

## **Guidelines for conducting research studies with the autism community**

### **Author Details.**

1: Emma Gowen.

Division of Neuroscience and Experimental Psychology, School of biological Sciences,  
Faculty of Biology, Medicine and Health Sciences, The University of Manchester.

Salfordautism.

[emma.gowen@manchester.ac.uk](mailto:emma.gowen@manchester.ac.uk)

2: Rachel Taylor.

The University of Bolton

3: Thomas Bleazard.

The University of Bolton.

4: Anat Greenstein.

The University of Bolton.

5: Peter Baimbridge.

Division of Neuroscience and Experimental Psychology, School of biological Sciences,  
Faculty of Biology, Medicine and Health Sciences, The University of Manchester.

Salfordautism.

6: Daniel Poole.

Division of Neuroscience and Experimental Psychology, School of biological Sciences,  
Faculty of Biology, Medicine and Health Sciences, The University of Manchester.

### **Abstract.**

There has been growing awareness of the concern expressed by autism communities that the majority of research conducted does not reflect the priorities or needs of autistic people and their families. Further, many autistic people report that they feel unable to influence research and desire greater involvement in the research process. Our research generated practical guidelines for researchers to consider when conducting autism research, in order to increase involvement, collaboration and trust between researchers and the autism community. These guidelines are based on the output of focus groups and interview discussions with twenty-two autistic adults and eight parents of autistic children, conducted during a series of workshops carried out as a collaboration between the research network Autism@Manchester and Salfordautism, an autism support group led and run by autistic professionals.

The guidelines are organised into four sections: (1) pre-study considerations, (2) recruitment of participants, (3) study visit considerations and (4) post-study considerations. These sections are structured to reflect the research pathway, to allow researchers to understand more easily how to incorporate the recommendations into their research. The recommendations promote effective communication and equal partnerships between the autism and research communities, so that the needs of participants pre-research, during and post- research are taken into account, and so that participants are supported to become involved in research at the level they choose. It is hoped that by implementing transparent and participatory approaches to their work, researchers might be able to reduce some of the dissatisfaction that members of the autism community feel towards research, leading to higher standards in autism research.

### **Keywords:**

Autism, participatory research, autism community, public involvement, Open Science

### **Introduction**

In recent years, there has been growing concern about a disconnect between researchers and the autism community (autistic people, their parents and family members) (Chown *et al.*, 2017; Milton, 2014; Milton and Bracher, 2013; Pellicano and Stears, 2011; Woods and Waltz, 2019). It has been shown that there is a large gap between research priorities identified by academics and funding bodies, and those identified by autistic people and their families (Pellicano, Dinsmore and Charman, 2014a). While the majority of funded research focuses on basic research into biology, brain function and cognition, the autistic community would prefer more research on aspects related to day-to-day living, such as improving services and developing programmes to enhance individuals' life skills. Indeed, in 2016 only 27% of the total research expenditure in the UK was spent on the top ten autism community priorities identified by the James Lind Alliance Priority Setting Partnership (Warner, Cooper and Cusack, 2019).

In addition, the autism community has reported dissatisfaction with the level of engagement they have had with research. Poor communication about research opportunities and findings prevents them from getting involved in and influencing research, and leads to dissatisfaction with interpretations drawn about research (Pellicano, Dinsmore and Charman, 2014b). In contrast, researchers viewed themselves as engaged with the autism community in terms of dissemination and consultation.

This disconnect may be due to a number of factors, such as lack of involvement of the autism community in priority-setting, use of demeaning language about autistic people when describing research, resistance on behalf of researchers to involving the autism community, and unrealistic expectations about research from the autism community (Nicolaidis *et al.*, 2011; Pellicano, Dinsmore and Charman, 2014b). In addition, charities that often work closely with research bodies and governments to set research priorities have not involved autistic people in decision-making, and often have their own agendas that are not the same as those of the community they claim to serve (Petric, Beadle-Brown and Bradshaw, 2017). This has reduced the opportunity for autistic people to influence research, and has further increased mistrust through negative "awareness" campaigns that promote charities but fail to change public perception of autism (Rosenblatt, 2018; Waltz, 2012).

A further contributing factor may be a lack of familiarity of researchers with “autism as it is lived” and “real autistic people” outside of the laboratory. This is likely to exaggerate the difficulties that non-autistic researchers have with understanding autistic people, termed “The double empathy problem,” where autistic and non-autistic people fail to understand each other due to the differences in how they experience the world (Milton, 2012; Milton, Heasman and Sheppard 2018). Applying this to research, non-autistic people may have difficulties in understanding concerns and experiences of autistic people, leading to a lack of appreciation of what autistic people might find difficult when taking part in research or how autistic people might interpret what researchers are doing. Consequently, studies may be designed in a way that causes autistic people to misinterpret what the researcher is trying to ask them to do, and/or to complete the research study in a state of anxiety, which will impact the data collection and potentially lead to unrepresentative findings.

