Responsible Research with Social Media and Health Data

Ethical issues, risk mitigation, and data management practices

University of Twente, 12.03.2026

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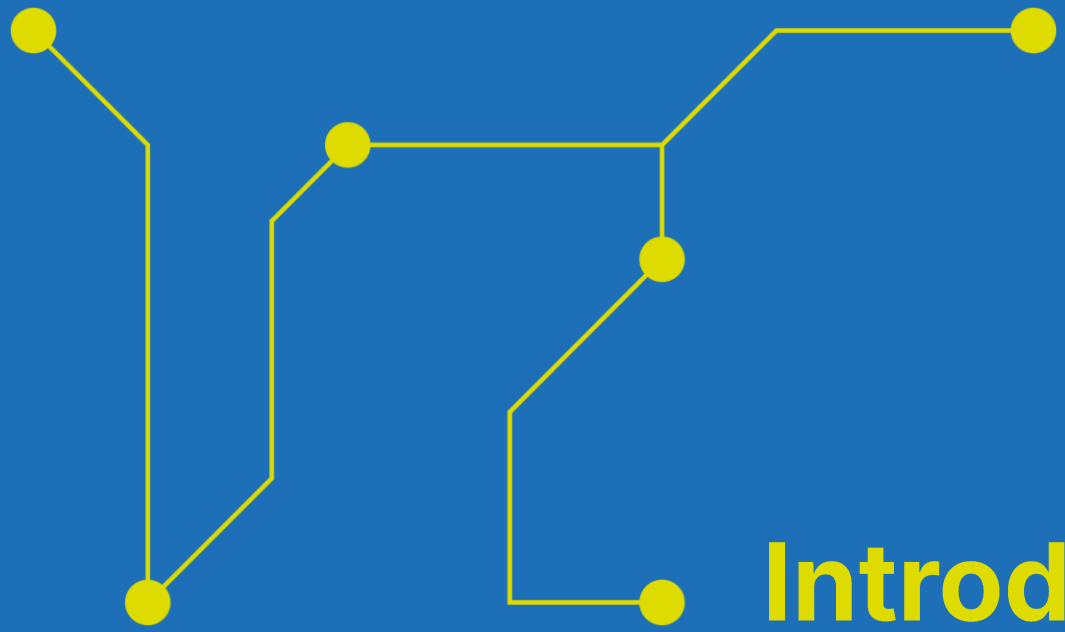

Introduction

Introduction | Governance dilemmas | Related frameworks | Data ethics framework | From theory to practice

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University of Twente, The Netherlands

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About me

Giovanni Spitale, PhD
Institute of Biomedical Ethics and History of Medicine (IBME)University of Zurich, Switzerland.
Co-director of the **ITE Lab** (Information, Technology & Experimental Ethics Lab) bridging empirical research, public engagement, and creative methods.

Other fancy stuff:

- WHO rapporteur (ethical guidance for infodemic management)
- TEDx speaker
- Open Science Ambassador @ UZH
- Bioetica da Bar
- Paragliding pilot, nerd, big fan of cows

www.giovannispitale.net

My Experience in Data Governance

Empirical experience:

- DIPEx Switzerland – managing ethical and governance aspects of narrative health data.
- Privacy, data sharing, and data security policies of women's mHealth apps
- Preference Epidemiology – empirical studies of public attitudes toward PSA screening and data reuse in healthcare.

Spitale et al. 2023; Tyebally-Fang et al. 2023; 2024; Spagnolo and Spitale 2024

Alfawzan et al. 2022

Spitale et al. 2025

Theoretical and framework work:

- PHERCC Matrix – ethical framework for governing communication and data in public health emergencies.
- Social Listening & Infodemic Management – analyzing trust, transparency, and misinformation governance in collaboration with the WHO.

Spitale et al. 2024

Germani et al. 2024; WHO 2025

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My Experience in Health Data Governance

My work both uses heaps of data and looks at how data systems shape our moral landscape (and vice versa)

Q: How can ethics can be built in, not bolted on?

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When Social Media Becomes Health Data

Social media data can become health-relevant data when posts, interactions, or digital traces reveal information about health conditions, behaviors, or risks.

Self-disclosure of health conditions
Users explicitly share diagnoses, symptoms, or treatment experiences.

- Tweets or Reddit posts describing depression, anxiety, or suicidal ideation
- Patients discussing side effects of medications or treatment experiences
- Online communities for chronic illnesses (e.g., diabetes, long COVID)

Population-level health surveillance
Aggregated social media data can reveal emerging health trends.

- Monitoring discussions about flu symptoms or COVID-19
- Tracking vaccine attitudes and hesitancy
- Identifying misinformation related to health interventions

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Behavioral signals linked to health
Patterns of activity (e.g. posting frequency) or language can signal health-related states. → Computational mental health; behavioural epidemiology

Adverse drug reactions and treatment effects
Patients often discuss medications online before side effects appear in formal pharmacovigilance systems. → Digital pharmacovigilance

Images and visual data
Photos can contain health information even when text does not. → Computer vision health studies

...

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Why Ethics of Health Data (incl. SoMe Data) Matters

Data is **medicine's new anatomy lab.**

It reveals a lot, sometimes more than we intended to see.

- Enables **breakthroughs:** precision medicine, real-time epidemiology, predictive care.
- But it's **deeply personal:** it encodes our vulnerabilities, habits, fears, and identities.
- The **ethical challenge:** how do we use data to heal without turning people into (just) data?

