

Data 4 Policy Values, Ethics, Governance



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Doing No Harm - Protecting Individual Rights

RESEARCH ETHICS – DATA PROTECTION – RISK MANAGEMENT

Nuremberg Code



<https://www.meduniwien.ac.at/web/en/about-us/news/detailsite/2017/news-in-february-2017/nuremberg-doctors-trial-was-an-important-milestone-in-the-development-of-bioethical-principles-in-medicine/>

20 doctors from the Nazi regime in Germany were tried in Nuremberg, the judgements being pronounced in August 1947. The trials and their consequences, which resulted in the Nuremberg Code, marked an important milestone in the development and implementation of bioethical principles in medicine. These principles continue to be developed and applied throughout the world today.

The Nuremberg Code (1947)

Permissible Medical Experiments

The great weight of the evidence before us to effect that certain types of medical experiments on human beings, when kept within reasonably well-defined bounds, conform to the ethics of the medical profession generally. The protagonists of the practice of human experimentation justify their views on the basis that such experiments yield results for the good of society that are unprocurable by other methods or means of study. All agree, however, that certain basic principles must be observed in order to satisfy moral, ethical and legal concepts:

https://media.tghn.org/medialibrary/2011/04/BMJ_No_7070_Volume_313_The_Nuremberg_Code.pdf

Belmont Report 1979

Appendix
Volume I

The Belmont Report

Ethical Principles
and Guidelines for
the Protection of
Human Subjects
of Research

The National Commission
for the Protection of Human Subjects
of Biomedical and Behavioral
Research

The *Belmont Report* explains the unifying ethical principles for using any human subjects for research which have formed the basis for the National Commission's topic-specific reports and regulations. The three ethical principles are:^[1]

Respect for persons: protecting the autonomy of all people and treating them with courtesy and respect and allowing for informed consent. Researchers must be truthful and conduct no deception (integrity);

Beneficence: the philosophy of "Do no harm" while maximizing benefits for the research project and minimizing risks to the research subjects; and

Justice: ensuring reasonable, non-exploitative, and well-considered procedures are administered fairly — the fair distribution of costs and benefits to *potential* research participants — and equally.

https://en.wikipedia.org/wiki/Belmont_Report

<https://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/index.html>

EU GDPR (overview)

Purpose

Protect individuals' fundamental rights and freedoms in relation to personal data.

Scope

Applies to all processing of personal data of people in the EU, including by organisations outside the EU.

Key principles

Lawfulness · fairness · transparency · purpose limitation · data minimisation · accuracy · security · accountability

Individual rights

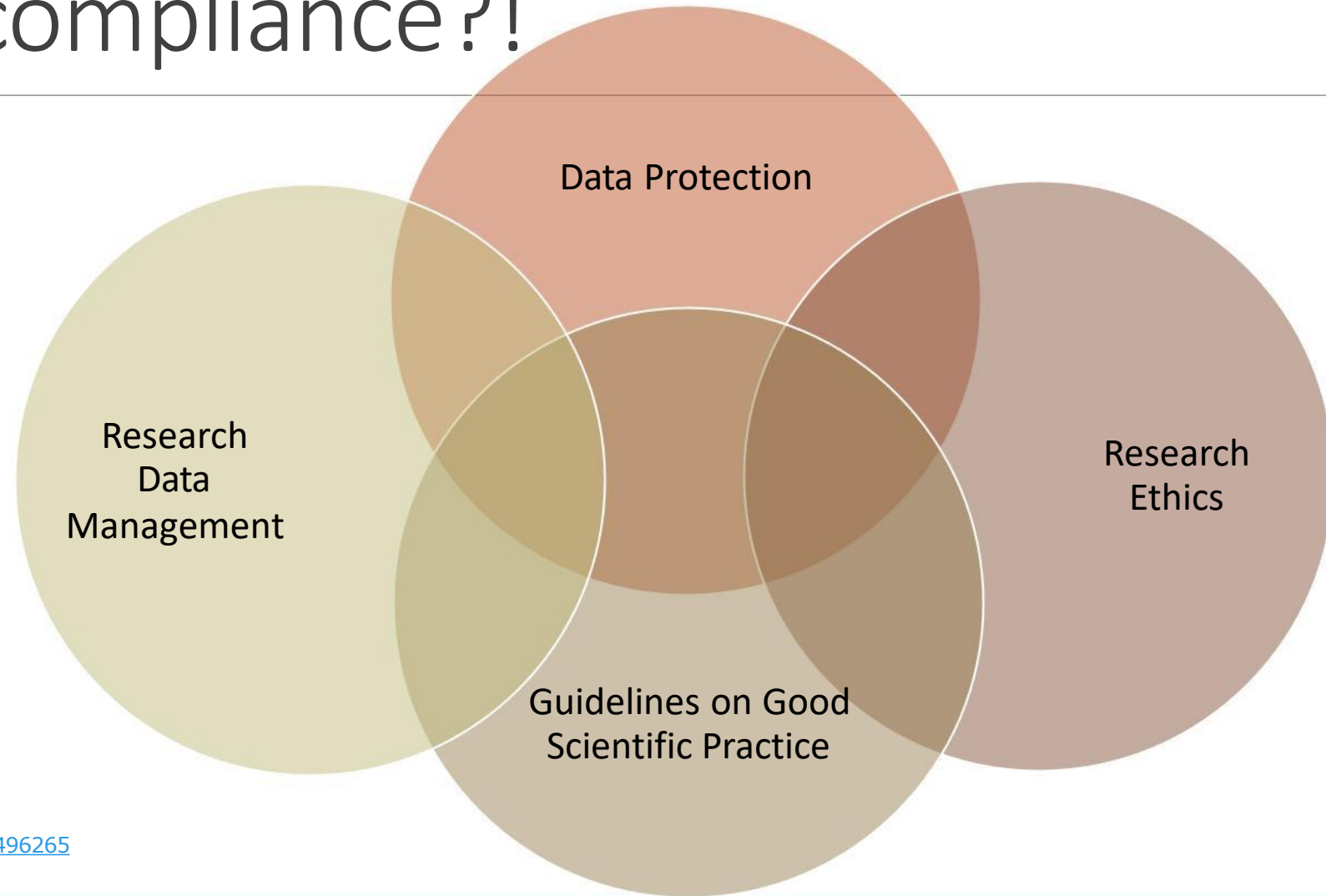
Access · correction · erasure · portability · objection · limits on automated decisions

Organisational duties

Legal basis & consent · privacy by design · security · breach notification · documentation

<https://eur-lex.europa.eu/en/legal-content/summary/general-data-protection-regulation-gdpr.html>

Lost in compliance?!



Source: <https://zenodo.org/records/18496265>

Professional Ethics

IN STATISTICAL PRACTICES

Ethical codes for data collection, manipulation, and use (David Hand)

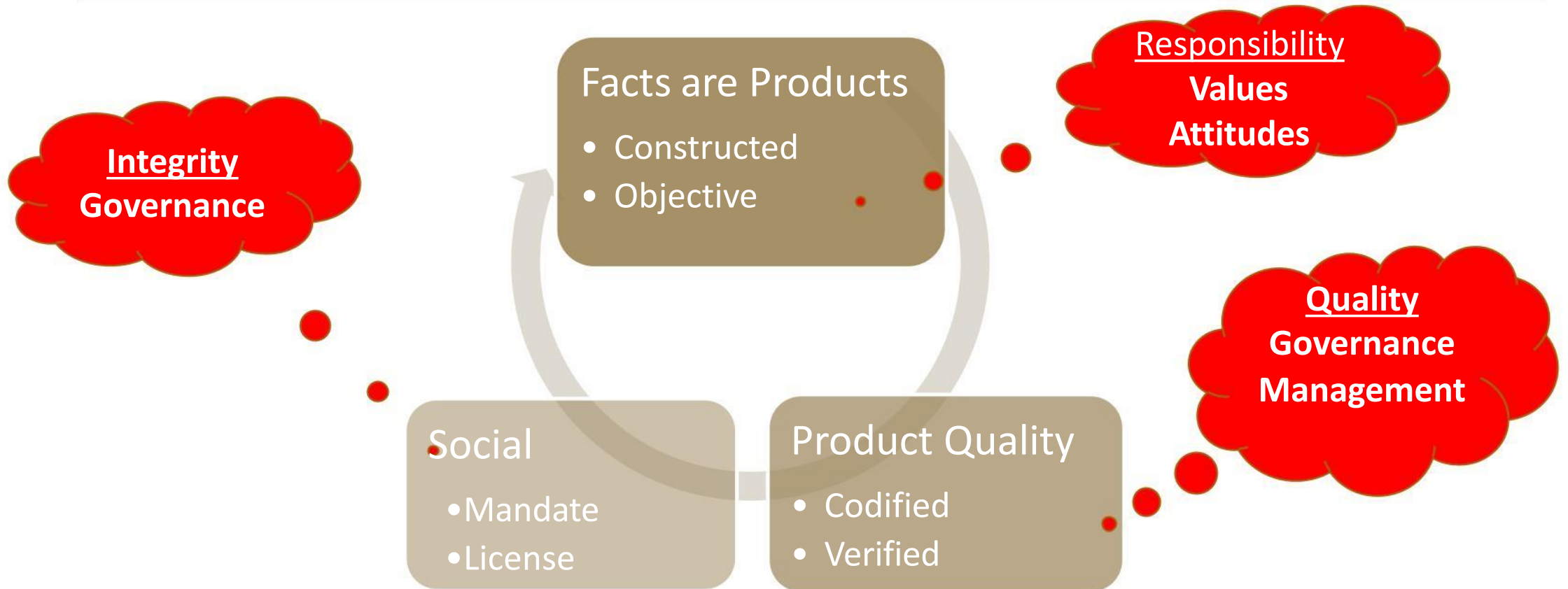
“have various functions, including things such as the following:

- providing guidance on how to behave in difficult circumstances;
- preserving privacy in a way that users and the public will find acceptable;
- ensuring that data are used in such a way as to benefit the public;
- reassuring customers, the public, and others about an organization’s integrity; and
- reassuring employees that they work for a trust-worthy organization.”


"However, the context of data science is so vast and diverse, and is changing so rapidly over time, that we cannot hope to put in place precise regulations. There cannot be a single and simple universal set of rules, and unexpected and unforeseen circumstances are certain to arise. The best we can hope for are some ethical principles that have to be interpreted or instantiated in particular applications. That is, the principles must be mapped to low-level guidance, and this is likely to be application specific.”

Hand, D. J. 2018. 'Aspects of Data Ethics in a Changing World: Where Are We Now?', Big Data, 6. <https://www.liebertpub.com/doi/pdfplus/10.1089/big.2018.0083>

Ethics and Governance in Statistics



Ethics, Good Governance Principles, e.g.

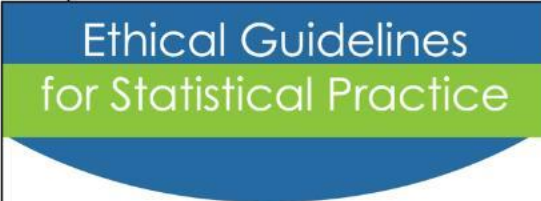


**International
Statistical
Institute**

DECLARATION ON PROFESSIONAL ETHICS

ADOPTED BY THE ISI COUNCIL
22 & 23 JULY 2010
REYKJAVIK, ICELAND


UPDATED VERSION
ENDORSED BY ISI EXECUTIVE COMMITTEE
17 JULY 2023
OTTAWA, CANADA




**Ethical Guidelines
for Statistical Practice**

Prepared by the Committee
on Professional Ethics of the
American Statistical Association

Approved by the ASA Board in February 2022



ASA AMERICAN STATISTICAL ASSOCIATION
Promoting the Practice and Profession of Statistics



Economic and Social Council

Distr.: General
28 October 2013

Substantive session of 2013
Agenda item 13 (c)

Resolution adopted by the Economic and Social Council on 24 July 2013


[on the recommendation of the Statistical Commission (E/2013/24)]

2013/21. Fundamental Principles of Official Statistics



**EUROPEAN STATISTICS
CODE OF PRACTICE**

*For the National Statistical Authorities
and Eurostat (EU statistical authority)*



**Recommendation of the OECD Council on Good Statistical
Practice**

As approved by the Council on 23 November 2015
[C(2015)128 - C(2015)128/CORR1 - C/M(2015)21]

Declaration on Professional Ethics

ADOPTED BY THE ISI COUNCIL, 22 & 23 July 2010, Reykjavik, Iceland.

Updated Version endorsed by ISI Executive Committee 17 JULY 2023, Ottawa, Canada.

<https://isi-web.org/declaration-professional-ethics>

ISI Responsibility

<https://isi-web.org/declaration-professional-ethics>

Ethical principles inherently reflect the obligations and responsibilities of – as well as the resulting conflicts faced by – statisticians to forces and pressures outside of their own performance, namely to and from:

- Society
- Employers, Clients, and Funders
- Colleagues
- Subjects

In carrying out his/her responsibilities, each statistician must be sensitive to the need to ensure that his/her actions are, first, consistent with the best interests of each group and, second, do not favor any group at the expense of any other, or conflict with any of the Principles.

ISI Values

<https://isi-web.org/declaration-professional-ethics>

1. Respect

- We respect the privacy of others and the promises of confidentiality given to them.
- ...

2. Professionalism

- The value Professionalism implies Responsibility, Competence and Expert Knowledge, and Informed Judgement.
- We work to understand our users' needs and develop relevant solutions.
- We use our statistical knowledge, data, and analyses for the Common Good to serve the society.
- ...

3. Truthfulness and Integrity

- The values of Truthfulness and Integrity are reflected in our work processes, that rely on Independence, Objectivity and Transparency.
- We produce statistical results using our science and are not influenced by pressure from politicians or funders
- ...

ISI Principles

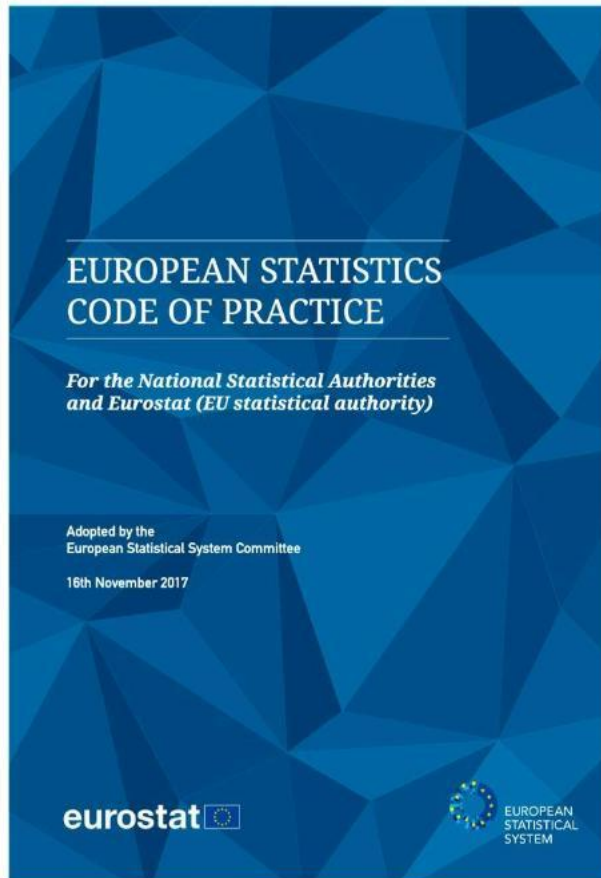
<https://isi-web.org/declaration-professional-ethics>

Pursuing Objectivity	Clarifying Obligations and Roles	Assessing Alternatives Impartially	Conflicting Interests
Avoiding Preempted Outcomes	Guarding Privileged Information	Exhibiting Professional Competence	Maintaining Confidence in Statistics
Exposing and Reviewing Methods and Findings	Communicating Ethical Principles	Bearing Responsibility for the Integrity of the Discipline	Protecting the Interests of Subjects

Good Governance

QUALITY, INTEGRITY OF PUBLIC STATISTICS

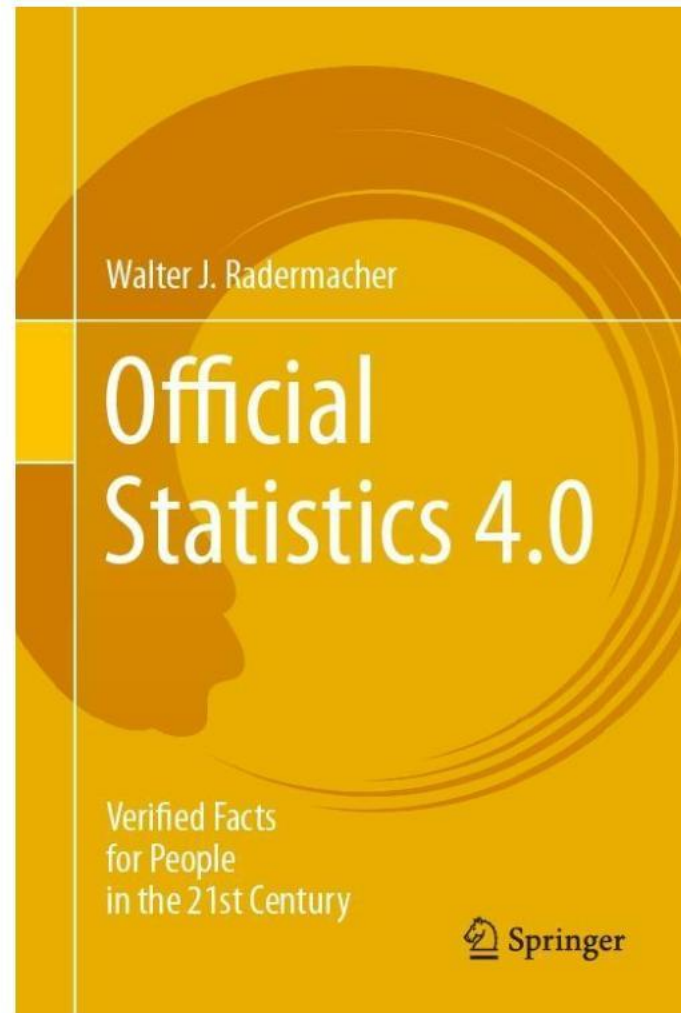
Codification: EU Statistics



Institutional environment	Statistical processes	Statistical output
<ol style="list-style-type: none"> 1. Professional independence 1bis. Coordination and cooperation 1. Mandate for data collection 2. Adequacy of resources 3. Commitment to quality 4. Statistical confidentiality 5. Impartiality and objectivity 	<ol style="list-style-type: none"> 7. Sound methodology 8. Appropriate statistical procedures 9. Non-excessive burden on respondents 10. Cost-effectiveness 	<ol style="list-style-type: none"> 11. Relevance 12. Accuracy and reliability 13. Timeliness and punctuality 14. Coherence and comparability 15. Accessibility and clarity

<https://ec.europa.eu/eurostat/web/products-catalogues/-/KS-02-18-142>

MUCHAS GRACIAS
MUITO OBRIGADO
VIELEN DANK
THANK YOU
MERCİ BIEN



 Walter J. Radermacher

 +49 15111782920

 wjr@outlook.de



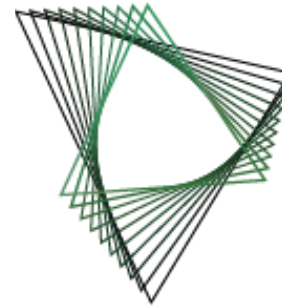
<https://www.springer.com/gp/book/9783030314910>

Funded by

DFG

Deutsche
Forschungsgemeinschaft

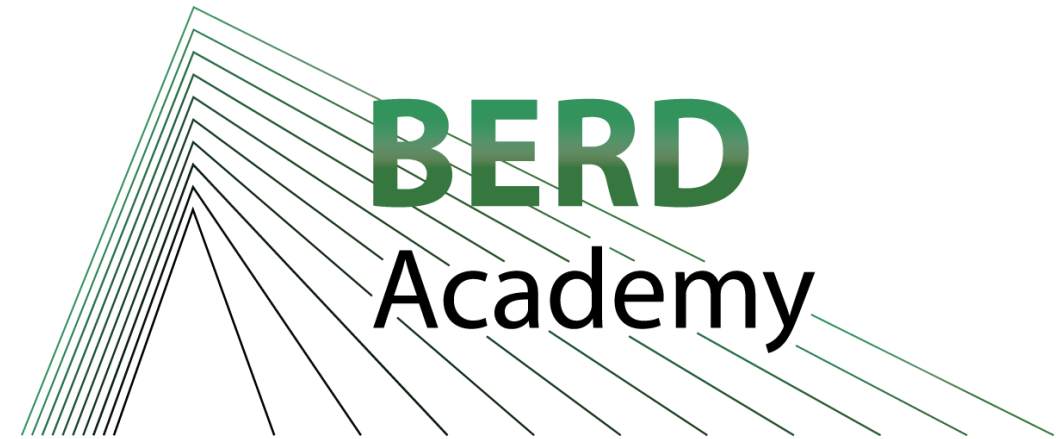
German Research Foundation



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*The views expressed in this video do not reflect those of the **BERD@NFDI** or the **Deutsche Forschungsgemeinschaft** (DFG, German Research Foundation).*



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