

Ethical Dilemmas in the Time of COVID-19

Mapping, understanding, building systemic resilience

Inaugural dissertation

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Many thanks to:

- To my wife Angela, who had quite a role in pushing me out of the nest;
- To my family, who built that nest in which I managed to grow;
- To this country, Switzerland, in which I never felt an unwelcomed stranger;
- To present and former colleagues, who managed to teach me stuff despite my hard head, and to bear my lack of social competence;
- To flying and to my flying community, who managed to keep me sane and healthy when 'fun' was not enough;
- To Natasha and Vanya, who are amazing conversationalists, took good care of me, and kept me well nourished during the last pull of my PhD;
- To Nikola, who gave me an opportunity, and the freedom to be myself.

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- World Health Organization (APW HEG COVID-19 Sep);
- Swiss State Secretariat for Education, Research and Innovation (bilateral research collaboration with Asia 2017-2020 – Special COVID-19 Call for Project Grants with China [including Hong Kong and Taiwan], Japan, South Korea, and the ASEAN [Association of Southeast Asian Nations] region).



TOPICS



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1. Introduction
2. Quarantine
3. The literature challenge
4. Emerging ethical issues
5. Bidirectional risk and crisis communication
6. Passive social listening
7. The value of people's voices
8. Future perspectives

1. Introduction



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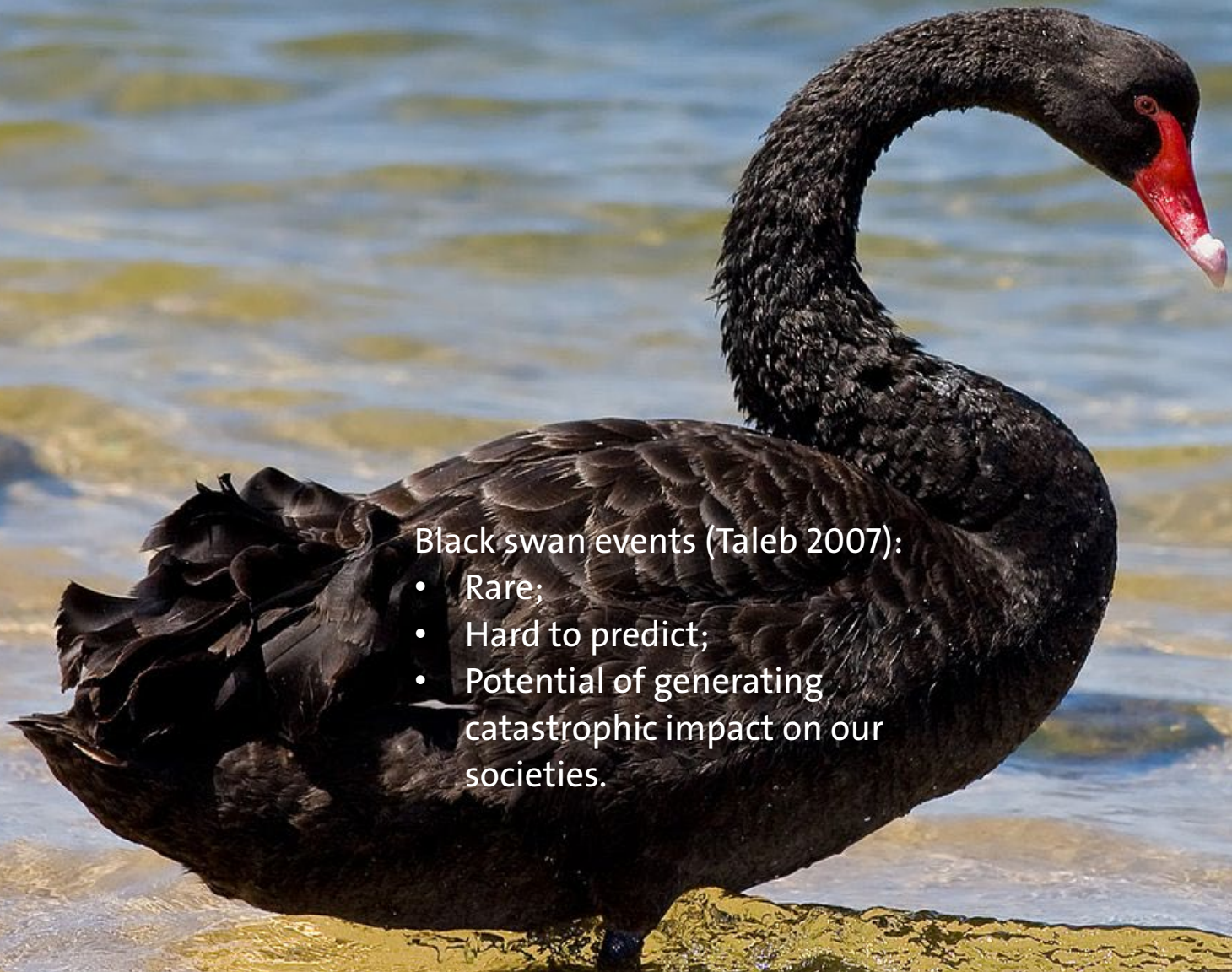
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PhD thesis

PhD proposal

**HIGH
IMPACT
PhD
MEMES**



Black swan events (Taleb 2007):

- Rare;
- Hard to predict;
- Potential of generating catastrophic impact on our societies.





2. Quarantine

Spitale, Giovanni. «COVID-19 and the Ethics of Quarantine: A Lesson from the Eyam Plague». *Medicine, Health Care, and Philosophy* 23, n. 4 (December 2020): 603–9. <https://doi.org/10.1007/s11019-020-09971-2>



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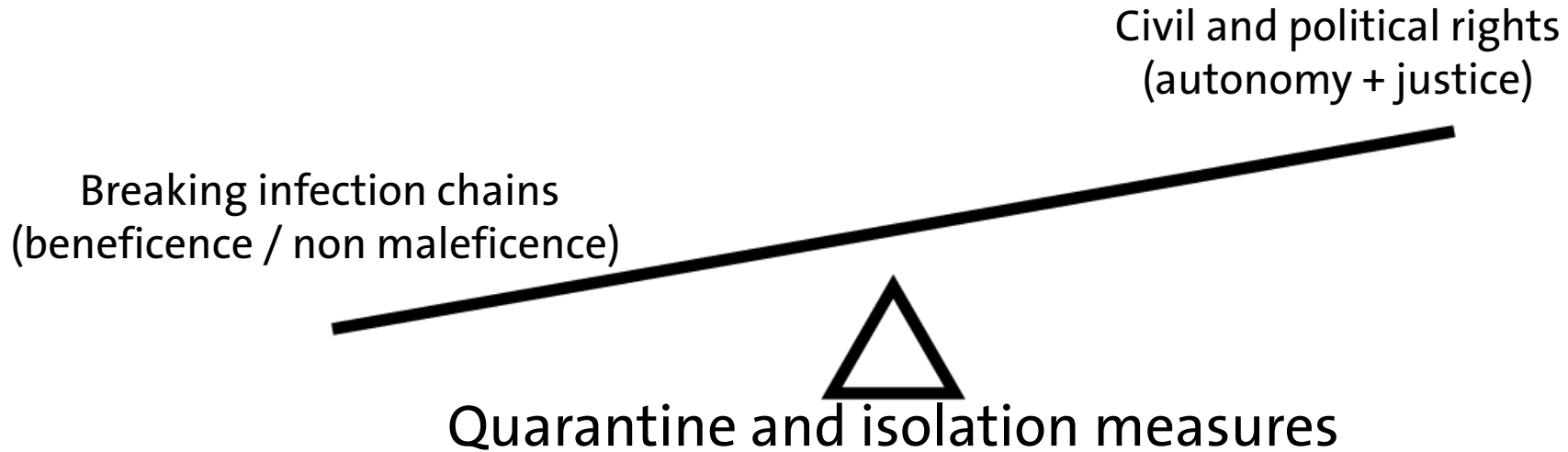
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When there is a COVID-19 outbreak but you're a scholar without social life





Quarantine





Quarantine





Quarantine

“a watch is constantly kept there night and day to keep the people in, the plague making us cruel, as doggs[sic], one to another”

(Pepys 1893, vol. IV)



Quarantine





Quarantine

1. Harm: indispensable to avoid causing harm to others;
2. Least restrictive or coercive means: education and discussion should precede prohibition or regulation;
3. Reciprocity: compensate for any inconvenience caused to individuals or groups subject to such measures;
4. Transparency: all stakeholders affected by public health measures must be involved

(Upshur 2002; 2003).



Quarantine

1. Risk of spreading the plague in the region;
2. Measures were as mild as possible and accompanied by information on prevention (e.g.: outdoor masses);
3. Continuous material support to the population of Eyam;
4. Quarantine decisions were not imposed but discussed openly within the community.



Key messages:

- Eyam managed to avoid what happened elsewhere in Europe (plague + social unrest + more plague);
- The same *actions* initiated in Eyam will not suffice in today's societies;
- But the same *principles* (as formalized by Upshur) could work:
 - Provide timely and correct information;
 - Deploy only measures justified by an actual risk;
 - Involve people in making choices that impact their life;
 - Sustain those who are impacted the most.

3. The literature challenge

Spitale, Giovanni. «Making Sense in the Flood. How to Cope with the Massive Flow of Digital Information in Medical Ethics». *Heliyon* 6, n. 7 (July 2020): e04426. <https://doi.org/10.1016/j.heliyon.2020.e04426>



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Mendeley

HIGH
IMPACT
PhD
MEMES



The literature challenge

Query	Meaning	Hits
("2020/10/01"[PDAT] : "2020/10/10"[PDAT])	Every paper indexed in 10 days	85,140
("2020/10/01"[PDAT] : "2020/10/10"[PDAT])AND covid[Title/Abstract]	Every paper indexed in 10 days mentioning «covid» in title or abstract	5,823
("2020/10/01"[PDAT] : "2020/10/10"[PDAT])AND Coronaviridae[MeSH]	Every paper indexed in 10 days mentioning «Coronaviridae» in MeSH terms	2,983



The literature challenge

“Despite the increased prevalence of bioethics research that seeks to use empirical data to answer normative research questions, there is no consensus as to what an appropriate methodology for this would be”.

(Davies et al. 2015)

Dialogical process	Combination of dialogical/consultative	Consultative process	Neither clearly dialogical nor consultative
<ul style="list-style-type: none">•Inter-ethics•Response evaluation hermeneutics•Moral experience hermeneutics•Moral conversation	<ul style="list-style-type: none">•Pragmatic hermeneutics•Deliberative democracy•Integrated empirical ethics	<ul style="list-style-type: none">•Encounters with experience•Phenomenological hermeneutics and wide reflective equilibrium•Wide reflective equilibrium and overlapping consensus•Network model with third person moral experience•Normative empirical reflective equilibrium•...	<ul style="list-style-type: none">•Interdisciplinary epoche•Ethics of public understanding•Micro-ethics•Oppositional collaboration•Complementary thesis•Distinct methodological collaboration•Phenomenological hermeneutics
4	3	22	7



How to survive?

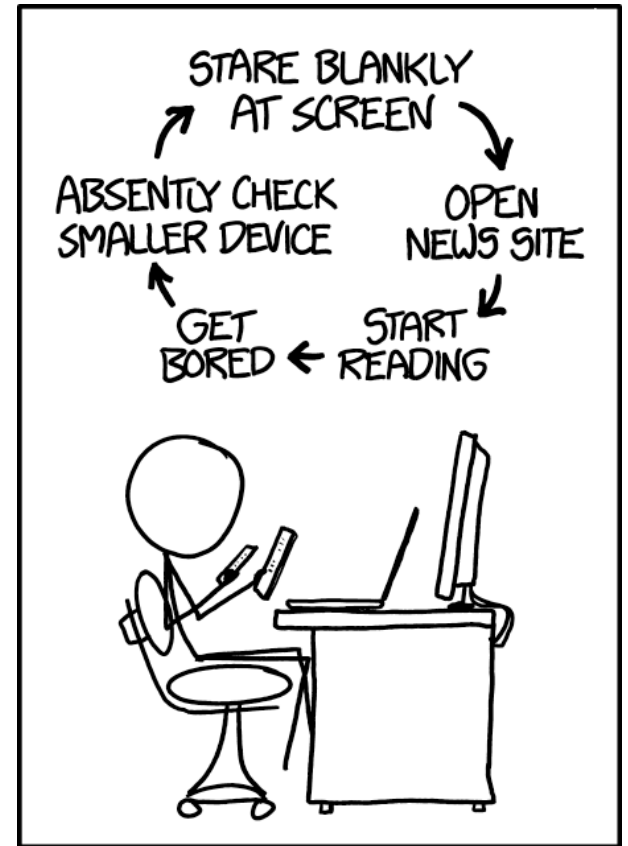
- “The newer, the better”
- “The most cited, the better”
- “Follow a specific tradition/approach”



The literature challenge

- “The newer, the better” -> not viable in medical ethics.
- “The most cited, the better” -> flawed in principle: positive feedback mechanism, marginalize articles that might be relevant, “reputation echo chamber”;
- “Follow a specific tradition/approach” -> flawed in principle: lack of global perspective on the field, “heritage echo chamber”.

