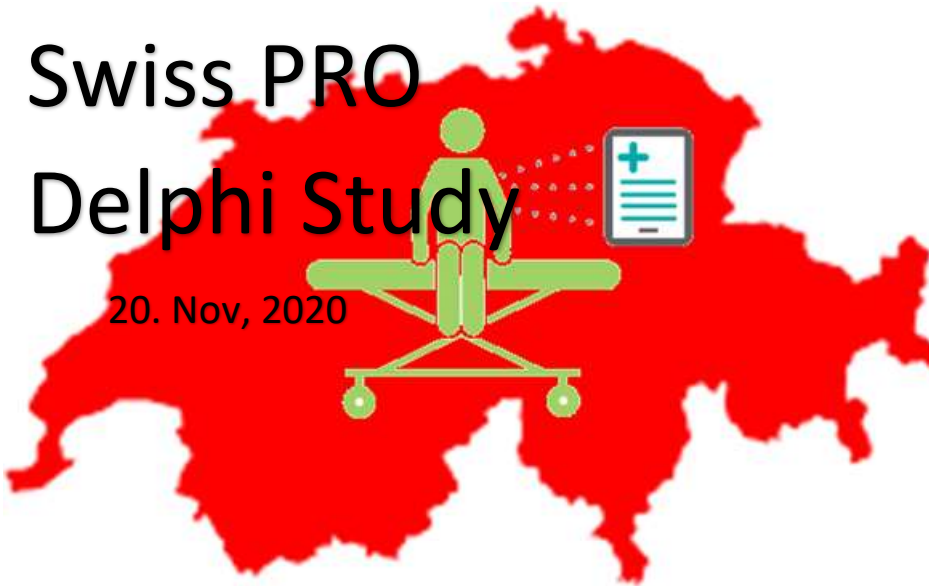


Swiss PRO Delphi Study

20. Nov, 2020

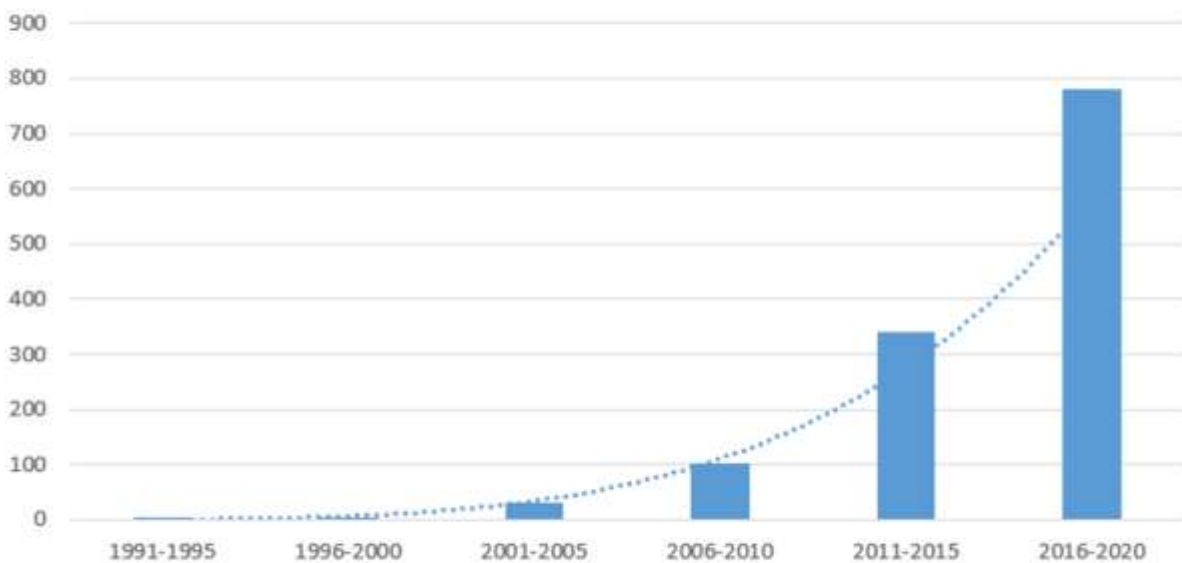


The European Medicines Agency defines a patient-reported outcome (PRO) measure as “any outcome evaluated directly by the patient himself and based on patient’s perception of a disease and its treatment(s)” (3). PRO measures (PROMs) are increasingly popular due to regulatory support for medical product labeling claims, as

well as their conversion to quality-adjusted life years (QALYs) for economic evaluations⁽¹⁾. PRO growth is also observed in Switzerland (Fig. 1).

