

Appendix 2 – Copy of Survey Questionnaires

Questionnaire

INTRO

Welcome to the Swiss Delphi Study on Patient-Reported Outcomes (PROs)

The goal of our meeting is to establish a consensus statement on PROs in Switzerland. This will include rounds of voting on the following aspects:

Content domains for generic PROs in Switzerland

Item selection for the PRO measurement instrument (PROM)

For this survey, you will first rate 3 general health domains.

Then, you will rate candidate items for inclusion in a generic PROM survey in Switzerland. You will be asked to rate each domain on a 4-point scale ranging from: 1(NOT Important) to 4(EXTREMELY Important).

The researchers have obtained your contact information for recruitment purposes only and will not have any way of knowing who completed this survey (responses are completely anonymized).

What's in it for you?

Later, we will convene via an online virtual meeting to discuss "key questions" and potential "position statements" we wish to issue as a working, expert-advocacy group for implementing PROs in Switzerland.

Your participation is immeasurably valuable, and thank you from the Project Co-PIs!

Prof. Markus Melloh, MD, PhD, MPH, MBA, ZHAW Institute of Health Sciences Director

Prof. Nikola Biller-Andorno, MD, PhD, MHBA, UZH Institute of Biomedical Ethics and History of Medicine Director For inquiries or assistance, please send an email to: kerr@zhaw.ch.

By continuing to the next page, I hereby indicate informed consent to participate in the enclosed survey. I understand that I may quit the survey at any time.

DEMO/BIO

What is your current age?

What gender do you identify with?

Female Male

Other (specify)

What is your native language? (You may select more than 1 option.)

German English French Italian

Other (please specify)

Which working domain would you say you most closely represent?

- Academia Government Industry
- Individual / Citizen / Self-organized (patient group)
- Other (please specify)

What is your professional background?

- Physician
- Epidemiologist Economist
- Clinimetrician / Psychometrician
- Other healthcare profession (please specify) Other (please specify)

What is your current level of work experience?

- > 10 years
- 6 - 10 years
- 1 - 5 years None

What is your level of experience with patient-reported outcomes (PROs)?

- A lot (> 10 years) Some (6 - 10 years)
- A little (1 - 5 years)
- None

Here you can openly specify what kind of experience you've had with PROs if you like (e.g., "PROs are part of daily professional work", or "I know the term and some research, but I've never used PROs", etc...)

DOMAINS

Physical health is defined as:

The body's condition, taking into consideration everything from the absence of disease to overall well-being, including regular physical exercise, good nutrition, and adequate rest

How important do you view Physical Health for the average or typical person of Switzerland?

- NOT important
- Slightly important

- Rather important
 EXTREMELY important

Mental health is defined as:

A state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community

How important do you view Mental Health for the average or typical person of Switzerland?

- NOT important
 Slightly important Rather important
 EXTREMELY important

Social health is defined as:

Well-being regarding social activities and relationships, including the ability to relate to individuals, groups, communities, and society as a whole.

How important do you view Social health for the average or typical person of Switzerland?

- NOT important
 Slightly important Rather important
 EXTREMELY important

Final page

Thank you for your participation in this survey!

We aim to use your responses to describe the case for integrating patient- reported outcomes (PROs) in the Swiss health system.

We hope that you will please respond to our next surveys: Your response / voice is invaluable!
For any follow-up queries regarding this survey, please contact: kerr@zhaw.ch.

Questionnaire

Physical Health Scales

Physical Function is defined as:

The ability to perform activities of daily living, such as physically moving from position to another, walking independently, feeding oneself or dressing oneself. Also, the ability to perform instrumental activities of daily living, such as managing transportation and shopping, meal preparation, or housecleaning.

How important do you view Physical Function for the average or typical person of Switzerland?

- NOT important
 Slightly important Rather important
 EXTREMELY important

Pain Interference is defined as:

Consequences of pain on relevant aspects of persons' lives and may include the impact of pain on social, cognitive, emotional, physical, and recreational activities as well as sleep and enjoyment in life.

How important do you view Pain Interference for the average or typical person of Switzerland?

- NOT important
 Slightly important Rather important
 EXTREMELY important

Fatigue is defined as:

An overwhelming, debilitating, and sustained sense of exhaustion that decreases one's ability to carry out daily activities, including the ability to work effectively and to function at one's usual level in family or social roles.

How important do you view Fatigue for the average or typical person of Switzerland?