The aim of this work is to provide practical guidelines for researchers to consider when embarking on autism research, in order to increase involvement, collaboration and trust between researchers and the autism community. The ultimate goal is to improve the experience and participation opportunities that autistic people have throughout the research process (i.e. from idea generation, through design, implementation, analysis, publication and dissemination).

### ***Research participation***

Different types of participation have been conceptualised as a ladder of power (Arnstein, 1969), ranging from non-participation (e.g. being told what to do), through tokenism (e.g. informing after the fact instead of consultation in advance) to citizen power (e.g. partnership), where planning and decision-making are shared. Citizen power is akin to “participatory research,” where researchers and members of the community being researched engage, on an equal footing, in a sustained and bi-directional manner, in collaboration and partnership. Participatory research arose in the latter twentieth century within the disabled peoples movement, and the slogan “nothing about us, without us” was particularly taken up by those with learning disabilities (Walmsley, 2004; Walmsley and Johnson, 2003; Walmsley, Strnadová and Johnson, 2018).

A more nuanced model of Arnstein’s ladder has since been suggested that emphasises co-production without always needing to aim for citizen power, using a variety of involvement methods that cater for a diverse community of “users” at different points in their life (Tritter and McCallum, 2006). For example, some may seek to become involved in a two-way dialogue as partners, while others may wish to provide input through questionnaires or even not wish to become involved. It is this more flexible approach that our work more closely aligns with, enabling autistic people to become involved at the level of participation they choose so that we can strive to produce reliable, meaningful research that can positively impact autistic people’s lives.

Increasing the opportunities for involvement and participatory research is important for increasing trust between researchers and the autism community, ensuring that the research priorities of autistic people are addressed and for creating research that is accessible, implemented and has real meaning for autistic people (Walmsley, Strnadová and Johnson, 2018). It also has direct benefits for the quality of research by improving design and feasibility, contextualising research in terms of real-world meaning, and ensuring epistemological and ethical integrity (Chown *et al.*, 2017; Grinker *et al.*, 2012; Milton and Bracher, 2013; Walmsley, Strnadová and Johnson, 2018; Woods and Waltz, 2019). Although still relatively rare, there are some examples of emerging partnerships, particularly in the UK and US that involve the autism community in priority-setting exercises. Recent examples include

the projects “Making the future together: Shaping autism research through meaningful participation” (Fletcher-Watson *et al.*, 2018); “Autism: Top 10 Research Priorities,” developed by the charity Autistica and the James Lind Alliance; the Participatory Autism Research Collective (PARC; Participatory Autism Research Collective, 2017); and the “Innovative Technologies for Autism: Critical Reflections on Digital Bubbles” seminar series (Parsons *et al.*, 2019). The Shaping Autism Research project has produced a starter pack for participatory autism research, providing some principles for how researchers, autistic people and their allies can work together in research (Pellicano *et al.*, 2017). In the US, the Academic Autism Spectrum Partnership in Research and Education (AASPIRE) is a more established partnership that brings the academic and autism communities together as equal partners to work on projects that are of relevance to autistic adults (Nicolaidis *et al.*, 2011). Further examples of participatory and autism-led research can also be found in Canada (Tesfaye *et al.*, 2019; Young *et al.*, 2019) and Sweden (Bertilsdotter Rosqvist, 2019).

### ***Research procedure and aims***

Our research builds on this emerging body of work by providing succinct and practical recommendations that researchers should take into account when conducting research with the autism community, in order to foster an ethos guided more by participatory research principles. The recommendations are targeted at autism researchers, but particularly those working in behavioural, cognitive and neuroscience fields where autistic adults or children generally visit a research site (e.g. a university or hospital). Currently, research into the biology, brain and cognition of autism is the most widely-funded autism research (for example, 56% of funded studies in the UK: Pellicano, Disimore and Carman, 2014a), so improving the autism community’s experience of this research may go some way to alleviating the disconnect with researchers.

The guidelines are based on focus group and interview discussions with autistic adults and parents of autistic children, conducted during a series of workshops that aimed to improve mutual understanding around the research process and to explore how the academic and autism communities could better work together on research. The project was carried out as a collaboration between Autism@Manchester and Salfordautism. Salfordautism is an autism support group led and run by autistic professionals serving the autism community in the Greater Manchester area in the UK. Autism@Manchester (Autism@Manchester, 2017) is a community of academics, clinicians, practitioners, autistic individuals and their families that encourages and facilitates collaboration and knowledge exchange around autism research. This collaboration enabled autistic input at all stages of the project, including funding proposal, design, recruitment, data collection, discussion of results and paper-writing.

The guidelines are organised into four sections: (1) pre-study considerations, (2) recruitment of participants (3), study visit considerations and (4) post-study considerations. These sections are structured to reflect the research pathway, to allow researchers to easily understand how to incorporate the recommendations into their research. These guidelines are aimed at autism researchers, particularly those with limited experience of working with the autism community or with participatory approaches (e.g. early career researchers, or established researchers who are entering the autism field). Within each section are recommendations that are ordered to start with the least onerous, minimum standards that might be expected of researchers, and building up towards more comprehensive models of inclusive working. The guidelines are also aimed at the autism community, to highlight ways of getting involved in research and to share expectations of best practice with researchers.

