflict and disagreement within the partnership
 - ▶ revisit the team’s roles and responsibilities, decision-making processes, and power dynamics to make sure that they are still appropriate, and make changes if needed
 - ▶ choose and implement strategies for monitoring and evaluating the partnership
 - ▶ celebrate when the team makes progress in moving forward either the partnership or the research project.

4. **Designing and implementing research.** This stage focuses on how a co-production partnership can approach the various processes involved in a research project. The team might:

- ▶ discuss and reach an agreement on the research question and aims. It is important that all team members understand the research question in the same way, and see the value in the research aims
- ▶ work together to design the research and select methods that can accommodate all stakeholders' priorities
- ▶ decide who will carry out data collection and analysis, and how this will happen
- ▶ agree on who will have ownership of project data, intellectual property, and other resources.

5. **Communicating and ensuring impact.** This stage is about dissemination of research findings. For more information on this topic, see **Inclusive Research Practice Guide 2: Disseminating research findings.**

6. **Beyond the project.** This stage addresses what happens to a co-production partnership when the research project ends. The team might:

- ▶ reflect on how the partnership has changed over time and what the team has achieved
- ▶ decide whether and how to evaluate the partnership (if this was not decided during an earlier stage)
- ▶ collaboratively decide whether to end or continue the partnership
- ▶ if they decide to continue the partnership, seek future opportunities for collaboration.

Reflective questions

During a co-produced research project, it may be helpful to reflect on progress and practices, individually or as a research team. Here are some examples of questions to consider (Davies et al., 2020):

- ▶ Does everyone in the team understand what co-production means and why we think it is useful for this project?
- ▶ Have we got the right people in our team? Are there any relevant groups missing or not represented?
- ▶ Are we making assumptions about who leads our meetings and our work?
- ▶ How do we allocate work? Do team members have the opportunity to take on different roles and responsibilities? Does everyone have the support they need to fulfil their responsibilities?
- ▶ Does everyone have enough information about what happens in between meetings?
- ▶ Is everyone able to contribute to discussions? Who is quiet and who dominates? Can we put strategies in place to help all team members to contribute?
- ▶ Does everyone know when decisions are being made? How are decisions made and who makes them? Does everyone understand what has been decided?

Co-production toolkits

There are many different guides and toolkits that have been developed to help academics and community members through the co-production process. If you are thinking about creating a co-production partnership, you may find it helpful to use one or more of these toolkits to guide you in establishing and maintaining your partnership.

- ▶ Rethinking research partnerships: Discussion guide and toolkit (Cornish et al., 2017)
- ▶ A map of resources for co-producing research in health and social care (Farr et al., 2020)
- ▶ Doing research inclusively: Guidelines for co-producing research with people with disability (Strnadova et al., 2020)
- ▶ Making co-production together guide and inclusion tools (Iriss, 2017)
- ▶ Stronger together: A guide for co-researchers working on co-produced research projects (Kaur & Kerrigan, 2020)

Supporting autistic people to produce community-led research



Participatory Research Practice Guide 3

This participatory research practice guide provides suggestions for supporting autistic people to produce community-led research.



What is community-led research?

In community-led research, the community comes up with an idea for a research project and invites researchers to help them produce the research. The community might need lots of help from researchers all throughout the research process or they might just need help occasionally, with certain tasks. An example of community-led research might be an all-autistic organisation that runs educational workshops for autistic people and wants to find out if their events are beneficial. They ask a researcher for advice on the best way to investigate this. The researcher helps the

organisation to design a study and they work together to get funding and ethical approval for the study. The organisation gathers data and the researcher gives advice on how to analyse the data. The organisation writes and publishes a report on their findings. The organisation makes all the decisions about the research, taking into account the researcher's advice. Research at this level might be appropriate when it is important for the community to have lots of power but the community doesn't have enough research experience to run the project by themselves.

Supporting community-led research

Community-led research is quite rare, so there is not a lot of evidence available to inform academics who want to support community-led research. The ways that an academic can support community-led research will vary depending on how much research experience the community members have, what kind of research the community is conducting, and what resources the community has available.

Ghanbarpour et al. (2018) developed an exploratory framework, comprising nine key elements, to inform community-led research:

1. Centre the people who are most impacted by the issue being studied

Members of the community that is being studied should lead the research project and have control over how the research is carried out. In autism research, community-led research should generally be conducted by autistic people, or autistic-led organisations/groups.

2. Embed language justice principles

The language used when talking about marginalised communities is usually based in the perspective of the dominant culture. For example, research about non-English-speaking communities is often conducted in English. "Language justice" means centring the language that the community uses, instead of the language that the dominant culture uses (Ghanbarpour et al., 2018). This can help to address power imbalances. In research with the autistic community, language justice might mean using identity-first language instead of person-first language, and neurodiversity-informed language instead of deficits-based language (e.g., Bottema-Beutel et al., 2021). It might also include using text-based communication or other alternatives as the primary form of communication, rather than speech.

