Empirical (bio) ethics 101
Case study: Concerns Around Opposition to the Green Pass in Italy

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Ca' Foscari
**Challenge
School**

GIOVANNI↓

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2012: BA in Philosopy @ UniPD
2015: MA in Philosophical Sciences @UniPD
2017: International Research Fellow @RUB, Institute for Medical Ethics and History of Medicine
2022: PhD @UZH, Institute of Biomedical Ethics and History of Medicine

Ongoing projects:
- DIPEx data management
- Boosting Public Discourse: Towards a Targeted, Evidence-Based Strategy to Improve Moral Reasoning
- Pandemics & Bioethics: Co-Designing a Graphic Novel
- Scoping review background document for the WHO-convened ethics panel on ethical considerations of infodemic management, with a particular focus on social listening

Other fancy stuff:
TEDx speaker @Trento 2016
Scientific coordinator of Academia Engelberg 2019
Open Science Ambassador @UZH
Guest editor @ International Journal of Public Health
Reviewer for a bunch of journals (including Medicine, Health Care and Philosophy, PLOS One, Reviewer for Public Health Ethics, JMIR, MHEP, …)
Paragliding pilot and nerd, big fan of cows

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2013: BSc in Biology @ University of Milan
2015: MSc in Molecular Biology @University of Milan / ETH Zurich
2018: Graduate Diploma, International Relations @ University of London
2019: PhD in Molecular Life Sciences @University of Zurich, Institute of Molecular Life Sciences
Since 2018: Director @Culturico
Since 2020: Post-doc @University of Zurich, Institute of Biomedical Ethics and History of Medicine
2023: Guest Lecturer @University of Pisa
Since 2023: Rapporteur @World Health Organization, Expert Group on Ethics of Infodemic Management and Social Listening
Since 2024: Visiting Fellow @Brown University, Information Futures Lab

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GENERAL AIMS

1. Introduce and discuss the concept of empirical (bio)ethics
2. Present methodological options and data sources for empirical (bio)ethics
3. Exercise!
4. Present and discuss some case studies (with dr. Germani)

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

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TODAY'S PLAN

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What's an infodemic?
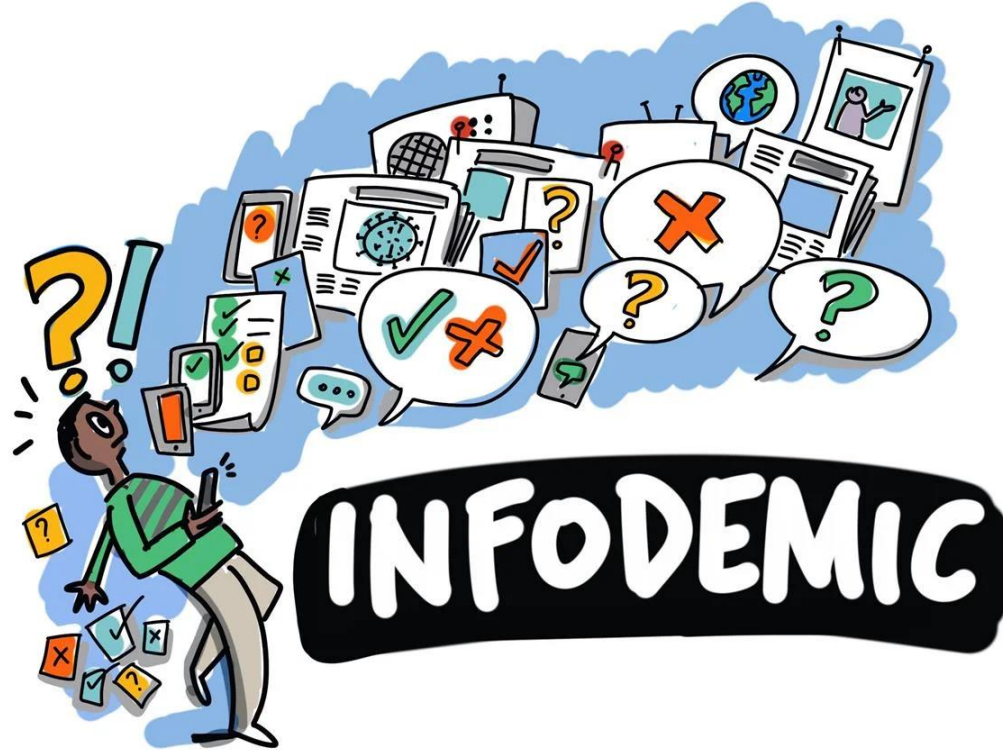How do we listen to people?
What are the ethical implications?

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11.04.2024

Introduction

Introduction

What is an infodemic?

- **Too much information,** including false or misleading information,
- in **digital and physical** environments,
- during a **disease outbreak**.

- Causes **confusion** and **risk-taking behaviours**,
- leads to **mistrust** in health authorities,
- **undermines** the public health **response**.

- Can **intensify or lengthen outbreaks**

- With growing **digitization**, information can **spread more rapidly**. This can help to more quickly fill information voids but can also amplify harmful messages.

WHO, Cross-Regional Statement on "Infodemic" in the Context of COVID-19

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Introduction

How to tackle an infodemic?

- provide **free, reliable, trustworthy, factual, multilingual, targeted, accurate, clear and science-based** information,
- ensure **dialogue and participation** of **all stakeholders** and affected communities during the preparedness, readiness and response,
- enhance **transparency, accountability and trust**, which is essential to achieving adequate support for and compliance by the general public,
- increase societal **resilience against disinformation**,

- <u>tackle the creation and circulation of false or manipulated information</u>, in an objective manner and with due respect for citizens' freedom of expression, as well as public order and safety.

