

WHO leads the way? Bridging ethics and practice in social listening and infodemic management



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- Infodemics and infodemic management
- Ethical aspects in theory and practice
- WHO Guidance document

Defining the issue

Process aims

Target

Development

Architecture

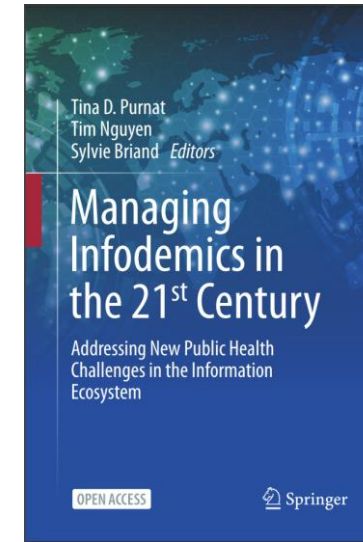
Challenges

Principles

Recommended actions

INFODEMIC

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



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“An infodemic is an overabundance of information, accurate or not, in the digital and physical space, accompanying an acute health event such as an outbreak or epidemic”

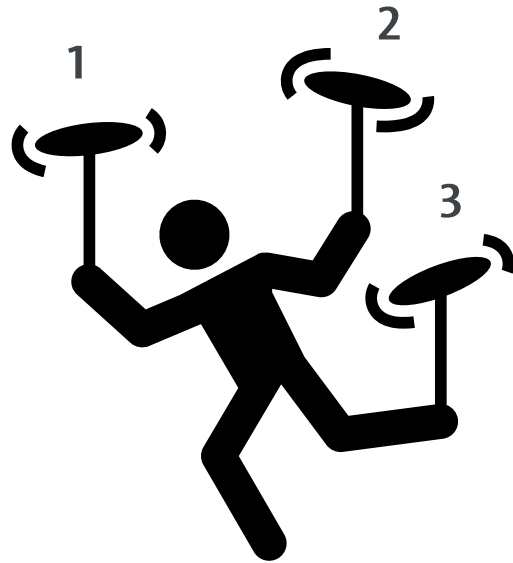
The systematic use of risk- and evidence-based analysis and approaches to manage the infodemic and reduce its impact on health behaviours during health emergencies.

Infodemic management

Managing the infodemic and reducing its impact



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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

...

Spitale G, Germani F, Biller-Andorno N. The PHERCC Matrix. <https://doi.org/10.1080/15265161.2023.2201191>

- 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.*



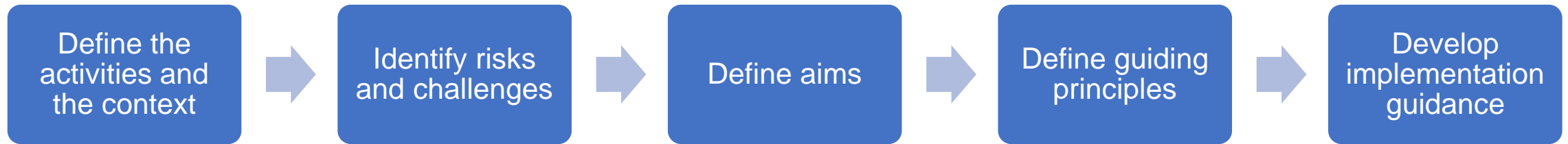
- Ministries of health, public health officials, agencies, national and international organizations
- **Media and journalists**, professional societies
- **Researchers** and academics
- **Tech companies** and social media platforms, as well as companies that can be **hired by main stakeholders** to conduct social listening
- **Community leaders**, civil society organizations, including e.g., patient or consumer organizations, grassroots fact-checking organizations, influencers, and digital partners



Infodemics? IM?

