Doing research in bioethics using empirical methods

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2012: BA in Philosopy @ UniPD
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2017: International Research Fellow @RUB, Institute for Medical Ethics and History of Medicine
2018: PhD student @UZH, Institute of Biomedical Ethics and History of Medicine

Ongoing projects:

- Autonomy and relations: investigating the role of shared decision making in young hemato-oncological patients.
- DIPEx International: Individual experiences with COVID-19
- PubliCo - an experimental online platform for COVID-19 related public perception

Other fancy stuff:
TEDx speaker @Trento 2016
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1. Introduce and discuss the concept of empirical bioethics
2. Present methodological options and data sources for empirical bioethics
3. Present and discuss some methodological case studies

4. (bonus point) avoid messing up too much with the language and see whether I'm still able to speak a decent Italian

1. Empirical ethics

2. PubliCo

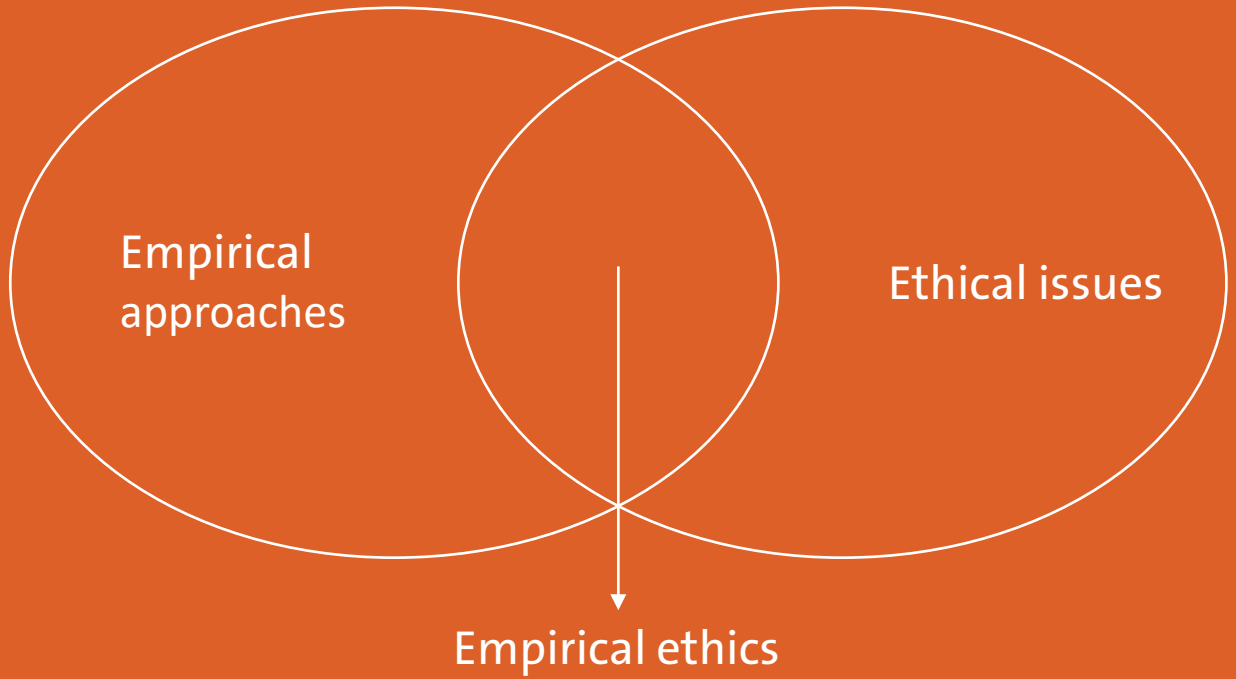
3. DIPEx International
COVID-19

SUMMARIZING:

1. What is empirical ethics?
2. Mixed methods approaches: PubliCo
3. Qualitative approaches: DIPEx

1. Empirical ethics

What is Empirical Ethics?



What is Empirical Ethics?

Musschenga 2005, DOI: 10.1080/03605310500253030:

- A logical next step in the development of practical ethics after the turn to “applied ethics.”
- Both descriptive and normative
- Aimed to improve the context sensitivity of ethics

Empirical ethics combines doing empirical—usually qualitative—(social) research
with philosophical (normative ethical) analysis and reflection

“in concentrating on questions of how medical decisions should be made, medical ethicists have paid surprisingly little attention to how they are in fact made”.

Why Empirical Ethics?

Musschenga 2005, DOI: 10.1080/03605310500253030:

- Traditional ethicists think that it is the task of legislators and policy-makers to reflect upon how to introduce and to implement moral principles in concrete settings. Empirical ethicists reject this view.

- The input of social research is already relevant in the phase of ethical theorizing.
- Ethicists should not limit themselves to formulating abstract and general principles. They have to specify and operationalize principles for particular contexts.

- Operationalizing a principle implies looking at:
    - those who are to be involved in the decision to act on that principle and
    - at the procedures that have to be designed
- To ensure that due care attends the decision.

- To translate basic principles into practice rules, one needs sociological hypotheses for evaluating the degree to which these rules are immune to potential misuse and abuse, immune also to the threat of “slippery slopes” leading to applications that are no longer covered by the basic principle (Birnbacher, 1999, p. 325).

Forgetting the context: organ donation rates in Greece and Chile

Greece
2011: new law adopting opt-out is passed

2013: the law comes in force (Bottis 2012).

The law was opposed by both the Orthodox Church and the Hellenic Transplant Organisation (HTO) (Bottis 2012) and met with considerable public opposition (Sotiropoulos & Machairas 2016).

2013: the law is softened to soft opt-out (relatives have a say) (Bottis 2012).

The introduction of the law took place at a time of low but increasing donation rates (3.6 donors pmp in 2000, rising to 8.9 pmp by 2008).

From 2011 onwards, a dramatic collapse in the donation rate began, and in 2013 it was still at 4.6 pmp; in the first six months of 2015, the value fell further to only 2.7 pmp (Moris et al. 2016).

This dramatic slump was related to the enormous economic crisis that has hit Greece hard since around 2010. However, it was also noted that other southern European countries, which were also hit hard by the financial crisis that began in 2008, had not experienced a drop in donor rates (Moris et al. 2016b).

Chile
after an increase in the donation rate in the 1990s, the number of donations stagnated since 2000 and has tended to decline since 2006 (Zúñiga-Fajuri 2015).

2010: new law adopting opt-out is passed
the law is applied in the sense of a soft opt-out, relatives continue to be asked about the presumed will of the deceased person (Domínguez & Rojas 2013).

2011: organ donation rates falls from 8.31 pmp (2000-2009) to 5.95 pmp; the opposition of families rises from 32% (2000-2009) to 50.4% (Domínguez & Rojas 2013).

2012: 2.8 million people had registered in the opposition register (16% of the population); 37% of the people who had renewed their identity card or their driver's licence in the period 2010 to 2011 refused organ donation (Zúñiga-Fajuri 2015).

2013: the law is tightened (retroactively!), non-donors have to notarise their refusal

2016: more than 4 million people registered as non donors; donation rate at 6.7 pmp, below the average from 2000-2009; refusal rates of relatives still over 50% (Kottow Lang 2016).

Source:
https://www.bag.admin.ch/dam/bag/de/dokumente/biomed/transplantationsmedizin/literaturbeurteilung-einfluss-von-zustimmungsmodellen-spenderegistern-und-angeh%C3%B6rigen-entscheid-auf-Organspenden.pdf.download.pdf/Literaturbeurteilung-Zustimmungsmodelle-Organspende.pdf

How to Empirical Ethics?

Davies, Ives and Dunn 2015, DOI: 10.1186/s12910-015-0010-3:

- There is no consensus as to what an appropriate methodology for empirical ethics would be. But existing methodologies can be classified on a spectrum with two main poles:

- Dialogical approaches, based around the formation of a dialogue between stakeholders and the attempt to reach a shared Understanding. The analysis, and reaching of a conclusion, is undertaken by the researcher and participants together.

- Consultative approaches tend to utilise an external 'thinker' who gathers data and analyses it independently of the data collection process, and then develops normative conclusions.

- "The heterogeneity we have observed is not a problem in itself. Difference adds to the richness of the field and, certainly in its infancy, a field such as empirical bioethics will surely benefit from experimentation and variety".

How to Empirical Ethics?

Ives et al. 2017, DOI: 10.1186/s12910-018-0304-3:

- Empirical bioethics research should address a normative issue that is oriented towards practice, integrating empirical methods with ethical arguments in order to address this normative issue.

- The method of integration should be explained and justified, including details of what is integrated with what, how and by whom.

- Empirical bioethics research ought to attend to the rigorous implementation of empirical methods, and import accepted standards of conduct from appropriate research paradigms.

- Empirical bioethics research should, if and where necessary, develop and amend empirical methods to facilitate collection of the data required to meet the aims of the research; but deviation from accepted disciplinary standards and practices ought to be acknowledged and justified.

- In empirical bioethics research, there should be explicit and robust normative analysis. 'Normative analysis' includes attempts to justify position X to person Y with the use of ethical reasoning, providing suggestion for improvement to position X based on ethical reasoning, or attempts to break down and make explicit a complex normative issue in order to gain a better understanding of it

Recommended readings

Molewijk et al. 2004, Scientific Contribution. Empirical data and moral theory. A plea for integrated empirical ethics.
DOI: 10.1023/B:MHEP.0000021848.75590.b0

Musschenga 2005, Empirical Ethics, Context-Sensitivity, and Contextualism.
DOI: 10.1080/03605310500253030

Widdershoven, McMillan, Hope, van der Scheer (eds.) 2008, Empirical Ethics in Psychiatry.
DOI: 10.1093/med/9780199297368.003.0003

Strech 2010, How factual do we want the facts? Criteria for a critical appraisal of empirical research for use in ethics
DOI: 10.1136/jme.2009.033225

Dunn, Sheehan, Hope, Parker 2012, Toward methodological innovation in empirical ethics research
DOI: 10.1017/S0963180112000242

Salloch, Wäscher, Vollmann, Schildmann 2015, The normative background of empirical-ethical research: first steps towards a transparent and reasoned approach in the selection of an ethical theory.
DOI: 10.1186/s12910-015-0016-x

Davies, Ives, Dunn 2015, A systematic review of empirical bioethics methodologies.
DOI: 10.1186/s12910-015-0010-3

Wangmo, Provoost 2017, The use of empirical research in bioethics: a survey of researchers in twelve European countries.
DOI: 10.1186/s12910-017-0239-0

Ives et al. 2018, Standards of practice in empirical bioethics research: towards a consensus.
DOI: 10.1186/s12910-018-0304-3

2. PubliCo

What happens during a public health crisis?