WHO, Cross-Regional Statement on "Infodemic" in the Context of COVID-19

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
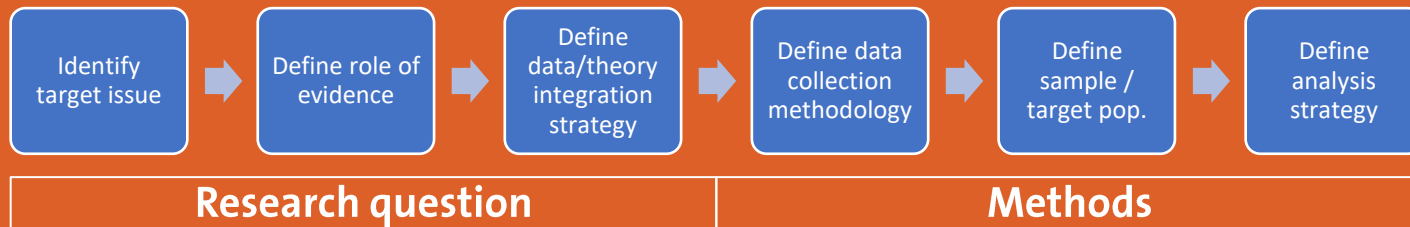
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Empirical Ethics 101

Planning

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Empirical Ethics 101
Doing

Clarify ethical issues	→	Define data management plan	→	Collect data	→	Analyze data	→	Integrate evidence and theory

