

Empirical (bio) ethics 101

Case study: Development of an Ethical Framework for Infodemic Management

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Institute of Biomedical Ethics
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GIOVANNI ↓



2012: BA in Philosophy @ 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

<https://orcid.org/0000-0002-6812-0979>

FEDERICO ↓



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



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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

TODAY'S PLAN



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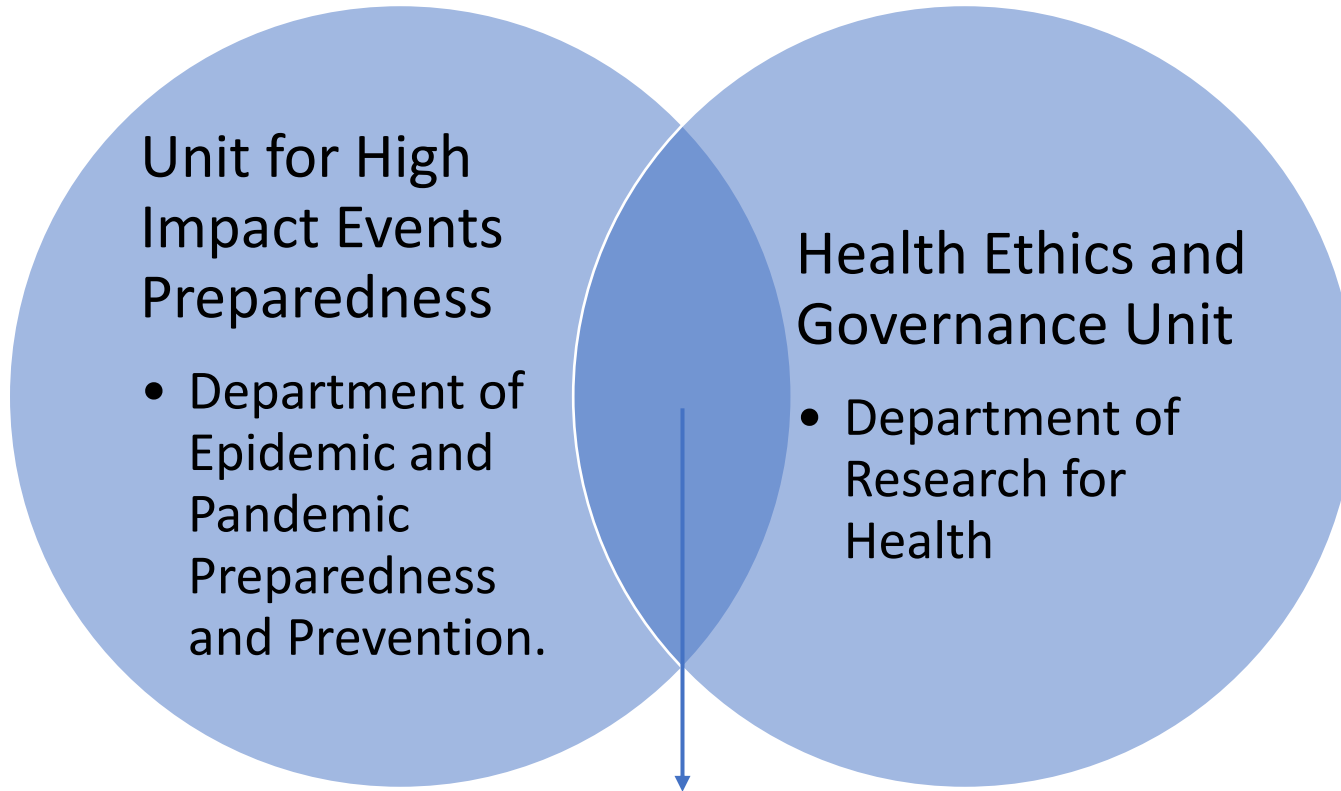
Institute of Biomedical Ethics
and History of Medicine

1. What are the ethical issues in social listening and infodemic management?
2. What should we consider as ethical aims?
3. How can this be translated into policy and practice tools?

Why Empirical Ethics?

Musschenga 2005:

- 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 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).



Unit for High
Impact Events
Preparedness

- Department of Epidemic and Pandemic Preparedness and Prevention.

Health Ethics and
Governance Unit

- Department of Research for Health

This process

WHO Secretariat: Katherine Littler, Co-Unit Head of Health Ethics & Governance in the Department of Research for Health in the Science Division of the World Health Organization, Sylvie Briand, Director of Pandemic and Epidemic Preparedness and Prevention in the Health Emergencies Programme, Tina Purnat, Team Lead for Infodemic Management in the Unit for High Impact Events Preparedness of the Department of Pandemic and Epidemic Preparedness and Prevention, John Reeder, Acting Chief Scientist and Director of Research for Health Department in the Science Division, Andreas Reis, Co-Unit Head of Health Ethics & Governance in the Department of Research for Health in the Science Division, and Sandra Varaidzo Machiri from the African Field Epidemiology Network in Zimbabwe.

Co-chairs of the group: Isabella Ballalai from the Brazilian Immunization Society and Calvin Ho from the Centre for Medical Ethics and Law at Hong Kong University.

Experts involved: Najeeb Al-Shorbaji from the Jordan Library and Information Association, Thalia Arawi from the American University of Beirut, Cherstyn Hurley from the Health Security Agency in the UK, Dimitra Lingri from the European Healthcare Fraud & Corruption Network (EHFCN) and the Department of Law at the Faculty of Law at Aristotle University of Thessaloniki in Greece, Stefan Mandic-Rajcevic from the Infodemiology Lab at the School of Medicine at the University of Belgrade in Serbia, Lisa Talia Moretti from AND Digital in the UK, Syed Nakazat from the DataLEADS Foundation in India, Claudia Pagliari from The Usher Institute at the University of Edinburgh in the UK, Alejandro Posada from Internews in Bogotá, Colombia, Ana Lorena Ruano from the Center of Studies for Governance and Equity in Health Systems in Guatemala, David Scales from the Weill Cornell Medical College at Cornell University in the USA, Max Smith from the School of Health Studies at Western University in Canada, Theresa M Senft from Macquarie University in Australia, Harry Sufehmi from MAFINDO in Indonesia, Ross Upshur from the Dalla Lana Faculty of Public Health at the University of Toronto in Canada, and Fatou Wurie from Harvard University in the USA.

Observers: Surangani Abeysekera from UNICEF, Guilherme Canela De Souza Godoi from UNESCO, Timothy K Mackey from the University of California, San Diego, Lee Hibbard from the Council of Europe, and Betsy Mitchell from the US Centers for Disease Control and Prevention.