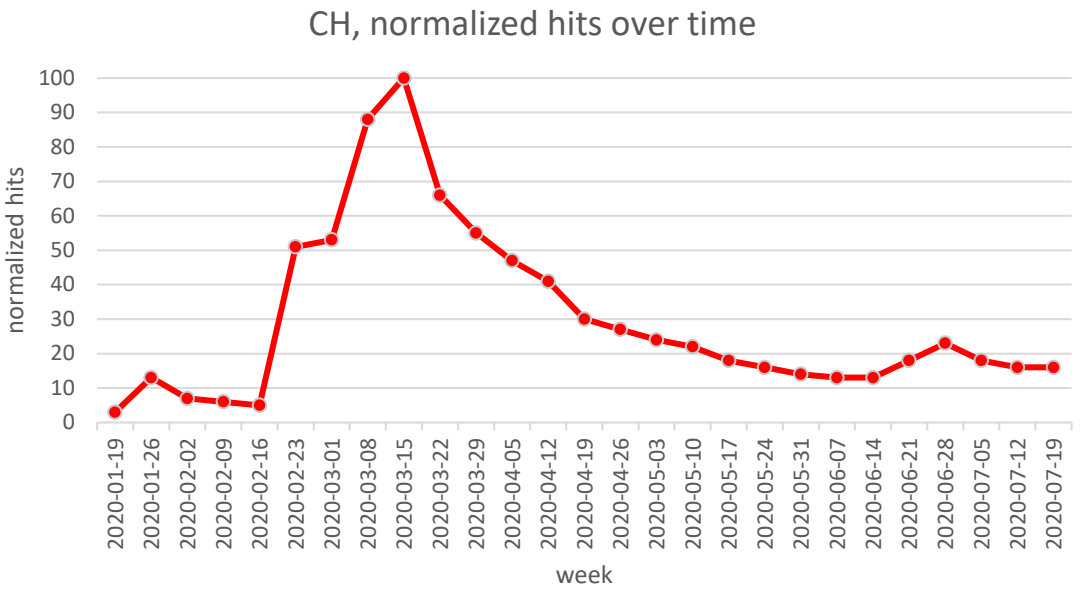
Public:
- What is this? Why is it happening?
- Lots of information become available at the same time. Is it all good?
- Who do I trust?
- How can I filter out non relevant or information?
- ...

Policy makers:
- Choices need to be made. Sometimes hard choices.
- What do people think? How do they behave?
- Are they willing to accept this or that measure?
- Which specific subset of the population is facing the hardest time?
- How do we prioritize interventions?
- ...

There is no “one size fits all” approach

Information consumption patterns

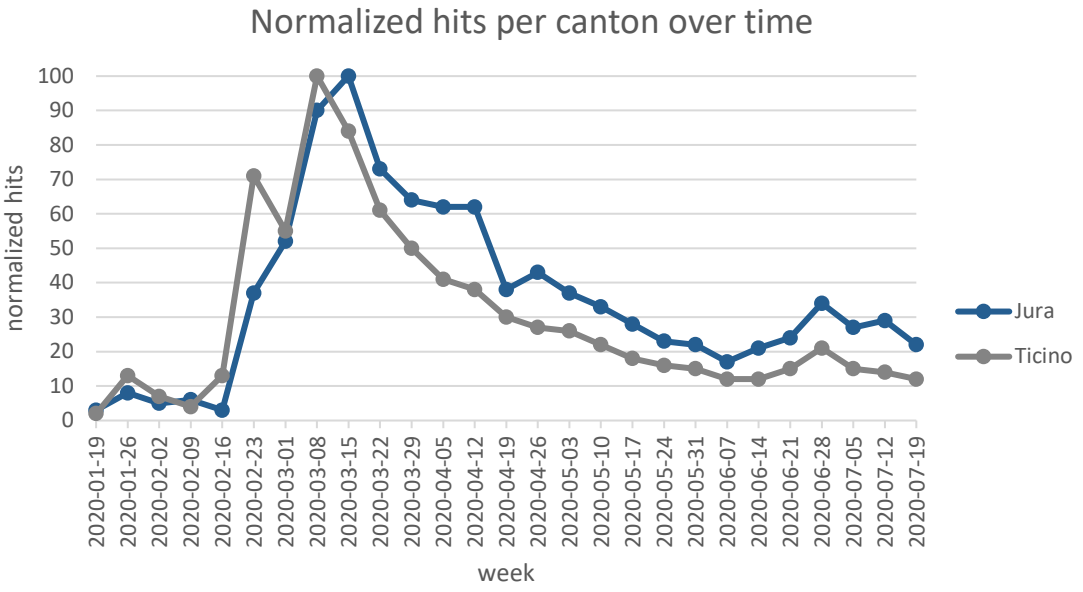
Query	Coronavirus + covid + 2019-nCoV + SARS-CoV2
Query type	keyword
Timeframe	27/07/19 - 27/07/20
Date of search	27 07 2020
Data source	Web searches
Location	CH (by canton)
Query category	all
Rationale for keyword	main semi-synonims for covid-19



Information consumption patterns

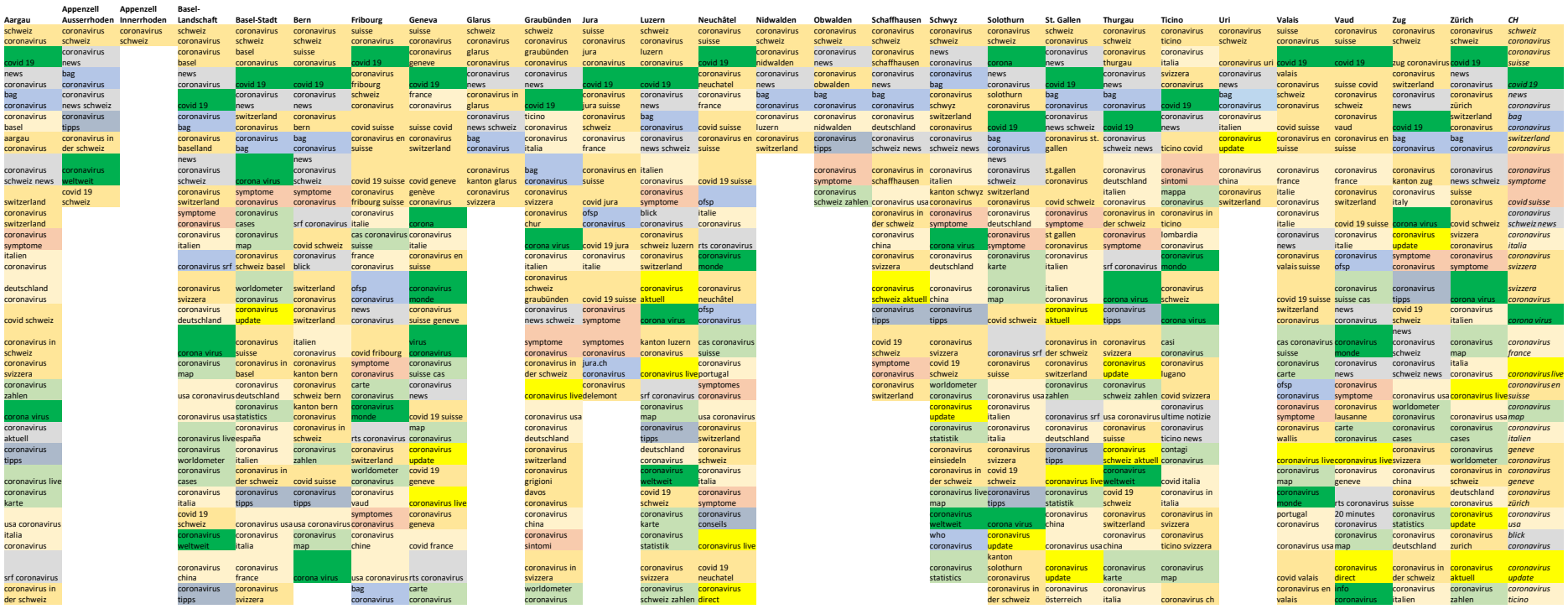
We analyzed the normalized hits per Canton over time and the top searches associated to the keywords in our list, defined by Google trends as “terms that are most frequently searched with the term you entered in the same search session, within the chosen category, country, or region”

Google Trends does not provide raw numbers, but only normalized hits. The normalization of data “indicates that the values vary from 0 to 100. The value 0 does not necessarily indicate no searches, but rather indicates very low search volumes that are not included in the results. (Mavragani and Ochoa 2019)

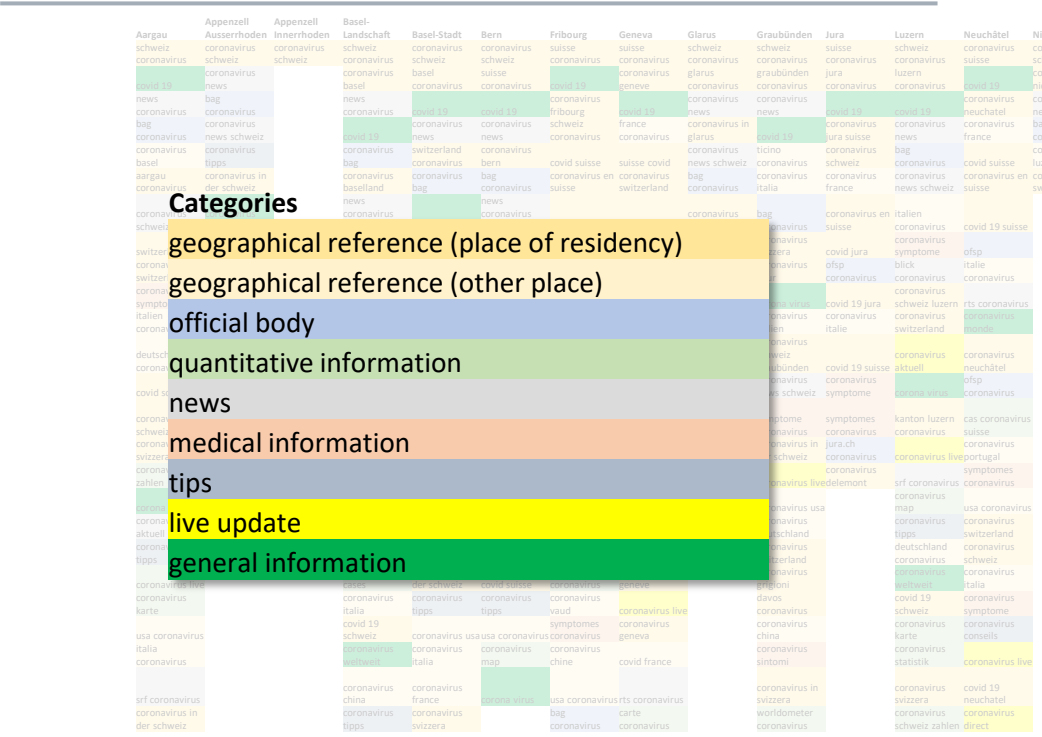


The series plotted (Jura and Ticino) are just an example of how within the same country different areas can consume information in different ways