Integrity/responsibility	Data collection	(Normative) analysis

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Passive social listening

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Passive social listening

Outreach
Privacy

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Passive social listening

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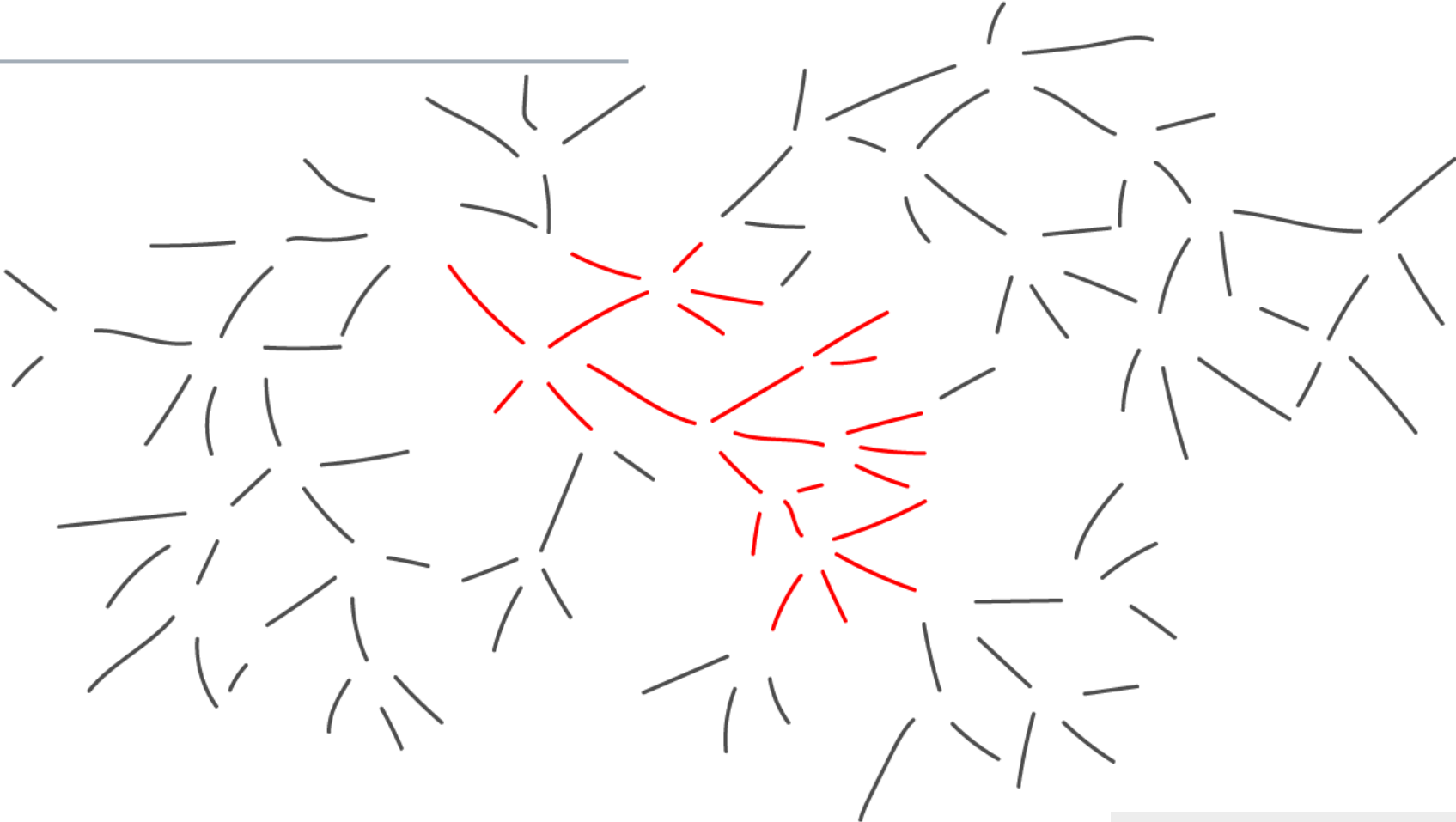
Passive social listening
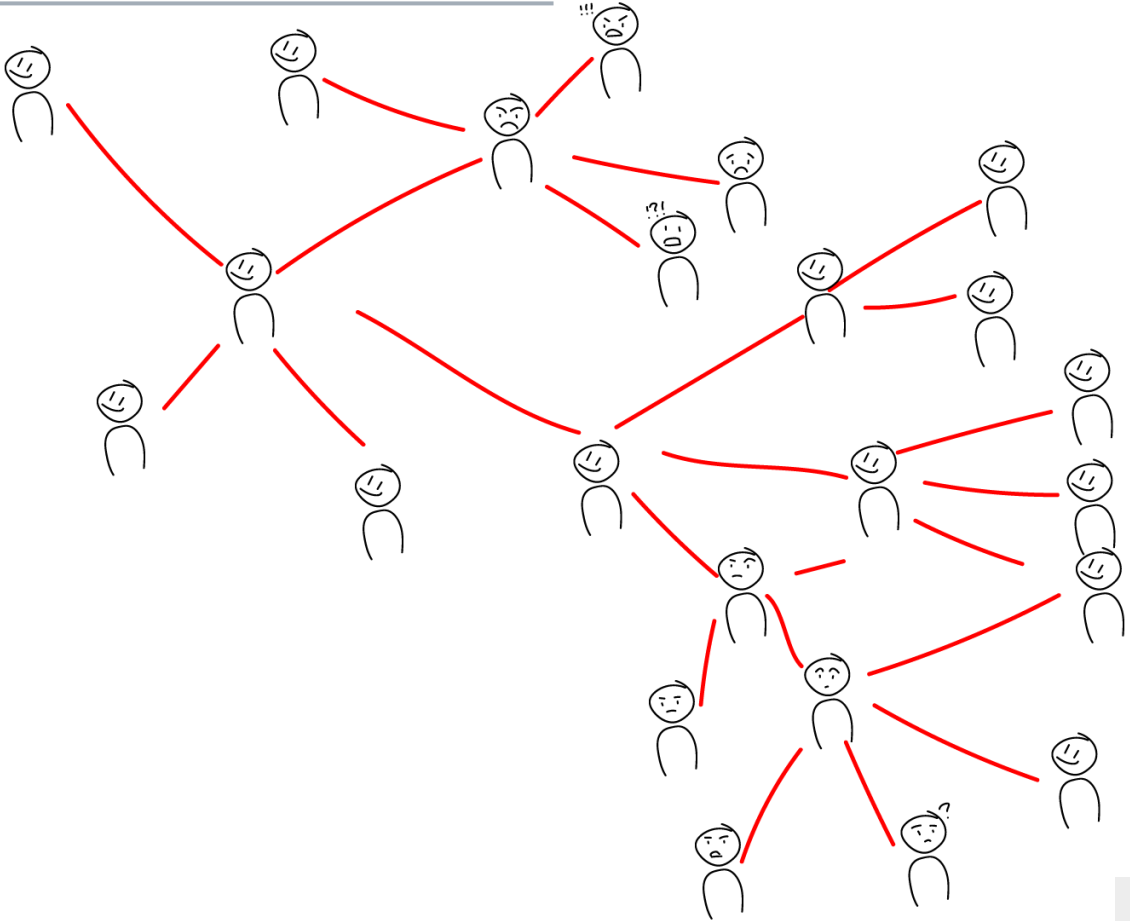
Passive social listening