1. Defining the problem

2. The process

3. Architecture

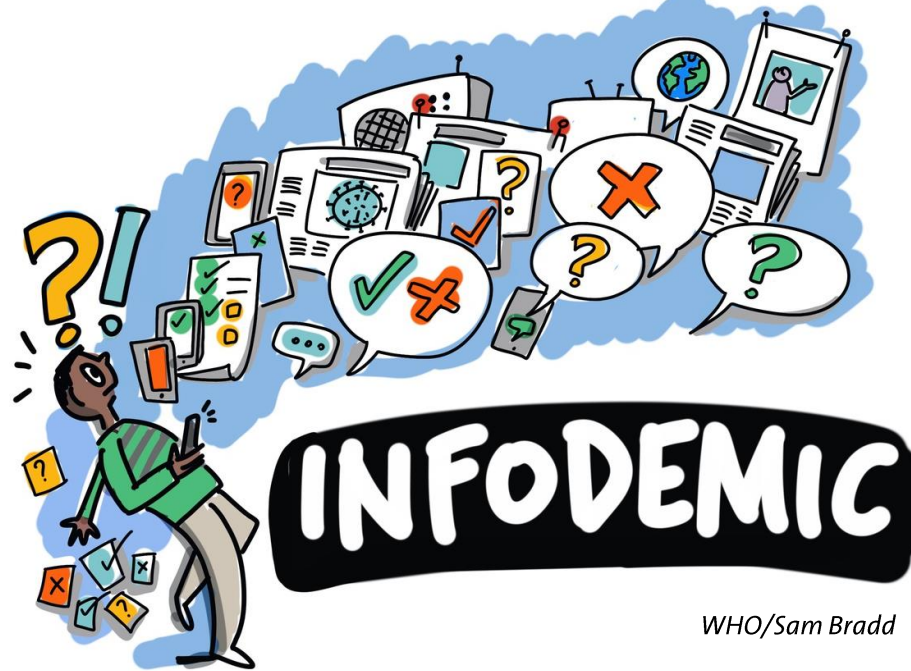
4. Core content

5. Systematic scoping review

SUMMARIZING:

- Identifies and defines management post-graduate challenges
- An ethical framework is necessary for effective academic management
- The development process is based on both literature and experts' views
- The architecture includes definitions, ethical challenges, process flow, principles, and stakeholder specific guidance
- Ethics is not an add-on, but rather a tool to measure the effectiveness of academic management

1. Defining the problem



WHO/Sam Bradd

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

- causes confusion and risk-taking behaviours that can harm health;
- leads to mistrust in health authorities;
- undermines the public health response;
- can intensify or lengthen outbreaks.



WHO/Sam Bradd

Infodemic management

the systematic use of risk- and evidence-based analysis and approaches to manage the infodemic and reduce its impact on health behaviours during health emergencies.

- Listening to community concerns and questions;
- Promoting understanding of risk and health expert advice;
- Building resilience to misinformation;
- Engaging and empowering communities to take positive action.

Defining the problem



1. **Effectiveness/Efficacy/public good/usefulness:** ability to produce benefit in real life conditions
2. **Autonomy** (understood differently in different cultures): the combination of intentionality, understanding and non-control
3. **Fairness/justice:** a comprehensive set of basic rights and liberties that can coexist with similar rights for all

Vulnerability of individuals and communities

Active and passive freedom of information

Trust, transparency, and trustworthiness

Privacy, confidentiality, and consent

Aims

- To guide **organizations and individuals** seeking advice on how to **ethically engage in social listening**,
- In concordance with the **protection and respect for human rights**,
- As part of an **infodemic management protocol**,
- **Before and during health emergencies.**

= Navigate the tensions detailed before and (try to) strike that balance.



2. The process

The process

Infodemics? IM?

Moral values to pursue?

How do we get there?