## Methodology

Thirty people took part in the study, including 22 autistic adults (20 male, 2 female) and eight parents of autistic children (6 mothers, 2 fathers). Participants were recruited from the Greater Manchester area through Autism@Manchester or Salfordautism mailing lists, and as well as via a UK-based conference for autistic people. All participants gave informed consent, and the study was approved by the University of Manchester Research Ethics Committee.

Five focus groups and two interviews were facilitated by authors of the paper (EG, AG, TB, PB, DP), each lasting approximately one hour and following an identical schedule. Two people opted for interviews, as they were more comfortable with this format rather than focus groups.

Participants recruited from the Greater Manchester area all attended at the same time for one focus group session. They were randomly divided into three groups of roughly equal size (without predefined criteria) and escorted to separate quiet rooms for the focus groups. Participants recruited at the conference could choose to attend a focus group session, which were included on the conference schedule at particular timeslots. If there were too many participants for a particular session (>5), extra participants were invited to return at a later time. Two focus groups and two interviews were conducted in a quiet room.

The focus group schedule (see *Box 1*) was generated through discussion within the research team. The participants were given access to the schedule in advance of the focus group, and were informed that they were welcome to complete interviews or written responses to focus group questions if preferred. All focus group participants were able to contribute verbally, and none used visual or augmentative communication methods. A note-taker was present at each focus group, but did not contribute to the discussion.

All focus groups and interviews were recorded and transcribed in full, with participants given a number to preserve their anonymity. The research team read through the transcribed documents and generated summaries and key recommendations for the four sections of the guideline. A more detailed analysis of participants' experiences and perceptions of research will be included in a future manuscript. Here, we have drawn out practical information regarding conducting research studies.

**Box 1: Focus group schedule**

1. What previous involvement have you had with research? What did you like/not like about it/would you participate again/What did you find easy/difficult? What do you think could have been done better and how?
2. Do you have any concerns about getting involved in research?
3. How would you like to get involved in the future?
4. What advantages are there to participating in research (thinking about the different ways you can participate as discussed in the introductory presentations)?
5. What do you think might put off or prevent autistic people or their families from taking part in research?
6. How might we make it easier for autistic people or their families to take part in research?
7. How would you normally expect to hear about things like opportunities to take part in research? [Internet / website, Email, Facebook, Twitter, from a friend/someone you know, Radio, TV, magazine]
8. What would be your preferred ways for hearing about opportunities to take part in research?
9. How do you think we should share the results of these workshops?

**Results: Recommendations**

This guidance provides practical recommendations in four areas:

- Pre-study considerations
- Recruitment of participants
- Study visit considerations
- Post-study considerations

Note that the recommendations are ordered to start with the least onerous, minimum standards that might be expected of researchers, and build up towards more comprehensive models of inclusive working.

## **Pre-study considerations**

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

A key component highlighted during focus groups is the need to ensure that research is not just done for the sake of research. Although participants expressed the need for basic research, its contribution towards real benefits should be kept in mind by discussing the research with the autism community. Following on from this, researchers need to make sure they clearly communicate the perceived benefit to the autism community when promoting research. Our participants also expressed fear about "secret research" – that researchers were holding information back about how the findings would be used. They wanted to have more information about who the researchers were and to understand the philosophy of the researchers before making the decision about becoming involved in the research. By involving the autism 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.

## **Sample quotes**

*"I think that it's really important for people who have an interest in researching autism to be very clear with those that they are inviting to contribute why they have an interest. What is their personal background? What has brought them to autism research?"*

*"I think the idea of autistic people actually having influence on the research that was done would be an excellent one... If it's not done that way, it can very easily fall into the trap of researchers who are not autistic, have their own reasons for being interested and they approach us and use us as sources of information to address what they believe to be important, which may not be what we think is important. People with autism are not true equal participants in the process of knowledge creation."*

## **Key recommendations**

1. Reciprocity should be a key consideration within research. No research should be done that is 'just for research's sake,' and all studies should have clear lines of outcomes and outputs that enhance or advance the scientific, social and physical representation of autism.
2. For transparency and to familiarise participants with the research team, provide introductory information such as photos, why the researchers are interested in autism research, what the perceived impact of the research will be on the autism community, and a brief biography 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.
3. Closely involve members of the autism community as partners in specific research projects from the beginning to end, with co-produced outputs.

4. Factor payment for time and expertise into research grants for consultants from the autism community that treat autistic experts by experience contributors as equal to formal academic researchers. If this is not possible, consider other ways of rewarding participants for their time (e.g. library access, honorary contracts).
5. Create an experts by experience panel with members of the autism community in order to have a collaborative approach to research questions and studies. This group would advise throughout the research project (from idea generation to dissemination) and meet with the researchers on a regular basis.
6. Lobby university ethics panels to make consultation with the autism community a pre-requisite for ethical approval of autism studies.