3. Use trauma-informed research practices

Many marginalised communities have a history of trauma, either at the community level and/or at the individual level. It is important to be aware that the community might still be suffering the consequences of historical or ongoing oppression. In the autistic community, issues like institutionalisation, abuse, and stigma can have traumatising consequences, even for people who have not been subject to those experiences personally. As well as community trauma, individual members of the research team may have their own current or past experiences of trauma that should be considered throughout the research process.

4. Acknowledge and address the community's history with research

Many marginalised communities have had negative and harmful experiences with research and researchers. Community members might feel that they have been stigmatised or exploited by researchers. In autism research, community members describe feeling left out of research, being treated like 'guinea pigs' or 'monkeys in a zoo', and perceive autism research as often failing to address the autistic community's needs (Pellicano et al., 2014). Acknowledging the community's previous experiences of research, particularly any experiences of harm, can be vital in supporting community members to work effectively as a research team.

5. Establish co-created principles and agreements

It may be useful to have an aspirational discussion about research where community members answer questions like, "In an ideal world, what would the research process involve?" and "What should positive and helpful research look like?". Based on this

discussion, the team can co-create principles to serve as a foundation for the project. These principles can guide both the research process and the interactions between community and academic team members. Ghanbarpour et al. (2018, p. 527) includes an example of one community-led research team's principles and agreements.

6. Maintain a high degree of autonomy for community researchers

Community members should have as much control as possible over the research project. This includes defining research question/s, choosing methodologies, recruiting participants, collecting and analysing data, and disseminating results in ways that will be beneficial to the community. It's important that community members also have the autonomy to request any capacity-building support or resources that they need. The influence of organisations or agendas that are external to the community should be minimised, although some externally imposed requirements (e.g., ethical research practices) will still apply.

7. Apply an equity frame

There are inequities in who has access to research knowledge and resources, and which knowledge and resources are considered credible. Academic researchers have academic training, and often other kinds of power and privilege as well, that facilitate their access to research knowledge and resources. Community members often do not have the same level of power, privilege, and access to research. This can result in academics being perceived as 'the experts' and undermine the community-led nature of the project. To address this, academics need to be reflexive and take action to mitigate power imbalances. It may be helpful if academics deliberately take a subordinate role, providing capacity-building, support, and access to knowledge and resources so that community members can perform research tasks themselves, rather than having the academic perform the task. Ongoing communication and reflection among team members is needed to maintain equitable relationships.

8. Scaffold capacity-building on community strengths

The community members conducting the research will bring their own unique knowledge and skills to the project. Any training or assistance for community members should build on these existing strengths. Ideally, capacity-building opportunities should be individualised to utilise and maximise community strengths. Importantly, capacity-building should not only focus on community members learning

Resources for community researchers

There are a number of toolkits and guides that have been designed to support community organisations/groups in conducting community-led research. The resources typically provide step-by-step instructions to guide community members through each stage of the research process, from developing research questions to disseminating findings.

- ▶ An introduction to research justice (Assil et al., 2013)
- ▶ Action research by, in, and for communities: A practical guide to community-led action research (Scottish Community Development Centre, nd)
- ▶ Community action guide on community-led research (International Accountability Project, 2018)

from academics; academics can also gain valuable knowledge and skills by learning from community members.

9. Recognise and value cultural intelligence

Lived experience as a member of a community can give community members a particular type of insider knowledge about the community, called "cultural intelligence" (Ghanbarpour et al., 2018). Cultural intelligence includes features like: knowledge of the community's culture, norms, priorities and history; shared identity with other community members; and social positioning within the community. In research, cultural intelligence can have benefits including a better understanding of which research questions will be meaningful to the community; more effective participant recruitment; trust and rapport with research participants; data analysis that is more consistent with participants' meanings; and more effective dissemination of findings to the community.

Involving autistic people as research participants



Inclusive Research Practice Guide 1



This inclusive research practice guide provides suggestions for involving autistic people as participants in research.

Involving autistic people as research participants

This guide can help researchers to design studies that are accessible for autistic participants. It is important to remember that autistic people are a diverse community. Different autistic people have different support needs, and each autistic person's individual support needs can vary across time and context. The strategies listed here may not be appropriate for all autistic people or all contexts. Where possible, ask each participant about their specific needs and preferences (e.g., using a tool like a Research Passport; see Ashworth et al., 2021) and tailor support accordingly.

