



PPI FROM THE PERSPECTIVE OF THE SWISS NATIONAL SCIENCE FOUNDATION

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18 March 2024

Content

PPI initiative at the SNSF and the IICT programme

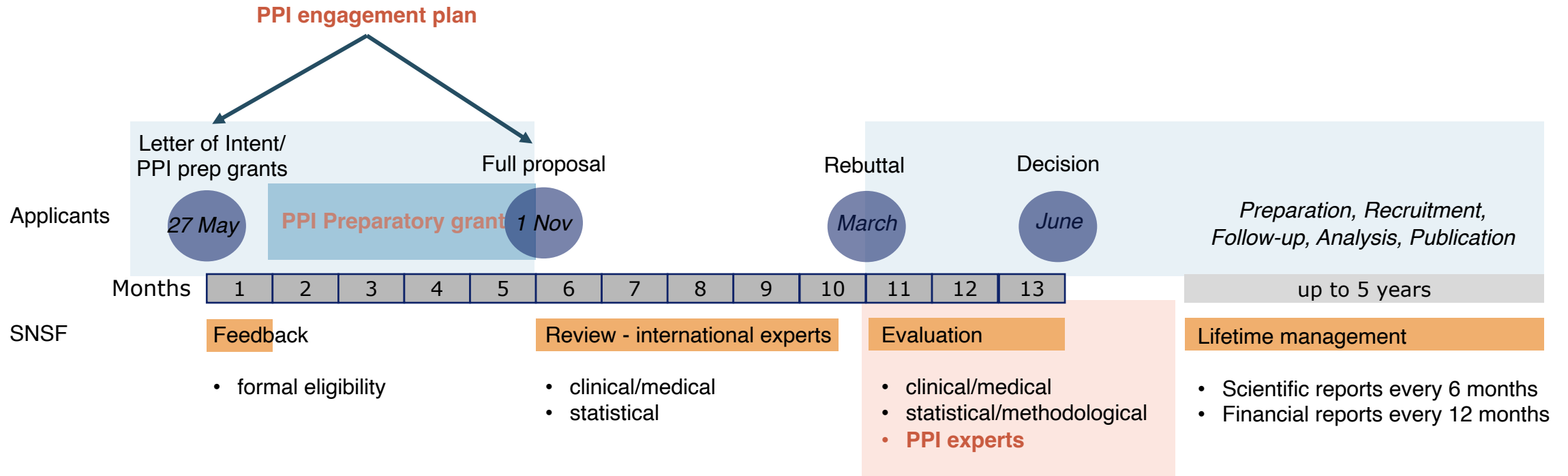
IICT evaluation – PPI

Practical recommendations for researchers

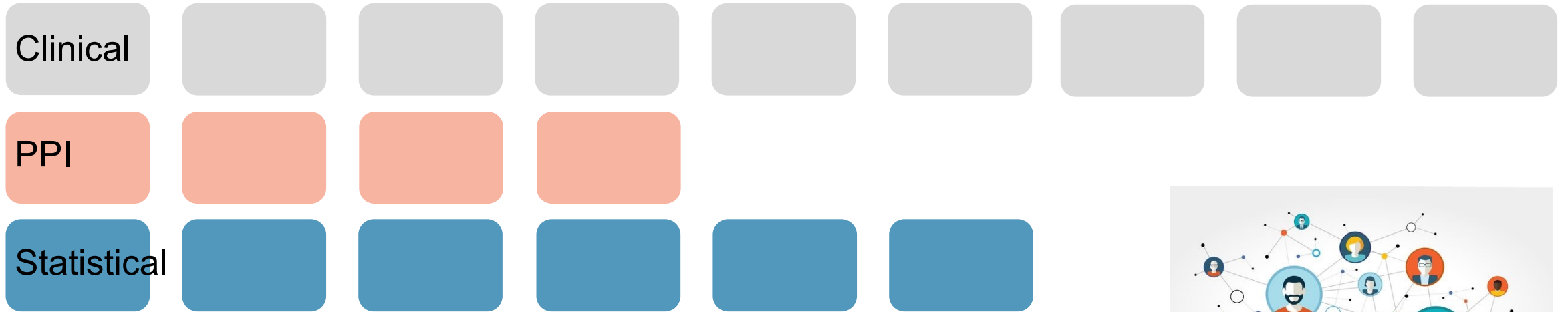
PPI initiative at the SNSF - background

- 2015** First call of the Investigator Initiated Clinical Trials (IICT) programme.
- 2018** Patient involvement is added as an evaluation criterion in the IICT programme.
- 2020** Patient and public representatives become an integral part of the IICT evaluation panel.
- 2022** PPI preparatory grant is added

PPI in the ICT programme – overview of the call



IICT panel composition



Everyone has an equal voice!