Information consumption patterns



Information consumption patterns

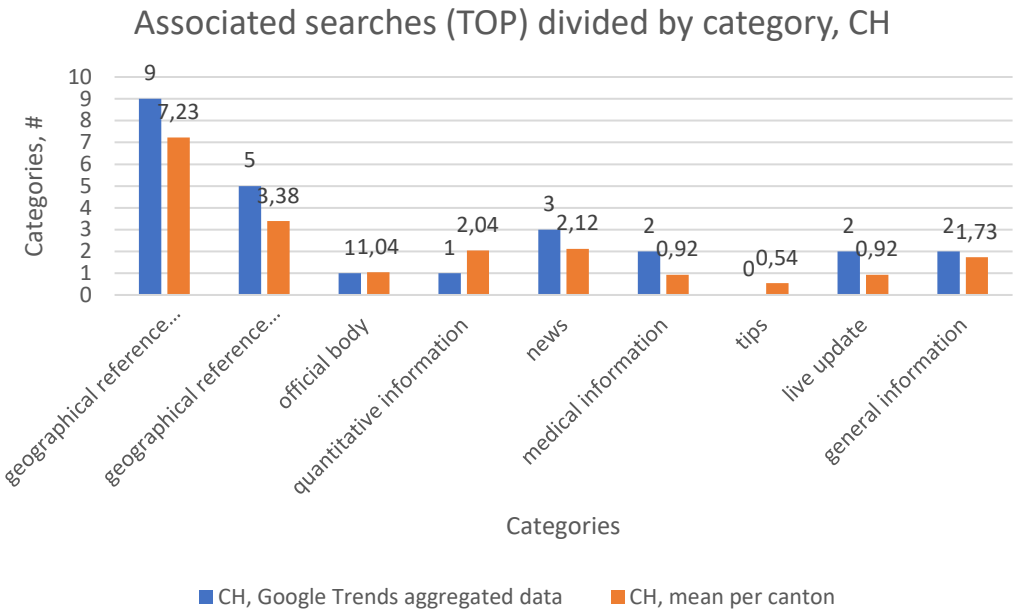


Category name	Explanation	Examples
geographical reference (place of residency)	Country, region or city the searcher lives in	“covid Suisse” “Aargau coronavirus”
geographical reference (other place)	Country, region or city that differs from the origin of the query	“Deutschland coronavirus” “Lombardia coronavirus”
official body	World health Organization, Federal Office for Public Health	“bag coronavirus” “who coronavirus”
quantitative information	Number of cases, number of deceased, other statistics	“worldometer coronavirus” “cas coronavirus suisse”
news	News, either specific to a place or general.	“coronavirus news schweiz” “rts coronavirus”
medical information	Information related to the diagnosis, treatment or outcome	“coronavirus symptome” “coronavirus sintomi”
tips	Suggestions and advice	“coronavirus tipps” “coronavirus conseils”
live update	Live updates on the pandemic situation	“coronavirus update” “coronavirus live”
general information	General information about the virus, the disease or the pandemic	“info coronavirus” “corona virus” “covid 19”

Information consumption patterns

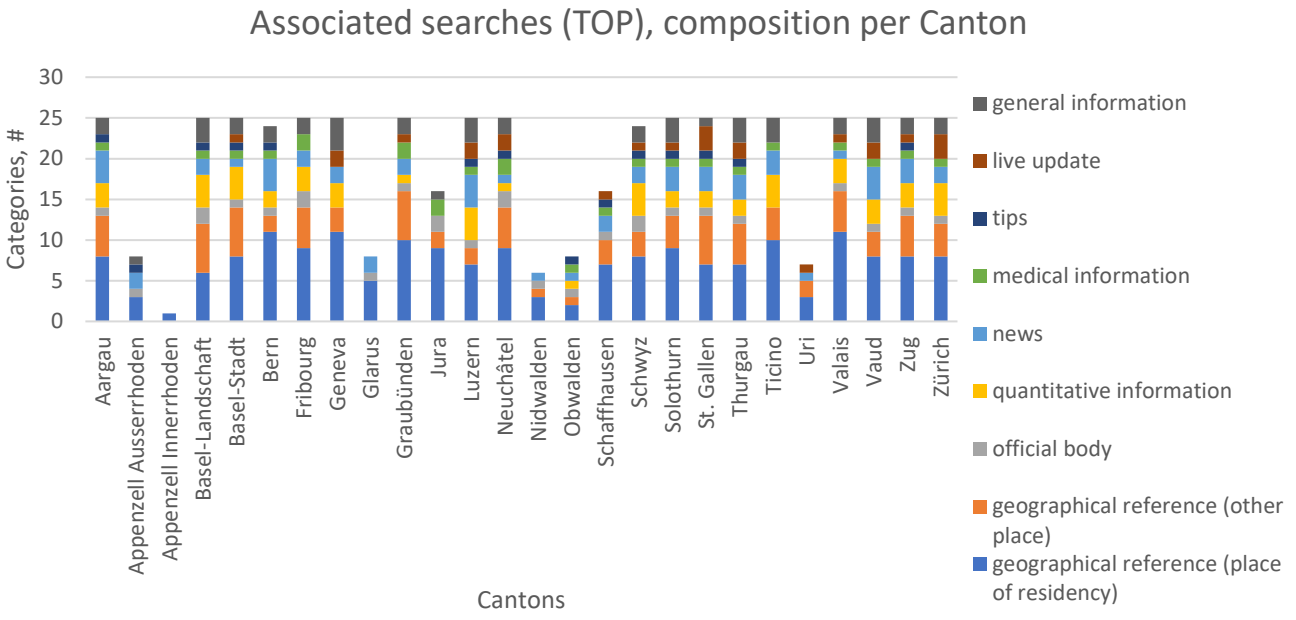
The count of the categories of the top associated searches allows to understand what macro-topics have been perceived as most interesting. Moreover, comparing the mean of the cantonal data to the aggregated data for the whole Country allows to see how some macro-topics can be considered important in some areas, but without emerging in the aggregated data.

It follows that, especially in Countries characterized by geographic, cultural and linguistic diversity as Switzerland, infoveillance studies using Google trends data need to be granular, using lower level data aggregation strategies.



Information consumption patterns

Categories	CH, SD per canton
geographical reference (place of residency)	2,83
geographical reference (other place)	1,98
news	1,18
quantitative information	1,56
general information	1,19
official body	0,60
medical information	0,63
live update	0,98
tips	0,51



Available information (and its limits)

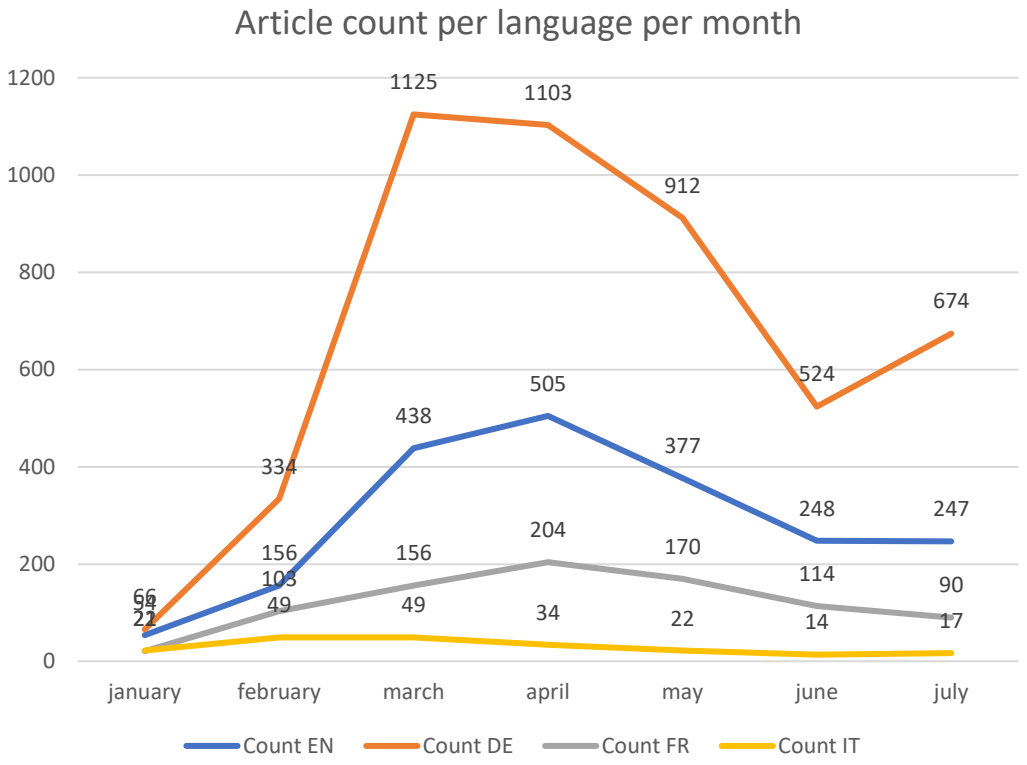
We used Factiva, a news monitoring and search engine developed and owned by Dow Jones, to gather and download all the news articles published between January and July 2020 on Covid-19 and Switzerland. (Cambria, Schuller, Xia and Havasi 2013)

The query is not limited to articles published by Swiss media, but to articles regarding Switzerland. The reason is simple: a Swiss user googling for "Schweiz Coronavirus" or for "Coronavirus Ticino" can easily find and read articles published by foreign media outlets. If the objective is capturing and describing the information trends to which people are exposed, this approach makes much more sense than limiting the analysis to articles published by Swiss media.

Syntax	Meaning
((coronavirus or Wuhan virus or corvid19 or corvid 19 or covid19 or covid 19 or ncov or novel coronavirus or sars) and (atleast3 coronavirus or atleast3 wuhan or atleast3 corvid* or atleast3 covid* or atleast3 ncov or atleast3 novel or atleast3 corona*))	Keywords for covid19; must appear at least 3 times in the text
and ns=(gsars or gout)	Subject is "novel coronaviruses" or "outbreaks and epidemics" and "general news"
and la=X	Language is X (DE, FR, IT, EN)
and rst=tmnb	Restrict to TMNB (major news and business publications)
and wc>300	At least 300 words
and date from 20191001 to 20200801	Date interval
and re=SWITZ	Region is Switzerland

Available information (and its limits)

	Results	Duplicates	Included
EN	2030	662	1368
DE	4741	1816	2925
FR	861	222	639
IT	209	52	157

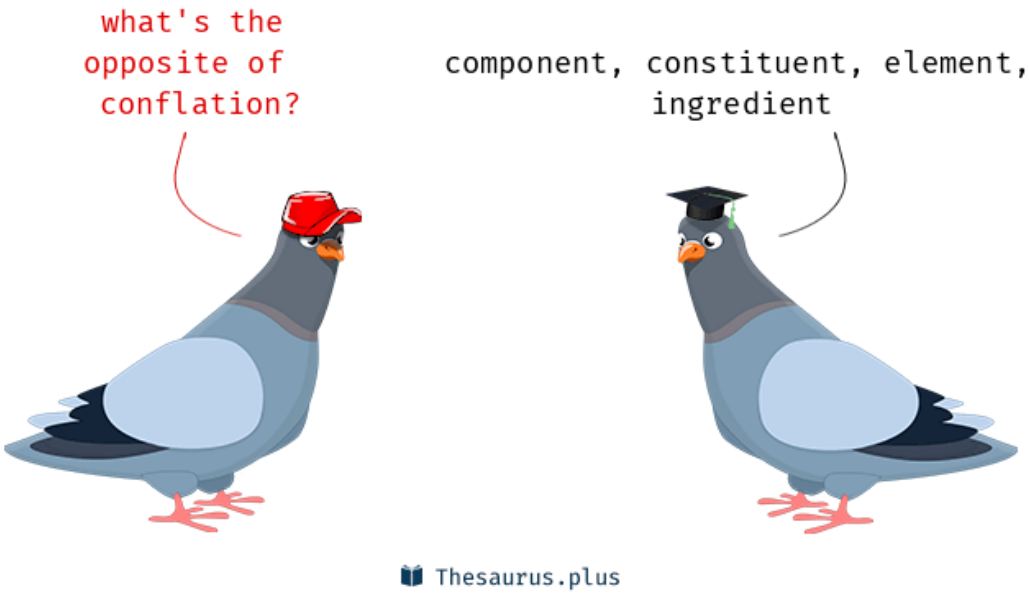


Available information (and its limits)

We analysed the content of the linguistic corpora using an ad-hoc pipeline written in Python, consisting of a parser and of a conventional NLP pipeline based on SpaCy (Spitale, Biller-Andorno and Merten 2020a, https://doi.org/10.5281/zenodo.3991821).

