



Institute of Biomedical Ethics and History of Medicine



Swiss Tropical and Public Health Institute Schweizerisches Tropen- und Public Health-Institut

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PubliCo means a lot of teamwork:

Giovanni Spitale

Institute of Biomedical Ethics and History of Medicine, University of Zurich, Zurich, Switzerland

Sonja Merten

Swiss Tropical and Public Health Institute, Basel, Switzerland

Kristen Jafflin

Swiss Tropical and Public Health Institute, Basel, Switzerland

Institute of Biomedical Ethics and History of Medicine, University of Zurich, Zurich, Switzerland

Bettina Schwind

Swiss Tropical and Public Health Institute, Basel, Switzerland

Institute of Biomedical Ethics and History of Medicine, University of Zurich, Zurich, Switzerland

Andrea Kaiser-Grolimund

Swiss Tropical and Public Health Institute, Basel, Switzerland

Institute of Social Anthropology, University of Basel, Basel, Switzerland

Nikola Biller-Andorno

Institute of Biomedical Ethics and History of Medicine, University of Zurich, Zurich, Switzerland

TOC

The need	The infodemic in the context of the COVID-19 crisis, how it impacts people and societies; the need for better ways to inform people and to understand their needs.
Strategy	The long way from "it would be nice to have" to "that's how we're gonna do it".
Pilot results	How the system is performing and what kind of data we are collecting.
What are we learning	Strenghts, challenges and opportunities towards better risk and crisis communication.
References	Stuff we wrote and stuff we read.



How to people feel during a public health crisis?

I am more at home. I don`t meet with friends in person. I actualy think the epidemic is quite interesting not necessairily positive but i don`t find it that worse either.

Data from PubliCo pilot, 1



How to people feel during a public health crisis?

As young adult I'm just sick of this whole situation. Obviously I don't like being forced staying at home but our government always switched from measurement to another. I think if we just stayed strictly at home for a period of time with no contact, maybe there haven't been a second wave. I wanna live my life going to concerts, meeting friends without feeling guilty and travel. I would totally accept a strict lockdown if there is a chance that I can live summer 2021 like every other summer. I just don't like this whole switching in measurements.

Data from PubliCo pilot, 2



How to people feel during a public health crisis?

I lost my job, I lost my flat and soon I'll be living from the Wellfare. Berset & Co. are stupid fuckers, blind on both eyes. It took them way too long to focus on children, way too long. It looks as if they have no agenda at all. I start understanding people who believe in a Corona conspiracy. Make Berset leave or I'm sure he will get killed.

Data from PubliCo pilot, 3



The need

Understanding peoples' views, ideas and opinion to develop fair and effective measures



Effectiveness and fairness

The interplay between fairness and effectiveness is **crucial** in democratic societies, and it's a tough nut to crack.

We might know a lot about what theoretically is an effective measure, but the way a conceptual measure is implemented in a specific context **could dramatically change its functional parameters**.

We have good definitions of fairness (from social justice theories, distributive justice theories, procedural justice theories, ...) but we know little about which groups are doing worse in the current situation.

Fair

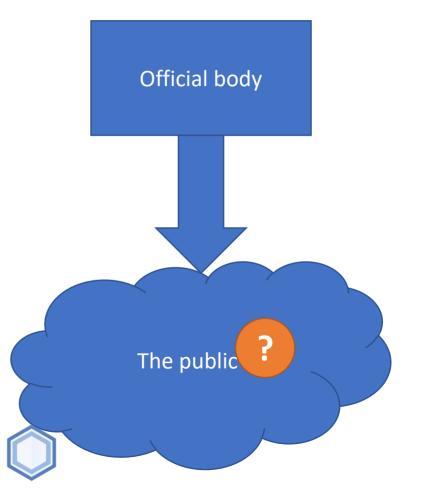
Effective

Providing and obtaining information

Information flow and policy making Go beyond **"one-way communication"**. People may differ in their understanding of the situation and their readiness to comply with policies.

