Swiss National Science Foundation

PPI FROM THE PERSPECTIVE OF THE SWISS NATIONAL SCIENCE FOUNDATION

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Content

PPI initiative at the SNSF and the IICT programme

IICT evaluation - PPI

Practical recommendations for researchers

PPI initiative at the SNSF - background

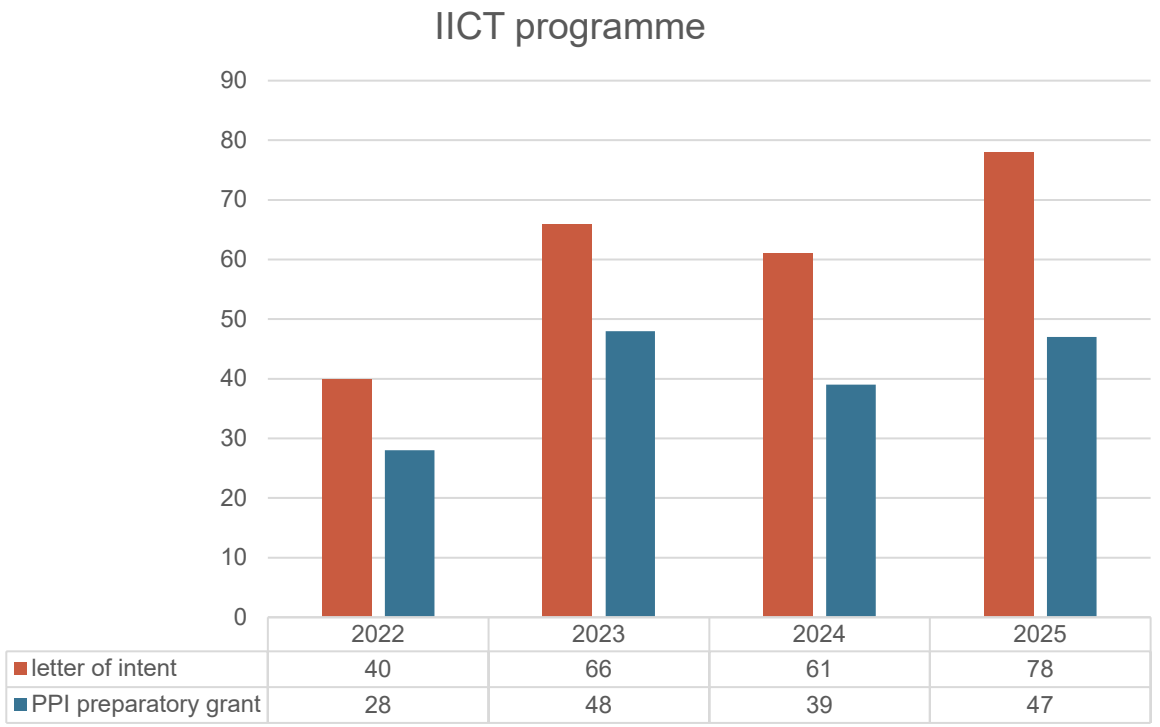
2015	First call of the Investigator Initiated Clinical Trials (IICT) programme
2018	Patient involvement is added as an evaluation criterion in the IICT programme
2020	Patient and public representatives become an integral part of the IICT evaluation panel
2022	PPI preparatory grant is added
2024	**New**: involvement of PPI experts during peer-review

PPI preparatory grant

– A preparatory grant for patient engagement during the development of the application of up to CHF 5000 can be requested

– Max. 4 months (July – October 2026)

– Submission with the letter of intent (for call 2026: 26 May 2026)

