Written Agreement

for Patient and Public Involvement (PPI) Activities Template

**Publication date**

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**Instructions for use**

This document is intended to clarify the tasks, time commitment, duration, and compensation of patient and public involvement (PPI) contributors for their PPI activities as well as the handling of personal and research-relevant data and conflicts of interest related to these activities.

The content of this template can be adapted as necessary. Headings and examples are suggestions and are not intended to be prescriptive or exhaustive. Text within [square brackets] is either information intended for the person preparing the final document that should be deleted or information intended for the PPI contributor that needs to be adapted (“OR” and “/” indicate a choice; please delete the option not chosen). The final document should not include any of the original square brackets.

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PPI contributors are responsible for paying taxes on their PPI remuneration and making the correct contributions to social insurances (old-age and survivors' insurance, invalidity insurance, loss of earnings compensation, and unemployment insurance). As a rule, PPI contributors must declare on their tax returns any remuneration received for their engagement in PPI activities. If their PPI remuneration is less than CHF 2,300 in one calendar year, PPI contributors do not have to make contributions to social insurances. This should potentially be clarified with an expert.

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Written Agreement

for Patient and Public Involvement (PPI) Activities

in [name of initiative/research project]

This written agreement [is made on [insert date] OR enters into force as from the date of the last party to sign it]. The agreement is by and between

[insert first and last name, address, phone number, and/or email address]

(hereinafter **PPI Contributor**)

and

[insert organisation], represented by [insert name of contact person and his/her, address, phone number, and/or email address],

(hereinafter [**insert name of organisation**]).

# **Objective and scope**

This written agreement between the PPI Contributor and [insert organisation/contact person] regulates the framework, tasks, time required, handling of personal and research-relevant data, and compensation for the PPI Contributor’s active involvement in the [insert name of initiative or research project].

[Optional: Insert a brief summary/description of the initiative/research project, written in lay language, with the following information: the background, objective, current status/phase, etc. of the initiative/research project.]

# **Involvement and commitment**

The **PPI Contributor** commits to being involved in the following activities and tasks related to this [initiative/research project]:

[The following list (not exhaustive) contains some examples of PPI activities taken from the [SCTO Remuneration Policy for Patient and Public Involvement (PPI) Activities](https://www.scto.ch/dam/jcr:6ba862c9-0dea-460b-99cc-6c0aae1487d1/SCTO%20PPI%20Remuneration%20Policy_V1.pdf). Additional examples can be found in the [SCTO's PPI Guide for Researchers](https://www.scto.ch/dam/jcr:c0daedf0-7fa1-4334-b154-997d6344d5be/SCTO%20PPI%20Guide%20Researchers_210713.pdf). Please tailor the examples to your initiative/research project.]

1. [Collaborate in defining the [initiative’s/research project’s] research question(s).]
2. [Give advice on study endpoints that matter most to patients (i.e. what the study should explore from the patient’s point of view).]
3. [Provide input on what level of risk most patients would be willing to take.]
4. [Assess the study’s benefits for the patients participating in it.]
5. [Provide practical input on how the study is conducted (i.e. how to make the study more meaningful and feasible as well as more comfortable and easier for patients and their relatives).]
6. [Support the development of patient information that is easy to understand.]
7. [Assess and interpret study results.]
8. [Support the communication of study results in lay language (i.e. help figure out how the study results can be communicated in an understandable way).]
9. [Evaluate the impact of patient involvement (e.g. with regards to the planning and implementation of the study).]
10. [Become a co-author of publications that communicate study results in lay language.]
11. [Join an advisory board or committee (e.g. Data and Safety Monitoring Board).]
12. [Participate in subgroup [insert name of subgroup] as a group member.]
13. [Lead subgroup [insert name of subgroup] as its project manager.]

The [task and activity/the tasks and activities] listed above will involve the PPI Contributor and the study team, and [they] will take place in the context of:

[See the list below (not exhaustive) for some examples. Please tailor the examples to your initiative/research project and add the task number(s) above that correspond(s) to each example.]

* [being an active part of the research/study team (responsible for designing, preparing, and implementing the study) and/or one of its committees (e.g. responsible for preparing new guidelines for treatment) (task [insert number(s) of the corresponding task(s) above])]

and/or

* [a survey (task [insert number(s) of the corresponding task(s) above])]
* [an interview (task [insert number(s) of the corresponding task(s) above])]
* [a focus group (task [insert number(s) of the corresponding task(s) above])]
* [a meeting/workshop/structured feedback session (task [insert number(s) of the corresponding task(s) above])]
* [An advisory board/committee meeting (task [insert number(s) of the corresponding task(s) above])]

Please note that meetings will be held [virtually OR in person at [insert meeting location]].

The **research team representatives** commit to doing the following:

[See the list below (not exhaustive). Please tailor the examples to your initiative/research project.]

* [Listen to, acknowledge, and value the complementary knowledge and expertise of the PPI Contributor.]
* [Use language that facilitates a common understanding (i.e. avoid terms that are overly complicated/scientific).]
* [Be transparent about the different aspects of the research project.]
* [Provide feedback on a regular basis to ensure the PPI Contributor feels involved.]
* [Give plenty of notice of meetings and send documents sufficiently in advance to enable the PPI Contributor to prepare for a meeting/task.]
* […]

# **Time commitment**

[Please tailor this section to what makes sense for your initiative/research project. Or delete this section if a time indication is not (yet) possible or is not needed.]