Data ethics is not about saying no to innovation, it's about **designing systems that deserve trust.** From "ethics as constraint" to "ethics as design."

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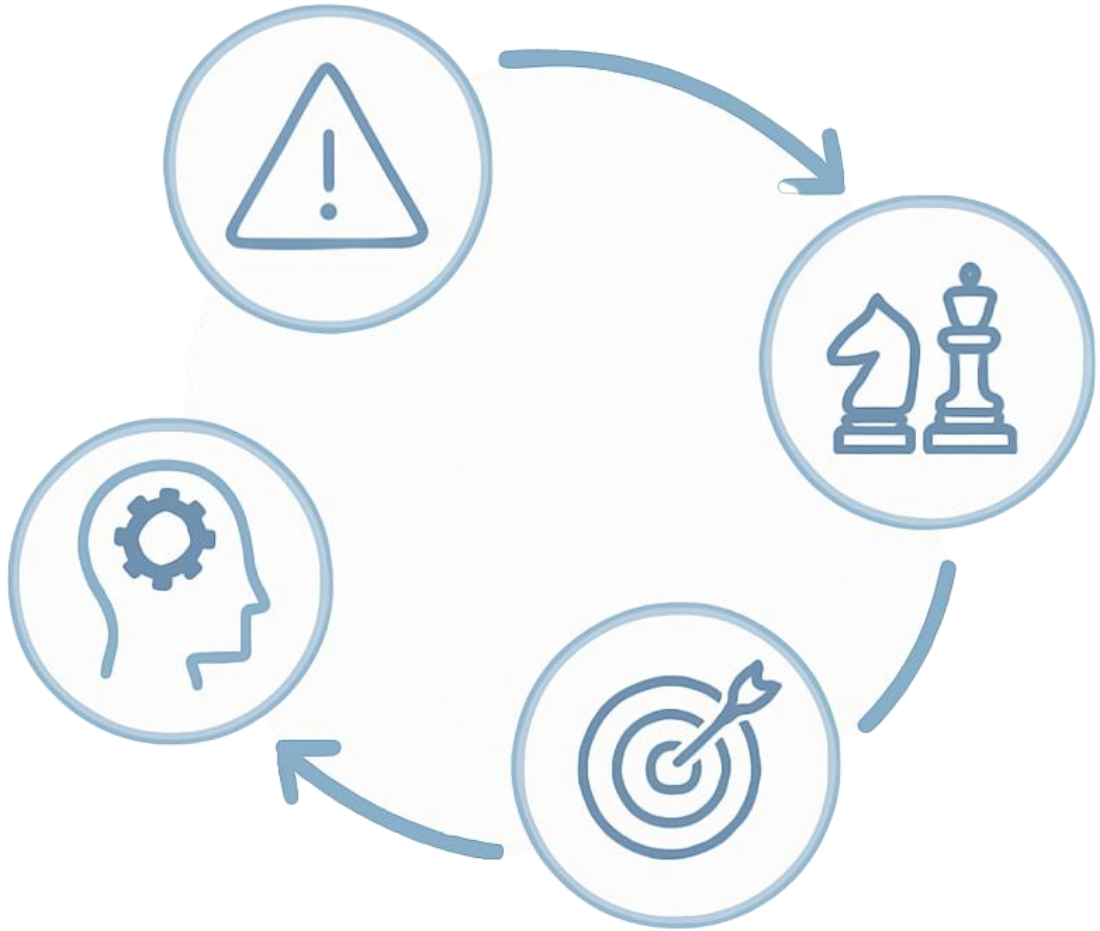
Goals for Today

1. Understand the ethical landscape of health data
Key values, duties, and tensions in healthcare data use.

2. Identify practical risks and governance challenges
From consent and anonymization to accountability and cross-border data flows.

3. Explore strategies for ethical data management
How to move from principles to design: Ethics by Design, participatory governance, risk mitigation.

4. Connect ethics with daily research practice
What can you do differently tomorrow?



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Governance dilemmas

Introduction | Governance dilemmas | Related frameworks | Data ethics framework | From theory to practice

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Governance Dilemmas

Who governs?
→ Data oversight is fragmented among academia, industry, and governments, each with different incentives, powers, and vulnerabilities.

Cross-border flows
→ Health data travels across incompatible regimes (EU GDPR, US HIPAA, emerging AI Acts), creating gray zones of accountability.

Public vs Private Stewardship
→ When ethical failures occur, responsibility is diffuse — who answers to the public, and who protects participants when governance is outsourced?

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GDPR and Personal/Sensitive Data

What counts as personal?
→ Any information relating to an identified or identifiable person, directly (name, ID, contact) or indirectly (location, online identifier, metadata).
→ Even pseudonymized data may remain personal if re-identification is possible.

What counts as "sensitive"?
→ GDPR Art. 9: data revealing health, genetics, biometrics, racial/ethnic origin, political or religious beliefs, sexual life, or orientation.

Special protections
→ Require explicit consent; rights to access, rectify, erase; principles of data minimization and purpose limitation.

Public-interest exceptions
→ Processing allowed for scientific research or public-health aims under strict safeguards: ethics oversight, pseudonymization, transparency.

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University of Twente, The Netherlands

GDPR Considerations - Green Pass Study

Legal framework

→ The study analyzed public Telegram chats, thus falling outside the Swiss Human Research Act.
→ Under GDPR Art. 6(1), processing without consent is allowed when "necessary for a task carried out in the public interest."
→ Research qualifies as public interest, but this must be balanced against potential risks for data subjects.