- NOT important
 Slightly important Rather important
 EXTREMELY important

Sleep Disturbance is defined as:

Sleep quality, sleep depth, and restoration associated with sleep; perceived difficulties and concerns with getting to sleep or staying asleep; and perceptions of the adequacy of and satisfaction with sleep.

How important do you view Sleep Disturbance for the average or typical person of Switzerland?

- NOT important
 Slightly important Rather important
 EXTREMELY important
-

Mental Health Scales

Depression is defined as:

High levels of negative affect and low levels of positive affect. It is often characterized by the experience of loss and feelings of hopelessness, helplessness, and worthlessness.

This includes negative mood, negative self-views, negative social cognition, and low engagement.

How important do you view Depression for the average or typical person of Switzerland?

- NOT important
 Slightly important Rather important
 EXTREMELY important

Anxiety is defined as:

Autonomic arousal and the experience of threat. This includes, fear (e.g., fearfulness, feelings of panic), anxious misery (e.g., worry, dread), hyperarousal (e.g., tension, nervousness, restlessness), and somatic symptoms related to arousal (e.g., racing or pounding heart, dizziness).

How important do you view Anxiety for the average or typical person of Switzerland?

- NOT important
 Slightly important Rather important
 EXTREMELY important

Social Health Scale

Ability to Participate in Social Roles and Activities is defined as:

Ability to perform one's usual social roles and activities, such as leisure activities, activities with friends, and activities with family.

How important do you view Social Roles and Activities for the average or typical person of Switzerland?

- NOT important
 Slightly important Rather important
EXTREMELY important

1 Physical Function

Below are 4 Physical Function questions.

Please rate each question for its relevance to the average/typical person of Switzerland:

Are you able to do chores such as vacuuming or yard work?

- NOT relevant
- Slightly relevant
- Rather relevant
- VERY relevant

Are you able to go up and down stairs at a normal pace?

- NOT relevant
- Slightly relevant
- Rather relevant
- VERY relevant

Are you able to go for a walk of at least 15 minutes?

- NOT relevant
- Slightly relevant
- Rather relevant
- VERY relevant

Are you able to run errands and shop?

- NOT relevant
 - Slightly relevant
 - Rather relevant
 - VERY relevant
-

2 Anxiety

Below are 4 Anxiety questions.

Please rate each item for its relevance to the average/typical person of Switzerland:

In the past 7 days, I felt fearful.

- NOT relevant
- Somewhat relevant
- Rather relevant
- VERY relevant

In the past 7 days, I found it hard to focus on anything other than my anxiety.

- NOT relevant
 - Slightly relevant
 - Rather relevant
 - VERY relevant
-

In the past 7 days, my worries overwhelmed me.

- NOT relevant
- Slightly relevant
- Rather relevant
- VERY relevant

In the past 7 days, I felt uneasy.

- NOT relevant
- Slightly relevant
- Rather relevant
- VERY relevant

3 Depression

Below are 4 Depression questions.

Please rate each question for its relevance to the average/typical person of Switzerland:

In the past 7 days, I felt worthless.

- NOT relevant
- Slightly relevant
- Rather relevant
- VERY relevant

In the past 7 days, I felt helpless.

- NOT relevant
- Slightly relevant
- Rather relevant
- VERY relevant

In the past 7 days, I felt depressed.

- NOT relevant
- Slightly relevant
- Rather relevant
- VERY relevant

In the past 7 days, I felt hopeless.

- NOT relevant
- Slightly relevant
- Rather relevant
- VERY relevant

4 Fatigue

Below are 4 Fatigue questions.

Please rate each question for its relevance to the average/typical person of Switzerland:

During the past 7 days, I feel fatigued.

- NOT relevant
-

-
- Slightly relevant
 - Rather relevant
 - VERY relevant

During the past 7 days, I have trouble starting things because I am tired.

- NOT relevant
- Slightly relevant
- Rather relevant
- VERY relevant

In the past 7 days, how run-down did you feel on average?

- NOT relevant
- Slightly relevant
- Rather relevant
- VERY relevant

In the past 7 days, how fatigued were you on average?