Solution: smart iterative search strategies + text mining

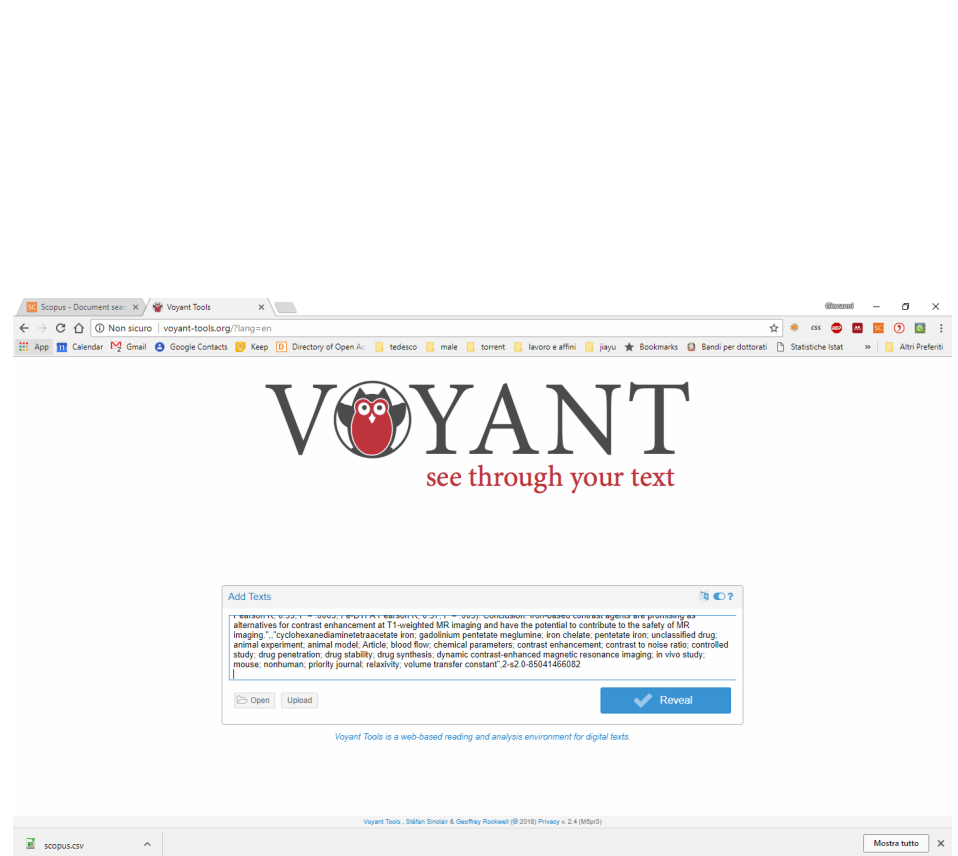


The literature challenge

Voyant Tools:

“A web-based text reading and analysis environment. It’s designed to make it easy for you to work with your own text or collection of texts in a variety of formats, including plain text, HTML, XML, PDF, RTF, and MS Word”
(Sinclair et al 2012).

- Free and open source;
- Well documented and easy to use;
- Runs both online or locally.



Smart Iterative Search Strategies

Define a preliminary query

Order and export the abstracts

Import the abstracts in Voyant Tools

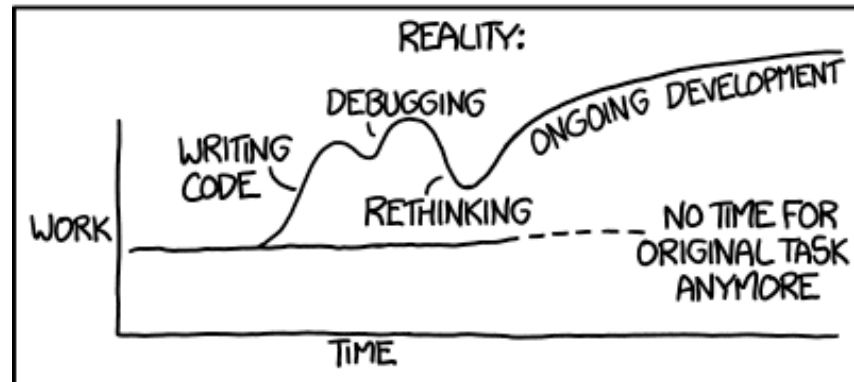
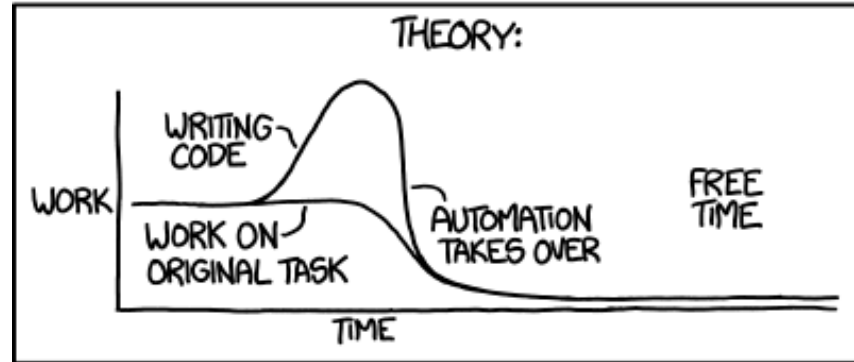
Identify emerging concepts

Refine and narrow down the query



The literature challenge

"I SPEND A LOT OF TIME ON THIS TASK.
I SHOULD WRITE A PROGRAM AUTOMATING IT!"





The literature challenge

(hematology[mh] OR hematologic diseases[mh]) AND (adolescent*[TiAb] OR teenager*[TiAb] OR "young adult"[TiAb] OR "young adults"[TiAb] OR aya[TiAb]) AND (((Share*[TiAb] OR sharing[TiAb] OR informed[TiAb] OR collaborat*[TiAb]) AND (decision*[TiAb] OR deciding[TiAb] OR choice*[TiAb] OR care*[TiAb])) OR ((patient*[TiAb]) AND (preference*[TiAb] OR view*[TiAb] OR involvement[TiAb] OR decision[TiAb] OR "decision making"[TiAb] OR attitude*[TiAb] OR participation[TiAb])))

Word combination	Frequency	%	Rank	Documents	Documents %
sickle cell disease	403	0,17	1	33	21,57
quality of life	393	0,16	2	81	52,94
end of life	225	0,09	3	39	25,49
in decision make	197	0,08	4	27	17,65
of pediatric oncology	172	0,07	5	33	21,57
to participate in	161	0,07	6	53	34,64
much likely to	149	0,06	7	62	40,52
pediatr blood cancer	131	0,05	8	30	19,61
parent of child	130	0,05	9	34	22,22
health care provider	120	0,05	10	35	22,88

The literature challenge

	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O
1	name	autonom	responsibilit	decisio	guidanc	impac	care	patier	physicia	nurse	famil	diseas	SDM	SUM	
2	TOTAL	175	450	3.869	2.157	1.258	6.482	14.964	5.768	2.246	6.084	11.397	112	54.962	
3	Sainio, Lauri 2003 - Cancer patients' decision-making regarding	2	1	239	6	7	50	238	58	86	39	99	8	833	
4	Tang, Lee 2004 - Cancer diagnosis and prognosis	7	1	12	5	8	48	314	74	17	113	225	0	824	
5	El Turabi, Abel et al. 2013 - Variation in reported experience	1	1	149	6	6	43	321	10	2	17	172	22	750	
6	Shepherd, Woodgate 2011 - A journey within a journey	0	6	5	49	13	103	14	15	53	186	248	0	692	
7	Knopf, Hornung et al. 2008 - Views of treatment decision making	3	11	295	15	5	50	124	88	7	17	26	27	668	
8	Langbecker, Ekberg et al. 2016 - What are the barriers	0	7	6	13	12	187	115	29	134	25	137	0	665	
9	Ishibashi, Ueda et al. 2010 - How to improve resilience	1	1	5	55	15	53	82	30	49	146	221	0	658	
10	Cohen, Botti 2015 - Cancer patients' perceptions	1	1	96	5	17	62	299	25	54	33	43	3	639	
11	Trarieux-Signol, Bordessoule et al. 2018 - Advance directives f	12	1	55	12	9	90	291	57	0	91	19	0	637	
12	Carey, Anderson et al. 2012 - How well are we meeting	0	3	246	16	6	22	130	35	4	25	137	8	632	
13	Coyne, Amory et al. 2014 - Children's participation in shared d	1	1	294	9	16	61	21	38	55	46	76	12	630	
14	Kappauf, Leykauf-Ammon et al. 2000 - Use of and attitudes held	0	1	5	14	4	30	295	137	2	31	101	0	620	
15	Brück, Pierzchlewska et al. 2012 - Dying of hematologic patient	2	0	8	16	9	62	337	30	6	66	83	0	619	
16	Pugh, Hough et al. 2017 - Lifestyle advice provision to teenage	0	0	14	160	4	37	143	33	37	13	170	0	611	
17	Daly, Kral et al. 2011 - The role of neuropsychological evaluat	1	10	3	5	11	50	18	68	4	54	354	0	578	
18	Kayle, Tanabe et al. 2016 - Challenges in Shifting Management R	10	62	18	30	6	93	5	43	29	86	184	0	566	
19	Parsons, Saiki-Craigill et al. 2007 - Telling children and adol	6	10	23	10	30	25	91	182	0	95	91	0	563	
20	Mack, Wolfe et al. 2011 - Parents' roles in decision making	2	7	250	7	5	29	60	131	1	22	46	1	561	
21	Glover, Shenoy et al. 2011 - Patterns of Social Support	0	0	6	122	14	30	190	24	10	40	122	0	558	
22	Gallo, Wilkie et al. 2016 - Reproductive Health CHOICES for You	1	1	189	11	8	15	16	24	10	55	221	0	551	
23	Tzelepis, Sanson-Fisher et al. 2015 - The quality of patient-ce	0	0	18	19	1	141	102	39	2	48	178	0	548	
24	Pfisteringer, Kattner et al. 2014 - The impact of a tumor	11	3	22	10	15	62	244	57	0	27	94	1	546	
25	Drevdahl, Dorcy 2012 - Transitions	0	2	131	6	2	57	158	8	16	54	110	0	544	
26	Rider, Malik et al. 2014 - Haematology patients and the interne	0	1	30	29	29	21	268	82	3	33	41	1	538	
27	Sandoval, Brown et al. 2006 - Factors that influence cancer pat	0	0	1	0	6	140	254	19	7	40	69	0	536	
28	Högberg, Stockelberg et al. 2015 - The meaning of web-based com	1	6	12	74	8	74	143	32	86	35	62	0	533	
29	Kleeberg, Feyer et al. 2008 - Patient satisfaction in outpatien	0	0	23	14	3	62	276	44	10	25	57	5	519	
30	Lafond, Kelly et al. 2015 - Establishing Feasibility of Early P	0	6	2	17	24	137	71	33	61	109	56	0	516	



Key messages:

- There is too much literature on almost everything, and often its classification is sloppy;
- SISS and text mining are a useful way to navigate the flood;
- ‘Distant reading’ complements and anticipates ‘close reading’, it does not replace it.
- About ambiguity: we need to develop a BeSH tree structure (and there are some attempts to do it, based also on my work – iOntoBioethics, Odeh et al. 2021)

4. Emerging ethical issues

Biller-Andorno, Nikola, and Spitale, Giovanni. « Ethical issues of COVID-19 – the emerging Big Five». *New England Journal of Medicine Catalyst* (accepted, May 2022. Preprint: <https://doi.org/10.5281/zenodo.6520032>)



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Static value based checklist

(Humans have to do the job and it's always outdated)



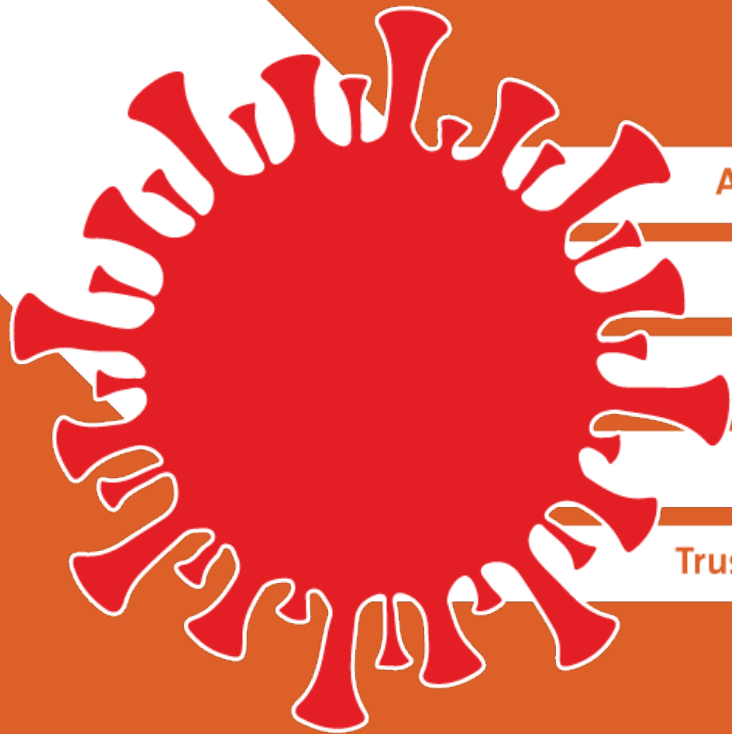
***Dynamic* value based checklist**

(Humans lay back and supervise, and it's always fresh)



The pandemic is like a prism

- Affects individuals, groups, and global community;
 - Impacts physical, mental and social wellbeing;
 - Triggers development and deploy of new technologies.
-
- Thus we can (must) map emerging ethical issues that require attention.



Autonomy, individual rights, and freedom

Privacy vs efficient and effective pandemic management

Equity, fairness, and solidarity under conditions of resource scarcity

Proportionality of measures, legitimization and procedures

Trust and trustworthiness



Emerging ethical issues

Query	Papers
The role of autonomy, rights and freedom in a pandemic	2215
Privacy vs. efficient and effective pandemic management	895
Equity, fairness and solidarity under conditions of resource scarcity	2659
Proportionality of measures: legitimation and procedures	55
Trust and trustworthiness	2311

("2019 Novel Coronavirus"[MeSH] OR 2019-nCoV[MeSH] OR "COVID-19 Virus"[MeSH] OR "COVID19 Virus"[MeSH] OR "Coronavirus Disease 2019 Virus"[MeSH] OR "SARS Coronavirus 2"[MeSH] OR "SARS-CoV-2 Virus"[MeSH] OR "Severe Acute Respiratory Syndrome Coronavirus 2"[MeSH] OR "Wuhan Coronavirus" [MeSH] OR "Wuhan Seafood Market Pneumonia Virus"[MeSH] OR "2019 Novel Coronavirus Disease"[MeSH] OR "2019 Novel Coronavirus Infection"[MeSH] OR "2019-nCoV Disease"[MeSH] OR "2019-nCoV Infection"[MeSH] OR "COVID-19 Pandemic"[MeSH] OR "COVID-19 Pandemics"[MeSH] OR "COVID-19 Virus Disease"[MeSH] OR "COVID-19 Virus Infection"[MeSH] OR COVID19 [MeSH] OR "Coronavirus Disease 2019"[MeSH] OR "Coronavirus Disease-19"[MeSH] OR "SARS Coronavirus 2 Infection"[MeSH] OR "SARS-CoV-2 Infection"[MeSH] OR "Severe Acute Respiratory Syndrome Coronavirus 2 Infection"[MeSH] OR COVID-19[TiAb]) AND (autonomy[TiAb] OR rights[TiAb] OR freedom[TiAb])



Emerging ethical issues

Autonomy, individual rights and freedom

- Quarantine, closed borders and curfews;
- Ban of events and gatherings including political demonstrations;
- Limits to social interactions;
- Disclosure of personal information (contact tracing);
- Vaccine enforcement;
- ...

