



# Inclusive Research Practice Guides and Checklists for Autism Research

Version 2

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Copies of these Guides and Checklists can be downloaded from the Autism CRC website [autismcrc.com.au](http://autismcrc.com.au)

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## Foreword

I am very proud to present the second version of the Inclusive Research Practice Guides developed for autism.

At Autism CRC, our aim is to transform lives through innovative and collaborative end-user driven research. To do this effectively, people on the autism spectrum need to be at the centre of everything we do. We understand, recognise and value that in terms of the lived experience, they are the true experts in the field.

Our researchers are committed to engaging individuals on the spectrum and their families throughout the research process from the development of our research agenda, through stages of planning, implementation, reflection, dissemination and provision of feedback.

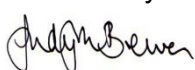
These Inclusive Research Practice Guides and accompanying Checklists are a practical resource for our researchers, and others around the world, to engage meaningfully with people on the spectrum. This is potentially 'game changing' in the field of autism and will not only assist research efforts to focus on the genuine needs of the autism community but ensure our research outcomes translate into practical and tangible benefits.

We are excited about the possibilities associated with the co-production of research. By producing these guides, we aspire to build further research capacity within the autism community and also to enhance the skills of our CRC researchers to partner with people on the spectrum and their families to co-produce research. This second version provides further guidance for researchers in working with people on the spectrum in the dissemination, evaluation and utilisation of findings.

It is important to note that this is not the end of this important task, but rather the beginning. For us, it is not about ticking a box but genuinely changing the way we do things, to truly value each other's skills and experiences, and to respect diversity. We look forward to continuing to improve the way we work with the autism community, and to updating these guides as our own programs develop.

These practices and guidelines could not have been developed without significant input from adults on the autism spectrum, along with other key people and leaders in autism research. I'd like to acknowledge and thank the following people and organisations for their invaluable assistance.

- Members of Autistic Self Advocacy Network of Australia and New Zealand ([www.asan-au.org](http://www.asan-au.org))
- Katharine Annear
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- Debra Costley, Aspect
- Marita Falkmer, Curtin University
- Sylvia Rodger AM



Judy Brewer AO  
Autism CRC Chair

## Autism CRC Statement

### Inclusive Research Practices with People on the Autism Spectrum and their Families

The Cooperative Research Centre for Living with Autism (Autism CRC) aims to transform the lives of people on the autism spectrum across the lifespan through innovative research focusing on the early years and diagnosis, the school years through enhancing teaching and learning, and helping adults find a place in society. People on the spectrum and their families are the ultimate end-users of CRC research outputs/findings and hence their voices/perspectives and involvement are critical to each stage of our work.

Our researchers are committed to engaging people on the spectrum and their families throughout the research process from the development of research ideas and priorities, through stages of planning, implementation, reflection, dissemination and provision of feedback.

There are many ways in which Autism CRC collaborates with people on the spectrum and their families.

- First, people on the spectrum and their families have the opportunity to be participants in research projects conducted across the lifespan.
- Second, they may offer their expertise as members of advisory groups to research projects and invited members of formal CRC committees.
- Third, people on the spectrum and their families can take an active interest in the outcomes of CRC research by signing up for our newsletters, attending interactive webinars or downloading videos and reports from the website.

Importantly, they may engage with researchers throughout the research process as co-producers of research. This refers to assisting with framing questions, providing input on research design, helping with research tasks such as providing input on survey readability/wording and accessibility, entering data, analysing data, providing input on interpretation of findings, co-writing and authoring papers and reports, and co-presenting research findings at meetings and conferences. Autism CRC has graduated inaugural members of the Research Academy- a group of researchers and people on the spectrum trained in co-production- and continues to look for new ways to further support and research co-production.

These activities recognise that people on the spectrum and their families have significant expertise to share with CRC researchers. In particular, they have a unique and valuable perspective gained through their lived experience. Through partnership with researchers we can share our respective expertise to conduct research which will transform lives. The following principles indicate how we will demonstrate our commitment to inclusive research.

## Inclusive Research Practices

- 1. We will use processes that ensure that people on the autism spectrum and their families are informed and willing participants who are respected and supported during all stages of the research process.**

For example, participant information sheets/consent forms might be adapted to include visual supports and mechanisms. Regular email newsletters might also be utilised to maintain contact with participants in our longitudinal studies.

- 2. Our research will be informed by people on the autism spectrum and their families.**

For example, the Autism CRC research programs were informed by an initial open forum with end-users including families and organisations representing people on the spectrum and their families, whose input led to the development of our research direction and deliverables. The CRC Board includes Directors who are on the spectrum and are parents of individuals on the spectrum, and people on the spectrum and their families have opportunities to participate in relevant CRC committees and decision-making bodies.

- 3. We aim to produce research that is meaningful to people on the autism spectrum and their families and can be quickly translated into practice and also to develop tools and resources that people on the spectrum can easily access and utilise.**

For example, our website ([www.autismcrc.com.au](http://www.autismcrc.com.au)) will provide free access to tools and resources in a user-friendly, downloadable format.

- 4. We will ensure that people on the autism spectrum and their families play a central role as both research participants and where appropriate co-researchers, and that their input is respected and their voices validated throughout the research process.**

For example, we will seek input from people on the spectrum and their families through research project advisory groups, and offer opportunities to provide input to survey design, wording and avenues for distribution. Where possible, we will seek to employ people with on the spectrum who are able to undertake specific tasks such as data entry and analysis.

- 5. Where people on the autism spectrum and their families have been co-producers of research we will provide opportunities for them to co-present research findings.**

For example, an adult on the spectrum might attend a conference with a CRC researcher and partner with a researcher to present project findings.

**6. We will make adjustments to research tools, reports and processes to ensure they are appropriate for people on the autism spectrum and their families, and reflect the diversity of individuals on the spectrum.**

For example, visual schedules and communication supports might be used during a research interview and alternative formats and autism friendly environments will be provided to obtain the perspectives of individuals on the spectrum and to make research participation easier.

**7. We will ensure that our research has real life and real world benefits for people on the autism spectrum and their families and will contribute to greater inclusion of people on the spectrum in the community.**

For example, research projects in schools will develop modules for teachers to help them to better accommodate students on the spectrum in their classes and help schools to develop more inclusive school communities that celebrate diversity.

**8. We will use the most appropriate research designs to effectively answer the research questions we ask and to ensure that the voices of people on the autism spectrum and their families are captured and respected.**

For example, we encourage, where appropriate, the use of inclusive research designs such as participatory action research and methods that incorporate a range of end-user perspectives and allow for input from diverse stakeholders.

**9. We will ensure our research acknowledges the strengths of individuals on the autism spectrum, as well as explores areas that need additional support.**

For example, a recognition of strengths is important particularly in education and employment projects.

**10. We will ensure that the input provided by people on the autism spectrum into research projects is acknowledged and valued, and that they are recompensed for their contribution to research projects.**

For example, travel and parking will be reimbursed and where appropriate payment of an honorarium may be planned for in a project research budget where there is a substantial and ongoing contribution on a regular basis.

Through these inclusive research practices, we acknowledge that effective research cannot occur without the input of the people who have the lived experience of autism. We aspire to build research capacity within the autistic community and to also enhance the skills of our CRC researchers to better partner with people with autism and their families as research participants and co-producers of research.

Adapted from <http://www.cds.med.usyd.edu.au/disability-inclusive-research-principles> (accessed 7 July 2014).



## Engaging Individuals on the Autism Spectrum and their Families in Research within the Autism CRC

### Why is this Important?

There is evidence from other areas of practice such as cancer care that where consumers are involved in the design of research and data collection tools such as questionnaires – the tools are better received by the participants. There is also evidence that involving consumers is helpful in improving the dissemination of research findings within the community. This a relatively new endeavour within research with individuals on the autism spectrum, however we believe that this will also be true.

Within the Autism CRC involving end-users (namely individuals on the spectrum, their families and service providers) in identifying research questions and priorities places the needs of individuals on the spectrum at the centre of our research. Involving individuals on the spectrum and their families in research:

- ensures that issues important to the autistic community are identified and prioritised
- supports the dissemination of research findings
- helps to translate research findings into real world practice where they are utilised
- ensures that resources focus on research that has benefit for and impact within the autistic community.

### How Might Individuals on the Spectrum and their Families be Engaged?

There are many ways to engage individuals in research endeavours:

- commenting on research priorities
- participating in advisory groups to research projects
- reviewing draft questionnaires
- co-facilitating focus groups
- co-designing research methodologies
- participating in pilot stages
- co-presenting findings
- assisting with dissemination of research findings.

### What is Required?

#### ***A Culture of Inclusion***

- Researchers embrace diversity, are accepting of difference and believe in and value the input of individuals on the spectrum and their families.
- Inclusive practices are embedded within the research organisation and its researchers.

#### ***Structures that Support Inclusive Research Practices***

- Adequate resources are provided to cover the cost of involving end-users in research processes in project budgets.

- Inclusive practices are supported by a communication strategy.
- Language used is accessible and understandable to everyone involved – namely avoid jargon. While it is often difficult to gain consensus on terminology, discuss with your end-users how they wish to be referred to. Consistent with discussions with end-users, we use the term ‘on the autism spectrum’ or ‘on the spectrum’.

### ***Practices that Support Inclusive Research***

- individuals on the spectrum are supported on research team and upskilled
- peer support workers/mentors are provided
- expectations and responsibilities are clear
- capacity within the research team is built with regard to inclusive practices
- policies for co-production in commissioning of research are developed.

### ***Review***

- monitoring and assessment of outcomes and impacts is undertaken
- achievements are celebrated
- review findings are used to ensure continuous learning.

## **What Resources can Assist Me?**

Autism CRC has developed a Statement on Inclusive Research Practices and a number of Practice Guides for Inclusive Research as well as Checklists to assist researchers to implement more inclusive research practices.

If you have any questions about these resources please contact Professor Sylvia Rodger (Director of Research and Education) [srodger@autismcrc.com.au](mailto:srodger@autismcrc.com.au).

## **Websites**

<http://consumerinvolvement.canceraustralia.gov.au>

<http://www.scie.org.uk/publications/guides/guide51/files/guide51.pdf>

<http://www.cds.med.usyd.edu.au/disability-inclusive-research-principles>

Jung, T., Harrow, J., & Pharoah, C. (2012). Co-producing research: Working together or falling apart? Centre for Charitable Giving and Philanthropy Briefing Note 8.

(<http://www.cgap.org.uk/uploads/Briefing%20Papers/CGAP%20Briefing%20Note%208%20-%20Co-producing%20research.pdf>)

Pellicano, L., Dinsmore, A., & Charman, T. (2013). A future made together: Shaping autism research in the UK. London: Institute of Education. [http://newsletters.ioe.ac.uk/A\\_Future\\_Made\\_Together\\_2013.pdf](http://newsletters.ioe.ac.uk/A_Future_Made_Together_2013.pdf)

Social Care Institute for Excellence (2013). Co-production in social care: What it is and how to do it. Adults' Services: SCIE guide 51. London: Social Care Institute for Excellence.

<http://www.scie.org.uk/publications/guides/guide51/files/guide51.pdf>

## Inclusive Research Practice Process for Autism Research



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## Inclusive Research Practice Guide 1: Engaging Individuals on the Autism Spectrum as Research Participants

*We will use processes that ensure that individuals on the autism spectrum and their families are informed and willing participants who are respected and supported during all stages of the research process.*

*We will ensure that individuals on the spectrum and their families play a central role as both research participants and where appropriate as co-researchers, and that their input is respected and their voices validated throughout the research process.*

*We will make adjustments to research tools, reports and processes to ensure they are appropriate for individuals on the spectrum and their families, and reflect the diversity of individuals on the spectrum.*

Consistent with the Autism CRC Statement on Inclusive Research Practices (Practices 1, 4 and 6), this Inclusive Research Practice Guide aims to provide researchers with suggestions regarding how to engage individuals on the spectrum as research participants, taking into account their strengths as well as areas in which they may require more support. It is important to note that individuals on the spectrum are an extremely heterogeneous group, hence there will be different requirements depending on whether research participants are children, adolescents or adults; and depending on their level of cognitive ability and communication skills, and familiarity with yourself/your team and research processes.

### Recruiting Individuals for Research

To ensure your recruitment is inclusive of all individuals (within your sampling frame), consider using multiple channels of communication to disseminate information about recruitment to studies (e.g., Autism Associations, ASAN, adult networks, local radio, social media). Contact Autism CRC's Communications Manager for assistance where needed.

### Study Information and Consent Practices

- ☑ Ensure information in participant information sheets/consent forms is clear, concise and informative and use visual supports where possible.
- ☑ Provide the opportunity for individuals on the spectrum to ask questions about their involvement. Actively listen and ensure the participant understands what is required. This may take time but is critical to informed consent. Ask clarifying questions to ensure that the participant is not providing a socially desirable response or indicating understanding when this is not the case.
- ☑ Use simple non-ambiguous language.
- ☑ Ensure plenty of white space on the page – better to have more pages than overcrowd one page.
- ☑ Be clear about what will be required and ensure that you stick to the steps that you outlined in the information sheet.
- ☑ Consider including visual supports (clip art, photographs, pictures) to illustrate key points.
- ☑ Consider including pictures of the researchers they are likely to meet, places they will need to visit and the research activity.