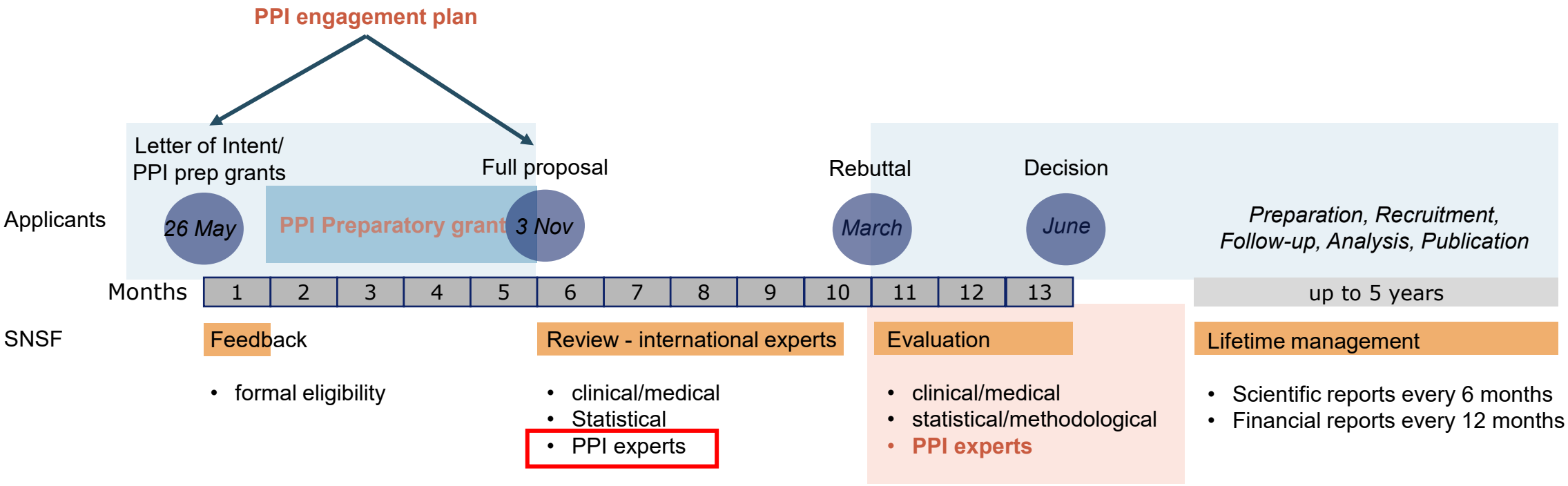


	2022	2023	2024	2025
letter of intent	40	66	61	78
PPI preparatory grant	28	48	39	47

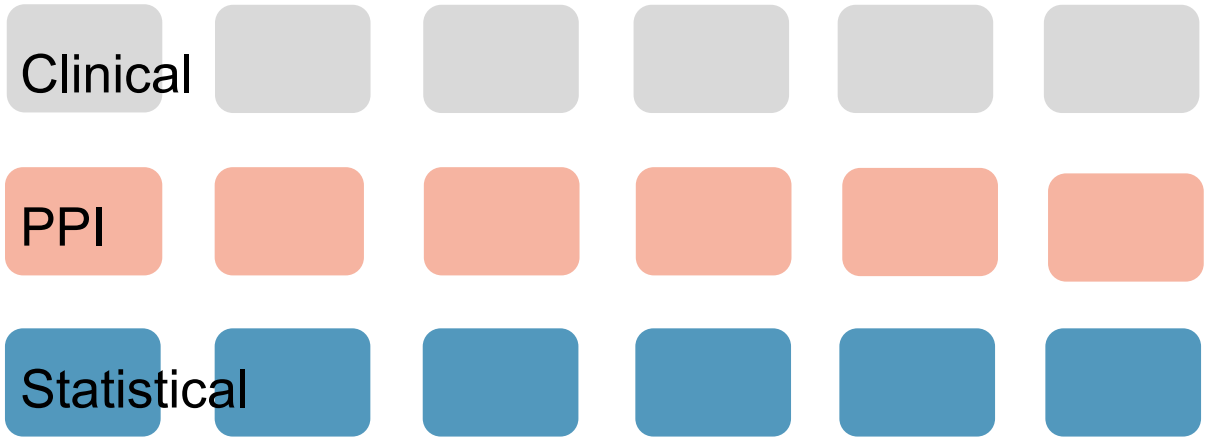
more information: [SNSF IICT website]