All of this for good reason. Still, there is some uneasiness around the sudden – albeit temporary – loss of personal liberties.



Emerging ethical issues

Privacy vs. efficient and effective pandemic management

- Contact tracing, reactance, compliance, ... ;
- Trade-offs between effectiveness and data protection;
- Potential risks (repurposing, data access, re-identification, security vulnerabilities, (im)possibility to withdraw consent);
- Low uptake due to low trust.

Clear communication on the scope, duration, and limitation of measures could be a crucial factor to improve the uptake.



Emerging ethical issues

Equity, fairness and solidarity under conditions of resource scarcity

- Ending a pandemic requires global cooperation;
- Scarce resources should be allocated according to need;
- Equitable distribution has proven a highly complex issue: maximizing utility, non-discrimination, fairness and protection of vulnerable groups.



Emerging ethical issues

Proportionality of measures: legitimation and procedures

- Top-down vs bottom up: shall we listen?
- How much controversy can we afford?
- Building resilience needs participation, communication, coordination, learning and polycentricity.

How proportionality is to be established in concrete cases (and by whom) is a question that currently intensely debated.



Emerging ethical issues

Trust and trustworthiness

- High demands on public trust;
- Little information -> misinformation and disinformation;
- Directive and unilateral information flows do not support trust.

A bidirectional approach is needed in the longer run – citizens need to know what health authorities want them to do, health authorities need to know how citizens perceive the situation.

Key messages:

- The analysis of bioethical literature on COVID-19 unveils 5 main areas (autonomy, privacy, equity, proportionality, trust);
- An algorithmic approach can help generating and updating value-based checklists to keep in focus relevant issues and identify new emerging ones.

5. Bidirectional risk and crisis communication

Spitale, Giovanni, Merten, Sonja, Jafflin, Kristen, Schwind, Bettina, Kaiser-Grolimund, Andrea, and Biller-Andorno, Nikola. «A Novel Risk and Crisis Communication Platform to Bridge the Gap Between Policy Makers and the Public in the Context of the COVID-19 Crisis (PubliCo): Protocol for a Mixed Methods Study». *JMIR Research Protocols* 10, n. 11 (November 2021): e33653. <https://doi.org/10.2196/33653>

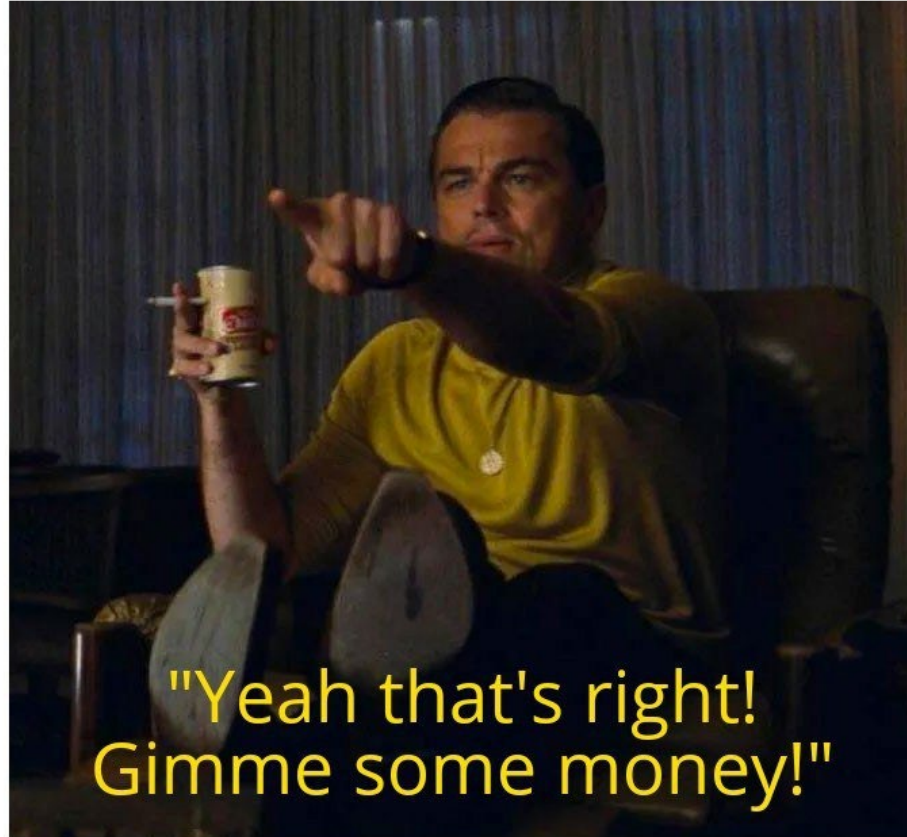


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The covid crisis highlights the urgent need to fund research

Me:



"Yeah that's right!
Gimme some money!"



Bidirectional risk and crisis communication



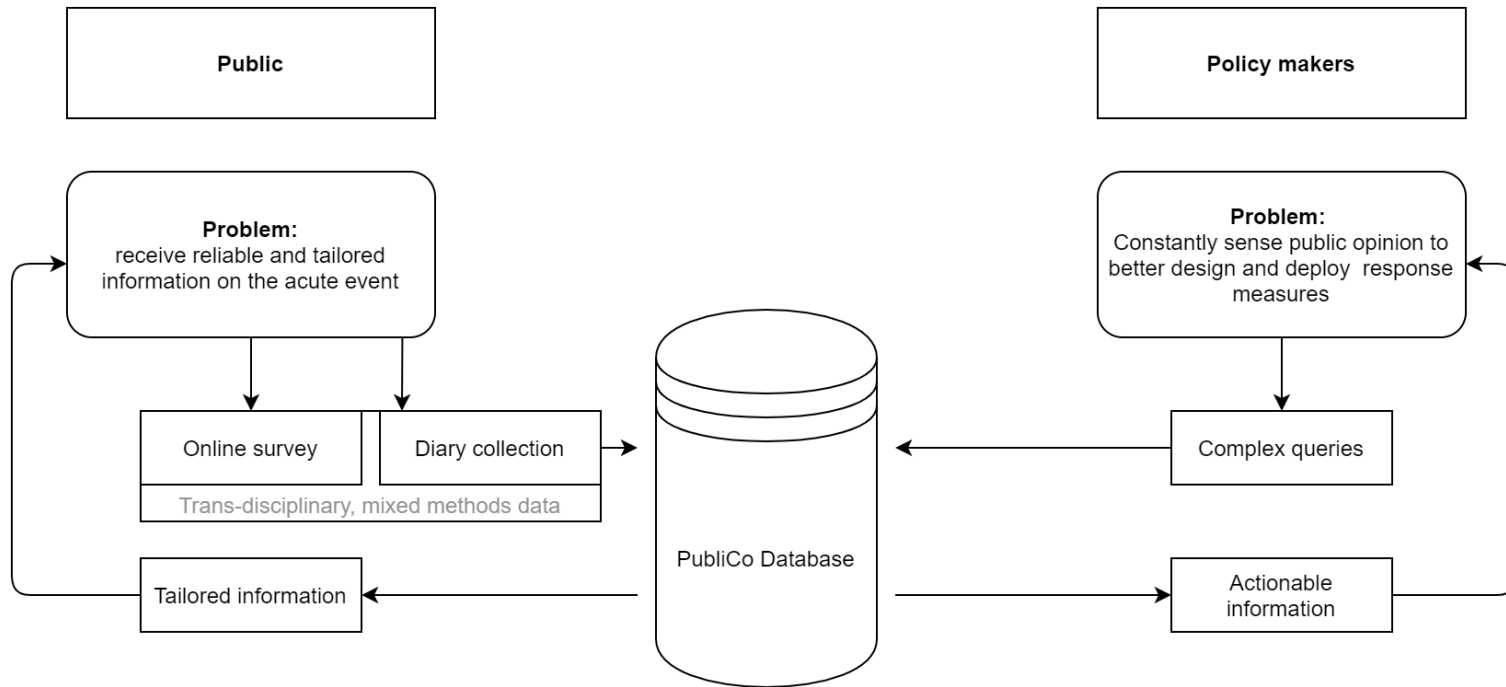
Collegium
Helveticum





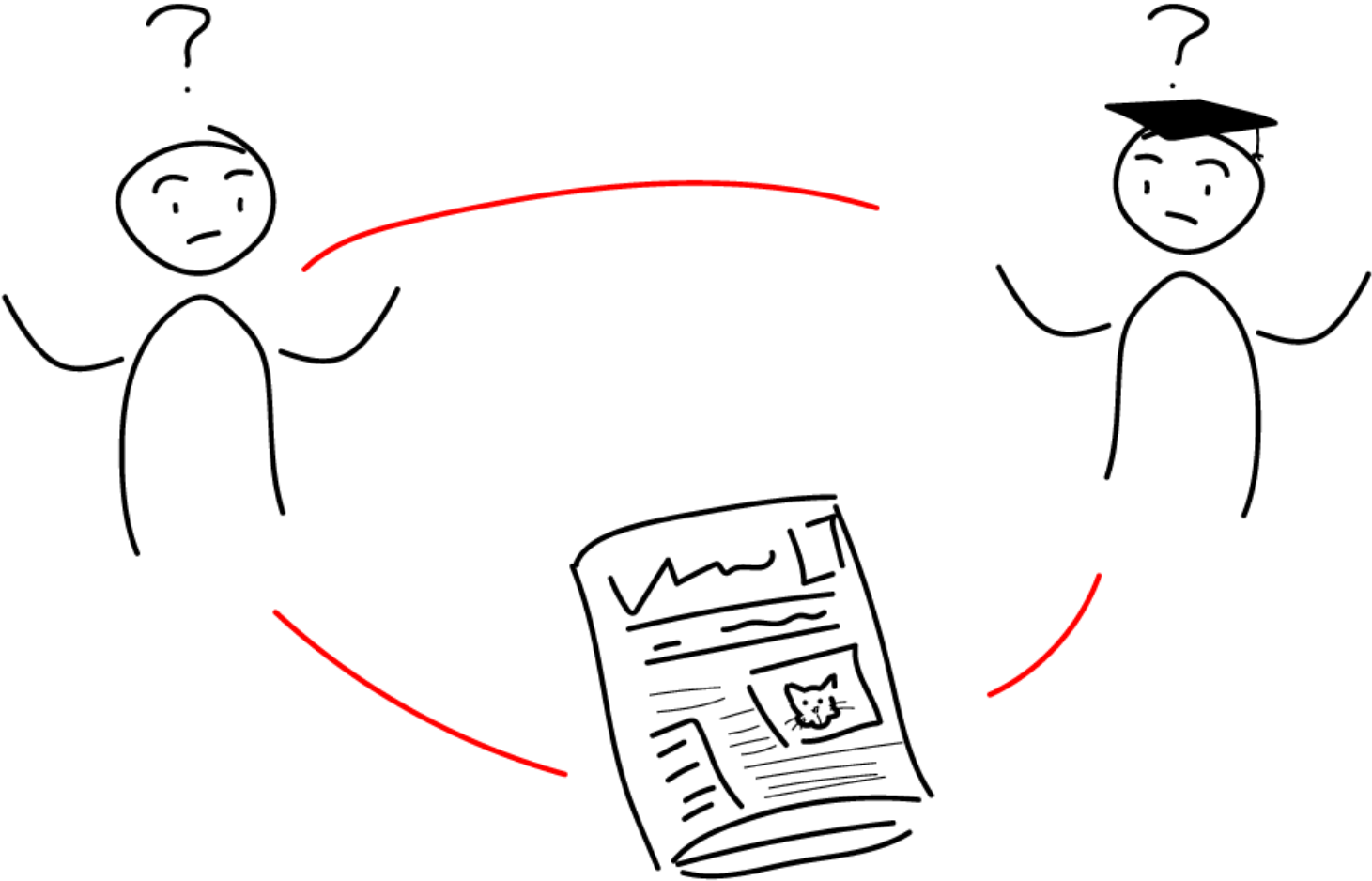
Bidirectional risk and crisis communication

Data flow in PubliCo



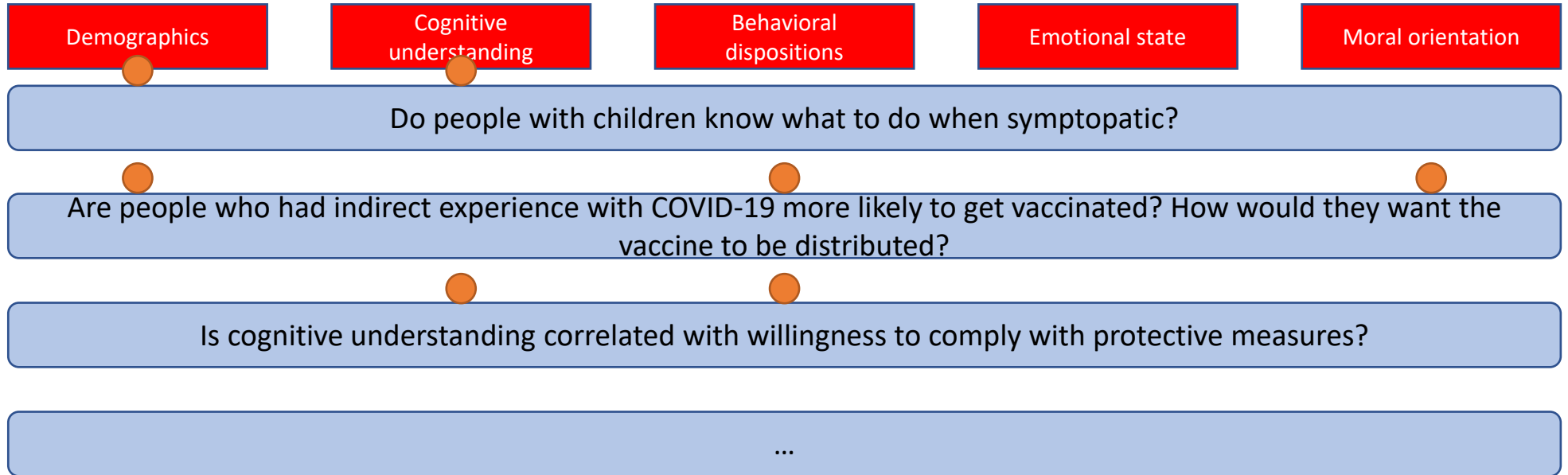


Bidirectional risk and crisis communication





Bidirectional risk and crisis communication





Bidirectional risk and crisis communication





Bidirectional risk and crisis communication





Key messages:

- PubliCo is a bidirectional RCC system with 3 main components: survey, diaries, analytics;
- It has been built and developed with a citizen science approach
- Aims to close the loop and provide feedback to policy makers – while providing tailored information to the public.