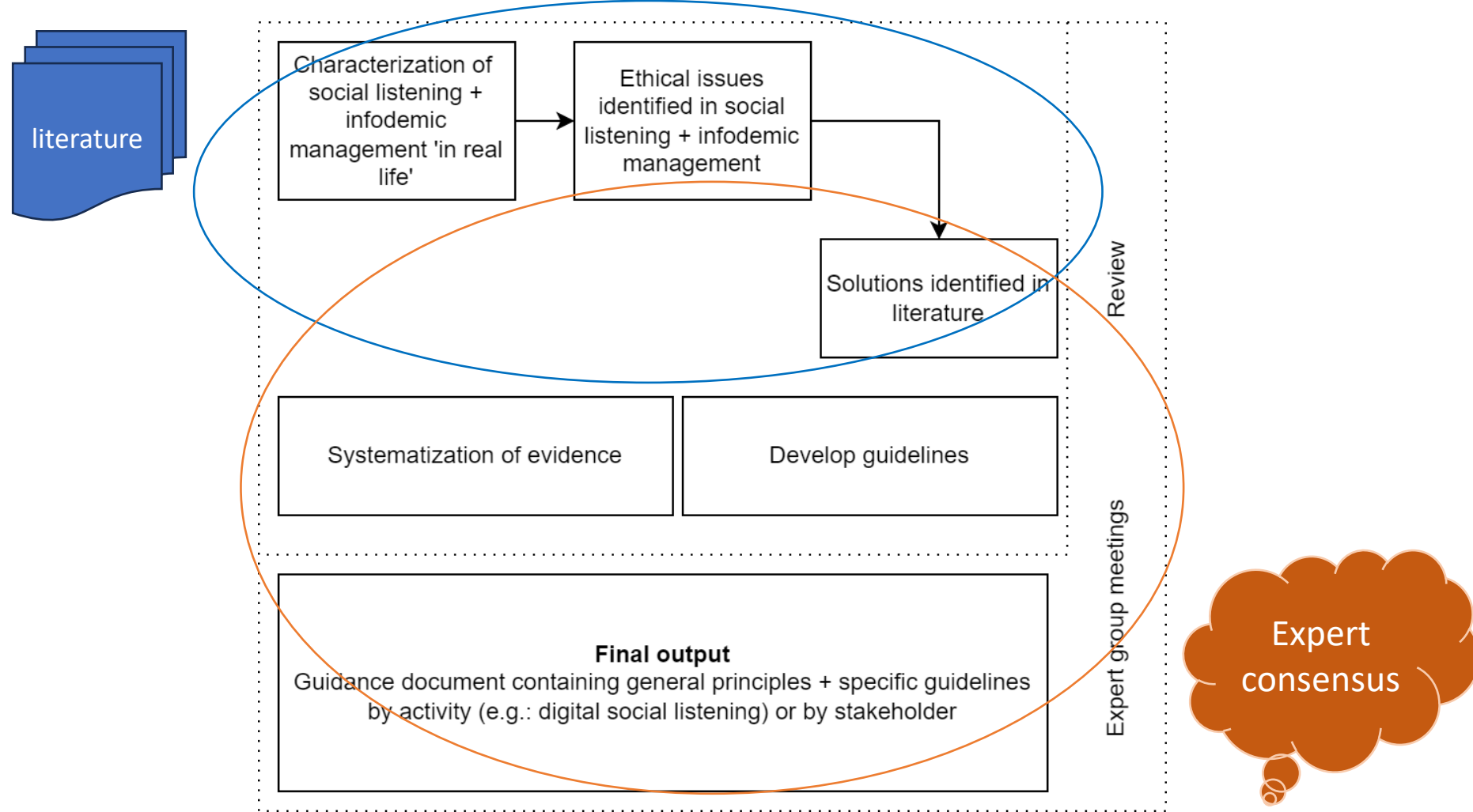
Moral values to pursue?

How do we get there?



Potential harm?

Where do we want to go?



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Ethical Considerations in Infodemic Management: Systematic Scoping Review

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- [Abstract](#)
- Introduction
- Methods
- Results
- Discussion
- References

Abstract

Background:

During health emergencies, effective infodemic management has become a paramount challenge. A new era marked by a rapidly changing information ecosystem, combined with the widespread dissemination of misinformation and disinformation, has magnified the complexity of the issue. For infodemic management measures to be effective, acceptable, and trustworthy, a robust framework of ethical considerations is needed.