SNSF

PPI in the IICT programme – overview of the call



IICT panel composition

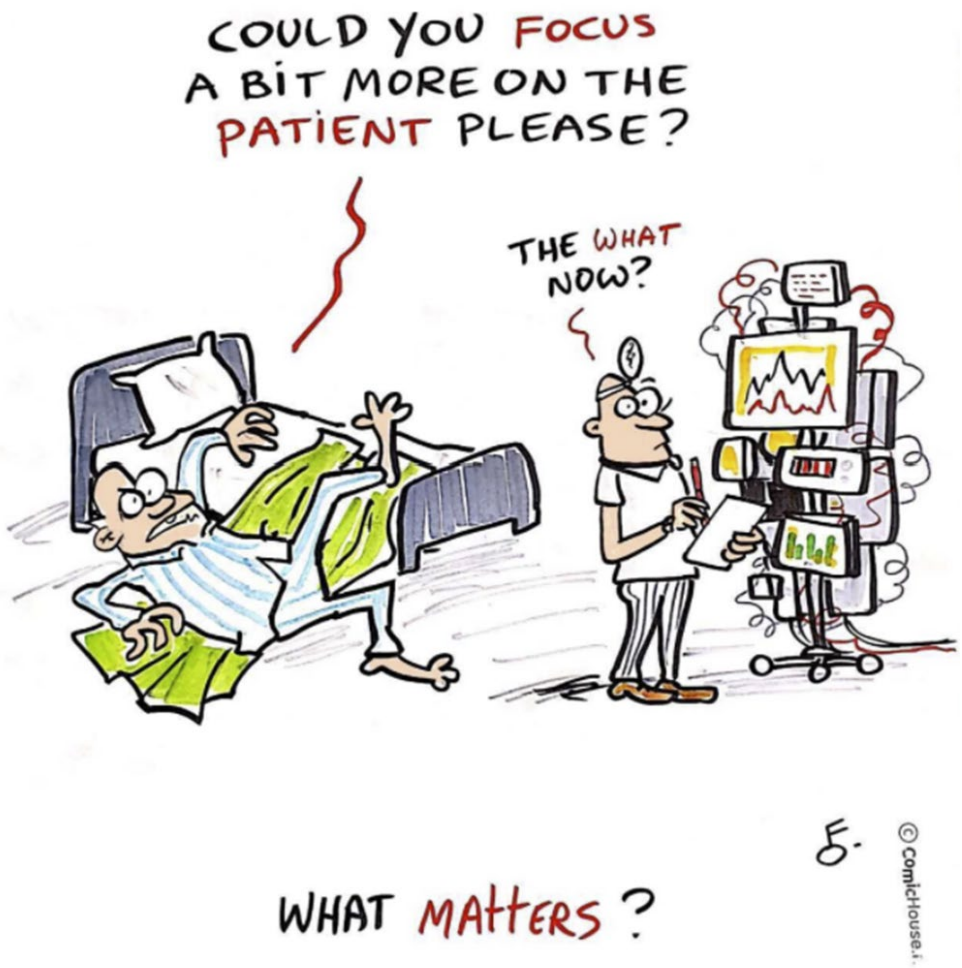


Everyone has an equal voice!

Evaluation criteria

a. Clinical relevance, originality, scientific value and topicality of the study;
b. Suitability of methodological approach and feasibility of the project;
c. **Documentation of patient and public involvement;**
d. Applicants' scientific track record and expertise in relation to the project.

What are we missing here?



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?

IICT Evaluation Criteria for PPI
-In a nutshell-

- Documentation of patient and public involvement.
- Summary for laypersons' clarity.
- Participation in research proposal preparation.
- Impact of patient input on study design.
- Evidence of actual patient participation.
- Participation during the clinical trial (roles, feasibility, data, payment).
- Dissemination of study progress and results.
- PPI-Evaluation plan.

PPI: Additional Aspects to Consider (personal experience)

- **Cultural Competence in PPI Activities:** Ensure PPI activities are culturally sensitive and inclusive to all patient backgrounds.
- **Patient-Led Research Agenda Setting:** Allow patients to have a say in setting research priorities.
- **Ongoing Training and Education for PPI**: Provide ongoing education and support for patient participants.
- **Feedback Mechanisms on Research Impact:** Create channels for patient feedback on how their involvement has impacted the research.
- **Incorporation of Patient Stories and Experiences:** Integrate patient stories and experiences to add a human element.
- **Flexibility in Participation**: Offer flexible participation options for patients.

Choosing the Right PPI Expert

Look for PPI experts with **relevant experience** and expertise.

The PPI expert should have a **track record** of successful PPI engagement.

Consider PPI experts who have worked with similar patient populations or research areas.

Ensure the PPI expert has **good communication skills** and can work effectively with researchers and patients.

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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. research question, design of the trial, endpoints).

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).

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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