

Patient and Stakeholder Involvement (PSI) Strategy (2020-2022)

Executive Summary



University of Stavanger

The aim of this strategy is that patient and stakeholder involvement (PSI) becomes an integral feature across all stages of the research process in all SHARE affiliated projects, from prioritisation and planning, management and conduct, to the dissemination of findings and implementation of change based on results. Genuine PSI can improve research quality and the relevance of research themes and outcomes.

Who

The following stakeholder groups may be involved as partners and collaborators in research activities at SHARE: patients and service users; carers and next-of-kin; patient and stakeholder organisations; healthcare professionals and managers, policy makers and regulatory authorities; and the public. All SHARE research projects, including PhD projects, should aim to carry out a formal stakeholder mapping or analysis to identify the most relevant stakeholders to involve, including at which stages of the research process involvement is needed and who to involve when.

How

It is encouraged to recruit relevant stakeholders as paid co-researchers and/or formal members of the research team, to encourage greater ownership of the project and its outcomes. Larger research projects should also involve stakeholders as members of an Expert Advisory Board and should establish user panels and/or resource groups with key stakeholders. A SHARE guide/handbook on 'how to do involvement', including how to recruit stakeholders, will be developed.

Activities that may include PSI

Patients and stakeholders can be involved in all stages of the research process, as follows:

Identifying and prioritising topics: identify areas where healthcare quality and safety research is needed; help prioritise research areas and which populations to study.

Designing and managing: contribute to the design and review of research projects, grant proposals, and study protocols; provide input on data collection methods; identify issues of ethical concern and factors that impact on participation; write or review information letters and consent forms; take part in participant recruitment and retention processes.

Undertaking: assist in carrying out research, by e.g. collecting data; assisting with the transcription and coding of data; contributing to data analysis and interpretation of research results.

Disseminating: contribute to project dissemination plans; co-author journal articles and co-present at conferences; contribute to teaching activities; report project results to relevant parties; ensure that research results are easily accessible to a public audience.

Implementing: contribute to the translation of new knowledge into practice, to facilitate actual change and improvement in healthcare services, policy development, etc.

Evaluating impact: co-design evaluation protocols; contribute to evaluation of the research process; evaluate the implementation of research findings; reflect on own role and experience.

All SHARE projects should strive to regularly evaluate, document and report activities, experiences, outcomes and impact concerning PSI, in cooperation with relevant collaborators and co-researchers. SHARE also encourages and will facilitate transfer of knowledge and experience of PSI between projects.

Organisational support and strategy follow-up

- SHARE has a lead PSI contact in a 20% position who is working alongside others to further develop and support PSI within SHARE. A SHARE PSI advisory panel will be established.
- Guidance, organisational policies and training on PSI for researchers will be developed.
- Training and support on involvement will be offered to collaborators/co-researchers.
- The Network for Carer Research at SHARE can facilitate PSI in projects on carer research.
- A PSI budget of 850.000 NOK per year for 2020-2022 is available for SHARE researchers.
- An annual PSI seminar will be hosted at the University of Stavanger.
- Regular follow-up activities will be undertaken to keep the strategy relevant and annual evaluations of the strategy will consider e.g. outcomes and impact.