Define the activities and the context



Identify risks and challenges



Define aims



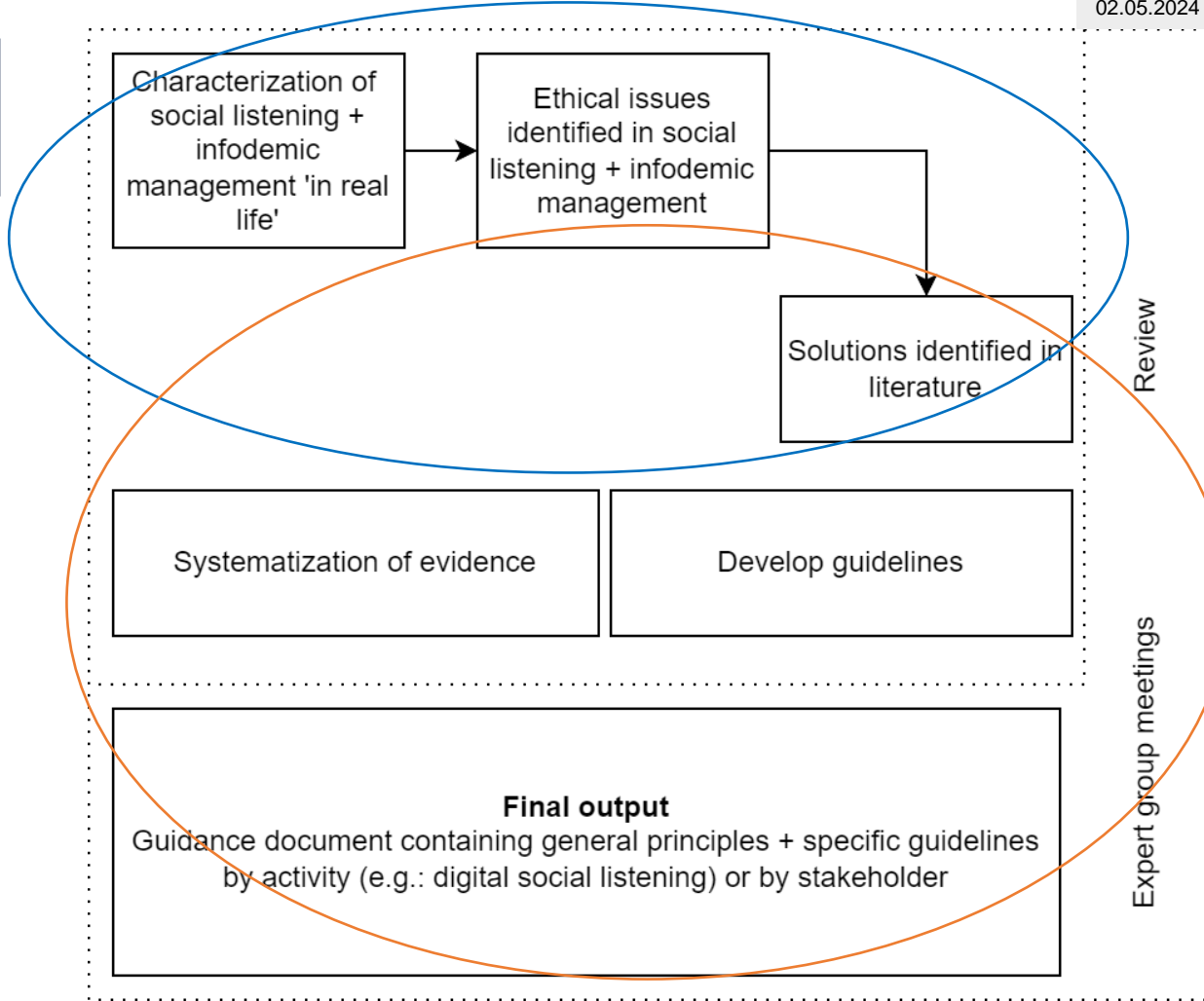
Define guiding principles



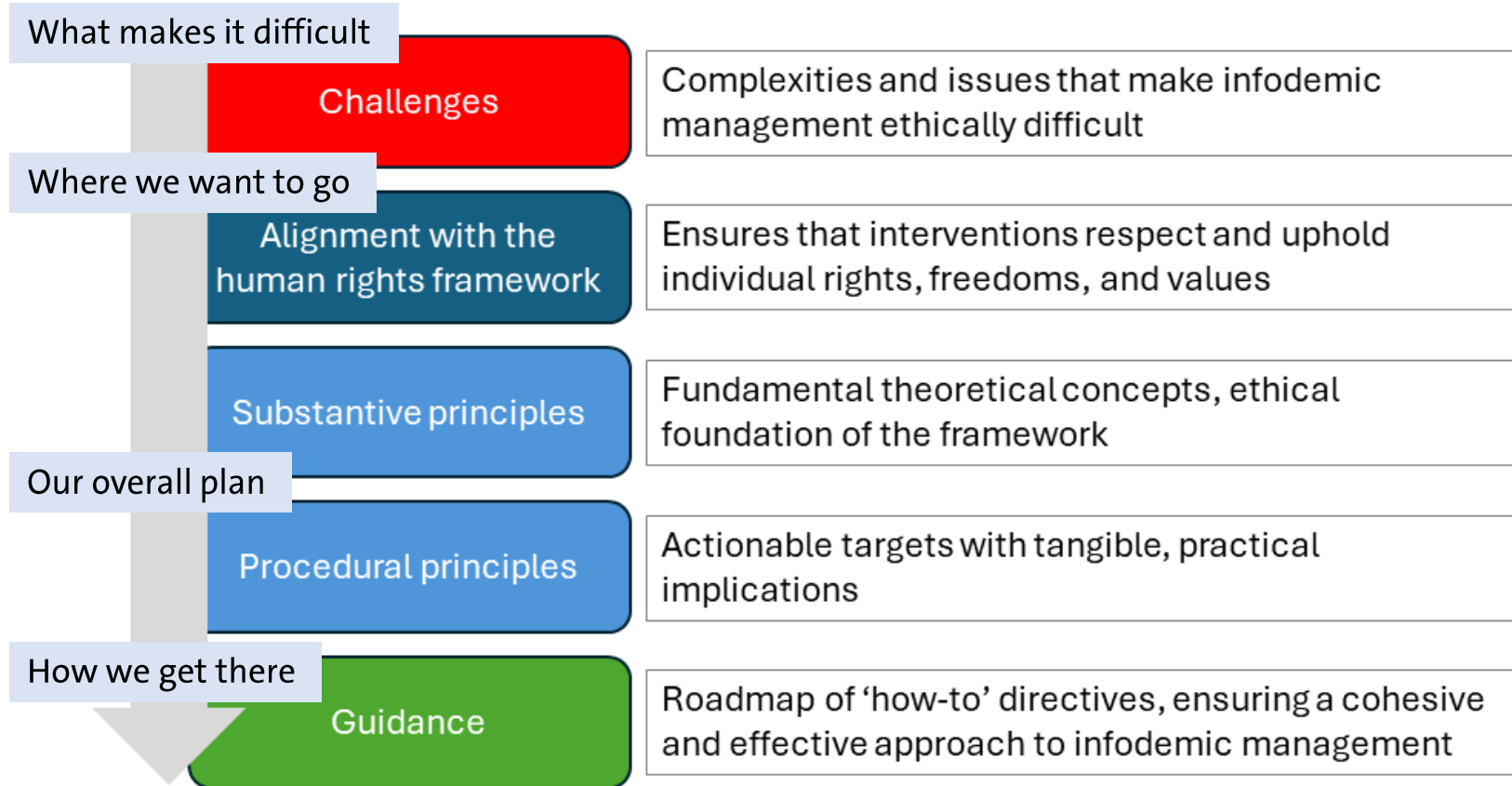
Develop implementation guidance

Potential harm?

Where do we want to go?



3. Architecture



4. Core content

Challenges

- Harm to people in vulnerable situations
- Erosion of trust
- Ineffective health systems response
- Data misuse, dual use, or unintended negative consequences of data collection
- Managing power imbalance, guaranteeing good governance, and establishing governance policy
- Censorship
- Navigating uncertainty (epistemic underdetermination, truth, revisability, reliability, certitude)
- Identifying legitimate actors
- Ensuring Infodemic management effectiveness while adhering to ethical standards
- Challenges of Artificial Intelligence (AI)