- NOT relevant
- Slightly relevant
- Rather relevant
- VERY relevant

5 Sleep Disturbance

Below are 4 Sleep Disturbance questions. Please rate each question for its relevance to the average/typical person of Switzerland:

In the past 7 days, my sleep quality was: Very Poor (1) to Very good (5)

- NOT relevant
- Slightly relevant
- Rather relevant
- VERY relevant

In the past 7 days, my sleep was refreshing: Not at all (1) to Very much (5)

- NOT relevant
- Slightly relevant
- Rather relevant
- VERY relevant

In the past 7 days, I had a problem with my sleep: Not at all (1) to Very much (5)

- NOT relevant
- Slightly relevant
- Rather relevant
- VERY relevant

In the past 7 days, I had difficulty falling asleep: Not at all (1) to Very much (5)

- NOT relevant
- Slightly relevant

-
- Rather relevant
 - VERY relevant
-

6 Ability to Participate in Social Roles & Activities

Below are 4 Ability to Participate in Social Roles and Activities questions. Please rate each question for its relevance to the average/typical person of Switzerland:

I have trouble doing all of my regular leisure activities with others.

- NOT relevant
- Slightly relevant
- Rather relevant
- VERY relevant

I have trouble doing all of the family activities that I want to do.

- NOT relevant
- Slightly relevant
- Rather relevant
- VERY relevant

I have trouble doing all of my usual work (include work at home).

- NOT relevant
- Slightly relevant
- Rather relevant
- VERY relevant

I have trouble doing all of the activities with friends that I want to do.

- NOT relevant
 - Slightly relevant
 - Rather relevant
 - VERY relevant
-

7 Pain Interference

Below are 4 Pain Interference questions. Please rate each question for its relevance to the average/typical person of Switzerland:

In the past 7 days, how much did pain interfere with your day to day activities?

- NOT relevant
- Slightly relevant
- Rather relevant
- VERY relevant

In the past 7 days, how much did pain interfere with work around the home?

- NOT relevant
- Slightly relevant
- Rather relevant
- VERY relevant

In the past 7 days, how much did pain interfere with your ability to participate in social activities?

- NOT relevant
- Slightly relevant
- Rather relevant
- VERY relevant

In the past 7 days, how much did pain interfere with your household chores?

- NOT relevant
- Slightly relevant
- Rather relevant
- VERY relevant

8 Pain Intensity

Below is 1 Pain Intensity question.

Please rate the question for its relevance to the average/typical person of Switzerland:

In the past 7 days, how would you rate your pain on average? No pain (1) to Worst pain imaginable (10)

- NOT relevant
- Slightly relevant
- Rather relevant
- VERY relevant

9 Final page

Thank you for your participation in this survey!

We aim to use your responses to describe the case for integrating patient-reported outcomes (PROs) in the Swiss health system.

Your response / voice is invaluable!

Thank you from this Project Study's Co-PIs,

Prof. Markus Melloh, MD, PhD, MPH, MBA, ZHAW Institute of Health Sciences Director

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For any follow-up queries regarding this survey, please contact:
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Questionnaire

1 Consensus Points

Please rate the following 3 consensus points according to agreement or disagreement. You may also give specific feedback with your vote (multiple response options).

A Swiss national PROs body consisting of PROs experts is needed to guide expert direction in all areas of health care, policy, and research.

If a PROs body is not directly housed at a national level, funding-specific opportunities should be provided for research housed at either academic or relevant health-services research institutions (Patientensicherheit Schweiz, Schweizerische Patientenorganisation SPO, FMH, etc.).

- Strongly Agree
- Rather Agree
- Rather Disagree
- Strongly Disagree
- Suggested Revision or Additional Commentary

The application of PROs must incorporate strategies and specific tools to support equity, diversity, and inclusion.

Any Swiss PRO Group should adhere to the "International Guidance Framework" for selecting PROMs by including patients / public citizens in the selection of PROMs' conceptual (constructs/domains) and measurement model (items). Furthermore, this Swiss PRO Group recognizes the need to re-evaluate extant translations of validated PROMS (German, French, Italian) for cultural adaptation and application within Switzerland.

- Strongly Agree
- Rather Agree
- Rather Disagree
- Strongly Disagree
- Suggested Revision or Additional Commentary

PROs support patients in becoming informed partners in achieving better health outcomes.

It is important to recognize that integrating PROs is not only a change for the health system, but a shift in shared-responsibility for the individual/patient as well. To the extent that self-managed health is promoted, PROs should be seen as facilitating this goal.

- Strongly Agree
- Rather Agree
- Rather Disagree
- Strongly Disagree
- Suggested Revision or Additional Commentary

While we are aiming for parsimony in our initial consensus statement (<5 consensus points), we welcome additional *general* consensus points that you may suggest to be considered for inclusion here.