## Scheduling Research Appointments

- ☑ Consider allowing a meet and greet appointment prior to the official interview/assessment session to familiarise the individual with the researcher/s and the environment.
- ☑ Consider the individual's or family's schedules to avoid peak traffic and busy times at hospitals/universities (e.g., class change over periods) when lifts and corridors/campus is crowded with a lot of movement of individuals.
- ☑ Depending on age of the individual, consider rest and meal times when making appointments. Often early in the day is better than later in the day. Older children and adults may have particular routines around meal times that cannot easily be interfered with (e.g., lunch is always at 12.30 pm and the person may become very anxious if an appointment goes late or looks like it will encroach on this time).
- ☑ Use pictures of the building, entry door or other key landmarks to help them navigate to the lab/office/clinic especially if the study requires attendance at a hospital or university.
- ☑ Make sure there are signs at entry points of buildings, lifts, in corridors (e.g., CRC logo) so that individuals can find you easily.
- ☑ Provide parking voucher and maps showing where to enter, park and mark the way to the research site.
- ☑ Provide your mobile number and ensure the person knows they can text you rather than having to call and speak to you if they need anything.
- ☑ Text the person on the day of the appointment to remind them.
- ☑ Ensure the individual or family is dealing with a consistent person with whom they become familiar and that they are provided with consistent information by members of the research team.

## Providing Autism Friendly Environments for Research

### Structuring the Physical Environment

Ensuring that environments are clear from clutter and organised with everything in its place can support individuals on the spectrum. This can also decrease anxiety levels by creating predictability. Individuals on the spectrum may also have difficulty processing sensory information. By understanding their sensory needs and making small changes to the physical environment, sensory sensitivities can be addressed to increase engagement and participation.

Whether you are interviewing, observing or engaging an individual on the spectrum in assessment tasks, there are some important considerations in making the environment autism friendly.

### Distractions

- Ensure the environment is quiet and there is minimal background noise (even the sound of a ticking clock on the wall can be distracting for some individuals).
- Consider the temperature of the environment and check that with the person.
- Avoid rooms with ceiling fans in summer as these can be very distracting for some individuals on the spectrum.
- Avoid venetian blinds that go down to the floor as these can be distracting for young children.

## Lighting

- Avoid too many pictures/posters on walls and too much visual clutter. Just have the necessary objects that you need for the research activities in the room.
- Individuals on the spectrum benefit from working in an environment which has clearly defined areas and boundaries for specific tasks. Children often perform better when facing a wall or in a cubicle/carrel.
- Ensure correct size and style of furniture (chairs, tables, desk etc.) for the individual's age and dimensions (e.g., child's feet on the floor at low table and chair).

Some individuals on the spectrum are hypersensitive to bright lights or fluorescent lights. This may adversely affect their concentration, interaction and behaviour.

- Use as much natural light as possible or alternatively try to use lower levels of light.
- Consider the type of lighting – fluorescent lights can be too bright. Ensure there are no flickering lights/bulbs.
- It is often not the lights themselves but the reflection of light on a wall or other surface that may be bothersome.
- Check to see if dimming lights or turning off down lights is better for the person on the spectrum. If there is no scope for change, sunglasses or tinted glasses may be worn inside depending on the severity of the sensitivity.
- Wearing a cap indoors can assist an individual who is sensitive to bright lights if they cannot be turned off.

## Sound

Individuals on the spectrum can often be highly sensitive to and distracted by sounds that their peers may not even notice such as a train far away or the high pitch of a researcher's voice. They can also become distressed at the sound of loud unexpected noises.

- Reduce environmental noise where possible by choosing carpeted rooms to reduce echoing as well as the scraping of chairs on the floor.
- Where possible, warn the individual about sudden noises such as when a fire drill siren may be about to ring.
- Encourage the individual to let you know when a particular noise is distracting or painful.

## Temperature

Individuals on the spectrum may react differently to temperatures. They may also have tactile sensitivities that may make it uncomfortable to wear particular clothes etc.

- As it is not always possible to adjust room temperatures, encourage individuals to have layers of clothes so as to make themselves comfortable throughout a session.
- Try and circulate air as much as possible.



## Smells

Smells that may not be detected by others may cause discomfort to individuals who are hypersensitive in this area.

- Avoid wearing strong perfumes, aftershaves and heavily scented deodorants.
- Some individuals may be sensitive to food smells from nearby kitchens or canteens. Consider this when choosing venues.

## Family and Spectrum Friendly Amenities

- Ensure there is waiting room space for families and siblings, if you are working with children, and that these are safe and provide toys/books for siblings to play with.
- Easy access to family friendly bathrooms – large enough for parents and prams, with access to change tables is important.
- Consider the bathroom environment – paper towels are better than noisy hand dryers.
- If you have a long interview/set of tasks to undertake – consider splitting it into two sessions or providing a break time and area for the person to relax (couch, supportive bean bag, floor cushions, quiet zone) without the requirement for social interaction.

## Supporting the Research Activities

- Ensure the individual knows what to expect during the session (what will happen, who will be present, how long it will take). Anxiety that impacts performance can occur if the individual does not know what to expect.
- Use visual supports within the environment.
- Consider using a visual timetable or checklist with all the activities on it, so that the individual can tick off, or place a token or sticker on each activity as it is finished. Let participants see what has been done and what is still to go. A reward, break time or reward points can be given to enhance motivation when a negotiated number of activities are completed.
- Use a timer or clock/phone if this helps them know how long or marks half way or assists them to know what is happening. Note that for some individuals this may cause anxiety if they perceive a time pressure and hence may not be appropriate.
- Have laminated red/stop; green/go; take a break/have a rest cards that the person can use or point to if they need to stop or have a break. A visual reminder/cue is often better than relying on them to tell you they need a rest especially if they are anxious.
- Match your language/instructions to the person's level of communicative ability – gain information from a parent/carer, teacher or speech pathologist regarding the best way to communicate with the individual if you are unsure.
- To avoid misjudging an individual's abilities, consider using pictures and visuals in all research materials.
- Check that the person has understood your questions/instructions. Watch out for acquiescence by using follow up questions. Check that your questions/instructions are clear.

## Engaging Participants in Studies with Multiple Contacts

Use significant others to assist if needed and ensure pilot testing of questions.

- Consider providing healthy snacks and drinks for breaks and after completion of work.
- Use regular short email newsletter updates to maintain contact with participants and remind them about the study and researchers involved.
- Sending birthday and season's greetings cards electronically may assist some individuals to stay engaged with a project, this may not be appropriate for all individuals.
- Fridge magnets with CRC Logo and contact number of key person in the study can be helpful.
- If there have been multiple contacts, explain where you are up to in the series. At the last session, explain that this is the final contact and provide an opportunity for closure and flag change of routine when the study is finished.

## After the Session

- Follow up with a thank you text, email or letter depending on the individual's preferred mode of communication.
- Provide feedback/results if this is part of your agreement (study procedure) to the person in a timely fashion (as stated in the information sheet) or as discussed.
- Provide an opportunity to ask questions if the report/feedback is written or to email you with questions.

See Checklist 1: Practices that Support Participation in Research for Individuals on the Autism Spectrum (page 47).



## Inclusive Research Practice Guide 2: Facilitating Research Groups with Individuals on the Autism Spectrum and Their Families

*We will use processes that ensure that people on the autism spectrum and their families are informed and willing participants who are respected and supported during all stages of the research process.*

*Our research will be informed by people with on the autism spectrum and their families.*

*We will ensure that people on the spectrum and their families play a central role as both research participants and where appropriate co-researchers, and that their input is respected and their voices validated throughout the research process.*

Consistent with the Autism CRC Statement on Inclusive Research Practices (Practices 1, 2 and 4), this good practice guide aims to provide researchers with suggestions regarding how to facilitate research groups with people on the spectrum, including focus groups, research advisory group meetings and other forums. It is important to note that people on the spectrum are an extremely heterogeneous group, hence there will be different requirements depending on whether research participants are children, adolescents or adults; verbal or non-verbal; and depending on the their level of cognitive ability and familiarity with yourself/your team and research processes.

### Co-facilitating

Consider whether you can co-facilitate the group with an individual on the spectrum who may be able to better understand the needs of the group and ensure that communication is clear. Refer to the Inclusive Research Practice Guide 6: Co-Producing Research with People on the Autism Spectrum and their Families for suggestions about how to support co-facilitators on the spectrum.

You may wish to identify a support person from your research team who is available should a second person be required in the room or to accompany someone who needs a break (e.g., to take a walk to de-stress or to fetch refreshments without disrupting the group).

### Scheduling Groups

- ☑ You may wish to schedule one-to-one sessions with individuals who are more comfortable relating in this way. A good approach is to offer two options to potential participants (i.e., “*would you prefer to meet one-on-one or are you comfortable participating in a group of around four people?*”).
- ☑ Consider the person’s or family’s schedules to avoid peak traffic and busy times at hospitals/universities (e.g., class change over periods) when lifts and corridors/campus is crowded with a lot of movement of people.
- ☑ Allow rest times and meal times when scheduling the group.
- ☑ Avoid inviting a large group – consider several smaller groups, not more than eight participants. Working groups with people on the spectrum will vary in size depending upon the composition and nature of the group, predominately activity based, one on one, or a mixture of both (e.g., if your group is comprised of individuals on the spectrum with cognitive and communicative capacity within the typical range you might limit the size to four to six people; for groups comprised of individuals with reduced cognitive or communicative capacity you may limit the size to two to four people).

- ☑ Establish a discrete time for the group with clear start and finishing times.

## Preparing for the Group

- ☑ Spend time preparing yourself and the group members for the session/meeting.
- ☑ Distribute any questions you would like answered well in advance so that participants have plenty of time to consider their responses.
- ☑ Provide parking vouchers, maps and clear directions to the venue and ensure you provide contact details in case participants are lost/delayed. Consider including pictures of the researchers they are likely to meet, places they will need to visit and the research activity.
- ☑ Enquire as to the availability and capability of participants being able to download and print out their own hard copies of written material such as directions, parking vouchers, contact names and numbers etc. Arrange the order of the information/material in chronological order of use/need on the specified day.
- ☑ Any questions to be addressed on the day that might require some reflective thought could be included in the pre-session information package.
- ☑ If a pre-session questionnaire is required, some participants may prefer a hard copy rather than an online version. There is a difficulty with both as there isn't an opportunity for clarification on points of confusion.
- ☑ Invite participants to visit the venue prior to the meeting if they would like to see the space and become comfortable with how to get to the venue.
- ☑ Prepare materials for the day, including a paper agenda and list of questions that each participant can have in front of them during the meeting.
- ☑ Consider including visual supports (clip art, photographs, pictures) for these documents. Make sure you have printed copies in case participants don't have access to a printer.
- ☑ Only use visual supports where they are pertinent otherwise they may become unnecessary distractions from the central issue. For example, direct visual supports that would be beneficial to some participants, particularly those with limited oral and/or word retrieval ability, may include photographs of: a) phone, b) computer, c) two people facing each other, d) a hard copy of a document (e.g., questionnaire). This could be of great assistance to the participants in choosing the means of dissemination they prefer and in the clarification of tasks.
- ☑ Provide name tags.
- ☑ You may wish to avoid using a whiteboard to avoid distracting/over-stimulating participants. Instead you may consider using printed material on paper that is in point format, allowing space for the participant to write a word or two as comment if they desire.
- ☑ Make sure your meeting space is appropriate for different sensory needs – avoid florescent lights, clutter, outside noise, fans and other noise in the room etc.
- ☑ Use pictures of the building, entry door or other key landmarks to help them navigate to the lab/office/clinic, especially if the study requires attendance at a hospital or university.
- ☑ Make sure there are signs at entry points of buildings, lifts, in corridors (e.g., CRC logo) so that people can find you easily.
- ☑ Signage within the building to the appropriate room and toilets is also desirable, and if the route is complicated make sure that signage covers both the route to toilet/room and also back to the room or exit. This is particularly important if there are several avenues converging at a hub.

## Preparing to Communicate Orally

The facilitator must provide enough time to speak with each participant separately. The time needed depends upon the individual participant's disposition towards vocal communication. Although some individuals may be very vocal, others could be very limited in fluency and in their ability to express themselves adequately within a short time frame.

If the facilitator doesn't have prior knowledge of the oral communication skills of each participant it could be beneficial to ask each person in turn to briefly state their name and age as a means of introduction, possibly also if they live in the city or the country. These details add a context to each individual and may be a means by which the facilitator can gauge the time needed to pace the progression of tasks. The factual nature of such information requires minimal response and should be an indicator of the shortest time needed by each individual to respond to simple unambiguous oral tasks.

The same brief introduction format as above may be beneficial to participants and facilitators.

## Establish Rapport and Support

A major difference between people on the spectrum and those who are not, is the manner in which they think and relate. Participants need to answer the question as it appears to them, which may be slightly different to how it was intended by the questioner.

Actively listening with patience and asking questions about what the person has said can take time but may provide valuable insight. This ensures that the needs of the participant to express him/herself and to convey understanding or seek clarification are aligned with the needs of the researcher for relevant data.

## During the Meeting/Session

Please review the Inclusive Research Practice Guide 1: Engaging Individuals on the Autism Spectrum as Research Participants for more information about creating an appropriate space for participants.

- ☑ Assume "ability" – but ensure you are taking all steps possible to support individuals on the spectrum to contribute.
- ☑ Allocate time at the beginning of the group to have a conversation about the format of the group and expectations around participation. Use simple, non-ambiguous language.
- ☑ Set guidelines about how participants will be asked to provide feedback (e.g., it may be easier for participants to take structured turns around the table rather than expecting them to provide feedback ad hoc or in a group discussion).
- ☑ Provide regular signposts about how the group is progressing through tasks (e.g., *"I know this can be tiring, you've nearly finished this section and shortly we'll have a break"* or *"You're going well on task"* or *"We have one more task to complete before we have a break for refreshments and the bathroom."*)
- ☑ Preface questions with how you expect participants to answer (e.g., *"Can you please briefly describe..."* or *"As briefly as possible..."* will signal that you aren't expecting a long and nuanced response).
- ☑ It may be useful to introduce yourself and your work as well as how long you have been involved in autism research so that members of the group are well-equipped to understand your experience with working with individuals on the spectrum.
- ☑ Participants could be asked to introduce themselves giving their name, age and possibly including whether they live in the city or the country in order to give some extra context around individual association. Some may prefer to speak in turn around the table to have a sense of structure,

however, others might be uncomfortable (check body language and ask them if they'd prefer to speak after most of the others have spoken). This flexibility could allow those who are more reserved and/or those who have difficulty communicating verbally, time to adjust and take cues from the more confident participants. This process may help the facilitator gauge the ability of each individual to respond to further requests for non-threatening factual information. Naturally, greater time would be needed for more complex questions.