Some good questions:

What are these people saying?

How and how much?

Who are they?

Why do they want a fake GP?

Are they vaccinated?

Are they antivaccinationists?

What are they afraid of?

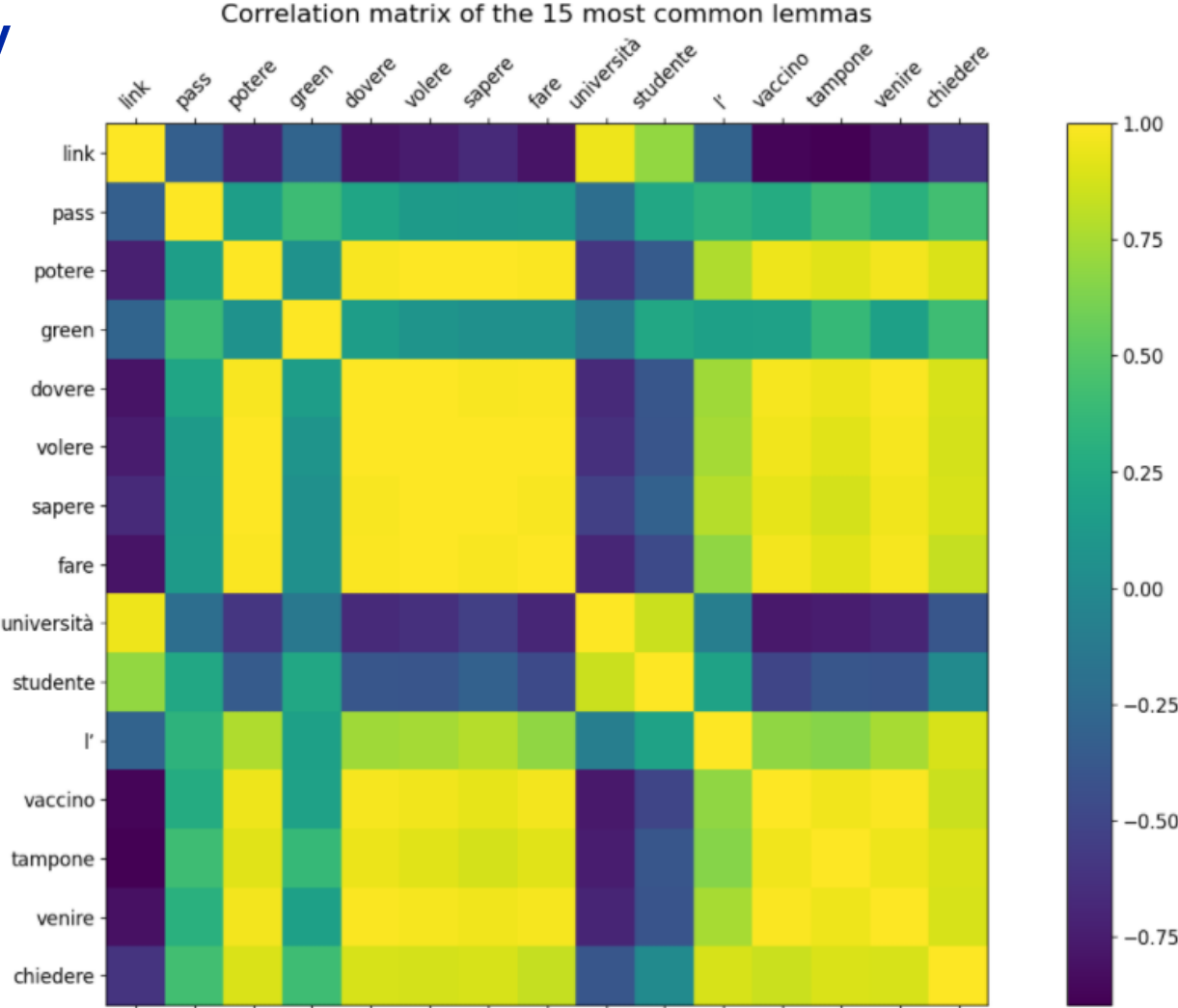What are their plans?

Passive social listening

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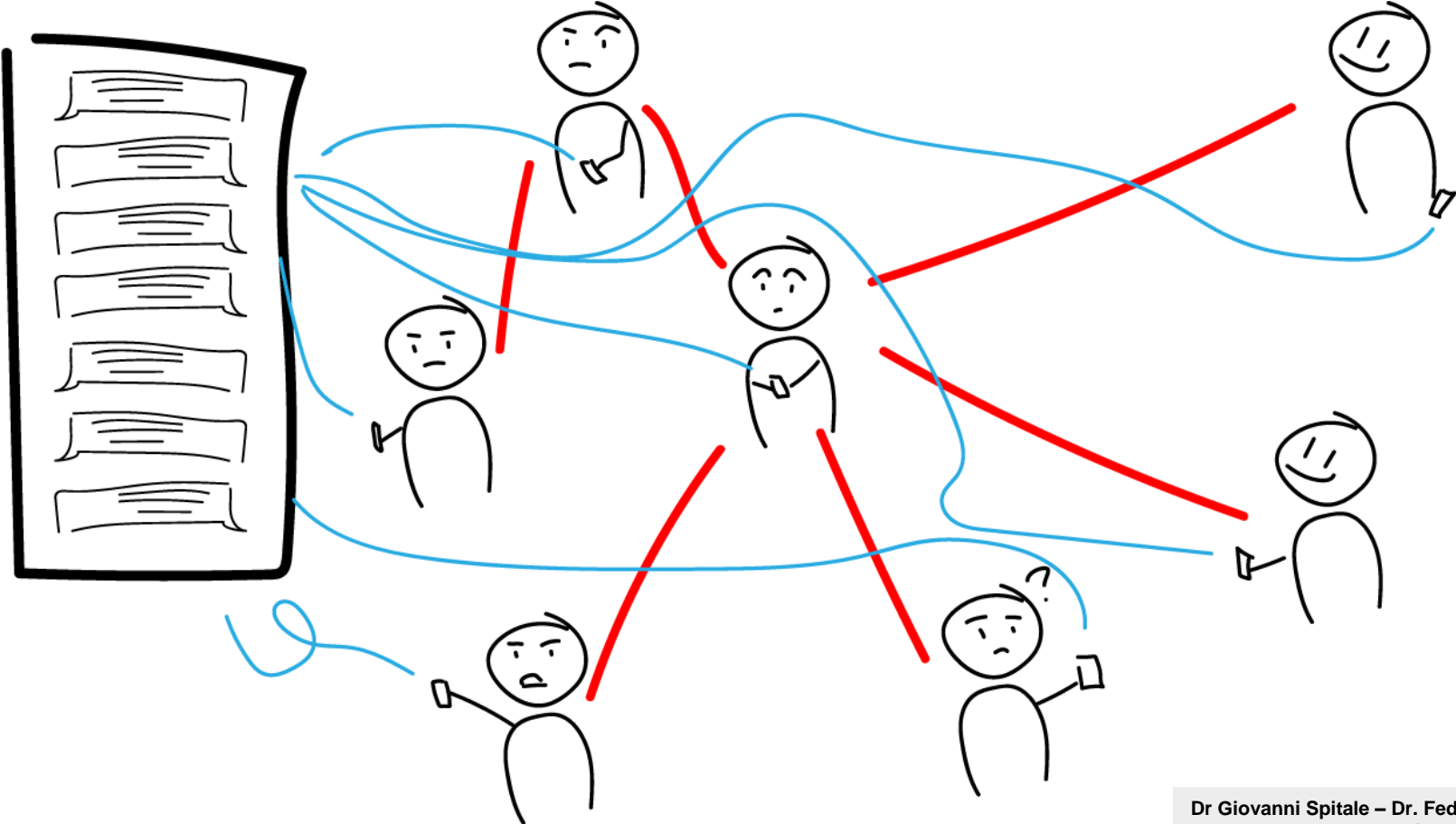
Passive social listening

