



SESSION II: Ethics and Participation in Autism Research

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Course Materials

The purpose of these materials is to help provide an introduction to the Summer Institute session on ethics and participation in autism research. The materials were

designed to prepare trainees who are unfamiliar with participatory research with the general background, to get the most educational benefit from Professor Pellicano's presentation. Toward this objective, we have prepared the following: (1) learning objectives for this session; (2) some key terms and concepts to become familiar with ethical issues and participatory research; (3) some recommended reading. These materials could be considered "prerequisites" in preparing for Professor Pellicano's presentation.

In collaboration with Professor Pellicano and Mr. Ne'eman, these materials were developed by **Laura G. Holmes, Ph.D.** (postdoctoral fellow at the Children's Hospital of Philadelphia Center for Autism Research; grahamholl@email.chop.edu), **Laura Crane, Ph.D.** (Senior Teaching and Engagement Fellow at the Centre for Research in Autism and Education; L.Crane@ucl.ac.uk), and **Tawny Tsang**, (doctoral student at University of California, Los Angeles; tsangtt89@ucla.edu). Feel free to contact us with questions/comments.

Register for this course and other sessions in this series by creating an account at <http://eweb.autism-insar.org/eweb/>

Learning Objectives

The Summer Institute for Autism Research was established in direct response to requests from early career researchers (graduate students, postdocs, etc.), who asked INSAR for greater training opportunities in multidisciplinary topics. In designing the Summer Institute, the priorities were: (1) to provide a multidisciplinary training platform for young scientists from various backgrounds; (2) allow international participation; and (3) make it freely available. Thus, the second Summer Institute covers broad topics (which are geared to researchers outside the respective topic areas), is offered over a free web platform, and allows researchers from around the world to connect with the presenter. The overarching goal of the Summer Institute is to expose junior scientists to topics they are not currently engaged in, with the hope that basic scientists and clinical

scientists could learn from each other to ultimately advance the understanding of autism.

The current session, Ethics and Participation in Autism Research, is led by Professor Liz Pellicano, Ari Ne'eman, and a team of trainees who worked in tandem to prepare these materials and the web presentation. The learning objectives for attendees of this session include:

- Ø To instill an awareness of ethical concerns regarding current trends in autism research and how these trends impact stakeholders (e.g., autistic people, their families, and the professionals who work with them).
- Ø To compare current research trends with stakeholder priorities.
- Ø To gain an understanding of the ways in which autistic people may be disenfranchised by current research practices.
- Ø To learn about barriers facing autistic people who want to become involved in autism research and how to overcome such barriers.
- Ø To discuss best practices to increase meaningful inclusion of autistic people at all stages of the research process (e.g., community-based participatory research, including the AASPIRE project).

Terminology

Academic Autism Spectrum Partnership in Research and Education (AASPIRE) Project brings together the academic community and the autistic community to develop and perform research projects relevant to the needs of adults on the autism spectrum, adhering to principles of Community Based Participatory Research in that academics and community members serve as equal partners throughout the research process.

<https://aaspire.org/>

Co-production is a term that refers to a way of working whereby decision-makers and citizens, or service providers and users, or autism researchers and the autistic community, work together to create a decision or a service or a piece of research which works for them all. The approach is value-driven and built on the principle that those who are affected by a service/piece of research are best placed to help design it.

Neurotypical (or NT), an abbreviation of neurologically typical, is a term used to describe people with 'typical brains'. It is commonly used in the autistic community to refer to people who are not on the autism spectrum.

<http://www.autismacceptancemonth.com/resources/101-3/autism/neurotypical/>

Neurodiversity refers to how all human minds and brains are different. Being autistic is a form of **neurodivergence**.

<http://www.thinkingautismguide.com/2015/10/neurotribes-and-proper-use-of.html>

The **autistic community** refers to autistic people (potentially including those who self-identify as autistic).

<http://www.autismacceptancemonth.com/resources/101-3/autism-acceptance/autistic-culture/autistic-community/>

The **autism community** refers to autistic people, their family members and friends and the professionals who support them (e.g., educators, clinicians).

<https://michellesuttonwrites.com/2015/11/22/the-autism-community-and-the-autistic-community/>

The **medical model of disability** views disability as a problem belonging to the disabled person. The focus is on ‘fixing’ or ‘curing’ the disabled individual. The medical model focuses on what is ‘wrong’ with a person, rather than focusing on what they can do and/or how they can be better supported. Autism is often framed within a medical model of disability, despite strong criticism from many members of the autistic community.

The **social model of disability** views disability as being caused by the way society is organised, as opposed to a person’s differences. It seeks to reduce or remove barriers for disabled people, and explains that this should occur by society changing, rather than the disabled person themselves changing. Many autistic advocates frame autism within a social model of disability, highlighting how society needs to be more accepting of autistic differences.

<https://www.identityfirstautistic.org/social-model-of-disability>

“**Nothing about us without us**” is a slogan (often used by disability rights advocates) to highlight how important decisions that affect a person’s life should not be made without full and meaningful participation of members of the group ultimately affected by the decisions.

<http://www.autistichoya.com/2012/03/include-us-in-conversation-what-nothing.html>

Participatory research (including community-based participatory research) involves a full and equal partnership between, for example, autistic/autism community members and researchers, in which all partners are genuinely and meaningfully involved at all stages of the research (developing a research question, designing the research, conducting the study, analysing and interpreting the findings, disseminating the results).

[see Nicolaidis et al., 2011 - <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3319698/>]

Recommended reading

Cusack, J. (2016). Participation and the gradual path to a better life for autistic people. *Autism*, 21, 131-132. doi: 10.1177/1362361316680155

Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, 20(4), 442-462. doi:10.1177/1362361315588200

Milton, D. E. M., & Bracher, M. (2013). Autistics speak but are they heard? *Medical Sociology Online*, 7, 61–69.

Nicolaidis, C., Raymaker, D., McDonald, K., Dern, S., Ashkenazy, E., Boisclair, C., Robertson, S., & 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*, 5, 143–150. doi: 10.1353/cpr.2011.0022

Pellicano, E., Dinsmore, A., & Charman, T. (2014). Views on researcher-community engagement in autism research in the United Kingdom: A mixed-methods study. *PLoS ONE*, 9(10): e109946. doi:10.1371/journal.pone.0109946

Pellicano, E., Dinsmore, A., & Charman, T. (2014). What should autism research focus upon? Community views and priorities from the UK. *Autism*, 18, 756-770. doi:10.1177/1362361314529627

Pellicano, E., & Stears, M. (2011). Bridging autism, science and society: Moving towards an ethically-informed approach to autism research. *Autism Research*, 4, 271-282. doi: 10.1002/aur.201