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Nothing about us without us? Ethics of research with underrepresented groups at the example of deaf people

Despite dynamic progress in the science, various social groups remain underrepresented in research and are beyond the reach of scientific actions. Deaf people are the example of such group, facing a unique situation. There is an epistemological dispute within science about the perception of deafness, which is recognised as a disability or a socio-cultural phenomenon. Deaf people themselves are in disadvantaged position, being rarely included in the scientific debate. Such a situation can be described as epistemic injustice. Alongside additional barriers to the research participation, such as using scientific jargon in research, this causes serious ethical and methodical risks related to the engagement of deaf people into research.

Despite such a complex situation, few studies investigate experiences of deaf people participating in research. Similarly, normative recommendations and guidelines on ethical involvement of deaf people are lacking.

Our project will address this gap. Our aim is to address the issue of epistemic injustice by exploring experiences of deaf people participating in research and analysing ethical ways of engaging deaf people in research. We will conduct in-depth interviews with deaf people and *Deaf studies* experts. Their results will inform an ethical analysis of deaf people engagement in research within the prof. Sagit Mor's framework of "Nothing about us without us". We will consult the ethical analysis with deaf people.

Our data-informed ethical analysis will contribute to facilitating deaf people involvement in research. Proposed project may became a basis for establishing inclusive, socially sensitive recommendations for the engagement of deaf people in research.