6. Passive social listening

Spitale, Giovanni, Biller-Andorno, Nikola, and Germani, Federico. «Concerns Around Opposition to the Green Pass in Italy: Social Listening Analysis by Using a Mixed Methods Approach». *Journal of Medical Internet Research* 24, n. 2 (February 2022): e34385. <https://doi.org/10.2196/34385>



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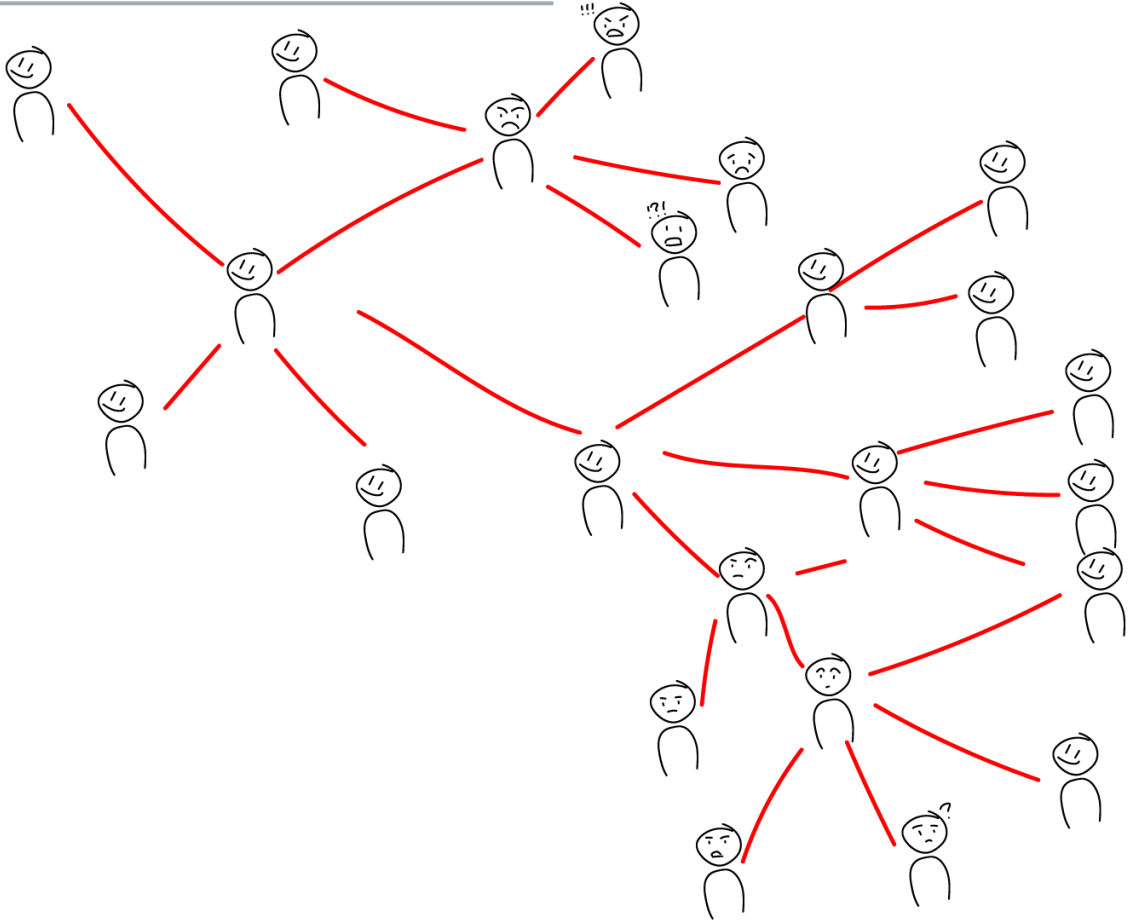
When you try a new
research method



"I have no idea of
what I'm doing"

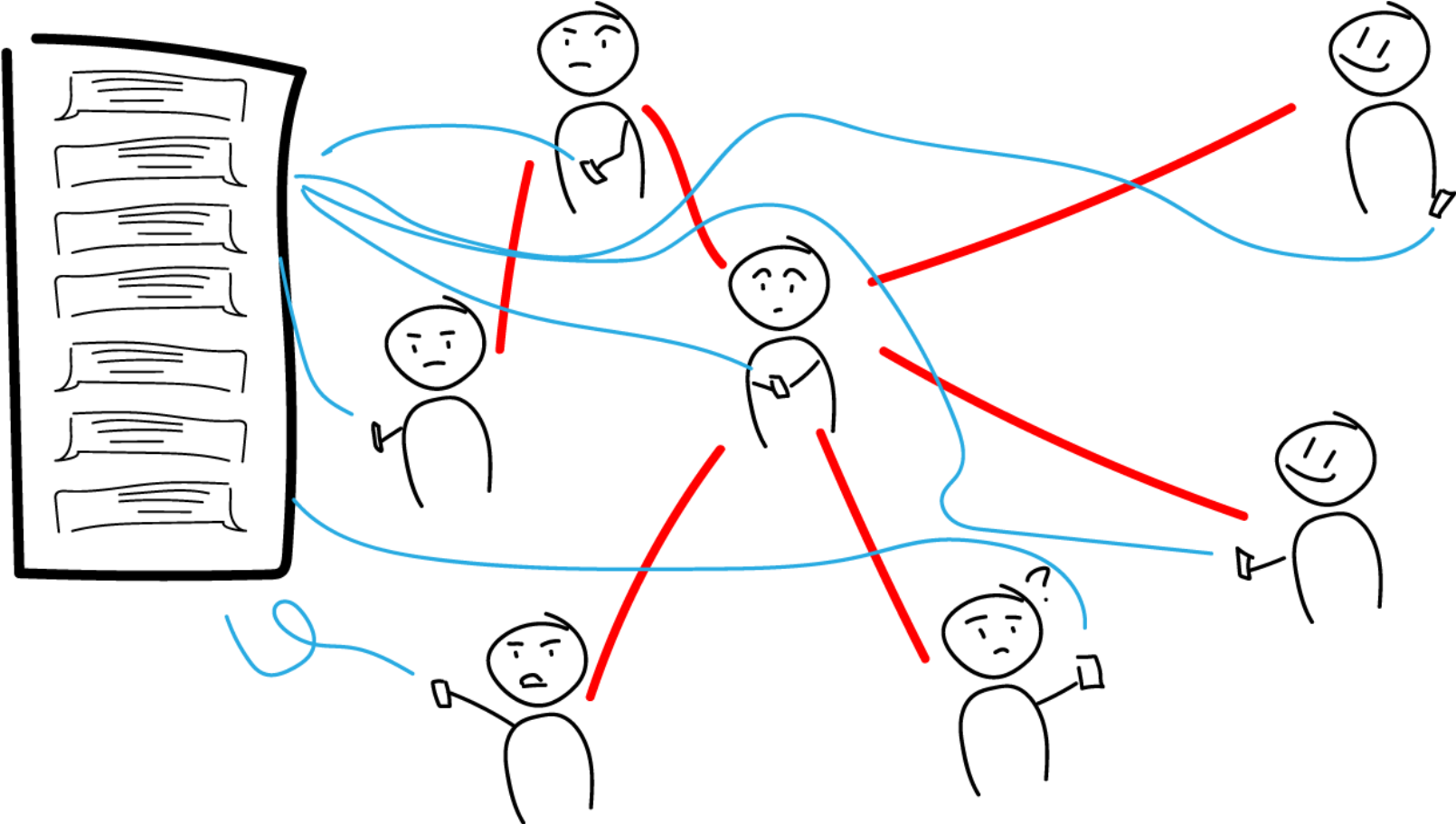


Passive social listening





Passive social listening



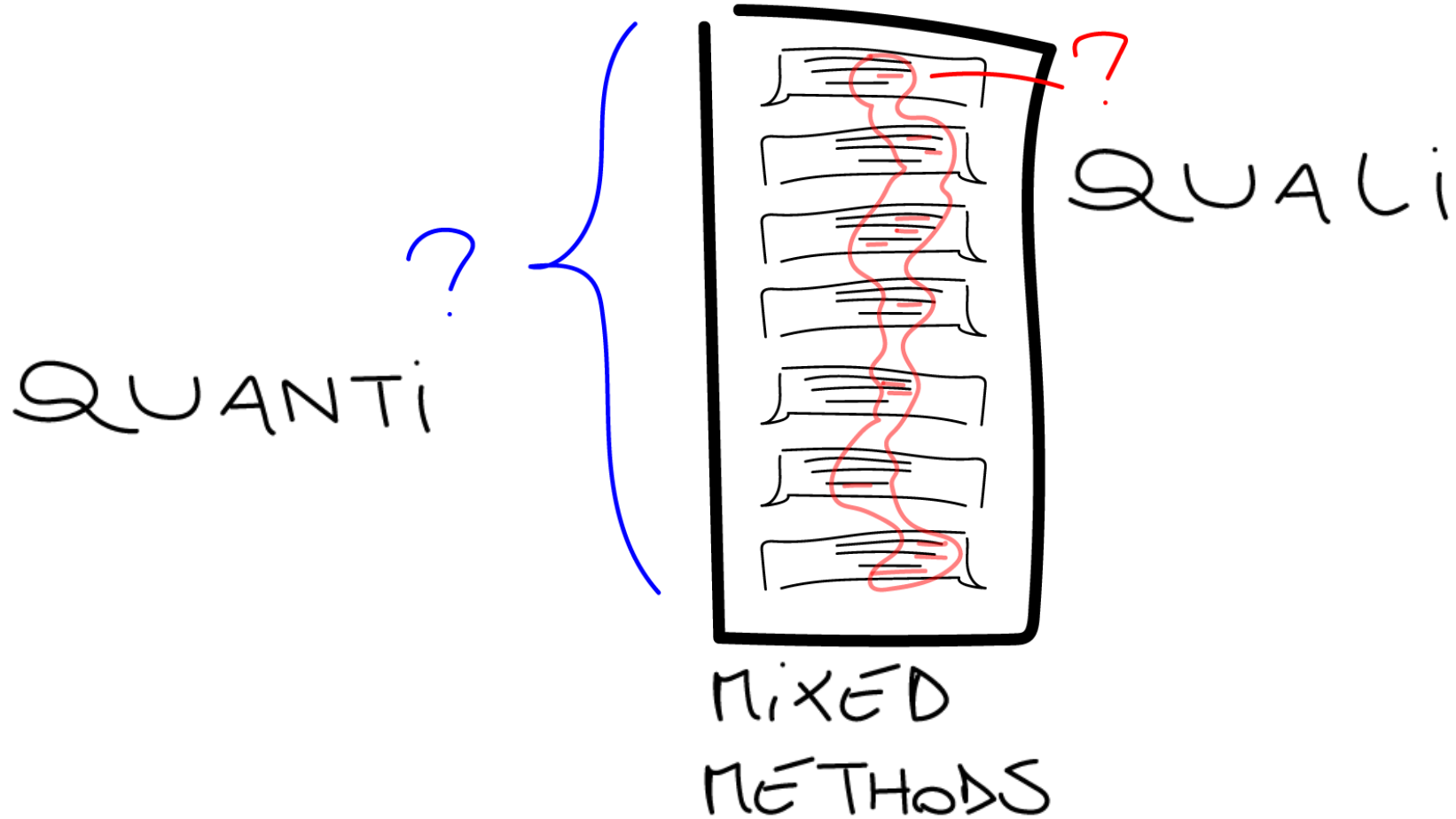


Passive social listening

Category	Group description	n of users	n of messages
no green pass	university, north	1770	7356
	university, center	5168	10464
	university, south	479	1879
	generic	12295	33707
	Total	19712	53406
control	parrots	296	48494
	videogames	750	43322
	generic	294	10588
	generic	210	1453
	generic	218	21611
	Total	1768	125468