Figure 1. Summary yearly-PRO publication frequency in Switzerland

Summary CH-PRO publication by 5-year periods

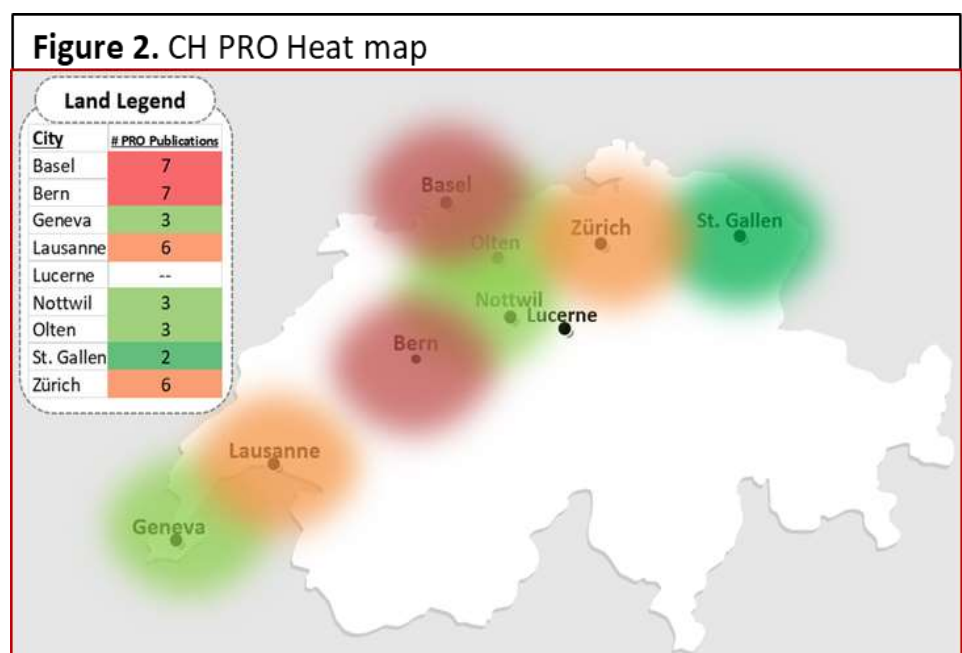


Note. Results are averaged combinatory-keyword searches (“patient-reported outcome” AND “Swiss”) across 3 databases: 1) PubMed, 2) Emcare, and 3) Google Scholar.

Indeed, Switzerland’s growth in PROs coincides with both professional and federal recommendations for improving Swiss healthcare quality (Table 1). As Vincent and Staines note in their recent FOPH report: “many health systems are interested in patient-reported outcome measures (PROMs), but implementation is associated with significant investment, which may be beyond the reach of a single canton or health system”.

