

NETWORK MEETING SWISS CITIZEN SCIENCE NETWORK

Bern, House of Academies - 21.09.2022

Schweiz forscht in Collaboration with the *Participatory Academy (PWA)*



AGENDA

1. Welcome and introduction round
2. Workshop on competencies
3. Competences: Best practice examples (BFH)
4. Inputs from the Network & *Schweiz forscht*
5. Next steps
6. Aperro

2. WORKSHOP ON COMPETENCIES

**How can competencies be acquired through
Citizen Science, made visible and valued?**

3. BEST PRACTICE & DISCUSSION

- Inputs from Chantal Britt & Karin van Holten
(BFH), *Competence Center Participatory Health Care*





Berner Fachhochschule
Haute école spécialisée bernoise
Bern University of Applied Sciences

ADDING VALUE THROUGH CITIZEN SCIENCE — A BEST PRACTICE EXAMPLE

Network Meeting, Science et Cité, Haus der Akademien

21 Sept. 2022

Citizen Science during a pandemic – pro and con

scientists interacted directly with citizens

citizens curious and interested, engaged with scientists and science

patients forced to read publications

Funding available, particularly at beginning

- Short timelines, no time for experiments
- part of population difficult to reach (evidence)
- Sick, scared, sceptical, frustrated (traumatized) citizens

PROJECT – LONG COVID CITIZEN SCIENCE BOARD

- PWA seed grant 2021
- Epidemiologists UZH & citizens Long Covid Switzerland
- LCCSB: 30-member panel, people with long covid or chronic disease myalgic encephalomyelitis
- Define citizen-centred priorities so that funds are used for most urgent & relevant research projects



Original Research Article | [Open Access](#) | [Published: 28 April 2022](#)

Long COVID Citizen Scientists: Developing a Needs-Based Research Agenda by Persons Affected by Long COVID

[Sarah Ziegler](#) , [Alessia Raineri](#), [Vasileios Nittas](#), [Natalie Rangelov](#), [Fabian Vollrath](#), [Chantal Britt](#) & [Milo A. Puhan](#)

[The Patient - Patient-Centered Outcomes Research](#) **15**, 565–576 (2022) | [Cite this article](#)

CHALLENGES

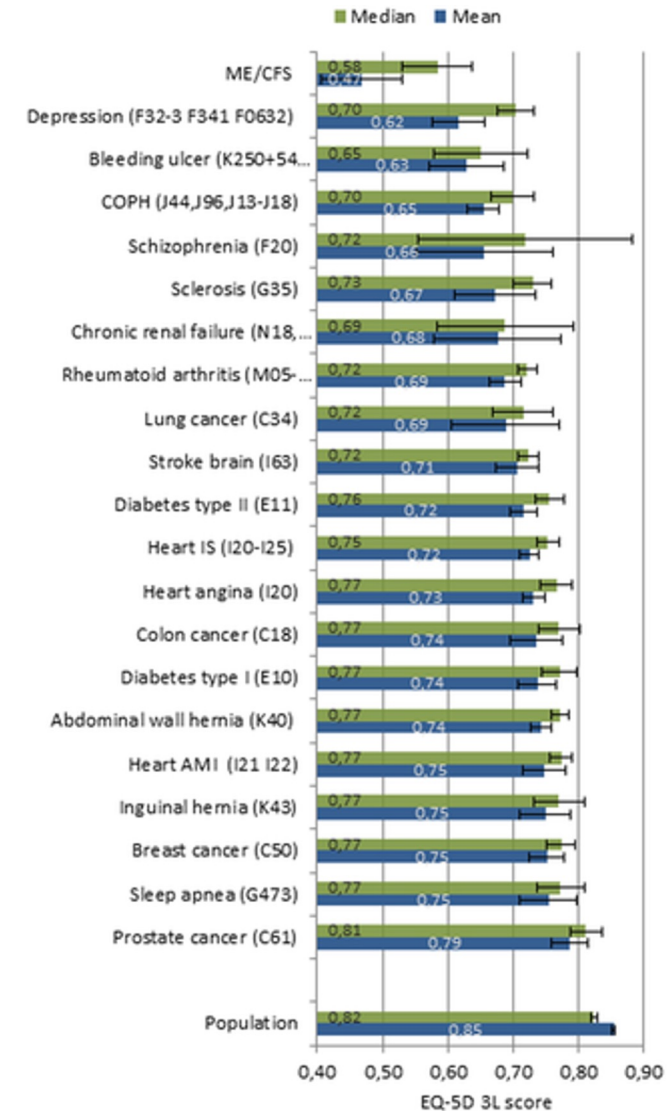
- **Competences:** scientific knowledge (study design, statistics, data literacy)
- **Abilities:** health status, energy, abilities
- **Capacities:** Lack of time/resources for contribution, but also **training, teaching**
- **Language:** Multilingualism, technical language, English
- **Complexity:** simplifications
- **Divergences:** Interests, motivation, goals (publication vs. life)
- **Appreciation:** citizen = lay person vs expert by experience
- **Active Involvement/Inclusiveness** partners vs participants
- **Communication,** dissemination, publication

AT WHICH STAGES WERE CITIZENS ABLE TO PARTICIPATE?