Recruitment

To ensure that autistic people are able to participate in research, they need to be able to access recruitment information. To make sure that your recruitment materials are accessible, you could:

- ▶ share recruitment materials using a variety of strategies to reach a range of different people. Consider sharing recruitment information via autism-specific organisations/service providers; autistic-led organisations; and social media.
- ▶ write recruitment materials in plain English. If possible, offer an Easy English option to improve accessibility.
- ▶ mention autistic involvement in recruitment materials. If the research involves autistic people as consultants or co-producers, and people are comfortable being identified, consider stating which research team members are autistic and which members are non-autistic.
- ▶ include clear instructions describing how to participate/express interest in the research. Include an email address, not just a phone number.

Participant information and consent

Once autistic people have found out about a research project that they are interested in participating in, it's important that they understand what they're being asked to do and are able to provide informed consent. To make sure that your Participant Information and Consent forms are accessible, you could:

- ▶ check that participant information and consent documents are clear, concise, and informative.
- ▶ write the documents in plain English, and if possible, offer an Easy English option to improve accessibility.
- ▶ for research with autistic children, consider also offering a child-friendly information sheet and/or social story about the research.
- ▶ give a detailed, step-by-step description of what participants will be asked to do.
- ▶ consider including photos of researchers that participants will meet, locations that participants will visit, and/or materials used in the research activity.
- ▶ give participants a chance to ask questions via email or phone and take the time to give detailed answers.

Planning face-to-face research

Once an autistic person has given consent to participate in a study, it's important that the activities they're asked to complete are accessible and that the participant's needs are met throughout the process. Strategies to help make this happens are outlined below.

- ▶ Consider giving participants a chance to meet the researcher/s and see the research location, by holding a “meet and greet” session before the data collection session/s.
- ▶ Offer participants a copy of the interview questions or other materials ahead of time, to give the participant time to process the information and consider their responses.
- ▶ Offer a range of different modes for participation. For example, interviews can be conducted by email or text-based chat as alternatives to spoken conversation.
- ▶ Schedule the research at a time that suits the participant, and make sure the participant knows how long the research session will take. Keep to the schedule as closely as possible.
- ▶ If possible, consider conducting the research session at the participant's home, or at another location of their choice.
- ▶ If the participant has to visit a new place (e.g., a university campus) to take part in the research, give clear and detailed directions for finding the research venue. Give the participant pictures and/or a map of the location and hang signs nearby. Alternatively, arrange to meet the participant in the car park/ at a public transport stop and walk with them to the research venue. Arrange a parking permit for the participant ahead of time, if needed.
- ▶ Give the participant your phone number and/or email address. Let them know that they can send you a text message or email rather than making a phone call, if they prefer.
- ▶ Send the participant a reminder email or text message the day before the research session.
- ▶ Avoid any last-minute changes or surprises as much as possible.
- ▶ Consider providing visual supports to help the participant keep track of progress throughout the session. For example, you might provide a list of all the tasks to complete during the session, which the participant can tick off as they finish each task. Also consider providing laminated “I need a break”, “Stop/Go”, and “Yes/No” cards to help participants communicate their needs during the session.
- ▶ Offer breaks regularly during the session.
- ▶ After the session, invite the participant to email through any extra comments or feedback that they might have forgotten or had difficulty expressing.
- ▶ If you have offered to send participants feedback/ results or an incentive, such as a gift card, make sure to do this as soon as possible.

Sensory considerations

- ▶ **Lighting** – Choose venues with natural light or soft lighting. Try to avoid fluorescent lights. Encourage participants to wear hats and/or sunglasses if needed.
- ▶ **Visual** – Reduce visual clutter by removing unnecessary decoration from walls and tables. Try to avoid venues that have bright colours or bold patterns on carpets, furniture, and décor.
- ▶ **Sound** – Minimise background noise as much as possible. Prevent unexpected loud noises by turning off hand-dryers in bathrooms, turning down volume on audiovisual equipment, and checking for scheduled testing of fire alarms. Provide disposable ear-plugs or encourage participants to wear their own headphones if needed.
- ▶ **Smell** – Avoid wearing perfume/aftershave, strongly scented deodorant, and other scented products. Do not bring strongly scented food to the venue.
- ▶ **Tactile and proprioception** – Provide a range of sensory/fidget tools or encourage participants to bring their own. Provide a range of different seating options such as stationary chairs, chairs with wheels, beanbags, and exercise balls. Encourage participants to move around the room and/or stim as needed.
- ▶ **Interoception** – Provide water and snacks, and regular bathroom breaks. Give options for regulating temperature, like a variety of indoor and outdoor spaces, or blankets.
- ▶ **Overload** – If possible, provide access to a low-sensory space where participants can take a break if needed.

For more detailed information about creating inclusive spaces for face-to-face research, see the **Autism CRC Guidelines for Creating Autistic Inclusive Environments** (Gatfield et al., 2018).