- ☑ If participants feel a relaxed pace is acceptable, this may reduce any anxiety. Many individuals would have often experienced situations where they feel that their opinions are not heard/valued and that others may be looking for a desired response rather than listening to what is being related.
- ☑ Avoid speaking too quickly.
- ☑ Provide a description and definitions for key terms if you need to use them. When a key word could have more than one meaning it could be a good idea to preface the question with a definition and possibly an example of the desired interpretation.
- ☑ Don't interrupt group members – provide plenty of time for responses and avoid prompting. Remember that the clearer your question, the easier it is for participants to answer. Avoid providing too many options (e.g., instead of asking "*what is your preferred method of contact?*" you might ask "*would you prefer email or telephone contact?*").
- ☑ Individuals may have ways of communicating that extend beyond words – extended silence may indicate confusion or that a person is having trouble getting their words out clearly, and rocking may indicate agitation or anxiety. Offer visual cues wherever possible to ensure multiple modes of communication are available.
- ☑ Avoid moving around the room because you may distract participants.
- ☑ Be clear about what will be required and ensure that you stick to the steps that you outline at the beginning of the group.

## After the Session

- ☑ Follow up with a thank you text, email or letter depending on the individual's preferred mode of communication.
- ☑ If appropriate to your study timeframes and methodology, you may wish to offer individuals the opportunity to email through additional comments/feedback in case they felt uncomfortable contributing during the group.
- ☑ Provide feedback/results if this is part of your agreement (study procedure) to the person in a timely fashion (as stated in the information sheet) or as discussed.
- ☑ Provide an opportunity to ask questions if the report/feedback is written for participants to email you with questions.

See Checklist 2: Practices that Support Research Inclusion of Individuals on the Autism Spectrum in Research and Focus Groups (page 50).

## **Inclusive Research Practice Guide 3: Partnering with Individuals on the Autism Spectrum and their Families on Advisory Groups or Committees**

*Our research will be informed by individuals on the autism spectrum and their families.*

*We aim to produce research that is meaningful to individuals on the spectrum and their families and can be quickly translated into practice and also to develop tools and resources that individuals on the spectrum can easily access and utilise.*

*We will ensure that individuals on the spectrum and their families play a central role as both research participants and where appropriate co-researchers, and that their input is respected and their voices validated throughout the research process.*

*We will ensure that our research has real life and real world benefits for individuals on the spectrum and their families and will contribute to greater inclusion of individuals on the spectrum in the community.*

*We will ensure that the input provided by people on the autism spectrum into research projects is acknowledged and valued, and that they are recompensed for their contribution to research projects.*

Consistent with the Autism CRC Statement on Inclusive Research Practices (Practice 2, 3, 4 and 7), this practice guide aims to provide researchers with suggestions regarding how to engage individuals on the spectrum and/or their families as members of advisory groups taking into account their strengths as well as areas in which they may require more support.

Examples of these inclusive practices include:

- (1) seeking input from individuals on the spectrum and/or their families through research project advisory groups
- (2) offering opportunities to provide input to survey design, wording, data entry, and analysis
- (3) advising avenues for distribution, and
- (4) participating in relevant CRC committees and decision-making bodies.

It is important to note that individuals on the spectrum are an extremely heterogeneous group; hence, not all the suggestions in this guide may be right for all individuals on the spectrum.

### **Recruiting Individuals to Advisory Groups**

To ensure inclusive recruitment, consider multiple channels of communication to disseminate information about the advisory group and desire for representation (e.g., Autism Associations, ASAN, adult networks, local radio).

### **Providing Autism Friendly Environments for Meetings**

Here are some considerations to make the environment in which meetings occur more autism friendly.

- ☑ Create a calm predictable environment to avoid distractions, disruptions and surprises.
- ☑ Put a 'do not disturb' sign on the door to minimise disruptions.
- ☑ Ensure the meeting room is quiet and there is minimal background noise (even the sound of a ticking clock on the wall can be distracting for some individuals).

- ☑ Consider the room temperature.
- ☑ Avoid rooms with ceiling fans in summer as these can be very distracting for some individuals on the spectrum.
- ☑ Avoid too many pictures/posters on walls and too much visual clutter to help individuals concentrate.
- ☑ Consider the type of lighting – fluorescent lights can be too bright. Ensure there are no flickering lights/bulbs. Check to see if dimming lights or turning off down lights is preferable. If there is no scope for change, it might be the individual on the spectrum may need to wear sunglasses or a cap/visor to block the light. This may need to be explained to other group members.
- ☑ Consider the availability of bathrooms – paper towels are better than noisy hand dryers.
- ☑ Offer individuals on the spectrum an opportunity to meet you and see the room prior to meetings (if it is the first time the group is to meet) so that they know what to expect and where to go.
- ☑ Try to keep meetings scheduled in the same room wherever possible. If there is a need for change of venue, try to provide as much warning as possible. If there is a last minute change, offer to meet the person somewhere familiar and take them to the new venue.
- ☑ Use visual supports within the environment.
- ☑ If you have lengthy meetings – consider splitting these into two sessions or providing a break time and area for the person to relax (couch, supportive bean bag, floor cushions, quiet zone) without the requirement for social interaction.

## Virtual Meetings

Sometimes meetings are held virtually where all members attend via teleconference or a web based meeting platform and at times there are some individuals at one site with others joining in virtually.

If there are several options (e.g., teleconference, skype, online chat, virtual meetings) provide the person on the spectrum a choice as to how they wish to engage with the group.

Where meetings are held virtually, the role of the chair is critical in facilitating discussion and working through the agenda.

Send out a virtual meeting code of conduct prior to the first meeting and at other times as a reminder if necessary. These are available on the web and remind individuals about minimising background noise at their end, not typing on a keyboard near the phone during meetings, switching mobile phones off, and other virtual meeting etiquette to ensure that everyone has an opportunity to be heard. See an example in the Appendix to this guide.

As individuals on the spectrum may be socially anxious, ensure that they have an opportunity to contribute. You could also ask them to send their thoughts about particular agenda items to the chair prior to a meeting so that the chair can defer to the person during the meeting and support their contribution.

## Scheduling Meetings

- ☑ Use pictures of the building, entry door or other key landmarks to help individuals on the spectrum get to a meeting room for the first time. Visual supports are easier for individuals on the spectrum than detailed written instructions.
- ☑ Make sure there are signs at entry points of buildings, lifts, in corridors (e.g., CRC logo) so that individuals can find you easily.
- ☑ Provide parking vouchers and maps showing where to enter, park and mark the way to the meeting room.



- ☑ Provide your mobile number and ensure the person knows they can text you rather than having to call and speak to you if they need directions.
- ☑ Try to keep meetings scheduled at a regular time and venue.

### **Supporting the Individual's Participation**

- ☑ Ensure that agendas and meeting papers are disseminated in plenty of time prior to meetings to enable all members to have the opportunity to read and reflect on the agenda/papers.
- ☑ Provide opportunity for individuals on the spectrum to check in with the chair or meeting secretary regarding any queries they might have prior to a meeting so that they are well prepared and anxiety can be minimised.
- ☑ Ensure the meeting protocol and ground rules are established and known to all members to ease comfort levels.
- ☑ The more individuals on the spectrum understand the meeting format, expectations, level of formality and requirements of their involvement, the more likely you will be able to maximise their participation. Meet with them at the outset before the first advisory group meeting so that they can ask questions and you can explain the above.
- ☑ Sometimes wearing perfumed sprays can be overwhelming for individuals on the spectrum, as is too much jewellery which can be visually distracting.
- ☑ Discuss with the person on the spectrum how they wish to be introduced and what they wish you or themselves to share about their background.
- ☑ Check to see if the individual on the spectrum has any particular requirements regarding how they receive the agenda and papers or minutes (hard, soft copy) that might assist their preparation for meetings.
- ☑ Checking in regularly with all meeting participants between meetings regarding whether they have any comments can also facilitate engagement.

See Checklist 3: Practices that Support Research Inclusion with Individuals on the Autism Spectrum in Advisory and Reference Groups (page 53).

## Inclusive Research Practice Guide 4: Providing Research Results to Individuals on the Autism Spectrum and their Families

*We aim to produce research that is meaningful to individuals on the autism spectrum and their families and can be quickly translated into practice and also to develop tools and resources that individuals on the spectrum can easily access and utilise.*

*We will make adjustments to research tools, reports and processes to ensure they are appropriate for individuals on the spectrum and their families, and reflect the diversity of individuals on the spectrum.*

Consistent with the Autism CRC Statement on Inclusive Research Practices (practices 3 and 6), this good practice guide aims to provide researchers with suggestions regarding how to provide feedback to individuals on the spectrum about research findings/outcomes, taking into account their strengths as well as areas in which they may require more support.

### Provision of Specific Feedback to Individuals/ Families

- ☒ Provide feedback/results if this is part of your agreement (study procedure) to the person in a timely fashion (as stated in the information sheet) or as discussed.
- ☒ Provide an opportunity to ask questions if the report/feedback is written or an opportunity to email you with questions.
- ☒ If providing feedback face to face, check for understanding of the findings. Encourage individuals to make comments and ask questions.
- ☒ Consider the audience of any written reports or verbal feedback – ensure that language is jargon free, respectful, comprehensible, and as positive as appropriate.
- ☒ Follow up with a phone call if reports are sent by email/mail and there is no appointment scheduled for specific feedback.
- ☒ Ensure you have the individual on the spectrum or parental consent to provide reports to other parties who might request these.

### Provision of General Feedback to Individuals and Families regarding Study Findings

- ☒ Consider multiple mechanisms for providing feedback such as study newsletter, podcast, video and/or YouTube clip.
- ☒ In written reports consider using visuals such as photographs, icons used in the study with which the participants will be familiar, and diagrams to schematically represent findings.
- ☒ Consider the literacy level of written material – use internet programs (e.g., <http://www.standards-schmandards.com/exhibits/rix>; <http://read-able.com>; Flesch Readability Index) to provide you with an indication. It is good practice for all written communication material (for lay audiences) to aim for year 5 level.

Quite often provision of results in electronic format is easier to access than hard copy. If using hard copy the larger font size (12-14 Verdana) is more accessible than the smaller fonts such as 10 Arial.



Remember this is not an academic presentation but a summary of key findings for a lay audience.

Consider co-producing this feedback with your advisory group or a select couple of individuals on the spectrum and/or their families to obtain feedback before dissemination.

See Inclusive Research Practice Guide 6: Co-Producing Research with People on the Autism Spectrum and their Families.

## **Additional Considerations**

It may be appropriate to consider other ways to feedback study results and translate knowledge for participants and communities, including:

- Resources for distribution within schools or community centres related to your research.
- Visual displays, including posters and brochures.
- Free talks for members of your community who might be interested in or assisted by your study findings.
- Stalls at public events/conferences/expos where individuals on the spectrum and/or their families might be attending (e.g., O-week at universities).
- Websites or downloadable PDFs with implications and suggestions based on your research for individuals on the spectrum and/or their families.
- Links for online resources, Autism associations and forums (see Autism CRC Communications Manager for assistance).
- Display artwork produced through research at a public exhibition.

Ask your advisory group members and/or select individuals on the spectrum and/or their families for suggestions about how your research findings may be useful to them and others, and gather their ideas about appropriate avenues for dissemination.

## **Communication and the Media**

Discuss your Communications Strategy (including any potential media coverage) with the Autism CRC Communications Manager, who can also help with the presentation of materials.

See Checklist 1: Practices that Support Participation in Research for Individuals on the Autism Spectrum (page 47).

## Inclusive Research Practice Guide 5: Co-Presenting Research with Individuals on the Autism Spectrum and their Families

*Where individuals on the autism spectrum and their families have been co-producers of research we will provide opportunities for them to co-present research findings.*

*We will ensure that the input provided by people on the autism spectrum into research projects is acknowledged and valued, and that they are recompensed for their contribution to research projects.*

Evidence suggests that co-presenting is associated with better knowledge translation as well as attitude change among the audience. Consistent with the Autism CRC Statement on Inclusive Research Practices (practice 5), this inclusive practice guide aims to provide researchers with suggestions regarding how to engage individuals on the spectrum as co-presenters, taking into account their strengths as well as areas in which they may require more support. These suggestions are relevant for individuals with and without cognitive and communication differences; however, additional considerations are likely to be required to support those with these differences such as use of alternative communication devices (with presentations pre-recorded) or use of pre-recorded videos.

### Before the Presentation

- ☑ Ensure payment of conference registration fees (if required), transport and other expenses to assist the person on the spectrum or significant other to co-present with you.
- ☑ Consider payment of an honorarium to acknowledge the person's time (e.g., with student education sessions, continuing professional development) required to co-present.
- ☑ Discuss with the person their role in the presentation, their comfort level and how much of the presentation they wish to prepare and deliver.
- ☑ Provide support with development of slides (if required) for example, easy to use templates, assistance with writing slides and adding pictures/videos.
- ☑ Offer clear directions regarding layout, content of slides and timing/length of their component of the presentation (e.g., maximum three dot points per slide).
- ☑ Provide an opportunity for the individual to provide feedback on the material you are presenting along with them.
- ☑ Brief the co-presenter about the length of the presentation. If the length is daunting consider bringing the individual in for a section with a person keeping track of time and providing support.
- ☑ Provide an opportunity to practice the presentation and have a dress rehearsal.
- ☑ Find out how the person wants to be supported during the presentation (e.g., typed script, off the cuff from slides, visual supports such as watch/timer).
- ☑ Have a discussion with the person about how they wish to manage questions (e.g., during the presentation, at the end, providing time to consider answers to questions, sending questions through prior to presentation to allow preparation).
- ☑ Ensure the person knows what to expect on the day of the presentation (where it is held, where you will meet, who will attend, where they can go to de-stress before and after the presentation).
- ☑ Discuss with the person how they wish to be introduced and level of disclosure about their diagnosis.