- **Citizens involved from planning to end**
- Helped define research questions
- Essential for recruitment
- Helped define and allocate roles
- Communication during project (motivation, goals)
- Feedback on processes, results, dissemination
- Communication, publication

COMPETENCES – WHAT DID CITIZENS OFFER & GAIN?

- Experts by **experience on new disease**
- Input on **quality of life** (s. graph), relevance for patients, disease burden
- **Network** of people affected, **credibility, trust**
- Highly **motivated** to actively contribute
- **Individual expertise, interests** (teaching, nursing, communication, research, psychology)



COMPETENCES – WHAT DID RESEARCHERS OFFER & GAIN?

- **Expertise and experience** in scientific projects
- **Network** in science, at universities, authorities
- Identify & understand lay peoples' concerns, needs
- Communication, mediation skills
- Project management under difficult conditions (time, money constraints, sick participants)
- (Importance of) training, coaching
- Empathy, patience, respect, appreciation (soft skills)
- Simplify complex processes, content

TAKE HOME MESSAGES

- **Role change:** put yourselves in the citizens' shoes,
- **Talk** to the citizens (not only surveys)
- **Identify key challenges** and sources of frustration
- **Identify, value & integrate existing competences**
- **Involvement:** can't involve too early, often or much
- **Communication:** Feedback, meet, inform about results, next steps, activities, progress, delays
- **Compare** goals, expectations, motivation
- **Show respect & appreciation** (empowerment, explanations, compensation)
- **(Shared) learning process**, flexibility/adaptations
- **Training, build competences**

DISCUSSION

- It's not just about competences (hard and soft skills), also abilities/capabilities, capacities, opportunities and level of inclusiveness
- Co-creation, inclusiveness, active involvement beyond participation
 - require commitment & investments & sacrifices
 - may impact efficiency, quality, speed, flexibility
 - create uncertainty
- Who identifies, assesses, values, integrates required and relevant competences (and how do you do that)?
- What do you need to invest or sacrifice to identify, value, train, teach, build competences to allow for active involvement & fully exploit potential?

4. INPUTS FROM THE NETWORK



4 INPUTS FROM PWA



Citizen Science P2P Learning Lab

Teil 1: 11. Oktober 2022, 13.30 - 17.30 Uhr

Teil 2: 1. Februar 2023, 13.30 - 17.30 Uhr

Universität Zürich, RAA-E-30, Rämistrasse 59, 8006 Zürich

Citizen Science Modular Research Course

Basis-Module am 18.10. (online) oder 15.11.2022, 13.30 - 17.30 Uhr

Universität Zürich, RAA-E-30, Rämistrasse 59, 8006 Zürich

4 INPUTS FROM SCIENCE ET CITÉ

CitSciHelvetia'23

"Citizen Science: Making impact participatory!" **29th & 30th March 2022 - Solothurn**
→ Call for Participation: Extended until 27.09.2022



4 INPUTS FROM SCIENCE ET CITE

- Project **Citizen Science in Switzerland: Contextual analysis, recommendations and Roadmap**

- Aim : define a common basis and develop appropriate initiatives to strengthen CS in Switzerland.

- Four thematics

1. Added value & impact
2. Visibility & Communication
3. Education
4. Funding

- Workshop during the CitSciHelvetia'23



4 INPUTS FROM SCIENCE ET CITE

- Project : Citizen Science in Switzerland : Contextual analysis, recommendations and Roadmap
- 4 thematics
 1. Added value & impact
 2. Visibility & Communication
 3. Education
 4. Funding
- A [miro board](#) is available for further inputs



5. NEXT STEPS

- Next Network meeting: Formats and Topics
- Our Newsletter: Call for inputs (your events and information) until October 15th

LINKS

Kompetenz Raster (Competence Grid)

- Personale Kompetenz
- Aktivitäts- und Handlungskompetenz
- Fach- und Methodenkompetenz
- sozial-kommunikative Kompetenz

Examples proof of competence / Beispiele Kompetenzen-Ausweisung

- [Benevol Dossier Freiwillig engagiert](#)
- [Intermundo Bostbox Interkulturell](#)