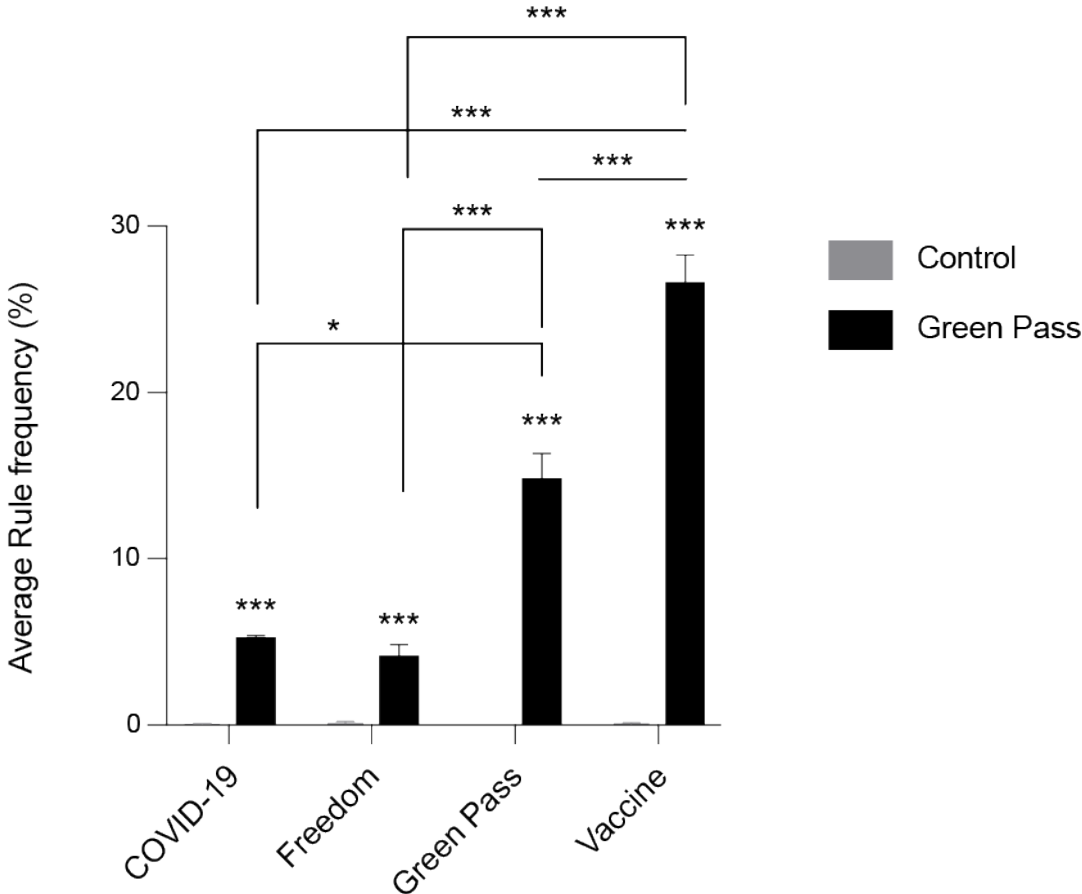


Passive social listening



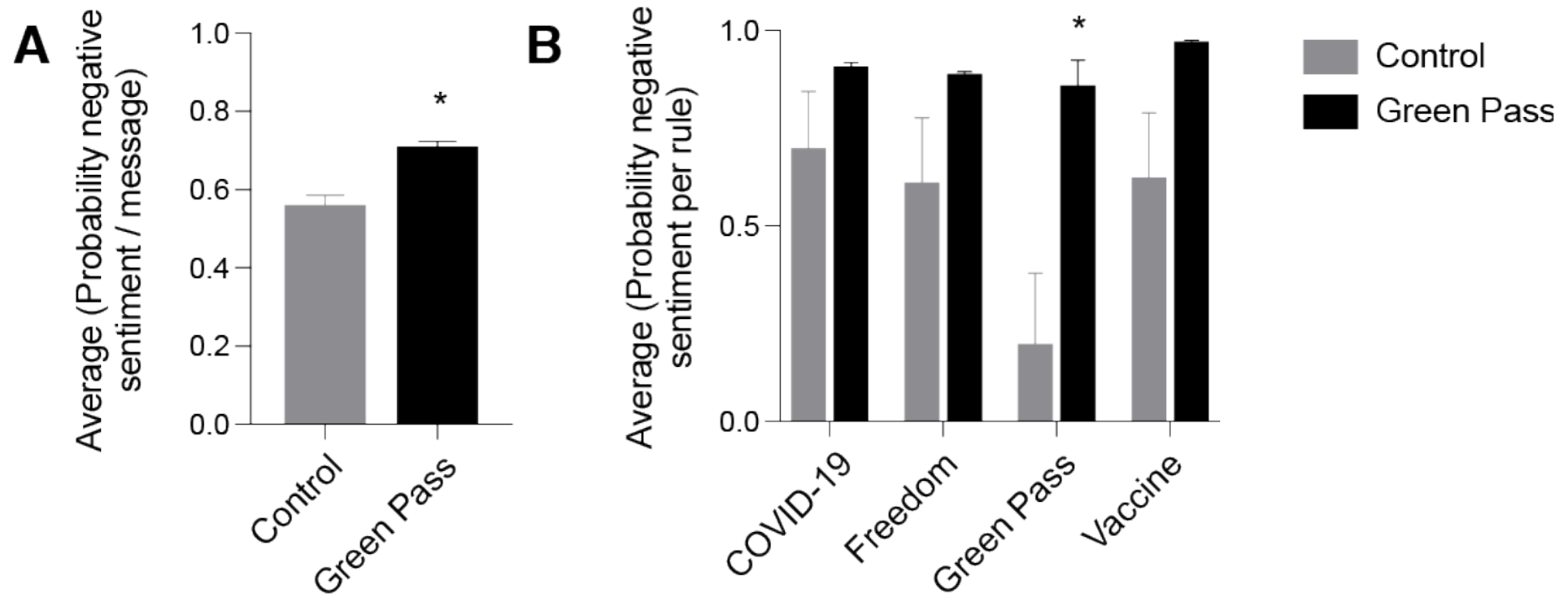


Passive social listening





Passive social listening





Passive social listening

Green pass and vaccines 1

On the other hand, it is a big mistake to take a stance on vaccines. Those who want to do so should do so. The point is only to be against this limitation of freedom and many vaccinated people are against the green pass. Do not introduce divisive or extremist elements that vote the initiative down (university, south, Pos. 742)



*how can one ignore the vaccine issue if it is literally the main option for getting a pass??
(university, north, Pos. 6693)*



Passive social listening

Green pass and vaccines 2

We must rebel, this vaccine is a gene therapy with no guarantee that it will work. Vaccinated people are just as infectious as unvaccinated people, it is clear that this vaccine does not protect against COVID. (university, north, Pos. 2612)

Their aim is to manipulate human beings by injecting them with a serum containing graphene, which can react with certain frequencies and modify the behaviour of cells. By changing the behaviour of cells, you can change the behaviour of human beings. (generic, Pos. 72471)





Passive social listening

It's a trap!

IT IS CLEAR THAT THE GREEN PASS IS AN INSTRUMENT OF POLITICAL DISCRIMINATION THAT HAS NO RELATION TO THE ACTUAL HEALTH STATUS... (university, center, Pos. 3572 – 3579)

Do you still have to realize that even if the Regime decides to withdraw the COVID PASS, to let you go back to work, you have already become citizens of a totalitarian Regime? Citizens of a lousy Regime based on lies, on the progressive elimination of freedoms, on the violent suppression of dissent? (generic, Pos. 2127)





Passive social listening

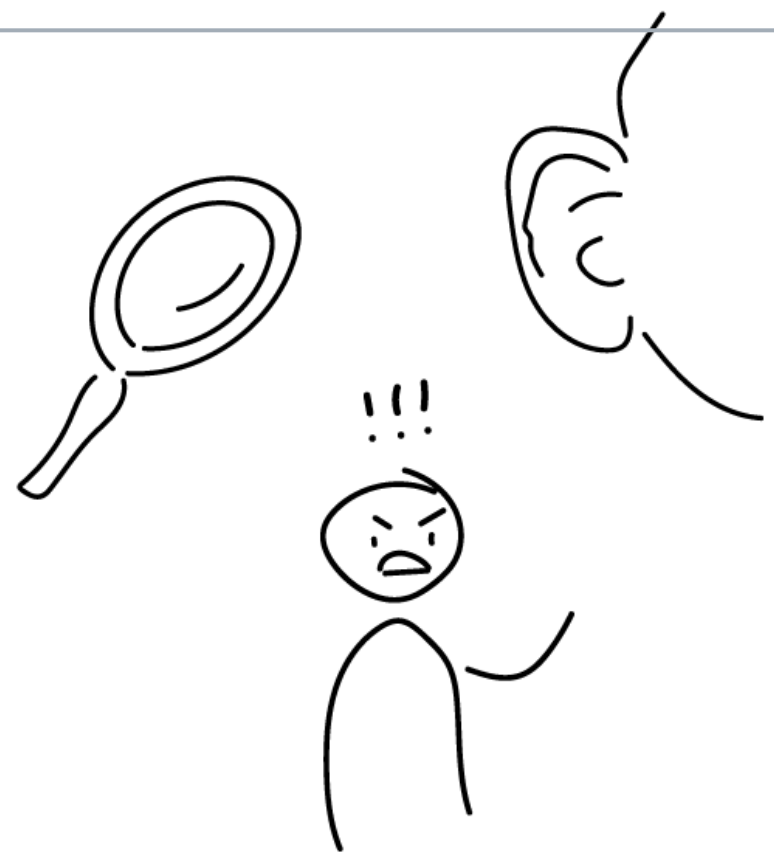
Vaccines are what this battle is for

The main argument must continue to be that one must be able to refuse an injection, whatever it may be. The body is mine and I decide. And if you were to be convinced that the serum prevents $x\%$ of the infection (as some try to suggest), would our whole battle fall apart? I certainly hope it's not the case. (university, north, Pos. 24367)

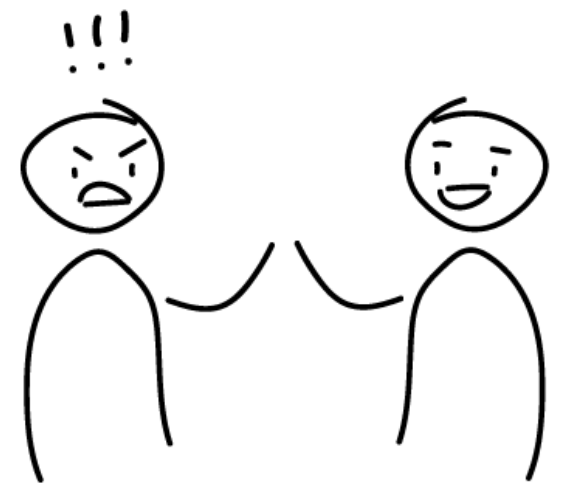




Passive social listening



PASSIVE



ACTIVE

Key messages:

- Passive social listening is incredibly effective;
- But eavesdropping other people's conversations erodes trust;
- Therefore on the long run this approach can start an arms race for privacy vs control (negative impact on effectiveness);
- Active social listening and direct engagement with communities can mitigate this risk.

7. The value of people's voices

Spitale, Giovanni, Glässel, Andrea, Tyebally-Fang, Mirriam, Mouton Dorey, Corine, and Biller-Andorno, Nikola.
«Patient narratives – a still undervalued resource for healthcare improvement». *Swiss Medical Weekly*
(submitted, May 2022. Preprint: <https://doi.org/10.5281/zenodo.6541400>)



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An iceberg floating in the ocean. The small tip above the water is labeled 'The paper', and the much larger submerged part is labeled 'The research work'.

The paper

**The research
work**



The value of people's voices

Individual Patient Experiences
Subjective narratives in which
participants tell their own
experience from their own point of
view

Database
Data are indexed and structured,
accessible to multiple actors for
different purposes



The value of people's voices

Interview guide

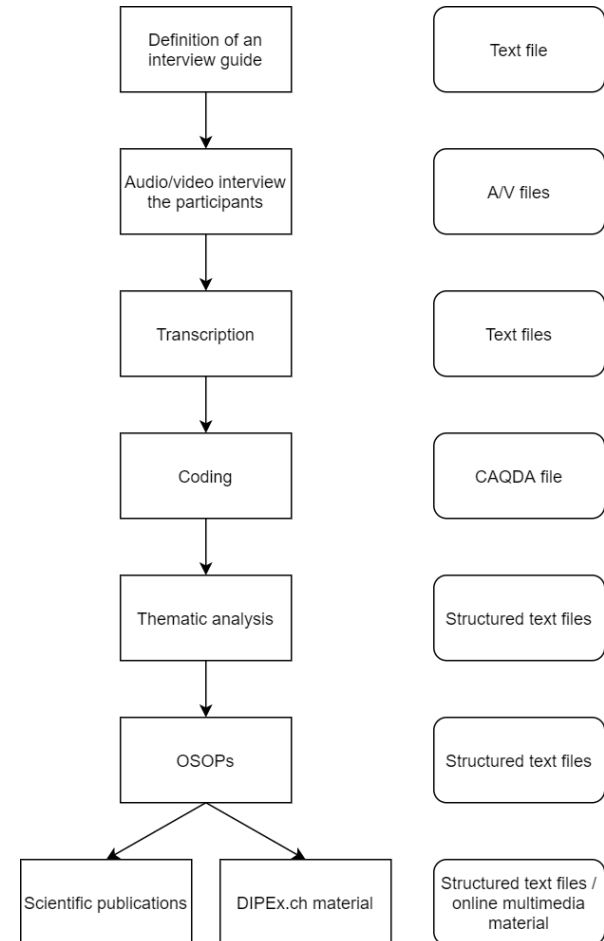
Semi-structured document listing the questions to ask and the prompts to give to the interviewee. Starts with an open section then follows specific topics of interest.

Interview files

The interview is audio and/or video recorded – according to the preferences of the interviewee – and then transcribed as text.

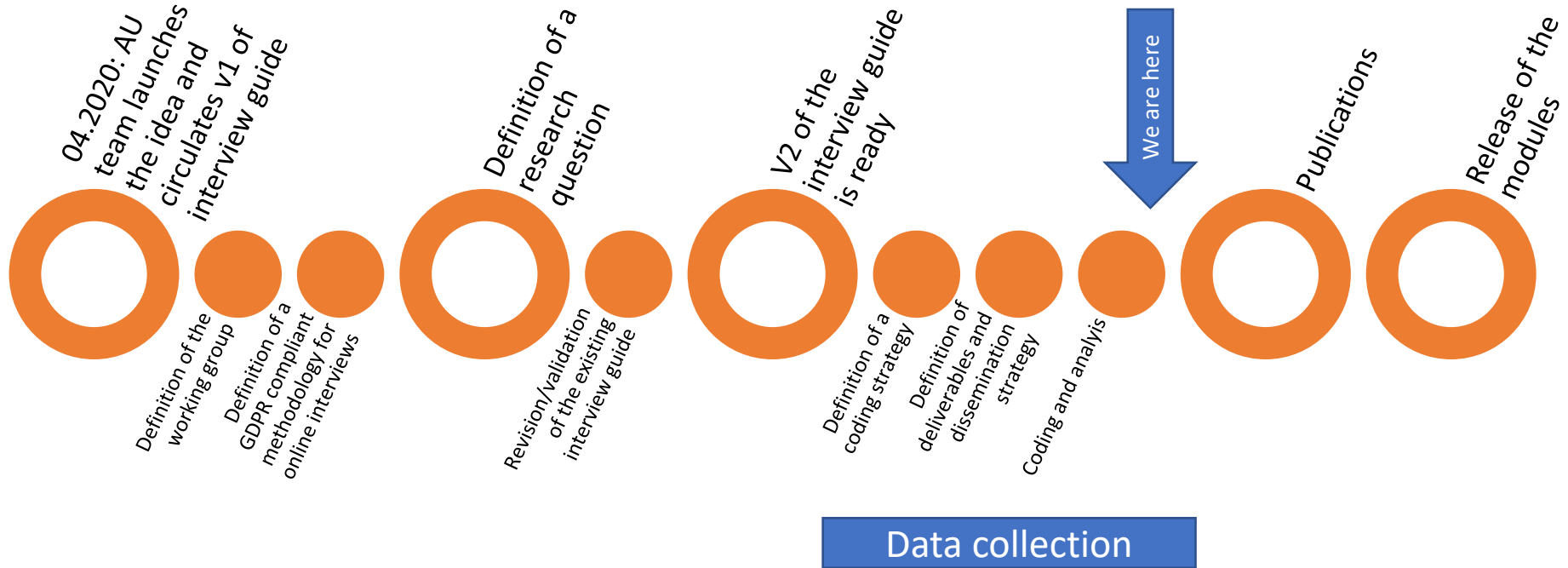
Coding

The interviews are loaded in a software for computer assisted qualitative data analysis. We define a specific coding tree and manually code the text (= assigning one or more labels to a meaningful passage)





