

RN 16 Sociology of Health and Illness
**CALL FOR PAPERS (Un)Making Europe: Capitalism,
Solidarities, Subjectivities**
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RN16_r: Citizen participation, genomics and bio-banking

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This session will consider the subjectivities of research participants in the context of biobanks and genomic research, focusing on consent limitations, trust, sharing, commercialization, different models and practices of citizen- and patient participation, and cultural influence in relation to family, community, religion and IT accessibility.

Full description

This session on Citizen participation, Genomics and Biobanking aims to attract contributions focusing on the subjectivities of research participants within the context of biobanks and genomic research.

With the current momentum of genomic research driving the shift to personalized medicine, the subjectivity of the research participant has gained increasing attention in the scientific community. Rather than passive donors of DNA samples, health or lifestyle data, ethical best practice now aims to put these individuals at the core of the research process as active partners with the potential to control the way their samples are used, and to be dynamically updated about research outcomes and societal impact.

This shift has significant effects on the dynamics within the genomic research community which are concretized and played out within the context of biobank governance structures. There is an interesting tension between facilitating the work of the bio-medical researchers who are driven to achieve optimum use of, and access to the samples, the governance structures aimed at addressing ethical and legal rights of participants, and the social implications of the research process. Issues of consent limitations, trust, sharing, and commercialization are key issues of concern and offer important avenues for sociological research. Furthermore, different models and practices of citizen- and patient participation (e.g. in the field of public engagement or citizen science) are of interest in this domain.

The cultural influence on attitudes and beliefs in relation to biobanking and genomic research is another key area of interest. Current research shows a marked difference in attitudes in Nordic countries where Biobanking is well established and public awareness is strong, to many other European countries where the majority of citizens have very little knowledge about the implications of genomic research and biobanking. The cultural impacts of issues such as Family, Community, Religion as well as IT literacy and accessibility would all be interesting areas for theoretical or empirical sociological work.

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