

Congress of the Swiss Sociological Association 2024
University of Applied Sciences Northwestern Switzerland, Basel (MuttENZ),
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Call for Papers

Workshop Session: Doing research about and with people that lack decision-making capacity

Organizers:

Anca-Cristina Sterie (Lausanne University Hospital)

Often in research, the standard procedure requires that participants give an oral and written consent that attests to their willingness to participate and their comprehension of the terms under which participation will take place. This implies that participants have decision-making capacity. Impaired decision-making capacity is often an excluding recruitment criteria. It can be caused by certain mental health conditions (such as schizophrenia), major neurocognitive disorders (such as dementia), or severe learning disabilities. While research on these populations is not prohibited, it is certainly hindered by ethics commissions and health institutions that often act as gatekeepers on the issue of patient recruitment. This is a paradox, since it is specifically these individuals who should benefit from research and yet, are discarded from participation because of their vulnerability. It also questions how the concept of 'vulnerability' is operationalized in project design and conceived by health professionals and researchers alike.

This workshop welcomes contributions addressing how we conduct research on topics that concern people that lack decision-making capacity, and in particular on how these individuals are involved in our studies. Is it, for example, sufficient to obtain data from their entourage and what are the limits of such indirect information? How do researchers cope with the requirements of ethics commissions and health institutions? Can a more participatory approach be devised to allow people that lack decision-making capacity to become partners and not just objects in research?

Deadline for submitting abstracts: 5 January 2024

Length of abstracts: max. 2000 characters

Language(s) of the workshop: English and French

Email address(es) to which proposals must be sent: anca-cristina.sterie@chuv.ch