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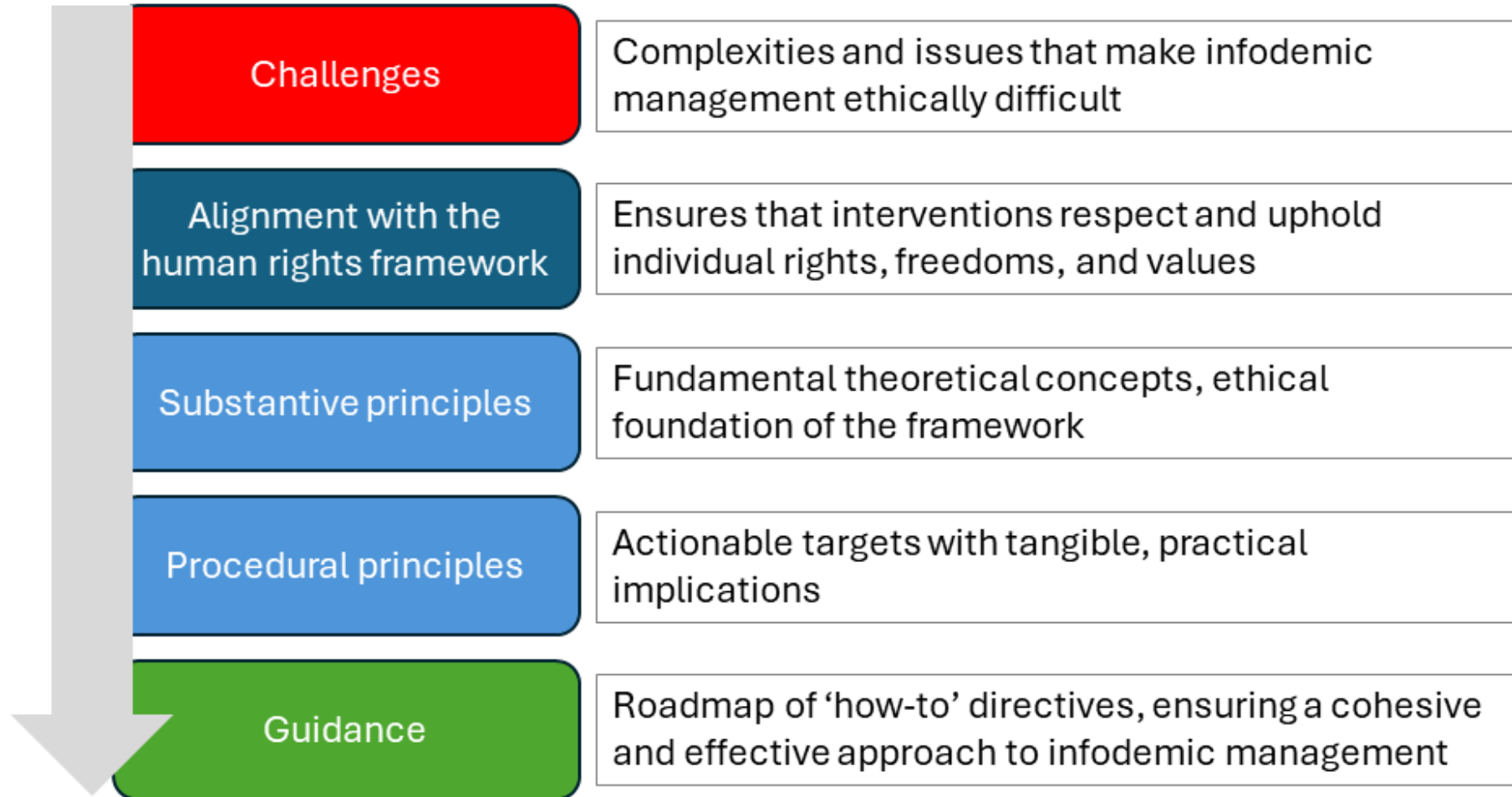
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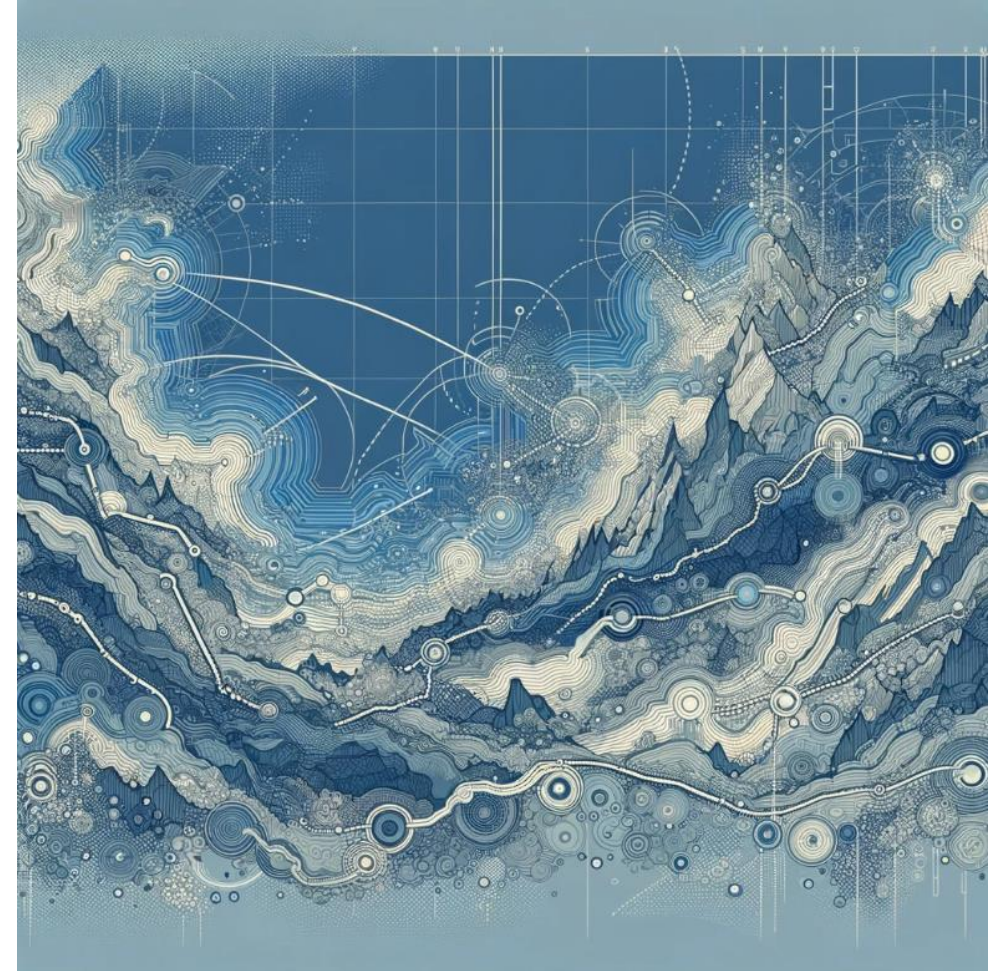
- Harm to people in vulnerable situations
- Erosion of trust
- Ineffective health systems response
- Data misuse, dual use, or unintended negative consequences of data collection
- Managing power imbalance, guaranteeing good governance, and establishing governance policy
- Censorship
- Navigating uncertainty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



