Expert by Experience Group
New virtual members Induction Pack

Autism@Manchester
The University of Manchester
http://www.autism.manchester.ac.uk/
A Very Warm Welcome

Thank you for your interest in joining the Virtual Expert by Experience group for autism@manchester.

In this induction pack we will tell you about:

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What is Autism@Manchester?

Autism@Manchester was founded in 2014 with funding from the University of Manchester Research Institute Pump Priming Scheme and is a network of academics, clinicians, practitioners, autistic individuals and their family and carers principally across Greater Manchester.

Organisations already involved in Autism@Manchester include:

- The University of Manchester
- Manchester Metropolitan University
- University of Salford, University of Bolton
- Manchester University NHS Foundation Trust
- Salfordautism

Autism@Manchester encourages and facilitates a more holistic approach to research in which academics, clinicians, practitioners, autistic individuals and their family and carers, can come together more easily to work and share knowledge. Increasingly aware of concerns expressed by the autistic community that researchers were not working on issues important to them, Autism@Manchester wanted to create an environment that encourages communication and collaboration between researchers, clinicians and the autism community. Also, because autism affects so many different aspects of life, researchers need to work across disciplines to produce effective research with real meaning and impact for autistic people.

Our key aims are to:

- Share knowledge and understanding
- Collaborate on the selection, design and conduct of research

In order to accomplish these goals, Autism@Manchester performs a number of activities including organising workshops and invited speakers on the topic of autism and the development of educational resources. We have also developed initiatives based on consultation with the autism community, including the circulation of newsletters and the 'expert by experience' advisory group that you are joining.

To support our activities we have received funding from The Wellcome Trust and the NHS Research Design Service. We would also like to acknowledge organisers of the Patient and Public Research User Group (RUG) for The Sense - Cog Project who have provided guidance on drawing up the documents for the Expert by Experience Group.
Why “expert by experience” involvement is important for autism researchers

What do we mean by ‘expert by experience’ and by ‘involvement’?

When we talk about “expert by experience”, we mean members of the public with the *lived* experience of autism. This could be autistic people, carers, parents and guardians or family members.

When we talk about ‘involvement’ we mean members of the autistic community getting involved in the research process itself rather than just being participants in or subjects of the research. Many people describe 'expert by experience' involvement in research as research that is done with or by the public and not to, about or for them.

There are many reasons why expert by experience involvement is important for autism research:

- Researchers do not always have first-hand experience of autism. It is important that autistic people, parents, carers and family members provide their personal experiences and perspectives to guide the design and delivery of the research.
- It is considered morally right for the public to be involved in any publicly-funded research that may have an impact on them.
- It can help to improve the quality, relevance and impact of research.
- It is Department of Health policy and a funding requirement of the National Institute of Health Research. In other words, researchers must actively involve the public in the design and conduct of their research in order to get their grant.

Please see the following link for discussion on the role of autistic people in research:

https://www.statnews.com/2017/05/10/autism-science-research-studies/
A brief introduction to research and how you can get involved

Research can be carried out in lots of different ways and in lots of different settings. Research can involve questionnaires, focus groups or interviews that can be carried out on paper or computers. It can involve recording people’s behaviour to certain situations. This might take the form or recording how fast someone is at pressing a button when they see a particular picture, recording their movements or recording brain activity using imaging equipment. Research can also involve taking body samples (e.g. blood) and using techniques to test for particular molecules in the blood.

Research involves a number of different stages and usually takes a long time to complete. Very often, the research will open up new questions that need answering before a definitive conclusion can be drawn. Knowledge is built up slowly, meaning that real-life outputs often happen years after the start date of the research rather than straight away. The knowledge built up during the research process can be seen as grains of sand that gradually build a foundation. However, good research should incorporate a clear understanding of how it may have real world implications in the future.

You can get involved in research in a number of different ways. This might be as a participant in the study, on an advisory group contributing to decisions about how best to carry out research (as with this expert by experience group) or as researchers/co-researchers where you are responsible for the whole process of research production.

The diagram below shows the different stages of the research process (in blue boxes), starting at the top with prioritising/shaping research. The ways that the public can input into this process are shown in italics. The aim of this expert by experience groups is to facilitate these types of input at all stages of the research process. This means you will get the chance to comment on research during the early design phase (e.g. shaping the questions asked and the design), when the results come out and when decisions are being made as to how those results could be used or disseminated.
Examples of PPI throughout the Research Process

Collaborate with researchers to evaluate the design and outputs

Have continued involvement in study to maintain focus

Develop patient information for new services

Jointly present findings

Inform researchers how they interpret the data

Prioritising/Shaping Research

Research Design

Clarify the Research question

Ensure methods are ethical

Define outcome measures

Help write patient study protocol/consent forms

Grant development/Gaining funding

Recruitment and Conducting research

Analysing and Interpreting

Dissemination

Implementation

Evaluation

The Research Process: Patients and the public can get involved at all stages

Please note that this figure is taken from the Patient and Public Research User Group (RUG) for The Sense - Cog Project
Our Virtual Expert by Experience Group

The group aims to achieve active and meaningful public involvement at all stages of the research process, with a common goal of ensuring research quality. Group members will act as critical friends on autism research from their own perspective of living with autism, advising and giving feedback about research via online mechanisms.