The [initiative/research project] is expected to last [insert number] [months/years]. The overall time commitment required to complete the [task/tasks] described above is approximately [insert number] hours [total OR per week/year]. [OR: The anticipated time required to complete the task/tasks described above is approximately [insert number] hours, of which [insert number] hours are for individual preparation.]

# **Support for the PPI Contributor**

To support the PPI Contributor as [he/she] fulfils [his/her] role/tasks, [insert contact person/study team/organisation] will provide [describe support measures (e.g. an introductory meeting, advice, and other support throughout the [initiative/research project])]. In addition, [insert contact person/study team/organisation] will arrange for specific training as the need arises.

# **Compensation and expense reimbursement**

Compensation for the [task/tasks] described in section 2 is based on [an hourly rate/an honorarium]. The PPI Contributor will be compensated in accordance with the [SCTO Remuneration Policy for Patient and Public Involvement (PPI) Activities](https://www.scto.ch/dam/jcr:6ba862c9-0dea-460b-99cc-6c0aae1487d1/SCTO%20PPI%20Remuneration%20Policy_V1.pdf)as follows:

|  |  |
| --- | --- |
| **Activity/task** | **[Hourly rate/Honorarium]** |
| Task [insert task number from section 2 (e.g. 1)]: [insert corresponding task description (e.g. Collaborate in defining the [initiative’s/research project’s] research question(s).)] | [insert hourly rate OR honorarium in Swiss francs] |
| Task [insert task number from section 2 (e.g. 7)]: [insert corresponding task description (e.g. Assess and interpret study results.)] | [insert hourly rate OR honorarium in Swiss francs] |
| […] |  |

[OR: The PPI Contributor does not wish to receive compensation for the [task/tasks] listed in section 2. If at any point in the future the PPI Contributor changes [his/her] mind and would like to be compensated, [insert organisation] will make the necessary arrangements to compensate work completed after the new agreement. No compensation will be given retrospectively.]

[Insert organisation] will compensate the PPI Contributor for [his/her] work and reimburse [him/her] for any personal expenses incurred in connection with travel and accommodation (including meals). To be eligible for reimbursement, travel tickets, receipts for other expenses, and hotel invoices must be submitted [optional: together with the completed expense claim form] to [insert organisation]. [Optional: Travel and other expenses exceeding xxx CHF must be approved in advance by [insert a person/position/department].] All payments to the PPI Contributor will be made to the bank account indicated at the end of this agreement [after services have been rendered OR [insert payment schedule]].

# **Handling of personal and research-related data and confidentiality**

In the context of the activities listed in section 2 of this agreement, the PPI Contributor may have access to project-specific documents and patient data that are confidential and sensitive (e.g. information identifying patients, their medical condition or treatment, etc.).

Both signatory parties agree to make reasonable efforts to mark their documents and data as confidential. If a document is unmarked or if information is disclosed orally, the party receiving the document or information should make reasonable efforts to clarify with the disclosing party whether the information is confidential or not.

The PPI Contributor confirms with [his/her] signature that [he/she] will not pass on any data or information that has been classified in any manner (e.g. orally or in writing) as confidential without the written permission of the [insert organisation] or the related patient.

[Insert organisation] also agrees that [insert organisation] will not use any part of the information supplied by the PPI Contributor and classified as confidential without permission of the PPI Contributor. Information provided and advice given by the PPI Contributor is to be used only within the scope of the [initiative/research project].

# **Conflicts of interest**

The PPI Contributor is required to disclose any involvement [he/she] has with other organisations, government entities, or companies that could result in a conflict of interest with the work described in section 2 of this agreement. Prior to starting the activities listed in section 2, the PPI Contributor needs to declare all potential conflicts of interest [optional: and complete and sign the [insert organisation’s] conflict of interest disclosure form].

# **Duration and termination of the agreement**

Both signatory parties agree to make every effort to fulfil their obligations under this agreement. The agreement begins on [the date this agreement is signed by both parties OR [insert date]] and ends [upon completion of the PPI Contributor’s involvement [specify involvement and when it will be completed] OR [insert date (e.g. research project’s end date)]]. If the start date or the end date changes for any reason, the party wishing to change or terminate this agreement will inform the other party as soon as possible. [If applicable: In the event of early termination, remuneration of the agreed honorarium will be paid on a pro rata basis for PPI work already done.]

# **Applicable law and place of jurisdiction**

Swiss law governs this agreement as well as all disputes and claims arising from and in connection with it that cannot be settled amicably by mediation. The place of jurisdiction is [insert city], Switzerland.

# **Execution**

This agreement is made in duplicate. Each party receives a signed copy.

# **Signatures**

The PPI Contributor and [insert name of organisation] agree to the above terms:

**PPI Contributor**

Date: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

By: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  
(Printed name) (Signature)

**[Insert name of organisation]**

Date: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

By: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  
(Printed name) (Signature)

PPI Contributor’s bank account details:

Full name of account holder \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Name of bank \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Bank address \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

IBAN \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

BIC/SWIFT code \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_