



Guidelines for conducting research with the autism community

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Guidelines for conducting research with the autistic community

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Website link:

<http://www.autism.manchester.ac.uk/research/projects/research-guidelines/>

Overview

This guidance covers the considerations that researchers should take into account when conducting research with the autistic community (autistic adults, parents of autistic children, family members and carers). It promotes effective communication and equal partnerships between the autism and research communities so that the needs of participants pre, during and post research are taken into account and that they are supported through the research pathway. Although the focus is on research with the autism community, it is anticipated that the recommendations will be helpful for all participants, not just those with autism. This guidance is based on discussions with the autistic community and it is anticipated that they will be reviewed and modified with further discussion over time. In particular, we would like to acknowledge that although Autism@Manchester aims to follow these guidelines it is likely that we are not achieving all the recommendations and there is always room for improvement.

Who is it for?

- Researchers in the field of autism
- The autistic community

Researcher responsibilities

Researchers are asked to take this guideline into account, alongside the individual needs, preferences and values of their participants and their research. The application of the recommendations in this guideline is not mandatory.

In addition to these guidelines, all individuals involved in research are expected to ensure that the highest standards of integrity, honesty and professionalism are adhered to, in respect of their own actions and how they respond to the actions of others. This relates to the whole extent of research work including, but not limited to: designing studies and experiments; generating, recording, archiving, analysing and interpreting data; sharing data and materials; applying for funding; presenting and publishing results; training new researchers, staff and students; and peer reviewing the work of other researchers. The direct and indirect involvements of colleagues, collaborators and others should always be acknowledged.

Where applicable, the group expects researchers to observe the standards of research practice set out in guidelines published by scientific and learned societies, and other relevant professional bodies. All researchers should be aware of the legal requirements which regulate their work including health and safety legislation, the Data Protection Act, the Freedom of Information Act and the Declaration of Helsinki – Ethical Principles for Medical Research Involving Human Subjects.

How was this guidance developed?

The recommendations in this guideline represent the view of Autism@Manchester, based on workshop consultations with the autistic community.

Background on workshop consultations

Autism@Manchester is a community of academics, clinicians, practitioners, autistic individuals and their families and carers working together to achieve quality research with real meaning for people with autism. It encourages and facilitates a more holistic approach to research so the autism and research communities can come together more easily to work and share knowledge about autism research. The ultimate goal is to enable researchers to produce quality research with real meaning for autistic people. In order to forward this goal, Autism@Manchester conducted a series of workshops with the autism community in order to improve mutual understanding around the research process, look at the impact of research on participants and explore how the academic and autism communities could better work together on research. These were conducted as a collaboration between Autism@Manchester and Salfordautism, an autism support group led and run by autistic professionals serving the autistic community in the Greater Manchester area.

This guideline reflects the discussions and suggestions made in the focus groups held with the autistic community during the workshops in consideration of their role as 'expert by experience.' Workshop participants were also consulted during the drafting of this document and their views incorporated.

Authors

Autism@Manchester: Emma Gowen¹, Rachel Taylor², Daniel Poole¹, Thomas Bleazard³, Anat Greenstein⁴, Peter Baimbridge⁵

1. Division of Neuroscience and Experimental Psychology, School of biological Sciences, Faculty of Biology, Medicine and Health Sciences, The University of Manchester
2. The University of Bolton
3. Division of Population Health, Health Services Research & Primary Care, School of Health Sciences, Faculty of Biology, Medicine and Health Sciences, The University of Manchester
4. Manchester Metropolitan University
5. Salfordautism

Recommendations

This guidance provides practical recommendations in four areas:

- Pre-Research considerations
- Recruitment of participants
- Procedural considerations
- Post-research considerations

Pre-research considerations

Interviews and focus group discussions with the autistic community showed that there is a strong desire for autistic people's involvement in research to go far beyond assuming the passive role of research participants, with the aspiration that the autistic community are involved at all levels of research from conception all the way through to writing of papers. There are also active researchers already within the autistic community and they could play integral parts in both the planning and the studies themselves.

A key component that was highlighted during focus groups is the need to ensure that research is not just done for the sake of research. Although there will always be a need for basic research, in order to move understanding forward, its contribution towards real benefit should be kept in mind by discussing the research with the autistic community. Following on from this, researchers need to make sure they clearly communicate the perceived benefit to the autism community when promoting research. The autistic community also expressed fear about “secret research” – that researchers were holding information back about how all the findings would be used. They wanted to have more information about who the researchers were and to understand the philosophy of the researcher before making the decision about becoming involved in the research. By involving the autistic community at all stages of the research and improving knowledge around how gaining ethical approval for studies removes the possibility of “secret research”, these fears can be minimised.

Key recommendations

- I. Create expert by experience panel in order to have a collaborative approach to research questions and studies.
- II. Use expert by experience panel as a pre-ethics check for research proposals.
- III. Closely involve members of the autistic community as partners in specific research projects from the beginning to end with co-produced outputs. Factor payment for their expertise into research grants.
- IV. Reciprocity should be a key consideration within research, no research should be done that is 'just for research sake' with clear lines of outcomes and outputs that enhance the scientific, social and physical representation of autism and associated areas of interest.
- V. Provide introductory information such as photos, research interests and a brief CV about the key people running the research. This could be in the form of a link to a website or information in the participant information sheet.