The virtual group allows input on research from a larger number and broader range of people within the autism community than would be able via our face to face group. It provides members of the autism community who are unable or do not wish to attend the face to face meetings with the opportunity to advise on various research projects. The virtual group is run as a LISTSERVE mailing list, provided by the University of Manchester. The group is called AATM-EXPERTGROUP. Researchers will email information to the list about their research via attachments or links and members can choose to either (1) provide comments that the whole group can see (like a discussion forum) (2) directly email the researcher any comments. Members will receive an email each time new comments or a new research project are added.

As with our face to face group, the virtual group has a duty to treat all information about the research as confidential and will be asked to confirm a confidentiality declaration when registering. Breach of this confidentiality may mean a member is removed from the group. If researchers are happy with verbal or written details about their research being discussed outside the virtual forum, they will make this clear in their presentation.
Group organisation

- As the aim of the group is to get advice from people with a *lived experience* of autism, group members consist of autistic adults, parents, carers and family members of children or adults with autism.
- There is no maximum group number
- Information about research projects will be mailed on an “as and when” basis. There may be quiet periods when no projects are circulated or there may be busier periods where there are several projects that are requesting comments. Group members can choose what projects and documents they wish to comment on.
- Members can make public comments that are visible to both the researcher and other group members by replying back to the email. Members can also choose to email the researcher directly with comments.
- Researchers will provide the group with an information document accompanying their research documents. This will briefly outline the research topic, stage of research, who the researchers are and what they would like the virtual group to particularly comment on.
- The information document will also indicate the date by which researchers would like any comments. This will be minimum of 1 week.
- If a group member is interested, there may be opportunity to become more involved with a particular research project. If so, the researcher will make this clear in their information document. This would be separate to the expert by experience group.
- Group members are free to leave the group at any time without giving a reason (although it would be nice to know why!)
- Members are asked to try to keep comments concise, professional and friendly. Importantly, we want members to enjoy the group and feel that they are in a friendly, safe and non-judging environment. If a member does not comply with this, they will be removed from the group.
- Advice from group members to the researchers should be from “the perspective of someone living with autism”. While many group members may have both “autism” and “professional” expertise, the focus should be on the “autism” perspective. If you do wish to provide technical, academic or detailed methodological questions, these should communicated directly to the researcher rather than via the discussion facility.
Instructions for joining and leaving the virtual group

- After reading this Induction Pack, contact Dr Emma Gowen (emma.gowen@manchester.ac.uk), indicating that you would like to join.

- You will receive an email asking you to reply to the following questions and statements
  
  o What is your connection to autism (e.g. are you an autistic person, family member or carer)?
  
  o As a member of the Autism@Manchester expert by experience group it is possible that you will see or hear confidential information in your role (e.g. details about ongoing and future research as well as personal details about participants, group or staff members). Please indicate that you agree to not:
    
    - Talk or write about information that you see or hear in your role
    - Pass any details to anyone other than group members and organizers.
  
  o Members are asked to try to keep comments concise, professional and friendly. Please indicate that you agree to comply with this.

- Once you have agreed to the statements, you will be added to the LISTSERVE group called AATM-EXPERTGROUP. You will receive a confirmation email, along with general LISTSERVE instructions.

- You can leave the group at any time by sending a blank email to: AATM-EXPERTGROUP-signoff-request@LISTSERV.MANCHESTER.AC.UK

Instructions for posting comments

When there is a post, you will receive an email with information about the research and what type of advice the researcher is asking for. You can either reply to the email with your comments, so that the researcher as well as the whole group can read them or just send your comments to the researcher (their email will be included in the original email). When replying to the email, please make sure you use the same subject line.
Group Organisers

Dr Emma Gowen
Senior Lecturer and chair of autism@manchester

Dr Lisa Miles
NIHR Biomedical Research Centre Operations Manager at Manchester University NHS Foundation Trust and mum to a son with autism

Peter Baimbridge
Autistic adult, Autism@Manchester coordinator and CEO of Salfordautism

Alexandra Sturrock
Speech and Language Therapist, PhD student, The University of Manchester

Who to contact if you have any questions

Please contact Dr Emma Gowen:
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