

Patient and Public Involvement (PPI)

Creating a Study-Specific PPI Panel

Faculty of Medicine

Department of Clinical Research

Step 1

IDENTIFY & INFORM PEOPLE WITH LIVED EXPERIENCE ABOUT STUDY-SPECIFIC PANEL

Project Study Team

- A. Seeks study-specific panel members with lived experience in area of study.
 - —We recommend asking 5-10 patients, carers, or relatives to get 2–3 members.
 - —Ask potential study-specific panel members to
 - read about <u>patient engagement on DCR website</u> (German).
 - —Share DCR PPI contact information with potential studyspecific panel members for questions.

email DCR ppi.dcr@unibe.ch call DCR (031 664 34 25)

Generally, study-specific panel members are

- —enrolled on the standing DCR panel
- —offered 60 CHF/hour (current as of Aug 2023)
- complete online DCR PPI training
- —attend 2–3 meetings per year (online or inperson)
- —devote 6–10 hours per project (usually 6–12 months)
- B. Ensures all project study team members complete <u>DCR</u> PPI researcher training.

Step 2

RECOMMEND PEOPLE WITH LIVED EXPERIENCE AS STUDY-SPECIFIC PANEL MEMBERS

Project Study Team

- C. If people with lived experiences agree to be contacted, use the Excel Workbook DCR provided to record their details and send it to the DCR PPI Team (ppi.dcr@unibe.ch).
 - —Remove _template and add _study title_date to the end of the file name.

DCR Bern	Creating a Study-Specific Patient and Public Involvement (PPI) Panel				
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Step 3

ENROL, TRAIN, & ASSIGN MEMBERS OF STUDY-SPECIFIC PANEL

DCR PPI Team

Most study-specific panels will have 5–6 total members, with 1–2 from the standing DCR panel and the rest from people with lived experience, who the project study team identifies and refers to DCR.

Study-specific panels are formed from 2 sources: project study team recommendations of patients, carers, and relatives with lived experiences and DCR panel members with general experiences. We send study project team the study-specific panel list once formed.

Standing DCR Panel

+

People with Lived Experiences

=

Study-Specific Panel

Once DCR receives information about people with lived experience, we contact them to

Sign and return DCR PPI agreement

A. **Sign the DCR PPI agreement**. DCR sends the legally vetted agreement enrolling them as members of standing DCR Panel, yet making it clear they are only committing to your study at this stage.

Complete DCR PPI training

B. **Complete DCR PPI training**. DCR sends link and requests panel members complete training by a particular date, which is contingent on project study team completing <u>DCR PPI researcher training</u> from Step 1.

Assign to studyspecific panel C. Assign study-specific panel. DCR uses a mix of people with lived experience the project study team recommends and general standing DCR panel members to form the study-specific panel.

Step 4

ADMINISTER STUDY-SPECIFIC PANEL

Project Study Team

- D. Organizes study-specific panel meetings, including scheduling, technology (if required), and all aspects of DCR PPI team members attending in person, such as transportation.
- E. Schedules planning meetings—at least 1 week before 1st panel meeting—with PIs and DCR PPI team.
- F. Coordinates and administers payments to panel members, including requesting hours and processing all reimbursements from the study budget.

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