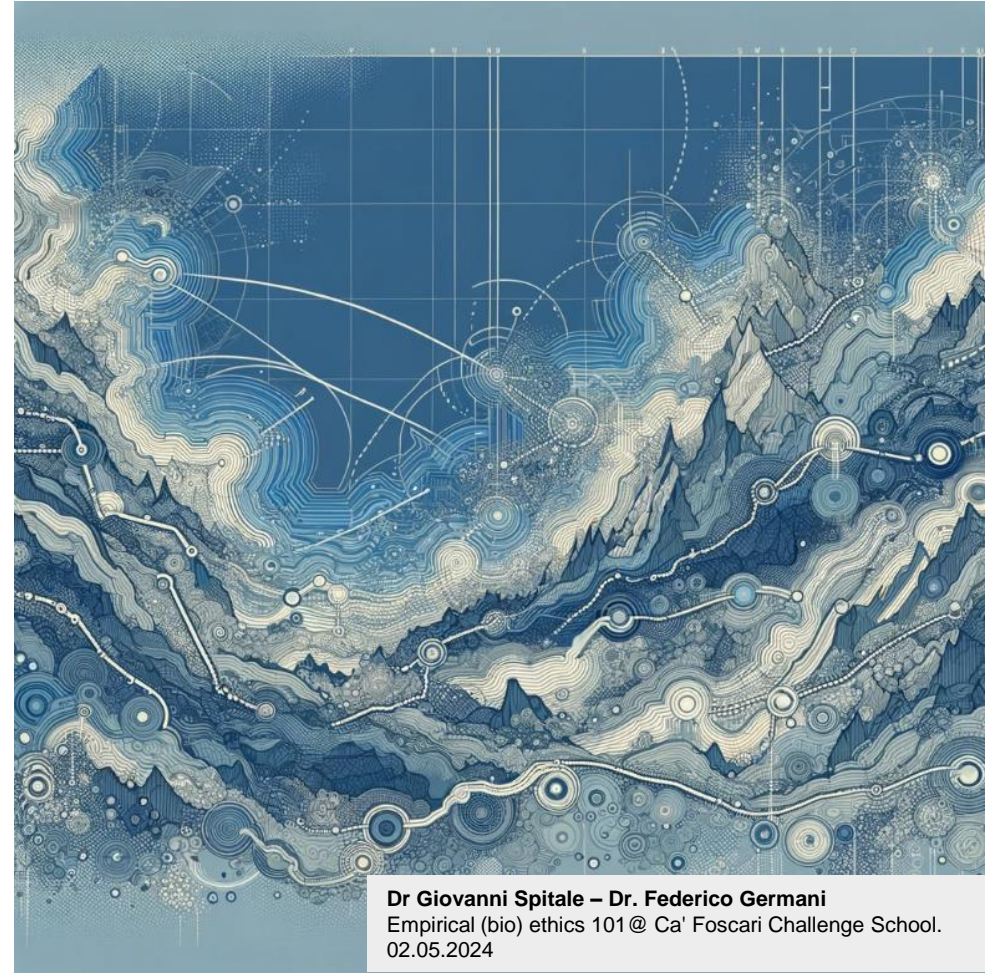
Substantive principles

- Freedom of expression
- Equity and vulnerability
- Epistemic justice
- Guaranteeing integrity of actors and actions
- Transparency
- For the common good: being driven by beneficence
- An application of the principles of necessity, utility, proportionality, and least intrusive approaches



Procedural principles

- Privacy
- Responsible large-scale data processing (Big Data and AI)
- Apply fair, equitable and inclusive processes of decision making
- Preserve and build trust, reciprocal trust, trustworthiness
- Integrating feedback
- Value community engagement
- Pursue understandability of communication



Recommended actions

Recommendations help shaping concrete actions according to ethical desirability.

Recommendations target specific stakeholders (e.g.: International health organizations; national governments; public health officials, ...) and specific infodemic management activities (e.g.: capacity building; planning infodemic response procedures; collecting infodemic insights; ...) with a pragmatic life cycle approach.



E.g: Privacy X Social listening

- 1. Prioritize anonymity; else, informed consent:** Whenever possible, operate on anonymized data. If not possible, obtain explicit and informed consent from individuals before collecting and using their data for infodemic monitoring and detection. Ensure that they understand the purpose and potential uses of their data.
- 2. Adhere to data protection regulations:** Comply with relevant data protection regulations and laws to safeguard user information. Ensure that all data handling processes adhere to legal requirements, such as the General Data Protection Regulation (GDPR).
- 3. Privacy by design:** Incorporate privacy considerations from the outset of infodemic management processes. Ensure that privacy safeguards are integral to the design and implementation of data collection and analysis methods, in order to guarantee that data points in the datasets are not attributable to individuals.
- 4. Proportionate data processing:** Only collect and process data that is necessary and proportionate for the specified infodemic management purposes. Conduct impact assessments to justify the need for such data processing.
- 5. Temporary restrictions:** If exceptions to privacy principles are deemed necessary, ensure that they are explicitly limited to the state of emergency and that they are legally justified, necessary, and proportionate. Implement safeguards to protect individuals' data and plan for a return to normal data processing after the state of emergency is lifted.

5. Systematic scoping review

INFODEMIC



- Too much information during a disease outbreak
- It causes confusion, risk-taking, and harms health.
- It leads to mistrust in authorities and undermine public health response
- It can worsen disease outbreaks.
- Growing digitization can amplify the spread of harmful messages.

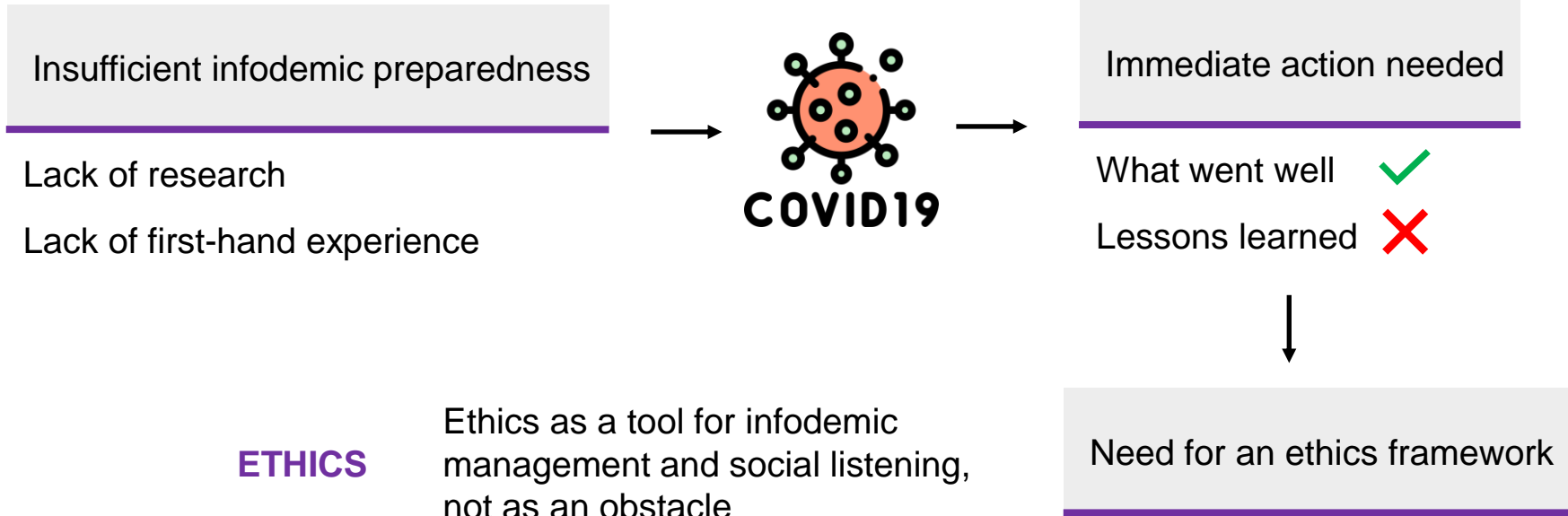
- The systematic use of risk- and evidence-based analysis and approaches to manage the infodemic and reduce its impact on health behaviours during health emergencies.