- ☑ Discuss with the person whether they would like an advocate/support person present during the presentation.
- ☑ Send a text the night before or morning of presentation as a reminder.
- ☑ Ask the individual what their triggers are, for example sounds, and discuss ways to minimise these.
- ☑ Find out how the individual shows stress- sometimes people smiling means they are very stressed and would like to get out of the situation.

### **At the Venue**

- ☑ If possible, have a rehearsal at the venue and ensure the person knows how to operate any audio-visual equipment or together plan who will do this.
- ☑ Check to see if the lighting or other features of the environment need modification in any way.
- ☑ Ensure the individual on the spectrum knows where the facilities and refreshments are and where they can find a quiet space prior to and after the presentation if required.
- ☑ Use laminated signage at the door to cue individuals who are late to enter quietly and discuss with the person on the spectrum how they will manage these sorts of distractions.
- ☑ Check to see if the co-presenter may be overwhelmed by the ambient noise of the audience (especially when large rooms start to fill). Discuss strategies with the co-presenter.
- ☑ If the co-presenter is likely to be overwhelmed by audience noise perhaps consider limiting audience size and place a 'please enter quietly' placard on all entries and ask the previous session chair to ask audience members to consider noise when entering the room.

### **During the Presentation**

- ☑ Stick to the plan you have made with the person on the spectrum (e.g., they will have a much greater need for structure and certainty than experienced presenters). This is no time to wing it or change things at the last minute!
- ☑ Let the person on the spectrum know if you are nervous and help them interpret your behaviour/responses in this situation.
- ☑ If the person on the spectrum wishes to have a support person with them (as well as you) ensure they are introduced to the audience and ensure that they have together worked out cues regarding when support is needed etc.
- ☑ Keep an eye on the person's energy levels particularly for questions and when they are approached after the presentation so that they are not overwhelmed.
- ☑ Offer an email address at the end of the presentation so that questions can be emailed to you/or the person for reply later.

### **After the Presentation**

- ☑ Offer the person on the spectrum some quiet time and space away from social demands.
- ☑ Provide feedback to the person about their presentation and follow that up with an email.
- ☑ Thank the person for their contribution and time and follow this up in writing.
- ☑ Ensure they are able to depart the venue easily (e.g., cab vouchers) and see them to the cab.
- ☑ Pass on any positive feedback received after the presentation by email or phone as appropriate.

- ☒ Seek their willingness to present in the future and their feedback on improvements or changes for future presentations.
- ☒ See if the person would like a coffee, tea or quiet debrief right away or perhaps later on.

See Checklist 4: Practices that Support Co-Presenting Research Findings with Individuals on the Autism Spectrum (page 56).

## Inclusive Research Practice Guide 6: Co-Producing Research with People on the Autism Spectrum and their Families

**Co-production – a meeting of minds coming together to find a shared solution**

*We will ensure that people on the autism spectrum and their families play a central role as both research participants and where appropriate co-researchers, and that their input is respected and their voices validated throughout the research process.*

*We will ensure that the input provided by people on the autism spectrum into research projects is acknowledged and valued, and that they are recompensed for their contribution to research projects.*

Consistent with the Autism CRC Statement on Inclusive Research Practices (practice 4), this good practice guide aims to provide researchers with suggestions regarding how to engage people on the spectrum as co-producers of research, taking into account their strengths as well as areas in which they may require more support. As research co-production is a relatively new concept, we first provide a definition and some features, benefits and requirements of research co-production prior to addressing ways in which researchers (typically referred to as co-researchers in these initiatives) can become involved in and develop skills in supporting research co-production.

### Definition – Research Co-production

Research co-production refers to engaging academic researchers and stakeholders, who are the end-users of the research, throughout the whole research process of jointly initiating, developing, and implementing a research project, analysing the data, and sharing or publicising the findings. When engaging in research co-production, the people involved are; co-researchers on the autism spectrum and/or their families, university co-researchers, service provider co-researchers, and peer mentors or those who support individuals on the spectrum and their families.

### Key Features of Co-production Initiatives

- Individuals on the spectrum and/or their families are viewed as people with knowledge, assets, skills and strengths.
- Barriers between individuals on the spectrum and/or their families and professionals are recognised and removed.
- The existing capabilities of each individual are enhanced.
- Reciprocity (getting something back for doing something for others) and mutuality (working together to achieve shared interests) are acknowledged.
- Peer and personal networks as well as professional networks are used.
- Individuals on the spectrum and their families work in equal partnership with researchers towards shared goals.
- Individuals on the spectrum and their families are involved with the aspects of research which best suit their skills, interests, and lived experience such as planning, development, implementation and dissemination.

*(adapted from Social Care Institute for Excellence, 2013)*

## Benefits of Research Co-production

Research co-production is increasingly seen as an effective way of ensuring research impact (Jung, Harrow, & Pharoah, 2012). Co-production of research acknowledges that research is a collective rather than a solitary endeavour. Co-production ensures that the research questions are relevant and important to individuals on the spectrum and their families (i.e., questions are determined and informed by end-users), that answers are sought from the right sources (i.e., the right people are identified as informants), and the most appropriate research methods are utilised.

## Requirements of Research Co-production

Pellicano, Dinsmore and Charman (2013) describe key requirements for developing research partnerships that move beyond tokenism to co-production. These include the need for:

- (1) strategic partnerships to ensure investment is directed to where it is needed
- (2) cross disciplinary research, and
- (3) listening, engaging and involving individuals on the spectrum and/or their families in the priority setting stage, translating findings into practice, and in dissemination in publically accessible formats.

Within Autism CRC, we recommend consideration of the specific needs of individuals on the spectrum and/or their families, good planning, development of clear shared expectations and communication, and transparency about research processes. The practices outlined in the other CRC Inclusive Research Guides will assist with planning, appreciation of the needs of individuals on the spectrum and their families, and the steps that can be taken to achieve these outcomes.

## Principles of Research Co-production

Equality	Everyone has assets. No one group or person is more important than another in the research team. All members have skills, abilities and other qualities. This requires a balance in power between professionals and individuals on the spectrum and /or their families. This takes time for individuals to get to know one another.
Transparency	Ensures all individuals understand the expectations about being involved.
Diversity	Diversity and inclusion are important values. It is recognised that individuals with cognitive and communication impairments, those who need high levels of support, those from ethnic minorities and lesbian, gay, bisexual and transgender communities, are more likely to be excluded.
Accessibility	Is a fundamental principle of co-production if individuals are to engage on an equal basis. Accessibility requires that all information is provided in appropriate formats so that everyone can participate. Attention to language so that everyone understands each other is essential. Encourage the individual to let you know when a particular noise is distracting or painful.

Reciprocity	Ensuring that people receive something back for putting something in is important so that individuals feel needed and valued.
Mutuality	All individuals involved in the research have responsibilities and expectations.

## Implementing Research Co-production for Individuals on the Spectrum

Implementing research co-production involves four key aspects – attending to culture, structure, practice, and review (Social Care Institute for Excellence, 2013), as well as understanding the strengths, contributions and needs of individuals on the spectrum.

Culture	<ul style="list-style-type: none"> <li>- the beliefs and values of the organisation and the way it works.</li> <li>• Ensure that co-production is embedded in the organisational culture especially among the leadership team.</li> <li>• Ensure culture is built on a shared understanding of co-production, principles for implementation.</li> <li>• Make sure the team endorses and commits to the key principles of co-production.</li> <li>• Develop a culture of being risk aware rather than risk averse. This requires being aware of risk, open to risk, taking a managed and planned approach to risks, and being prepared for things to go wrong and addressing these.</li> </ul>
Structure	<ul style="list-style-type: none"> <li>- the way the organisation is arranged, including internal systems.</li> <li>• Identify and involve the right people.</li> <li>• Involve all individuals who will take part from the start.</li> <li>• Value and reward people who take part in research co-production – consider payment, covering travel costs, refreshments, time banks. An hour of each person's time is considered to be equal.</li> <li>• Ensure adequate resources to cover the cost of co-production activities – this can be time consuming and requires resources for building the project and for support (McKenzie &amp; Hanley, 2007).</li> <li>• Ensure that co-production is supported by a communication strategy.</li> <li>• Ensure that language used is accessible and understandable to everyone involved – flexible strategies are needed that use a range of different approaches to communication (e.g., social media).</li> <li>• Build on existing structures and resources.</li> </ul>
Practice	<ul style="list-style-type: none"> <li>- how the organisation and its people carry out their work.</li> <li>• Ensure individuals on the spectrum are supported by including several individuals on the spectrum in the research team and providing peer support workers/ mentors if required.</li> </ul>



## Review

## Individuals on the Spectrum and their Families

- Set up expectations (e.g., terms of reference for the group) and responsibilities about meeting attendance and involvement from the outset so that working relationships develop.
  - Ensure all individuals are accessible to each other so that nobody is excluded (e.g., email and contact details).
  - Ensure everyone has enough information to take part in decision making.
  - Ensure everyone involved is trained in principles and philosophy of co-production and any skills they will need for the work they will do.
  - Consider an independent facilitator (rather than researcher) to support the process – ensure the person is acceptable to everyone.
  - Provide support to build capacity within the research team.
  - Peer support workers or mentors may assist individuals on the spectrum to engage in research co-production, this may involve:
    - identifying peer support personnel/volunteers,
    - assisting the individual on the spectrum in preparing for meetings,
    - helping bridge jargon/language gaps and upskilling the individual and research team,
    - advocating for inclusive research practices and highlighting when communication has been unclear or tasks have been unrealistic or unclear,
    - mentoring the individual in communicating with the team through written and verbal feedback depending on his/her communicative abilities and preferences,
    - debriefing with the individual after research meetings.
  - Ensure there are policies for co-production in commissioning of research.
- monitoring and assessment of outcomes and impacts.
- Conduct regular reviews to ensure co-production is making a difference.
  - Monitor progress, mark achievements and milestones (celebrate these), as well as identify where improvements can be made.
  - Co-produce reviews and evaluations.
  - Use review findings to ensure continuous learning.
  - Consider ways of showing the impact of co-production.

Ensure all those involved consult the Inclusive Research Practice Guides for suggestions regarding research participation, dissemination, advisory groups, and co-presenting with individuals on the spectrum and/or their families.



In summary, co-production of research is a relatively new concept and not easy to do well. While this and the associated guides provide a springboard to help with your team's deliberations, much more is needed. Documenting your experiences and practice examples is likely to be worthwhile, as this is how we all learn.

Disseminating these experiences at conferences and through scientific journals as well as in community forums attended by the autistic community, will assist all of us as co-researchers as we continually learn, reflect, and develop and improve our inclusive research practices. We encourage Autism CRC scholars and researchers to share their experiences informally as well as formally, for the benefit of our whole community.

## References

- Jung, T., Harrow, J., & Pharoah, C. (2012). Co-producing research: Working together or falling apart? Centre for Charitable Giving and Philanthropy Briefing Note 8. (<http://www.cgap.org.uk/uploads/Briefing%20Papers/CGAP%20Briefing%20Note%208%20-%20Co-producing%20research.pdf> Accessed 22 August 2014)
- McKenzie, A., & Hanley, B. (2007). Consumer and community participation in health and medical research: A practical guide for health and medical research organisations. Accessed 20 August 2014 [www.sph.uwa.edu.au](http://www.sph.uwa.edu.au)
- Pellicano, L., Dinsmore, A., & Charman, T. (2013). A future made together: Shaping autism research in the UK. London: Institute of Education. ([http://newsletters.ioe.ac.uk/A\\_Future\\_Made\\_Together\\_2013.pdf](http://newsletters.ioe.ac.uk/A_Future_Made_Together_2013.pdf) Accessed 22 August 2014)
- Social Care Institute for Excellence (2013). Co-production in social care: What it is and how to do it. Adults' Services: SCIE guide 51. London: Social Care Institute for Excellence. (<http://www.scie.org.uk/publications/guides/guide51/files/guide51.pdf> Accessed 4 July 2014).

See Checklist 5: Practices that Support Individuals on the Autism Spectrum in the Co-Production of Research (page 58).

## Inclusive Research Practice Guide 7: Recruiting and Retaining Individuals on the Autism Spectrum as Research Participants in Longitudinal Studies

*We will use processes that ensure that individuals on the autism spectrum and their families are informed and willing participants who are respected and supported during all stages of the research process.*

*We will ensure that individuals on the spectrum and their families play a central role as both research participants and where appropriate co-researchers, and that their input is respected and their voices validated throughout the research process.*

*We will make adjustments to research tools, reports and processes to ensure they are appropriate for individuals on the spectrum and their families and reflect the diversity of individuals on the autism spectrum.*

*We will ensure that the input provided by people on the autism spectrum into research projects is acknowledged and valued, and that they are recompensed for their contribution to research projects.*

Consistent with the Autism CRC Statement on Inclusive Research Practices (practices 1, 4 and 6), this Inclusive Research Practice Guide aims to provide researchers with suggestions regarding how to engage individuals on the spectrum as research participants, taking into account their strengths as well as areas in which they may require more support. It is important to note that individuals on the autism spectrum are an extremely heterogeneous group, hence there will be different requirements depending on whether research participants are children, adolescents or adults; and depending on their level of cognitive ability and communication skills, and familiarity with yourself/your team and research processes.

Based on the findings of a study with 167 Australian participants conducted by Haas, Costley, Falkmer, Richdale and Sofronoff (2014) for Autism CRC, the following measures and approaches are recommended in order to optimise participant recruitment and retention of adults on the spectrum in longitudinal projects.