Recruitment of participants

The recruitment of participants is vital for research. Underutilised avenues for potential recruitment include social media sites, autism web sites, links with GPs, the NHS and support groups. Workshop participants reported missing opportunities due to adverts being scattered and that a single directory of research opportunities would be ideal.

The researchers should clearly outline to all actual and potential participants what taking part in study will involve. This approach will minimise the chance of stress and anxiety induced by unexpected activities during the research. For example, autistic participants in research studies have mentioned the shock and anxiety associated with being presented with a task that was not mentioned in the participant information sheet (e.g. the ADOS), leading to potentially incorrect responses on the test.

Responses during the workshop indicated that the autistic community value taking part in research. Participants commented that taking part in research provided them with the opportunity to discuss autism with others and visit new places and enabled them to gain more knowledge and understanding about themselves or their children. Researchers should take these motivations into account when developing research protocol and recruitment documents (e.g. participant information sheets, debriefing notes) so that sufficient information about the research and findings is provided during and following the visit.

Key recommendations

- I. Actively seek more connections with the autistic community via the internet, key stakeholder agencies and other associated organisations, such as schools, play groups and community centres.
- II. The outcome of the research is not just the research, a move towards looking at what other gains can be made by the participants should be discussed in all project proposals. A participation impact assessment should be a key consideration of all research. In particular consider:
 - a. What information can you give to participants about the research, the findings and their own personal results
 - b. Ask whether the participant requires time to visit the local area and try to accommodate this.
- III. Clear information, including the need for screening tests (if applicable) should be made available to all potential participants. Having an expert by experience group read through this information will aid clarity.

Procedural considerations

Access to buildings where research is taking place and also the routes that are available to get to the buildings need to be taken into account. Providing clear information including pictures of the route and the rooms to be used within the research was considered good practice for autistic participants, but only when there is certainty that there wouldn't be any changes on the day.

A key recommendation from focus group discussions was that a good way to avoid anxiety and reduce stress is to provide a taxi service or organise alternative transport. Having a person to meet and greet at the door of the building or at the transport station was also considered useful. Refreshments and a quiet area should be provided (1) on arrival to allow participants the time to relax and unwind following travelling to a venue as autistic people often find travelling particularly stressful and (2) during the visit as autistic participants highlight the taxing and tiring nature of some research.

Childcare and other caring responsibilities should be a part of the discussion within the project proposal with key dates/times being avoided if possible. Provision of a crèche should be considered if possible within the dynamics of the research.

Participants discussed the difficulties associated with completing diagnostic tests repeatedly (such as the ADOS) when taking part in studies at different institutions. They were unclear as to whether to respond as they originally had or to change their response according to their knowledge of the test. Researchers from different groups or universities should attempt to share details of these screening tests amongst themselves (with the participants' consent).

Key recommendations

- I. Reduce anxiety and stress of getting to the research by planning out how participants can best get to the venue and provide clear, up-to-date instructions and pictures.
- II. Think about access to the venue and whether there a need to arrange someone to meet the participant at an arrival point
- III. Provision of a comfortable relaxation area should be made, including provision of refreshments prior to and during the research, for those participants who may need it.
- IV. Duration of planned breaks during the research should be flexible to allow extra time for those who need it.
- V. Consider childcare or other caring responsibilities when planning the research.
- VI. Incorporate provision of data sharing into ethics applications to allow sharing of screening tests amongst researchers to reduce the burden on researchers and participants

Post-research considerations

Immediately after the research has finished ensure a full debriefing is provided, including information on what the research was about and what will happen to the findings. It may be beneficial to share adverts about other research projects from the research group or other institutions that the participant may be interested in along with information for further support if needed once a study is complete. Doing this on an ongoing basis would help general understanding of research and the subject area, as well as supporting the maintenance of any pools of individuals developed.

An area of great concern for participants is the unavailability of research outcomes, such as publications or knowledge developed, to the autism community. This is due to problems in locating relevant research, accessing published papers due to pay-wall restrictions and difficulties understanding papers that are written in highly specialised jargon. Researchers should aim to write a lay summary of their findings and disseminate this to their participants. A mixed approach to delivery of findings is suggested using posters, videos, drawings, pictures and written media. It is imperative that all participants are able to access the findings, so researchers should consider how best to cascade any papers, documents or posters alongside the need to publish in open access journals. If publishing in closed journals, sharing of pre-prints would be an option. Workshop participants suggested using social media and websites relevant to autism as well as a discussion based arena so that people can engage with the findings and comment on them.

Workshop participants particularly highlighted this final point relating to the discussion of findings. Opportunities to discuss research findings with researchers provide a way of making researchers more aware of autistic ideas and interpretations. Therefore, a more reciprocal and cyclical view is recommended, in which the researchers share their findings and receive feedback that may alter the interpretations of results or spring new ideas for research.

Key recommendations

- I. Post research support is as important as procedural considerations, so information should always be provided to all participants as to 'what happens next?'
- II. Dissemination of the research findings should have the autistic community at the heart of it.
 - a. Disseminate a lay summary of the study findings to participants
 - b. Consider using a variety of media
 - c. Use a variety of dissemination methods such as emailing participants, using social media or in particular a discussion forum
- III. Regular expert by experience panels and workshops related to the research project should be held to enable discussion of research findings.