### **Recruitment of participants**

Participants expressed a desire to take part in research, and wanted it to be easier to find out how to get involved. They reported missing opportunities for integrating the promotion of research with services or sites used by the autism community (social media sites, autism web sites, links with GPs, the NHS and support groups), and stated that a single directory of research opportunities would be ideal.

Researchers should clearly outline to all actual and potential participants what taking part in the study will involve and why the research is taking place. They should also explicitly detail exactly what is going to happen to the participant in additional information about the study. This approach will minimise the chance of stress and anxiety induced by unexpected activities during the research.

Responses during the workshop indicated that members of the autism 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. They also appreciated financial compensation, which may be provided in return for participating. In particular, participants stressed the value of participating in research after receiving their diagnosis as a useful way to learn more about themselves and to counter post-diagnosis isolation and confusion. Indeed, researchers are well-placed to direct participants to or directly share relevant existing literature that participants may express an interest in. Researchers should take these motivations into account when developing research protocols 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.

### ***Sample quotes***

*“What was annoying was that they sent out a load of instructions saying what to expect on the day, which was great, but then on the day they sprang a half an hour autism assessment on me, which really bothered me. And so I made up a really psychopathic story.”*

*“It almost becomes a virtuous circle...because the place that diagnosed me gave me some information about the autism forum, so then I learnt about all these things (research studies) that were happening that didn't have a website or anything like that, and my friend's place*



*that diagnosed them, didn't send them something like that. So it's difficult, because that's how you end up with the same people involved, over and over."*

### **Key recommendations**

1. Include details of what the study will involve and why it is taking place in a participant information sheet. In addition, provide clear information, including explicit and accurate information about *exactly* what the participant is going to be asked to do. Consider creating an accessible version of the participant information sheet with the critical information in large print, separating blocks of text into separate paragraphs.
2. Use multimedia sources, such as videos and photos, which the participant can be sent alongside the participant information sheet to display *exactly* what the participant is going to be asked to do, and to introduce the participant to the research team (e.g. a "What to expect" document).
3. The outcome of the research is not just the publications: 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 for all research. In particular:
  - a. Where possible, ensure participants are able to receive a fair rate of financial compensation in return for taking part in studies. Make sure the participant is made aware in advance of how much they can expect to receive and how (and when) they can expect to receive it.
  - b. Ask whether the participant requires time to visit the local area, and try to accommodate this.
  - c. Consider what information can you give to participants about the research, the findings and their own personal results. Consider a regularly updated website containing background information about the project, links to further information, publications and updates on study findings.
4. Have an experts by experience group read through information that will be received by participants to ensure that the material is clear as possible.
5. Actively seek more connections with the autism community via the Internet, key stakeholder agencies, the NHS/health system and other associated organisations, such as schools, playgroups and community centres

### **Study visit considerations**

Travel and access to buildings where research is taking place was highlighted as a major cause of anxiety for participants, both in advance and on the day of the study. Providing clear information, including pictures or videos of the route and the rooms to be used within the research, was considered good practice for autistic participants. Parents slightly differed from autistic adults on this point, suggesting that this information should only be provided when there is certainty that there will not be any changes on the day, as otherwise the changes may cause confusion and distress for their child and adversely affect the research, or even prevent participation. Autistic adults indicated that as much advance information as possible is needed to reduce anxiety associated with travel to research studies, but appreciated that some changes would be expected and are beyond the researchers' control.

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 participants at the door of the building, transport station or a familiar place was also considered useful. Refreshments and a quiet area should be provided (1) on arrival to allow participants time to 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 standard tests repeatedly (such as the Autistic Diagnostic Observation Schedule) when taking part in studies at different institutions. They were unclear about 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 standard tests amongst themselves (with the participants' consent). These problems may be obviated by formal documentation of original diagnostic tests being sought and available.

### **Sample quotes**

*“Actually finding the location of the place was pretty stressful, and it was in a building that was not easily accessible with a pram. So I could have done with a bit more help to get in. There were various sections locked off as well... just basic stuff sometimes.”*

*“I find the more times I do an ADOS or a DISCO or whatever, I find it quite difficult sticking to what I said the original first time... because I know what would be a more autistic answer.”*

### **Key recommendations**

1. Reduce the anxiety and stress of getting to the research site by planning out how participants can best get to the venue. Provide clear, up-to-date instructions (including address and postcode) and pictures/videos so that participants can familiarise themselves with the area in advance.
2. Discuss access to the venue with the participant, including whether there is a need to arrange someone to meet the participant at a common arrival point.
3. Duration and frequency of planned breaks during the research should be flexible to allow extra time for those who need it. Refreshments should be provided before and during the research, for those participants who may wish or need it.
4. Provide a comfortable, quiet relaxation area with subdued lighting.
5. Consider childcare or other caring responsibilities when planning the research, such as adding to the budget in a grant proposal to cover the costs of childminding during research participation, or making provision for conducting the research at weekends or evenings.

6. Incorporate provision of data-sharing into ethics applications to allow sharing of screening tests amongst researchers, in order to reduce the burden on participants.