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

Lemma Frequency

Correlation matrix of the 15 most common lemmas
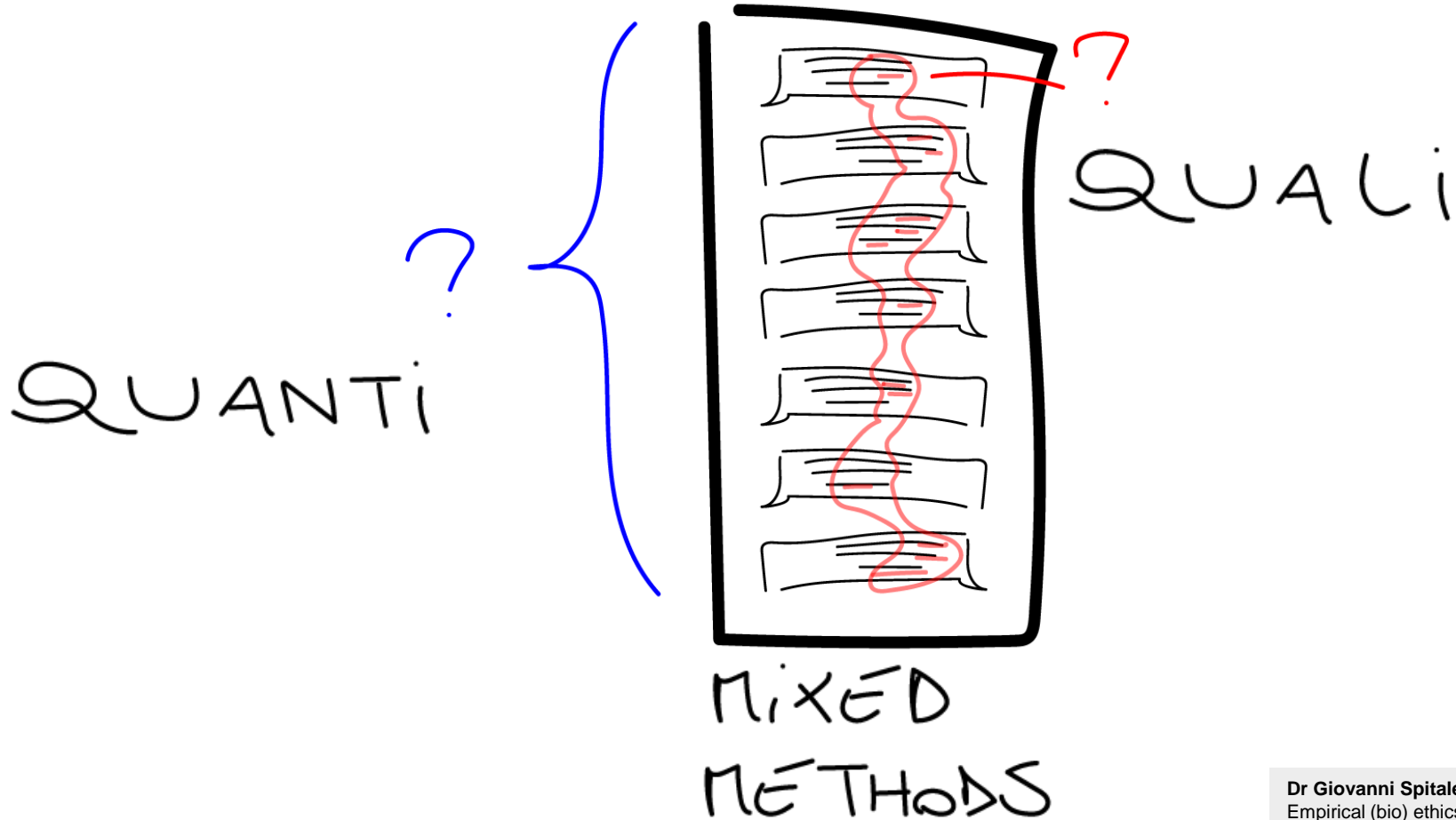
Lemma Frequency
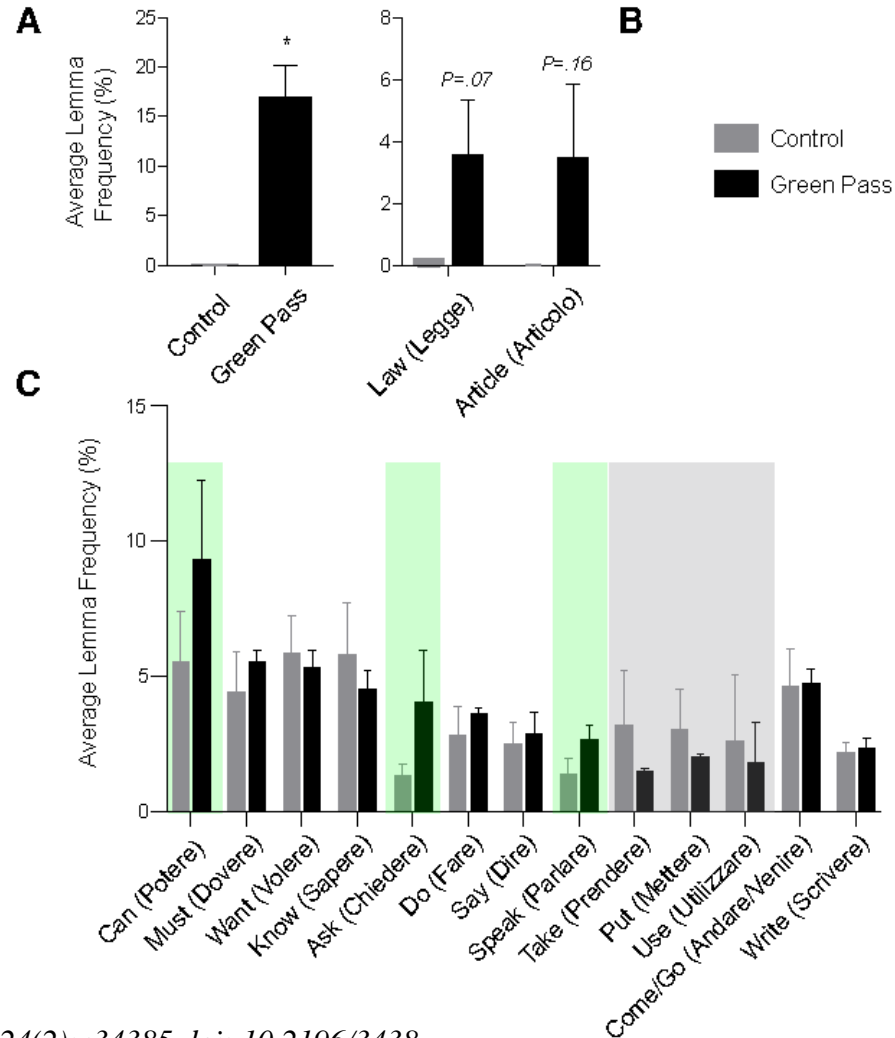
Rule Frequency

