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

SHARE Center for Resilience in Healthcare

University of Stavanger

Contents

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Executive Summary

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.

<u>Disseminating</u>: 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.

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

<u>Evaluating impact</u>: 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.

Background

This research involvement strategy has been developed to encourage and facilitate a greater degree and a broader spectrum of patient and stakeholder involvement (PSI) across all of SHARE's research activities, to increase the overall relevance and impact of the research conducted within SHARE. In order to form a comprehensive, nuanced and accurate picture of the healthcare services, it is important to include the perspectives of those who rely on these services for their health, as well as those who provide, govern and regulate healthcare. Genuine involvement has the potential to improve the quality of research and the relevance of research themes and outcomes. Collaboration with researchers, patients and other healthcare stakeholders can, for example, contribute to research that better reflects user needs and priorities; improved research design; and increased recruitment and participation throughout a research study. Patients and other stakeholders may be involved throughout all phases of the research process, from prioritisation and planning, management and conduct, to the dissemination of findings and implementation of change based on results. Patient and stakeholder involvement can thus illuminate new knowledge and facilitate insights into a broad variety of user-centred, clinical, managerial, and governmental perspectives, while also ensuring that research findings are targeted for expedient implementation across multiple levels of the healthcare system, in aid of service development and improvement.

The aim of this document is to outline a vision for SHARE's PSI strategy, and to provide an overview of how we aim to accomplish this vision and what the SHARE Centre hopes to achieve from its PSI activities. The main target group for the strategy are all SHARE affiliated researchers, in addition to all patient and stakeholder representatives that engage in some form of research collaboration with SHARE. The strategy development process was led by a working group consisting of PhD candidates Stig Bjønness and Inger J. Bergerød, post-doctoral researchers Petter Viksveen and Veslemøy Guise, and Centre Lead Karina Aase. The working group, with input from Centre Coordinator Lene Schibevaag, drafted an initial strategy document. All SHARE researchers and board members were subsequently invited via email to provide feedback on the strategy as part of a consultation process, which also involved presentation of the strategy at one of the Centre's monthly research meetings. A group of patient and stakeholder representatives from across the Centre's main research projects were also directly consulted during this process and contributed important input by email and in face-to-face meetings. In addition, the Centre for Public Engagement at St George's University of London (UK) contributed valuable feedback on an earlier draft of this document.

A vision for patient and stakeholder involvement within SHARE

As a part of SHARE's overarching vision of reforming the understanding of quality and safety of current healthcare systems[1], patient and stakeholder involvement (PSI) in SHARE's research activities is a key strategic priority for the Centre. This entails fostering and continually developing a culture of inclusion and respect in all of SHARE's work and activities, with the aim that patient and stakeholder involvement becomes an integral feature of all stages of the research process in SHARE affiliated projects. This vision for involvement will be achieved by actively including representatives from relevant stakeholder groups as partners in a range of theoretical, methodological, and practical research activities at SHARE.

Definition of patient and stakeholder involvement (PSI)

Involvement refers to the *active* involvement in research from people who use healthcare services, their carers, and other healthcare stakeholders, rather than people contributing only as research subjects. In essence, PSI in healthcare services research is when research is done *with* the people who use or provide services, rather than research that is done to, about or for them by others.[2] 'Involvement' is distinct from both 'participation', where patients and stakeholders are recruited as participants in research, and 'engagement', where researchers share knowledge and information with the public or otherwise engage in dialogue with healthcare stakeholders at the end of the research process. Thus, the use of the term 'PSI' implies that patients and stakeholders are actively involved in research, often across all stages of the research process and for the entire duration of a project as members of the research team.

From the inception of SHARE, we have used the term 'PSI' instead of the term 'PPI' (Patient and Public Involvement). This is because 'PSI' is a term more suited to the research conducted within SHARE, which is primarily focused on health services research from a quality and safety perspective. An expanded range of stakeholders than are typically considered as part of the 'PPI' term (usually restricted to patients, carers, user organisations and the public) are relevant as key partners in our research. Notably, healthcare system workers such as healthcare professionals, managers and regulatory representatives are crucially important stakeholders for the health services research conducted within SHARE.

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[1] SHARE Research Strategy, 2018-2022
[2] www.invo.org.uk/

Who are we going to involve and how?