The value of people's voices



The value of people's voices

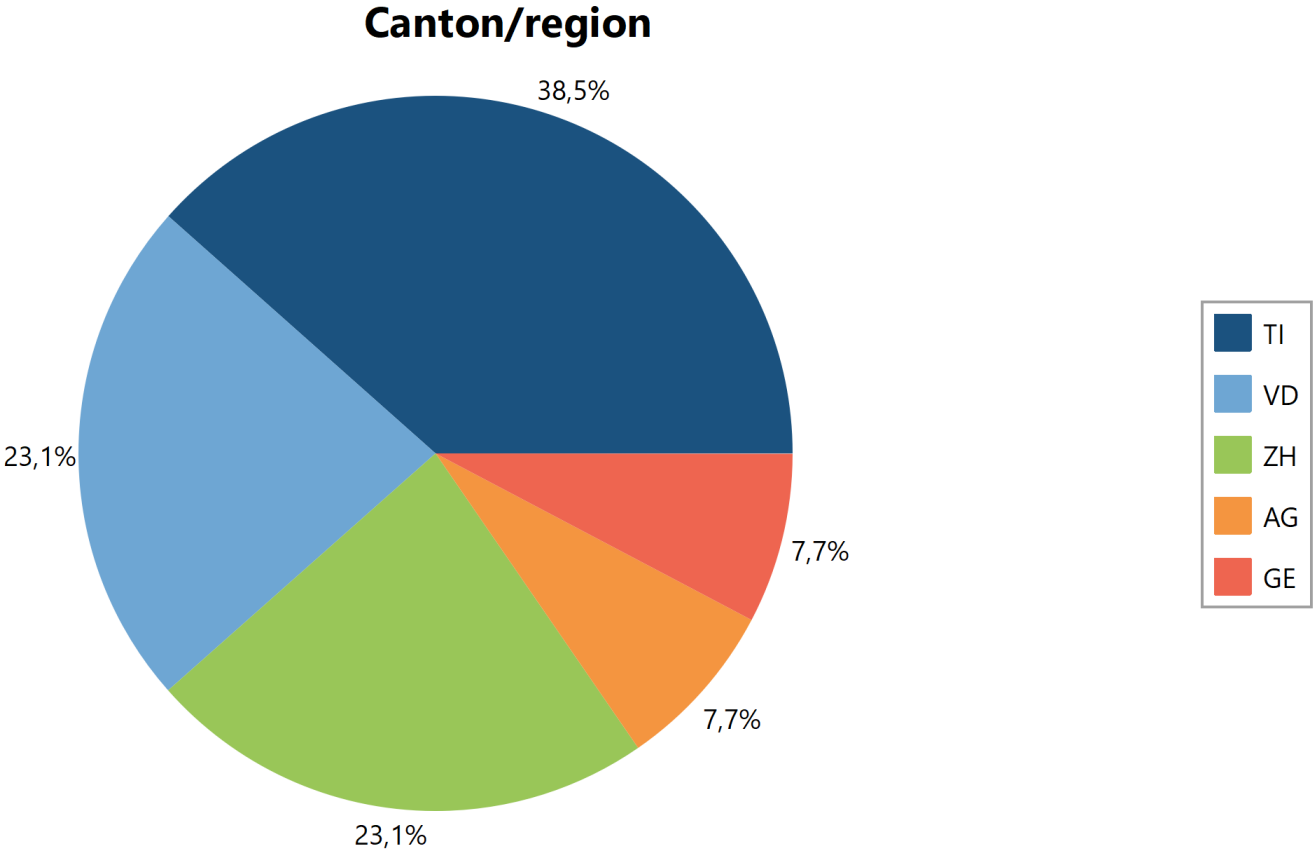
Country	People	Status	ITW guide used	Target population
USA	Rachel Grob, Jane Alice Evered, Madison Wynn	7 interviews recorded	standard plus additions	Recovered patients (including healthcare workers)
the Netherlands	Nienke Verheij, Manna Alma	20 interviews coded (short, by phone)	different guide, will use the standard for new interviews	Recovered patients
Brazil	Alicia Navarro de Souza, Maria Inês Gandolfo Conceição, Ana Claudia Germani, Juliano Luna Ivone Cabral	32 interviews recorded, coding in progress	standard plus additions (spirituality, social inequality)	Recovered patients (including healthcare workers); at least 2 with long covid
Germany	Martina Breuning, Christine Holmberg, Anne Thier	15 existing itws with different itw guide (useful for comparisons) + 4 with long covid patients (standard itw guide)	different guide + standard	Recovered patients + healthcare workers
Switzerland	Nikola Biller-Andorno, Susanne Jobges, Corine Mouton Dorey, Giovanni Spitale	13 interviews recorded; coding in progress.	standard plus additions (icu)	recovered patients (including healthcare workers) (with a focus on ICU for a related project)
Japan	Rika Sato, Akiko Sawada, Rie Toyomoto, Emiko Wada	11 interviews recorded; coding in progress, target: 50.	standard	For COVID-19 interviews: recovered patients (9) and family members (2) (including 1 bereaved)
Spain	Vinita Mahtani, Emilio Sanz, Elisa Torres, Alicia Mora, Víctor Expósito	13 interviews recorded, coding in progress	standard	recovered patients (including healthcare workers) and one caregiver
Australia	Lorraine Smith, Renata Kokanovic, Kate Johnston-Ataata, Anna Urbanowicz	8 interviews recorded, coding in progress	standard	recovered patients (including healthcare workers when available)
UK	Lisa Hinton, Annelieke Driessen, Sue Ziebland, Tanvi Rai, Anna Dowrick, Kaveri Qureshi, Kate Hunt, Ashley Brown, Louise Locock	61 interviews recorded, coding in progress, target: 150	standard plus additions	Three studies: 1 - recovered ICU patients and relatives of deceased patients, 2 - seldom heard groups in the UK, particularly Black, Asian and other minority groups, 3 – patients with long covid
Canada	Susan Law, Ilja Ormel, Michelle Marcinow, Linda Rozmovits	15 interviews recorded, 1 transcript not returned, 14 interviews coded	standard plus additions (covid and pregnancy)	recovered patients (including healthcare workers)



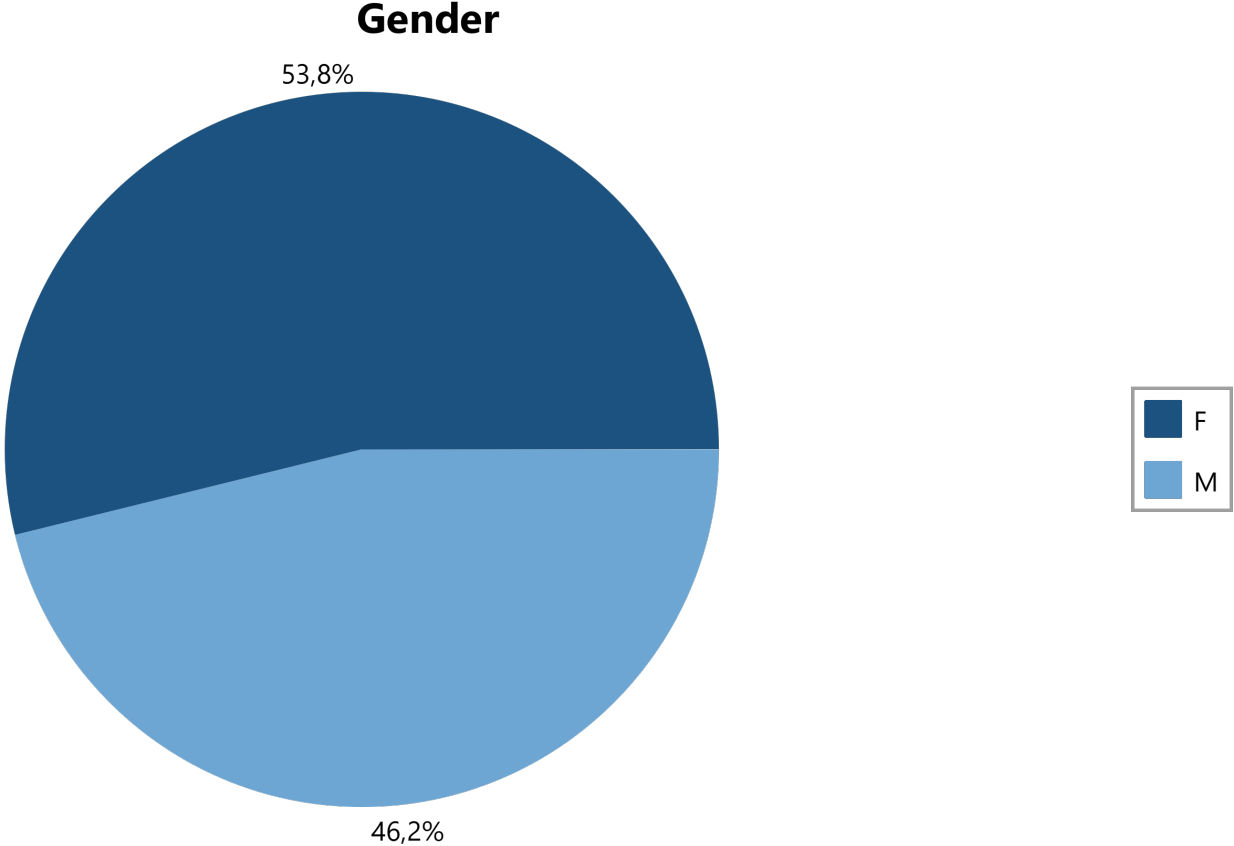
10 Countries
195 interviews
... and more are coming!