Sentiment Analysis

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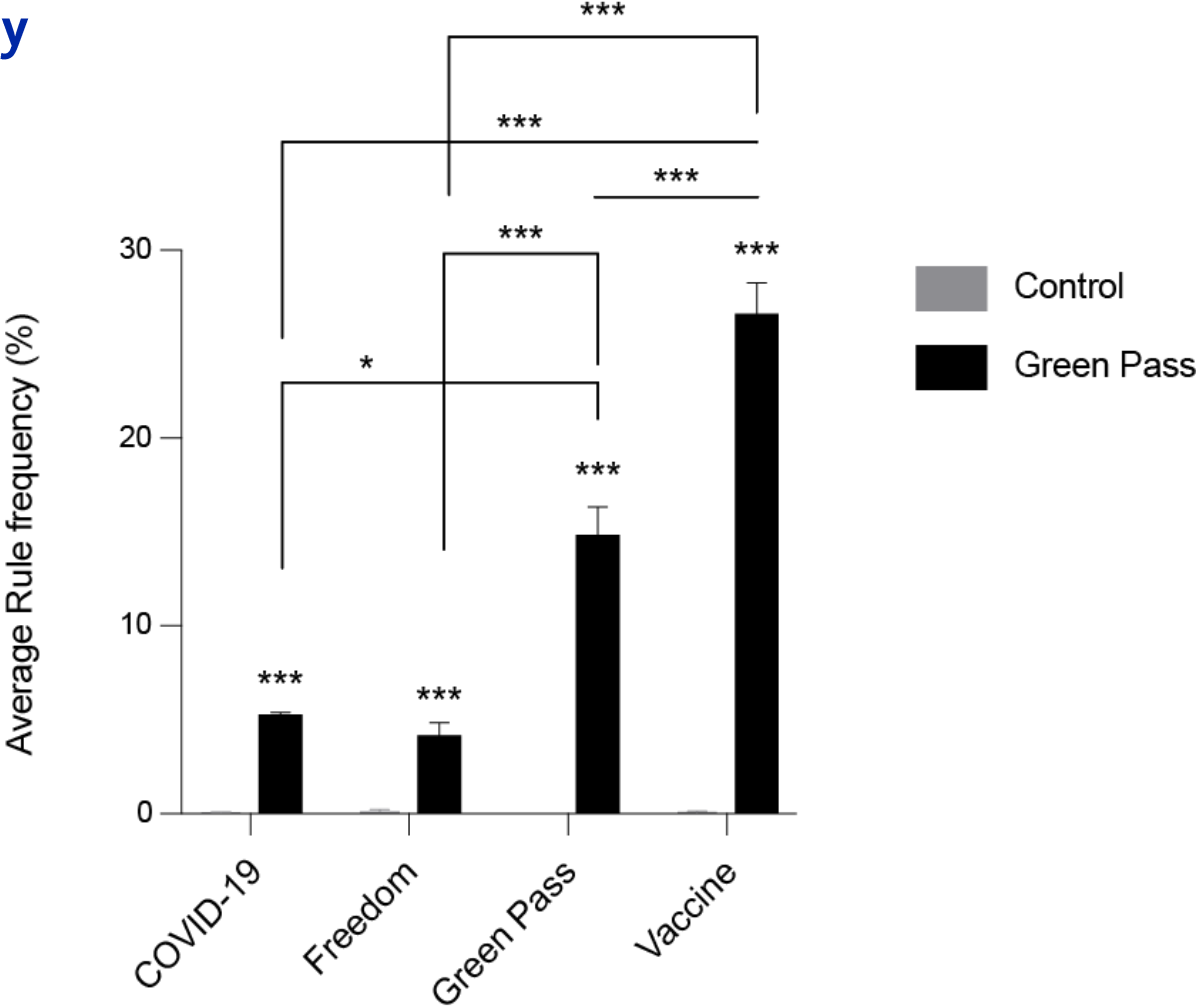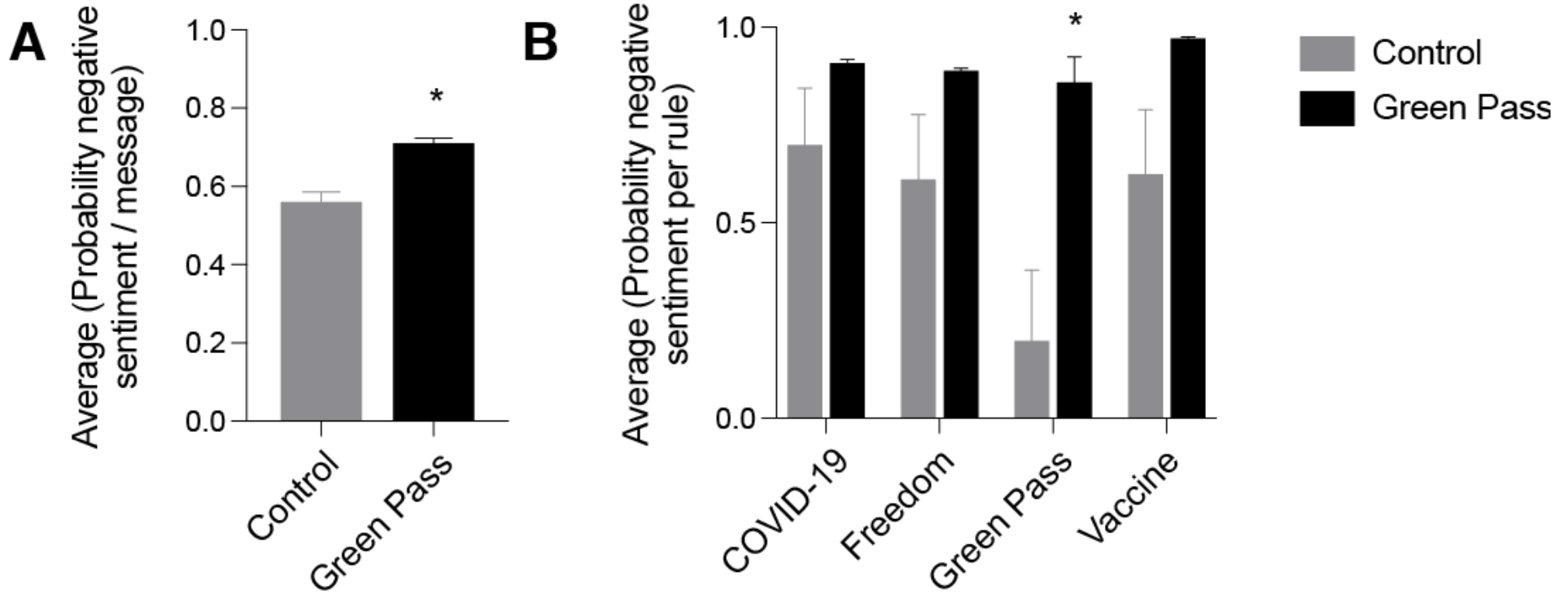
Qualitative Results