INFODEMIC MANAGEMENT



SOCIAL LISTENING

- Monitoring and integrating analysis from diverse data sources (social, behavioral, media, and epidemiological)
- Systematic analysis, generating intelligence, helps structuring judgment and producing actionable recommendations.



*Submitted to JMIR AI
(103 studies included in the review)*

Evidence-based guidance
(Scoping review)

**WHO Expert Group on
ETHICAL CONSIDERATIONS OF SOCIAL LISTENING AND
INFODEMIC MANAGEMENT**

Publication expected late 2024



Guidance document - Ethical considerations of
social listening and infodemic management



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**World Health
Organization**



INFODEMIC

OR

What happens during infodemics
(Misinformation, information voids,
etc.)

AND

Response (to misinformation,
information voids, etc.)

OR

Social listening

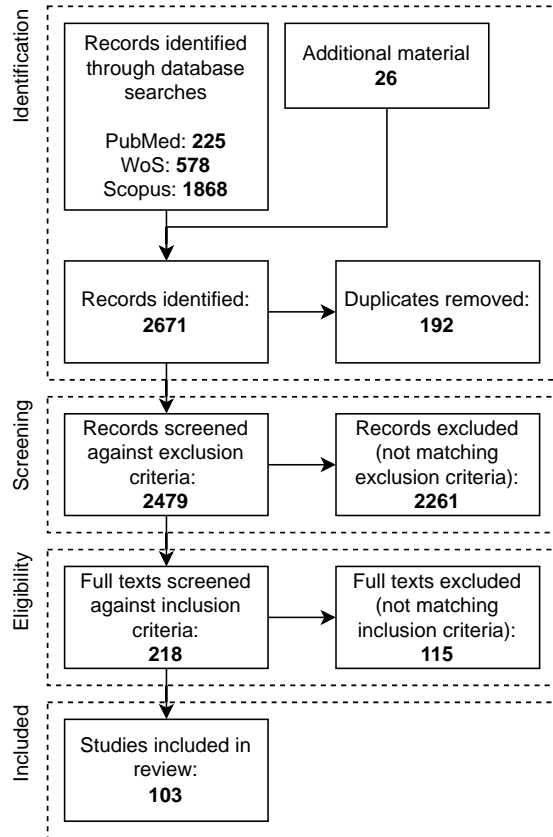
AND

Context (which emergency, chronic
emergency, etc.)

AND

ETHICS

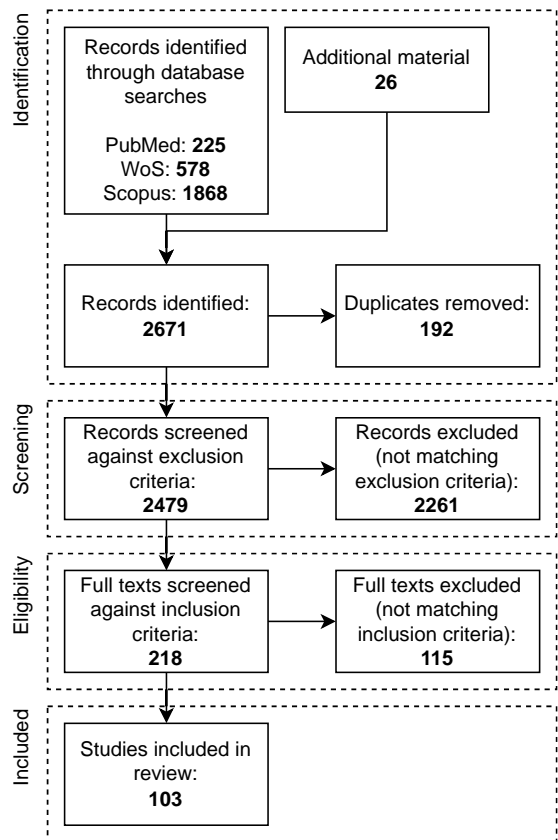




INCLUSION CRITERIA

full text is available AND
full text mentions **social listening** or **infodemic management** (directly or indirectly, see 'infodemics (expanded)' in query definition/query v3)
OR (full text mentions outbreak, epidemic, pandemic OR full text mentions public health, risk for public health, public health emergency, and related concepts (both 'acute' and 'chronic')) AND
full text mentions **ethics or ethical aspects**





Assessment

Paper already assessed as: include

See inclusion criteria ▼

Include?
 Yes Maybe No

Country: United States (US) x ▼

Year: 2023 - +

Health emergency/issue

Study type
 Theoretical
 Empirical
 Literature review
 Viewpoint/commentary
 Other

Methodological notes





Item type	
Journal Paper	88
Document	9
Preprint	2
Report	2
Presentation	1
Book	1



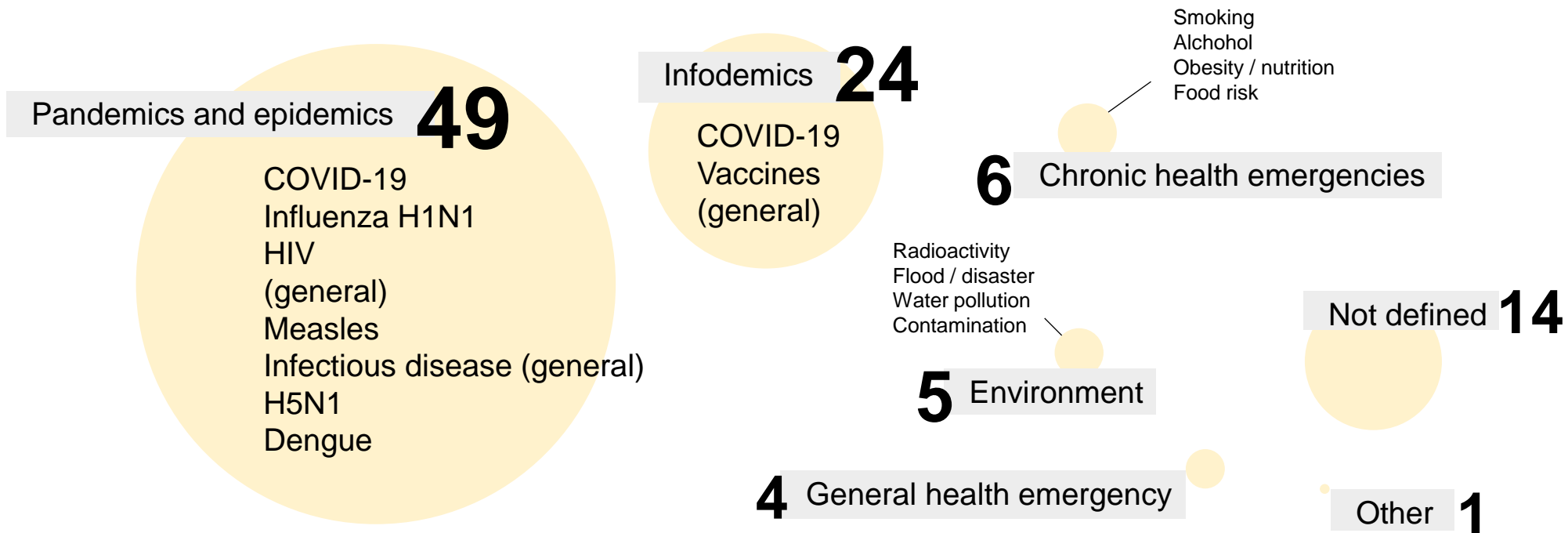
Study type	
Theoretical	45
EMPIRICAL	35
Viewpoint/commentary	14
Other	5
Literature review	4