### **Show Sensitivity to the Full Spectrum of Individual Needs and Preferences of all Participants**

To maximise the levels of both comfort and satisfaction for the broadest range of participants while taking part in the study:

- ☑ Purposefully design and implement the study to be sensitive to the very broad spectrum of all potential participants' differing communication, social and cognitive skills and preferences, lifestyles, and sensory needs.
- ☑ Take into account the incompatibility of the preferences for some participants with those of others.

Practical recommendations to implement this sensitivity to the spectrum of individual's needs and preferences include:

- ☑ Select event venues that cater for sensory issues experienced by some people on the spectrum, such as discomfort with excessive noise, light and crowds.
- ☑ Offer options for data collection that do not require face-to-face communication or travel.
- ☑ Provide the facility for participants to give additional explanations for any responses to questions.
- ☑ Provide the facility for participants to give feedback to the research team on research methods.
- ☑ Eliminate ambiguity and potential for multiple meanings or interpretations in any communication.

- ☑ Establish relationships of trust with participants on the spectrum who have an intellectual disability prior to any recruitment or data collection.
- ☑ Provide the option to come to the home environment of participants on the spectrum who have an intellectual disability to collect data.
- ☑ Provide reminders and information for any events and activities.
- ☑ Avoid any stereotyping of the attributes of people on the spectrum.

In addition, it is appropriate that all researchers and other staff involved in the design and administration of research projects have training in and/or knowledge of the lived experience of people living on the autism spectrum.

### **Maximise the Range of Options for Participants to Engage with the Research**

Maximise the range of options available to participants for engaging with the project, and clearly communicate these options to participants, such as:

- how, when and where to participate
- a choice of modes of participation that
  - provide exposure to social interactions
  - do not require any social interaction
- opt-in/out to receive communications
- options for preferred format for communication and materials e.g. digital/print, telephone/ email/ post/ face to face
- opt-in/out to receive rewards and incentives
- options for different types of rewards and incentives
- a range of options for additional involvement in the research project that are appropriate for and sensitive to different participants' interests, capacity and skills.

### **Tailor Recruitment Methods to Most Effectively Reach Different Groups of Participants**

To most effectively reach and appeal to each specific category of participants, tailor the community networks, methods, communication channels and messages that are used for participant recruitment to match the profile of each participant category.

#### ***Participants on the Spectrum***

- Recruitment communications via social media, through the many autism support networks, support groups and service providers can be an effective initial step in recruiting.
- Effective methods for further recruitment are:
  - Enlisting the support and assistance of those individuals in the autism community who are active, high profile and well-connected advocates for this community can be particularly effective in recruiting participants, as it provides credentialed and trusted access to potential participants.
  - Snowballing, by encouraging both neuro-typical and people on the spectrum who have already joined the study to enlist any relatives and friends on the spectrum to also join.

### ***Participants on the Spectrum who have an Intellectual Disability and their Carers***

- The most challenging participants to recruit into an autism spectrum study are those on the spectrum who have an intellectual disability.
- Recruiting these participants requires the longest amount of time and the greatest amount of effort.
- Rather than directly recruiting, a more effective way can be to first recruit their Carers as co-participants. Research indicates that carers fulfil a role as the participant's 'gatekeeper' and as a general rule are the conduit for all communications and consent/assent.
- Carers of participants can be most effectively identified and reached through disability networks, rather than through the autism community.
- While some Carers can be reached via social media, the primary sources of Carers have been found to be through the assistance and co-ordination of disability carer network organisations and disability service providers. Giving a short presentation about your research project to meetings of such groups is an effective way of generating interest and sourcing participants.
- Identifying and linking in to existing, established disability carer support groups, particularly those organised by or co-ordinated via disability service providers can provide credentialed and trusted access to Carers of participants on the spectrum who have an intellectual disability.

### ***Neuro-typical Participants***

While the potential pool of neuro-typical participants could be considered to be anyone in the general population who is not on the spectrum, the experience of researchers is that those neuro-typical participants who most likely to be interested in taking part in research about autism are those who value their personal association through family or friends with a person on the spectrum.

Two methods found to be effective in recruiting neuro-typical participants are:

- Recruitment communication via social media through autism support networks, support groups and service providers.
- Snowballing, by encouraging those participants who are already recruited to the study to enlist their relatives and friends to also join the study as participants.

### ***Project Co-ordination***

For collaborative projects, it is recommended that the lead research partner develops a single set of communication materials, with consistent text, content, messages and visuals and thus a clear and distinctive project branding, combined with a co-ordinated approach and schedule to recruitment methods. This ensures a cost-effective use of resources in recruitment and consistent recruitment communications and branding of the study across all locations and partners.

### **Key-in the Participants' Motivations for Engagement, using Effective Recruitment and Retention Communications**

- ☑ Clearly communicate the purpose and the pragmatic, results-oriented nature of the Autism CRC research projects.
- ☑ Provide the option to receive ongoing updates on the progress of the research project and a final report on the study results and outcomes, with a focus on pragmatic programs to assist people on the spectrum that are being or will be developed and implemented as a result of the study findings.

- ✓ Provide feedback to participants about the impact that their contribution has made to autism research.
- ✓ Provide participants with a means of connecting with and learning about the wider Autism CRC program and community.
- ✓ Each category of participant will also be most responsive to recruitment messages that are tailored to appeal to their specific key motivations for participating in autism research.

### **Take Care in Offering Extrinsic Rewards for Participation**

- ✓ When using extrinsic rewards for participation, offer a choice of either cash (or pre-paid credit card) or a range of vouchers, for a small value, such as \$30 for a two hour contribution, and offer these clearly as acknowledgement and appreciation of the participant's contribution.
- ✓ As an alternative to accepting cash or a gift voucher, also provide the option for participants to donate the value of any reward to either a CRC research project or an autism related charity.
- ✓ Exclude birthday cards, 'tell-a-friend' rewards and gifts (especially branded items such as pens, hats and mugs) from any incentive program, as these types of rewards are likely to generate a negative reaction from many participants on the spectrum, carers and neuro-typical participants and may represent a 'waste' of resources.

The exceptions to this are:

- if the project is dealing solely with participants with autism and an intellectual disability, or
- if the researcher has established a personal one-on-one relationship with the individual participant.

### **Offer Reimbursement for Travel, for a Fixed Amount**

Offer participants a standard, flat payment for the travel cost of each round trip they make to participate in a project activity (i.e., an amount that is not linked to the individual distance travelled or fares/petrol purchased, but is the same value for all participants), paid to participants via either a pre-paid credit card, a generic voucher or direct bank transfer.

### **Provide Connection and a Safe, Caring Community for Participants**

Research indicates that many participants in autism research are likely to enjoy a sense of satisfaction in belonging to a community of like-minded people with similar interests with whom they could share and exchange information, ideas and narratives about their life experiences.

Initiatives and activities that offer such participants a sense of belonging to a community of like-minded people with similar interests with whom they can share and exchange include:

- A secure project website that:
  - provides a single, central hub for all project information, communications and activities
  - engenders a sense of belonging and membership, and
  - provides opportunities for online interaction between participants, and also with the research team.
- Task-oriented forums, discussion groups and social groups where participants can interact with each other and to meet with and hear from the research team, with a focus around topics related to the spectrum or autism research.
- Invitations to join a group of participants at social events conducted by autism organisations, such as art exhibitions and entertainment/performances. Projects could consider offering participants either free or discounted entry to such events, as part of any reward program for the project.

## Reference

Haas, K., Costley, D., Falkmer, T., Richdale, A. & Sofronoff, K. (2014). Optimising the recruitment and retention of adults for longitudinal autism spectrum research: a mixed methods study. Executive Summary Report (Tables 1, 2A, 2B, 2C and D). Cooperative Research Centre for Living with Autism Spectrum Disorders, Brisbane.

See Checklist 6: Recruiting and Retaining Individuals on the Autism Spectrum as Research Participants in Longitudinal Studies (page 62).

## Inclusive Research Practice Guide 8: Evaluation of Research Outcomes and Impact

*We will use processes that ensure people on the autism spectrum and their families are informed and willing participants who are respected and supported during all stages of the research process.*

*We will ensure that people on the spectrum and their families play a central role as both research participants and where appropriate as co-researchers, and that their input is respected and their voices validated throughout the research process.*

Consistent with the *Autism CRC Statement on Inclusive Research Practices* (practices 1 and 4), this Inclusive Research Practice Guide aims to provide researchers with suggestions regarding how to engage individuals on the spectrum (taking into account their strengths as well as areas in which they may require more support) in the evaluation of research outcomes and impact. Evaluation of research outcomes and impact is an important but sometimes forgotten stage of the research process.

This process involves comparing the results achieved by the project and the predetermined objectives. It also involves drawing conclusions and evaluating the relative success of the activity, what it might mean for Autism CRC partners, stakeholders (including end-users on the spectrum) and all involved. The process of measuring and evaluating various elements of a research project should be ongoing, providing information and insight that enables the research team to monitor, track, assess, modify, improve and report on the value of their efforts in the short and longer term.

It is useful to develop a monitoring and evaluation plan from the outset of the research project, as a way of tracking whether key project milestones are delivered on time and on budget. This plan can be reviewed at regular research team meetings as a way of keeping the team focused and on track. Additionally there is a specific focus of evaluation at the end of the project that focuses on the research outcomes. At a later stage, research impact can be addressed as it is translated into everyday practice, policy, processes or services; but this takes time. It is, however, useful for the team to consider research impact and how it might be measured/addressed from the outset.

### Monitoring and Evaluation Plans

These plans (1) describe how project achievements are to be measured, (2) document consensus to enable transparency, accountability and responsibility, (3) guide implementation, and (4) preserve team memory. In developing a monitoring and evaluation plan, these should be useful (assist with decision making, resource allocation, assessment of performance), feasible (realistic and practical), ethically sound, and accurate. Key components that should be discussed by the team with input from those on the spectrum include:

- What does the research project want to change and how?
- What are the specific objectives leading to change?
- What are the indicators (of change) and how are they measured?
- What will project success look like?
- How will the monitoring and evaluation data be collected and analysed?
- What will be the impact of the research on end-users?

### Steps in Developing a Monitoring and Evaluation Plan

#### 1. *Engaging with End-users and Stakeholders*

Stakeholder and end-user consultation is critical and their participation should be regular, relevant and timely. See Inclusive Research Practice Guides 2, 3, and 4 for assistance here. It is critical to understand



various perspectives and integrate these into the plan. The authentic needs of the end-user groups and what impact will look like for these groups must be articulated. What will be better? Changed? And How?

Promoting participation of individuals on the spectrum, and where relevant carers/parents, helps to clarify expectations and provides a sense of involvement, ownership, and responsibility.

## **2. Developing the Plan**

It is important to identify project inputs, outputs, outcomes and impact.

*Project inputs* refer to the elements that team members and partners bring to a research project, such as financing, in-kind support (e.g., data bases, access to schools, research labs) and the lived experience of being on the spectrum. These are used within the project in order to carry it out.

*Research activities* are those activities undertaken within research projects including education, communication and engagement activities.

*Research outputs* are products, training packages, educational outputs (PhD students or teachers trained) or activities resulting from the CRC research. Sometimes these are referred to as deliverables. What is to be produced or undertaken? What is to be delivered?

*Research usage* refers to how the research is utilised, for example, how many students trained, teachers undertaking professional development, GPs who access health resources developed by a CRC project, adults engaged in employment who used our vocational/educational tools. Who and how many 'used' our products?

*Research outcomes* refers to what happened as a result of the research outputs and activities. These may include changes in behaviours, attitudes, policies, school practices and funding systems.

*Research impact* describes the effects and outcomes of the research in terms of value and benefit as a result of research outputs/products. These may include health gains, productivity gains, increased school or employment success and the monetary (economic) and social value/benefit of these outcomes. Each project will have its own way of specifying likely research impacts. Those on the autism spectrum have a special role to play in identifying research impact and its measurement within the autistic community.

Consensus should be reached among the research team based on input from advisory groups and the consultations undertaken regarding the project objectives, what is expected to change, and what impact this will have. This will enable identification of the elements that need to be measured and how these will be measured.

## **3. Determine the Methodology**

This requires consideration of the theoretical framework, appropriate methods for data collection and analysis, and how information will be recorded, analysed and reported. Resource availability, cost and time also need to be considered. Individuals on the spectrum are able to provide researchers important perspectives and critique on measurement of research outcomes and their utility, from the perspective of the lived experience. Also on methods of data collection that are suitable within the autistic community and interpretation of findings that seek to understand the autistic perspective. As the outcomes Autism CRC seek may relate to transforming the lives of people on the spectrum, theirs is the ultimate perspective on which our research rests in order to determine success regarding efficacy and impact. Our research must not only include but value highly the perspective/s of those on the autism spectrum in evaluating success. Other Inclusive Research Practice Guides provide assistance with this- particularly Guides 2, 3, and 6.



#### **4. Assign Responsibilities for Implementation**

The roles and responsibilities of various stakeholders need to be described for accountability and reporting.

#### **5. Setting Targets**

Targets set with stakeholders enable everyone to understand what the plan is expected to achieve. These need to be realistic however there may need to be flexibility regarding change in direction over time. There may be a need to respond to new events, opportunities and issues over time.

#### **6. Defining Reporting, Dissemination and Utilisation of Results**

End-users information and learning needs must be addressed throughout to ensure utilization of findings from the research project. Preliminary findings can be presented at strategically timed user meetings/workshops, such that they are tailored to specific stakeholders' interests and needs. Content and format will need to vary with end-user needs and the audience- keeping a careful eye on technical language and complexity. As discussed in Inclusive Research Practice Guide 9, identification of appropriate outlets and means of dissemination will be important- enhanced by the views of those on the spectrum informing researchers or as peer researchers on teams.

### **Measuring the Impact of Research**

Examples of impact outcomes include indicators that demonstrate:

- change in understanding of autism, subtypes, schooling, adult life etc.
- enhancement of health and well-being in autistic community members as a result of research outputs/activities
- contribution to the knowledge base for both the autistic community as well as researchers
- change in clinical, diagnostic, educational, employment or research practice
- implementation of policy or legislation in areas such as education, employment, health, disability
- extent of interdisciplinary research
- scientific impact
- collaboration patterns
- research productivity
- publication practices
- economic benefits
- citation impact (number of times researchers are cited in other publications).

