

Tuesday late morning session Track B, Tuesday, Sep 23 2025, 11:30-13:00

Location: Seminar 1

Session: Research Culture

Chair: Nina Peršak

OR-03

Dialogue towards ethical participation. A qualitative study of Deaf people's research experiences

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Research engagement of Deaf people raises several ethical challenges. Research itself is a field of dispute about deafness. Various deafness-related fields function rather separately and develop their own epistemologies. Moreover, Deaf communities around the world are diverse in the recognition of group identities, shared history and faced marginalisation. Despite such a complex situation, there is a few research exploring experiences of Deaf people from participation and engagement in research aiming to inform and facilitate ethical research conduct.

Our study aimed to explore the experiences, opinions and needs of Deaf people related to research participation. We also wanted to highlight the ethical issues present within the research process, the relations between researchers and participants, as well as consider the impact of research on the community. To facilitate deep expressions and reach a diverse group of Deaf people, we conducted a bilingual (Polish and Polish Sign Language) open-ended online questionnaire. We received 52 responses and analysed results using an experiential approach to reflexive thematic analysis.

We employed a semi-participatory design, including pre-design consultations with Deaf community members, and several meetings with an advisory group of Deaf people during the course of thematic analysis. Together, we developed six themes reflecting the current and desired state of things, as well as potential means to achieve them: (i) We want to develop research among Deaf people, (ii) Science is not accessible to us, (iii) We have bad experiences, (iv) Science gives new opportunities and perspectives, (v) We want full accessibility, and (vi) Let us establish trust. They highlight the issues of social and epistemic (in)justice for Deaf people, and also the need for greater research accessibility and dialogue with both Deaf communities and individual participants and/or co-researchers. Thus, these themes were embraced under one overarching theme: It's all about dialogue.

Our research enable us to include the perspectives of Deaf people into debates on ethical participation and engagement in research. It may contribute to enhancing ethical inclusion of Deaf people (as well as other underrepresented populations) in research and support the development of evidence-informed normative recommendations for scientific cooperation between Deaf people and researchers.