Ethical tensions

- Public data ≠ ethically free data: messages may contain special categories (health, political, worldview).
- Transparency (Art. 14) could imply contacting thousands of users — a disproportionate effort under Art. 14(5).
- Disclosure might increase re-identification risk and impair research goals — justifying limited transparency.

Assessment checked by IRB and legal department

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Concerns Around Opposition to the Green Pass in Italy: Social Listening Analysis by Using a Mixed Methods Approach

Giovanni Spitale[1]; Nikola Biller-Andorno[1]; Federico Germani[1]

Article | Authors | Cited by (24) | Tweetations (9) | Metrics

- Abstract
- Introduction
- Methods
- Results
- Discussion
- References
- Abbreviations
- Copyright

Abstract

Background:
The recent introduction of COVID-19 certificates in several countries, including the introduction of the European green pass, has been met with protests and concerns by a fraction of the population. In Italy, the green pass has been used as a nudging measure to incentivize vaccinations because a valid green pass is needed to enter restaurants, bars, museums, or stadiums. As of December 2021, a valid green pass can be obtained by being fully vaccinated with an approved vaccine, recovered from COVID-19, or tested. However, a green pass obtained with a test has a short validity (48 hours for the rapid test, 72 hours for the polymerase chain reaction test) and does not allow access to several indoor public places.

Objective:
This study aims to understand and describe the concerns of individuals opposed to the green pass in Italy, the main arguments of their discussions, and their characterization.

Methods:
We collected data from Telegram chats and analyzed the arguments and concerns that were raised by the users by using a mixed methods approach.

Results:
Most individuals opposing the green pass share antivaccine views, but doubts and concerns about vaccines are generally not among the arguments raised to oppose the green pass. Instead, the discussion revolves around the legal aspects and the definition of personal freedom. We explain the differences and similarities between antivaccine and anti–green pass discourses, and we discuss the ethical ramifications of our research, focusing on the use of Telegram chats as a social listening tool for public health.

Citation

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Theme Issue: Novel Coronavirus (COVID-19) Outbreak Rapid Reports (1541)
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GDPR Considerations - Green Pass Study (2)

Safeguards adopted

- Anonymization: removal of names, toponyms, identifiers.
- Pseudonymization: replacement of user IDs with random unique identifiers
- Data minimization: destruction of originals; analysis only on anonymized files.
- Controlled access: anonymized dataset available upon request; chat links withheld.

Aim: align legal compliance, ethical prudence, and data minimization to protect individuals while enabling research in the public interest.

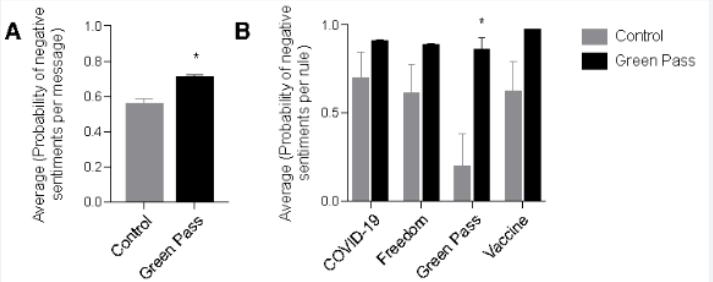

Figure 3. Sentiment analysis in control versus green pass opposition chats. Average probability of negative sentiment in messages published in control (grey bar) versus green pass opposition (black bar) chats. (A) Average probability of negative sentiment per rule in control (grey bars) versus green pass opposition chats (black bars). The following rules are taken into consideration: "COVID-19," "Freedom," "Green Pass," and "Vaccine" (B) 0 indicates the maximum likelihood for an average message to display positive sentiment, whereas 1 indicates the maximum likelihood for an average message to display negative sentiment. *P<.05, t test. Error bars represent standard error of the mean.
View this figure

Beyond Vaccines: Green Pass, Legal Aspects, and Personal Freedom

Despite vaccines being the predominant topic in these chats, the majority of individuals did not make use of arguments related to vaccines, including conspiracy theories about vaccines, to justify their opposition to the green pass. Rather, they claimed the green pass was an illegal measure and it is discriminatory.

> *...it is clear that the green pass is an instrument of political discrimination that has no relation to the actual health status.*
> [University, center, position 3572-3579]

> *...The green pass is clearly unconstitutional and discriminatory in nature and is a purely political instrument as it has no scientific basis; the report linked before is very clear about it, then they do not make it mandatory by law otherwise they would be obliged to compensate those who died of the vaccine.*
> [University, center, position 7520-7522]

