

Ethical considerations in Participatory Action Research (PAR)

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Conclusion

Ethical considerations in PAR are difficult to predict and must be considered continuously when involving users in designing e-health support.



Background

Although there is a trend towards developing health care in a user-centered direction, e-health support initiatives are often planned by professionals and researchers.

But....

There is a risk that the professionals' views are placed above the patient's needs.

Ongoing research

Type 2 diabetes is a common chronic disease with strong focus on self-care. This research intends to lay foundation for a future development of an e-health support tool for persons with diabetes type 2. As Participatory Action Research (PAR) is a research strategy particularly intended for involvement and empowerment this method was used.

Aim

The aim was to describe the PAR methods used in the project with special attention to issues about ethical considerations.

Method

The multistage focus group method and future workshop provided the opportunity for mutual learning between participants and the participants got ownership in the discussions. An ethical research application was approved before the research started.

Findings

Issues about privacy violation, harm, exclusion and power were paid attention to throughout the project.

The risk of privacy violation was obvious. The multistage focus group method was deliberately chosen as a strategy to create a climate of trust.

The risk that newly diagnosed persons would be harmed by meeting persons in later stages with diabetes complications was also considered. A division into homogenous groups was used to minimize the risk.

By only including frequent users of modern information technology there was a risk that only their views would be considered. To avoid that risk, nobody was excluded because of age or technology use.

E-health initiatives are often planned by the researcher and/or professionals. The future workshops allowed the users voices to be heard and became a tool to equalize power.

Using the multistage focus group method provided benefits such as learning from other people's way of solving problems and feelings of not being alone.