

PPI resources for NDS applicants

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Patients & Public Involvement (PPI) encourages fruitful, sustainable, and enduring partnerships between scientists and patient organizations, co-leading the way for systematic patient-centered research.

Participation (Passive): Patients participate in a research study as subjects/participants or patient representatives support recruitment.

Engagement (Active): Patients or patient representatives co-create information for dissemination and where patients disseminate information and knowledge about the research project and its results.

Involvement (Proactive): Patients or patient representatives are actively involved in research projects, i.e., where research is carried out 'with' or 'by' patients or patient representatives rather than 'to', 'about' or 'for' them.

> Patient as official partner / co-investigator to:

- Identify patient needs,
- Highlight new research directions,
- Design, develop, co-write research proposals,
- Implement research,
- Contribute to interpretation and findings.

Identifying and prioritizing:

- Patients/stakeholders identify relevant research topics through consultation

Evaluating impact:

- Collaborate with researchers to assess the research process
- Evaluate the impact of the involvement on the research
- Patients/public reflect on their role / what they learned

Designing and managing:

- Ensure protocol/methods are patients appropriate
- Assist with recruitment & retention strategies
- Define outcome measures
- Assist in steering project
- Develop research tools
- Review/draft informed consent forms
- Produce patient/participant-friendly research updates (communication)

Implementing:

- Increase the likelihood of results being implemented due to patient support/lobbying
- Assessment of value
- Analysis of benefit/risk

Funding and commission:

- Review & draft research funding proposals
- Ensure the research & methods are ethical

Disseminating:

- Advice on avenues for dissemination
- Jointly present research findings
- Contribution to publications
- Draft lay summaries of results
- Collaborate in publishing results, e.g., via charities/patient groups
- Undertaking and analyzing:
 - Collaborate in data collection, e.g., with phone apps, conducting interviews/surveys
 - Analyze/interpret data & results

Please consider the SCTO guide for Researchers¹ (in collaboration with the SNSF) and the PPI fact sheet² (available on <https://www.scto.ch/en/publications/fact-sheets.html>).

¹ Direct download: https://www.scto.ch/dam/jcr:c0daedf0-7fa1-4334-b154-997d6344d5be/SCTO_PPI_Guide_Researchers_210713.pdf

² Direct download: https://www.scto.ch/dam/jcr:7939fcf2-bf6d-4e1a-a9bf-3333aa11a408/SCTO_FactSheet_PPI_V1_210427_EN.pdf