Who

The stakeholder groups most relevant to the research that SHARE conducts are defined in the table below, based on original work by the Patient-Centered Outcomes Research Institute[3].

Stakeholder Group	Description	Example
Patients / Service users	People with current or past experience of illness or injury; people at risk for health problems or who use healthcare services	A person who has Type I diabetes
Carers	Family members, friends, or other person who provides care and support to patients / healthcare service users	The wife of a man receiving homecare, or the parents of a child w. mental health issues
Patient and User Organisations; Stake-holder Organisations	Representatives for organisations who advocate for the interests of patients, carers, healthcare professionals, or other stakeholder	An employee of an organisation representing stroke survivors
Healthcare Professionals	Practitioners of healthcare, including doctors, nurses, paramedics, and other allied health professionals	A general practitioner in primary care services
Clinical or Organisational Managers	People (with or without a healthcare background) in managerial roles with varying degrees of responsibility for the governance of healthcare organisations, such as hospitals and community health centres	A hospital ward manager or primary care clinic administrator
Industry	Representatives of companies that design or produce diagnostics, devices, technologies, pharmaceuticals, and other similar industries	The chief medical officer of a device manufacturer
Learning Institutions	People who deliver healthcare training and professional education, including trade or professional associations representing these institutions	Nursing students or teachers at a nursing school
Policy Makers	People who help craft public policy at any level of government	A policy adviser in a local government body
Regulatory Authorities	Representatives of a government agency that monitors and regulates the performance of healthcare organisations	A regulator from the Norwegian Board of Health Supervision
The Public	Members of the public who have an interest in improving healthcare services	An older citizen consulting on homecare service development
Other	Other healthcare stakeholders not covered by the categories above	An ombudsperson who receives and manages complaints about care quality

Patient and stakeholder involvement may occur directly through individual patients, carers, professionals and other stakeholders, or indirectly through representation and participation from

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[3] www.pcori.org/engagement/engagement-health-research-literature-explorer/engagement-health-research-literature

e.g. user organisations or staff associations. Relevant patient and stakeholder representatives or group representatives can be sought according to the research topics and settings in question in a given research project. In this process, it may be important to consider who the stakeholders are for the research project, based on for example gender, age, ethnicity, or knowledge and experience of using or working in a particular service. Clearly defined selection criteria to ensure the right user in the right place may be necessary in some contexts. Furthermore, all SHARE research projects, including PhD projects, should aim to carry out a formal stakeholder mapping or analysis to identify those users and stakeholders most relevant for involvement, including at which stages of the research process involvement is needed and who to involve when.

How

Involvement in research can be conceptualized according to three different approaches on the following continuum: consultation, collaboration, and user led. These are defined below:

- Consultation: researchers consult with stakeholders to seek knowledge and advice on any aspect of the research and apply responses to guide decision-making in the project;
- Collaboration: stakeholders are active and on-going partners throughout a research project, e.g. as research team members holding co-researcher positions; and
- User led: stakeholders set the research agenda, make decisions on research design, and lead the research management process.

Involvement can take place within a specific research project or in a broader sense with stakeholders serving on ethics committees, advisory boards, review panels, etc.

SHARE researchers are urged to strive for active collaboration with patients and stakeholders in all their research activities. If possible, 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 their Expert Advisory Board, and should establish user panels and/or resource groups with key stakeholders and actively involve the panels/groups as relevant, throughout the project period. A SHARE guide/handbook on 'how to do involvement', including how to recruit stakeholders, will be developed during the strategy period 2020-2022.

Activities that may include PSI

Patients and stakeholders can be involved in a range of activities at all stages of the research process, including during the planning, conduct, and dissemination of research. The research process, or research cycle, is here divided into the following stages: Identifying and prioritising topics; Designing and managing; Undertaking; Disseminating; Implementing; and Evaluating impact. The stages of the research cycle are illustrated in Figure 1. Inspired by important work on PPI in research by INVOLVE[4], examples of involvement in each of the stages are described below, with some suggestions for how to achieve active involvement at each stage.
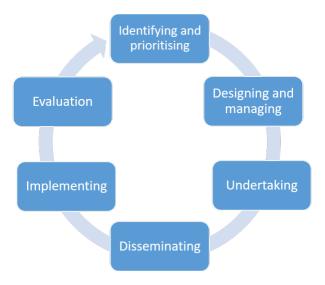

Figure 1: The research cycle

Identifying and prioritising topics

During this initial phase, patients and stakeholders can influence what will be researched by

- identifying areas where healthcare quality and safety research is needed; and
- helping to set priorities for the type of research that SHARE will undertake and which populations to study.