Selective opinion polls cannot fill this gap. One-time online or phone surveys (SRF 2020; tagesschau.de 2020; Betsch et al. 2020) encounter important limits in view of the rapidly evolving situation – they are **resource-intense**, **limited in scope**, typically **design items in a top-down way**, struggle with **high non-response rates** and **provide snapshots** rather than continuous monitoring (Gould et al. 2009; Kaplan and Baron-Epel 2015).

Policy-makers might rely on a **suboptimal picture of reality** in order to make their choices that are expected to be timely and responsive. **Consensus has become fragile**.



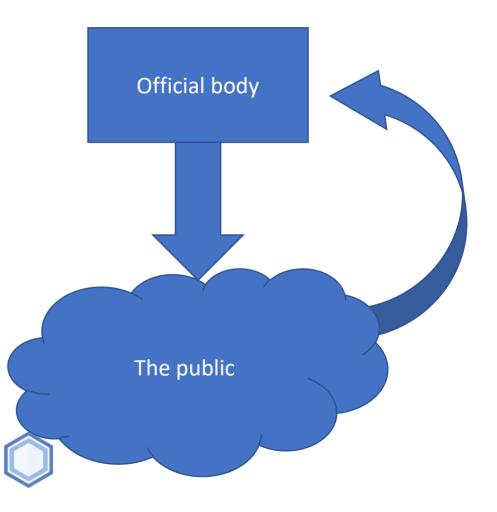
Providing and obtaining information

Let's close the loop

Understanding how mitigation measures are received by the population allows for an estimation of how effective they are going to be and may thus influence not only communication strategies but also policy choices (Plough et al. 2011; van der Weerd et al. 2011).

It will also help us understand **to what extent policy decisions match with citizens' moral values** and preferences regarding, e.g., the allocation of scarce medical resources, contact tracing, or obligatory mask wearing (Kaplan and Baron-Epel 2015).

Since using a "one size fits all" approach as mitigation measures in the context of epidemics has noticeable limitations, **local and subgroup data are critically needed** to deploy **more efficient strategies** (SteelFisher et al. 2012).

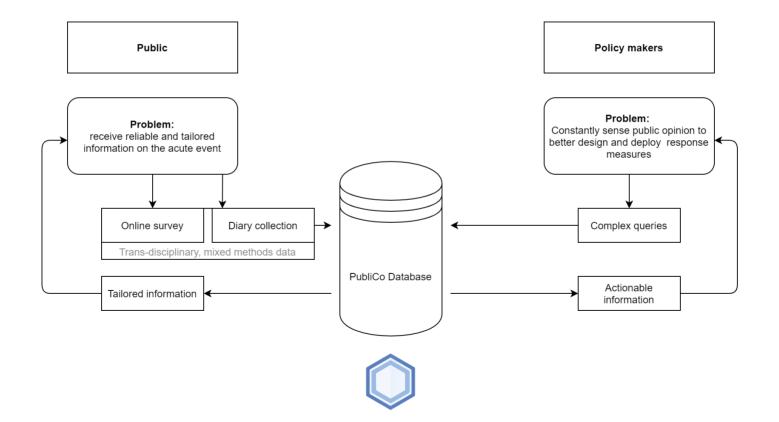






Our first idea

Data flow in PubliCo



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Tech stack

BELKA

- React (JS Frontend)
- SurveyJS
- Typescript
- Django (Backend)
- MariaDB
- Docker
- CicleCl
- NGINX (web server)
- All the data is stored in a university-owned server