### **Post-study considerations**

Participants discussed the need for improved communication after research projects. Immediately after the research has finished, ensure a full debriefing is provided, including information on what the research was about, what will happen to the findings and when they can expect to hear about the outcomes of the study. It may be beneficial to share advertisements 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. Doing this on an ongoing basis would promote general understanding of research and the subject area, and encourage future participation.

Participants expressed a desire to be able to read research findings as a way of making sense of their or their child's condition, but were greatly concerned about 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 understanding papers that are written in unfamiliar language. Researchers should write a lay summary of their findings and disseminate this to participants. A mixed approach to delivery of findings is suggested, using posters, videos, drawings, pictures and written media. Workshop participants suggested using social media and websites relevant to autism, as well as having a discussion arena where 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 interpretation of results, and develop new ideas for research that are relevant to the experiences of the autism community.

### **Sample quotes**

*"I think the downfall from my point of view, or any participant's point of view, is that you are not able to get feedback. Otherwise it's 'thank you, here's your money—bugger off.' It's the fact that it might be an opportunity for the participant to actually learn something about themselves."*

*"I struggle with the concept of you doing all this research and having all this knowledge and expertise and then it not being shared. So it doesn't affect policy and it doesn't filter down to the professionals who are supposed to have knowledge but half the time don't. And those are the people who we really need to benefit from this experience."*

### **Key recommendations**

1. Post-research support is as important as procedural considerations, so information should always be provided to all participants as to 'what happens next?' regarding the research

findings. If possible, indicate when participants might expect to receive a summary of the findings.

2. Dissemination of the research findings should have the autism community at the heart of it:
  - a. Disseminate a lay summary of the study findings to participants. Consider disseminating to non-participating but relevant stakeholder groups, such as the National Autistic Society and autism support groups or societies.
  - b. Publish findings in open access journals. Where this is not possible, make pre-prints of the work available. Share published research with all study participants (if consent has been given).
  - c. Consider using a variety of media: videos were proposed as a particularly valuable way of communicating findings.
  - d. Use a variety of dissemination methods, such as emailing participants, directing participants to a website, using social media or, in particular, having a discussion forum.
3. Arrange open seminars and workshops related to the research project to enable discussion of research findings. Support for these should be included in grant applications.

## Summary

This guidance covers the considerations that researchers should take into account when conducting research with the autism community. It promotes effective communication and equal partnerships between the autism and research communities, to ensure that the needs of participants pre-, during and post- study are taken into account and that they are supported through the research pathway. Key messages include the need to have participatory involvement at all stages in research, communication about the real-world impact of the research, clear information around the background of the research and what will occur during the research visit, accessible dissemination of accessible findings, and the ability to discuss research findings.

It is recommended that researchers read these guidelines alongside the Shaping Autism Research project starter pack for participatory autism research (Pellicano *et al.*, 2017) and familiarise themselves with wider literature on the application, relevance and benefit of participatory research (Chown *et al.* 2017; Milton, 2012; 2014; Milton and Bracher, 2013; Shippee *et al.* 2013; Walmsley, 2004; Walmsley, Strnadová and Johnson, 2018). These guidelines compliment this literature in terms of the need for early and sustained reciprocal partnership, but they additionally provide succinct and practical recommendations for putting this into place with a particular emphasis on biology, brain and cognition research.

Furthermore, there is a growing movement in the quantitative social sciences towards a more transparent model of how research is conducted, including making methods and datasets openly available, in order to produce more reliable, replicable findings (the Open Science Movement: see Mufano *et al.*, 2017; Nosek *et al.*, 2015). As practices (gradually) change, this creates an opportunity to demand new standards of inclusive research in parallel. Indeed, the intended outcome of producing transparent and reliable research with real meaning for the autism community is closely aligned with the goals of Open Science. One example relates to the “replication crisis” (Button *et al.* 2013;

Ioannidis, 2005; Macleod *et al.*, 2014) where published studies are often underpowered (small participant numbers) and consequently do not replicate. Autism research tends to involve very small participant numbers, which is a particular problem in producing reliable findings, as within-group variance in autism is high. We expect that by making the aims of research more interesting to the autism community and improving their experiences of and involvement in research, this will encourage greater trust in researchers and more participation in research studies (see also Haas *et al.*, 2016).

It is hoped that the concise, practical layout of these guidelines in a way that reflects the research pathway will enable researchers less familiar with working with autistic participants to implement many of the recommendations. Although it may not always be possible to follow all the guidelines for every project due to limited resources, there are a number of recommendations that all researchers should be able to implement, and which should be expected as a minimum requirement for autism studies.

It is also anticipated that the recommendations will be helpful for all research participants, not just those with autism. The experience of participants is an often-neglected aspect of study design, but emphasizing that researchers should reflect more on the participant's experience during research is a simple way to reduce some of the variability inherent in human data. Indeed, some of the recommendations, such as sharing advance information (e.g. photos), fit with the Universal Design for Learning (UDL) framework (CAST, 2011), which is a set of principles that aims to provide equal opportunities to learn through flexible, supportive and individual approaches.