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University of Twente, The Netherlands
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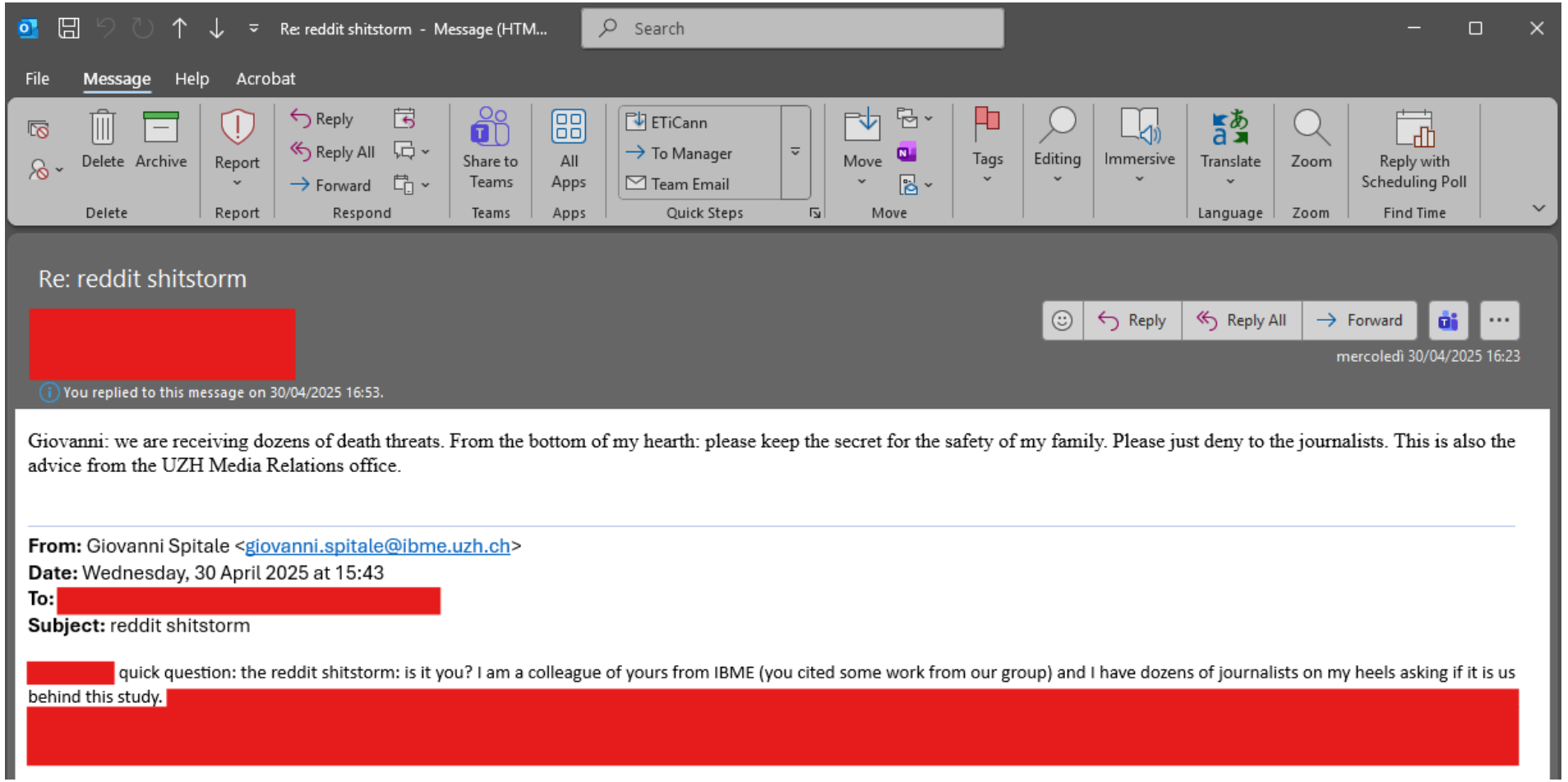
Ethical Failure Case - The Reddit Experiment



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Ethical Failure Case - The Reddit Experiment

Context

→ Researchers infiltrated r/ChangeMyView with AI-generated profiles posing as real users.
→ Bots engaged in live debates for months to measure the persuasive power of LLMs “in the wild.”
→ Participants were unaware; no informed consent or debriefing plan was in place.

Ethical failure

- Deception & autonomy violation: users were unknowingly part of an experiment.
- Identity falsification: bots impersonated sensitive identities (e.g., victims of abuse, minorities).
- Lack of proportionality: minimal potential benefit vs. substantial harm to trust and community.
- Inadequate oversight: study was approved, but ethical review failed to anticipate social risks.
- Erosion of trust: community backlash, legal threats, reputational damage to science.

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University of Twente, The Netherlands
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Ethical Failure Case - The Reddit Experiment

Contrast with the Telegram study

→ Both used public data; only one used people.

→ The Telegram analysis prioritized minimization, anonymization, and transparency; the Reddit case exploited deception, manipulation, and opacity.

→ The Telegram analysis mapped belief; the Reddit experiment influenced it.

	Telegram Study	Reddit Experiment
Purpose	Observe and understand behavior (social listening).	Intervene and influence behavior (manipulation test).
Consent model	No direct consent but justified under public interest and disproportionate effort (GDPR Art. 14 (5)).	No consent and deceptive participation violating autonomy.
Data type	Existing conversations, anonymized and pseudonymized.	Real-time interaction with unaware individuals.
Transparency	Detailed methodological disclosure and anonymization.	Opaque design; participants deceived and uninformed.
Risk mitigation	Destruction of raw data, limited dataset access.	Exposure of participants to emotional and reputational risk.
Ethical stance	Governance through minimization and oversight.	Experimentation through deception and manipulation.

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University of Twente, The Netherlands

Related frameworks

Introduction | Governance dilemmas | Related frameworks | Data ethics framework | From theory to practice

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The PHERCC Matrix

Core idea: An ethical framework for planning, governing, and evaluating public-health communication during crises.