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)

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Qualitative Results

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)

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Qualitative Results

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)

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Qualitative Results

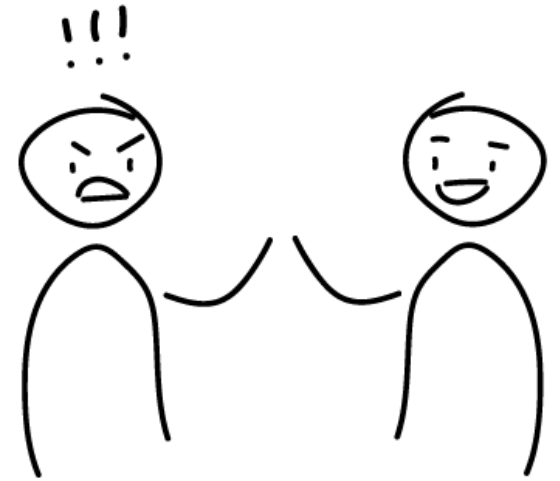Vaccines are what this battle is for

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)

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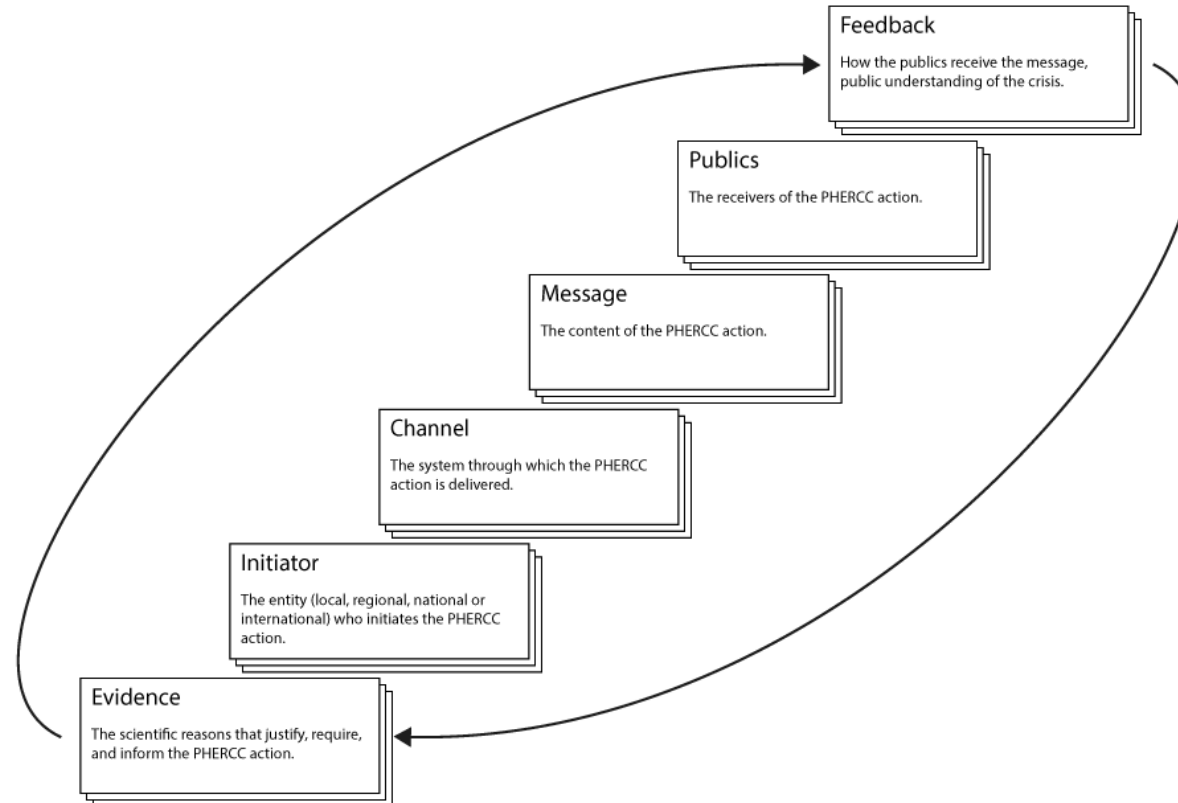11.04.2024

Ethical implications
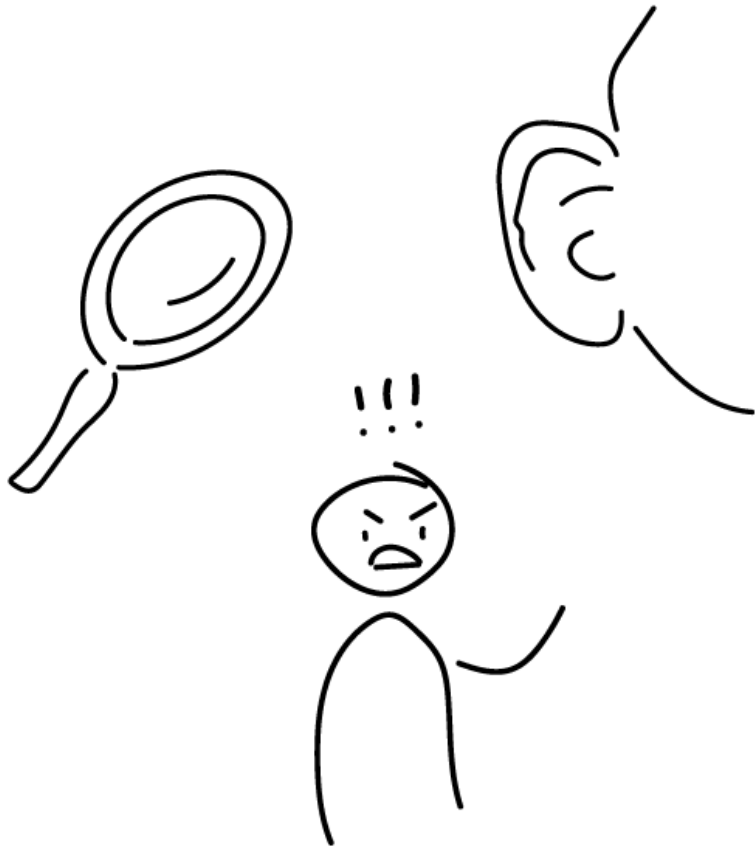
PASSIVE

ACTIVE

PHERCC Ethics

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 (2022. https://www.tandfonline.com/doi/full/10.1080/15265161.2023.2201191)

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Ethical implications

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Ethical implications

The Looped Ladder of PHERCC

Ethical implications

The PHERCC matrix

Process					
Evidence The scientifical reasons that justify, require, and inform the PHERCC action.	**Initiatior** The entity (local, regional, national or international) who initiates the PHERCC action.	**Channel** The system through which the PHERCC action is delivered.	**Message** The content of the PHERCC action.	**Public** The receiver(s) of the PHERCC action.	**Feedback** How the public receives the message, what the public knows about the crisis.

Principles	Evidence	Initiatior	Channel	Message	Public	Feedback
Openness	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 feeback openly accessible (after anonymization) to everyone?
Transparency	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?
Inclusivity	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?
Understandability	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?
Privacy	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:

- 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.

DIY, hands-on learning is fun

Resources for the curious

The Telegram paper: https://www.jmir.org/2022/2/e34385

The software: https://zenodo.org/record/5534045#.YaiVltDMKUm

A test run on a toy dataset: https://drive.switch.ch/index.php/s/F0AIT3z8wRADu2j

Toy data for DIY enthusiasts: https://drive.switch.ch/index.php/s/arv4qZbLqoALBIm

The PHERCC paper: https://www.tandfonline.com/doi/full/10.1080/15265161.2023.2201191

Another very cool paper about active social listening:
https://www.researchprotocols.org/2021/11/e33653

Thanks for
Your time!

it's over, I swear

Download the slides here