Planning group research

If the research is being conducted with a group of participants, you may want to consider these additional suggestions outlined below.

- ▶ Offer one-on-one participation as an alternative to the group setting, if possible.
- ▶ Before the session, give participants an idea of what the group session will involve. For example, how many participants will be in the group? What type of activities will they do?
- ▶ Before the session, find out what each participant's communication preferences are, and accommodate these. Alternatively, make sure that the group session is designed to accommodate a range of communication preferences including speech, writing, typing, and so on.
- ▶ Provide a schedule with clear start and finish times, plus time for breaks. Follow the schedule as closely as possible.
- ▶ Provide name tags for everyone in the room (including researcher/s). Also consider using colour communication badges/stickers (Autistic Self Advocacy Network, nd) to indicate communication preferences.
- ▶ At the start of the group session, allow time to have a conversation about the format of the session and establish expectations about participation. Keep expectations flexible to accommodate participants' needs. For example, some participants may be comfortable contributing immediately, while others may not be comfortable contributing until later in the session.
- ▶ Be prepared to support participants by gently directing the group's focus back to the task if they become distracted. If a task involves multiple steps, be prepared to support participants in working through the steps.
- ▶ Give regular updates about progress through the session. For example, "In 15 minutes we'll stop for a break", or "There are two more activities and then the session will be finished".

Disseminating research findings



Inclusive Research Practice Guide 2



This inclusive research practice guide provides suggestions for disseminating research findings to and with autistic people.

What is dissemination?

Dissemination means communicating research findings to the people who are interested and/or need to know (National Institute for Health Research, 2019; Thanki, nd). People who might be interested in the outcomes of autism research include:

- ▶ autistic people
- ▶ parents, friends, family members and other supporters of autistic people
- ▶ service providers who work with autistic people
- ▶ education and health professionals
- ▶ autism researchers
- ▶ government and policy makers
- ▶ funding bodies.

Effective dissemination should make research findings available and accessible to all the above listed groups. Research dissemination is a critical part of the research process, because findings cannot be used or translated into practice if they are not made public (National Institute for Health Research, 2019; Thanki, nd).

Dissemination methods and materials

There are many different formats for disseminating research findings. Different dissemination formats will be appropriate for different research findings, audiences, contexts, and budgets (Carpenter et al., 2005; National Health and Medical Research Council, 2019; Thanki, nd). Some dissemination options include:

Written

- ▶ Journal articles
- ▶ Reports
- ▶ Books/book chapters
- ▶ Executive summaries
- ▶ Policy briefs
- ▶ Newsletters (email or mail)
- ▶ Newspaper articles and press releases
- ▶ Online media articles
- ▶ Websites
- ▶ Blog posts
- ▶ Social media posts

Spoken/audiovisual

- ▶ Conference presentations
- ▶ Public talks/lectures
- ▶ Radio interviews
- ▶ TV interviews
- ▶ YouTube/online videos
- ▶ Films and documentaries

Visual

- ▶ Posters
- ▶ Visual snapshots/summaries
- ▶ Videos
- ▶ Exhibitions
- ▶ PowerPoint slide shows

Other

- ▶ Data files
- ▶ Fiction or non-fiction stories
- ▶ Poetry
- ▶ Artwork
- ▶ Dance
- ▶ Music
- ▶ Theatre

Planning for dissemination

Dissemination works best when it is planned from the outset of a research project. So, it is a good idea to develop a dissemination plan early on. The plan can then be reviewed and updated regularly, as the research progresses. Below are some important elements to consider when creating a dissemination plan (National Health and Medical Research Council, 2019; National Institute for Health Research, 2019; World Health Organisation, 2014).

Objective

Why are you disseminating your research findings? What do you want to achieve through dissemination? For example, do you want to improve understanding, change practice, or influence policy? Keep this objective in mind as you create your dissemination plan.

Audience

Who do you want to share your research findings with? Often, there will be multiple audiences for your work – for example, other academic researchers; community members who were involved in the research; and the broader community. Which aspects of your work might be relevant to each audience? How much do they already know about the topic? Dissemination methods and materials should be tailored to each of the audiences.

Message

What is the one key message that you want people to take away from the research? How can this message be communicated so that it will resonate with the audience/s? Think about what problem/s the research addresses, and what makes your research unique. Focus on the potential impact of your findings.

Partners

Who can you work with to disseminate the findings? Which groups or individuals might want to amplify your message? Consider whether the findings might be relevant to any professional bodies, advocacy groups, service providers or other groups. It can be helpful to work with these partners from early in the research process to make sure that your dissemination materials are relevant, accessible, and useful.

Resources

What resources are available to implement dissemination? What additional resources might be needed and how can these be accessed? Resources might include, for example, funding, personnel, skills and expertise, and formal and informal networks. Identify which resources will be needed for each activity in the dissemination plan, and who will be responsible for implementing each activity.