The NLP pipeline adopts a very simple approach, coherent with the purpose of this part of the study: tokenization, lemmatization, named entity recognition.

The overall idea is to reduce the corpora to a list of concepts to be tracked over time and to be confronted with the results of the Google trends data analysis.



Available information (and its limits)

Lemmatization
Reduction of the complexity of a text by substituting every word with its root, or lemma. When lemmatizing with a lookup table approach, the algorithm confronts every token of a given corpus with the content of a lookup table which lists flexed forms and their corresponding non-flexed forms (lemma). The limit of this approach is that it is as good as the lookup table it employs, which needs to be as accurate and as complete as possible.

SpaCy provides lookup tables for efficient and rather precise lemmatizing in all the languages that are relevant for this project. We performed lemmatization on the subcorpora in German, French Italian and English

German lemmas per month

#	lemma	total	jan	feb	mar	apr	may	jun	jul	mean
1	prozent	10196	175	724	1572	2164	3112	730	1719	1456.57
2	million	7784	28	126	759	1420	3535	511	1405	1112.0
3	coronavirus	7064	323	1000	2530	1309	936	470	496	1009.14
4	schweiz	7041	219	383	2178	1328	1204	868	861	1005.86
5	euro	5113	15	138	572	725	2803	119	741	730.43
6	unternehmen	4092	33	175	914	856	1192	319	603	584.57
7	milliarde	4066	20	127	630	842	1241	263	943	580.86
8	mensch	3959	126	261	1227	964	600	357	424	565.57
9	schweizer	3911	87	289	1018	769	621	442	685	558.71
10	land	3494	65	305	933	694	685	449	363	499.14
11	woche	3486	54	180	1125	904	562	320	341	498.0
12	zahl	3451	69	307	950	854	582	284	405	493.0
13	fall	3396	163	473	1156	574	390	297	343	485.14
14	virus	3333	157	570	1145	589	430	177	265	476.14
15	person	3258	91	213	999	613	481	342	519	465.43
16	kanton	3234	27	189	1073	657	445	315	528	462.0
17	quartal	3193	7	46	122	680	1698	99	541	456.14
18	2020	2994	21	101	504	724	690	384	570	427.71
19	stark	2988	32	196	718	648	772	270	352	426.86
20	document	2946	62	176	764	639	540	342	423	420.86

Available information (and its limits)

NER
A more refined technique employed in text mining to conflate texts (Nadeau and Sekine. 2007; Kaur and Gupta. 2010).
NER can recognize the category of a given word, allowing to define subsets of concepts in the corpus.

In the context of this project, information extraction by means of NER serves the purpose of validating what emerged with the analysis of lemmas, allowing in the meantime to gather more fine-grained information.

German entities per month

#	entity	cat.	total	jan	feb	mar	apr	may	jun	jul	mean
1	Coronavirus	MISC	4855	219	741	1842	842	626	273	312	693.57
2	Schweiz	LOC	4442	166	262	1352	825	736	559	542	634.57
3	Schweizer	MISC	3193	64	245	825	641	494	379	545	456.14
4	Virus	MISC	2832	138	492	977	493	337	163	232	404.57
5	Deutschland	LOC	2038	46	147	674	373	439	207	152	291.14
6	China	LOC	1985	220	522	459	306	265	81	132	283.57
7	Corona-Krise	MISC	1696	4	5	400	436	463	148	240	242.29
8	Zürich	LOC	1562	35	67	233	359	414	115	339	223.14
9	Italien	LOC	1419	8	241	638	260	128	97	47	202.71
10	Coronavirus	COVID19	1394	86	218	444	295	174	103	74	199.14
11	BAG	ORG	1383	119	109	442	216	166	132	199	197.57
12	der Schweiz	LOC	1247	27	84	427	222	216	122	149	178.14
13	Covid-19	MISC	1246	6	52	268	294	300	139	187	178.0
14	Bern	LOC	1234	28	53	239	205	294	227	188	176.29
15	Europa	LOC	1115	18	123	291	215	262	93	113	159.29
16	Frankreich	LOC	870	13	40	276	174	209	88	70	124.29
17	Quarantäne	MISC	830	26	111	251	79	97	73	193	118.57
18	USA	LOC	813	16	74	136	176	200	76	135	116.14
19	Österreich	LOC	720	4	40	259	95	173	80	69	102.86
20	Corona-Krise	LOC	704	4	5	139	220	179	59	98	100.57

Available information (and its limits)

Lemmas

German: compared to the other linguistic subcorpora, indicates a public discourse highly focused on quantitative aspects of the pandemic (“prozent”, “million”, “milliarde”, “zahl”).

French: focused on describing the pandemic and its effects on people. It is rather interesting to notice the opposed trends of “pandemie” and “epidemie”: the first increases by time, while the second decreases, with the swap point happening between march and april.

Italian: focused on cases and fatalities more than the other ones. It is also the subcorpus in which “oms” ranks higher, indicating a higher attention for official WHO news and/or reports. The Italian subcorpus is also the only one in which “China” appears in the top 20 lemmas.

English: dominated by information reported from other sources (“say”), which makes sense, given the fact that English is not an official language of the Confederation.

Under the surface of common lemmas it is possible to notice a higher attention to the economic and financial impact of the pandemic.

NER

The most frequent category of named entities in the German subcorpus is LOC, i.e. geographical places. This information allows to contextualize and expand what emerged in the lemma analysis. The most named countries are either the neighboring ones or the ones in which the pandemic it more strongly.

“BAG” is the first organization mentioned.

French: a similar situation, with lots of mentions of Countries that are either neighboring or hit severely by the pandemic.

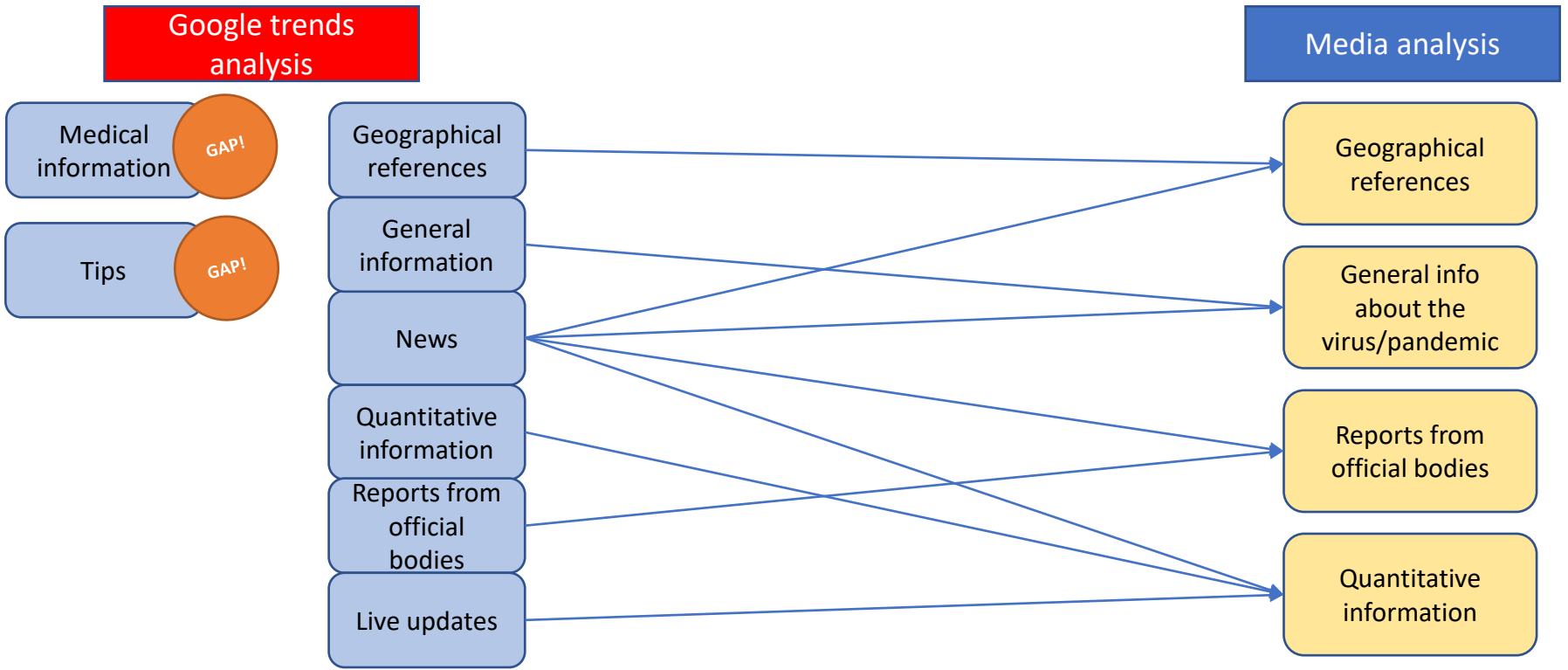
The first organization mentioned is “OMS”, followed by “Conseil fédéral” and by “OFSP”.

Italian named entities go in the same direction: the most mentioned Countries are either hit severely by the pandemic or neighboring . “OMS” is the second most frequent entity, after “coronavirus”.

English named entities follow an almost identical pattern: Countries with significant outbreaks, nearby Countries, the WHO.