## **Limitations and future directions**

We would like to highlight that these guidelines are by no means exhaustive, and it is anticipated that they will be reviewed and modified, and will evolve with further discussion over time. In addition, they do not cover how to capture and incorporate the view of those less able to contribute in traditional ways, such as children or those with learning or communication disabilities. In view of the underrepresentation of autistic individuals with learning difficulties in research (Russell *et al.*, 2019; Warner, Cooper and Cusack, 2019), guidelines that include this group are essential to increase participation and reduce selection bias that threatens the generalisation of research findings.

It is also important to highlight that these guidelines are based on individuals in the UK, so certain recommendations may be less applicable in other countries. We did not record demographics relating to income, education or ethnic background, but it is likely that demographics may affect interpretation and content of the guidelines. A useful next step would be to undertake a wider consultation including different demographics and nationalities.

In the current study we investigated the views of autistic adults and non-autistic parents together. Overall, the opinions expressed by both groups were closely aligned. However, it is important to note that there are diverse perspectives on neurodiversity between parents, and these perspectives can conflict with those of autistic people (Bagatell, 2010; Lagan, 2011). It is possible that the current sample of parents was insufficient for any differences in opinion to emerge. It would be valuable to conduct focused studies exploring the views of larger groups of parents and autistic adults separately,

to better understand any subtle differences in their perspectives on how autism research should be conducted (see also Kapp *et al.*, 2012).

This research indicates a number of other future directions to work towards. First, initiatives should be developed to encourage more autistic individuals to become autism researchers. Supporting autistic people to lead autism research is the best way to ensure that the direction of autism research is focused on autistic people's priorities. The UK charity Autistica has moved in this direction with the introduction of the Charles Sharland scheme, which funds autistic individuals to carry out their own research project in an autism research lab. Additionally, universities need to provide a supportive environment for autistic people (Lei *et al.* 2018), and there needs to be links between university autism researchers and younger autistic individuals who are considering their career options. A related consideration is that researchers could look to create work experience opportunities for autistic people, even those who are not necessarily considering a career in autism research. Underemployment of autistic people is a major concern (National Autistic Society, 2016) and there are many opportunities for generic skills development when working in a research setting, which would bolster a person's CV and may increase their prospects of finding more permanent work. In addition, having a variety of autistic people working in a research team and involved in discussions around research is likely to have a positive impact on the way that non-autistic researchers understand autism and approach research. At Autism@Manchester, we have paired up with the Disability and Advisory Support Service and the Careers Service at the University of Manchester to create a short internship for autistic university students to work in an autism research lab.

Second, universities need to work together. Achieving certain standards of practice in working and relating to the autism community is important, as participants can be put off research generally following bad experiences in a particular study. Greater collaboration in recruitment and data-sharing is needed to produce more reliable research findings.

Third, lobbying ethics boards to require participatory approaches before studies can be approved would incorporate participatory standards into university governance.

Fourth, and most importantly, researchers should ensure that adequate resources are factored into grants to pay for participatory research practices (e.g. consultancy of the autism community, experts by experience advisory groups). Many funders require realistic impact statements, and by incorporating participatory methods into their projects, researchers may be able to influence funder attitudes to supporting participatory research (Fletcher-Watson *et al.*, 2018).

## **Conclusion**

Currently, biological, cognitive and behavioural research are the most widely funded areas of autism research. We have provided practical guidelines for researchers who conduct studies in which autistic people and their families may be asked to go to a research site. We hope that by implementing transparent and participatory approaches to their work, researchers can reduce some of the dissatisfaction that members of the autism community feel towards research, leading to greater participation of autistic people, and higher quality research in terms of design, and ethical and epistemological integrity.

## Acknowledgements

We would like to thank the workshop participants for their time and input towards the project.

Funding. The project was funded by a Wellcome Trust Institutional Support Fund award (reference no. 105610). Thomas Bleazard was supported by a Medical Research Council Doctoral Training Partnership award.

