

A user-led study on stigma resilience: experiences and recommendations for future user research

Catherine van Zelst, May 2015

INTRODUCTION

This tool describes how a user-led study can be organized. It is written from the perspective of an expert by experience.

EU-GEI Work Package 7 included a user-led stigma project on stigmatization in psychosis conducted at the Department of Psychiatry and Neuropsychology of Maastricht University. The topic of stigma is considered to be very important by service users with various mental health complaints. This is an important reason for conducting research on this topic with implications for the service user's daily life.

Since stigma - stereotypes, prejudice and discrimination - is hard to tackle, it is important to focus on what one can do his or herself to cope with stigma and diminish the negative consequences it can have on the individual, and on his or her family and the society as a whole as well.

In this report experiences and activities of two projects are described: Attitude and D-STIGMI (*Destigmatizing Mental Illness*). Focus is on the various ways in which service users/experts by experience were involved in both projects. Recommendations for future user-led studies are summarized.

USER RESEARCH CENTRE

The user-led study contributed to the start of a "User Research Centre" (URC). This URC collaborates with (other) recovery-oriented initiatives to study and improve mental health care, promote recovery and diminish negative consequences of stigmatization.

PROJECTS

The idea to assist people with severe mental illness in becoming more stigma resilient resulted in the development of the intervention of D-STIGMI, a psycho-education coping skills training. This development started in an attitude project ("Attitude": a Dutch project on attitude change in mental health care), in which information was discussed and gathered about experiences related to stigma, recovery and mental illness in working groups consisting of service users/experts by experience, relatives and mental health professionals. Information was included in this group program that was evaluated in the Randomized Controlled Trial (RCT) D-STIGMI.

D-STIGMI: Service user involvement during the research process

In the D-STIGMI study, service users were involved in diverse elements of the research process. This process and the different roles service users had during the diverse stages of the research process are described below.

Design

The research proposal was written by an expert by experience. Feedback from both promotor in this PhD project was integrated in the proposal.

Questionnaires and interviews were chosen for evaluation of the participants (baseline, post-treatment and follow-up measurement).

As already mentioned, the intervention of the D-STIGMI RCT was partly developed in the Attitude project.

The newspaper reading group (control group of the RCT) was designed together with a mental health professional and an expert by experience, both of who were involved in the pilot of the group programs in the RCT as well.

Recommendation for future research:

- Ask (other) service users about their opinion about the research design (amount of questionnaires administered, estimated time per evaluation, etc.) and the questionnaires as well.

Recruitment

For the purpose of recruiting participants flyers, posters and a website for volunteers for participating in research at our research department, were used. Information of the study was also published at other websites, in magazines (both articles and interviews) and advertisements were placed in local newspapers.

Experts by experience were also involved in the recruitment of participants. Recruitment proved to be difficult in the D-STIGMI study.

Recommendation for future research:

- Involve more service users for the recruitment of participants. Investing more time in recruiting participants, using social media as well, may improve recruitment rates in future studies.

Data collection

No service users/experts by experience were involved in administering the questionnaires and interviews in D-STIGMI. Experts by experience were involved as trainers of the psycho-education coping skills training (intervention of the RCT) and the newspaper reading group (control condition of the RCT).

Recommendation for future research:

- Explore what is needed to involve experts by experience in administering questionnaires to participants.
- Keep involving experts by experience in training participants in group programs.

Data analyses

Data of D-STIGMI are currently being analyzed.

Recommendation for future research

- More collaboration with other (service user) researchers in analyzing the data.

Writing up

Experts by experience will be involved in discussion of findings.

Recommendation for future research:

- Involve experts by experience in discussing and writing down the findings of your research.

Dissemination

Diverse presentations were held on conferences and in other settings to clients, mental health professions, relatives etc. during the whole course of the PhD project. Interviews were done for radio, magazines and television.

Recommendation for future research:

- Experts by experience can be asked to present at conferences, just like other researchers. They can also support scientific findings with lessons learned from personal experience with mental illness.

GENERAL RECOMMENDATIONS

To experts by experience

- Plan regular meetings with supervisors/promoters and research team.
- Be sure there is good coaching available.
- Collaborate with other researchers.
- Gain experience with research abroad.
- Think about whether and how to disclose to employers and colleagues.
- Set your own boundaries with respect to talking about/being open about personal mental health issues.
- Explore what terms you prefer: Expert by experience? Researcher with lived experience? Having a mental illness? Service user?
- Let your own lived experience be of extra value in research.

- When do you prefer addressing yourself as an expert by experience? Be aware of implications.
- Listen to each other's viewpoints in an objective way and try to connect views on the research topics.
- When you feel you are not understood in your role as an expert by experience, be clearer and specific on what you think is important.
- Try to build bridges between service users and professionals.

Whole researcher team

- Involve experts by experience from the start of the development of a research plan or group program.
- Involve experts by experience in every element of the study, including ethics.
- Make clear appointments about finishing tasks (who does what and when).
- Value each other's contributions, also when these are based on lived experience.
- Be aware that teaching others is as important as learning from others.

To employers

- Create an atmosphere in which mental health complaints can be discussed.
- Give the expert by experience opportunities to present his or her own work/results of the study, to be informed on other studies and to meet other researchers in the field on conferences.
- Think about payment of all experts by experiences involved in the study.
- Make courses accessible, for instance on self-management during a PhD, time management, presenting in English, and courses about topics in the field of research.

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