







Missione 4 Istruzione e Ricerca

BETWEEN PRIVATIZATION
OF KNOWLEDGE AND
OPEN SCIENCE"
(=CLIPKOS)

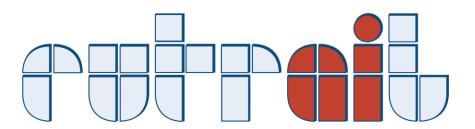
Data Access and Usage in Health Care: Toward Responsibility and Trust

5 + 6 June 2025





Euregio Platform on Human Dignity and Human Rights







Challenges of *Ethical* Technology Assessment





Why ethical TA?



1. Technical Inspection Agencies 19th cty

→ focus on security and functionality ("danger to life and limb")

e.g. Registro Italiano Navale (RINA S.p.A.) 1861 Dampfkessel Überwachungsverein (TÜV) 1866



- → technical inspections *are not* "ethical"
- → of course: there are ethical concerns (loss of human dignity / alienation)
- → however: not inherent to technology



2. Emergence of TA in the 1960s

- → expanded focus of (unintented, long-term) impacts of technology (e.g. atomic energy, arms race, environmental pollution)
 - → ethical issues shift toward technology itself



→ TA not explicitly ethical with respect to the human being (humanity)

even though: digital technologies advancing rapidly (microprocessors, industrial robots, centralized computer systems, *etc*.)



3. Ethical TA in the digital age

→ biological/medical and personal *data* are becoming massively *accessible* and *usable* for digital and automated proccessing

e.g. Human Genome Project 1984/1987 concerns about "transparent humans/citizens"



"Citizens are at risk of becoming transparant humans if data protection is not effectively safeguarded by law"

Hans Peter Bull, *Datenschutz, oder Die Angst vorm Computer* (1984)



Faced with technologies of AI and synthetic biology the human being becomes unsure about the question of their own nature.

There is not a "natural" trust (anymore) that technology might not threaten the essence of what it means to be human – and what life means in general.



On the one hand

guiding idea: functional machinal understanding of the human being and life in general dominating terminology (system, brain, behaviour, information, input/output etc.) is developed in cybernetics, cognitive sciences, life sciences, computer sciences, psychology, etc.

common denominator: production of huge amounts of data









On the other hand

calls for HumanE-AI, responsible AI, trustworthy AI, mindful AI, digital humanism, digital sovereignity, transparency, fairness, etc.



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calls for HumanE-AI, responsible AI, trustworthy AI, mindful AI, digital humanism, digital sovereignity, transparency, fairness, etc.

First principle of biomedical ethics "Autonomy / Personal liberty" (Beauchamp/Childress, 1979)



The major challenge of *ethical* TA

→ Necessity of functional AND non-functional requirements

Why is this not so easy?

Because non-functional requirements – and ethical foundations – do not originate in academic theory / cannot be extracted from any kind of data



The era of industrialization/technologization: the cradle of technological progress and development as we know it today is at the same time – the age of enlightenment: providing a fairly clear general concept of humanity, based on human dignity, freedom, autonomy and centered around personhood



18th and 19th century

- → a general, or universal idea of humanity that was commonly shared
- → that was compatible with and adequate to the state of technological progress at the time
- > rooted in a particular intellectual, cultural, religious tradition and in specific societal conditions



Today

Technological progress is a worldwide process and globally accepted development, the unquestionable (or inevitable?) shape of the future of the planet

There is not an adequate corresponding universal idea of humanity, equally well trusted and globally accepted



- For (us) Europeans it is one and the same tradition
 - → hence, a particular responsibility
 - → critical reflection on the European history



The major challenge of ethical TA

- → Necessity of functional AND non-functional requirements
 - → Socio-technical scenarios
 - → Dialogue of different types of knowledge/openness for different discourses

















technical discourse









technical discourse

domain specific discourse









technical discourse

domain specific discourse

- → different in light of an ethical TA
- → incentive for self-reflection
- → attention to non-functional aspects
- → awareness of potential "moral hazards"





I wish ourselves an insightful conference.