Social listening in infodemic management for public health emergencies: Guidance on ethical considerations







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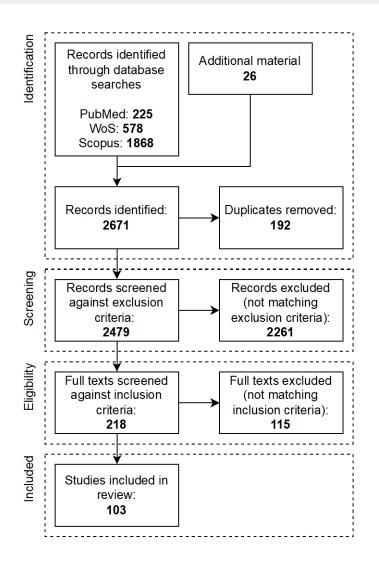
Focus: social listening and infodemic management as defined in search strategies











INCLUSION CRITERIA

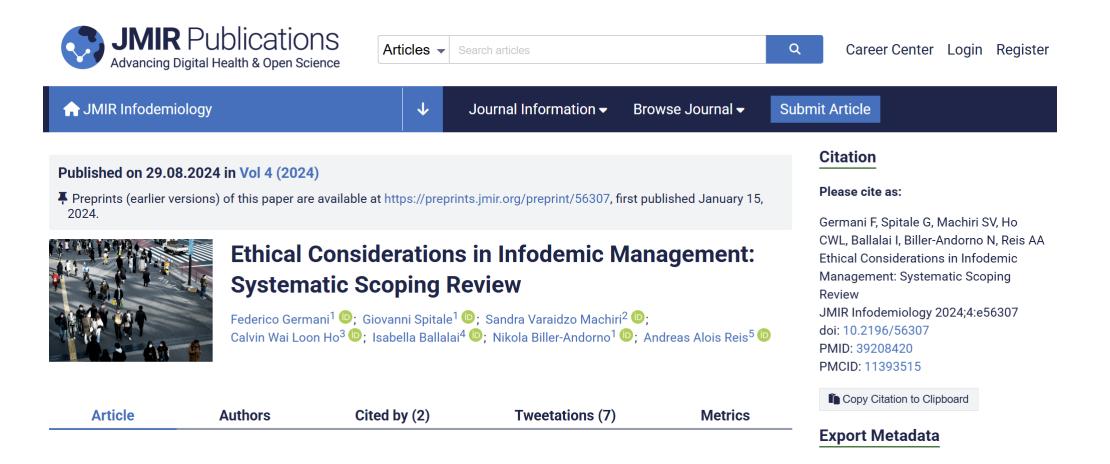
full text is available (in English) AND
full text mentions social listening or infodemic
management (directly or indirectly, see \'infodemics
(expanded)\' in query definition/query v3) OR
full text mentions outbreak, epidemic, pandemic OR
full text mentions public health, risk for public health, public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





Ethical Considerations in Infodemic Management: Guidance Document



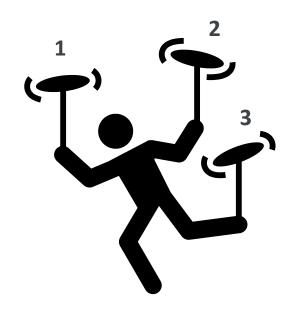


Germani F, Spitale G, et al. Ethical Considerations in Infodemic Management: Systematic Scoping Review. https://doi.org/10.2196/56307









- 1. Effectiveness/Efficacy/public good/usefulness
- 2. Autonomy
- 3. Fairness/justice

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.











Complexities and issues that make infodemic management ethically difficult

Ensures that interventions respect and uphold individual rights, freedoms, and values

Fundamental theoretical concepts, ethical foundation of the framework

Actionable targets with tangible, practical implications

Roadmap of 'how-to' directives, ensuring a cohesive and effective approach to infodemic management





- 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, promoting good governance, and establishing governance policy
- Restrictions to freedom of expression
- 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)









Universal declaration of Human Rights

Fundamental rights and freedoms to which all individuals are entitled.



Principles and Guidelines on Human Rights & Public Health Emergencies

Principles and obligations integral to human rights in the landscape of public health emergencies



Digital Rights

Fundamental rights and freedoms that individuals possess in the digital realm.





SUBSTANTIVE PRINCIPLES

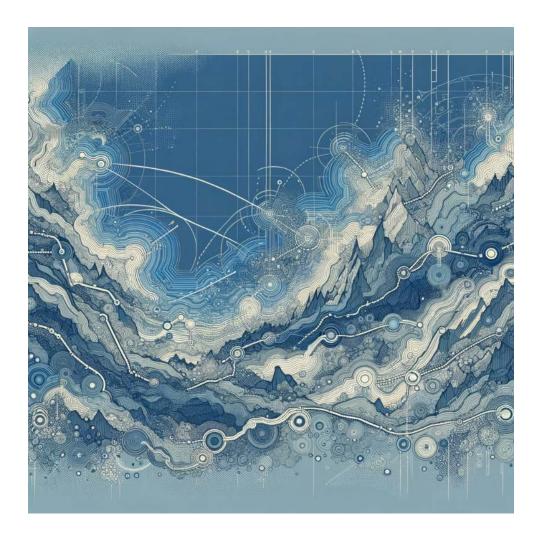
- Freedom of expression
- Equity and vulnerability
- Epistemic justice
- Guaranteeing integrity of actors and actions
- Transparency
- For the common good







- Promoting privacy
- Responsible large-scale automated data processing
- Apply fair, equitable and inclusive processes of decision making
- Trust
- Feedback integration
- Community engagement
- Pursuing 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 makin	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 for your attention.

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