

QUEST Fund for Patient & Stakeholder Engagement

The active engagement of patients and other stakeholders can increase the relevance and usefulness of research for those affected. To foster Patient & Stakeholder Engagement (PSE) at Charité, the BIH QUEST Center starts a fund to support researchers with the implementation of PSE in their research projects. All BIH and Charité researchers are eligible to apply.

Background

There is an increasing demand from funders, journals, patients, patient organisations, and the society for the active engagement of patients and other relevant stakeholders in health research (Patient & Stakeholder Engagement, PSE). Taking the views and needs of patients and other stakeholders (e.g., relatives) into account can increase the relevance and usefulness of research for those who are affected by it. Patients and their relatives have different perspectives on their disease and can therefore provide new insights that may otherwise remain hidden from researchers. In addition, specific questions or outcomes may be of particular importance to them, which researchers may not have thought of or which they may consider less relevant.

By **active engagement**, we do not mean recruiting patients as participants in clinical trials or other quantitative or qualitative studies like interviews or surveys. Active engagement means that they have a say in the planning, conduct, and/or dissemination of a study or research project. This includes, for example, the definition of patient-relevant outcomes or the joint development of an intervention or dissemination strategy. This can be achieved, for example, by involving patients as co-researchers, by setting up a Patient Advisory Board or by conducting workshops with patients and other relevant stakeholders. However, this requires resources that are not always available to researchers.

Funding objectives

The QUEST PSE Fund aims to support researchers in the process of their research to encourage the active and meaningful involvement of patients and other relevant stakeholder (e.g., relatives). We support PSE activities e.g., in already funded projects that do not have sufficient resources for PSE yet, or to bring the patients' voice into the planning and design of new project ideas.

The grants will fund PSE activities like:

- Reimbursement of patients and other relevant stakeholders (and family caregivers or assistants, if necessary) and honoraria for activities such as participating in workshops or advisory boards
- Travel costs for activities such as participating in workshops, visiting meetings or conferences that are explicitly related to PSE



- Costs for workshops, e.g., rental fees for venue and equipment, external moderators and/or PSE experts, reasonable catering costs
- Printing materials and other means of dissemination and communication

Eligibility and other formalities

Researchers of Charité – Universitätsmedizin Berlin including Berlin Institute of Health (excluding members of the QUEST Center) can apply for a funding **up to 2.000 EUR**. The funding has to be spent **until the end of 2022**. Researchers can only apply one time each.

The general principles of efficiency and economy as specified within the budgetary and legal provisions of the Federal Budget Code (Bundeshaushaltsordnung) apply.

Application

To apply for the QUEST PSE fund, please send an email to quest@bih-charite.de with a short statement about how you want to actively engage patients in your project and which resources (including estimated expenses) you would need.

Decision

The funding decision will be made by order of received applications until the QUEST PSE fund is spent. Most important, the statement must include a clear reference to the aim of the call, i.e. the support of active patient engagement in research. After the funding period, the successful applicants consent to submit a brief report, and they agree that their PSE activities will be mentioned on the QUEST webpage.

If you have questions regarding the call, feel free to contact Dr. Sarah Weschke, officer for Patient & Stakeholder Engagement at the BIH QUEST Center: sarah.weschke@bih-charite.de

You can find more information on Patient & Stakeholder Engagement here.