## References

- Arnstein, S.R. (1969) "A ladder of citizen participation," *Journal of the American Institute of Planners*, 35(4): 216–224.
- Attride-Stirling, J. (2001) "Thematic networks: An analytic tool for qualitative research," *Qualitative Research*, 1(3): 385–405. doi: 10.1177/146879410100100307.
- Autism@Manchester (2017) "Autism@Manchester." Retrieved from: <http://www.autism.manchester.ac.uk>
- Bagatell, N. (2010) "From cure to community: Transforming notions of autism," *Ethos*, 38(1): 33–55. doi: 10.1111/j.1548-1352.2009.01080.x.
- Bertilsson Rosqvist, H. (2019) "Knowing what to do: Exploring meanings of development and peer support aimed at people with autism," *International Journal of Inclusive Education*, 23(2): 174–187. doi: 10.1080/13603116.2018.1427807.
- Button, K.S., Ioannidis, J.P.A., Mokrysz, C., Nosek, B.A., Flint, J., Robinson, E.S.J. and Munafò, M.R. (2013) "Power failure: Why small sample size undermines the reliability of neuroscience," *Nature Reviews Neuroscience*, 14: 365–376. doi: 10.1038/nrn3475.
- CAST (2011). *Universal Design for Learning Guidelines*, version 2.0. Wakefield, MA: CAST.
- Chown, N., Robinson J, Beardon, L., Downing, J., Hughes, E., Leatherland, J., Fox, K., Hickman, L. and MacGregor, D. (2017) "Improving research about us, with us: A draft framework for inclusive autism research," *Disability & Society*, 32(5): 720–734. doi: 10.1080/09687599.2017.1320273.
- Fletcher-Watson, S., Adams, J., Brook, K., Charman, T., Crane, L., Cusack, J., Leekam, S., Milton, D., Parr, J.R., and Pellicano, E. (2018) "Making the future together: Shaping autism research through meaningful participation," *Autism*, 23(4): 943–953. doi: 10.1177/1362361318786721.
- Grinker, R.R., Chambers, N., Njongwe, N., Lagman, A.E., Guthrie, W., Stronach, S., Richard, B.O., Kauchali, S., Killian, B., Chhagan, M., Yucel, F., Kudumu, M., Barker-Cummings, C., Grether, J. and Wetherbyet, A.M. (2012) "'Communities' in community engagement: Lessons learned from autism research in South Korea and South Africa," *Autism Research*, 5(3): 201–210. doi: 10.1002/aur.1229.
- Haas, K., Costley, D., Falkmer, M., Richdale, A., Sofronoff, K. and Falkmer, T. (2016) "Factors Influencing the research participation of adults with autism spectrum disorders," *Journal of Autism and Developmental Disorders*, 46(5): 1793–805. doi: 10.1007/s10803-016-2708-6.
- Ioannidis, J.P.A. (2005) "Why most published research findings are false," *PLoS Medicine*, 2(8): e124. doi: 10.1371/journal.pmed.0020124.

- Kapp, S.K., Gillespie-Lynch, K., Sherman LE and Hutman T (2012) “Deficit, difference or both?: Autism and neurodiversity,” *Developmental Psychology*, 49(1): 59- 71. doi: 10.1037/a0028353.
- Lagan, M. (2011) “Parental voices and controversies in autism.” *Disability & Society*, 26(2): 193-205. doi: 10.1080/09687599.2011.544059.
- Lei, J., Calley, S., Brosnan, M., Ashwin, C. and Russell, A. (2018) “Evaluation of a transition to university programme for students with autism spectrum disorder,” *Journal of Autism and Developmental Disorders*: 1-15. doi: 10.1007/s10803-018-3776-6.
- Macleod M.R., Michie, S., Roberts, I., Dirnagl, U., Chalmers, I., Ioannidis, J.P., Al-Shahi Salman, R., Chan, A.W. and Glasziou, P. (2014) “Biomedical research: Increasing value, reducing waste,” *Lancet*, 383(9912): 101-104. doi: 10.1016/S0140-6736(13)62329-6.
- Milton, D.E. (2012) “On the ontological status of autism: The ‘double empathy problem’,” *Disability & Society*, 27(6): 883–887. doi: 10.1080/09687599.2012.710008.
- Milton, D.E. (2014) “Autistic expertise: A critical reflection on the production of knowledge in autism studies,” *Autism*, 18(7): 794–802. doi: 10.1177/1362361314525281.
- Milton, D.E. and Bracher, M. (2013) “Autistics speak but are they heard?,” *Journal of the BSA Medsoc Group*, 7(2): 61–69. Retrieved from: [http://www.medicalsociologyonline.org/resources/Vol7Iss2/MSo\\_7.2\\_Autistics-speak-but-are-they-heard\\_Milton-and-Bracher.pdf](http://www.medicalsociologyonline.org/resources/Vol7Iss2/MSo_7.2_Autistics-speak-but-are-they-heard_Milton-and-Bracher.pdf)
- Milton, D.E., Heasman, B. and Sheppard, E. (2018) “Double empathy.” In: Volkmar, F. (Ed.) *Encyclopedia of Autism Spectrum Disorders*. New York: Springer. doi: 10.1007/978-1-4614-6435-8.
- Munafò, M.R., Nosek, B.A., Bishop, D.V.M., Button, K.S., Chambers, C.D., Percie du Sert, N., Simonsohn, U., Wagenmakers, E.J., Ware, J.J. and Ioannidis, J.P.A. (2017) “A manifesto for reproducible science,” *Nature Human Behaviour*, 1(1): no. 0021. doi: 10.1038/s41562-016-0021.
- National Autistic Society (2016) *The Autism Unemployment Gap: Too Much Information in the Workplace*. London: National Autistic Society. Retrieved from: <https://www.autism.org.uk/get-involved/campaign/employment.aspx>
- Nicolaidis, C., Raymaker, D., McDonald, K., Dern, S., Ashkenazy, E., Boisclair, C., Robertson, S. and Baggs, A. (2011) “Collaboration strategies in nontraditional community-based participatory research partnerships: Lessons from an academic–community partnership with autistic self-advocates,” *Progress in Community Health Partnerships: Research, Education, and Action*, 5(2): 143-150. doi: 10.1353/cpr.2011.0022.
- Nosek, B.A., Alter, G. and Banks G.C. *et al.* (2015) “Promoting an open research culture,” *Science*, 348(6242): 1422-1425. doi: 10.1126/science.aab2374.
- Parsons, S., Yuill, N., Good, J. and Brosnan, M. (2019): “Whose agenda? Who knows best? Whose voice?: Co-creating a technology research roadmap with autism stakeholders,” *Disability & Society*. doi: 10.1080/09687599.2019.1624152
- Pellicano, E., Crane, L., Gaudion, K., *et al.* (2017) *Participatory Autism Research: A Starter Pack*. London: UCL Institute of Education. doi: 10.1002/aur.201
- Pellicano, E. and Stears M (2011) “Bridging autism, science and society: Moving towards an ethically informed approach to autism research,” *Autism Research*, 4(4): 271–282. doi: 10.1002/aur.201