PRO Quotes	Source
<p>2017 – The most important requirements for a successful national program are ability to measure and monitor safety and quality... It is important to identify reliable outcome measures and to include patient-reported outcome measures (PROMs).</p>	 Allegranzi et al., (2017) Qualität und Sicherheit der Schweizerischen Gesundheitsversorgung Verbessern. Empfehlungen und Vorschläge für die Bundesstrategie. 2. Bericht
<p>2018 – PROMs bieten die Grundlage für eine gute Indikations- und Ergebnisqualität und könnten zur Vermeidung unnötiger Behandlungen beitragen. Sie stellen den Kosten des Gesundheitswesens sowohl den Nutzen für die Patientinnen und Patienten wie auch auf Systemebene (Arbeitsfähigkeit, Aufrechterhaltung der Selbständigkeit) gegenüber.</p>	 Hostettler et al., (2018). Patient-reported outcome measures: Die Patientensicht zählt. <i>Schweizerische Ärztezeitung</i> , 40, 1348-1352. DOI: https://doi.org/10.4414/saez.2018.17187
<p>2019 – PROMs need to feature prominently in the national strategy. PROMS and other means of gaining feedback from patients and caregivers need to be more strongly embedded in all healthcare organizations.</p>	 Vincent, C., & Staines, A. (2019). Enhancing the Quality and Safety of Swiss Healthcare. National report commissioned by FOPH

Our recent review of Swiss usage indicated twice as many disease-specific vs. generic PROs. Generic PROs have the advantages of comparing treatments across diseases and conditions. Taken together, despite “hotspots” of PRO use in Switzerland (Fig. 2), a national program on PROs is lacking and needed.



We aim to initiate this program with the current stakeholder meeting’s goal of generating a consensus statement, as well as endorsement of a generic-PROM measure for future survey distribution.



SWISS PRO DELPHI STUDY Aim:

The aim of our Stakeholder meeting is to found a comprehensive initiative for PROs in Switzerland. The multi-round Delphi process will include educational introduction, voting on domains and items, as well as generation of additional items and discussion of key questions.

In order to orient participants (you) to our key questions and first rounds, please briefly view Table 2 below for key terms and definitions on the theme of PROMs.

Table 2. Terminology and definitions	
Health-related quality of life (HRQoL)	A combination of a person’s physical, mental and social wellbeing; not merely the absence of disease
Patient-reported outcome (PRO)	Any outcome evaluated directly by the patient himself and based on patient’s perception of a disease and its treatment(s)
Patient-reported outcome measure (PROM)	The tools or instruments used to measure PROs either directly or as change scores plus the information and documentation that support its use. PROMs can be general in nature or disease-specific.
Physical health	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 (<u>Medical News Today</u>)
Mental health	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 (<u>WHO</u>)
Social health	Well-being regarding social activities and relationships, including the ability to relate to individuals, groups, communities, and society as a whole. (<u>PROMIS</u>)

Below are a few Key Questions we have developed to stimulate our future, virtual-stakeholder meeting.

Table 3. Key Questions for PRO Stakeholders
1. Do you think it is valuable to add patient reports to the medical field?
2. How best to assess the patient perspective?
3. Is there evidence for generic PROMs’ adoption into daily clinical practice?