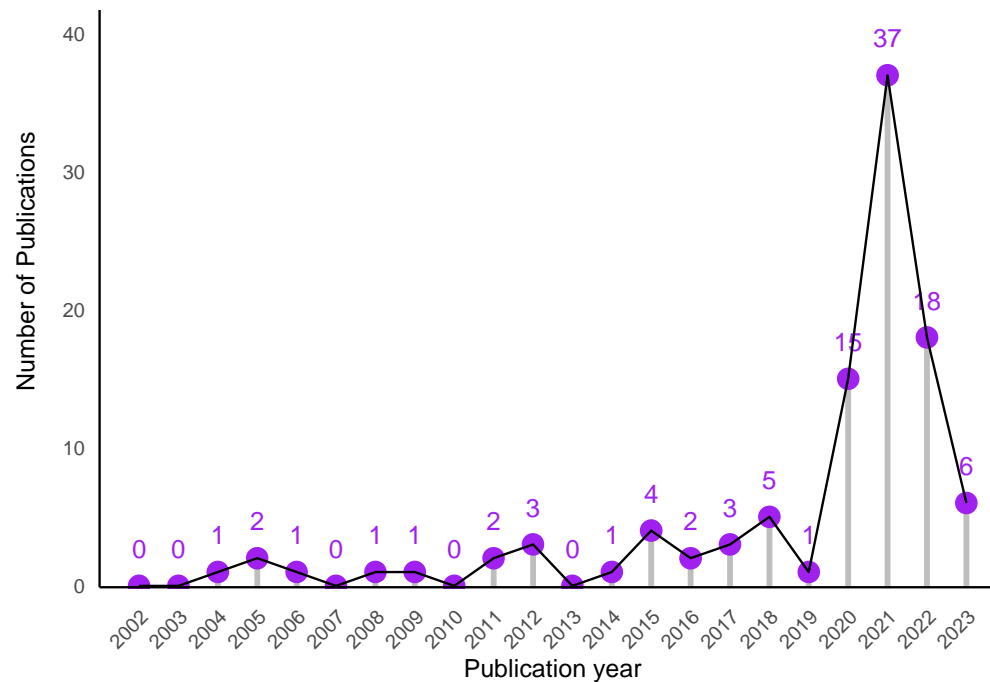
Methodology	
Observational	30
Cross-sectional	28
Descriptive	21
Quantitative	12
Qualitative	11
Mixed methods	11
Analytical	8
Longitudinal	7
Experimental	5



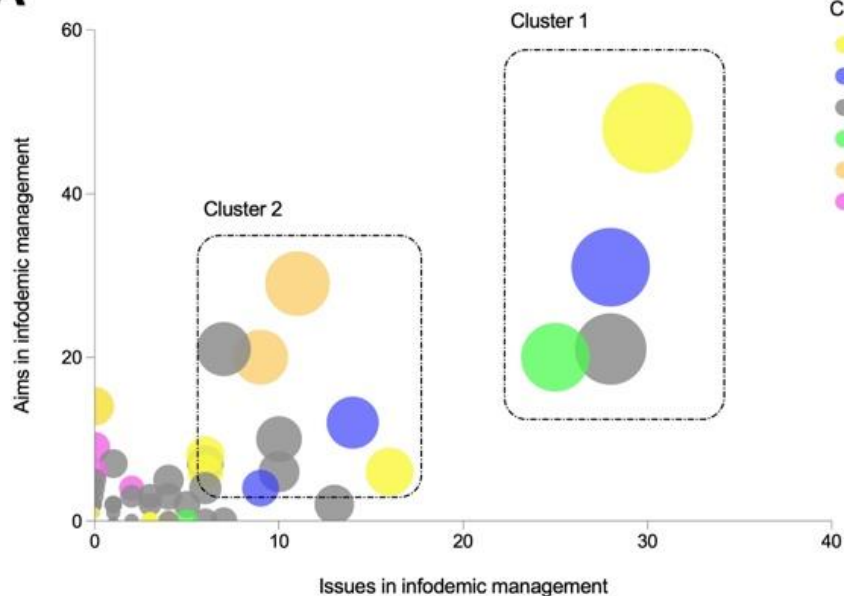
TYPE OF HEALTH EMERGENCY (number of studies)