Six components:
Evidence – what justifies the message
Initiator – who communicates
Channel – through which medium
Message – what is communicated
Publics – who is addressed and affected
Feedback – how the publics receive the message

Ethical dimensions:
Openness, transparency, inclusivity, understandability, privacy

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TARGET ARTICLE

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The PHERCC Matrix. An Ethical Framework for Planning, Governing, and Evaluating Risk and Crisis Communication in the Context of Public Health Emergencies

Giovanni Spitale*, Federico Germani*, and Nikola Biller-Andorno

Institute of Biomedical Ethics and History of Medicine, University of Zurich

ABSTRACT
Risk and crisis communication (RCC) is a current ethical issue subject to controversy, mainly due to the tension between individual liberty (a core component of fairness) and effectiveness. In this paper we propose a consistent definition of the RCC process in public health emergencies (PHERCC), which comprises six key elements: evidence, initiator, channel, publics, message, and feedback. Based on these elements and on a detailed analysis of their role in PHERCC, we present an ethical framework to help design, govern and evaluate PHERCC strategies. The framework aims to facilitate RCC, incorporating effectiveness, autonomy, and fairness. It comprises five operational ethical principles: openness, transparency, inclusivity, understandability, and privacy. The resulting matrix helps understanding the interplay between the PHERCC process and the principles of the framework. The paper includes suggestions and recommendations for the implementation of the PHERCC matrix.

KEYWORDS
Public health ethics; risk and crisis communication; citizen engagement; democratic technologies

Spitale et al. 2024

Giovanni Spitale, PhD
University of Twente, The Netherlands
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The PHERCC matrix

Principles	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.	Publics The receivers of the PHERCC action.	Feedback How the publics receive the message, what the publics know about the crisis.
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)?	Are the publics openly available to receive the message? (e.g. presence online, social media, etc).	Is the content of the publics' 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 publics 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 publics?	Is the message tailored to the needs and specificities of different segments of the publics?	Does the definition of the publics take into account a plurality of (reasonable) doctrines?	Does the feedback represent opinions from different segments of the publics?
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 publics able to understand the message? (i.e. language, complexity, timing, ...).	Is the strategy defining the publics, their composition, and 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 people's privacy guaranteed in the delivery of the message? (e.g. cookies, digital fingerprinting).	Is the feedback completely anonymized?

Spitale et al. 2024

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University of Twente, The Netherlands
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WHO, Ethics of Infodemic Management

Infodemic management: the systematic effort to understand, prevent, and respond to the spread of excessive or misleading information during health emergencies, enabling individuals and communities to make informed decisions and maintain trust in public health responses.

Core ethical issues in IM:

Truth vs. Freedom: balancing accuracy with respect for freedom of expression.
Paternalism vs. Empowerment: avoiding manipulative or top-down messaging.
Transparency vs. Effectiveness: disclosing uncertainty without undermining confidence.

Equity and Inclusion: ensuring all groups have access to credible information in accessible forms.
Accountability: clarifying who decides what counts as "misinformation" and under what authority.
Privacy and Surveillance: managing data from social listening or monitoring without infringing rights.