The entire dataset is available (Spitale, Biller-Andorno and Merten 2020b, https://doi.org/10.5281/zenodo.4036071)

Available information (and its limits)



The general picture:

- Information overload (high numbers of available media)
- Difficulties in finding or consuming information from official sources (low searches for “official body”)
- No personalization (besides the confirmation bubble caused by Google’s algorithms)
- Chance to generate infodemics (this same analysis can be used to write LOTS of clickbait stuff)

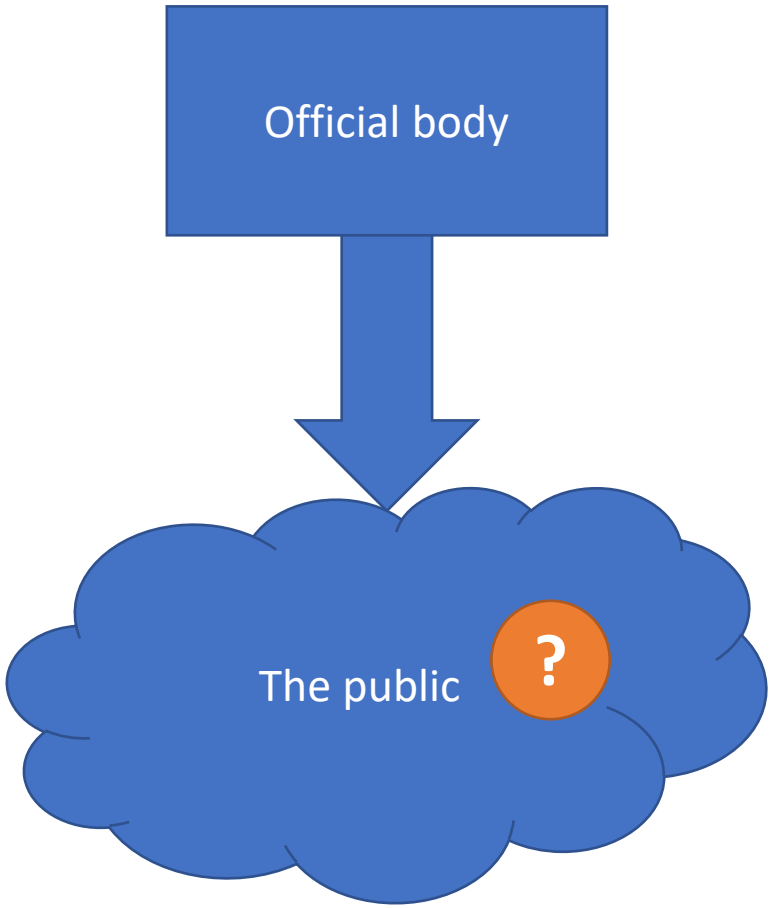
Providing and obtaining information

Information flow and policy making

So far, there has been mainly “one-way communication”. We do not know much about how subgroups may differ in their understanding of the situation and their readiness to comply with policies, and how this is affected by their preferred information sources.

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. Even if the mainstream public sentiment today is to cooperate with and endorse public policy, this consensus may become fragile if misunderstandings or unrest in certain parts of the population are disregarded.

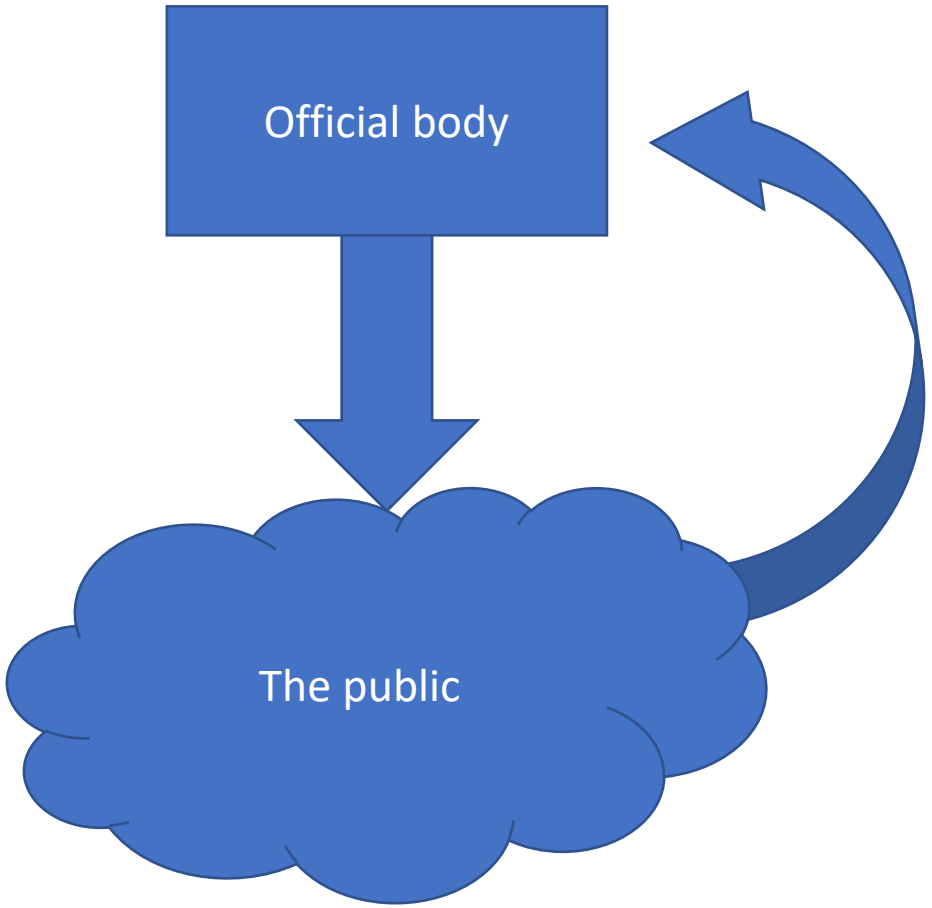


Providing and obtaining information

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).