Methods

How will you disseminate your findings? For example, will they be shared face-to-face, online, or through other media? Will you host workshops, attend conferences, or plan other events? Will you use one method or multiple methods? Think about where and how the audience/s are likely to get information.

Materials

What type/s of content will be disseminated? For example, you might want to share research data files; publish written articles or reports; share videos, images, or other media; speak about findings in a talk; or use a range of other content. Consider which types of content will be most effective for sharing the key message and which types of content the audience is most likely to engage with.

Timing

When will the findings be disseminated? How often will content be shared, and over what timeframe? Consider whether dissemination will be integrated throughout the project (e.g., press releases at different stages to generate interest in the research), or will happen only at the end of the project. Plan to take advantage of existing opportunities, like conferences.

Risks

What could go wrong? Think about the potential risks involved in disseminating the findings. Consider issues like budget and time constraints; intellectual property rights; the cultural and political climate; and how the audience/s might respond to your materials. Develop a “Plan B” to mitigate or manage these risks.

Evaluation

How will you evaluate the success of your dissemination efforts? It is important to know if your materials reached the intended audience/s, and what impact your dissemination had. Think about what your dissemination goals are, and what indicators you might use to measure success. Potential indicators include: the number of citations an academic paper receives; the number of hits on a website; the number of inquiries from media or the community; feedback from community members; or observable changes in policy or practice. It may be useful to embed evaluation measures in your dissemination materials; for example, by including a short feedback survey on the project website.

What makes dissemination effective?

Most effective dissemination strategies have a few features in common (University of Regina Community Research Unit, 2011). These are:

1. They are audience-oriented

Research dissemination is communication, and different people communicate in different ways. Good dissemination considers the audience’s needs, current knowledge level, and language preferences.

2. They focus on goals

Good dissemination should not just report the research findings, it should reflect the broader purpose of the project. Dissemination should help the audience understand why the research was done, what makes the results important, and what actions should happen next.

3. They use methods and materials selectively

There are a whole host of different ways to disseminate research findings. In effective dissemination, only the methods and materials that are most appropriate for a given project are used.

4. They are accessible

Good dissemination makes information available to audiences with diverse needs and who face barriers to access. This includes consideration of access issues relevant to disability, caring responsibilities, cultural and linguistic background, low literacy, level of education, and financial hardship, among others.

5. They use resources wisely

Good dissemination uses a combination of formal and informal resources to communicate research findings as widely as possible. Formal resources might include journal articles, academic conferences, or official media and communications networks. Informal resources might include personal networks, or social media.

6. They allow for two-way communication

Dissemination is more effective when it is based on relationships and dialogue, rather than a one-way flow of information.

7. They are clear and focused

Good dissemination materials are concise and to the point; highlight key findings and recommendations; look nice and are easy to read; and include images, figures, or bullet points as well as text.

Accessibility

Dissemination materials designed for the autistic community and broader lay community need to be accessible (National Health and Medical Research Council, 2019; University of Regina Community Research Unit, 2011). It is important to consider the audience's range of different abilities and circumstances. This means that dissemination materials should:

- ▶ be available for free or low cost
- ▶ be written in plain English and/or Easy English, and also in other languages if possible
- ▶ include child-friendly materials if the research is relevant to children
- ▶ be available in different levels of detail, such as a one-page overview, a summary report, and a full report
- ▶ be presented in a range of formats; for example, a written report and a video, online and in hard copy
- ▶ include closed captions, transcripts, and/or alt text for all videos and images
- ▶ show respect for autistic people (e.g., by avoiding deficit-based language)
- ▶ be actively disseminated to the autistic community. Autistic-led advocacy and community groups, service providers, and social media can help to share the dissemination materials with the intended audience.

Working with autistic co-producers or consultants when designing dissemination materials can help to make sure that the materials are accessible.

Reporting on community engagement

Dissemination materials should include a description of whether and how community members were involved in the research process. These are important details that are often left out of dissemination materials. To try and address this, some academic journals including The BMJ and Autism now require authors to include a 'patient and public involvement' or 'community involvement' statement in manuscripts.

The GRIPP2 reporting checklists (Staniszewska et al., 2017) are useful tools that explain how to write about community engagement in journal articles and other dissemination materials. At a minimum, try to describe the following:

1. **Aim** – What was the aim of community engagement in this study? What were we hoping to achieve through community engagement?
2. **Methods** – How did we engage with community members in the research?

3. **Results** – What were the specific outcomes of community engagement? Include any positive or negative impacts.
4. **Discussion** – How did community engagement influence the research project overall?
5. **Reflections** – Reflect critically on the process of community engagement. Discuss what went well and what didn't, so that others can learn from the experience.