Evaluation criteria

- Originality, clinical relevance, scientific value and topicality of the study;
- Suitability of methodological approach and feasibility of the project;
- Documentation of patient and public involvement;**
- Applicants' scientific track record and expertise in relation to the project.

What do PPI experts evaluate in the panel – before submission

Summary for laypersons

- Has the lay summary been written in such a way that someone unfamiliar with research can understand the aim of the study?

Participation in the preparation of the research proposal

- **Consultation:** Were patient representatives consulted before the research questions, endpoints and recruitment strategy were defined?
- **Impact:** Was the input of patient representatives included in the development of the proposed study? Have the applicants described how the patient representatives' input influenced the study design?
- **Evidence:** Is there clear evidence of patient participation beyond a statement of intent?

What do PPI experts evaluate in the panel - DURING

Participation during the clinical trial

- **Responsibilities and rights:** Have patient representatives been assigned a specific role in the study management? Are expectations clearly defined? Has the research team made arrangements for training and supporting the patient representatives?
- **Feasibility:** Is the research plan feasible from the perspective of the study participants in terms of the burden on the participants (questionnaires, tests, treatment, number of contacts, time required, logistics)?
- **Sensitive data:** Are there particular data protection issues with this patient group? Have the applicants discussed these issues with the patient representatives?
- **Payment of patient representatives:** Has the research team provided sufficient remuneration for patient representatives? What is the reimbursement strategy?

What do PPI experts evaluate in the panel - AFTER

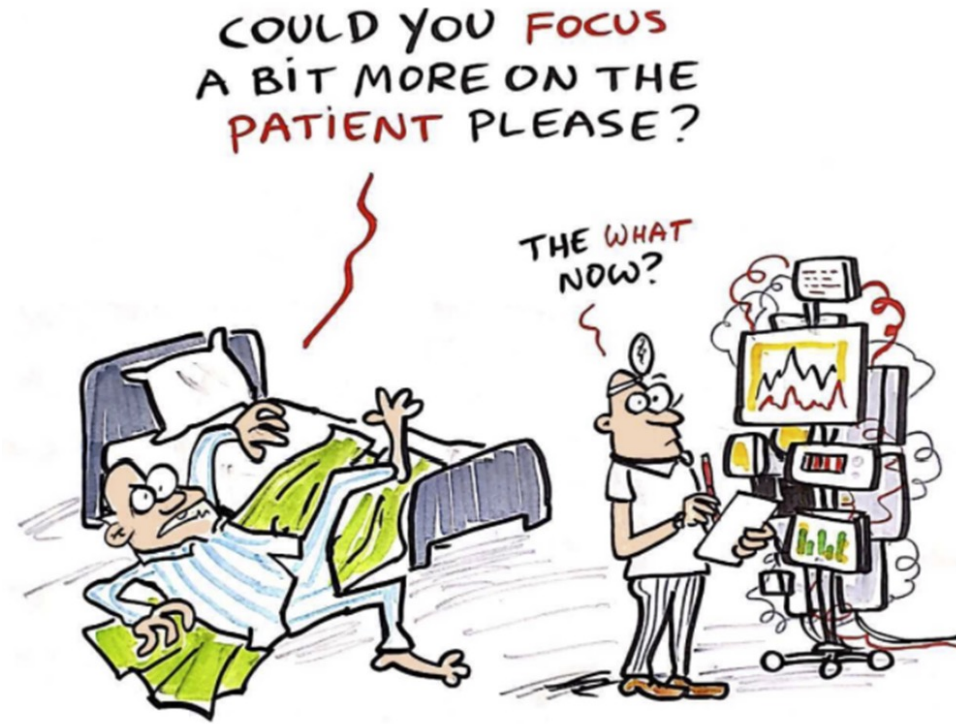
Dissemination...