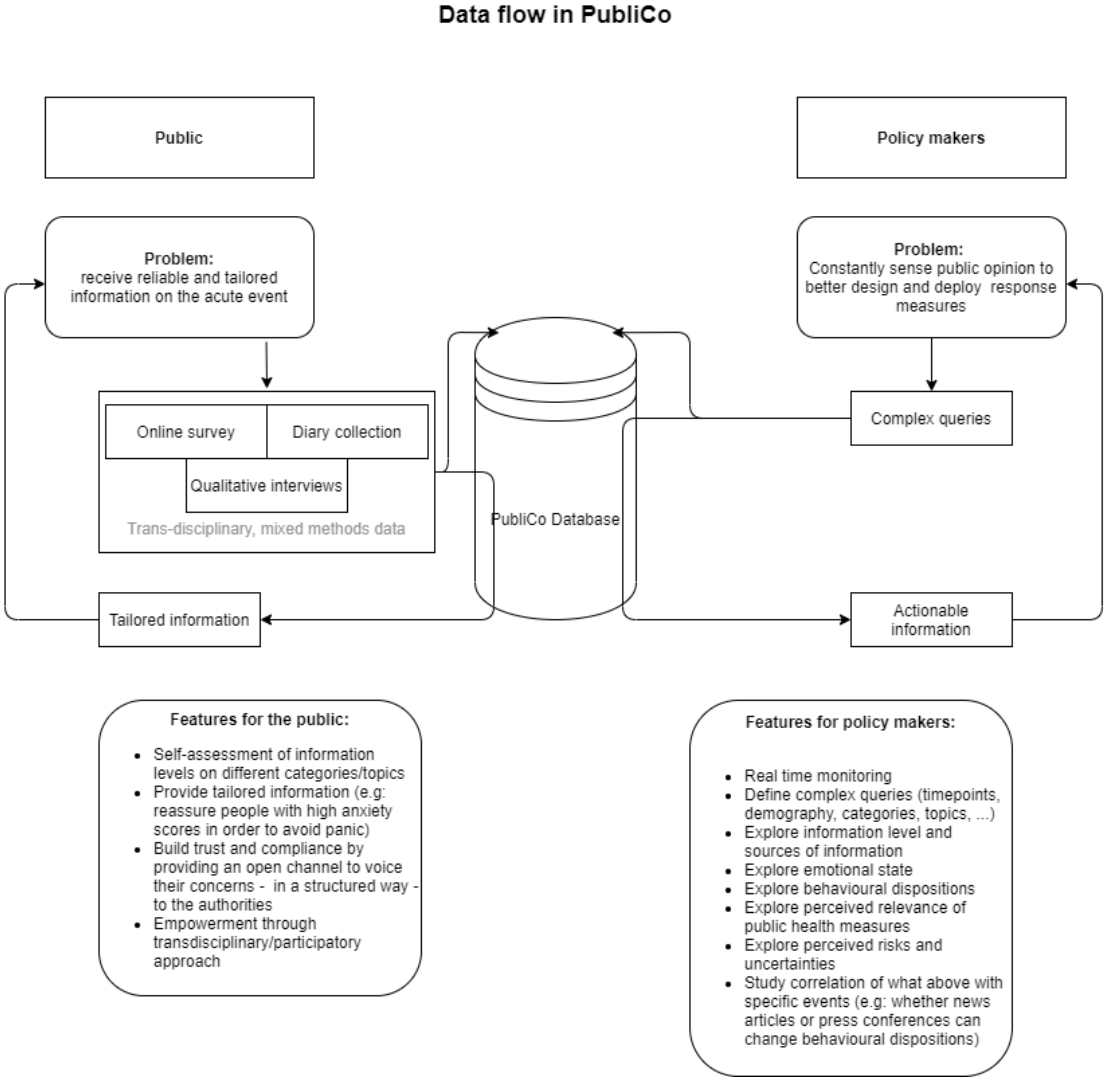


Providing and obtaining information

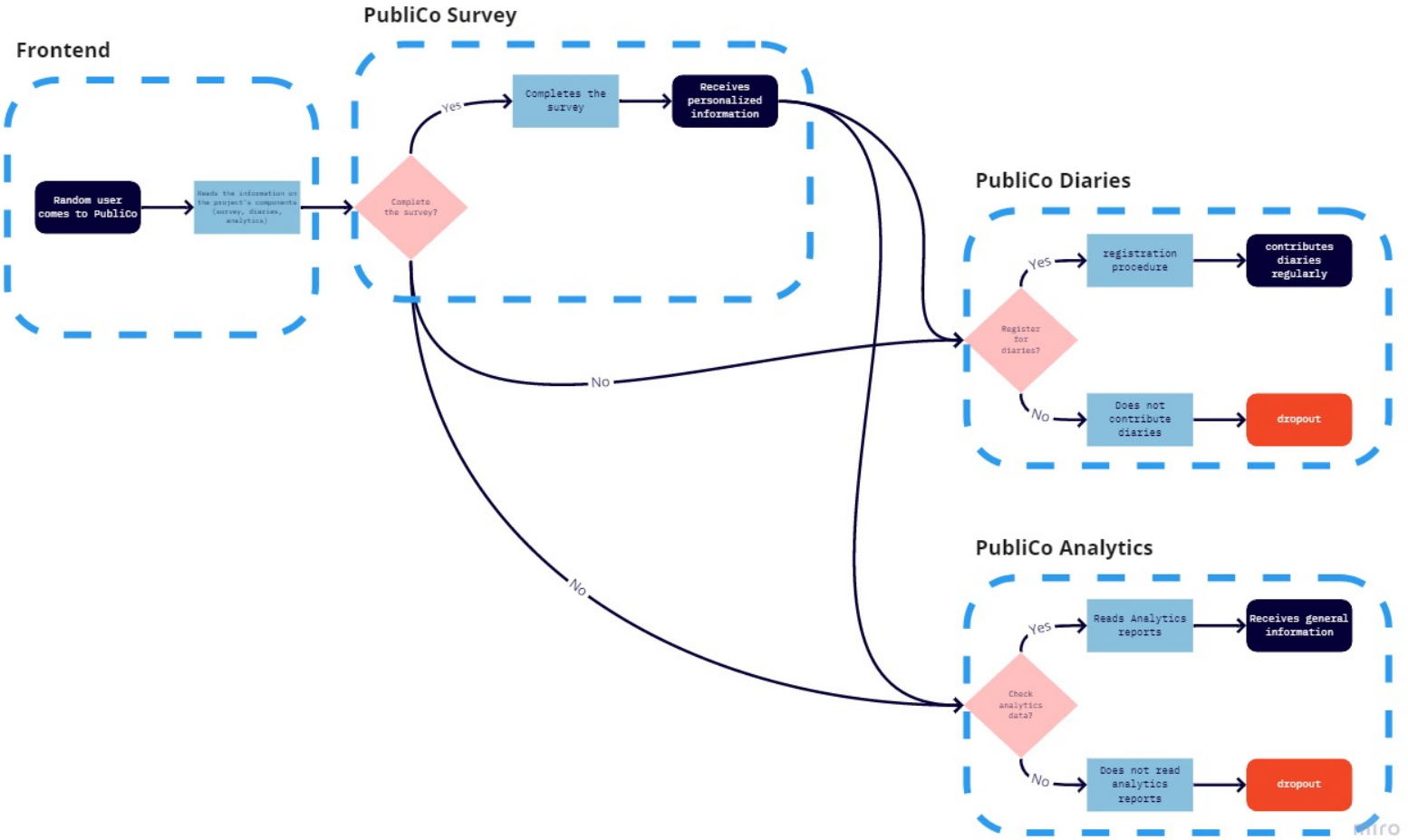
PubliCo will provide:

- Personalized information to users from the general public, based on their answers to the survey;
- Actionable information to policy makers, based on the answers given by respondents, on the content of their diaries, and potentially on the content of qualitative interviews (ongoing side-project)

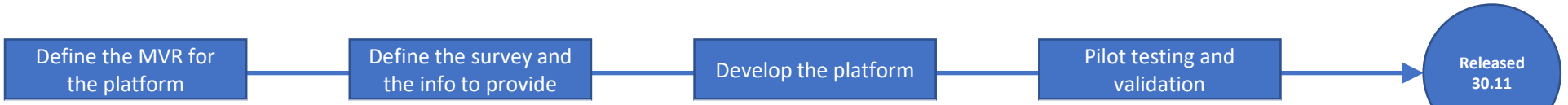
The trick:
It's not "yet another survey". You do it because it's short, it's nice, it's safe, it's democratic, it's a way to voice your opinion, but most of all because you get something back: personalized information.



Providing and obtaining information



How do we make it?



PubliCo Survey: multilingual, gamified, mobile first, easy to use, simple, provides personalized info
PubliCo diaries: login-based diary collection for citizen scientists
PubliCo analytics: dashboard presenting aggregated data from PubliCo Survey, allows definition of subsamples, shows descriptive stats, possibly some correlations, possibly NER on diaries

Google trends data: used to understand what people are looking for when searching for covid19 related keywords.
Factiva data: used to understand what the media are communicating.
NIH BSSR collection: used to unserstand what current behavioural and social science research is focusing on.

Developed by Belka, a software house with extensive experience in user interface design
Hosted on UZH virtual servers for data security; **written** in Python/ Javascript, nodeJS; **anonymous by design** for the survey component; **pseudonymous by design** for the diary component;
FAIR open data sharing by design: data are findable, accessible, interoperable and reusable thanks to easy export systems, efficient metadata labeling, open standards (also for the diary component).

Pilot-testing of the interface with former participants to DIPEx studies
Validation of the survey and of the information to provide by citizen scientists and by an expert panel

How do we make it?

Information we collect/provide:

Demographics

- Nationality
- Canton of residency
- Since when in CH
- Age
- Gender
- Education
- Marital status
- Has children
- Living arrangement
- Health condition
- Personal experience with COVID-19

Cognitive understanding

- Symptomps
- Transmission
- What to do if symptomatic

Behavioral dispositions

- Current behavior
- Excessive measures
- Comparison with others
- Anticipated vaccination behavior
- General disruptions

Emotional state

- Anxiety
- Depression
- Somatization
- Global severity index

Moral orientation

- Government response (Federal and cantonal
- Vaccine distribution
- Vaccine prioritization
- Access to testing
- Testing prioritization

Caveat: this list is preliminary. The survey content still needs to be validated by citizen scientists and by the expert council.

How do we make it?

For the public:

Demographics	Cognitive understanding	Behavioral dispositions	Emotional state	Moral orientation
Geographical references	Tips	Tips	Tips	Reports from official bodies
General information	Medical information	Medical information		
Quantitative information and live updates				

- Health condition
- Personal experience with COVID-19

- Symptomatic
- behavior
- General disruptions

- Global severity index

- Vaccine distribution
- Vaccine prioritization
- Access to testing
- Testing prioritization

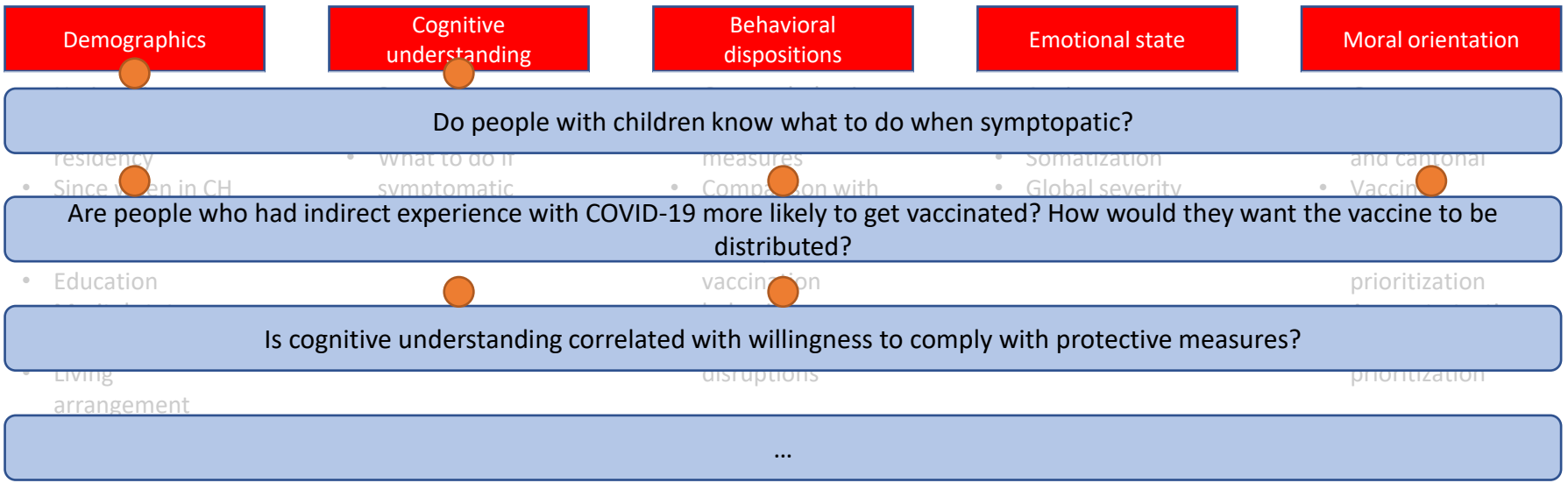
+ Comparison with others

- ~~News~~

Information is provided in blocks and determined by scoring, language, and demographics.

How do we make it?

For policy makers:



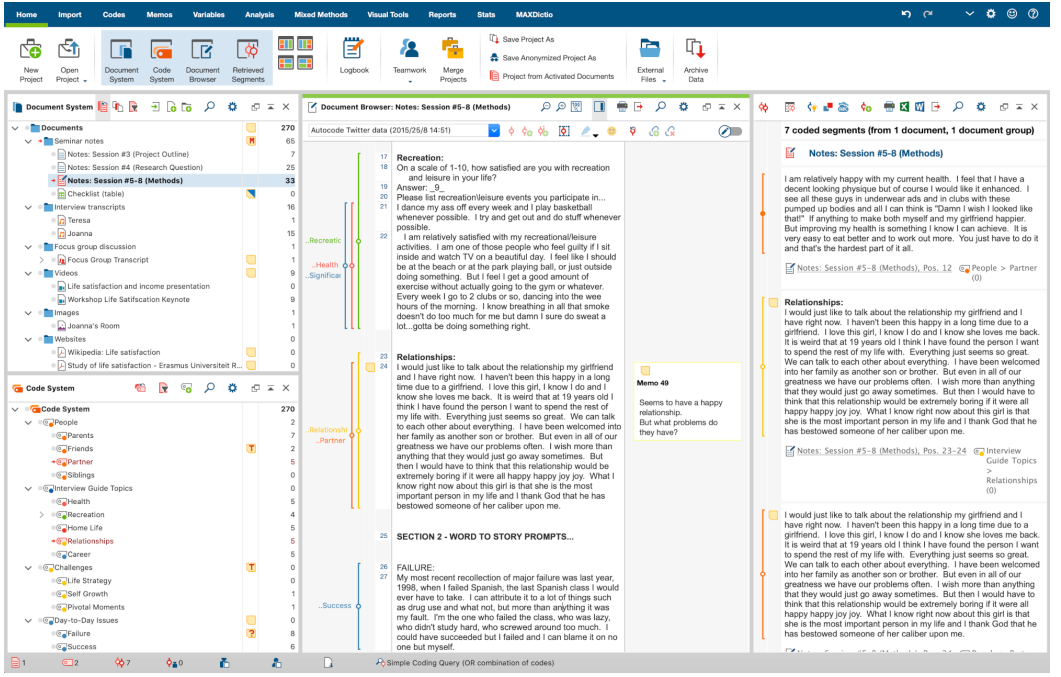
All the data is displayed and available for download and further research. Custom queries can be built within the system.
Data are accompanied by interpretative documents (PubliCo briefs)

How do we make it?

Diaries
Citizen scientists will be asked to keep a diary with their reflections on how COVID-19 and related policy measures affect their daily routine, social practices, values and priorities (Alaszewski 2006; Hawkes, Houghton and Rowe 2009).
Citizen scientists can also keep their diaries offline and have the text entered by project staff afterwards.

These data will inform the revision or generation of new quantitative items, and allow a deeper, more contextualized analysis investigated (Ziebland and McPherson 2006; Strauss and Corbin 1998).