If community members were not engaged in the research, it is still useful to say this in dissemination materials. This can just mean including a sentence like "community members were not engaged in this research project". Doing this helps people and organisations keep track of how often community engagement is happening, and what kind of impact community engagement might be having on research.

Resources for dissemination

Dissemination planning – Template 1

Date	
Research Partners	
Dissemination objective/s	
Target audience/s	
Key message	
Potential dissemination partners	
Resources and funding available	
Resources and funding needed	
Dissemination method/s and materials	
Timeline	
Potential risks	
Risk management strategies	
Dissemination goals and success indicators	

Dissemination planning – Template 2

Method/ material	Target audience/s	Resources and funding	Deadline/s	Potential risks and management strategies	Dissemination goals and success indicators	People responsible

Evaluating research process and impact



Inclusive Research Practice Guide 3



This inclusive research practice guide provides suggestions for evaluating autism research process and impact.

What does evaluating research mean?

Evaluating research means assessing whether the research project ran how it was supposed to and/or whether it achieved the intended goals. Evaluation can take many different forms and should be tailored for each research project, taking into account factors like the aims of the research, the aims of the evaluation, and the resources available. It is best to start planning for evaluation early in the research process. Evaluation often focuses on assessing the

positive outcomes of research, but it is important to also identify any negative impacts or harm that the research may have caused.

When planning evaluation, decisions need to be made about **what, when, why, and how** to evaluate the research. Each of these decisions is explained in this guide.

What to evaluate

There are two main elements of research that can be the focus of evaluation.

Output, outcome and impact evaluation involves evaluating the end result of the research – what did the research produce, and how did it benefit society? *Outputs* refer to the products and publications that result from the research project. *Outcomes* refer to the short- and medium- term effects of the research. *Impacts* refer to the long-term, direct or indirect effects of the research (Guthrie et al., 2013; Organisation for Economic Co-operation and Development, 2010). For example, in a research project aiming to improve mental health outcomes for autistic adults, *outputs* might be an autism-specific mindfulness treatment program, and a publication about pilot testing of the program. An *outcome* might be that 70% of autistic adults who participate in the program have improved mental health after six months. *Impacts* might include a reduction in the number of autistic people admitted to inpatient psychiatric care over the following two years, and increased government funding for autism-specific mindfulness-based mental health support. Evaluation of outputs, outcomes, and impact is often referred to collectively as *impact evaluation*.

Process evaluation involves evaluating the research process itself – did the research project run how it was supposed to? Process evaluation examines issues like how different resources were used, the roles that different team members played, and how contextual factors influenced the research project. Process evaluation can give insight into how and why a research project achieved (or didn't achieve) particular outcomes and impacts. Process evaluation typically uses methods including interviews and/or focus groups with the research team and/or participants; observation of the research process; and analysis of research notes, researcher diaries, and/or meeting minutes (Limbani et al., 2019). Process evaluation can be particularly important in participatory research, as it can give insight into the extent and effectiveness of community engagement throughout the research process (Butterfoss, 2006). This is discussed in more detail in the section **Evaluating community engagement** on page 45.

When to evaluate

Research evaluation can be classified as either formative or summative. **Formative evaluation** is typically conducted during the research process. The goal of formative evaluation is to monitor progress, learn from experience, and adapt going forward. Formative evaluation usually uses flexible methods that can be tailored to suit each individual research project. Formative evaluation is useful when a research team wants to know what they are doing well, what they could do better, and what changes they could make to improve their performance.

Summative evaluation is typically conducted towards

the end of the research process or after a project has concluded. The goal of summative evaluation is to assess the overall performance and success of the research project. Summative evaluation usually follows a fixed process and gathers data on a specific set of indicators, which can be used to compare different research projects/teams against benchmarks. Summative evaluation is useful when a research team needs to demonstrate the merit and value of their work (Guthrie et al., 2013; Reed et al., 2021).

Why evaluate

There are four main purposes for conducting a research evaluation (Guthrie et al., 2013; Rogers et al., 2015). Any research evaluation will usually be carried out for one or more of these reasons:

1. **Advocacy:** to demonstrate the benefits of research, to improve public understanding of research, and/or to advocate for changes to policy and practice.
2. **Accountability:** to hold researchers accountable for the quality of their work and the use of the project's resources, particularly funding.
3. **Analysis:** to understand the factors that produce effective research and help to improve future research.
4. **Allocation:** to decide where to invest research funding in the future.

How to evaluate

There are five main methods that are commonly used to evaluate research (Reed et al., 2021).