The value of people's voices

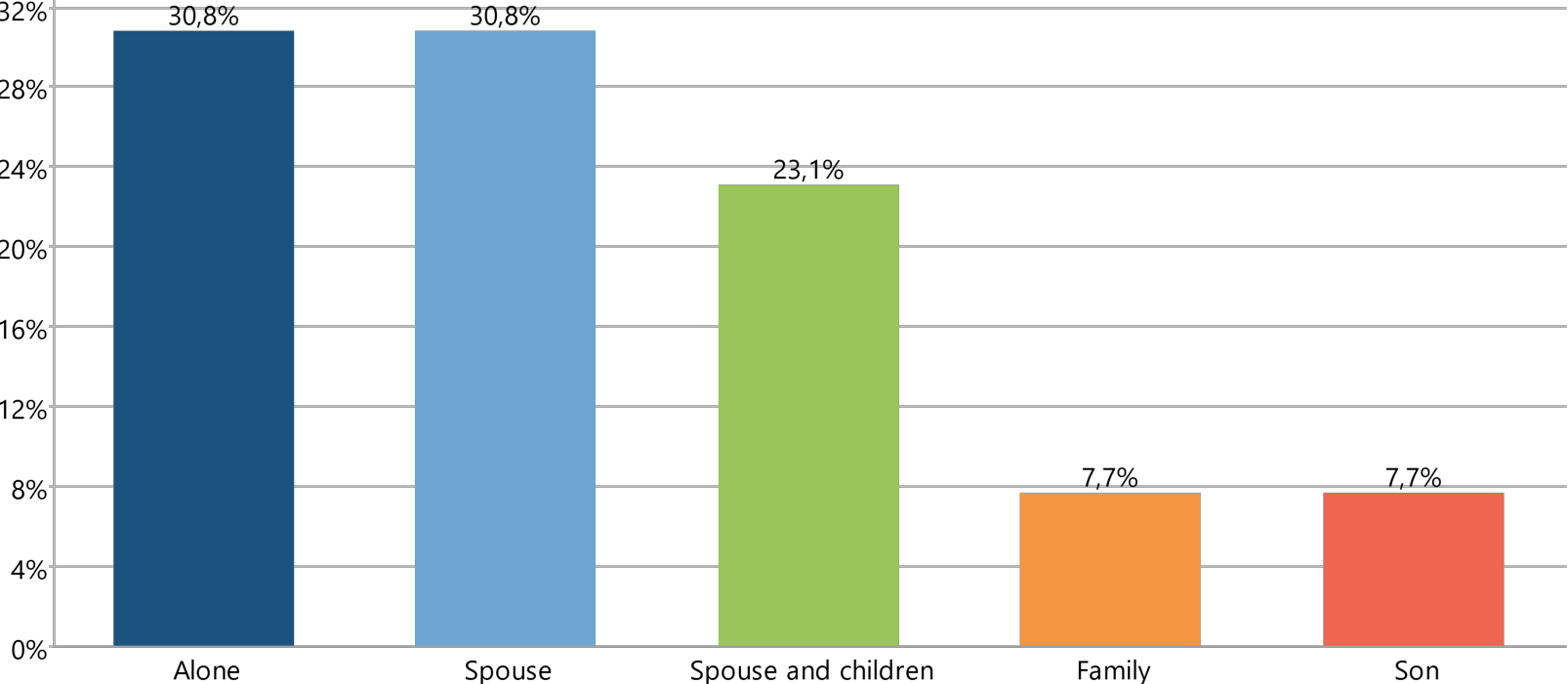


The value of people's voices



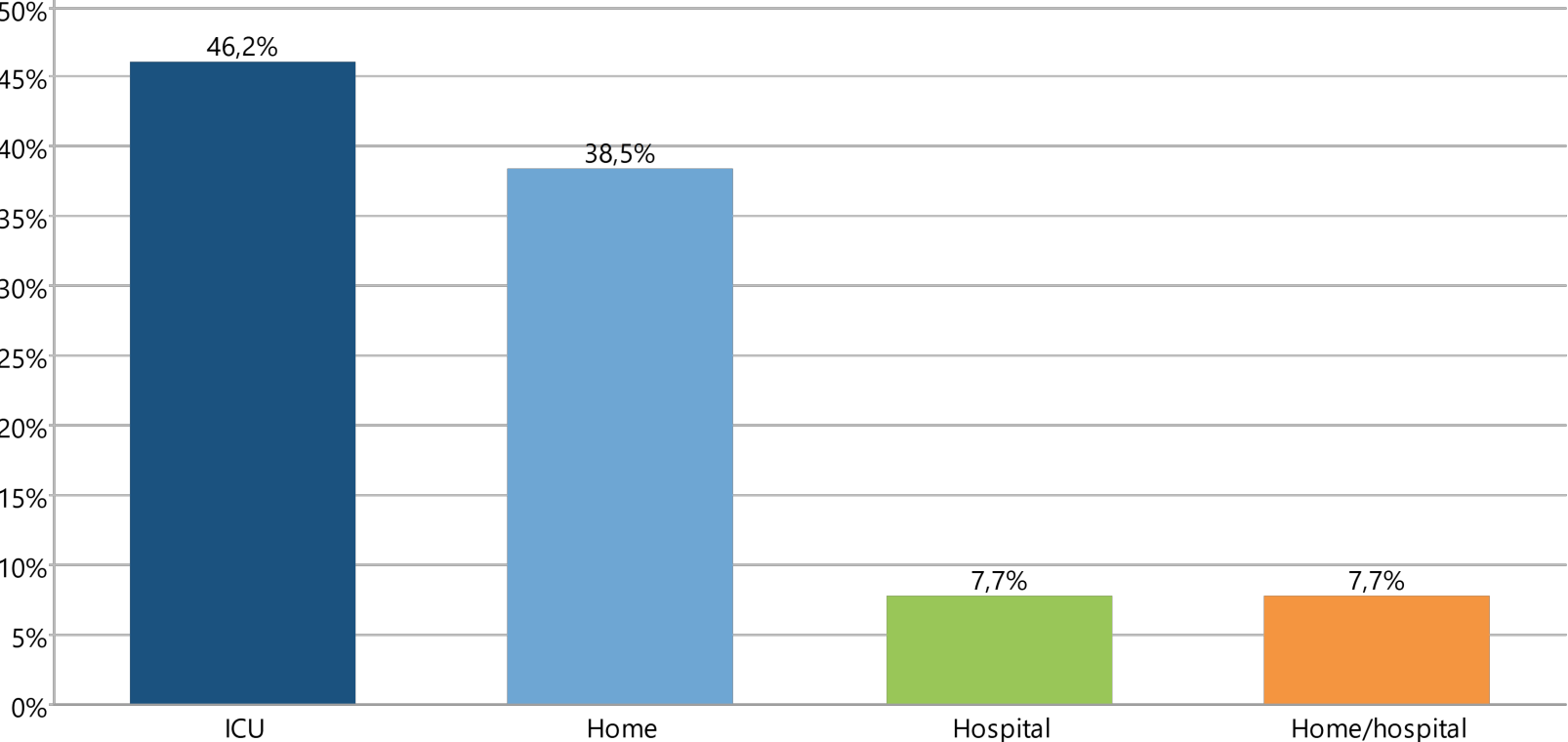
The value of people's voices

Lives with (parents, partner, others, ...)



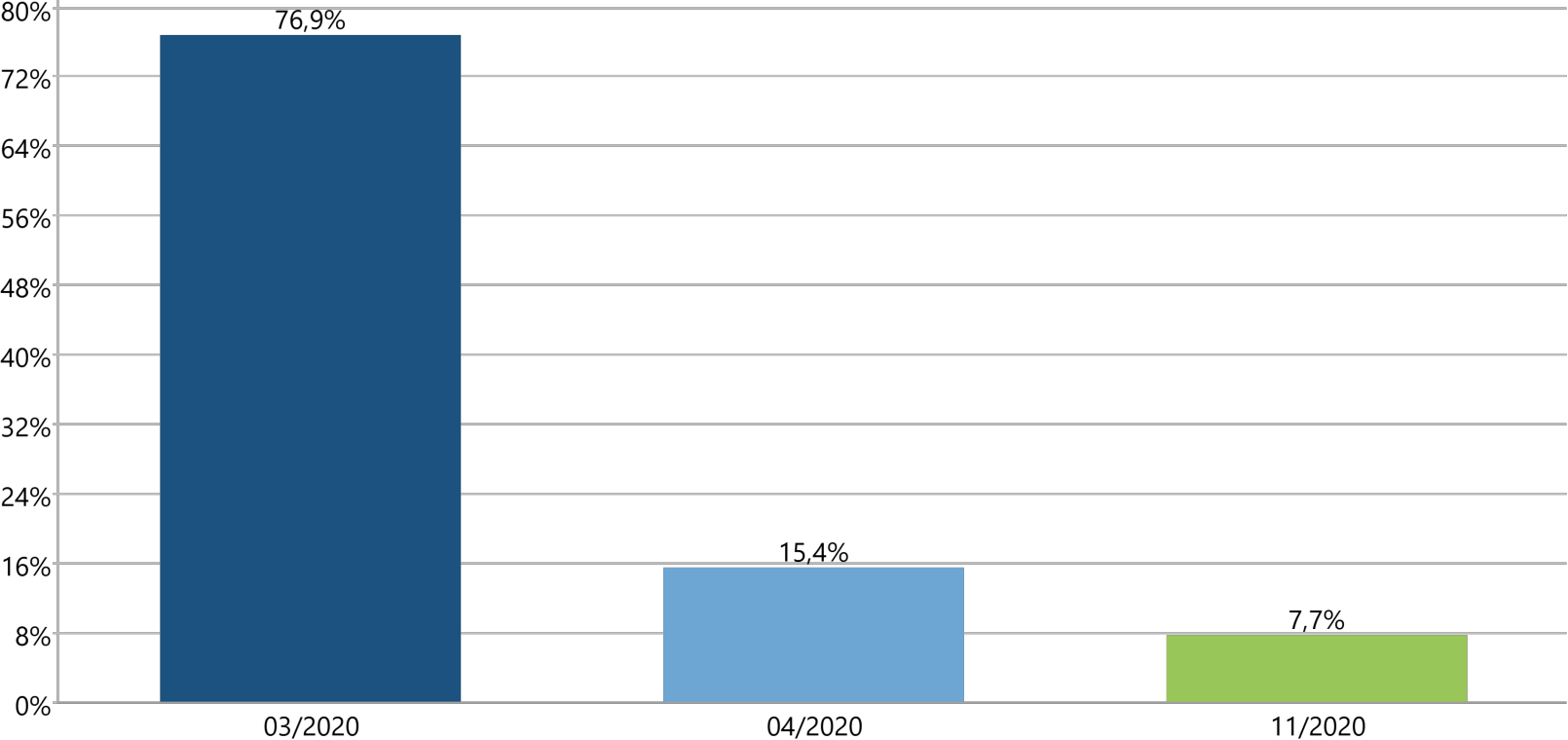
The value of people's voices

Setting of health care (home, hospital, ICU, ...)



The value of people's voices

Time of diagnosis (year/month)





The value of people's voices

But we had wonderful neighbours who -- and a granddaughter who lives close, who picked up food for us. So we were in a good position. ...

(AU, social support)

even today I was talking to a preceptor at the Clinic, "hey, I got a call from a friend of mine who is using chloroquine, it looks crazy! She cannot have chloroquine, there is no evidence." Then I was very quiet. Until today. My fellows don't know I used it. [...]

But the media and medical literature started not to provide information at a speed that we needed to generate this discussion there at the Clinic. So, we started receiving a lot of information via WhatsApp.

(BR, Local political conflicts/contexts)

E: And some guy came in and said you need to be intubated right now, and that's the last thing I remember. <<laughs>> Until I woke up like about two weeks later. In the ICU and the hoses in me everywhere and strapped down.

(CH, urgency and (lack of) consent)

Building codes in an international setting...

...is extra tricky:

- Why do I think this is important?
- What are my own cultural biases in interpreting this (fragment of) a narrative?
- Are there any other possible interpretations?
- Can this experience be transversal, or it is intrinsically connected to the context in which it happened?
- What do others see here?

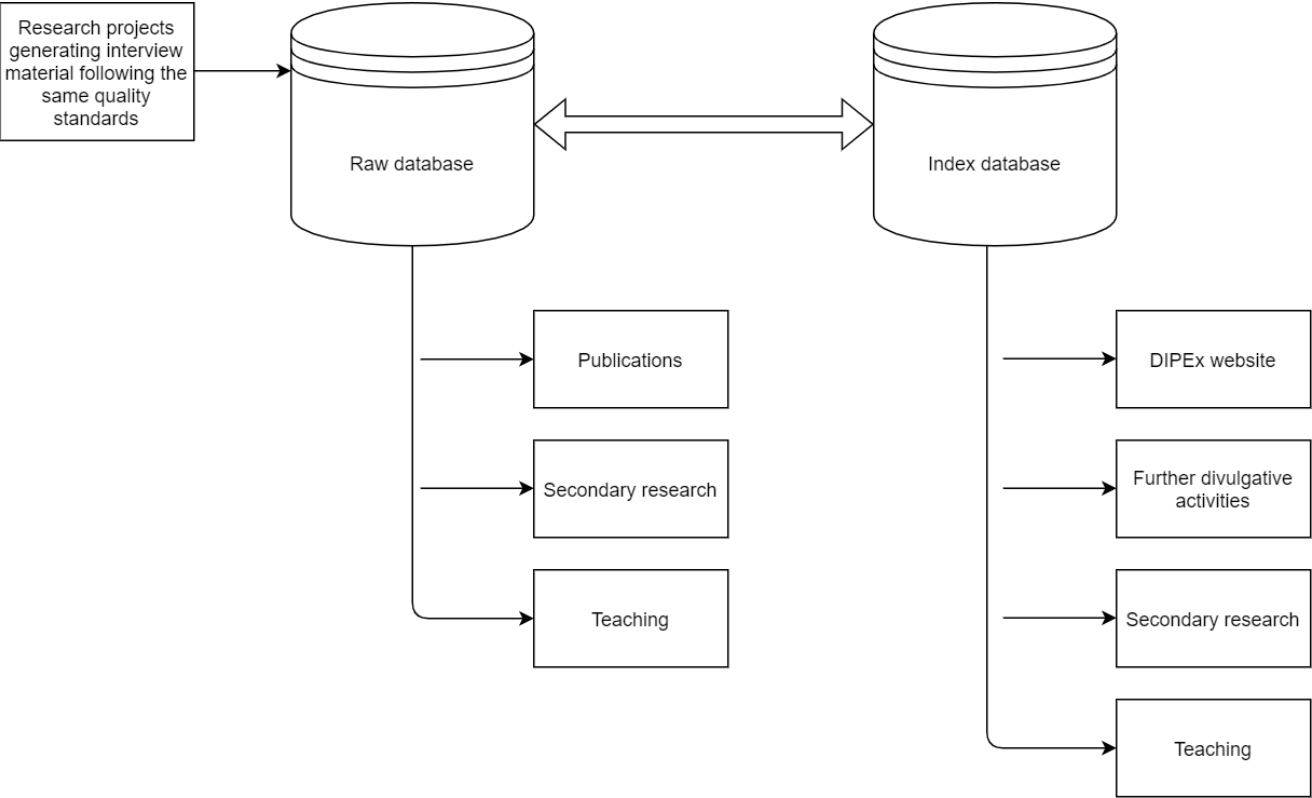
The value of people's voices

134 codes in the shared branch
(to have comparable data)

Complete freedom to work in the local branch
(to capture local or specific phenomena)



The value of people's voices





The value of people's voices

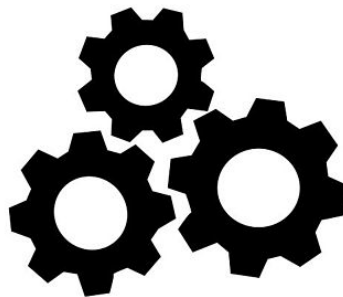
Findable



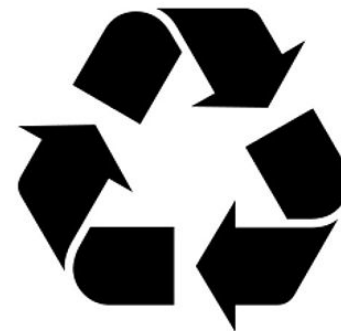
Accessible



Interoperable



Reusable





Key messages:

- Rigorous qualitative data are a useful lens to study complex phenomena, crucial in:
 - Improving person centered care,
 - patient empowerment,
 - HCP training.
- A solid data structure allows international collaborations and comparisons;
- A database infrastructure allows FAIR data stewardship (multiple specific interfaces, maximized data reuse);
- This requires consistent processes and standards.

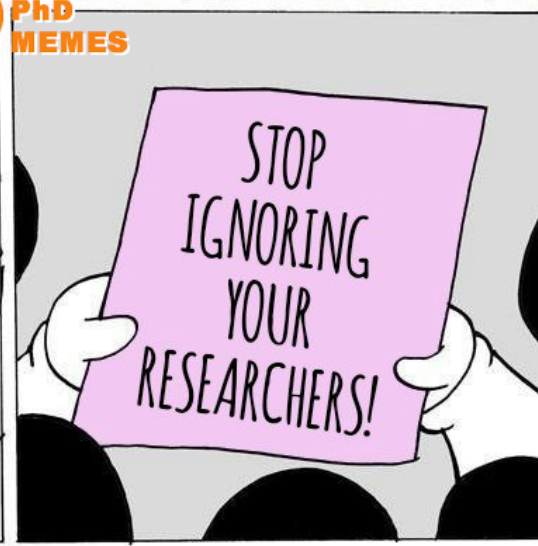
8. Future perspectives

Spitale, Giovanni, Germani, Federico (co-first), and Biller-Andorno, Nikola. «The PHERCC matrix. An ethical framework for planning, governing, and evaluating Risk and Crisis Communication in the context of Public Health Emergencies». *American Journal of Bioethics* (submitted, May 2022. Preprint: <https://doi.org/10.5281/zenodo.6559205>)



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**HIGH
IMPACT
PhD
MEMES**



PHERCC?

- Some research (but from business) -> reputation repair.
- Detect, notify and report on public health threats;
- Disseminate information and recommendations for the population;
- Increase communities' resilience to disasters via people-centred multi-hazard communication mechanisms and social technologies.