PSI in the identification and prioritisation of research topics is fundamental to SHARE's PSI strategy. By actively collaborating with patients and stakeholders at an early stage to identify pertinent areas of research, we can ensure that the research conducted by SHARE meets important needs of service users and providers across the healthcare system. Such partnerships can feature opportunities for mutual learning and shared decision-making regarding the relative importance

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[4] Briefing notes for researchers: public involvement in NHS, public health and social care research (2012)

of research topics, settings, and populations to study. This can be achieved through PSI in, for example, brainstorming workshops, user panels or resource/reference groups, research networks, and research project steering groups.

Designing and managing

During this phase, patients and stakeholders can join in research design and management by e.g.

- contributing to the design of research projects and proposals;
- helping develop or review research grant proposals and study protocols;
- providing input to decisions on study aims, research questions, and outcomes of interest;
- providing input on selection of data collection methods and outcome measures, alongside design and development of research tools such as interview guides and questionnaires;
- identifying issues of ethical concern (including risk assessment) in projects and provide advice on how to handle these;
- identifying factors that can promote/inhibit participation and assess the possible burdens for research participants;
- helping write or review information letters and consent forms for study participants; and
- leading, advising on, or assisting in participant recruitment and retention processes.

PSI in overall research design as well as the development of grant applications and/or research tools and information can ensure that research projects, processes, and intended outcomes remain relevant to the needs of patients and stakeholders (e.g. by appropriately framing research questions). PSI in the management of research projects may occur through active stakeholder membership in project steering groups or as collaborators in project management teams. Patients can also take or share the role of principal investigators in a study, in which case they are employed as paid members of the research team. Their contextual knowledge and insights may add significant value to the co-design of data collection and analysis processes.

Undertaking

During this phase, patients and stakeholders can get involved in carrying out research, often as members of the research team, by e.g.

- collecting data, including gathering and reviewing documents, undertaking library-based searches, conducting interviews, and facilitating focus groups;
- assisting with the transcription and coding of data; and
- contributing to data analysis and interpretation of research results.

PSI in the undertaking of research can strengthen the rigour and quality of data collection and analysis processes. As a result, PSI can reveal new perspectives in the interpretation and understanding of research results. For example, co-researchers may identify or describe themes in ways that other researchers have missed. Patients and stakeholders who will be involved in data collection require appropriate training and support to carry out the required research roles.

Disseminating

During this phase, patients and stakeholders can be involved by e.g.

- contributing to the development of project dissemination plans;
- being included as co-authors in journal articles, co-presenters at conferences, or having their contributions acknowledged in journal articles and reports;
- contributing to teaching activities;
- producing progress reports or newsletters to keep stakeholders and the public informed throughout a project;
- helping to ensure project results are reported back to all those who consulted, collaborated or participated, including patient organisations, support groups and service providers; and
- helping to ensure that research results and associated information are easily accessible to a public audience, e.g. by summarising research findings in clear, user-friendly language.

Active PSI in the dissemination of research results helps our findings reach a wider audience than without such involvement, as patients and stakeholders will often have access to social media networks, publicity channels, interest groups and forums that researchers may either not be aware of or have access to. Stakeholders who have been involved throughout the research process are more likely to fully participate in dissemination activities. SHARE researchers are therefore encouraged to involve patients and other stakeholders early in the research process, to support their contextual knowledge of the research and their pride in project ownership.

Implementing

PSI can contribute to the translation of new knowledge into real-world practice, leading to actual change and improvement in healthcare services. Those with a personal stake in research are more likely to put in extra effort to ensure that change happens as a result. They may even be better placed than researchers to establish relationships with key agencies and policy makers. Thus, PSI can influence and facilitate the implementation of research findings and outcomes into clinical or managerial practice, as well as contributing to policy development.