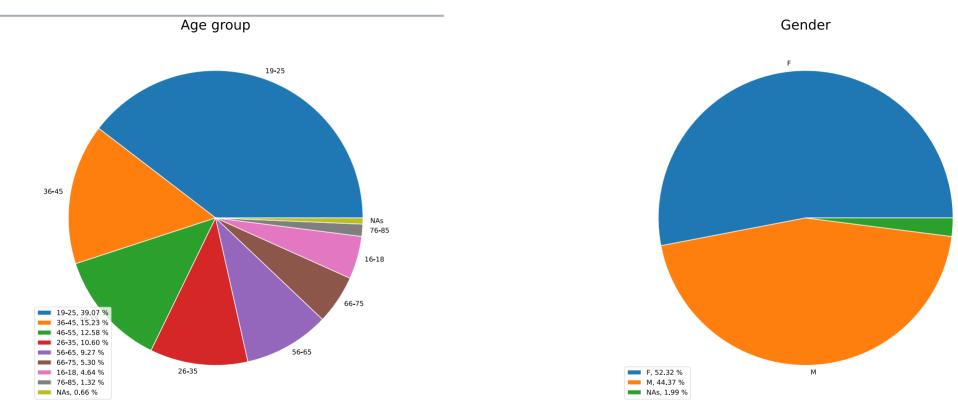
Key ethical features

- We are transparent, free and open:
 - Every step of the process is public and accessible, from the protocol to the data.
- We guarantee anonymity:
 - No cookies, no behavioural tracking, no personal or digital identifiers.
- We do listen:
 - What are people looking for? What information do they find?
 - Is our approach relevant? Citizen science validation.
- We try to understand:
 - Include qualitative components (my message to policy makers, diaries, free text fields).
 - Encourage people to speak their mind rather than just measuring scores.
 - Allow users to use the data and generate own hypotheses.
- We give something back:
 - Collect AND provide information (individual feedback and aggregated data).