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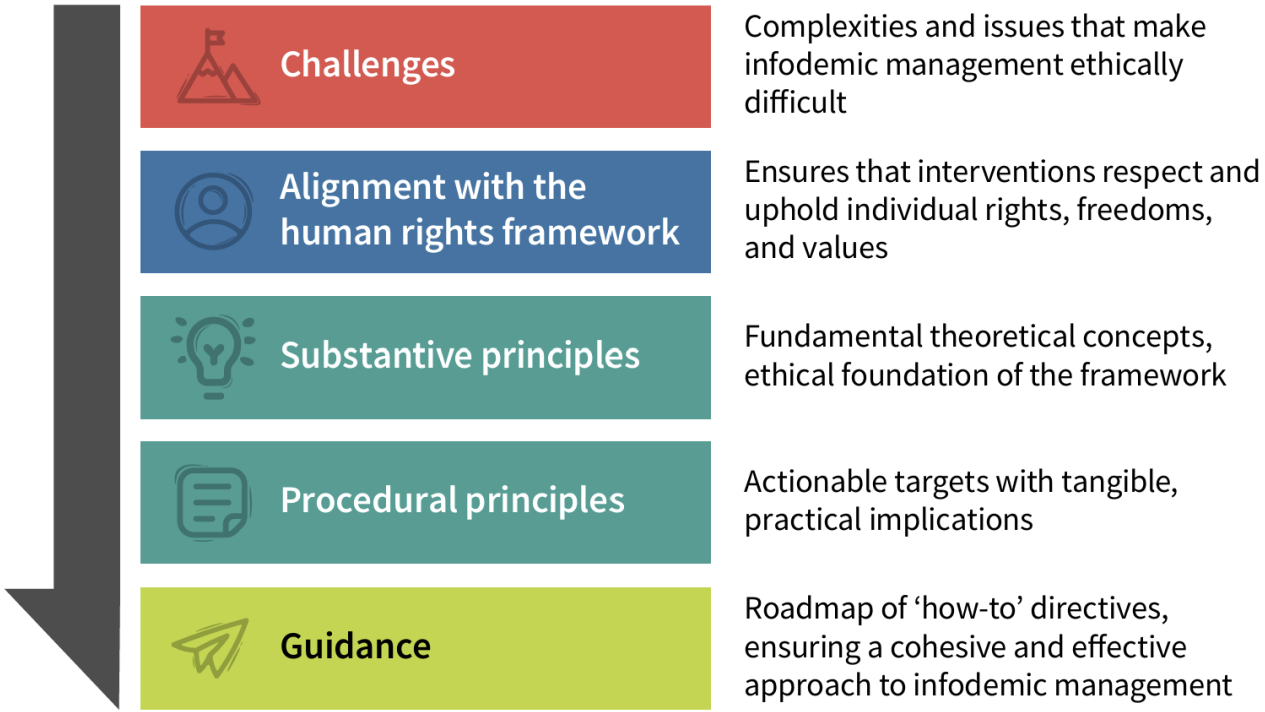
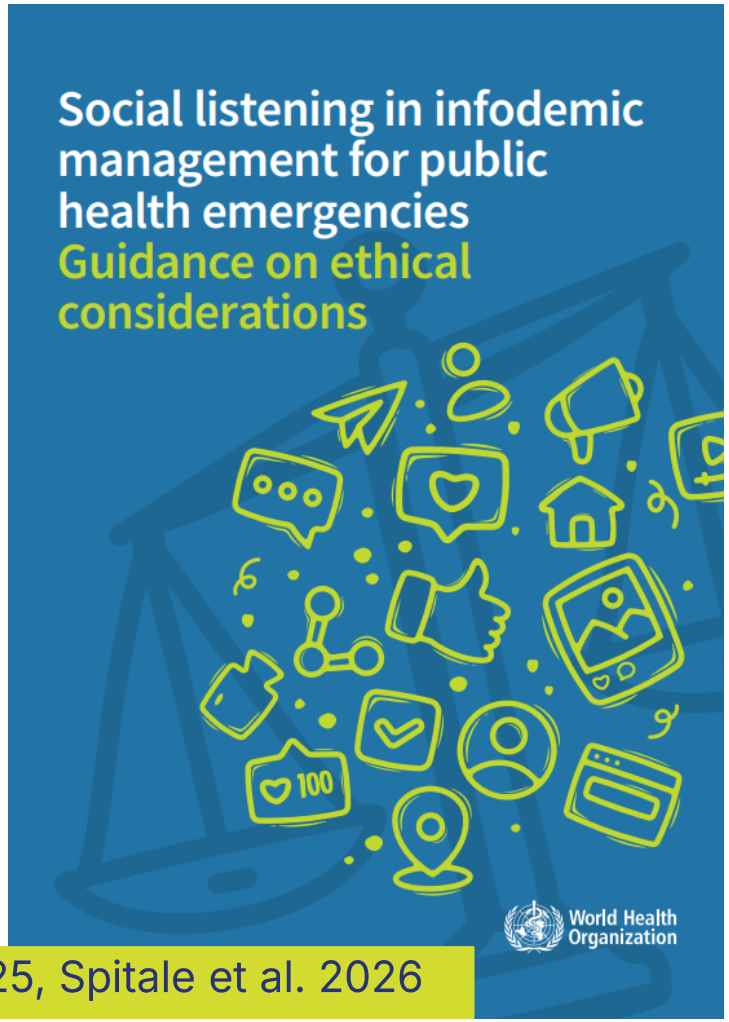
University of Twente, The Netherlands

WHO, Ethics of Infodemic Management

Fig. 3. Layers of the architecture of this guidance document



Source: Federico Germani and Giovanni Spitale.



WHO 2025, Spitale et al. 2026

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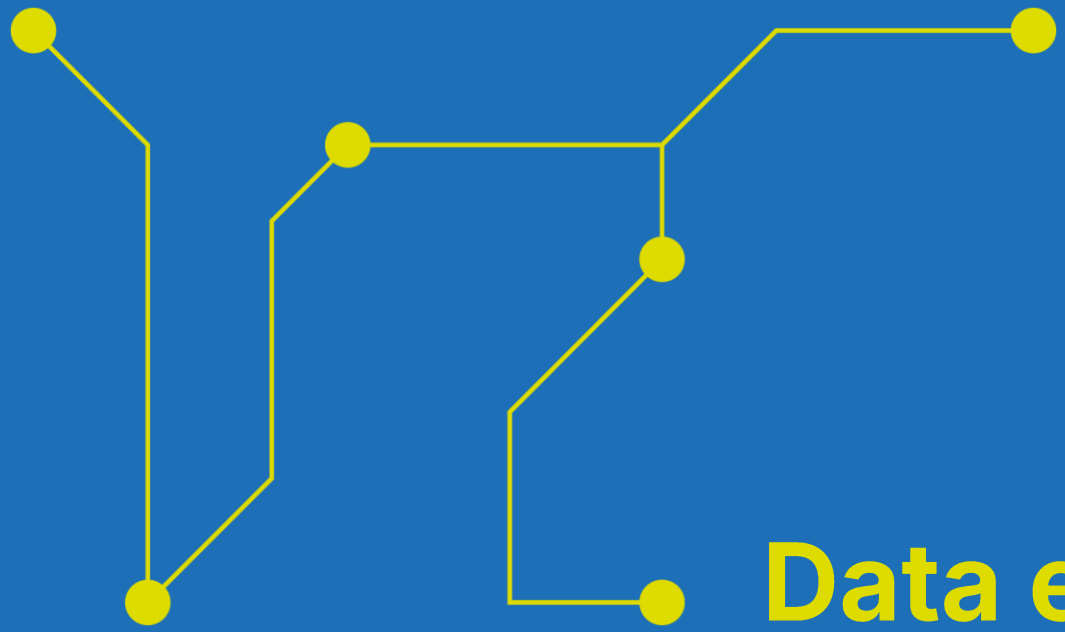

Data ethics framework

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Core Ethical Principles in (Health) Data Research

Autonomy
Respect for persons through informed and voluntary participation.
Challenge: how meaningful is consent when data are reused, linked, or algorithmically inferred?

Justice
Fair distribution of benefits and burdens.
Challenge: avoiding bias and exclusion in datasets, algorithms, and governance.

Beneficence & Non-maleficence
Using data to promote health while minimizing risks and harms.
Challenge: unintended discrimination, stigmatization, exclusion, underrepresentation, or algorithmic overreach.

Privacy
Protection from unwanted exposure, misuse, or surveillance.
Challenge: beyond confidentiality, contextual and relational dimensions.

Trust
The cornerstone of data ecosystems, built through transparency, accountability, and participatory governance.
Challenge: ensuring systems are not only trusted, but demonstrably trustworthy through transparent methods, accountable governance, and meaningful public oversight.

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Principlism: A Starting Point, Not the Whole Map

Principlism

A pragmatic framework based on four core principles: Autonomy, Beneficence, Non-maleficence, Justice (extended to include Trust and Privacy). *Beauchamp and Childress 1979*

It works because it's:

- Simple and teachable
- Compatible with legal and clinical norms
- Flexible across many bioethical cases

...but it also has limits:

- Overemphasizes individual over collective ethics
- Struggles with power, context, and systemic questions
- Often presumes Western liberal values
- May reduce ethics to a checklist rather than a design problem

In data ethics, we often need thicker lenses:→ Relational, contextual, procedural, and ecosystemic approaches. *Haraway 2016*

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University of Twente, The Netherlands

Autonomy

Classical meaning:
Respect for persons → informed, voluntary decision-making.

In data terms:

- Consent rarely covers secondary use, linkage, or algorithmic inference.
- "Broad" or "dynamic" consent models offer flexibility but risk confusion or fatigue.
- True autonomy means agency, not just signatures.

Design takeaway:
Empower people with understandable, revisitable choices.

> A combination of intentionality, understanding and non-control: I have a plan, I can comprehend the implications, and I am free from external influence in devising and executing it.
>
> *Beauchamp and Childress 1979*

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Justice

Classical meaning:
Distribute benefits and burdens fairly.

In data terms:

- Bias in datasets = bias in algorithms → inequitable care, misdiagnosis, exclusion.
- Global data asymmetries: who contributes data, who profits?
- Governance inclusion: who decides what "fair" means?

Design takeaway:
Justice requires reflexivity about who benefits, who risks harm, and who is heard.

An equilibrium between contribution and return: each person should bear burdens and receive benefits according to morally relevant criteria (need, effort, merit, or equality)rather than power, chance, or privilege.

Beauchamp and Childress 1979

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Beneficence & Non-maleficence

Classical meaning:
Promote well-being; prevent or minimize harm.

In data terms:

- "Doing good" can't justify opaque data practices or excessive collection.
- Harms can be invisible: stigmatization, data breaches, misuse by third parties.
- Ethics review ≠ sufficient safeguard, continuous monitoring is key.

Design takeaway:
Build risk-mitigation and accountability into every stage of data use.

> To advance the good and to contain the harm. The deliberate pursuit of well-being coupled with the discipline of caution — a balance between initiative and restraint, where every act of care demands both intention to help and vigilance not to wound.
>
> *Beauchamp and Childress 1979*

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University of Twente, The Netherlands

Privacy

Classical meaning:
Protection of personal information and control over disclosure.

In data terms:

- De-identification ≠ anonymity; linkage re-identifies easily (k-anonimity).
- "Contextual integrity" (Nissenbaum): privacy depends on norms of data flow.
- Group privacy matters (genomics, social listening, community datasets).

Design takeaway:
Privacy must be relational, adaptive, and continuous, not a one-off safeguard.

The right to a space of control over one's informational self, to decide how data that reveal who we are may circulate, combine, or persist within collective systems.

Spitale et al. 2024; Germani et al. 2025; Nissembaum 2004

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University of Twente, The Netherlands
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Trust

Classical meaning:
Confidence that others act responsibly and transparently.

In data terms:

- Trust underpins data sharing, research participation, and institutional legitimacy.
- Once broken (e.g. through scandal, opacity, exclusion), it's hard to rebuild.
- Trust demands transparency, reciprocity, and community engagement.

Design takeaway:
Trust is earned by design through openness, competence, and fairness.

A reciprocal confidence that others will act transparently, competently, and fairly; it is the fragile social contract that turns data sharing from exposure into cooperation.

Spitale et al. 2024;
Germani et al. 2025

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From theory to practice

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From Principles to Practice: Where Ethics Meets Data

(Health) data is never neutral.
It lives where ideals collide with infrastructures, incentives, and speed.

Typical fault lines:

- Autonomy ↔ Utility: Informed consent vs. secondary use, reuse, and AI inference.
- Privacy ↔ Openness: Data protection vs. open-science imperatives.
- Justice ↔ Innovation: Equity and inclusion vs. commercial and technical advantage.
- Beneficence ↔ Risk: Doing good faster vs. cutting ethical corners.
- Trust ↔ Performance: Transparency takes time; efficiency rarely waits.

Every data decision is an ethical design choice.

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University of Twente, The Netherlands
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Ethical Dilemmas in (Health) Data Management

1. Consent beyond its limits
A dataset collected for one study becomes useful for another. Do you reuse it, or stop at the boundary of the original consent?

2. The illusion of anonymity
You de-identify patient records, but linkage with another dataset could re-identify individuals. How much uncertainty is acceptable?

3. Openness vs. protection
Funding bodies demand open data, but participants come from stigmatized groups. What matters more: reproducibility or safety?

4. Commercial partnerships
A hospital partners with a tech company to develop predictive models. Who owns the data, and who carries the ethical risk?

5. Algorithmic triage
A model trained on biased data reproduces disparities in access or diagnosis. Is correction a technical fix or a moral obligation?

These are not edge cases!!! They are the daily grammar of data ethics.

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University of Twente, The Netherlands
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Building Ethical Data Systems

Privacy-by-Design
Embed ethical safeguards from the start: encryption, minimization, deletion protocols, human oversight.

Transparency-by-Design
Make data uses visible, explainable, and traceable to those affected, not just in policies, but in interfaces.

Accountability Mechanisms
Assign clear ownership for ethical oversight: ethics boards, data protection officers, reproducible pipelines.

Participatory Governance
Include patients, publics, and communities in shaping data policies and consent processes.

Proportional Openness
Balance open science with harm prevention: openness as instrumental, not absolute.

Good governance is architecture for trust.

ITE LAB
Information Technology & Experimental Ethics

University of Zurich[UZH]
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Giovanni Spitale, PhD
University of Twente, The Netherlands
12.03.2026

Ten Questions for Ethical Data Design

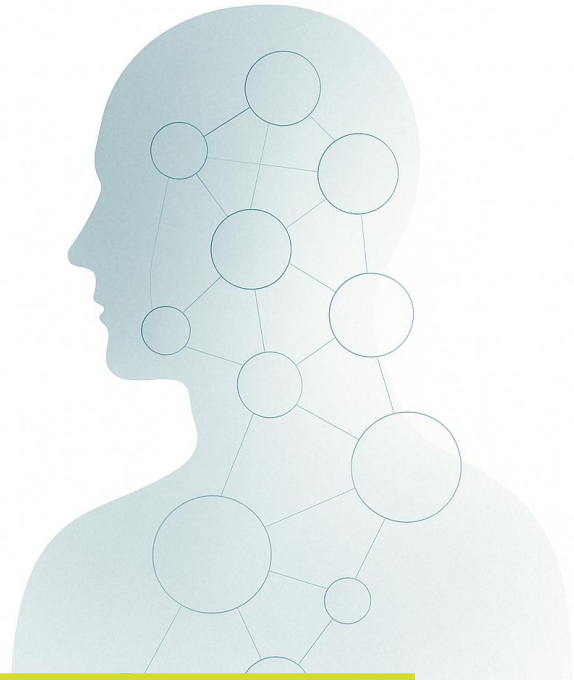
Purpose
→ Why is this data being collected or reused?
→ Is the goal proportionate to the risks it introduces?

People
→ Who is affected, represented, or excluded?
→ Are participants or communities meaningfully involved?

Process
→ How is consent, governance, and oversight implemented?
→ Are safeguards and responsibilities clearly defined?

Power
→ Who decides what's fair, open, or beneficial?
→ Are there mechanisms to challenge or revise those decisions?

Provenance
→ Where does the data come from and where does it go?
→ Can every transformation be traced and justified?



If you can answer these ten questions transparently, your data system is ethically robust. If not, it's just efficient.

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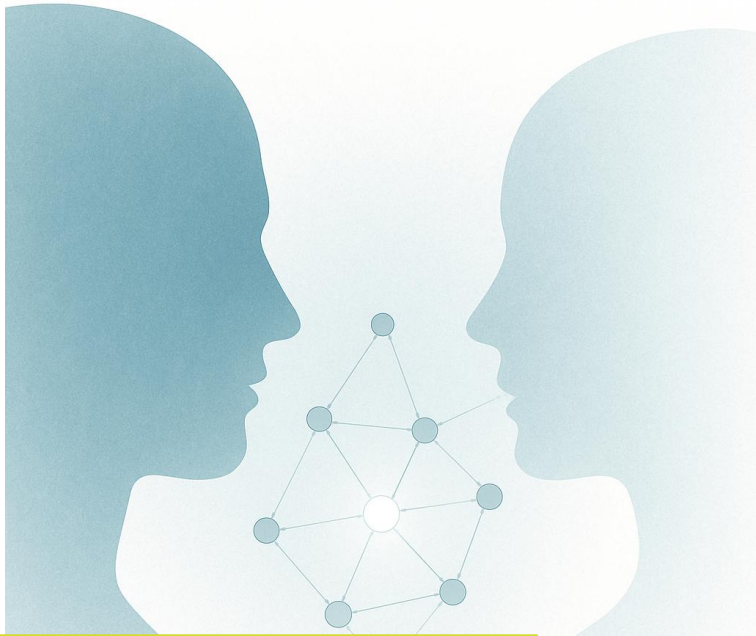
Reflection: Your Data, Your Ethics

Work in pairs. Take two minutes to think about a project you're involved in (research, clinical, or administrative).

Ask yourself:

- Which ethical tension (from earlier) defines it most — autonomy vs. utility? privacy vs. openness?
- Where do your current safeguards come from — regulation, culture, or conscience?
- Who gets a say when ethical questions arise — and who doesn't?
- If you had to explain your data ethics in one sentence, what would it be?



Ethics is not about what you know: it's about what you design, decide, and defend.

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Let’s keep talking

giovanni.spitale@ibme.uzh.ch

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Giovanni Spitale, PhD
University of Twente, The Netherlands

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Giovanni Spitale, PhD
University of Twente, The Netherlands