Evaluation

During this phase, patients and stakeholders can be involved by e.g.

- co-designing the evaluation protocol;

- evaluating the research process together with research team members;

- evaluating the implementation of research findings in real-world practice; and

- reflecting on their own role and experience in the project as a collaborative stakeholder and what they have learned.

All SHARE projects should build into their work how they will monitor and assess patient and stakeholder involvement as an intrinsic part of the research process. This work should feature cooperation with patient and stakeholder collaborators and co-researchers. Such assessments will contribute to continual development and improvement in SHARE's PSI practices and associated activities. Letting others know about what worked well (or not), how, and why will contribute valuable knowledge to the evidence base on the drivers for PSI in research. This can be achieved by including information on experiences and outcomes of PSI in research reports and journal articles. This includes what was learned by welcoming PSI to the research team and its impact on the research process, such as PSI leading to changes in the research direction or to different study outcomes. Together with the stakeholder representatives concerned, all SHARE research projects should strive to regularly evaluate, document and report activities, experiences and outcomes concerning PSI, focusing on research impact as well as the personal impact for those involved. SHARE will also encourage and facilitate the transfer of knowledge and experience of PSI between projects, for example as part of the Centre's monthly research meetings.

Organisational support of PSI

SHARE has a lead PSI contact in Veslemøy Guise, who holds a 20% position on coordination of PSI through the Resilience in Healthcare (RiH) project. She is currently working alongside others to further develop and support the vision for PSI within SHARE. This includes the establishment of a SHARE PSI advisory panel which will feature a broad variety of patient and stakeholder representatives who will meet at regular intervals. The main function of this panel will be to provide input and contribute advice on involvement to research projects and activities across SHARE. A primary focus will be for the PSI panel/board to contribute at the *Identifying and Prioritising* and *Dissemination* stages of the research process.

The following are some additional measures that are currently in place to support PSI within SHARE, or which will be put in place during the strategy period:

- Guidance and training for researchers, including development of a guide/handbook on 'how to do involvement', and collation of resource material on involvement

- Training and support for PSI collaborators, including a research involvement guide

- Undertaking systematic stakeholder mapping/analyses in a sample of ongoing and finalised SHARE projects, to strengthen knowledge and practical competence of PSI within SHARE.

- The Network for Carer Research (Nettverk for pårørendeforskning) is coordinated by SHARE. The Network consists of ca. 170 researchers, clinical practitioners, carers, and other stakeholder groups. It is open to SHARE researchers and can function as a facilitator for PSI in projects focused on carer research.

- Hosting annual PSI seminars at the University of Stavanger. The first such seminar was held in September 2019 on the topic mental health and stigma, and was attended by 380 youths from local secondary schools. The seminar was initiated, planned and hosted by user representatives from the InvolveMENT project. A second SHARE PSI seminar will take place during 2020.

- Engaging in a formal clarification and alignment of expectations, to ensure that stakeholders and researchers gain a common understanding of the purpose and extent of involvement and support, as well as the purpose of a given project that features involvement. This orientation is especially important for stakeholders who have no previous research experience.

Suggested PSI guidance and policies that should be further developed in the strategy period:

- A handbook/training module for SHARE researchers on 'how to do involvement'

- Expenses and compensation policy for PSI contributors

- Template for code of conduct agreement for PSI representatives collaborating with and/or acting on behalf of SHARE

- Template for confidentiality agreements for PSI representatives (e.g. regarding access to sensitive research material)

Budget for PSI activities

SHARE is committed to making proper funding available to facilitate PSI across our research activities. For the strategic period 2020-2022, SHARE has a budget for PSI activities at 2.5 million NOK, funded through the RiH project. This is the equivalent to 850.000 NOK per year over the strategy period. All PhD projects will have funding available in order to actively involve relevant stakeholders throughout their project period, for example to compensate for stakeholders' time used in the research activities, hire co-researchers, organise user panels or to fund seminars, dissemination activities, etc. This PSI budget will be managed as part of the overall RiH budget. Researchers can access these funds by suggesting activities and budget to the lead PSI contact in SHARE who will consult with the RiH project manager.