1. **Experimental and statistical methods.** These types of evaluation usually compare an experimental group with a control group using a process like a Randomised Controlled Trial, and using statistical methods to analyse results. These methods are useful for establishing causal relationships – i.e., showing that research caused a particular outcome (Rogers et al., 2015). For example, in a research program aiming to develop a new medication, a Randomised Controlled Trial might be a good method for evaluating the effectiveness of the new medication.
2. **Systems analysis methods.** These are usually used to explore complex cause-and-effect relationships in situations where multiple factors might influence research impact, or when a research project was one of multiple factors that led to a particular impact. For example, systems analysis might be used to evaluate whether and how research findings interact with policy changes to produce particular social impacts. Systems analysis is usually conducted using a range of quantitative and qualitative methods.
3. **Text, oral and arts-based methods.** These types of evaluation are useful for explaining and contextualising impact, and can give in-depth insights into how and why a research project was or was not effective. These evaluations typically use qualitative methods like interviews, focus groups, observation, opinion polls, testimonials, photovoice, drawing, music, storytelling, etc. For a comprehensive evaluation, text, oral, and arts-based methods can be combined with quantitative evaluation methods.
4. **Indicator-based approaches.** These types of evaluation identify and measure specific variables that indicate that impacts have been achieved. A wide range of methods can be used to measure the indicator variables, depending on the specific variables selected. Some of the most well-established evaluation frameworks, including the Payback Framework (Donovan & Hanney, 2011) and Social Impact Assessment Methods through Productive Interactions (SIAMPI, Spaapen et al., 2011) are indicator-based approaches to evaluation.
5. **Evidence synthesis approaches.** These are usually used when multiple research projects have investigated the same research question, particularly if there is contradictory evidence arising from different studies. Evidence synthesis approaches to evaluation include systematic reviews, meta-analyses, and various other review methods.

Evaluating community engagement

In participatory research, it is important to not only evaluate the process and impact of the research project, but also to evaluate the process and impact of community engagement within the project. Evaluating community engagement allows us to:

- ▶ understand the extent and quality of community engagement
- ▶ identify things that we could improve or do differently in the engagement process (Popay & Collins, 2014)
- ▶ assess whether community engagement made a difference to the project processes or impacts, and if so, what difference it made (Deverka et al., 2012; Wilson et al., 2015)
- ▶ understand the processes by which community engagement made a difference to the research – what is it about community engagement that made the research better or worse? (Schulz et al., 2003; Smajgl & Ward, 2015)
- ▶ justify the additional costs and time associated with community engagement (Popay & Collins, 2014; Stocks et al., 2015)
- ▶ show community members that they have influenced the research (Popay & Collins, 2014)
- ▶ contribute to the evidence base on participatory autism research.

Evaluating community engagement in research can be complicated. Autism research is conducted across many different fields, in many different contexts, and involves a range of different people. Different research projects might engage community members for different reasons, in different roles, or using different methods. This diversity means that there is no ‘one size fits all’ framework for evaluating community engagement. Instead, like evaluations of research process and impact, we need to tailor a specific evaluation of community engagement for each research project. *The Public Involvement Impact Assessment Framework* (PiiAF, Popay & Collins, 2014) provides a guide for conducting a tailored evaluation of community engagement.

Evaluation of community engagement can be carried out in a similar way to evaluation of research process and impact, involving the decisions and methods described above. In evaluating community

engagement, it is important to evaluate the process of engagement, not just the impact. In participatory research, **how the team worked together** to produce the research is just as important as what the team produced (Schulz et al., 2003; see Wilson et al., 2015 for an example). It is essential to **include community members in evaluating community engagement**, because research shows that academic and community members tend to have different perceptions of participatory research. In autism research, for example, academics perceive that the community is frequently engaged in research, whereas autistic people and other stakeholders report that community members are rarely or occasionally involved (Pellicano et al., 2014).

Some questions to consider in evaluating the **process** of community engagement might include:

- ▶ When were community members engaged (at which stages of the research process)?
- ▶ Which level/s did community members engage at?
- ▶ What role/s did community members play?
- ▶ What were the relationships between community and academic team members like?
- ▶ Did team members trust and value each other as equal partners?
- ▶ Did community members have power and control during the research process?

Some questions to consider in evaluating the **impact** of community engagement might include:

- ▶ Did community engagement change or inform the research question?
- ▶ Did community engagement influence the research methodology or methods?
- ▶ Were more, fewer, or different participants recruited compared to a typical research project?
- ▶ Was data collection conducted differently due to community members’ input?
- ▶ Did community engagement lead to different results?
- ▶ Did community members help with interpreting findings in different ways?
- ▶ Did community members disseminate findings to a different or broader audience?

