

PARTICIPATORY RESEARCH PERSPECTIVE

Collaboration and participation of end users in research

Involving individuals vs organisations

Heta Pukki, M.Ed.
London, 10/11/2023

My involvement in R4N

- Participatory research committee
- Representing my personal lived experience as:
 - Autistic person
 - Family member, friend, colleague of many neurodivergent people
 - Working in projects, training, translation, personal and school assistance, NGOs, in volunteer and professional roles, for the past 25 years
 - M.Ed. in Special Pedagogy, focusing on autistic adults
 - Some small contributions to research projects, peer-reviewed articles
 - Experience in working with and within autistic-led organisations

NOT representing any organisation in my involvement in R4N; all views expressed in this presentation are mine only.



My lived experience - perspectives

- The neurodivergent people I know, live and work with include, among others:
 - People with one, two or more diagnoses
 - Disabled and non-disabled people
 - People needing medical interventions because of neurological differences, and people who do not need it
 - Autistic people with significant disability associated with co-occurring conditions, but not autism as such
 - Numerous people who seem to mainly suffer from lack of access to the most basic medical care for common ailments

My lived experience - perspectives

- The organisations I have worked with involve a broad range of people, most of them neither needing 24-hour care nor academic high achievers
 - Polarised debates about autism research that pitch two extremes against each other seem alien and irrelevant from this background
- The majority unemployed, under-employed, struggling with lack of services and accommodations, and with some level of mental health issues

Suggestions to grantees

Some educated guesses on how to involve end users effectively

1. Do not try to re-invent participatory practices

There is plenty of literature. Take the time to read it, to save time later.



The screenshot shows the top portion of a journal article page. At the top, there is a dark red header with the publisher's name 'Mary Ann Liebert, Inc. publishers' in white script and a logo of a tree. To the right of the header are the links 'ABOUT US' and 'PUBLICATIONS'. Below the header, the breadcrumb navigation reads 'Autism in Adulthood > Vol. 4, No. 2 > Guest Editorial'. To the right of the breadcrumb are icons for 'Open Access' and Creative Commons Attribution-NonCommercial-ShareAlike 4.0 International license. The main title of the article is 'Autistic Perspectives on the Future of Clinical Autism Research' in a large, bold, black font. Below the title, the authors are listed: Heta Pukki (with an ORCID icon and an envelope icon), Jorn Bettin, Avery Grey Outlaw, Joshua Hennessy, Kabie Brook, Martijn Dekker, Mary Doherty (with an ORCID icon), Sebastian C.K. Shaw (with an ORCID icon), Jo Bervoets, Silke Rudolph, Thibault Corneloup, Kylieanne Derwent, Onemoo Lee, Yadira Garcia Rojas, Wenn Lawson, Monica Vidal Gutierrez, Kosjenka Petek, Myria Tsiakkirou, Annikka Suoninen, Jo Minchin, and a 'See all authors' link with a dropdown arrow. Below the authors, the publication date and DOI are shown: 'Published Online: 9 Jun 2022 | https://doi.org/10.1089/aut.2022.0017'. At the bottom of the page, there are three navigation options: 'Sections' with a hamburger menu icon, 'PDF/EPUB' with a document icon, and 'Permissions & Citations' with a wrench icon, followed by a 'Share' link with a share icon.

Mary Ann Liebert, Inc. publishers

ABOUT US PUBLICATIONS

Autism in Adulthood > Vol. 4, No. 2 > Guest Editorial

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Autistic Perspectives on the Future of Clinical Autism Research

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Published Online: 9 Jun 2022 | <https://doi.org/10.1089/aut.2022.0017>

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Suggestions to grantees

2. Involve people from the beginning and all the way to the end

... including the formulation of research questions, post-publication discourse, and discussions about funding applications for future projects.

Suggestions to grantees

3. Try to see your topic in the context of what the target groups are talking about

The priorities of the organisations or communities may not match the topics you are studying.

They will ask: What exactly is the ultimate aim of this technology you are developing? How does it relate to our perceived needs and priorities?

e.g. *Autistic Priorities survey* by EUCAP, 2021

Suggestions to grantees

How does your research topic relate to these? Does it address any high priority?
Autistic Priorities survey by EUCAP, 2021:

Perceptions of potential risks and expected benefits of various types of research

Top priorities:

- Research on service systems to help autistic people
- Research on acceptance and integration

Second highest priorities:

- Research on co-occurring mental health problems
- Research on co-occurring physical health problems

Suggestions to grantees

How does your research topic relate to these perceptions of risk or low benefit?

Perceptions of potential risks and expected benefits of various types of research

Lower priority:

- Research on psychological therapies to reduce intensity of autism

Perceived as non-beneficial or risky:

- Research on medications to reduce intensity of autism
- Research on treating or curing 'core symptoms' of autism
- Research on preventing the birth of autistic children

Suggestions to grantees

How does your research topic relate to autistic people's preferences concerning AI?

“Involvement of autistic people in AI research and product development have been minimal. AIRA maps autistic people's knowledge, perceptions and needs regarding different uses of AI, with the aim of helping autistic voices to be heard in this field. The preparation of a multi-language survey for this has started in spring 2023.”



Suggestions to grantees

4. Involve people who are difficult to reach

The majority of the group you wish to help may be poor, excluded, traumatised, unfamiliar with the rules and processes of the academic world.

Budget your funding so that you will not need to exclude people because they can't afford to participate.

Suggestions to grantees

5. Involve representatives of organisations, not isolated individuals only

Create confidentiality agreements that allow the person to discuss their work with their community.

Benefit from having many lived experiences funneled through a representative with a broader perspective.

Benefit from the organisation replacing the representative if necessary.

Even out some of the power imbalance of individuals engaging with teams and powerful organisations.

Take the risk of potentially having to find out that an entire end user organisation disagrees with you, and having to change course rather than change participants.

Links and contact information

- Questions about this presentation: h.pukki@gmail.com
- Collaboration with autistic-led organisations: European Council of Autistic People (EUCAP) board: eb@eucap.eu
- Autistic Perspectives article:
<https://www.liebertpub.com/doi/full/10.1089/aut.2022.0017>
- EUCAP survey 2021: <https://eucap.eu/eucap-2021-survey/>
- Artificial Intelligence and the Rights of Autistic People (AIRA) project:
<https://eucap.eu/aira/>
 - survey: <https://eucap.eu/survey-aira>