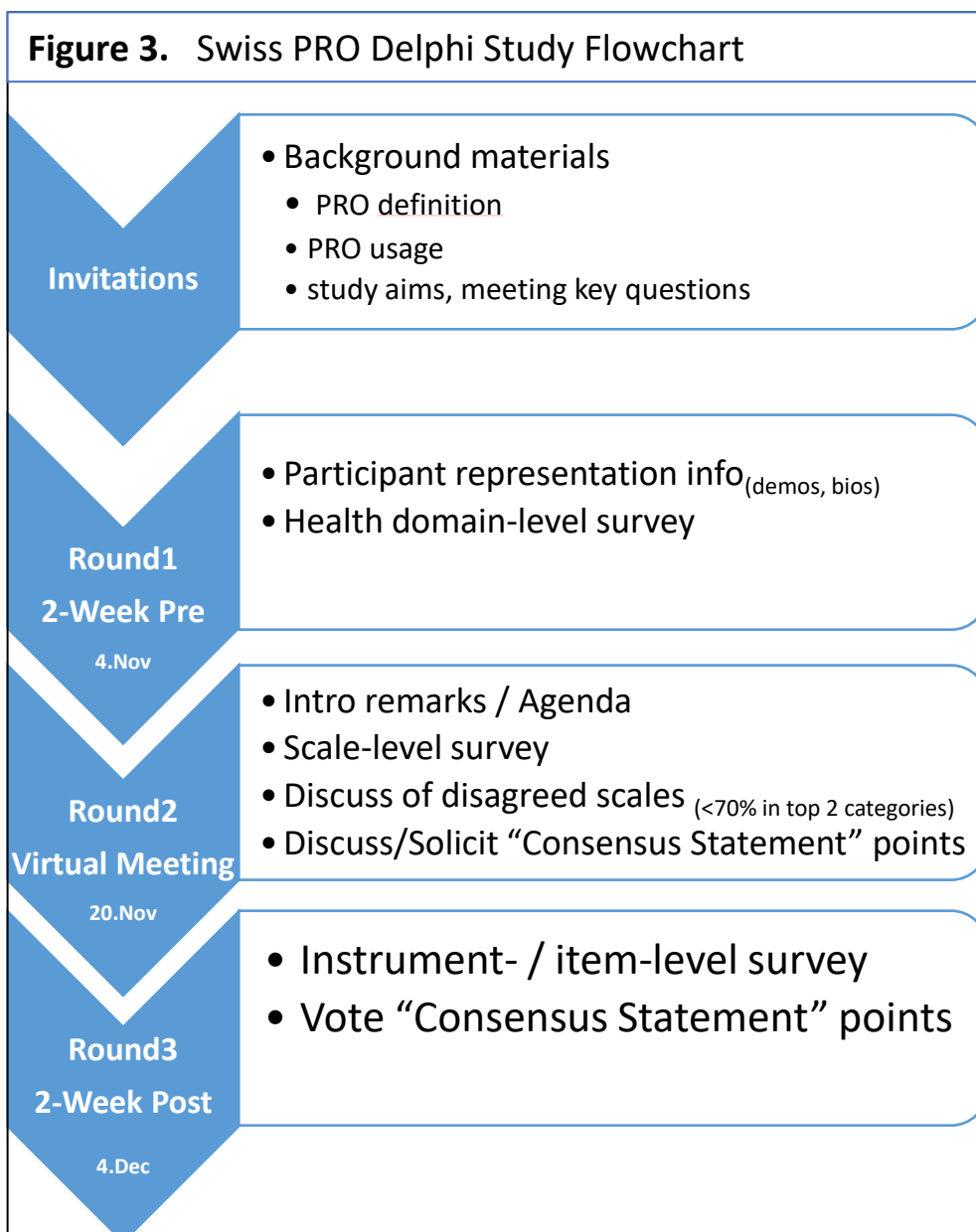
PROs offer value-added for stakeholders across levels of the healthcare system. For furthering your understanding PROs value for different stakeholders, please see Table 3 below.

Table 4. The value of PRO data for different stakeholders.

PRO impact	Patient	Clinical provider	Academic researcher	Institution/ employer org.	Payer	Research fund. agency	Regulatory agency
Evaluation of novel treatments	✓	✓	✓		✓	✓	✓
Shared decision making	✓	✓					
Evaluating provider Performance	✓	✓		✓	✓		
Determining treatment effectiveness	✓	✓	✓		✓	✓	
System-level quality improvement		✓		✓	✓		✓

NOTE. PRO = patient-reported outcome.

To illustrate the content and process of the Swiss PRO Delphi Study, please view Figure 3 below detailing the timeline and tasks / outputs from each round.



Stakeholder Characteristics by Invitation and Round				
Characteristic	No. (%) of Respondents			
	Invited	Round 1	Round 2	Round 3
Age	X			
Sex	X			
Domain	X			
Academia	X			
Industry	X			
Government	X			
Public (patients)				
Professional Background	X			
Physician	X			
Clinimetrician/Psychometrician	X			
Epidemiologist	X			
Other Health Professional	X			
Other				
Level of Work Experience	X			
A lot (>10 years)	X			
Some (6-10 years)	X			
A little (1-5 years)	X			
None				
Level of PRO Experience	X			
A lot (>10 years)	X			
Some (6-10 years)	X			
A little (1-5 years)	X			
None				