Resources for evaluation

Evaluation decisions

What will you evaluate?			
<input type="checkbox"/> Process	<input type="checkbox"/> Outputs, outcomes, and impact	<input type="checkbox"/> Both	
When will you evaluate?			
<input type="checkbox"/> Formative	<input type="checkbox"/> Summative	<input type="checkbox"/> Both	
Why will you evaluate? (select all that apply)			
<input type="checkbox"/> Advocacy	<input type="checkbox"/> Accountability	<input type="checkbox"/> Analysis	<input type="checkbox"/> Allocation
How will you evaluate? (select all that apply)			
<input type="checkbox"/> Experimental or statistical methods	<input type="checkbox"/> Systems analysis methods		
<input type="checkbox"/> Textual, oral, and arts-based methods	<input type="checkbox"/> Indicator-based approaches		

Resources for evaluating community engagement

Community Engagement in Research Index (adapted from Khodyakov et al., 2013)

How much were you involved in each of the following stages of the research process?	Not at all (1)	A little bit (2)	Somewhat (3)	Moderately (4)	Very (5)	N/A – the project didn't include this
Developing community-based theories of the research						
Grant proposal writing						
Background research						
Choosing research methods						
Developing sampling procedures						
Designing or modifying interview/survey questions						
Recruiting study participants						
Implementing the intervention						
Collecting primary data						
Analysing data						
Interpreting study findings						
Writing reports and journal articles						
Giving presentations at meetings and conferences						

Example questions for a semi-structured evaluation interview

1. Tell me about your role in the project team.

Probe questions:

- a) *What other experience (if any) do you have in autism research?*
- b) *What other experience do you have with autism professionally / personally?*

2. Tell me about your experience of the project overall.

Probe questions:

- a) *What do you think the team/project did well?*
- b) *What do you think the team/project could have improved on?*

3. Tell me about how the different members of the project team worked together.

Probe questions:

- a) *Did different people have different roles and responsibilities within the team? What did this look like?*
- b) *What methods did you use to communicate and make decisions?*
- c) *Was there any conflict or disagreement amongst the team during the research process? If so, how did you manage this?*
- d) *Do you think that the team's neurodiversity affected the way you worked together? If so, how?*

4. What have been the outcomes of the project to date, academically and personally?

Probe questions:

- a) *Do you think that having autistic people involved in the project had an impact on the outcomes of the project? In what ways?*
- b) *What were the challenges of having a neurodiverse team working on this project?*
- c) *What were the benefits of having a neurodiverse team working on this project?*
- d) *What steps could we take in the future to improve the ways that we work with autistic people to produce research?*

Quality Involvement Questionnaire (Morrow et al., 2010)

Part 1: Personal factors					
Your ability <i>To what extent do you feel you are able to:</i>	Not at all 0	Low 1	→ 2	→ 3	High 4
Access research resources (e.g., money, facilities, information)					
Achieve your own goals through the research					
Make a contribution to the research					
Make decisions about how to do the research					
Express your views about research topics					
Discuss research issues					
Take on new research challenges					
Your potential <i>To what extent do you feel there is potential for you to...</i>	Not at all 0	Low 1	→ 2	→ 3	High 4
Choose the type of role you play in the research					
Bring your own ideas and values to the research					
Work in ways that suit you					
Gain status, expertise, or credibility because of your involvement					
Identify and organise your research ideas and priorities					
Your sense of being <i>To what extent do you feel...</i>	Not at all 0	Low 1	→ 2	→ 3	High 4
Valued as a partner (not controlled)					
Enabled (rather than constrained)					
Empowered (rather than exploited)					
Consenting (happy to be involved), not coerced (unhappy about it)					
It is acceptable that different people have different responsibilities and decisions to make about the research					

Part 2: Research contexts

Research relationships <i>Thinking about research relationships, to what extent do you think...</i>	Not at all 0	Low 1	→ 2	→ 3	High 4
The researchers have the right reasons for wanting to work with you					
There is sufficient funding to make involvement work					
You have enough information about involvement					
The way the researchers work with you is supportive					
The way the researchers communicate with you is supportive					
The types of goals that the researchers want are what you want					
Ways of doing research <i>Thinking about the research itself, to what extent do you think...</i>	Not at all 0	Low 1	→ 2	→ 3	High 4
There is a clear role in the research for you					
The skills/experience needed for the role are clear to you					
The responsibilities for the role are clear to you					
You are aware of the legal and ethical “rules” for doing research (e.g., confidentiality)					
Research structures <i>Thinking about the research organisation, to what extent do you think your involvement is...</i>	Not at all 0	Low 1	→ 2	→ 3	High 4
Not just part of a project, it is valued as part of the work of the organisation					
Supported by research ethics and governance systems					
Helped because of research structures (networks, links with other studies etc.)					
Noticed and recorded as part of the work of the research organisation					

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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



Evidence

Guided by evidence-based research and peer review



Independence

Maintaining autonomy and integrity



Cooperation

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



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