

# PPI resources for NDS applicants

Olivier Menzel and David Haerry, October 2021 – Version 2 February 2022

Patient & Public Involvement (PPI) encourages fruitful, meaningful, and enduring partnerships between scientists and patients/members of the public, co-leading the way for systematic patient-centered research.

## PPI is not:

**Participation (passive):** When patients or members of the public participate in a research study as subjects/participants.

**Engagement:** When researchers disseminate information and knowledge about a research project and its results to patients and members of the public.

## PPI is:

**Involvement (proactive):** When patients/members of the public are actively involved in research projects; that is, where research is carried out 'with' or 'by' patients/members of the public rather than 'about' or 'for' them.

## Some examples of PPI throughout the research cycle

### Identification of research topics

- Patients/stakeholders identify relevant research topics or unmet needs through consultation

### Funding and ethics commission processes:

- Review & draft research funding proposals
- Help ensure research & methods are ethical

### Study design and management:

- Participate in steering projects (e.g. as members of an advisory board)
- Ensure protocol/methods are appropriate and acceptable to patients
- Assist with recruitment and retention strategies
- Define outcome measures
- Assess value
- Analyze benefit/risk
- Develop/pilot research tools
- Review/draft informed consent forms
- Produce patient/participant-friendly research updates (communication)

**Implementation:**

- Collaborate in data collection, e.g., with phone apps, conducting interviews/surveys
- Contribute to analysis/interpretation of data & results
- Form part of research team
- Support recruitment efforts.

**Dissemination & follow-up:**

- Co-create information for dissemination
- Advise on avenues for dissemination
- Draft lay summaries of results
- Jointly present research findings
- Contribute to publications
- Collaborate in publishing results, e.g., via charities/patient groups
- Increase the likelihood of results being implemented due to patient support/lobbying.

**Evaluation**

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

Plan appropriate resources for your PPI plan, including remuneration for PPI experts.

Please consider the SCTO guide for Researchers (in collaboration with the SNSF) and the PPI fact sheet<sup>2</sup>(available on <https://www.scto.ch/en/patient-and-public-involvement.html>).