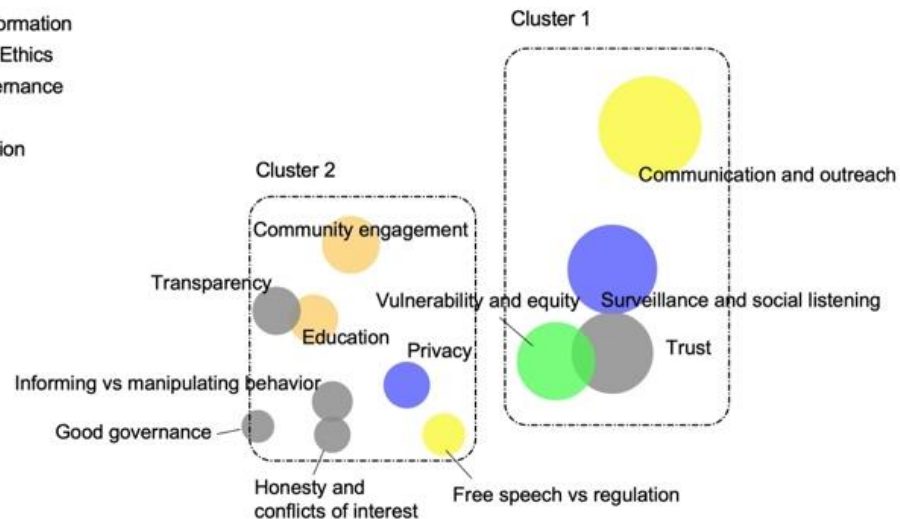
PUBLICATION YEAR

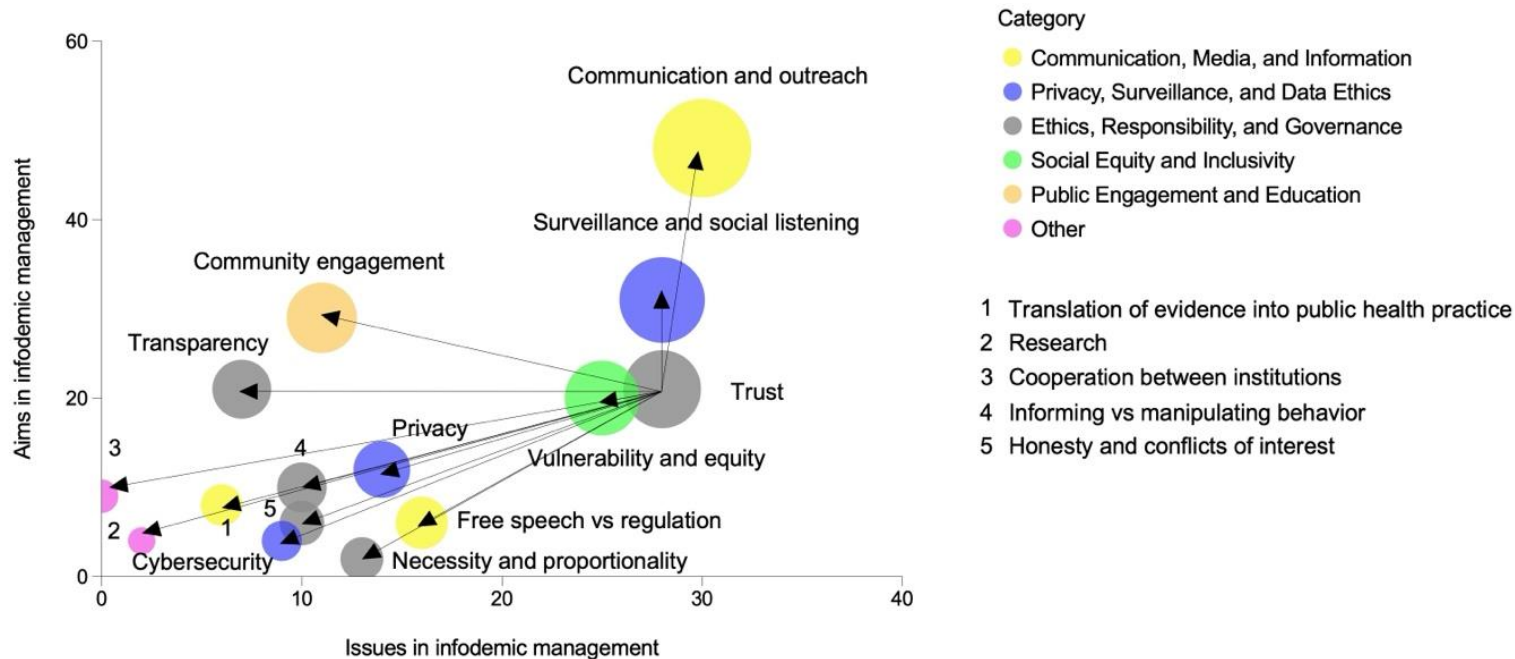


A



B





1 TRUST



Embrace Public Involvement

Avoid top-down approaches; involve the public.



Prioritize Ethics

Avoid profit-oriented mindsets, focus on public welfare.



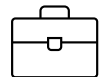
Build Trust in Research

Strengthen trust in research and researchers.



Maintain Integrity

Refrain from manipulating the public, even for good causes.



Demonstrate Credibility

Be credible and rely on expertise.



Inform, Don't Shape Policy

Provide objective information to inform public policy.



Collaborate

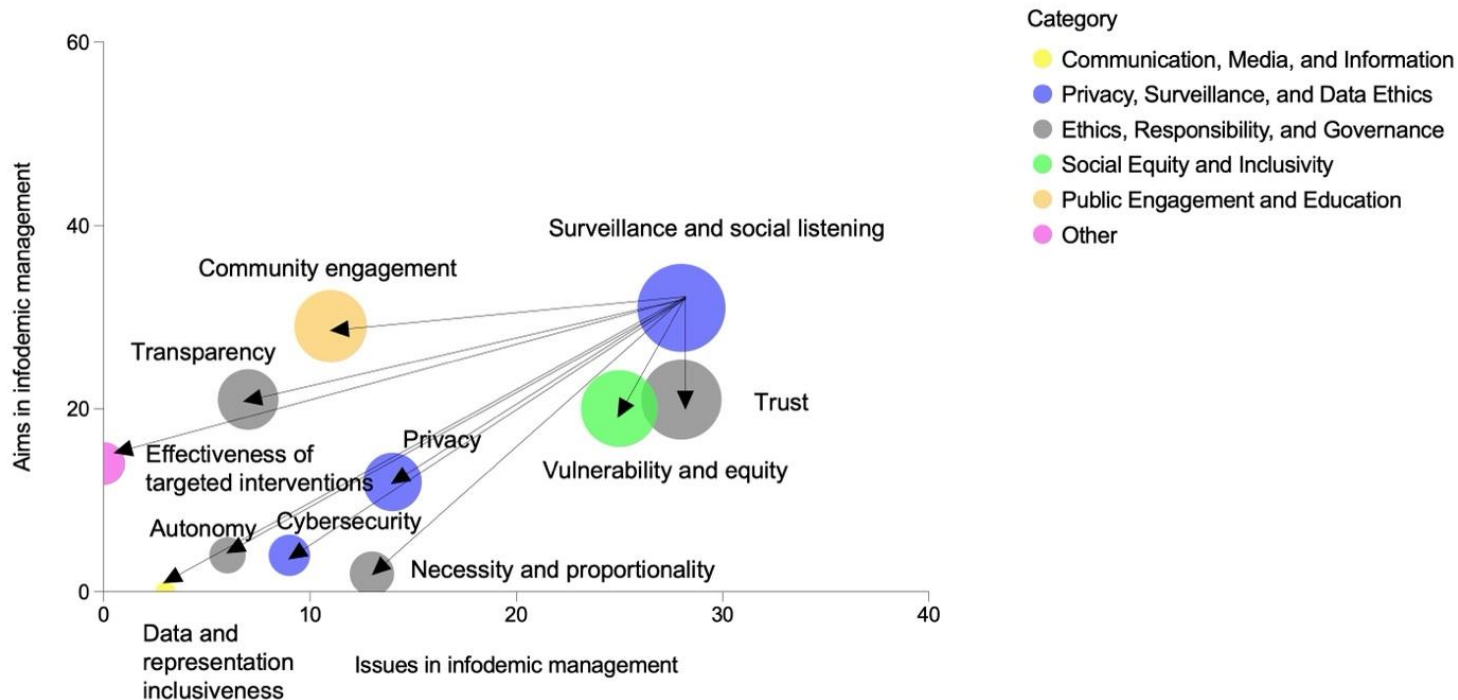
Collaborate with various stakeholders for inclusive decision-making.