The analysis of written diaries will be semi-automatized by means of NLP (e.g. lemmas, NER, ...) and finalized by human coding of the text with CAQDA software. This way not only the platform will be more cost effective, but more importantly faster in the analysis and in the delivery of actionable information.

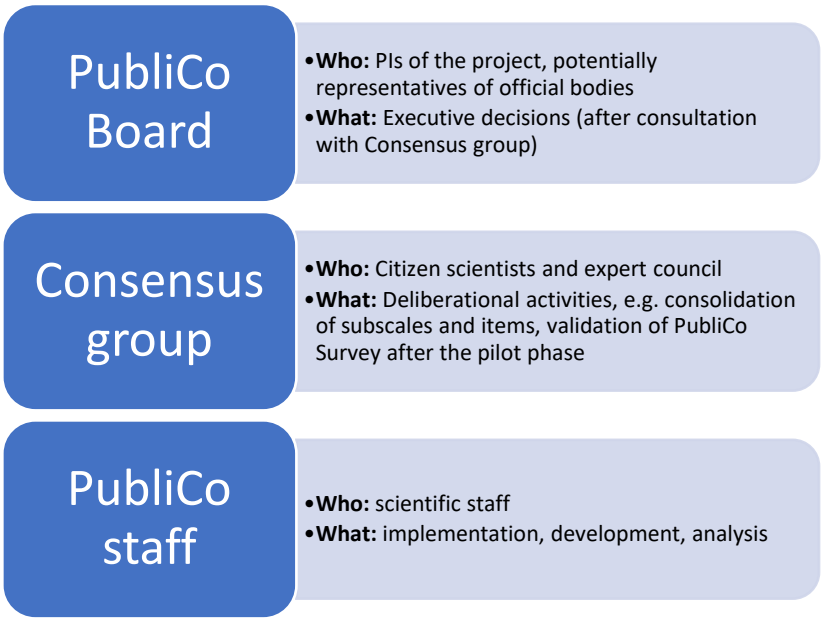


Transparency, privacy and governance

Transparency
All the data used to develop the tool and to justify its necessity are publicly available (Google Trends, NLP pipeline, text mining data, NIH BSSR collection) with CC-BY-SA license. All the future data generated by PubliCo will be publicly available as well, through PubliCo Analytics, under the same license. Citizens are included in the development of the survey.

Privacy
PubliCo Survey is anonymous by design. It is impossible to attribute answers to individual persons. Users are identified only with a numeric ID which is randomly generated. PubliCo Diaries is pseudonymous by design. Researchers can access the demography of users for analysis, but not their identity. De-pseudonymization through content analysis is still possible, therefore this is the only data that will be made public after analysis (and manual check for consistent and effective pseudonymization).

Governance



More than a COVID-19 response tool!

PubliCo is (already):
- Modular, flexible and customizable
- Multilingual
- Light to run and to load
- Supports multiple surveys/diary collections at the same time
- Supports presets ready to use

After field testing and validation PubliCo can become a generic response tool for public health emergencies.

Recommended readings

Spitale et al. 2020, PubliCo. A new risk and crisis communication platform to bridge the gap between policy makers and the public in the context of the COVID-19 crisis [protocol/preprint].
DOI: 10.5281/zenodo.4312695

Spitale, Biller-Andorno, Merten 2020, Lemmas and Named Entities analysis in major media outlets regarding Switzerland and Covid-19 [dataset].
DOI: 10.5281/zenodo.4036070

Spitale, Biller-Andorno, Merten 2020, Factiva parser and NLP pipeline for news articles related to COVID-19 [software].
DOI: 10.5281/zenodo.3991613

Spitale 2020, COVID-19 and the ethics of quarantine: a lesson from the Eyam plague.
DOI: 10.1007/s11019-020-09971-2

www.publico.community

3. DIPEx International COVID-19

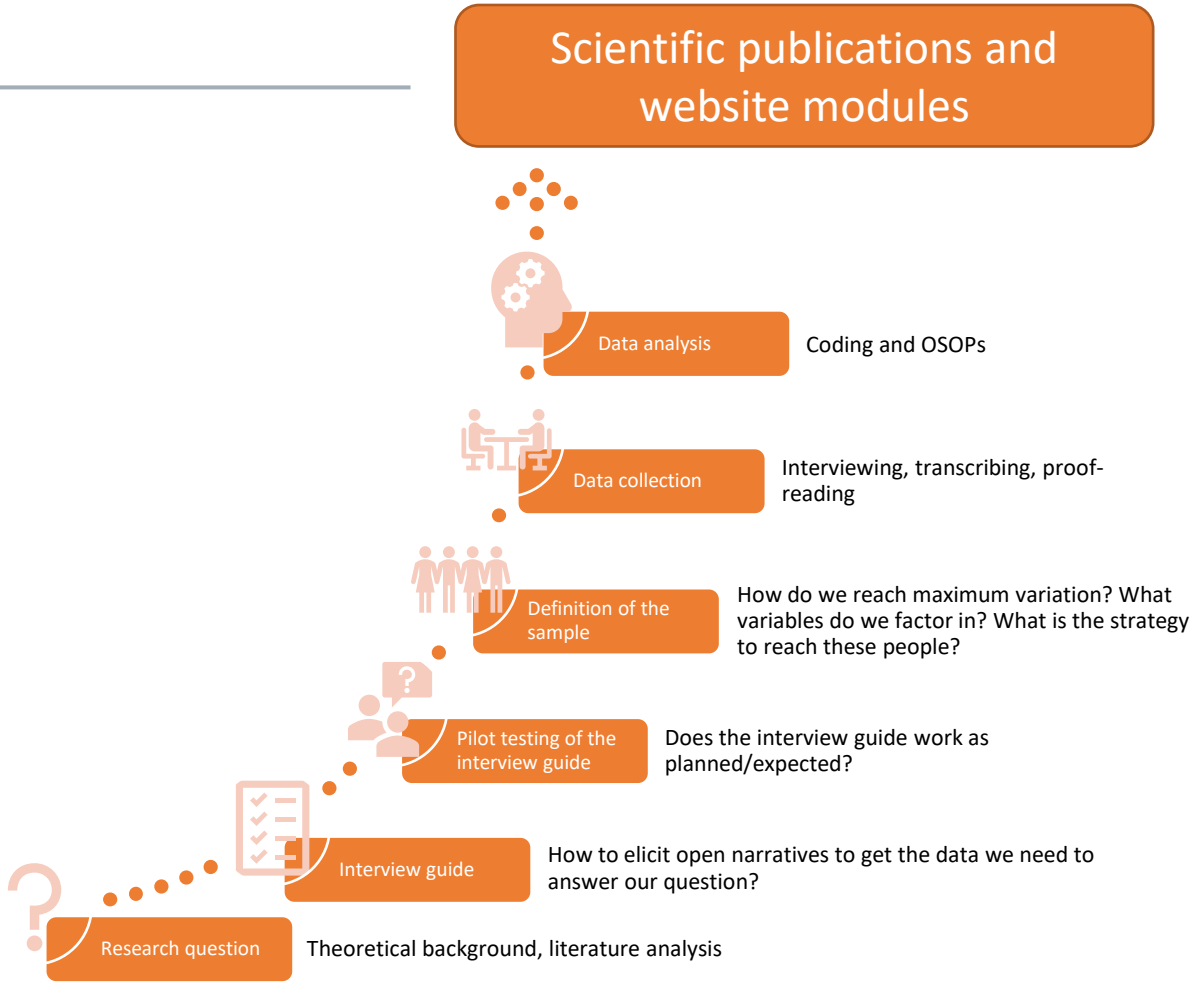
What is DIPEx?

Ziebland, Grob and Schlesinger 2020, DOI: 10.1186/s12910-018-0304-3:

- In 1999, general practitioner Ann McPherson (1945–2011) and clinical pharmacologist Andrew Herxheimer (1925–2016) shared the drive home from a conference which had featured the work of the Cochrane Collaboration. Comparing their own recent experiences of hospital treatments, they developed the idea for a public-facing database of people's experiences of health, illness and care, as a complement to Cochrane's assemblage of systematic reviews of evidence related to clinical outcomes. This led to the establishment of the DIPEx (Database of Individual Patient Experiences) project.

- DIPEx focuses on individuals, emphasizing the common themes and polyphonic perspectives on experiences within a health system. The DIPEx approach does this in three ways:
  - by seeking interviews with a wide sample of participants, from different backgrounds and locations, to maximize variation based on respondent attributes;
  - by asking about experiences in an open-ended way that allows for unexpected responses;
  - by interviewing people in their home and other settings that fosters participation by those less likely to give voice to their experiences via other channels.

The process in a nutshell



Our role, our responsibilities

"Patients' stories can change curricula and achieve a Trojan horse effect as they smuggle in, and make memorable, key curriculum points. Narratives can **engage the emotions**, developing and sustaining **interest**, which is so closely related to **motivation to learn**."

(Ziebland, Grob and Schlesinger 2020)

Our role, our responsibilities

"Of 4226 documents, 17 studies met the inclusion criteria. The studies investigated 10 different sources of Web-based patient narratives. Sample sizes ranged from 23 to 2458. The mean score of the quality assessment was 82.6 (range 61-100). Effects regarding five different purposes were identified as follows: **provide information, engage, model behavior, persuade, and comfort.** We found positive effects in every category and negative effects in one category (persuade)."

(Drewniak, Glässel, Hodel and Biller-Andorno 2020)

The story so far

Bergamo, Italy, March 2020. Morgues are so overwhelmed that military trucks are needed to dispose of the dead.

The story so far

Milan, Italy, March 2020. ICUs fill up at an alarming rate. Patients face sub-optimal treatment due to scarcity of crucial resources (medications, personnel, beds, ...)

The story so far

Vicenza, Italy, March 2020. Hospital staff keeps striving and doing their best not only to cure, but also to care...

The story so far

Bologna, Italy, March 2020. ...despite difficult conditions: massacring shifts, few protections, extreme pressure

The story so far

Zurich, Switzerland, April 2020. Societies, shaken by the pandemic, respond with flash mobs and other initiatives to support “the heroes” working in “first line”.

The story so far

Kriens-Pilatus region, Switzerland, April 2020. People do what they can in order to feel close, to transmit togetherness and support.

The story so far

Zurich, Switzerland, April 2020. The point is: we need hope, and we need to spread it as much as possible.

The story so far

USA, April 2020. Lockdown and quarantine measures start to have detrimental effects on societies and on people’s behaviour.

The story so far

Swiss-German border, April 2020. Borders used to be just lines, at least in Europe. Now they manifest again as fences.