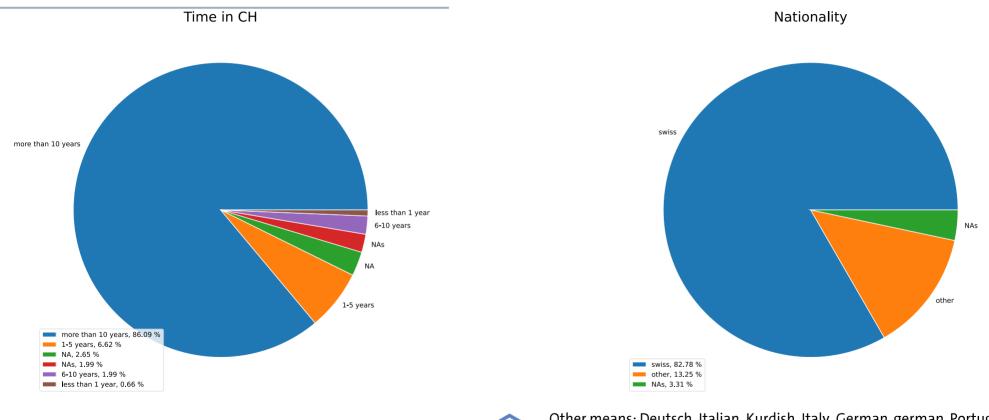
Pilot results





NAs

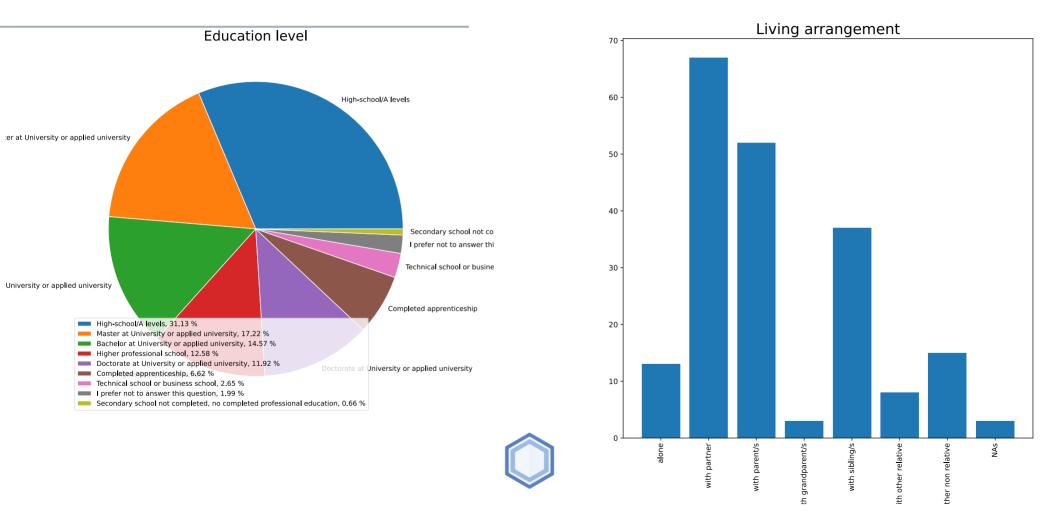




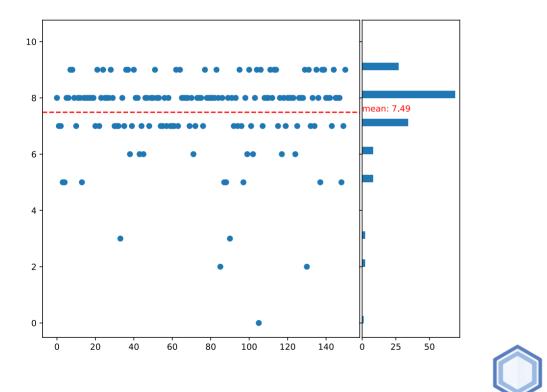


Other means: Deutsch, Italian, Kurdish, Italy, German, german, Portugal, US, French, Dutch, brazilian, swiss, german, Deutsch, Ethiopian, deutsch, Spanish, Deutsch,

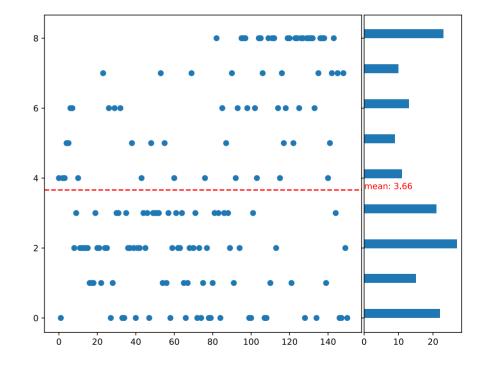
Turkish, Deutsch, Deutsch, German, Nigeria



Cognitive understanding/ main symptoms



Moral orientation / reactance



On the X axis: progressive number of the respondent. On the Y axis: score of the respondent.

What we are learning



Strenghts

- Transparent processes and access to data (including intermediate data) fosters trust.
- Inclusive approaches from the very beginning let us design better instruments, and let people perceive themselves as **co-actors in research** rather than as subjects of research.
- Anonimity guaranteed by transparency, clear data policies, and data hosted on reputable institutions' machines put people in the condition to freely express their opinions even when they are very critical.
- Qualitative data and co-generation of interpretations can deeply enrich the analysis (magnitude AND meaning of phenomena)





- Provide **personalized information** that is needed, relevant, precise, and clear based on **empirical evidence**.
- Provide information that is simple to understand and useful to elicit specific behaviours.
- Provide information that is non judgemental especially on morally loaded topics in order to elicit specific reflections.
- Complement information with **links to official sources** that might be difficult to find for lay users.
- **Provide resources** when relevant, e.g. contacts to associations or organizations for psychological health.



Challenges

- Targeted information vs. creating «information bubbles».
- Any role for censorship (e.g. anonymized diary entries presenting conspiracy theories)?
- Information vs. nudging/implicit blaming & shaming.
- Cultural: public trust that citizens' voices are taken seriously.
- Political: Potential abuse in non-democratic societies (surveillance, identification of citizens with «deviant» opinions, predictive modelling as a first step towarsd controlling).
- Contextualization of the analysis: free access to data means that data can be freely misinterpreted.
- Risk of propagating own bias when preparing the information feedback: what seems simple or obvious to who writes the text could be perceived in a completely different way by the users.



https://publico.community/survey/18

- Are the questions appropriate?
- Is the wording clear?
- Is there anything you'd like to add?
- Is there anything you'd like to remove?

Email your considerations at giovanni.spitale@ibme.uzh.ch



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