Yearly PSI budget during the strategic period:

2020

628.000 NOK for hiring co-researchers, wages, compensation for time used by stakeholders

120.000 NOK for organising user panels, seminars, etc.

80.000 NOK for dissemination activities

2021

648.000 NOK for hiring co-researchers, wages, compensation for time used by stakeholders

120.000 NOK for organising user panels, seminars, etc.

80.000 NOK for dissemination activities

2022

648.000 NOK for hiring co-researchers, wages, compensation for time used by stakeholders

120.000 NOK for organising user panels, seminars, etc.

80.000 NOK for dissemination activities

PSI strategy follow-up

- Disseminate the strategy to all SHARE researchers, e.g. via the SHARE website and at monthly research meetings, with the expectation that they familiarise themselves with its contents and reflect on how they can best aim to implement the parts relevant to their work. All projects should develop specific measures of how to implement the strategy.

- Undertake regular follow-up activities to keep the strategy relevant, including discussion in monthly research meetings, and annual evaluations of the strategy conducted by the SHARE management team, the SHARE board, and the SHARE PSI panel. These evaluations will consider e.g. the ways the strategy has been followed up; its outcomes and impact; and any aspects that need further work and engagement.

Examples of PSI practices in current SHARE research projects

InvolveMENT – To strengthen adolescents' mental health services (2016-2020)

Twelve adolescents have been actively involved as adolescent representatives and co-researchers through all phases of the InvolveMENT project. This includes research planning, study design, undertaking research, and disseminating research results. For example, adolescent co-researchers have, with SHARE researchers' support and guidance, provided feedback to funding applications; initiated, developed and carried out mental health surveys; co-authored peer-reviewed articles; presented results at seminars and conferences, and organised a mental health seminar for adolescents at the University of Stavanger. The group of adolescent representatives and co-researchers includes both youth with an ethnic Norwegian background and those with other ethnic backgrounds, as well as youth with and without personal experiences with mental health challenges and use of mental health services. They either receive remuneration (at an hourly rate) or contribute in kind to the research as part of their compulsory high school extra-curricular experiences programme.

SAFE-LEAD – Improving quality and safety in primary care (2016-2020)

Patient and next-of-kin perspectives have been key throughout the SAFE-LEAD project, with active user involvement in of project development, design, data collection, analysis, and dissemination of results. One patient representative and one next-of-kin representative have acted as paid co-researchers. In addition, three nurse counsellors from the Centre for Development of Institutional care and Home care services (USHT) have been employed as paid co-researchers with responsibility for the recruitment of participants and study sites. An unpaid USHT manager has participated in semi-annual project meetings. A representative from the Patient and User Ombudsman has been involved in project development and application for funding, and has had a key role in the stakeholder network, and in intervention design and pilot testing. Managers from nursing home and home care services have also been involved in intervention design and pilot testing. A patient from a nursing home study site also participated in pilot-testing.

QUALinCLINstud – Quality in clinical supervision and assessment of student nurses in nursing homes (2018-2022)

Project stakeholders include nursing homes, the nursing education sector, and Stavanger municipality. The project applies a social co-creative process to determine appropriateness of the research results in clinical supervision and assessment of student nurses. Involvement, engagement and participation represent core components of the approach in which the end result is to develop a web based supervision and assessment program for use in clinical studies in nursing education. Stakeholders' needs, user interface, and value in use for students, teachers and nurse mentors are vital elements of the process. User involvement is ensured by recruitment of two registered nurses as part-time co-researchers. In addition, user panels and resource groups with key stakeholders (nurse teachers, student nurses, nurse mentors) have been established to ensure active involvement and consultation. Dialogue meetings and workshops with stakeholders are held regularly as part of the program development process.

RiH – Resilience in Healthcare (2018-2023)

Patient and stakeholder involvement is organised as a separate work package (WP2) in the RiH project, providing resources for and facilitating PSI in the other work packages across the project. The focus of WP2 is furthermore to study the impact of PSI on resilience in healthcare, including the development and assessment of methods for patient and stakeholder involvement. Stakeholders were involved in the development of the grant proposal, and are represented on the Expert Advisory Board. As the RiH project progresses, patients and other key stakeholders will continue to be systematically involved in multiple ways across project activities. This includes the recruitment of patient and stakeholder representatives to a WP2 steering group and as co-researchers, which is currently underway.