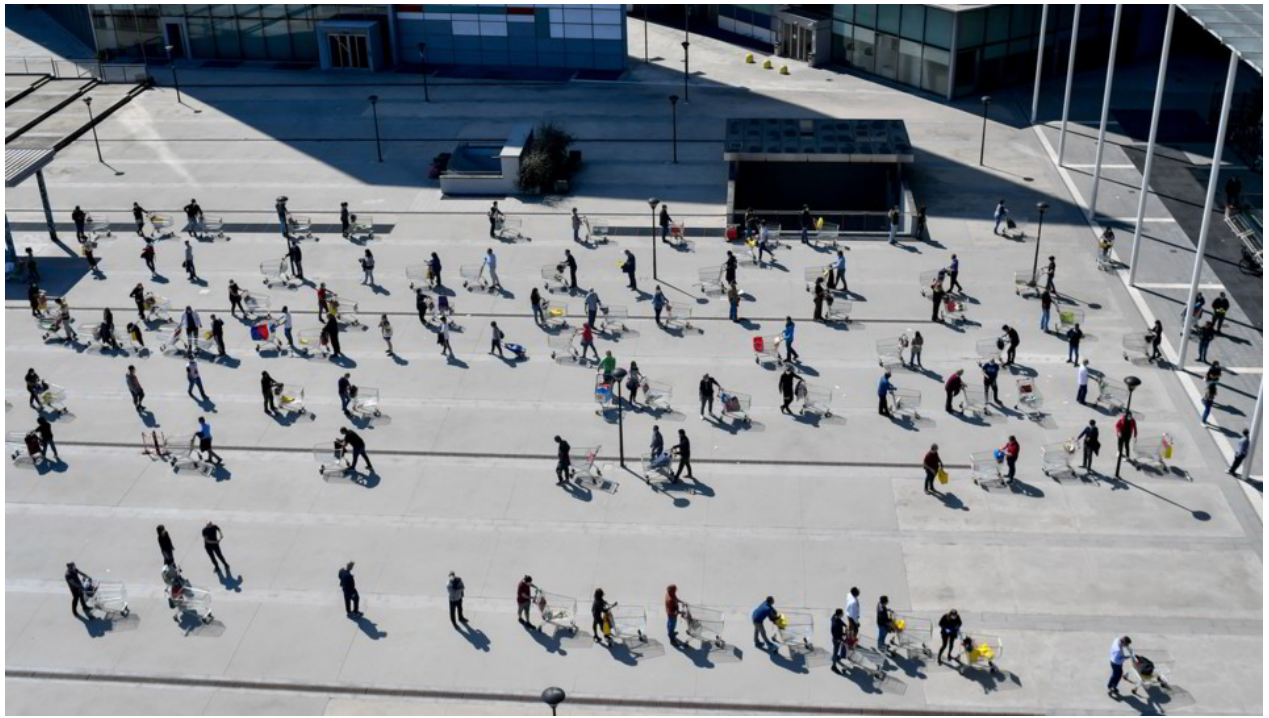
The story so far

Lugano, Switzerland, April 2020. We cannot meet our loved ones, and when we can the awareness of the risks makes it painful, especially for the elderly.

The story so far

Sion, Switzerland, April 2020. Also young generations are paying a heavy toll. Mitigation strategies work, but they are workarounds, not solutions

The story so far



Milan, Italy, April 2020. People try to be compliant and to get used to this new lifestyle, keeping in mind the “common good”.

The story so far

New York, USA, May 2020. The pandemic keeps spreading. Hart island is just one of the many mass burial sites across the world.

The story so far

Toronto, Canada, May 2020. Few months of pandemic are sufficient to see the rise of protests against lockdowns and preventive measures in general.

The story so far

Berlin, Germany, August 2020. “Small, vocal minorities” protesting against preventive measures grow bigger...

The story so far

Turin, Italy, October 2020. ...and angrier.

The story so far

March (left) and October (right).
Eight months of pandemic had this effect.

Can we make a difference?

Yes. For patients and their families.
- Recognizing and honoring the challenges these people are facing
- Providing instruments to help understanding what they are going through
- ...

Yes. For formal and non formal care givers
- Recognizing and honoring the extraordinary efforts of these people
- Providing insights and knowledge to improve the care/cure processes
- ...

Yes. For policy makers.
- From “case” to “person”. Add significance to quantitative information. Shed light on the human and subjective component of the pandemic, often neglected in public health discourses dominated by numbers.
- Provide information and feedback on what people believe and how people are faring
- ...

Yes. For our societies.
- Generate empathy, providing stories that complement information, eliciting pro-social behaviours.
- Counteract narratives that diminish the value of human life (of the elderly, of people with pre-existing conditions, ...)
- ...

Should we make a difference?

“Empirical research and theory can tell us how best to do this important work of social justice. Empirical research, and the public health statistics that surveillance and research generate, can tell us what groups are falling the most behind, and in what ways”.

(Powers and Faden 2006, p. 195)

“Act only according to that maxim by which you can at the same time will that it should become a universal law.”

(Kant 1785)

Who's in?

Country	People	Status	ITW guide used	Target population
USA	Rachel Grob, Jane Alice Evered, Madison Wynn	data collection starting in november	standard plus additions	Recovered patients (including healthcare workers)
the Netherlands	Nienke Verheij, Manna Alma	20 interviews coded (short, by phone); waiting for ethics approval for video interviews, hope to start in november	different guide, will use the standard for new interviews	Recovered patients
Brazil	Alicia Regina Navarro Dias de Souza, Nelson Felice de Barros	done some preliminary interviews with health care professionals, plus 2/3 patients	standard plus additions (spirituality, social inequality)	Recovered patients (including healthcare workers)
Germany	Martina Breuning, Christine Holmberg, Anne Thier	15 existing itws with different itw guide (useful for comparisons)	different guide	Recovered patients
Switzerland	Nikola Biller-Andorno, Susanne Jobges, Corine Mouton Dorey, Giovanni Spitale	data collection practically finished (11 itws); checking for theoretical saturation in order to decide whether to include more participants.	standard plus additions (icu)	recovered patients (including healthcare workers) (with a focus on ICU for a related project)
Japan	Rika Sato, Akiko Sawada, Yoko Setoyama	Applied for ethics approval to DIPEx-Japan inner ethics committee. Looking for funding for a nation-wide project. Until then, we'll do it small scale.	standard	For COVID-19 interviews: recovered patients and family members (including the bereaved)
Spain	Vinita Mahtani, Emilio Sanchez, Elisa Torres, Alicia Mora	data collection in progress, adaptable itw guide in case of need	standard	recovered patients (including healthcare workers)
Australia	Lorraine Smith, Renata Kokanovic, Kate Johnston-Ataata, Anna Urbanowicz	2 interviews completed, more to come	standard	recovered patients (including healthcare workers when available)
UK	Lisa Hinton	about to start data collection	standard plus additions	recovered ICU patients and relatives of deceased patients
Canada	Susan Law, Ilja Ormel, Michelle Marcinow	about to start data collection, ethics cleared, interviewee's recruitment in progress	standard plus additions (covid and pregnancy)	recovered patients (including healthcare workers)

Our question

In light of the DIPEx International commitment to study individual experiences that people have with health and illness, in order to understand where did people struggle and where did they learn, this research project aims to clarify what we can comprehend from the experiences of COVID-19 survivors from the Countries that participate to this study.

This research project is focused on action-oriented research, intended as “a participatory process concerned with developing practical knowing in the pursuit of worthwhile human purposes. It seeks to bring together action and reflection, theory and practice, in participation with others, in the pursuit of practical solutions to issues of pressing concern to people, and more generally the flourishing of individual persons and their communities” (Reason and Bradbury 2008, p. 4).

This research project aims to **provide information and support** to patients, families, carers, friends and healthcare professionals about the experience of and recovery from COVID-19, and consequently to understand how **response strategies** (intended both on a clinical and on a social level) to the current public health crisis and to future significant threats to public health can be **reshaped and ameliorated,** learning from recovered patients with lived experience of COVID-19.

In detail, our objective is to investigate:
What are the experiences of COVID-19 survivors across the world, taking into account the **clinical trajectory** (first signs, diagnosis, treatment and recovery)?
What are the experiences of COVID-19 survivors across the world, taking into account the **social trajectory** (sources of information, role of the national governments, “horizontal communication”, trust and mistrust, inequality, uncertainty and coping with uncertainty, prevention measures - including their impact -)? How did these experiences change over time, during the different phases of the pandemic?

What we are doing, where we are standing

Each first time comes with challenges

The coding/analysis problem

- Quantitative complexity: 10 teams, 10-15 interviews per team -> **100/150 interviews**
- Linguistical complexity: **9 languages:** English, Dutch, Portuguese, German, Swiss German, French, Italian, Japanese, Spanish
- Contextual complexity: **10 Countries** with different healthcare systems, norms, beliefs, …

Our hypotheses

- No sharing of raw data due to data protection reasons (and language);
- Sharing of preliminary coding trees in order to set the grounds for producing meaningful analyses on overlapping topics;
- Ideally we will have 2 categories of codes: 1. descriptive, wide codes (e.g: info sources, diagnosis, ...) and 2. context specific, interpretative micro codes - (e.g: inequality)
- Comparative work on intermediate material (heavily commented OSOPs) with itw snippets in the original language
- “Axial coding”, interpretation and analysis

Deliverables

Intermediate deliverables

- Research question
- Interview guide
- Coding trees (in English)
- OSOPs (snippets in the original language, comments in English)

Final deliverables

- Publication focused on the methods
- Publications focused on the RQ
- Module(s)

Recommended readings

Herxheimer et al. 2000, Database of patients' experiences (DIPEx): a multi-media approach to sharing experiences and information
DOI: 10.1016/S0140-6736(00)02174-7

Ryan, Räisänen 2008, "It's like you are just a spectator in this thing": Experiencing social life the 'aspie' way.
DOI: 10.1016/j.emospa.2009.02.001

Armstrong, Powell 2009, Patient perspectives on health advice posted on Internet discussion boards: a qualitative study.
DOI: 10.1111/j.1369-7625.2009.00543.x

Ziebland, Lavie-Ajayi, Lucius-Hoene 2015, The role of the Internet for people with chronic pain: examples from the DIPEx International Project.
DOI: 10.1177/2049463714555438

Giesler et al. 2017, Effect of a Website That Presents Patients' Experiences on Self-Efficacy and Patient Competence of Colorectal Cancer Patients: Web-Based Randomized Controlled Trial.
DOI: 10.2196/jmir.7639

Ziebland, Grob, Schlesinger 2020, Polyphonic perspectives on health and care: Reflections from two decades of the DIPEx project.
DOI: 10.1177/1355819620948909

Drewniak et al. 2020, Risks and Benefits of Web-Based Patient Narratives: Systematic Review.
DOI: 10.2196/15772

https://dipexinternational.org/

SUMMARIZING:

1. What is empirical ethics?
2. Mixed-methods approaches: PubliCo
3. Qualitative approaches: DIPEx

Could I have your feedback?

This helps me improving both the content and my teaching skills

https://rattocloud.hopto.me/index.php/apps/forms/4mQFcQyqjQq6KzAA

University of Zurich[UZH]
Institute of Biomedical Ethics
and History of Medicine

THANKS FOR YOUR TIME!

(I include this random owl from the internet in all of my presentations because I lost a bet some years ago)

To download this presentation:

https://drive.switch.ch/index.php/s/THxkxZ4PDS1GNEv

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and History of Medicine