- Pellicano, E., Dinsmore, A. and Charman, T. (2014a) "What should autism research focus upon? Community views and priorities from the United Kingdom," *Autism*, 18(7): 756–70. doi: 10.1177/1362361314529627.
- Pellicano, E., Dinsmore, A. and Charman, T. (2014b) "Views on researcher-community engagement in autism research in the United Kingdom: A mixed-methods study," *PLoS ONE*, 9(10). doi: 10.1371/journal.pone.0109946.
- Petri, G., Beadle-Brown, J. and Bradshaw, J. (2017) "'More honoured in the breach than in the observance': Self-advocacy and human rights," *Laws*, 6(4): 26. doi: 10.3390/laws6040026.
- Rosenblatt, A. (2018) "Autism, advocacy organizations, and past injustice," *Disability Studies Quarterly*, 38(4). doi: 10.18061/dsq.v38i4.6222.
- Russell, G., Mandy, W., Elliott, D., White, R., Pittwood, T. and Ford, T. (2019) "Selection bias on intellectual ability in autism research: A cross-sectional review and meta-analysis," *Molecular Autism*, 10(9). doi: 10.1186/s13229-019-0260-x
- Shippee, N.D., Garces, J.P.D., Lopez, G.J.P., Wang, S., Elriyah, T.A, Nabhan, M., Brito, J.P., Boehmer, K., Hasan, R., Firwana, B., Erwin, P.J., Montori, V.M. and Murad, M.H. (2013) "Patient and service user engagement in research: a systematic review and synthesized framework," *Health Expectations*, 18(5): 1151–1166. doi: 10.1111/hex.12090.
- Tesfaye, R., Courchesne, V., Yusuf, A., Savion-Lemieux, T., Singh, I., Shikako-Thomas, K., Miranda, P., Waddell, C., Smith, I.M., Nicholas, D., Szatmari, P., Bennett, T., Duku, E., Georgiades, S., Kerns, C., Vaillancourt, T., Zaidman-Zait, A., Zwaigenbaum, L. and Elsabbagh, M. (2019) "Assuming ability of youth with autism: Synthesis of methods capturing the first-person perspectives of children and youth with disabilities," *Autism*. doi: 10.1177/1362361319831487
- Tritter, J.Q. and McCallum, A. (2006) "The snakes and ladders of user involvement: Moving beyond Arnstein," *Health Policy*, 76(2): 156–168. doi: 10.1016/j.healthpol.2005.05.008.
- Young, A., Nicholas, D.B., Chamberlain, S.P., Suapa, N., Gale, N. and Bailey, A.J. (2019) "Exploring and building autism service capacity in rural and remote regions: Participatory action research in rural Alberta and British Columbia, Canada," *Autism*, 23(5): 1143-1151. doi: 10.1177/1362361318801340.
- Walmsley, J. and Johnson, K. (2003). *Inclusive Research with People with Learning Disabilities: Past, Present and Future*. London: Jessica Kingsley Publishers.
- Walmsley, J., Strnadová, I. and Johnson, K. (2018) "The added value of inclusive research," *Journal of Applied Research in Intellectual Disabilities*, 31: 751-759. doi: 10.1111/jar.12431.
- Waltz, M. (2012) "Images and narratives of autism within charity discourses," *Disability & Society*, 27(2): 219-233. doi: 10.1080/09687599.2012.631796.
- Warner, G., Cooper, H. and Cusack, J. (2019) *A Review of the Autism Research Funding Landscape in the United Kingdom*. London: Autistica.
- Woods, R. and Waltz, M. (2019). "The strength of autistic expertise and its implications for autism knowledge production: A response to Damian Milton," *Autonomy, the Critical Journal of Interdisciplinary Autism Studies*, 1(6). Retrieved from: <http://www.larry-arnold.net/Autonomy/index.php/autonomy/article/view/CO2/html>