The Becker Medical Library Model for Assessment of Research Impact provides a list of indicators to document evidence of research impact:

- advancement of knowledge
- clinical implementation
- implementation (community, relevant services, school based implementation)
- community benefit
- legislation and policy
- economic benefit.

### **How to Build Pathways to Impact**

- Build relationships and networks including those with individuals on the autism spectrum
- Cultivate champions within your team including individuals on the spectrum Ideas travel through networks and relationships – foster these
- Ensure the pathways to impact are active before and during a research project and soon after
- Develop expertise in your field and be a trustworthy source of evidence
- Address areas of policy interest
- Get decision makers involved in the research

- Join relevant committees and insert your findings into decision making
- Consider Action Research designs
- Don't wait for publication. Disseminate early (See Inclusive Research Practice Guide 9)
- Be opportunistic
- Present, present, present the research findings.

## References

World Health Organisation (2014). Monitoring and Evaluating an Implementation Research Project. Module 6. [http://www.who.int/tdr/publications/year/2014/participant-workbook6\\_030414.pdf](http://www.who.int/tdr/publications/year/2014/participant-workbook6_030414.pdf)  
[https://becker.wustl.edu/sites/default/files/becker\\_model-reference.pdf](https://becker.wustl.edu/sites/default/files/becker_model-reference.pdf)

## Useful Resources

University of Kansas (2015) Toolkit on Evaluation. [http://ctb.ku.edu/en/evaluating-initiative#node\\_toolkits\\_full\\_group\\_outline](http://ctb.ku.edu/en/evaluating-initiative#node_toolkits_full_group_outline)

The Community Tool Box is a public service of the [University of Kansas](http://www.ku.edu). It is developed and managed by the [KU Work Group for Community Health and Development](http://www.ku.edu/workgroup) and partners nationally and internationally. The Community Tool Box is a part of the KU Work Group's role as a designated World Health Organization Collaborating Centre for Community Health and Development

Section 1. Measuring Success: Evaluating Comprehensive Community Initiatives Sections 1-8  
<http://ctb.ku.edu/en/table-of-contents/evaluate/evaluate-community-initiatives/measure-success/main>

See Checklist 7: Practices that Support Evaluation of Research Outcomes and Impact (page 65).

## Inclusive Research Practice Guide 9: Disseminating and Utilising Findings

*We will use processes that ensure people on the autism spectrum and their families are informed and willing participants who are respected and supported during all stages of the research process.*

*We will ensure that people on the spectrum and their families play a central role as both research participants and where appropriate as co-researchers, and that their input is respected and their voices validated throughout the research process.*

Consistent with the Autism CRC Statement on Inclusive Research Practices (1 and 4), this Inclusive Research Practice Guide aims to provide researchers with suggestions regarding how to engage individuals on the autism spectrum in the dissemination and utilisation of findings. The Guide takes into account individuals' strengths and areas in which more support may be required. Dissemination, utilisation of findings and translation of these into practice is an important but sometimes forgotten stage of the research process. Dissemination is a key responsibility of all researchers as it is particularly important in 'closing the loop' for research participants and funding agencies. Essentially, dissemination refers to sharing the research findings with target audiences who will benefit from the study. These target audiences reach beyond the traditionally narrow realms of academia: researchers, conference attendees, and peers who read research journals. Whilst these are important audiences, responsible dissemination demands that a wider audience/demographic receives these research findings. It is vital that access to the findings is promoted and facilitated particularly to those on the autism spectrum, research participants, families/carers, service providers, Government policy makers, employers, and depending on the focus of the study- education and health professionals. Dissemination is a condition of some funding bodies and is critical within the Autism CRC as knowledge translation and utilisation are key outputs/ deliverables. Findings cannot be used or translated into practice if they are not made public.

### Planning for Dissemination

Dissemination works best when it is considered and planned for from the outset. Therefore, it is wise to develop a publication plan or strategy with the whole research team.

This plan needs to be reviewed regularly, as the research being undertaken is modified.

Various publication avenues need to be considered, not only for the technical findings (scientific journals) and conferences, but also for the autistic community and whatever agencies, government, schools or other bodies might benefit from the findings.

It is prudent to consider and document the people assigned responsibility for various aspects of the dissemination strategy.

It is critical that input from peer researchers and/or advisory group members on the autism spectrum is sought in order to ascertain the most efficient and successful means of accessing the autistic community and providing feedback to research participants.

It is always best to start early.

## What are the Components of a Dissemination Plan?

Developing a dissemination plan can facilitate translation of the research into practice. A plan involves the following elements:

1. Research findings and products – what is to be disseminated?
2. End-users – who will it apply to or who will apply it in practice?
3. Dissemination partners – through which individuals, organisations and networks can end-users be reached? Peer researchers or advisory group members have a really important role to play here.
4. Communication – how will research outcomes be conveyed?
5. Evaluation – how will what worked be determined?
6. Dissemination work plan – where will we start?

Some useful tools to help develop a dissemination plan can be found at:

Carpenter, D., Nieva, V., Albaghal, T., & Sorra, J. (2005). Development of a planning tool to guide research dissemination. *Advances in Patient Safety: From Research to Implementation*, 4, 83-91. Retrieved from <http://www.ahrq.gov/professionals/quality-patient-safety/patient-safety-resources/resources/advances-in-patient-safety/vol4/planningtool.html>  
<http://www.ahrq.gov/qual/advances/planningtool.htm>

## Forms of Dissemination

There are many forms of dissemination as seen in the table below.

Written	Oral / Audio Visual	Visual	Other
Journal articles/papers	Conference posters	Posters	Poetry
Reports	Public talks/lectures	Visual summaries	Plays
Books/chapters	Conference presentations	Exhibitions	Art work
Executive summaries	Talks for special groups	Videos	Dance
Newsletters (mail/email)	Radio	Photo-voice galleries	Music
Newspaper articles – press releases	Television	Power-point slide shows	
Online media articles	You Tube clips		
Websites	Video/films/documentaries		
Facebook	Websites		
Twitter	Seminars		
Blogs			
Policy briefs			

## **Who is the Audience? Are there Different Audiences for Different Components of Research Findings?**

It is really important to firstly identify the audience/s and the messages appropriate for each demographic/group, then consider how the messages might best be conveyed. Audiences might include researchers, professionals/ clinicians across health, education, employment, early intervention, school sectors, government departments, service provider organisations, individuals on the spectrum, parents/carers of those on the spectrum, and the lay public to name a few.

Being clear about the audience and their needs, abilities, and interests is critical. Those with the lived experience, such as individuals on the spectrum and parents/carers of those on the spectrum will provide significant insights regarding understanding the specific demographic/audience and the key messages and dissemination strategies they feel will be most suitable for the audience with whom they identify.

## **How to Choose the Right Form of Dissemination for Research Findings?**

- Know the audience/s
- Consider audience needs, abilities, interests
- Identify key messages for specific audiences – it is likely that there will be slightly different messages for different audiences
- What will make the most impact?
- Engage with peer researchers to determine messages and the right form of dissemination
- Consider age/stage of audience, literacy levels, preferred modalities and level of knowledge likely in that community to date.

## **Faster Routes**

Given the time taken from submitting papers to academic journals to publication can be between 3 and 24 months or longer, this contributes significantly to the research-practice gap. Final reports may also be embargoed until publication is approved (and manuscripts are in press). Hence faster routes for dissemination may need to be sought. Some of these include:

- blogs
- tweets
- Facebook
- mobile phone texts
- websites
- YouTube
- newsletter updates
- conferences
- public talks/ presentations
- workshops.

When considering using faster routes, it is important to consider the impact of using these on future publication in journals, chapters, formal written reports and so on.

## Dissemination Approaches

Dissemination or knowledge translation activities essentially fall into two types, end-of-grant and integrated knowledge translation activities.

- **End-of-grant** activities are focused on translating knowledge into effective communication tools and disseminating those to a particular audience and present completed findings. These come after the research.
- **Integrated** approaches allow for more innovation and are effective in providing timely solutions and release of findings. They are more dynamic and involvement of stakeholders (particularly those on the spectrum or other target groups such as professionals/clinicians) is crucial.

In all of the research team's considerations it is important to determine the extent of the resources at your disposal as some dissemination avenues can be expensive and require specific expertise (videos, films, exhibitions) and ensure you can work within your budget. Importantly it is worth considering timing and windows of opportunity which may be strategic for your findings to reach the widest possible audiences (e.g., book launches at conferences, media releases aligned with Autism Awareness week, workshops at events, policy briefings at a time particular discussions are happening at a government level).

End-users on the spectrum can be of assistance with writing and reviewing the key research messages for their community. They may also provide ideas for dissemination by informing the team about forthcoming events and activities within the autistic community, the release date of various advocacy group newsletters, and the means of accessing the particular organisations such as autism group/advocacy network email lists. Apart from access, those on the autism spectrum will also provide valuable insights into the culture of specific groups, based upon their intimate knowledge and their lived experience, as to what has the best chance of being mutually beneficial and what might be best avoided.

## References

World Health Organisation, (2014). Toolkit for Research and Training in Tropical Diseases. Module 5 Disseminating Research Findings. [http://www.who.int/tdr/publications/year/2014/participant-workbook5\\_030414.pdf](http://www.who.int/tdr/publications/year/2014/participant-workbook5_030414.pdf)

See Checklist 8: Practices that Support Evaluation of Research Outcomes and Impact (page 67).

## Checklist 1: Practices that Support Participation in Research for Individuals on the Autism Spectrum

*Autism CRC aims to support the participation of individuals on the autism spectrum and their families in research projects as participants. This checklist will help researchers to check that they are considering key aspects which can increase the involvement of individuals on the spectrum in their research endeavours.*

### 1. Recruitment

Recruitment aims to engage the most appropriate individuals within the research project and tap the most relevant sources and networks.

Questions	Yes	No	Unsure
Are you using multiple channels of communication to recruit participants?			
If using the media or social media, have you connected with the Autism CRC Communication Manager to obtain assistance?			

### 2. Study information and consent practices

Study information and consent practices are cognisant of the information processing and literacy of individuals on the spectrum.

Questions	Yes	No	Unsure
Has there been consideration of language use? Is the language simple, clear and unambiguous?			
Have you considered use of visual supports, white space, format, photographs?			
Have you checked for understanding and provided opportunities for questions?			

### 3. Scheduling research appointments

Research appointments are scheduled to support the engagement of individuals on the spectrum.

Questions	Yes	No	Unsure
Consideration of meet and greet appointments made for familiarisation where needed?			



Consideration of the time and scheduling of appointments in relation to traffic, family commitments, location and how busy it is, child's rest times etc?			
Consideration of parking, maps, building access, directions and photographic support, parking vouchers etc?			
Have mobile numbers been provided?			
Have you ensured consistent team members are being dealt with to minimise changes for family/individuals?			

#### 4. Autism friendly environments

Attention is given to the physical and sensory aspects of the research environment as well as other aspects which make the environment more autism and family friendly?

Questions	Yes	No	Unsure
Have the physical and sensory aspects of the environment been considered?			
Have distractions been avoided?			
Have family friendly amenities been provided?			
Are bathrooms nearby without noisy hand dryers?			
Is there a chill out or calm down area/zone?			

#### 5. Supporting the research activities

There is consideration of the requirements of individuals on the spectrum to enable the research activities to be conducted easily.

Questions	Yes	No	Unsure
Are expectations clear?			
Are visual timetables used where necessary to assist with task completion?			
Are rest breaks and snack/toilet breaks scheduled?			
Is the language used by research assistants in keeping with the individual's level of understanding?			
Are alternative means of communication used when necessary?			
Have you checked for understanding of instructions?			
Have you incorporated time for individuals to process and consider their responses especially when complex questions are asked?			

## 6. Follow up

There is adequate follow up after sessions.

Questions	Yes	No	Unsure
Has a thank you been sent after the session using the person's preferred mode of communication?			
Are feedback or assessment results provided if negotiated?			
Have you checked with end-users on the spectrum regularly regarding feedback about meetings and their comfort levels?			
Has there been an opportunity to ask questions about the specific findings?			

## 7. Provision of research results to families and individuals on the spectrum

Individuals on the spectrum and their families are provided with results of research in lay language so that they are aware of what the study has found.

Questions	Yes	No	Unsure
Have multiple mechanisms been considered to provide study results – podcast, video, study newsletter etc?			
Have you used visuals to assist with representing findings?			
Have you considered the literacy level of written materials?			
Have you considered font size, use of white space?			
Have you ensured that you are writing for a lay not academic audience?			
Have you considered outlets such as network meetings, booths at conferences, stalls, free talks to disseminate results?			
Have you considered the media or social media? Have you contacted Autism CRC Communications Manager?			

See Inclusive Research Practice Guide 1: Engaging Individuals on the Autism Spectrum as Research Participants (page 12) and Inclusive Research Practice Guide 4: Providing Research Results to Individuals on the Autism Spectrum and Their Families (page 24).

## Checklist 2: Practices that Support Inclusion of Individuals on the Autism Spectrum in Research and Focus Groups

*Inclusive research groups demonstrate an understanding of the value of each member and how they contribute to achieving the goal. All activities occur in groups or teams and the group's approach is an essential element of successful engagement of individuals on the autism spectrum. This checklist can be completed as a way of reviewing your research or focus groups.*

### 1. Champions

Champions are researchers who promote the benefits of engagement with individuals on the spectrum in your research team.

Questions	Yes	No	Unsure
Do you have champions who are actively committed to engagement with individuals on the spectrum?			
Do your champions advocate and promote understanding about end-user involvement within your team and across the organisation?			

### 2. Mutual respect

Individuals on the spectrum are respected and valued for their contribution. Their views are actively sought, listened to and considered.