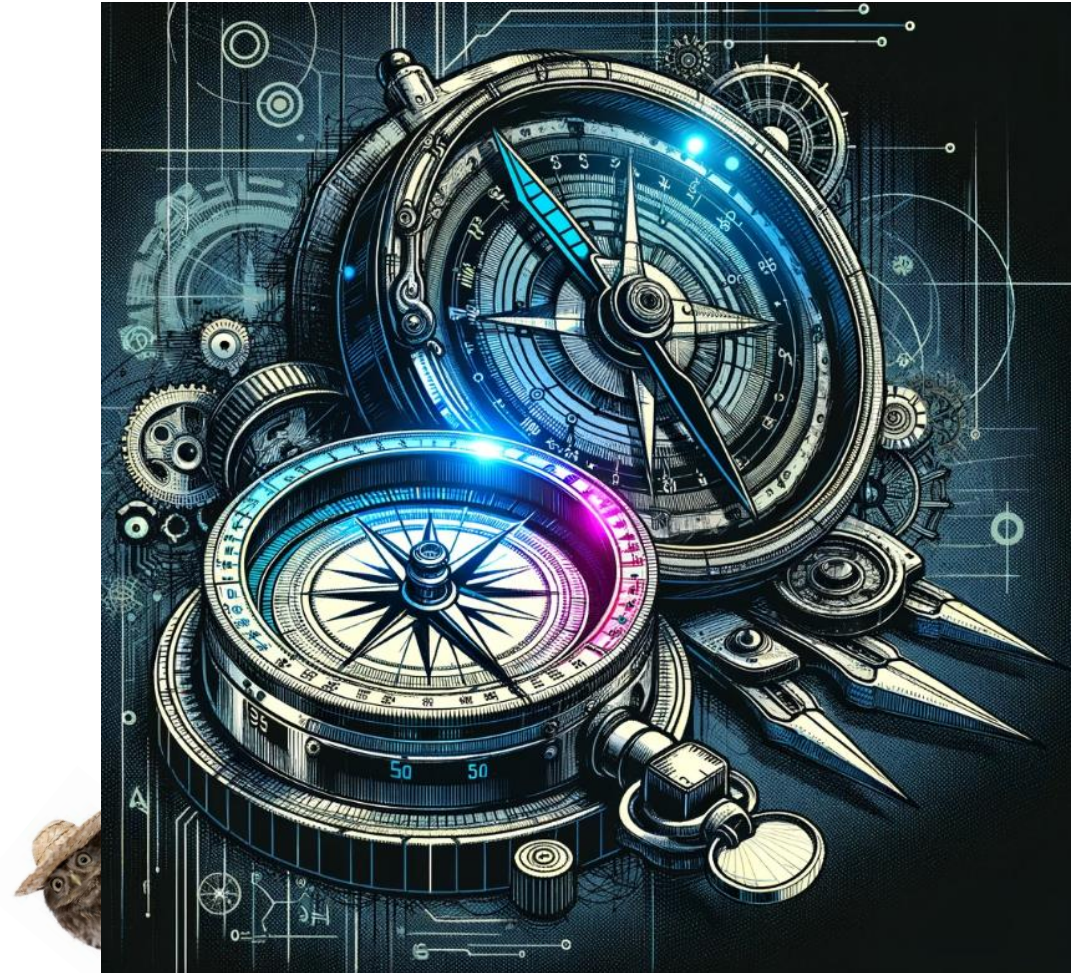
- Freedom of expression
- Equity and vulnerability
- Epistemic justice
- Guaranteeing integrity of actors and actions
- Transparency
- For the common good: being driven by beneficence
- An application of the principles of necessity, utility, proportionality, and least intrusive approaches



- 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



- Help shaping concrete actions according to ethical desirability.
- Target specific stakeholders (e.g.: International health organizations; national governments; public health officials, ...)
- Apply to specific infodemic management activities (e.g.: capacity building; planning infodemic response procedures; collecting infodemic insights; ...) with a pragmatic life cycle approach.



Elements of IM	Procedural principles						
	Privacy	Responsible large-scale data processing	Fair decision making	Trust	Feedback integration	Community engagement	Understandability
Monitoring and detection of narratives, questions, concerns, and misinformation in the information ecosystem	●						
Science and health communication							
Education and training to build resilience to misinformation							
Engagement							
Laws, regulations, and ethics general edit for language							

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.

Thank you!



University of
Zurich ^{UZH}



World Health
Organization

infodemic
MANAGEMENT