(Sendai framework 2015, 21)



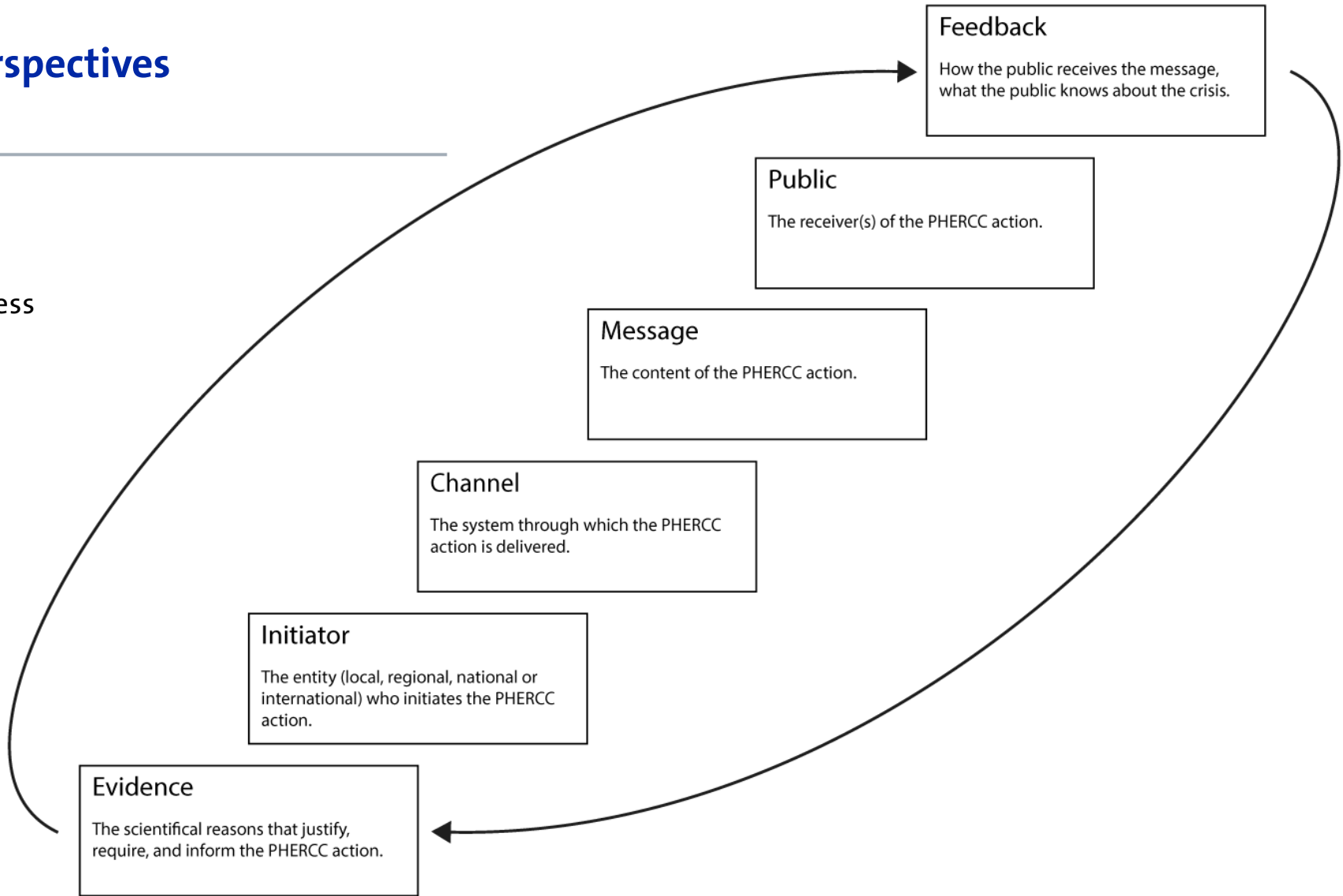
PHERCC!

- Define:
 - Aims,
 - Stakeholders,
 - Process (+issues),
 - Approach;
- Provide theoretical reflection and practical guidance for planning, governing, and evaluating PHERCC actions;
- Contribute a solid foundation for better PHERCC in the future.



Future perspectives

The PHERCC process
A looped ladder





Fair or effective?

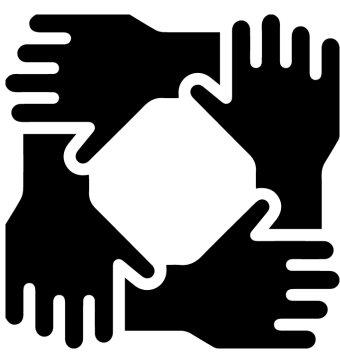
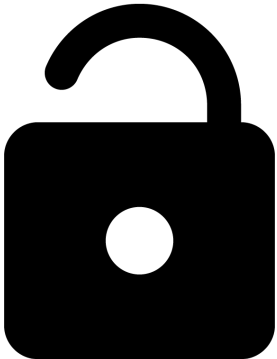
- You can enforce 'hard' risk response strategies;
- You cannot enforce understanding and communication!

To achieve its aims (eliciting specific protective behaviors across different segments of the public and increasing risk awareness) PHERCC needs the public to be on board.

- There is no tradeoff between fairness or effectiveness;
- Fairness is a *conditio sine qua non* for effectiveness.








Future perspectives



Future perspectives

The PHERCC matrix

Principles	
Openness	
Transparency	
Inclusivity	
Understandability	
Privacy	

Process					
Evidence	Initiator	Channel	Message	Public	Feedback
The scientific reasons that justify, require, and inform the PHERCC action.	The entity (local, regional, national or international) who initiates the PHERCC action.	The system through which the PHERCC action is delivered.	The content of the PHERCC action.	The receiver(s) of the PHERCC action.	How the public receives the message, what the public knows about the crisis.
Is the evidence of public domain and accessible?	Is the initiator committed to open policies?	Is the channel infrastructure developed with open source software?	Is the message distributed under an open license (e.g. CC-BY-SA)?	Is the public openly available to receive the message? (e.g. presence online, social media, etc).	Is the content of the public's feedback openly accessible (after anonymization) to everyone?
Has the evidence been generated through a transparent process?	Is it clear who the initiator is, and under which principles or regulations they operate?	Is it clear who operates the channel and how the channel works?	Is the aim of the message transparent? (e.g. eliciting a specific behaviour, enhancing understanding, ...)	Is (aggregated and anonymized) information about the public visible and inferable?	Is it clear how the feedback was collected and by whom?
Is the evidence generated taking into account different socio-demographic segments?	Does the initiator include a plurality of voices in the definition of the strategy and of the content?	Does the information delivery strategy take into account the specific needs of different segments of the public?	Is the message tailored to the needs and specificities of different segments of the public?	Does the definition of the public take into account a plurality of (reasonable) doctrines?	Does the feedback represent opinions from different segments of the public?
Is the evidence accompanied by interpretative notes and metadata?	Is it clear what are the goals (long - and short- term) of the initiator?	Is it simple to understand how the channel works?	Is everyone from the public able to understand the message? (i.e. language, complexity, timing, ...).	Is the strategy defining the public, its composition, and its segmentation clearly understandable?	Are the content and the representativity of the feedback clearly understandable?
Is the evidence completely anonymized?	Is the individual privacy of the initiator's employees guaranteed (to balance with transparency)?	Does the channel protect users' privacy (e.g. no tracking technologies)?	Does the message contain information that could compromise anyone's privacy?	Is citizens' privacy guaranteed in the delivery of the message? (e.g. cookies, digital fingerprinting).	Is the feedback completely anonymized?

Key messages:

- Novel area, much more research is needed!
- PHERCC is dense of ethical implications and potential pitfalls, needs guidance;
- No tradeoffs between fairness and effectiveness;
- Process x Principles = the PHERCC matrix.

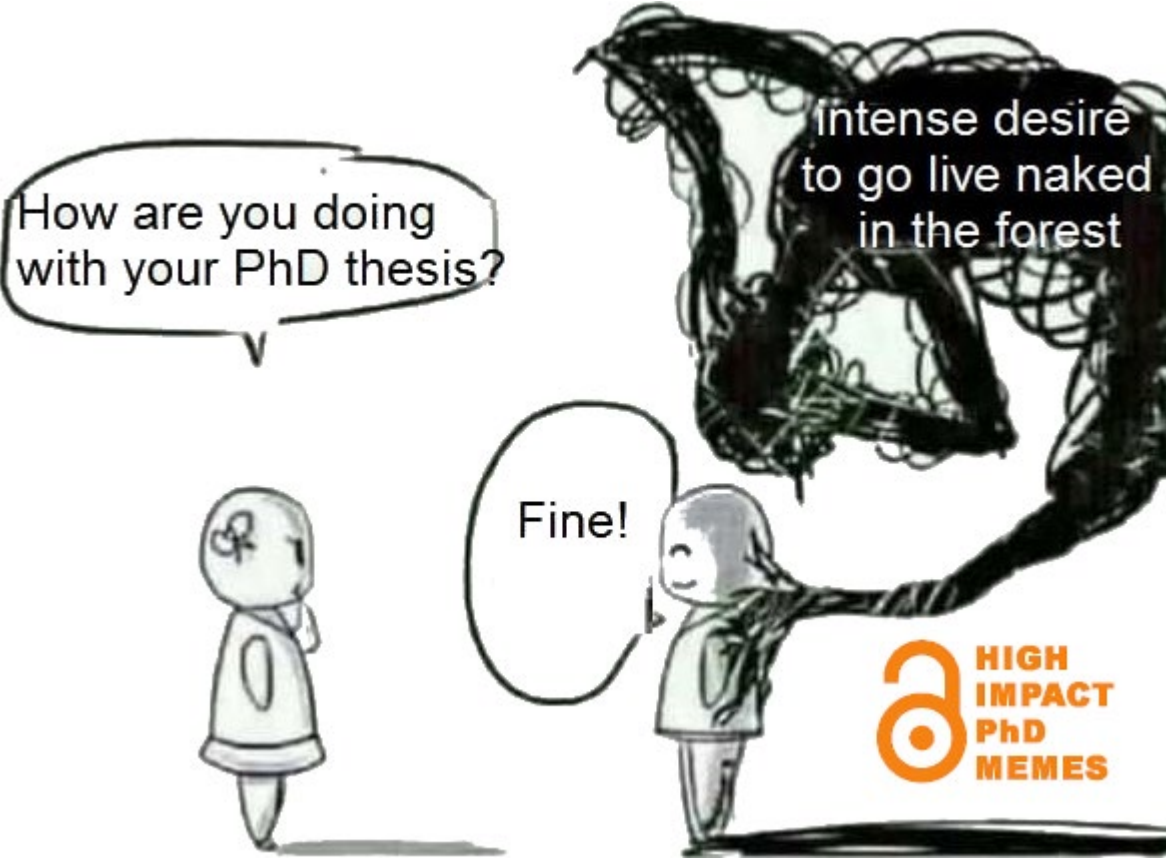
Develop and bolster people-centred multi-hazard communication mechanisms and social technologies that are both fair and effective.

9. Conclusion



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How are you doing with your PhD thesis?

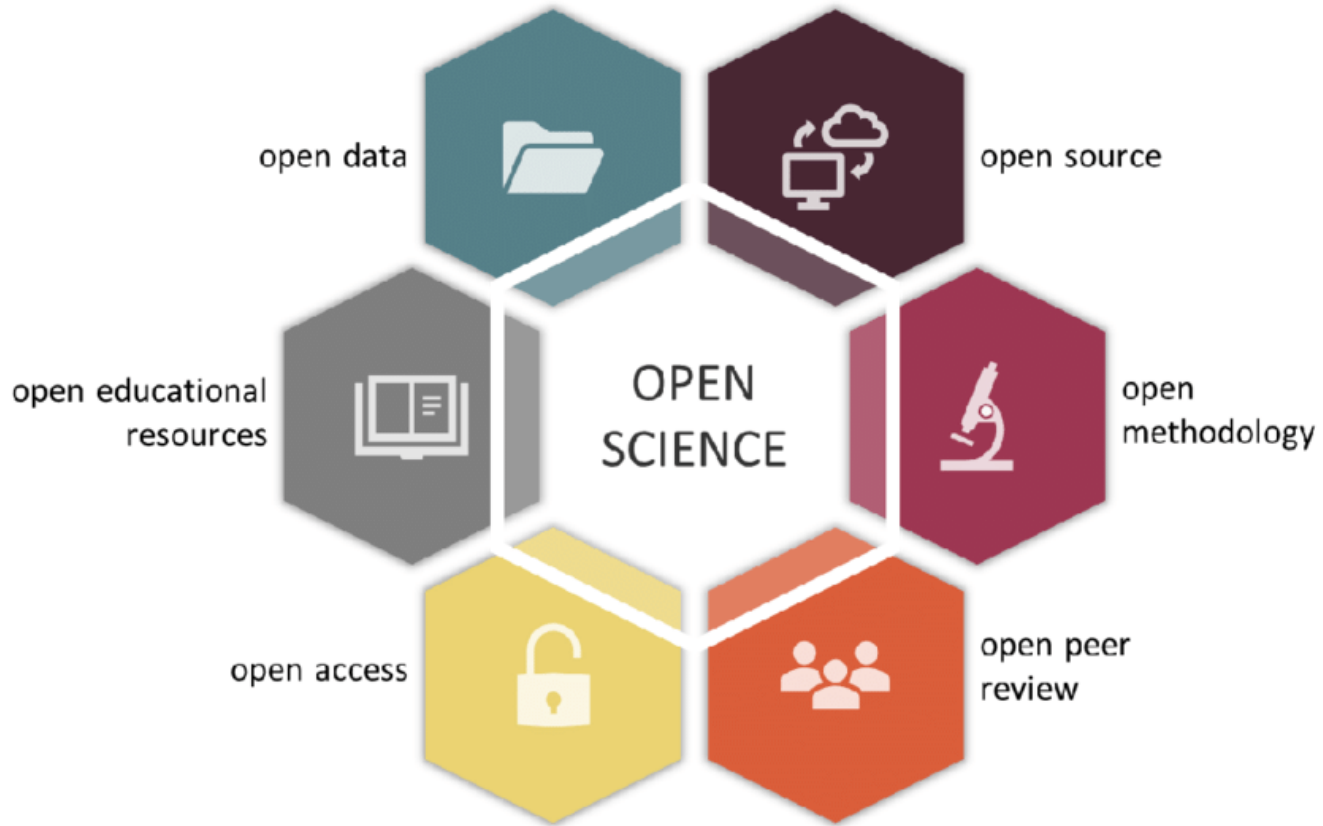
Fine!

intense desire
to go live naked
in the forest

**HIGH
IMPACT
PhD
MEMES**



Conclusion





Something's happening and it might be on my dish

Let's navigate it in a smart and fast way...

...mapping emerging issues across the board...

...and building novel instruments
able to listen to people in a
variety of ways.

Systematize in a precise,
solid and applicable way
what we learnt on one
specific issue

Ethics to graphic novels

Gamified empowerment
for public discourse



**Guess who
is looking
at memes
instead of
submitting
manuscripts**



DO THINGS IN
THE RIGHT TIME,
WITH CALM
AND SERENITY



DO EVERYTHING
UNDER THE
DEADLINE IN
TOTAL PANIC

Sketching Science



SO LONG, AND THANKS FOR ALL THE FISH.

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