- **...to the patients:** Are the progress and results of the study communicated to patients, and if so, by what means? Communication channels? Timing? Active or passive? Are the proposed forms of communication appropriate to reach the target group?
- **...outside the study:** How do researchers ensure that all people for whom the results are relevant (including health care providers, professional associations or health insurers) can be informed about the results? Are the results made available to and understood by a lay audience?

PPI-Evaluation

- How do the applicants intend to evaluate PPI and its impact during and after the study?

What are we missing here?



WHAT MATTERS?

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Additional aspects to consider (personal experience)

- **Cultural Competence in PPI Activities:** Ensuring that PPI activities are culturally sensitive and inclusive, accommodating diverse patient backgrounds and perspectives. This involves understanding and respecting cultural differences and ensuring representation from various cultural groups in the research process.
- **Patient-led Research Agenda Setting:** Allowing patients to have a more prominent role in setting the research agenda or priorities. This could include patient-led forums or workshops where they can voice the areas they feel are most important for research.
- **Ongoing Training and Education for PPI:** Beyond initial training, providing ongoing education and support for patient participants to keep them informed and engaged throughout the research process. This could include regular updates on research progress and additional training sessions as needed.

Additional aspects to consider (personal experience)

- **Feedback Mechanisms on Research Impact:** Establishing clear channels through which patients can receive feedback about how their involvement has impacted the research, thus validating their contributions and enhancing the sense of accomplishment and purpose.
- **Incorporation of Patient Stories and Experiences:** Systematically collecting and integrating patient stories and experiences into the research, to bring a human element to the data and findings, making the research more relatable and impactful.
- **Flexibility in Participation:** Offering flexible participation options for patients, recognizing that health conditions may affect their ability to contribute consistently. This might involve flexible scheduling or the option to contribute remotely.

Practical advice to researchers

General

Involve patient representatives and relevant patient organisations in the development of your proposal **from the beginning**.

Application preparation

Develop the application **together** with the patient representatives and integrate their knowledge (e.g. summary for laypersons).

Use the supporting material from the SCTO ([Patient and Public Involvement](#)).

Application submission

Show what the feedback from patient representatives was and how it was incorporated into the study design (=impact).

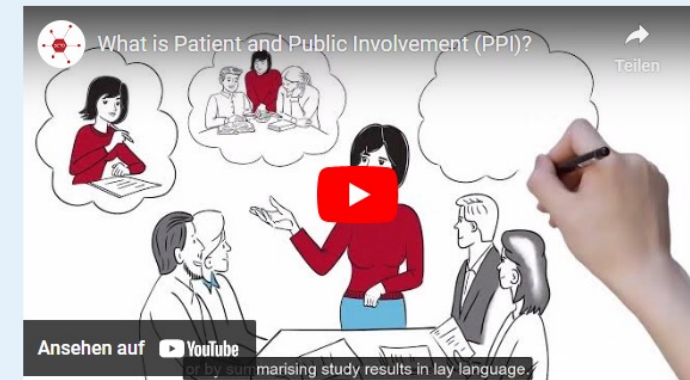
Provide clear **evidence** that patient representatives commit to participate (including role and compensation strategy).

PATIENT AND PUBLIC INVOLVEMENT

Patient and public involvement in clinical research

A partnership based on both mutual trust and transparent communication is what forms the foundation of a dialogue between researchers and those affected by research. The SCTO promotes this dialogue and advocates for the support and implementation of patient and public involvement (PPI) in academic clinical research.

What exactly is PPI?



Video is available in the following languages: [EN](#), [FR](#), [DE](#), [IT](#)

Practical advice to researchers – please consider

Patient-centered outcome measures (PROMs)

The SNSF highly recommends considering PROMs

The collection of internationally recognised PROMs by the International Consortium for Health and Outcomes Measures ICHOM <https://www.ichom.org/patient-centered-outcome-measures/>

Priority-setting partnership

The James Lind Alliance brings patients, carers and clinician groups together to identify evidence uncertainties which are important to these groups.

The resulting ‘Top 10’ lists of jointly agreed uncertainties as research questions can be a great source of input when defining a research question. <https://www.jla.nihr.ac.uk/priority-setting-partnerships/>



For questions

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