Questions	None	Some	The majority
Do the researchers and individuals on the spectrum in your groups demonstrate respect for the expertise of each participant?			
Are the views of individuals on the spectrum actively sought, listened to and considered?			
Have you allowed the time and opportunity for all group members to contribute?			

### 3. Equality

Individuals on the spectrum are considered equal members of the group.

Questions	None	Some	The majority
Do the professionals/researchers in your groups consider the contribution of individuals on the spectrum to be of equal merit to that of other group members?			
Do individuals on the spectrum feel that their contribution is of equal value?			

## 4. Communication

Professionals and individuals on the spectrum communicate in a meaningful way that builds knowledge, understanding and mutual respect.

Questions	None	Some	The majority
Do the professionals/researchers in your groups communicate with individuals on the spectrum in similar ways to how they might communicate with other group members taking into account their specific needs?			
Do professionals/researchers and individuals on the spectrum communicate effectively with one another both in and outside of groups?			

## 5. Attention to the environment

There is attention to the physical and sensory environment and how it may impact individuals on the spectrum attending groups.

Questions	Yes	No	Unsure
Have you considered the sensory and physical environment and autism friendliness when choosing a location for meetings?			
Have you checked with end-users on the spectrum about any issues in the environment that may affect their engagement?			
Have you considered additional requirements for virtual meetings to ensure end-users are able to participate equitably?			

## 6. Supporting the participation of individuals on the spectrum

There is attention to supporting the participation of individuals on the spectrum within research and focus groups.

Questions	Yes	No	Unsure
Have you considered timeliness of meeting papers, meeting protocols and ground rules, expectations, disclosure so that all members are on the same page?			
Have you checked with end-users on the spectrum regularly regarding feedback about meetings and their comfort levels?			
Have you considered a co-facilitator on the spectrum to assist with conducting focus groups?			
Have you assisted individuals on the spectrum to prepare adequately for group meetings?			
Have you scheduled groups at appropriate times to enable engagement of those on the spectrum?			

Adapted from Cancer Australia, National Framework for Consumer Involvement in Cancer Control. Consumer Involvement Toolkit. Inclusive Groups Checklist. ([http://consumerinvolvement.canceraustralia.gov.au/sites/default/files/doc-lib/accessible/service\\_managers/m8-44m3.1-10\\_checklist\\_sharedfocuschecklist.pdf](http://consumerinvolvement.canceraustralia.gov.au/sites/default/files/doc-lib/accessible/service_managers/m8-44m3.1-10_checklist_sharedfocuschecklist.pdf)) and Capable Consumer Checklist ([http://consumerinvolvement.canceraustralia.gov.au/sites/default/files/doc-lib/accessible/service\\_managers/m3.1-6\\_checklist\\_capableconsumerchecklist.pdf](http://consumerinvolvement.canceraustralia.gov.au/sites/default/files/doc-lib/accessible/service_managers/m3.1-6_checklist_capableconsumerchecklist.pdf))

See Inclusive Research Practice Guide 2: Facilitating Research Groups with Individuals on the Autism Spectrum and their Families (page 17).

## Checklist 3: Practices that Support Inclusion of Individuals on the Autism Spectrum in Advisory and Reference Groups

*The aim is to help individuals on the autism spectrum to utilise the knowledge developed from their experience and to be able to represent their views and those of others on the spectrum. Some of the questions here relate to the capabilities that individuals bring and some relate to your organisation's responsibilities. Invariably group members will be at different stages of development and experience in relation to participating in advisory or reference groups.*

### 1. End-user experience

End-users have experience with autism either as a carer, family member or someone on the spectrum.

Questions	None <sup>1</sup>	Some	The majority
Do your end-users have a personal experience of autism?			
Do your end-users bring a strategic approach to their advisory group involvement?			
Do your end-users disseminate information and provide feedback through their networks?			

1. If you have ticked none you may need to provide further support or training to your advisory group members.

### 2. End-user motivation

End-users are motivated to participate in a largely voluntary role to improve outcomes for others.

Questions	None	Some	The majority
Are your end-users motivated to contribute and improve your research outcomes?			
Are your end-users selected through a process that matches their capability to the role?			

### 3. End-user capability to match the environment

End-users develop their skills and capabilities to meet the requirements of the role.

Questions	None	Some	The majority
Are your end-users supported and trained in group participation?			
Are your end-users motivated to develop their capability?			

#### 4. End-user understanding of context

End-users develop an understanding of the health, education, disability, employment context where they are involved.

Questions	None	Some	The majority
Do your end-users have an understanding of the context of your research?			
Do your end-users understand the different types of roles that end-users might engage with in research?			

#### 5. End-user support and networks

End-users seek support through connections with end-user organisations, networks and support groups.

Questions	None	Some	The majority
Are your end-users offered assistance with sitting fees, travel and accommodation expenses?			
Are your end-users linked to end-user networks and organisations outside of your service?			

#### 6. Combined learning and professional development

Professionals and end-users undertake learning and professional development activities together and learn from each other's knowledge and experience.

Questions	None	Some	The majority
Have your end-users and professionals undertaken professional development activities together?			

#### 7. End-user mentoring

End-users support other end-users to actively participate and develop in the role of end-user representatives.

Questions	None	Some	The majority
Do your end-users support each other through any kind of formal or informal peer mentoring?			
Do your end-users encourage participation of groups who are not well represented such as those with intellectual disability or significant communication challenges?			



## 8. Attention to the environment

There is attention to the physical and sensory environment and how it may impact on individuals on the spectrum attending groups.

Questions	Yes	No	Unsure
Have you considered the sensory and physical environment and autism friendliness when choosing a location for meetings?			
Have you checked with end-users about any issues in the environment that may affect their engagement?			
Have you considered additional requirements for virtual meetings to ensure end-users are able to participate equitably?			

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Adapted from Cancer Australia, *National Framework for Consumer Involvement in Cancer Control*. Consumer Involvement Toolkit. Inclusive Groups Checklist. ([http://consumerinvolvement.canceraustralia.gov.au/sites/default/files/doc-lib/accessible/service\\_managers/m8-44m3.1-10\\_checklist\\_sharedfocuschecklist.pdf](http://consumerinvolvement.canceraustralia.gov.au/sites/default/files/doc-lib/accessible/service_managers/m8-44m3.1-10_checklist_sharedfocuschecklist.pdf)) and Capable Consumer Checklist ([http://consumerinvolvement.canceraustralia.gov.au/sites/default/files/doc-lib/accessible/service\\_managers/m3.1-6\\_checklist\\_capableconsumerchecklist.pdf](http://consumerinvolvement.canceraustralia.gov.au/sites/default/files/doc-lib/accessible/service_managers/m3.1-6_checklist_capableconsumerchecklist.pdf))

See Inclusive Research Practice Guide 3: Partnering with Individuals on the Autism Spectrum and their Families on Advisory Groups or Committees (page 21).

## Checklist 4: Practices that Support Co-Presenting Research Findings with Individuals on the Autism Spectrum

*Autism CRC aims to support the participation of individuals on the autism spectrum and their families in co-presenting research findings with researchers at conferences, meetings and in other fora. Co-presenting is associated with positive attitude change among the audience. This checklist will assist you to reflect on your experience and to check whether you have considered key elements in supporting success in co-presentation.*

### 1. Before the presentation

There are a number of considerations in the lead up to a presentation.

Questions	Yes	No	Unsure
Did you pay for conference registration fees, transport and other expenses if required?			
Did you discuss each of your roles in the presentation?			
Did you provide support with slides or other artwork?			
Did you provide clear directions about what was required?			
Did you have a dress rehearsal and opportunities for practice?			
Did you discuss how the individual wishes to be supported during the presentation including managing questions or ambient noise?			
Did the person know what to expect on the day?			
Did you check on anxiety triggers and how the person manages these?			

### 2. At the venue

A few simple tips can assist to make the day go well at the venue itself.

Questions	Yes	No	Unsure
Did you stick to your plan?			
Did you check out features of the environment that may have been of concern and ensure the person knew where facilities were?			
Were you able to rehearse at the venue?			
Did you minimise disruptions and distractions during the presentation?			

### 3. During the presentation

Checking how the person wishes to be supported during the presentation will assist you to know how to help.

Questions	Yes	No	Unsure
Did you stick to your joint plan?			
Did you consider having a support person assist the individual on the spectrum- or did you do this?			
Did you watch energy levels and the length of the presentation?			
Did you manage questions in a way that provided the individual with time to consider their response?			

### 4. After the presentation

Questions	Yes	No	Unsure
Did the person need some quiet time and space away from social demands?			
Did you provide feedback about the presentation and allow the individual to provide you with feedback?			
Did you thank the person in writing or text or phone afterwards?			
Did you assist the person to depart the venue and ensure they had transport?			
Did you pass on any positive feedback to the individual received after the presentation?			
Did you check how the individual felt about the presentation and whether he/she would be interested in presentations in the future?			

See Inclusive Research Practice Guide 5: Co-Presenting Research with Individuals on the Autism Spectrum and their Families (page 26).

## Checklist 5: Practices that Support Individuals on the Autism Spectrum in the Co-Production of Research

*The aim is to help end-users to utilise the knowledge developed from their experience and to be able to represent their views. Some of the questions relate to the capabilities individuals on the autism spectrum bring and some relate to your own or your organisation's responsibilities. Invariably individuals on the spectrum will be at different stages of development and experience in relation to participating in research co-production. This checklist will complement other research tools to help you reflect on your co-production practices.*

### 1. End-user experience

End-users have experience with autism either as a carer, family member or someone on the spectrum.

Questions	None	Some	The majority
Have you selected co-producers who are end-users with a personal experience of autism?			
Do your end-users bring a strategic approach to their research involvement?			
Do your end-users disseminate information and provide feedback through their networks?			

### 2. End-user motivation

End-users are motivated to participate in a largely voluntary role to improve outcomes for others.

Questions	None	Some	The majority
Are your end-users motivated to contribute and improve your research outcomes?			
Are your end-users selected through a process that matches their capability to the role?			

### 3. End-user capability to match the environment

End-users develop their skills and capabilities to meet the requirements of the role.

Questions	None	Some	The majority
Are your end-users supported and trained to engage with the research process?			
Have you considered the use of peer mentors to support the individuals on the spectrum?			

#### 4. End-user understanding of research context

End-users develop an understanding of the health, education, disability, and employment context in which the research takes place.

Questions	None	Some	The majority
Do your end-users have an understanding of the context of your research?			
Do your end-users understand the different types of end-user engagement in research?			

#### 5. Accessible information and support

End-users and professionals develop accessible information for people with on the spectrum that results from the research findings.

Questions	Not yet	Just starting	Established
Do you have a system for involving end-users in the development of resources resulting from research findings?			
Are your end-users involved in these projects from the very beginning?			
Are end-users' views sought regarding utilisation and knowledge translation?			

#### 6. Research and evaluation

End-users are involved in the design, conduct, translation and evaluation of research.

Questions	None	Some	The majority
Are your end-users involved in setting research priorities?			
Do your end-users participate in the design, development, implementation and evaluation of research?			
Are end-users involved in evaluation of knowledge translation and resource utilisation?			
Have you evaluated your end-user involvement in research co-production?			

## 7. End-user support and networks

End-users seek support through connections with end-user organisations, networks and support groups.

Questions	None	Some	The majority
Are your end-users offered assistance with sitting fees, travel and accommodation expenses?			
Are your end-users linked to end-user networks and organisations outside of your service?			

## 8. End-user mentoring

End-users support other end-users to actively participate and develop in the role of end-user representatives.

Questions	None	Some	The majority
Do your end-users support each other through any kind of formal or informal peer mentoring?			
Do your end-users encourage participation of groups who are not well represented including those with cognitive and/or communication challenges?			

## 9. Learning and development about research

End-users undertake learning and development opportunities to build their expertise in research participation and contribute to conferences and journals to share their expertise.

Questions	None	Some	The majority
Are your end-users offered regular professional development alongside other research team members?			
Have your end-users been invited to participate in conferences or co-author journal articles?			

## 10. Policy development

End-users participate in policy development to improve outcomes for individuals on the spectrum.

Questions	None	Some	The majority
Do your end-users help set policy priorities?			
Are your end-users involved in developing policy proposals?			
Do your end-users review and evaluate policy programs and initiatives?			

## 11. Benchmarking and linkages

End-users and professionals develop performance measures for the effectiveness of end-user involvement and to facilitate benchmarking opportunities for quality improvement.

Questions	None	Some	The majority
Are your end-users involved in developing measures for benchmarking end-user involvement?			

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Adapted from Cancer Australia, *National Framework for Consumer Involvement in Cancer Control*. Consumer Involvement Toolkit. Inclusive Groups Checklist. ([http://consumerinvolvement.canceraustralia.gov.au/sites/default/files/doc-lib/accessible/service\\_managers/m8-44m3.1-10\\_checklist\\_sharedfocuschecklist.pdf](http://consumerinvolvement.canceraustralia.gov.au/sites/default/files/doc-lib/accessible/service_managers/m8-44m3.1-10_checklist_sharedfocuschecklist.pdf)) and Capable Consumer Checklist ([http://consumerinvolvement.canceraustralia.gov.au/sites/default/files/doc-lib/accessible/service\\_managers/m3.1-6\\_checklist\\_capableconsumerchecklist.pdf](http://consumerinvolvement.canceraustralia.gov.au/sites/default/files/doc-lib/accessible/service_managers/m3.1-6_checklist_capableconsumerchecklist.pdf))

See Inclusive Research Practice Guide 6: Co-Producing Research with People on the Autism Spectrum and their Families (page 29).



## Checklist 6: Recruiting and Retaining Individuals on the Autism Spectrum as Research Participants in Longitudinal Studies

*The aim is to help researchers to utilise the knowledge developed from the experiences of end-users regarding research participation in longitudinal studies. This checklist will complement other research tools to help you reflect on your recruitment and retention strategies for longitudinal studies.*

### 1. Sensitivity to the full spectrum

The full range of individuals who are on the spectrum, considering co-occurring health conditions, sensory sensitivities, communication and cognitive capacities, as well as the input of parents and carers is acknowledged.

