Analytics on Health Data: Ethical Considerations

Analytics on health data: problems and conflicts

- What are health data?
- Who owns health data?
- How have research health data to be treated when anonymisation is not possible?
- Is it fair to anonymise health data?
- Have collections of health data to be treated different than single data?
- How much effort is justified to protect health data?
- Usability vs. security, which security constraints are necessary?
- Are we obliged to offer data security and safety beyond the legal requirements?

Ethics?

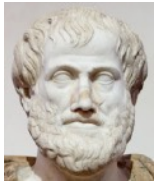
- **Ethics: Moral philosophy**

- Moral duties: what shall I do in a specific situation
- Ethical conflict: when moral principles contradict
- Applied ethics: reasoning on ways to solve practical ethical conflicts

Ethics vs. Law

Set of guidelines	Set of rules and regulations
Imposed by individuals, groups, society	Imposed by government
Enforced by explicit sanctions (fines, prison)	Enforced by conscience, peers, media, society…
Legal binding for everybody	Non-binding or binding within a group
Abstract	Expressed and published in writing

Ethical theories



- Aristotle (384 BC - 322 BC), virtue ethics
  Nicomachean Ethics: "How to live in happiness?"
  *Short answer: "*Live a life of virtue.*"*
- Immanuel Kant (1724 - 1804), deontological ethics
  Metaphysik der Sitten, 1797: "What should I do?"
  "Act only according to that maxim whereby you can, at the same time, will that it should become a universal law."
- Peter Singer (*1946), utilitarianism
  Practical Ethics, 1980, 1993, 2011: "How should beings' interests be weighed?"
  Beings interests should be weighted according to that being's concrete properties.

Biomedical ethics

Principles of Biomedical Ethics, Tom L. Beauchamp & James F. Childress [1](1977, 2009, 7th ed.):

- **Respect for autonomy**
  - Informed consent
  - Privacy
  - Confidentiality
- **Nonmaleficence**
- **Beneficence**
- **Justice**

Computer ethics

ACM Code of Ethics and Professional Conduct [2] (1972, 1992, 2018)
ACM: Association for Computing Machinery

Section 1 - **General moral principles**

- Principle 1.1 - Contribute to society
- Principle 1.2 - Avoid harm
- Principle 1.3 - Honesty
- Principle 1.4 - Nondiscrimination
- Principle 1.5 - Respect for creators
- Principle 1.6 - Privacy
- Principle 1.7 - Confidentiality

ACM code of conduct (2018) II

Section 2 - **Professional responsibilities**

- Principle 2.1 - Quality
- Principle 2.2 - