La ricerca empirica in bioetica: un'introduzione

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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
- WHO ethics guidance on social listening and infodemic management
- TERA - Translating Ethics into Regulations and Action

Other fancy stuff:

TEDx speaker @Trento 2016
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GENERAL AIMS

1. Introduce and discuss the concept of empirical (bio)ethics
2. Present methodological options for empirical (bio)ethics
3. Exercise!
4. Present and discuss a case study – empirical (bio)ethics in (bio)ethics-to-policy

1. Empirical (bio)ethics

2. …In practice

3. Empirical ethics in ethics to policy

SUMMARIZING:

1. Theory – What is empirical (bio)ethics?
2. Methods – Methodological options in empirical (bio)ethics
3. Practice – How to develop an empirical (bio)ethics project
4. Example – Empirical (bio)ethics in (bio)ethics to policy

1. Empirical (bio)ethics

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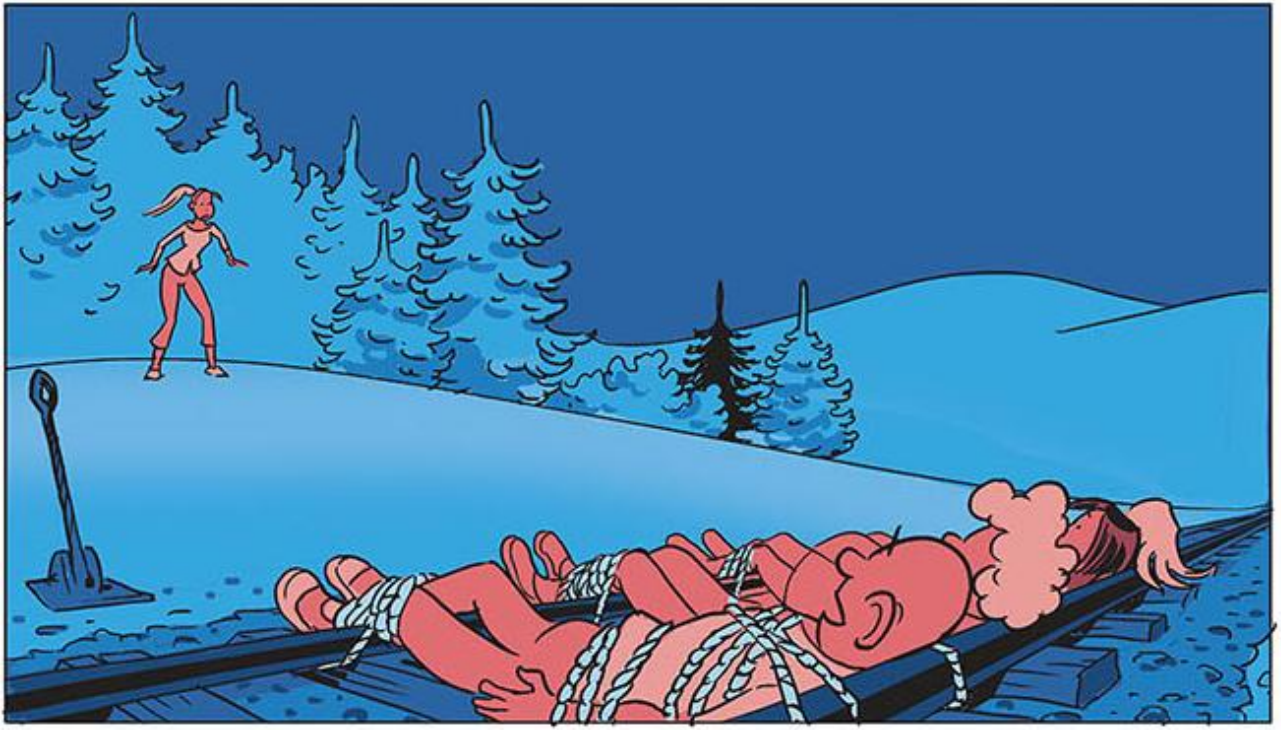

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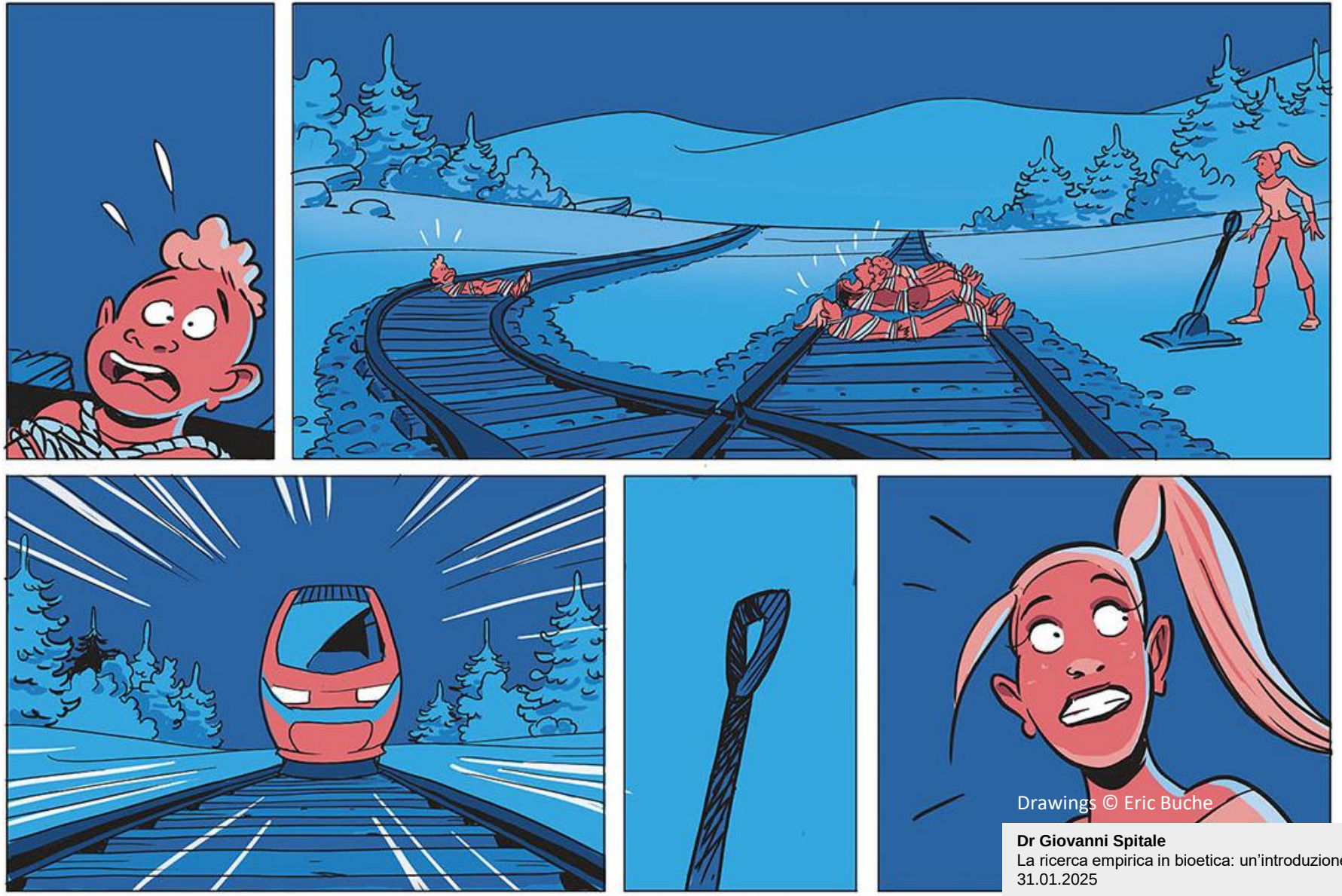

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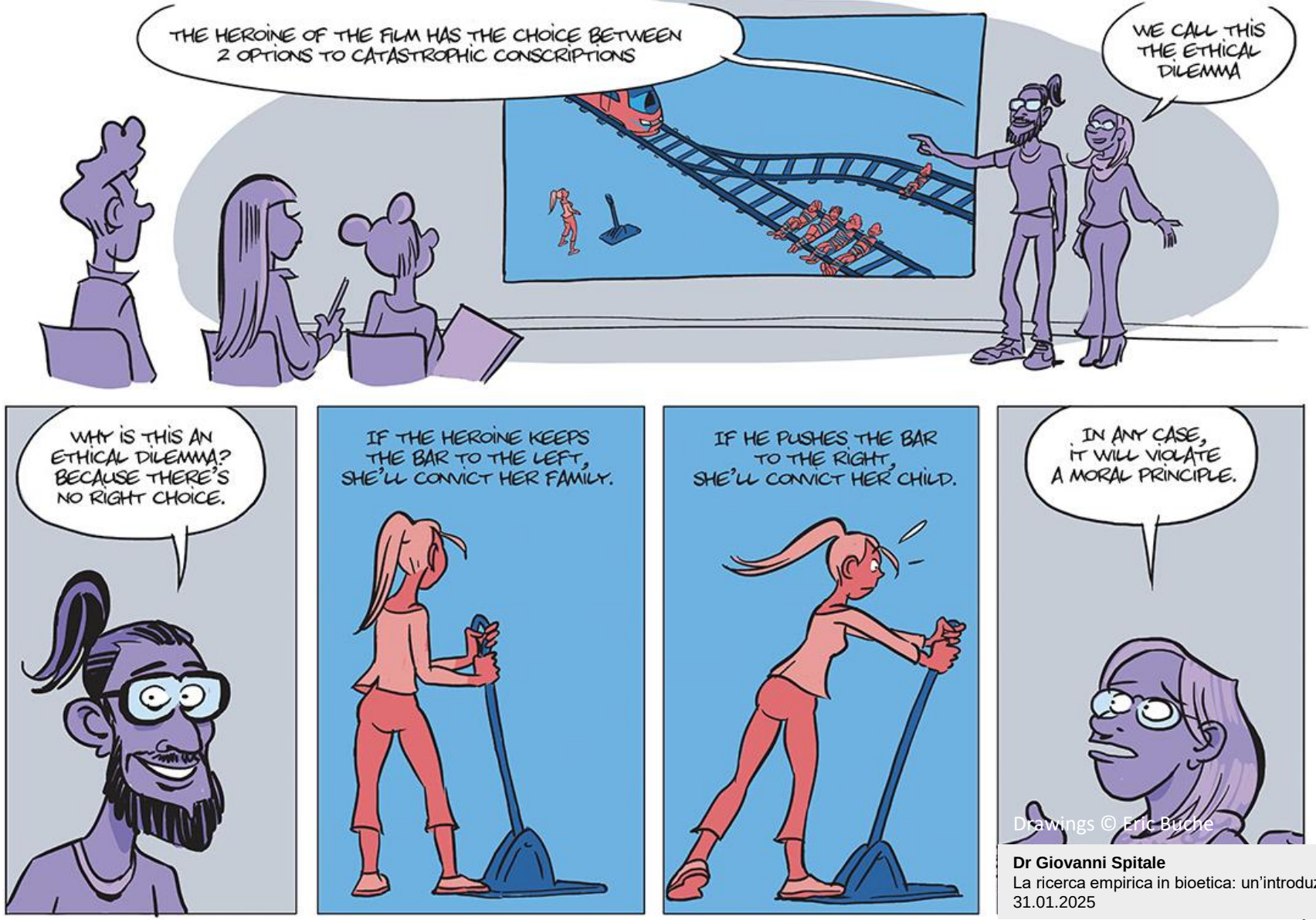
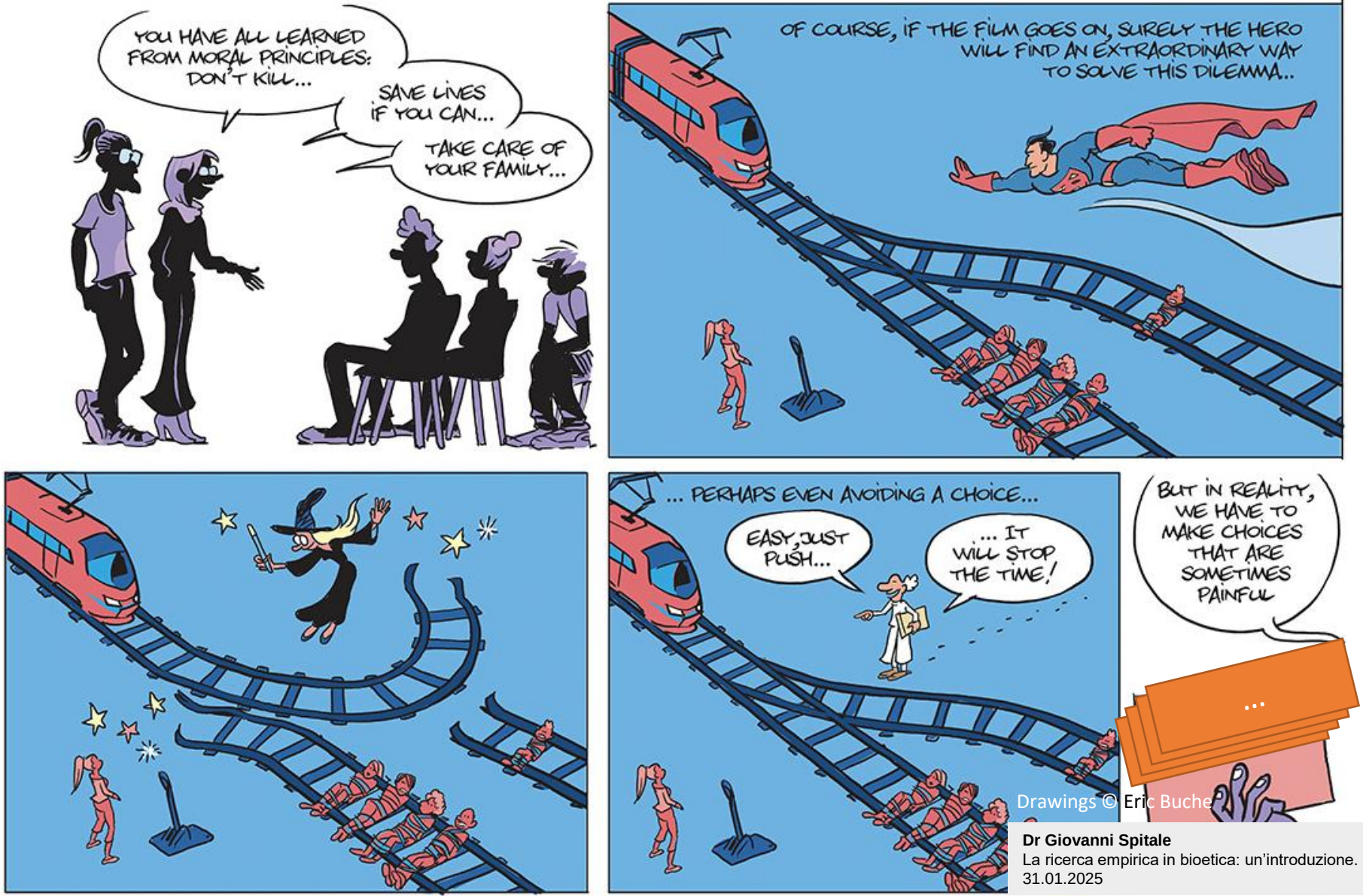



YOU HAVE ALL LEARNED FROM MORAL PRINCIPLES: DON'T KILL...
SAVE LIVES IF YOU CAN...
TAKE CARE OF YOUR FAMILY...
OF COURSE, IF THE FILM GOES ON, SURELY THE HERO WILL FIND AN EXTRAORDINARY WAY TO SOLVE THIS DILEMMA..
... PERHAPS EVEN AVOIDING A CHOICE...
EASY, JUST PUSH...
... IT WILL STOP THE TIME!
BUT IN REALITY, WE HAVE TO MAKE CHOICES THAT ARE SOMETIMES PAINFUL
...
Drawings © Eric Buche

What is Empirical Ethics?

Ethics?

Rational justification of moral judgments

Descriptive – studies how *things happen* and how they impact on moral norms

Normative – prescribes how *things should happen* based on moral norms
(rights, obligations, fairness, specific virtues, …)

What is Empirical Ethics?

Musschenga 2005:

- A logical next step in the development of practical ethics after the turn to “applied ethics.”
- Both descriptive and normative
- Aimed to improve the context sensitivity of ethics

Empirical ethics combines doing empirical research with philosophical (normative ethical) analysis and reflection

“in concentrating on questions of how medical decisions should be made, medical ethicists have paid surprisingly little attention to how they are in fact made”.

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).

Forgetting the context: organ donation rates in Greece and Chile

Greece
2011: new law adopting opt-out is passed

2013: the law comes in force (Bottis 2012).

The law was opposed by both the Orthodox Church and the Hellenic Transplant Organisation (HTO) (Bottis 2012) and met with considerable public opposition (Sotiropoulos & Machairas 2016).

2013: the law is softened to soft opt-out (relatives have a say) (Bottis 2012).

The introduction of the law took place at a time of low but increasing donation rates (3.6 donors pmp in 2000, rising to 8.9 pmp by 2008).

From 2011 onwards, a dramatic collapse in the donation rate began, and in 2013 it was still at 4.6 pmp; in the first six months of 2015, the value fell further to only 2.7 pmp (Moris et al. 2016).

This dramatic slump was related to the enormous economic crisis that has hit Greece hard since around 2010. However, it was also noted that other southern European countries, which were also hit hard by the financial crisis that began in 2008, had not experienced a drop in donor rates (Moris et al. 2016b).

Chile
after an increase in the donation rate in the 1990s, the number of donations stagnated since 2000 and has tended to decline since 2006 (Zúñiga-Fajuri 2015).

2010: new law adopting opt-out is passed
the law is applied in the sense of a soft opt-out, relatives continue to be asked about the presumed will of the deceased person (Domínguez & Rojas 2013).

2011: organ donation rates falls from 8.31 pmp (2000-2009) to 5.95 pmp; the opposition of families rises from 32% (2000-2009) to 50.4% (Domínguez & Rojas 2013).

2012: 2.8 million people had registered in the opposition register (16% of the population); 37% of the people who had renewed their identity card or their driver's licence in the period 2010 to 2011 refused organ donation (Zúñiga-Fajuri 2015).

2013: the law is tightened (retroactively!), non-donors have to notarise their refusal

2016: more than 4 million people registered as non donors; donation rate at 6.7 pmp, below the average from 2000-2009; refusal rates of relatives still over 50% (Kottow Lang 2016).

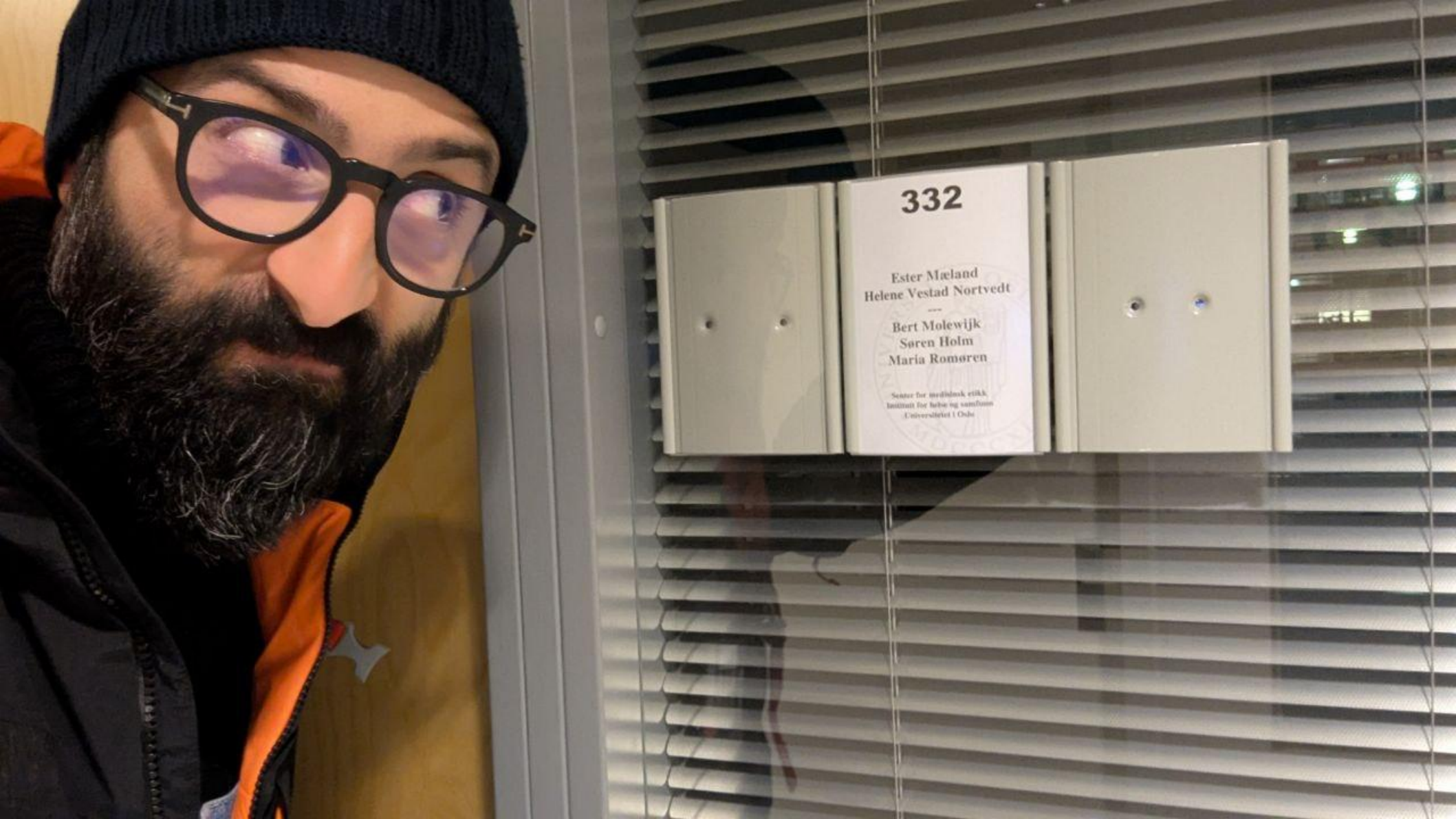
Source:
https://www.bag.admin.ch/dam/bag/de/dokumente/biomed/transplantationsmedizin/literaturbeurteilung-einfluss-von-zustimmungsmodellen-spenderegistern-und-angeh%C3%B6rigen-entscheid-auf-Organspenden.pdf.download.pdf/Literaturbeurteilung-Zustimmungsmodelle-Organspende.pdf

The role of evidence in empirical ethics

APPROACHES	I Fundamental distinction descriptive-prescriptive sciences	II Moral authority in	III Central goal(s)	IV Type of normativity	V Use of empirical data	VI Method	VII Interaction empirical data and moral theory	VIII Cooperation with descriptive sciences
PRESCRIPTIVE APPLIED ETHICISTS	Yes	Moral theory	Evaluate social practice	External	A] Conditional (consequentialism); B] As object of study (in order to judge);	Deductive (top-down, theory-based) [THEORY → DATA]	One way (top-down)	Symbiotic
THEORISTS	Yes	Moral theory	Improve moral theory	External	As a means to refine theory	Take cognisance of empirical results [THEORY → DATA → THEORY]	One way	Symbiotic
CRITICAL APPLIED ETHICISTS	Yes	Both moral theory and social practice	Evaluate social practice, Improve moral theory	External and internal	A] As object of study; B] As a means to improve moral theory (e.g. validity check of empirical background assumptions)	Deductive and inductive (mutually confront empirical data with moral theory) [THEORY ↔ DATA]	Weak interaction	Symbiotic, integrative (conceptual importation)
INTEGRATED EMPIRICAL ETHICS	No	Experience within social practice (theory is seen as a practice)	Interpretation, Evaluation, Methodology development	Research process, material context and meta-normativity	As subject of study	Integrative (continuity of method between ethics and social science) [THEORY ≈ DATA]	Strong interaction	Integrative (mutual constitutive)
PARTICULARISTS	No	Social practice	Interpretation, Explanation	Internal	As subject of study	Inductive and case-based reasoning [ONLY DATA]	No interaction	Integrative (theoretical unity)

BERT MOLEWIJK ET AL.

Source: Molewijk et al. 2004, https://doi.org/10.1023/B:MHEP.0000021848.75590.b0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Prescriptive applied ethicist

View on moral authority:
Moral theory is the ultimate authority and remains unchallenged by empirical data.

Role of empirical data:
Empirical data are used as tools to apply moral theory, ensuring its prescriptive function aligns with social practices.
Data are not used to critique or revise the theory.

Method:
Deductive (top-down): moral conclusions are derived from moral theory, and data are applied to validate those conclusions.

Key Features:
Empirical data play an instrumental role, serving the pre-established moral theory. The theory remains static, focusing on consistent application across contexts.

Example:
Consider a consequentialist ethicist evaluating the morality of euthanasia. The ethicist begins with the principle that maximizing happiness and minimizing suffering are paramount.

Empirical data are collected to determine whether patients who undergo euthanasia experience less overall suffering compared to those who do not.

The empirical data serve only to verify the principle's application in specific contexts (e.g., by showing that euthanasia reduces suffering). However, if the data revealed that euthanasia leads to more suffering (due to family grief or societal anxiety), the moral theory itself would remain unchanged. The theory would still prioritize minimizing suffering, but its application might shift (e.g., rejecting euthanasia as a practical option).

Empirical data guide implementation but do not challenge the theory itself.

Source: Molewijk et al. 2004, https://doi.org/10.1023/B:MHEP.0000021848.75590.b0

Theorists

View on moral authority:
Similar to prescriptive ethicists, they regard moral theory as the final arbiter but are more open to minor refinements informed by empirical data.

Role of empirical data:
Empirical data are instrumental in refining moral theories but do not challenge their core principles. The focus is on improving the theoretical understanding of ethics rather than applying it directly to practice.

Method:
Neither purely deductive nor inductive, but empirical insights influence the theory indirectly.

Key features:
Focus on theoretical refinement rather than reforming practices.
Uses empirical data to enhance the precision and relevance of moral theories.

Example
A philosopher is refining the principle of autonomy. Initially, the theory assumes that informed consent is sufficient to respect patient autonomy.

However, empirical research shows that many patients do not fully understand the medical information provided, even when they sign informed consent forms. Patients often rely on physicians' guidance, contradicting the purely individualistic notion of autonomy.

The theorist uses these findings to refine the principle, suggesting that autonomy includes relational aspects, such as the role of trust and guidance from healthcare providers.

While the core idea of respecting autonomy remains intact, the theory evolves to acknowledge the practical complexities uncovered by the data. The primary focus remains on improving the theoretical understanding, rather than directly reforming practices.

Source: Molewijk et al. 2004, https://doi.org/10.1023/B:MHEP.0000021848.75590.b0

Critical Applied Ethicists

View on moral authority:
Neither moral theory nor social practice is the final arbiter; both are subject to critique and potential revision.

Role of empirical data:
Empirical data serve as both objects of study (e.g., understanding a practice) and tools for improving moral theory.
The interaction is dynamic, allowing mutual adjustment of theory and practice.

Method:
Both deductive and inductive, with iterative interactions between empirical data and theory.

Key features:
This approach challenges assumptions within moral theories by validating or questioning them through empirical evidence.

Example
Imagine an ethicist exploring the principle of justice in healthcare resource allocation. They use empirical data on how different demographic groups perceive fairness in the allocation of scarce medical resources.

Suppose the ethicist identifies a discrepancy: certain minority groups consistently feel excluded from decision-making processes.

The ethicist critiques the current theories of distributive justice by highlighting their failure to address systemic inequalities. At the same time, the social practice (how resources are distributed) is also critiqued for perpetuating inequities.

Based on the interplay between theory and data, the ethicist suggests adjustments to both: revising the theory to incorporate equity as a procedural value and reforming the allocation process to ensure marginalized voices are included. This iterative process transforms both theory and practice.

Source: Molewijk et al. 2004, https://doi.org/10.1023/B:MHEP.0000021848.75590.b0

Integrated Empirical Ethicists

View on moral authority:
Morality arises from the interplay between moral theory and the specific context of a social practice.

Role of empirical data:
Empirical data and moral theory are interdependent, with neither taking precedence. Data inform theory, and theory shapes the interpretation and evaluation of data.

Method:
Integrative: ethicists and social scientists collaborate continuously throughout the research process, from planning to interpretation. Rejects the strict division between descriptive (facts) and prescriptive (values) sciences.

Key features:
Emphasis on contextual relevance rather than universal applicability. Recognizes that "facts" inherently contain normative assumptions and are shaped by methodological choices.

Example
A research team investigates the concept of patient autonomy in the context of aneurysm treatment. They collaborate closely, with ethicists, sociologists, and psychologists working together throughout the study.

They assess how the presentation of risk information (e.g., using graphs, percentages, or verbal descriptions) affects patients' decisions. The team discovers that certain visual formats (e.g., vertical bar graphs) increase the perception of risk, potentially discouraging surgery.

The ethicists analyze how these findings reveal normative assumptions embedded in the communication of facts—such as the implicit suggestion that higher risks should deter patients.

The team integrates this insight into a revised approach to patient autonomy, emphasizing shared decision-making that accounts for how risk information is framed.

Facts and values are seen as interdependent, and the research process itself is shaped by continuous collaboration between disciplines.

Source: Molewijk et al. 2004, https://doi.org/10.1023/B:MHEP.0000021848.75590.b0

Particularists

View on moral authority:
The morality of specific social practices holds intrinsic authority and is not directly connected to external moral theories.

Role of empirical data:
Empirical data are essential for interpreting and understanding the contextual morality of a specific practice.
There is no integration with or critique from moral theory.

Method:
Inductive and context-specific, relying heavily on case-based reasoning and ethnographic approaches.

Key features:
Strong emphasis on the context-dependent nature of morality, rejecting universal principles.

Example
A particularist ethicist studies end-of-life care in a rural community. They conduct ethnographic research, interviewing families and observing rituals around death and dying.

They find that the community's values emphasize collective decision-making and spiritual care, which differ from mainstream, individualistic notions of autonomy in bioethics.

The ethicist does not attempt to connect these practices to external moral theories like autonomy or beneficence. Instead, they focus on understanding the internal logic of the community's practices. For example, they describe how the community's approach to shared decision-making fosters a sense of unity and closure.

This understanding is not generalized or connected to a universal theory but instead highlights the moral values embedded within the specific social context.

Source: Molewijk et al. 2004, https://doi.org/10.1023/B:MHEP.0000021848.75590.b0

How to Empirical Ethics?

Davies, Ives and Dunn 2015:

- There is no consensus as to what an appropriate methodology for empirical ethics would be. But existing methodologies can be classified on a spectrum with two main poles:

- Dialogical approaches, based around the formation of a dialogue between stakeholders and the attempt to reach a shared Understanding. The analysis, and reaching of a conclusion, is undertaken by the researcher and participants together.

- Consultative approaches tend to use an external 'thinker' who gathers data and analyses it, and then develops normative conclusions.

- "The heterogeneity we have observed is not a problem in itself. Difference adds to the richness of the field and, certainly in its infancy, a field such as empirical bioethics will surely benefit from experimentation and variety".

How to Empirical Ethics?

Ives et al. 2017:

- Empirical bioethics research should address a normative issue that is oriented towards practice, integrating empirical methods with ethical arguments in order to address this normative issue.

- The method of integration should be explained and justified.

- Empirical bioethics research should, if and where necessary, develop and amend empirical methods to facilitate collection of the data required to meet the aims of the research; but deviation from accepted standards ought to be acknowledged and justified.

- In empirical bioethics research, there should be explicit and robust normative analysis.
'Normative analysis' includes attempts to justify position X to person Y with the use of ethical reasoning, providing suggestion for improvement to position X based on ethical reasoning, or attempts to break down and make explicit a complex normative issue in order to gain a better understanding of it

Recommended readings

Molewijk et al. 2004, Scientific Contribution. Empirical data and moral theory. A plea for integrated empirical ethics.
DOI: 10.1023/B:MHEP.0000021848.75590.b0

Musschenga 2005, Empirical Ethics, Context-Sensitivity, and Contextualism.
DOI: 10.1080/03605310500253030

Widdershoven, McMillan, Hope, van der Scheer (eds.) 2008, Empirical Ethics in Psychiatry.
DOI: 10.1093/med/9780199297368.003.0003

Strech 2010, How factual do we want the facts? Criteria for a critical appraisal of empirical research for use in ethics
DOI: 10.1136/jme.2009.033225

Dunn, Sheehan, Hope, Parker 2012, Toward methodological innovation in empirical ethics research
DOI: 10.1017/S0963180112000242

Salloch, Wäscher, Vollmann, Schildmann 2015, The normative background of empirical-ethical research: first steps towards a transparent and reasoned approach in the selection of an ethical theory.
DOI: 10.1186/s12910-015-0016-x

Davies, Ives, Dunn 2015, A systematic review of empirical bioethics methodologies.
DOI: 10.1186/s12910-015-0010-3

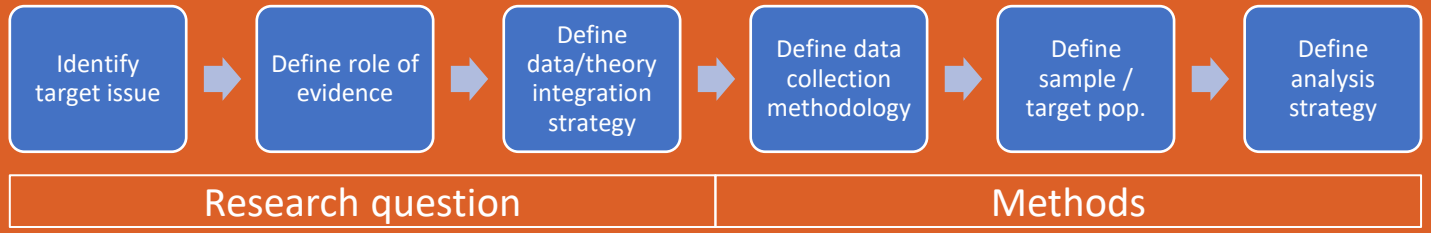
Wangmo, Provoost 2017, The use of empirical research in bioethics: a survey of researchers in twelve European countries.
DOI: 10.1186/s12910-017-0239-0

Ives et al. 2018, Standards of practice in empirical bioethics research: towards a consensus.
DOI: 10.1186/s12910-018-0304-3

2. …In practice

Empirical Ethics 101

Planning



The issue determines the methods!
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Empirical Approaches

Observational vs Experimental

Observational: observing and collecting data on individuals or groups without intervening in any way

Experimental: manipulating one or more variables to determine their effect on an outcome. Examples include randomized controlled trials and quasi-experimental studies.

Descriptive vs Analytical

Descriptive: describe the characteristics of a particular group or population, without attempting to establish cause-and-effect relationships.

Analytical: attempt to establish cause-and-effect relationships between variables. Examples include case-control studies and cohort studies.

Qualitative vs Quantitative vs Mixed methods

Quali: non-numerical data such as interviews, focus groups, and observations to explore subjective experiences, attitudes, and beliefs.

Quanti: numerical data and statistical analysis to test hypotheses and make predictions.

MM: integrate qualitative and quantitative approaches

Longitudinal vs Cross-sectional

Longitudinal: follow individuals or groups over an extended period to study changes in behavior or health outcomes over time.

Cross-sectional: collect data at a single point in time to study the prevalence or distribution of a particular condition or behavior in a population.

The Big Fat Methods Table

Method	Time Frame	Scope	Control Level	Common Applications	Research Question (ex.)
Randomized Controlled Trials (RCTs)	Short to Medium	Specific population	High (randomized groups)	Medicine, Psychology, Education	Does the new vaccine reduce the incidence of disease compared to the placebo?
Experiments	Short to Medium	Specific variables	High (controlled conditions)	Psychology, Physics, Chemistry	Can altering the layout of a workspace increase productivity?
Case-Control Studies	Short to Medium	Specific cases and controls	Medium	Epidemiology, Sociology	Is exposure to a particular pollutant associated with an increased risk of developing asthma?
Cohort Studies	Long (years)	Specific cohort over time	Low to Medium	Public Health, Sociology	What are the long-term health effects of air pollution in urban areas on its residents?
Case Studies	Variable	Single or few cases	Variable	Psychology, Business, Law	What strategies did a successful start-up use to enter a competitive market?
Focus Groups	Short	Group dynamics, opinions	None (discussion based)	Marketing, Political Science	How do potential customers perceive our new product concept?
Interviews	Variable	Individuals	Low (qualitative)	Sociology, Market Research	How do individuals who work remotely perceive the balance between work and personal life?
Ethnography	Long (immersive)	Cultural/social dynamics	None (participant observation)	Anthropology, Sociology	How does the daily use of technology influence social behaviors in a rural community?
Observational Studies	Variable	Natural settings	None (no intervention)	Astronomy, Ecology	How does the introduction of a new species affect the existing ecosystem?
Cross-Sectional Surveys	Single point	Large populations	None (observational)	Epidemiology, Sociology, Marketing	What is the current level of public awareness and concern about climate change?
Longitudinal Surveys	Long (years)	Same subjects over time	None (observational)	Psychology, Education	How do changes in economic policy affect the saving patterns of households over 20 years?
Delphi Method	Variable	Expert opinions	None (iterative feedback)	Policy Analysis, Forecasting	What are the anticipated impacts of artificial intelligence on job markets over the next decade?
...	...	...	...	...	...

Methods

Randomized Controlled Trials (RCTs):
RCTs are considered the gold standard in clinical research. They involve randomly assigning participants to either a treatment group or a control group. This method is used to rigorously test the efficacy of a new treatment, drug, or intervention. The randomization helps minimize bias and ensures that the results are solely due to the intervention and not external factors.

Experiments:
Experiments involve manipulating one or more independent variables to observe their effect on a dependent variable. This method allows researchers to establish cause-and-effect relationships. Experiments can be conducted in controlled environments like laboratories or in natural settings.

Case-control studies:
In case-control studies, individuals who have a particular condition (cases) are compared to those who do not (controls). This method is often used in epidemiology to identify factors that may contribute to a medical condition or disease.

Cohort studies:
Cohort studies follow a group of people over time to observe how certain factors affect the incidence of outcomes like diseases. Participants are selected based on their exposure to a particular factor rather than their current health status. This method is useful for studying the long-term effects of exposures or interventions.

Case studies:
Case studies involve an in-depth examination of a single case or a small group of cases. This method is used to explore complex issues in real-life contexts, particularly when the boundaries between the phenomenon and context are not clearly evident.

Focus groups:
Focus groups involve guided group discussions to gather opinions, beliefs, and attitudes about a particular topic. This method is useful in exploratory research and is commonly used in market research and social sciences.

Methods

Interviews:
Interviews are a qualitative research method where data is collected through direct dialogue with individuals. They can be structured, semi-structured, or unstructured, allowing for an in-depth understanding of the participant's perspectives.

Etnography:
Ethnography involves studying people in their natural environment through observation and participation. This method is commonly used in anthropology and sociology to understand cultural and social phenomena.

Observational studies:
Observational studies involve monitoring subjects without manipulating the study environment. This method is used to observe natural behavior patterns, outcomes, and correlations in various fields, including epidemiology and sociology.

Cross-sectional surveys:
Cross-sectional surveys are used to gather information at a single point in time. This method is commonly used in public health, sociology, and market research to assess the prevalence of conditions or opinions in a population.

Longitudinal surveys:
Longitudinal surveys involve repeated observations of the same variables over an extended period. This method is useful for studying changes over time and is commonly used in psychology, sociology, and epidemiology.

Delphi method:
The Delphi method is a structured communication technique that relies on a panel of experts. It involves several rounds of questionnaires, with the feedback from each round used to refine the questions for the next. This method is used for consensus-building and forecasting in various fields, including policy-making and business.

Empirical Ethics 101

Doing

One example

Observational or Experimental?

Descriptive or Analytical?

Qualitative or Quantitative or Mixed methods?

Longitudinal or Cross-sectional?

J Med Internet Res. 2022 Feb 16;24(2):e34385. doi: 10.2196/34385.

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]

Affiliations + expand

PMID: 35156930 PMCID: PMC8852653 DOI: 10.2196/34385

Free PMC article

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.

Another example

Randomized Controlled Trial (RCT)?
Experiment?
Case-Control Study?
Cohort Study?
Case Study?
Focus Group?
Interview?
Ethnography?
Observational Study?
Cross-Sectional Survey?
Longitudinal Survey?
Delphi Method?

AI model GPT-3 (dis)informs us better than humans

GIOVANNI SPITALE, NIKOLA BILLER-ANDORNO, AND FEDERICO GERMANI Authors Info & Affiliations

SCIENCE ADVANCES · 28 Jun 2023 · Vol 9, Issue 26 · DOI: 10.1126/sciadv.adh1850

Abstract

Artificial intelligence (AI) is changing the way we create and evaluate information, and this is happening during an infodemic, which has been having marked effects on global health. Here, we evaluate whether recruited individuals can distinguish disinformation from accurate information, structured in the form of tweets, and determine whether a tweet is organic or synthetic, i.e., whether it has been written by a Twitter user or by the AI model GPT-3. The results of our preregistered study, including 697 participants, show that GPT-3 is a double-edge sword: In comparison with humans, it can produce accurate information that is easier to understand, but it can also produce more compelling disinformation. We also show that humans cannot distinguish between tweets generated by GPT-3 and written by real Twitter users. Starting from our results, we reflect on the dangers of AI for disinformation and on how information campaigns can be improved to benefit global health.

Exercise

Download the files here

Work in groups (30')
- Discuss the proposed scenario
- Fill in the template file:
  - Identify a relevant target issue (could be the one proposed, or a different one)
  - Define the role of evidence and the integration strategy
  - Think about the methods

Back to the plenary
- Pitch you project (rapid fire, 2' per project)

Exercise

Group 1
Jurassic Judgments: An Empirical Ethics Investigation into the Moral Implications of Dinosaur Cloning

With de-extinction technology now a reality, the return of dinosaurs is no longer the stuff of science fiction—it is a question of ethics. But should we bring back species that nature has already consigned to history? Supporters argue that de-extinction corrects past extinctions. Others see it as scientific hubris, warning that these creatures evolved for a world vastly different from ours. Can ecosystems today support apex predators from a prehistoric era? Would reintroduced dinosaurs be treated as wildlife, research specimens, or corporate-owned attractions? Beyond ecological concerns, there are philosophical and moral dilemmas. Does resurrecting a species truly restore it, or is it merely a genetic imitation? If these creatures lack a natural evolutionary trajectory, do they have an intrinsic right to exist? Should humans be responsible for their survival, regulation, and containment? Even more pressing is the question of genetic modification—if dinosaurs are brought back, should we alter them for compatibility with the modern world? Should we edit their genomes to make them safer, smaller, more controllable, or even more marketable? At what point does science shift from restoration to invention?

Exercise

Group 2
Virtue in the Void: The Ethics of Autonomous Decision-Making in AI Space Explorers

As autonomous AI ventures deeper into the cosmos, humanity faces a profound ethical challenge: What moral framework should guide machines in the absence of human oversight? Unmanned AI explorers may encounter new worlds, unknown life forms, or civilizations beyond our understanding. Should they follow a strict non-interference directive, preserving alien ecosystems as they are found? Or should they be allowed to modify environments for human colonization, prioritizing our species' survival and expansion? The challenge extends beyond exploration. If AI makes first contact, should it act as a neutral observer, a diplomat, or an enforcer of human interests? What happens when AI must decide between protecting an alien species or completing its programmed objectives? As we send autonomous machines beyond our reach, we must ask: Are we building explorers, stewards, or conquerors?

Exercise

Group 3
Zombie Outbreak Ethics: A Theoretical Framework for Resource Allocation in a Pandemic

As a lethal zombie virus spreads, society collapses into a state of emergency where medical supplies, food, and security become scarce commodities. Governments and healthcare institutions face an impossible ethical choice: Who gets saved, and who is left behind? Triage protocols, designed for conventional pandemics, fail to account for the uncertain status of the infected. Are they still persons with rights, or merely vectors of contagion? Some argue that treatment efforts should focus solely on the uninfected, maximizing survival. Others advocate for humane containment, refusing to abandon the infected to a fate worse than death. Experimental treatments offer hope, but at what cost? Allocating resources to uncertain cures may doom thousands who could have been saved. And does it count as human experimentation? Beyond healthcare, societies must decide how to enforce order. Should infected individuals be quarantined, euthanized, or what else? How do governments prevent panicked citizens from resorting to violence and lawlessness?

Exercise

Group 4
Temporal Trespass: Ethical Analysis of Time-Travel Interventions on Historical Events

With time travel now a reality, humanity faces an unprecedented ethical dilemma: Should history be changed, and if so, by whom? The ability to prevent atrocities, avert disasters, or guide civilizations toward progress is a temptation few can ignore. Yet even the smallest intervention risks unraveling the intricate web of cause and effect, creating unintended consequences or paradoxes. Is it ethical to erase a catastrophic event is erased, if this leads to the de-existence of people born due facts and choices connected to it? Is it ethical to override the choices of past societies, imposing modern values on those who never consented to intervention? Some argue that history is not fixed but a fluid narrative, and intervention is inevitable—whether for good or ill. As travelers stand at the crossroads of history, the fundamental question remains: Do we have the right to change what was, simply because we can?

Exercise

Group 5
Neural Nexus: Ethical Governance of Mind-Melding Technology

As mind-melding technology advances, the boundaries between individuals blur. Neural interfaces enable direct sharing of thoughts, emotions, and memories, creating unprecedented levels of intimacy, collaboration, and understanding. But at what point does connection become control? In personal relationships, emotional transparency can foster deep trust—or erode personal space. In workplaces, corporations demand productivity-enhancing "sync shifts", where employees temporarily merge cognitive functions for maximum efficiency. Governments experiment with thought surveillance, justifying it as a crime-prevention tool. If your thoughts can be accessed, can they also be rewritten? At the societal level, some embrace the potential for a global neural collective, believing it could eliminate conflict through shared experience. Others fear the loss of autonomy—when individuality dissolves into the hive mind, who decides which thoughts belong to whom?

Exercise

Group 6
Terraforming Titans: Ethics of Planetary Engineering

As humanity embarks on the transformation of Mars into a habitable world, profound ethical dilemmas emerge. Terraforming promises to provide breathable air, liquid water, and sustainable ecosystems, but at what cost? Does Mars have a right to remain untouched? Even if life on Mars is limited to microbial extremophiles, do we have a duty to preserve its natural evolution? The introduction of Earth-based bacteria and engineered organisms could irreversibly alter Martian ecosystems before we even understand them. Some argue that reshaping Mars for human survival is a moral imperative, a solution to Earth's overpopulation and dwindling resources. Others warn that such actions might constitute planetary-scale environmental destruction, eliminating any chance of studying an independent extraterrestrial biosphere and its future evolution. Beyond scientific concerns, terraforming also raises questions of intergenerational responsibility. Once started, the process cannot be undone. Future generations will inherit a Mars dictated by today's decisions—whether that means an Earth-like world, a hybrid environment, or an untouched conservation park.

Exercise

Group 7
The Unnatural Horde: The Ethics of Bioengineered Warriors (courtesy of Dr. F. Zilio)

In the depths of Isengard, Saruman the White defies the natural order, fusing orcs and humans to create the Uruk-hai—a new breed of warriors, stronger, faster, and immune to the weaknesses of their predecessors. But in his pursuit of power, he raises an unsettling ethical question: Is it ever justifiable to create life solely for war? The Uruk-hai are bred for obedience, efficiency, and brutality. Their existence is the result of species manipulation for a forced purpose. If a creature is designed solely to serve, does it possess moral worth? Should it be granted autonomy, or is it merely a tool of its creator? Beyond individual rights, the weaponization of life itself presents an ethical dilemma. If creating artificial beings for war is acceptable, where does the line end? Would the widespread adoption of engineered soldiers lead to an endless cycle of forced creation and destruction? And what of their place in the world after the war? Should they be considered a new species with the right to self-determination, or are they an aberration to be erased? As the Uruk-hai march under the White Hand, their existence forces Middle-earth to confront the dark consequences of playing Eru Iluvatar.

Exercise

Group 8
Cybersovereignty – (in)equality and human enhancement

The Neuro-Elites, enhanced with hyper-intelligent neural interfaces, dictate global policies from towering metropolises, while Augmented Enforcers—equipped with enhanced reflexes, reinforced limbs, and subdermal armor—maintain strict order. The Raw, able to afford minimal implants, are relegated to the slums, struggling to compete in a world that no longer values natural human abilities. A black market for rogue modifications flourishes, offering unregulated cybernetic implants at a great cost—both physically and legally. Meanwhile, a radical faction known as the Biopurists emerges, advocating for the protection of natural humanity and sabotaging cybernetic infrastructure. Will cybernetic elites leave behind their organic origins altogether? Will the unenhanced be seen as an outdated species, or will they reclaim control over their destiny?

Exercise

Download the files here

Work in groups (30')
- Discuss the proposed scenario
- Fill in the template file:
  - Identify a relevant target issue (could be the one proposed, or a different one)
  - Define the role of evidence and the integration strategy
  - Think about the methods

Back to the plenary
- Pitch you project (rapid fire, 2' per project)

3. Empirical ethics in ethics to policy

Translational ethics

Bærøe 2014; Bærøe 2024:

- Translational research in medicine requires researchers to identify the steps to transfer basic scientific discoveries […] to bedside decision-making.

- Translational ethics is a specific approach to bioethics that focuses on the ethical justification of strategies for bridging the theory-practice gap.
  It incorporates normative, empirical, and foundational ethics research and continues to develop through application and in the face of new ethical challenges.

- The theory-practice gap (or translation gap) in translational ethics is the divide between philosophical reflection and real-world practice in ethics.
  It is the gap that translational ethics seeks to bridge.

- Translational ethics aims to:
  - Facilitate the practical impacts of academic bioethics by ensuring it is well-informed by real-world ethical issues;
  - Support targeted and ethical justifications of the actual impact of academic work in real-world contexts;
  - Promote self-reflexivity on own positioning among philosophers and practitioners working in bioethics;
  - Improve the translation of ethics across the theory-practice gap by combining justified philosophical and practical efforts;
  - Analyze and address the limitations of bioethics' influence on policy-making,
    acknowledging that bioethical perspectives often compete with other interests like economic and political ones;
  - Recognize the importance of context in ethical decision-making, avoiding conclusions that are overly influenced by local, arbitrary factors.


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(Bio)ethics-to-policy 1

Bærøe 2014; Bærøe 2024:

- Lack of public confidence in the impact of bioethics on policies, partly due to conflicts over values.

- Other social movements may occupy the space where bioethics could influence politicians.

- Bioethics needs more meta-ethical work on the connection between academic ethics and real-world practice:
  - Studying both how and how *should* ethical ideas influence policy;
  - Simply transferring theoretical ethical conclusions into policy is insufficient;
  - The socio-political dimensions of both academic and real-world ethics must be considered.

(Bio)ethics-to-policy 2

Bærøe 2014; Bærøe 2024:

- EtP can shape the field of practice by advocating for theoretically justified bioethical policies.

- Clarify own posture:
  - When bioethicists actively influence policy with their own personal viewpoints, they should clarify that they are acting as citizens, not as experts with exclusive political authority (lobbyist/activist);
  - Else, they can play an authoritative role by introducing justified analytical approaches and structuring deliberation processes (expert/advisor).

- Any attempt to translate ethics into policy must consider fair processes of decision-making:
  - Ensuring that stakeholders are involved in the process and that their views are taken into account;
  - Recognize the potential for conflict with existing political decision-making structures and address these issues.

- Policies resulting from translational ethics should be:
  - Sustainable – meet current needs without compromising future generations (justice across generations and social groups);
  - Context-aware – policies should be informed by both ethical principles and contextual realities (but without compromising rigor).

Translational movements to policy

Bærøe 2014; Bærøe 2024:

- Translating ethics into policy involves translational movements which can take different forms:
    - Academic work that facilitates practical conclusions, such as developing frameworks for ethical deliberation;
    - Political or moral engagement, where researchers advocate for their views;
    - Implementation strategies for shaping practice;
    - Practical work done by practitioners who seek to apply ethical principles in real-world situations, including policy development.

from section 1

How to Empirical Ethics?

Davies, Ives and Dunn 2015:

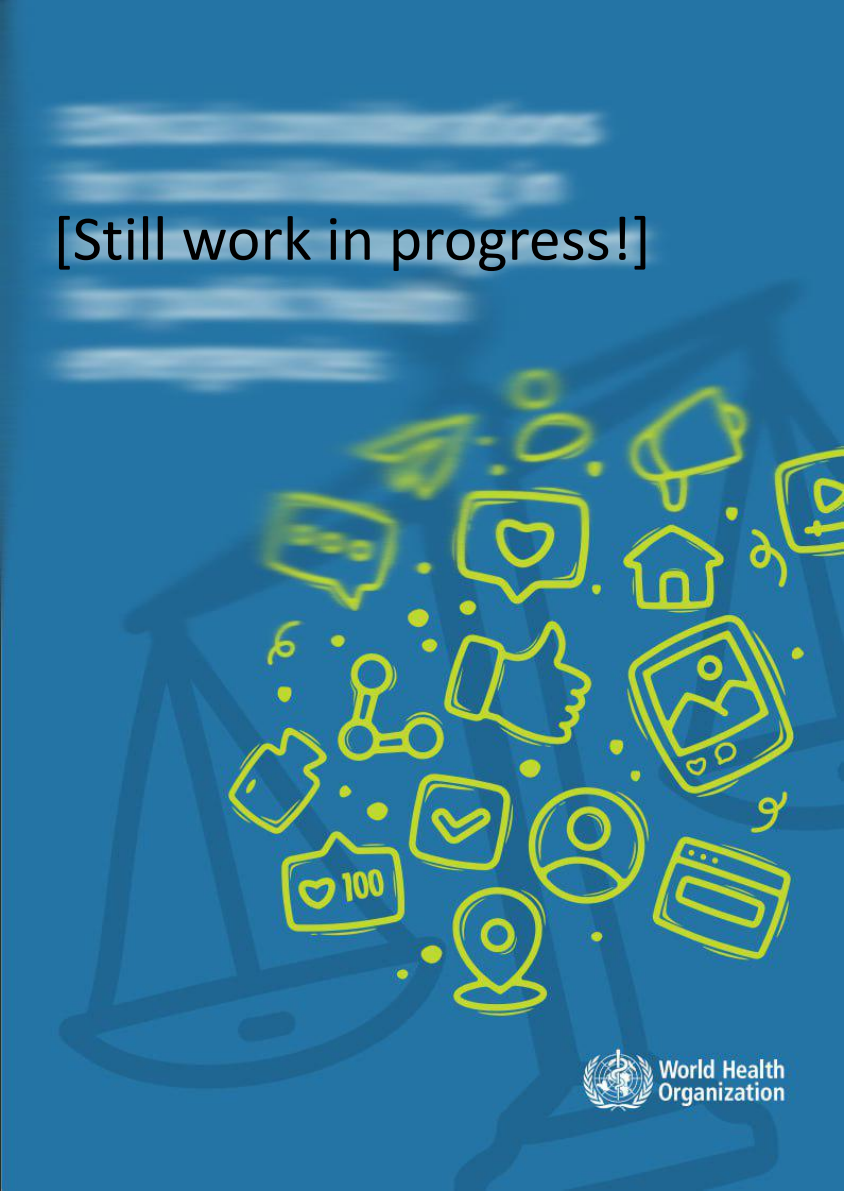
- There is no consensus as to what an appropriate methodology for empirical ethics would be. But existing methodologies can be classified on a spectrum with two main poles:

- Dialogical approaches, based around the formation of a dialogue between stakeholders and the attempt to reach a shared Understanding. The analysis, and reaching of a conclusion, is undertaken by the researcher and participants together.

- Consultative approaches tend to use an external 'thinker' who gathers data and analyses it independently of the data collection process, and then develops normative conclusions.

- "The heterogeneity we have observed is not a problem in itself. Difference adds to the richness of the field and, certainly in its infancy, a field such as empirical bioethics will surely benefit from experimentation and variety".

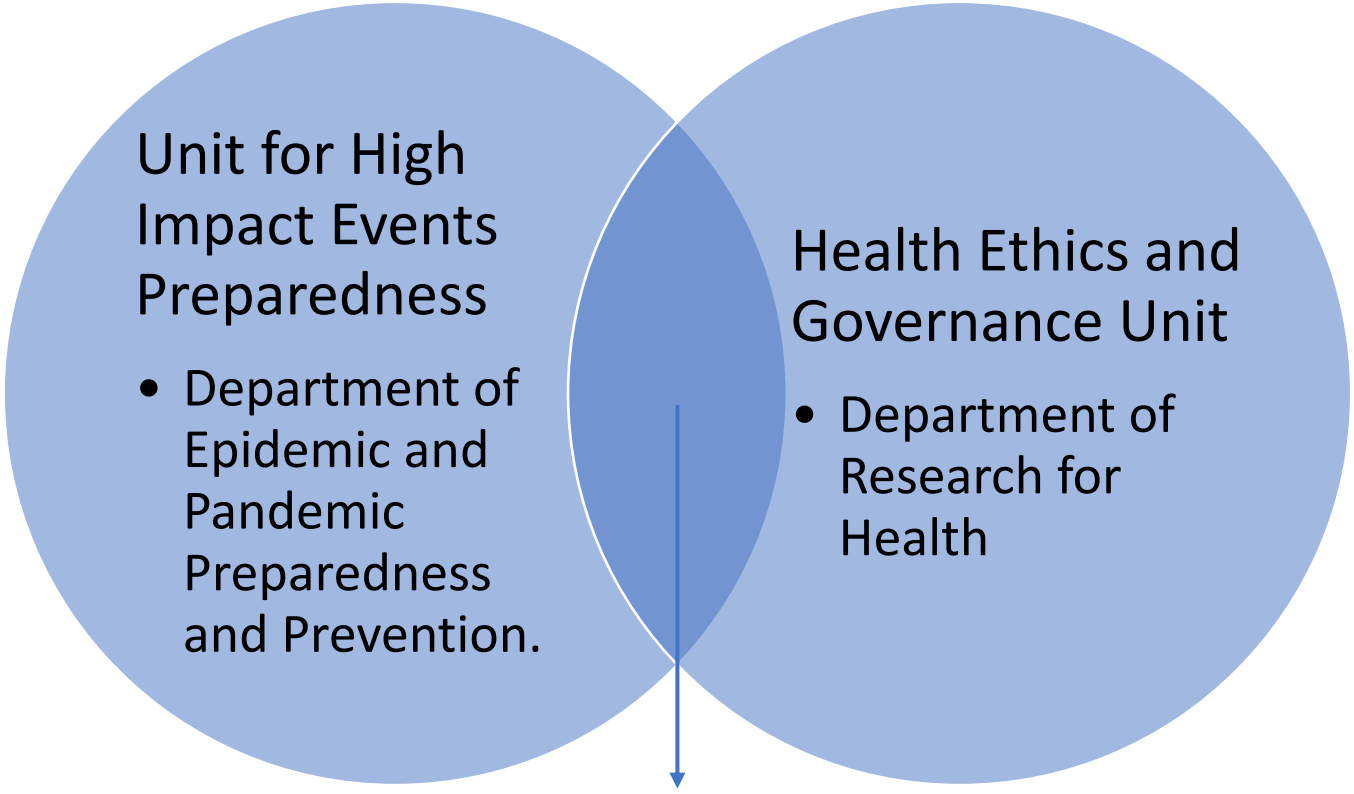
[Still work in progress!]



Ethical Framework for infodemic management and social listening

WHO Guidance

World Health Organization



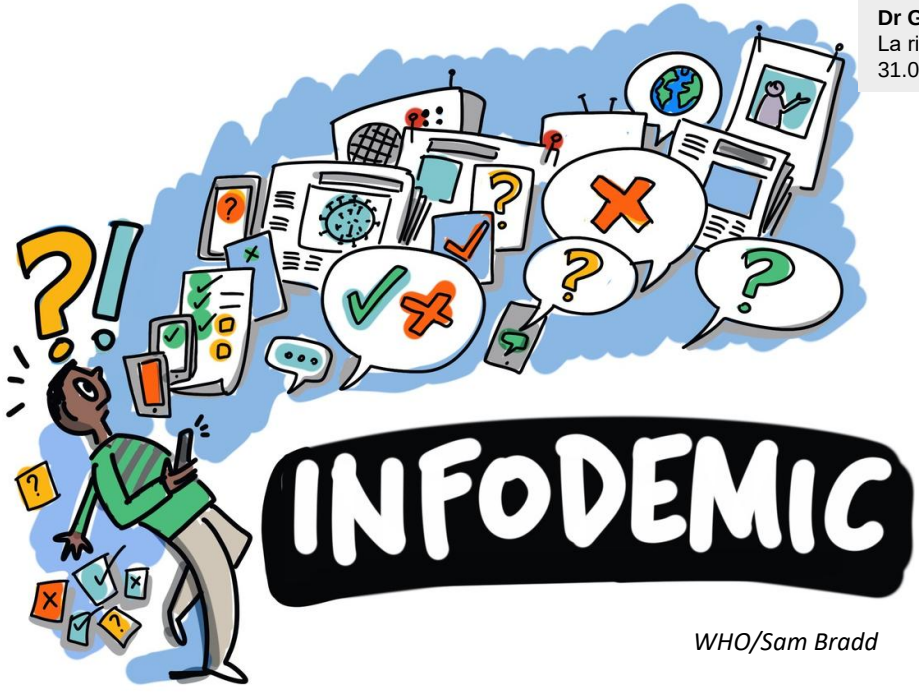
This process

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 Abeyesekera 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.



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

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

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.

The process

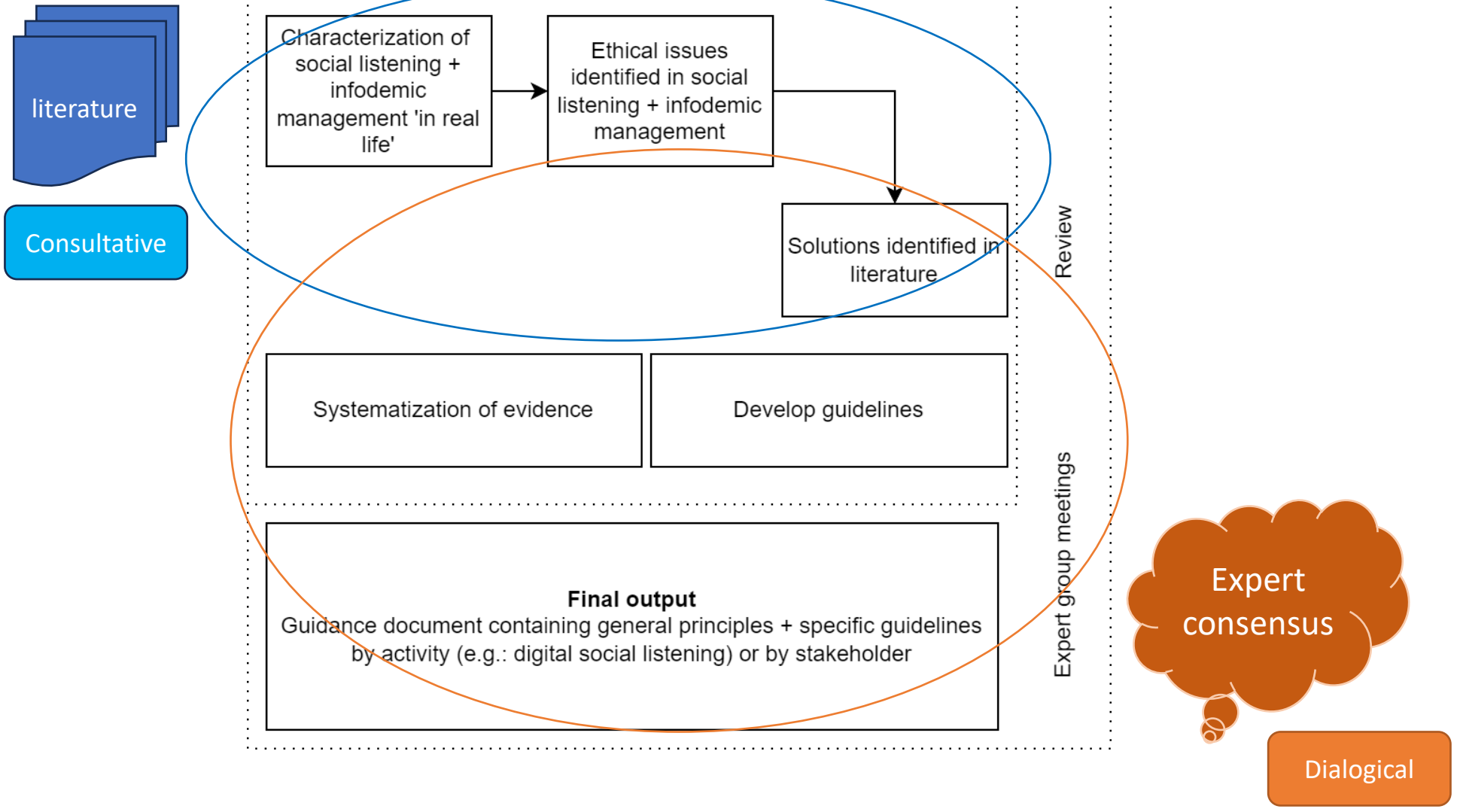
Infodemics? IM?

Moral values to pursue?

How do we get there?

Potential harm?

Where do we want to go?


literature
Consultative
Characterization of social listening + infodemic management 'in real life'
Ethical issues identified in social listening + infodemic management
Solutions identified in literature
Review
Systematization of evidence
Develop guidelines
Final output
Guidance document containing general principles + specific guidelines by activity (e.g.: digital social listening) or by stakeholder
Expert group meetings
Expert consensus
Dialogical

Review: query

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

AND

Response (to misinformation, information voids, etc.)

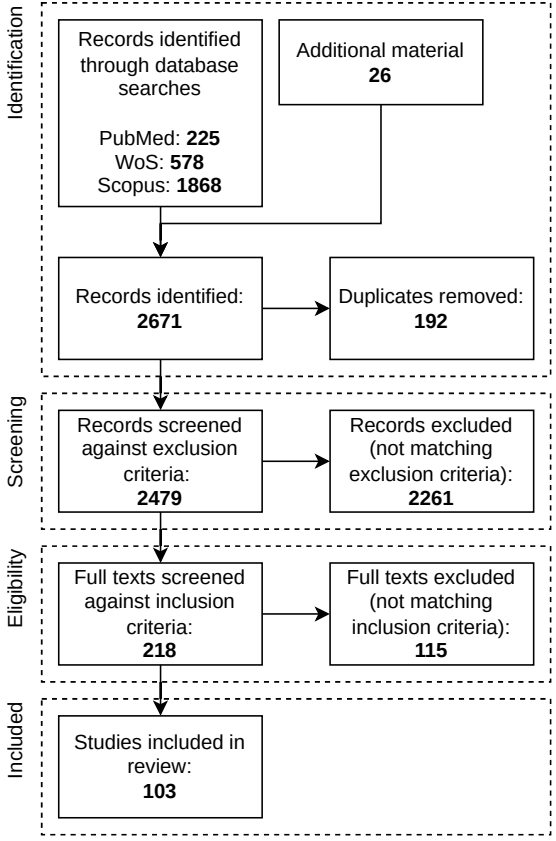
OR

Social listening

AND

Context (which emergency, chronic emergency, etc.)) AND ETHICS

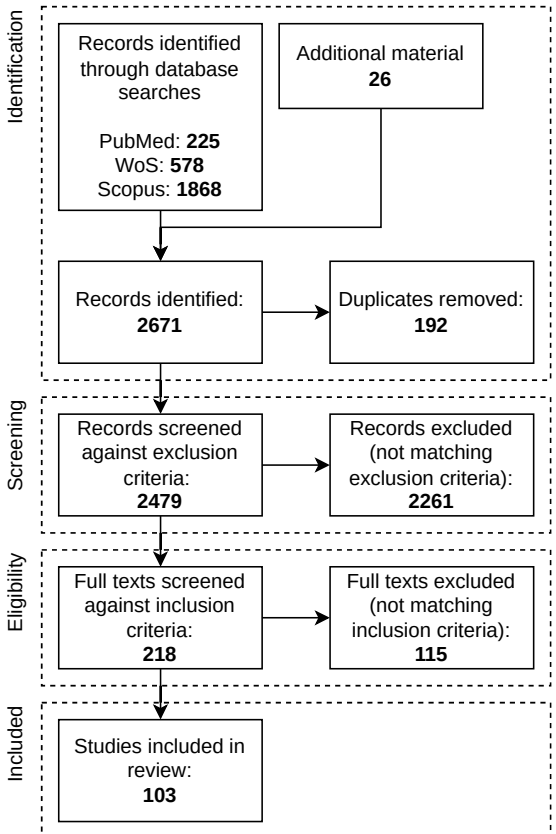
Review: screening

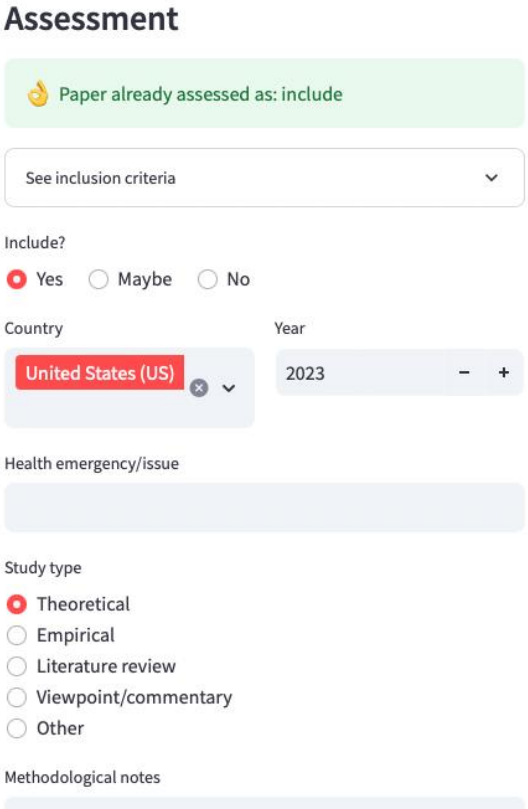


INCLUSION CRITERIA

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**

Review: content assessment





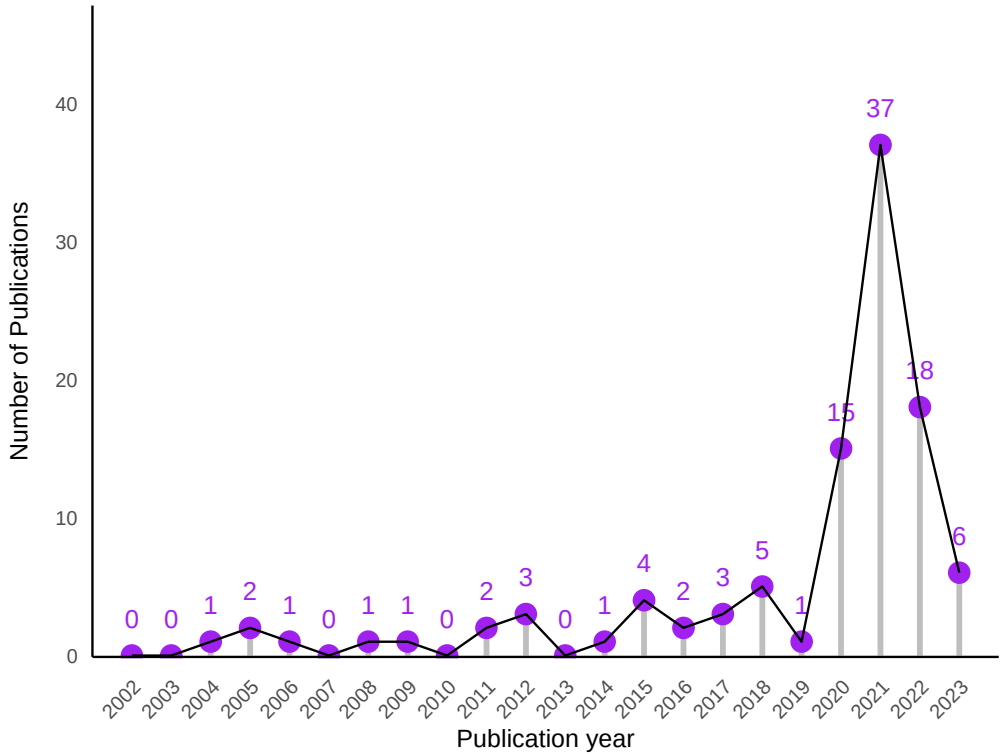
Review: characterization of literature

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

Review: publication year of studies



Review: types of health emergencies

Pandemics and epidemics 49

COVID-19
Influenza H1N1
HIV
(general)
Measles
Infectious disease (general)
H5N1
Dengue

Infodemics 24

COVID-19
Vaccines
(general)

6 Chronic health emergencies

Smoking
Alchohol
Obesity / nutrition
Food risk

5 Environment

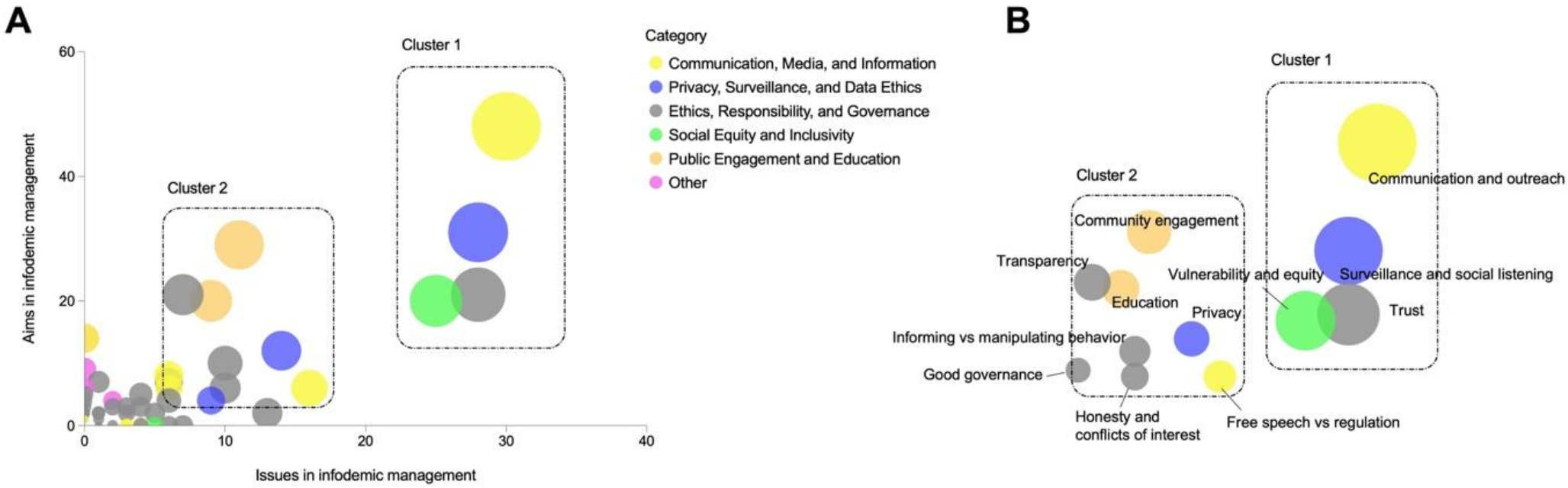
Radioactivity
Flood / disaster
Water pollution
Contamination

Not defined 14

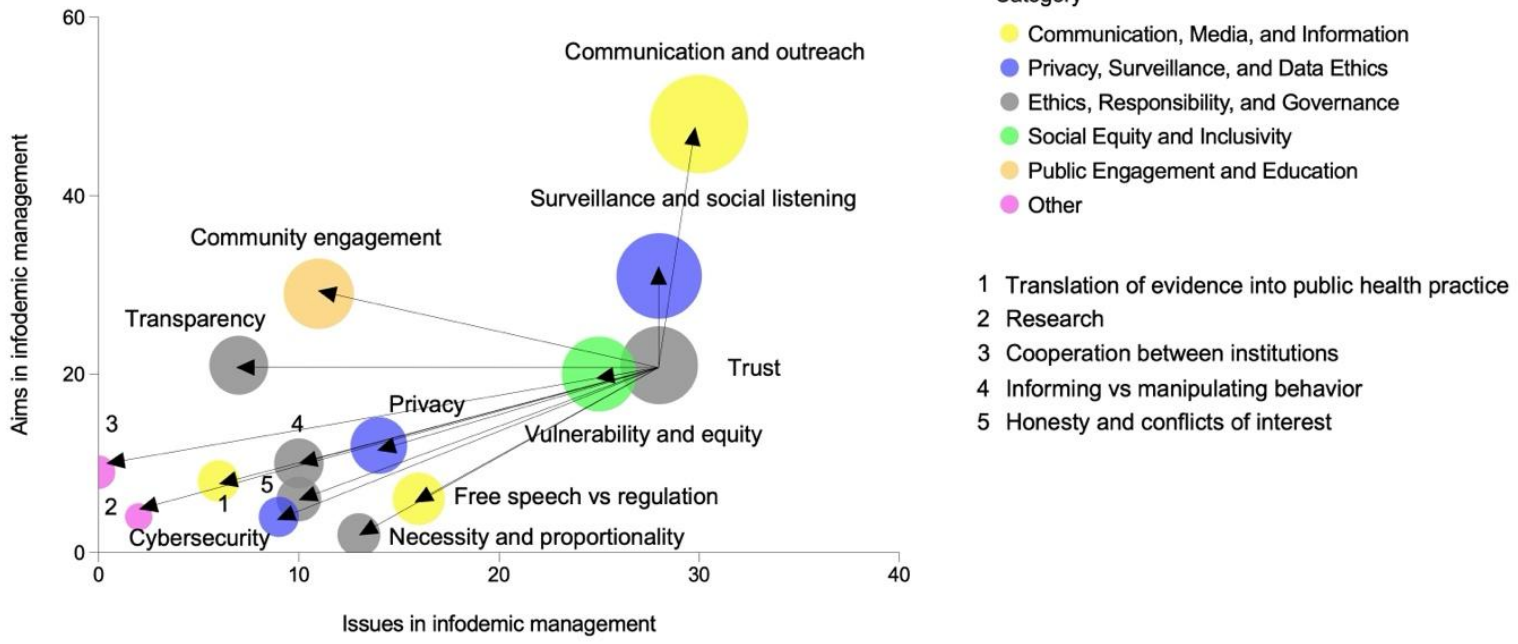
4 General health emergency

Other 1

Review: analysis



Review: analysis



Review: solutions

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.

Review: main takeaways

How to improve

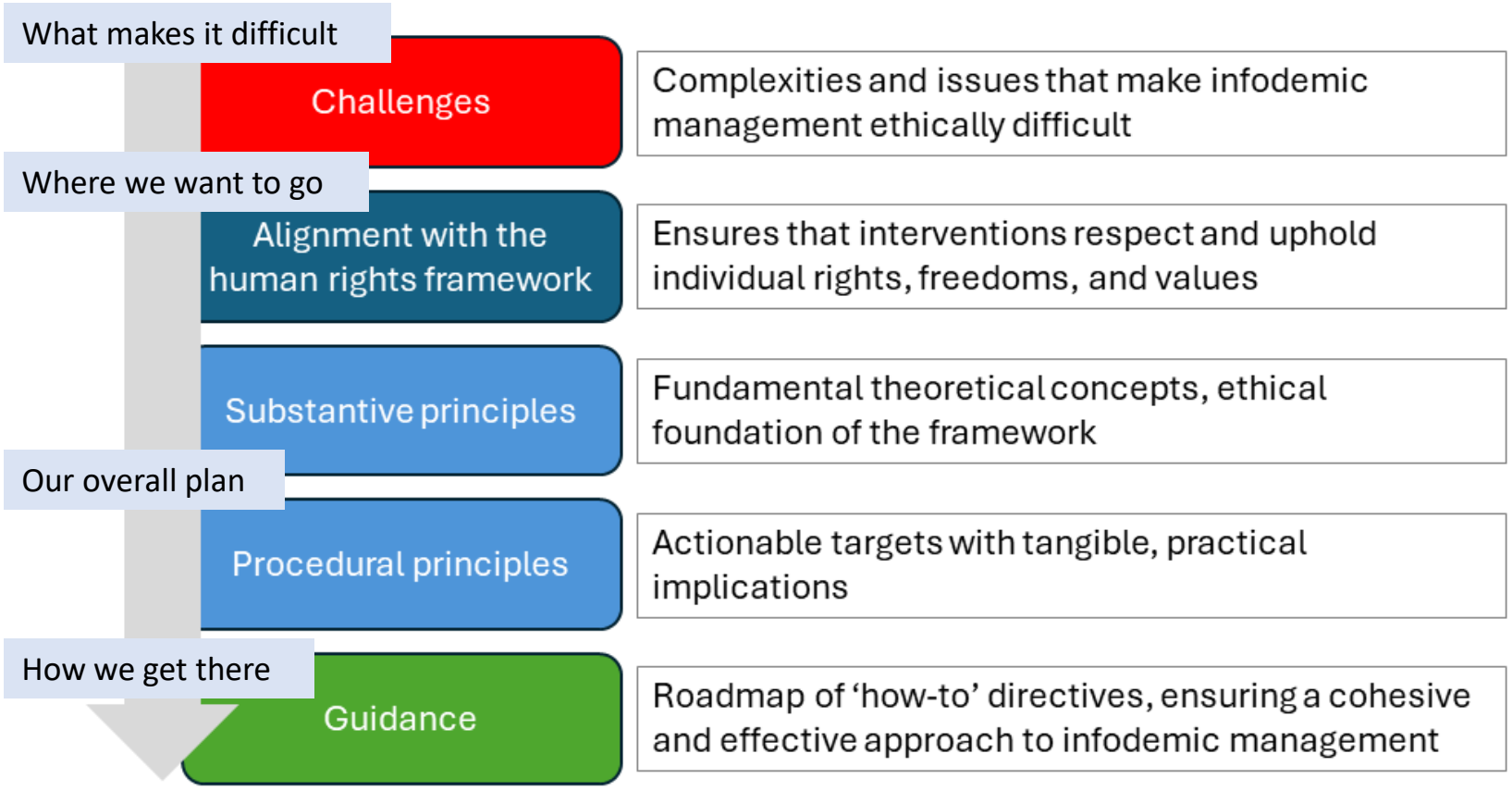
1. Public engagement
2. Active social listening
3. Transparency
4. Acknowledging uncertainty
5. Building resiliency

REDUCE POLARIZATION and increase TRUST

Improved public health response

Adherence to public health measures

Guidance: structure



Guidance: challenges

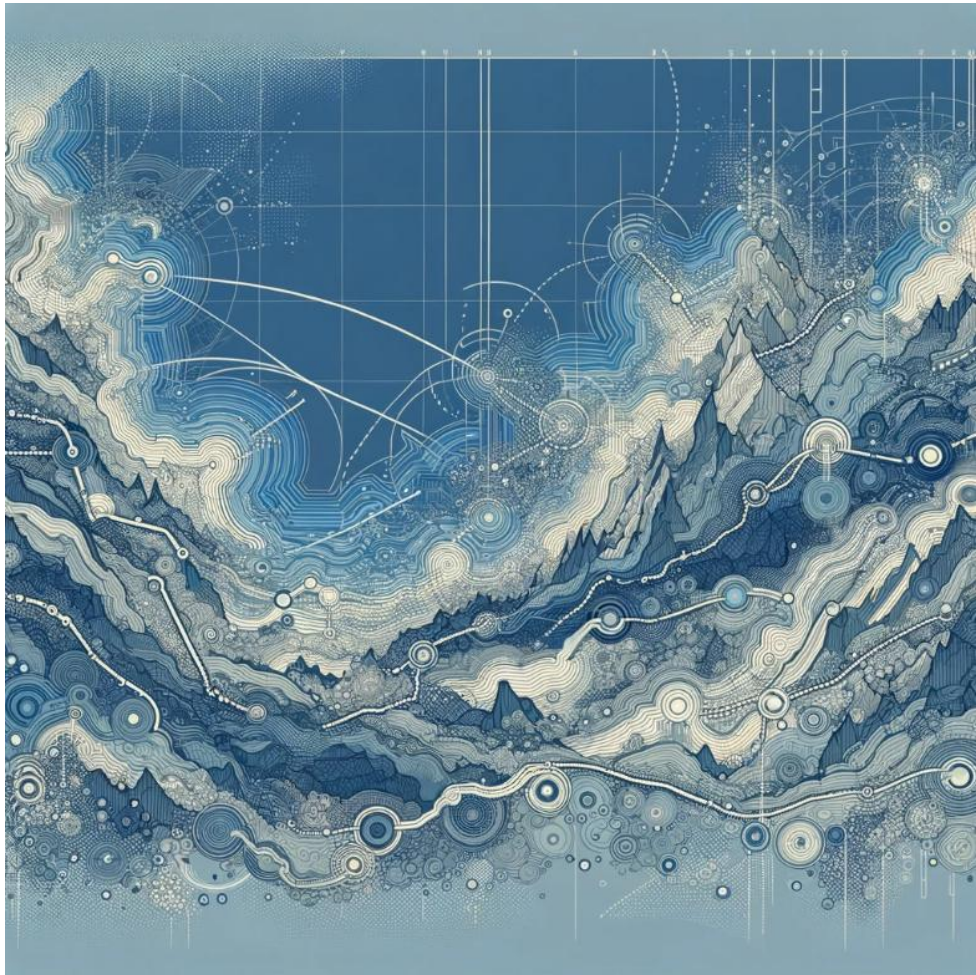
- Harm to people in vulnerable situations
- Erosion of trust
- Ineffective health systems response
- Data misuse, dual use, or unintended negative consequences of data collection
- Managing power imbalance, guaranteeing good governance, and establishing governance policy
- Restrictions to freedom of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

Guidance: 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

Guidance: procedural principles

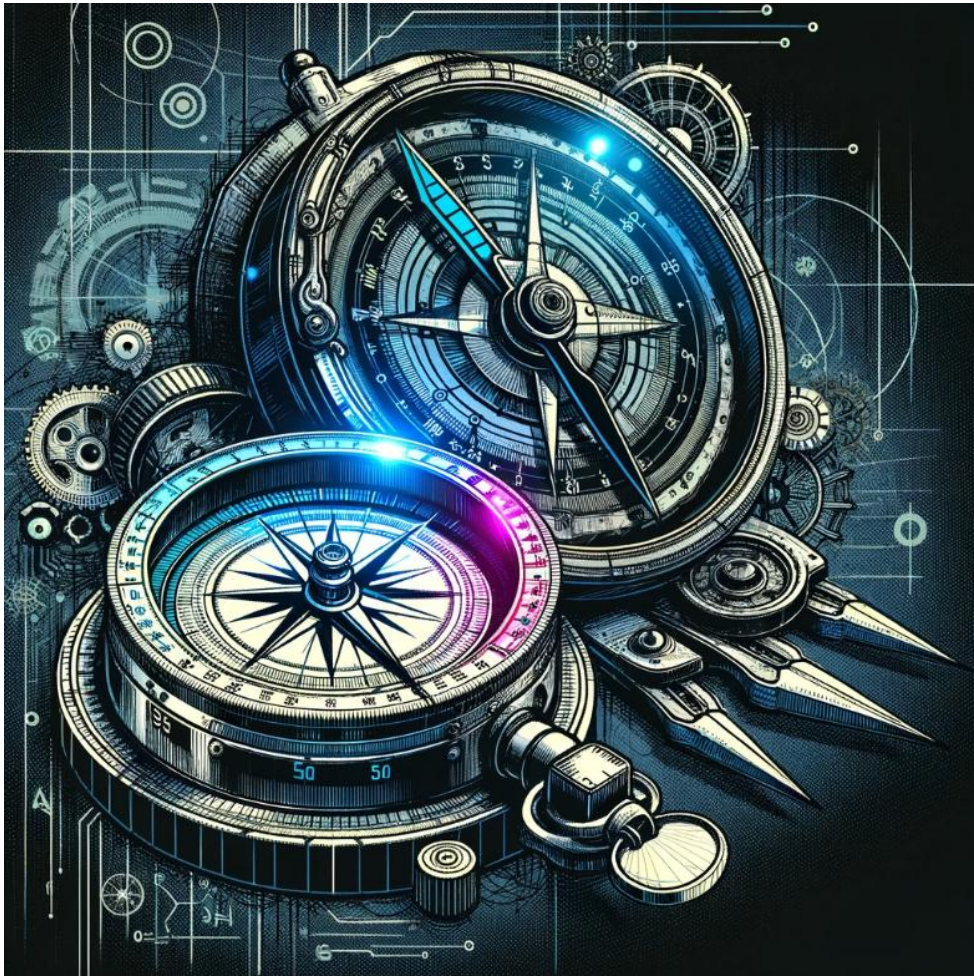
- Promoting privacy
- Responsible large-scale automated data processing
- Apply fair, equitable and inclusive processes of decision making
- Trust
- Feedback integration
- Community engagement
- Pursue understandability of communication



Guidance: 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.



Guidance: example. 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.

Recommended readings

Bærøe K. 2014, Translational ethics: an analytical framework of translational movements between theory and practice and a sketch of a comprehensive approach.
DOI: 10.1186/1472-6939-15-71

Bærøe K. 2024, Translational bioethics: Reflections on what it can be and how it should work.
DOI: 10.1111/bioe.13263

Purnat T., Nguyen T., and Briand S. (eds) 2023. Managing Infodemics in the 21st Century.
DOI: 10.1007/978-3-031-27789-4

Germani F., Spitale G., Machiri S.V., Ho C.W.L., Ballalai I., Biller-Andorno N. et al. 2024, Ethical considerations in infodemic management: systematic scoping review.
DOI: 10.2196/56307

Spitale G., Germani F., Biller-Andorno N. 2024. The PHERCC matrix. An ethical framework for planning, governing, and evaluating risk and crisis communication in the context of public health emergencies.
DOI: 10.1080/15265161.2023.2201191

Spitale G., Germani F. 2023, Ethical considerations on social listening and infodemic management.
DOI: 10.17605/OSF.IO/28D73.

SUMMARIZING:

1. **Theory – What is empirical (bio)ethics?**
2. **Methods – Methodological options in empirical (bio)ethics**
3. **Practice – How to develop an empirical (bio)ethics project**
4. **Example – Empirical (bio)ethics in (bio)ethics-to-policy**

Download the slides here ->

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