Business-like Approach

Consider branding and advertising services to highlight public benefits.





2 SURVEILLANCE AND SOCIAL LISTENING



Informed Consent

Include informed consent in social listening, except in situations of necessity and with relevant protection in place.



Transparent Data Collection

Publicly explain data collection and social listening strategies.



Prioritize Active Listening

Prefer active social listening practices.



Ethical Boundaries

Avoid using social listening for dissent tracking.



Minimize Bias

Strive for data representativeness to minimize biases in social listening.



Real-time Monitoring

Monitor information flows in real-time, including offline sources



Address Public Concerns

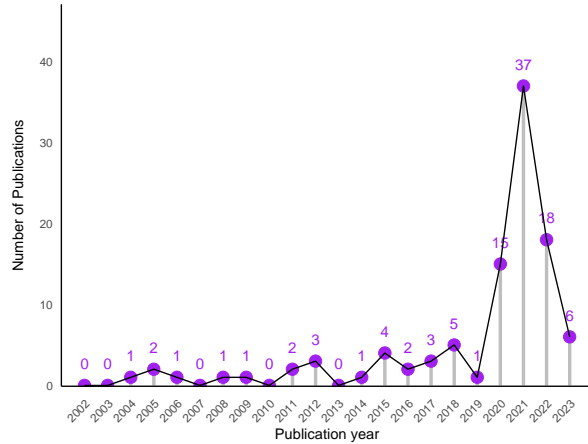
Consider public concerns when shaping infodemic management strategies based on social listening analytics.



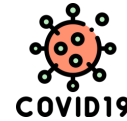
Protect Privacy Rights

Guarantee privacy throughout the social listening process.





Crisis response in a context of **BROAD** epistemic underdetermination



FIELD experience

Research



University of Zurich ^{UZH}



World Health Organization



How to improve

- 1 Public engagement
- 2 Active social listening
- 3 Transparency
- 4 Acknowledging uncertainty
- 5 Building resiliency



REDUCE POLARIZATION and increase TRUST

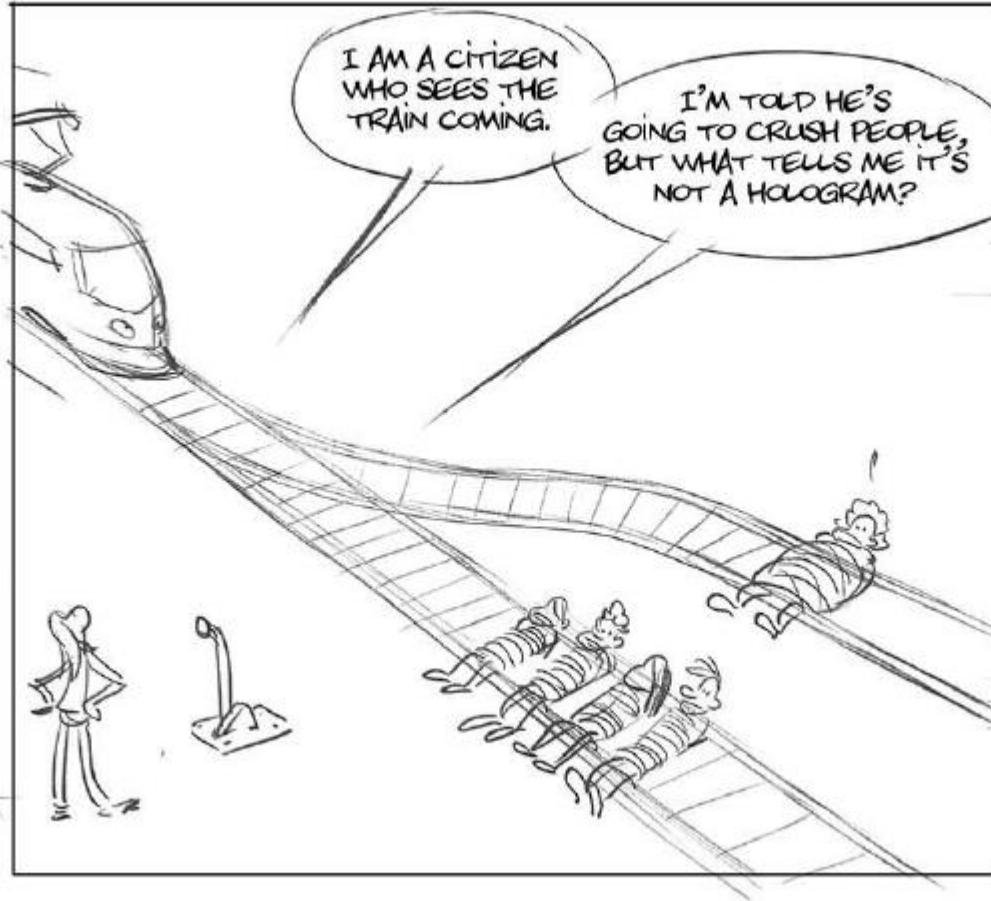


Improved public health response
Adherence to public health measures



SUMMARIZING:

- Infodemics and infodemic management pose significant **challenges**.
- An **ethical framework** is necessary for effective infodemic management.
- The development process is based on both **literature and experts' views**.
- The architecture includes **definitions, ethical challenges, process aims, principles, and stakeholder-specific guidance**
- Ethics is not an obstacle, but rather a **tool** to enhance the effectiveness of infodemic management





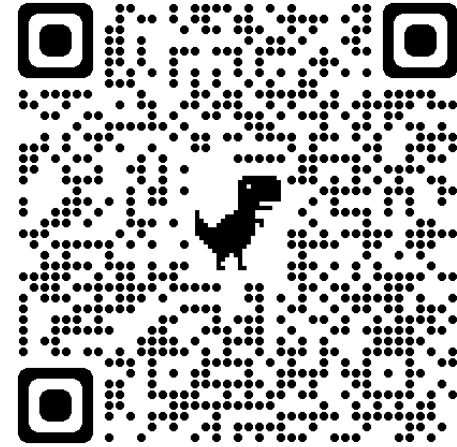
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Thanks for
Your time!
it's over, I swear

Download the slides [here](#)



Bucke