Questions	Not at all	To some extent	To a great extent
To what extent have you aimed to maximise the levels of both comfort and satisfaction for a broad range of participants taking part in the study?			
To what extent have the staff involved in the design and administration of research projects had training in and/or knowledge of the lived experience of people on the spectrum?			
To what extent have you considered the co-occurring health conditions, sensory sensitivities, communication and cognitive capacities of individuals on the spectrum?			
To what extent have you considered the input of parents and carers, where relevant (depending on participant age and the presence of co-existing cognitive impairments)?			

### 2. Maximise the range of options for participants to engage with the research

The range of options available to participants for engaging with the project, and clearly communicating these options to participants is maximised.

Questions	Not at all	To some extent	To a great extent
To what extent have you considered how and when individuals on the autism spectrum might engage?			
To what extent have you provided choices in how individuals participate such as interview, focus group, survey, online, face to face, by phone etc?			

To what extent have you considered options for preferred format for communication and materials?			
To what extent have you considered opting in or out with regard to rewards and incentives?			

### 3. Tailor recruitment methods

Recruitment methods are tailored to meet the needs of participants depending on their profile, networks and communication preferences.

Questions	Not at all	To some extent	To a great extent
To what extent have you considered the participant needs of your target group – on the spectrum, with an intellectual disability and neurotypical?			
To what extent have you considered the needs of carers and families of individuals on the spectrum?			
Have you developed a set of communication materials with consistent messages and visuals and clear project branding?			
Where there are multiple project parties, have you developed a consistent recruitment communications strategy?			

### 4. Participants' motivations for engagement

Participants' motivation for engagement in research studies have been considered in design of recruitment strategy and consideration of incentives/rewards.

Questions	Not at all	To some extent	To a great extent
To what extent have you communicated the purpose and end-user application/outcomes of the project?			
To what extent have you considered provision of ongoing updates, final reports, and provision of findings in an autism friendly manner to participants?			
To what extent have you provided a means for participant learning about the project, the CRC program and the autism community?			

## 5. Extrinsic rewards

Extrinsic rewards for participation are considered carefully with options provided regarding their use/acceptance by participants.

Questions	Not at all	To some extent	To a great extent
If using extrinsic rewards for participation, have you considered offering a range of choices e.g. vouchers, gift card or cash?			
Have you considered providing the option of participants donating the value of the reward to the research project or autism charity in lieu of cash or gift voucher?			
Have you tailored the use of rewards to the participant category/profile? For example, those with an intellectual disability are more likely to appreciate project branded items.			
Have you ensured that you provide reimbursement for travel costs and parking as a standard feature to acknowledge the direct costs incurred by participants?			

## 6. Safe, caring research community

Ensure a safe caring community during research activities that helps participants on the spectrum to belong to a community of like-minded people with diverse life experiences who are assisting/working with researchers.

Questions	Not at all	To some extent	To a great extent
To what extent have you considered the environment and the way you set up research groups and tasks to ensure that participants feel a sense of belonging to a research and autism community?			
To what extent have you considered a secure project website, a repository of project materials, opportunities for online discussion between participants and the research team?			
To what extent have you considered invitations to join an autism community event or invitations to hear the findings of the research reported in person, online or via hard copy?			

See Inclusive Research Practice Guide 7: Recruiting and Retaining Individuals on the Autism Spectrum as Research Participants in Longitudinal Studies (page 34).

## Checklist 7: Practices that Support Evaluation of Research Outcomes and Impact

*Autism CRC aims to support the participation of individuals on the spectrum and their families in research evaluation. This checklist will help peer researchers to check that they are considering key aspects which can increase the voice of the lived experience in project evaluation.*

### 1. Considerations prior to commencing the project

Prior to commencement the team should consider questions related to the project outcomes, likely impact, and evaluation.

Questions	Yes	No	Unsure
What do you want to change and how?			
What are the specific project objectives leading to change?			
What are the indicators of change and how are they measured?			
What will project success look like?			
How will the monitoring and evaluation data be analysed?			
What will be the impact of the research on the lives of those on the spectrum?			

### 2. Developing a monitoring and evaluation plan

#### 2.1 Engaging with end-users and stakeholders

Questions	Yes	No	Unsure
Have you planned for regular, relevant and timely engagement with end-users and stakeholders?			
Have you asked what project impact will look like for these groups?			
Have you considered the authentic needs of the end-users who will benefit from the project?			

#### 2.2 Developing the Plan

Questions	Yes	No	Unsure
Have you identified project inputs (the elements that team members and partners bring to the project including the lived experience of being on the spectrum)?			
Have you identified the research activities undertaken within the project, such as education and communication?			

Have you identified research outputs, sometimes called deliverables, such as products, training packages, educational outputs?			
Have you identified how the research will be utilised, such as whom and how many people will use the outputs?			
Have you identified research outcomes which are what happened as a result of the research activities and outputs (e.g. change in behaviour, attitudes, policies, school practices)?			
Have you considered research impact- that is, the effects or outcomes of the research in terms of value and benefit as a result of the outputs?			
Have you ensured that individuals with the lived experience have provided input into the research impacts and their measurement?			

### 2.3 Determine the methodology

Questions	None	Some	The majority
Have you agreed on methods of data collection, analysis and reporting?			
Have those with the lived experience provided input into the research outcomes and their utility?			
In analysis of findings have you sought to understand the autistic perspective?			

### 2.4 Assign responsibility and set targets

Questions	None	Some	The majority
Are expectations of all involved clear?			
Have roles and responsibilities been described and agreed?			
Have you set targets /timeframe milestones with end-users and stakeholders so all are clear on expected progress?			

### 2.5 Reporting, dissemination and utilisation of results

Questions	Yes	No	Unsure
Have you addressed end-users information and learning needs throughout to ensure utilisation of findings?			
Have appropriate dissemination avenues been considered to meet end-users needs and those of other stakeholders?			
Have you varied language, style and format to meet various end-user and stakeholder needs rather than researcher needs?			
Have you considered technical language and complexity, and adjusted where required?			

See Inclusive Research Practice Guide 8: Evaluation of Research Outcomes and Impact (page 39).

## Checklist 8: Practices that Support Dissemination and Utilisation of Findings

*Autism CRC aims to support the participation of individuals on the spectrum and their families in research dissemination and utilisation. This checklist will help peer researchers to check that they are considering key aspects which can increase the voice of those with the lived experience in disseminating, translating and utilising findings. Those on the spectrum will have specific insights into how best to engage with the autistic community and the appropriate messaging.*

### 1. Planning for dissemination

Making research findings public is the only way to ensure that they can be translated into practice, however, translation of knowledge requires more than just making findings public.

Questions	Yes	No	Unsure
Are you considering dissemination from the outset of the project?			
Are you clear about the likely avenues for dissemination for this project?			
As well as considering scientific journals and conferences, have you identified other avenues for dissemination?			
Are you planning opportunities for co-presenting findings/outcomes with people on the spectrum?			
Have you considered what agencies, systems, government departments or other bodies might benefit from the findings?			
Have you developed with your peer researchers/advisors, a strategy for engaging with the autistic community?			

### 2. Components of dissemination

#### 2.1 Forms of dissemination

Questions	Yes	No	Unsure
Have you considered written forms of communication and who they might suit best?			
Have you considered oral/audio visual means of communication and who they might suit best?			
Have you considered visual means of disseminating findings (e.g. posters, exhibitions, visual summaries)?			
Are there other means of dissemination (e.g. poetry, plays, art, dance, music) that might be best for a particular audience?			

## 2.2. Considering the audience/s

Questions	Yes	No	Unsure
Have you identified your audience/s?			
Have you identified which findings/outcomes are best suited for which audience?			
Have you considered the needs, interests, and abilities of your various audience/s and how best to engage with them?			
Have you considered which key messages need to be addressed with which audiences (where relevant)?			
Have you considered who is best to present to which audiences? Has co-presenting been considered?			
Have you ensured that individuals with the lived experience have provided input into the dissemination strategy and key messages for various audiences?			

## 2.3 Dissemination approaches

Questions	None	Some	The majority
Have you considered social media, blogs, tweets, Facebook and/or YouTube videos including potential risks and their management?			
Have those with the lived experience provided input into the dissemination strategy?			
Have you considered integrated (as you go) as well as end of grant activities?			
Have you realistically considered the resources (e.g. budget and human resources) available?			

## 2.4 Reporting, dissemination and utilisation of results

Questions	Yes	No	Unsure
Have you addressed end-users information and learning needs throughout to ensure utilisation of findings?			
Have appropriate dissemination avenues been considered to meet end-users needs and those of other stakeholders?			
Have you varied language, style and format to meet various end-user and stakeholder needs rather than researcher needs?			
Have you considered technical language and complexity, and adjusted where required?			

See Inclusive Research Practice Guide 9: Disseminating and Utilising Findings (page 43).



## Teleconference and Virtual Meeting Etiquette

### 1. Choose a quiet location.

Everyone else in the meeting hears every noise you make, and in virtual meetings they can see what is going on around you. Close your door and consider putting a “Do Not Disturb – Meeting In Session” sign on the door. If you don’t have a private office, find an available office or conference room to use for this purpose. Reserve a quiet location so this won’t be left up to chance. Even if you use the mute button on your device when you are not speaking, you still need to be in a quiet location for when you un-mute your device when you speak.

### 2. Learn how to use the technology.

Become familiar with your equipment and/or software before the meeting. Arrange a practice meeting with the organiser if it is the first time you have used the technology. Learn how to use the features, particularly the mute function which will allow you to suspend audio input. For virtual meetings, also learn how to share your audio and webcam.

### 3. Call in on time.

Most teleconference providers or systems feature a call announcement when someone joins the call. This can be a chime, bell or some other sound. Each time someone joins the call late, a word or two from the ongoing discussion is lost to everyone already on the call. Would you walk into a conference late if a chime sounded through the public address system when you opened the door, instead of the words the speaker was saying? That’s exactly what happens when you call into a teleconference late.

With virtual meetings, people often introduce themselves at the beginning of the meeting and any technological issues are resolved. You could miss this opportunity if you are late to join the meeting.

### 4. Stop sharing your audio.

Learn how to stop sharing your audio in advance and consider other locations and/or equipment if your technology doesn’t have mute. Even if you are behind a closed door in your private office, there is the possibility of noise. This is particularly true if you simply can’t devote your full attention to the call and think you have to check your e-mail, thumb through your mail, or whisper to someone who just walked into your office.

The keyboard sounds, the paper rustling or virtually anything you decide to do will make noise, so please use the mute button or feature on your phone. Also, don't forget to take your device off mute when you want to join a conversation. Then put it back on mute until the next time you want to join the conversation/ meeting.

Remember though that you are in a meeting so don't get distracted by e-mail or web-surfing, and try not to eat or drink so you can be respond to questions directed at you.

**5. Never put the call on hold if teleconferencing.**

Whether you think you have music on hold or not, do not put a teleconference call on hold. There are many different features on phone systems that can start to work either right away or after a call has been on hold for a while. All of these features will disrupt the conference call in a major way. Everyone else on the call is powerless to correct the problem. In some cases dozens of people will be wasting their time trying to pick out a conversation around the "music on hold" or "We value your call. Please continue to hold and someone will be right with you." announcement from your system. If you simply must make a call, hang up your phone. The simple "tone" announcement on most conference call systems that tell us someone left the call is infinitely preferably to almost total disruption of someone putting the call on hold.

**6. Avoid mobile/cordless phones and Wi-Fi.**

If you need to use a mobile or cordless phone so you can move around during a conference call, perhaps you should consider having someone else attend the call in your place. The potential static and poor connections of these types of phones is likely to lower the quality and value of the conference call for everyone. If you are traveling and must use a cellular phone, find a location that has excellent service (lots of reception bars) and don't move around during the call. Also make sure your battery has sufficient charge to last for the entire call and keep in mind the quiet location and all the other teleconference etiquette tips.

If you attending a virtual meeting, connect to the internet via a cord rather than Wi-Fi if possible. Often the speed will be faster and result in clearer streaming. If you need to use Wi-Fi, move your device to the place where you get the best internet connection (the most

bars). If there is a delay between your speech and audio, stop sharing your webcam.

**7. Do you need a speakerphone or wide angled camera?**

If you have a group participating in a meeting at your location, it might make it more valuable to get them together and use a speakerphone for a teleconference, or a wide angled camera for a virtual meeting. A wide angled camera will allow multiple people in the room to join in on the one stream.

If using speakerphone though, consider it is probably being used at several locations, including the site where the teleconference is being moderated. Speakerphones, particularly those built into your desktop phone, can add to the overall noise of the teleconference and create a “hollow” or “tunnel” sound on the call. So if you need one, by all means use one. But if it’s just you alone at your location, consider whether or not you need to use one.

**8. Turn off call waiting if using a phone.**

If you have this feature on your phone, everyone on the call will hear the sound it makes when someone is trying to reach you. This feature is not only something you have on your cellular phone, but can be found on many other kinds of phone systems as well.

**9. State your name before speaking.**

Since teleconference call attendees are not all in the same room, it is important for others on the line to know who is speaking so that they can better understand the context of your comments. In some cases you may also want to state your role, company, or location after your name; this is most relevant when your conference call includes people from other groups or organisations that have never met you face-to-face.

If your virtual meeting includes people using audio but not video, it is important that you to state your name before talking as they will not be able to see who is speaking.

**10. Be aware of audio and/or video delay.**

Virtual meetings often have a two or three second delay between when a person speaks and when the information is heard and seen by others. This can lead to people speaking over each other. If you are running the meeting, make sure that you leave enough time for someone to answer a question. As a participant, you can raise your hand to alert the meeting chair to the fact that you wish to speak.



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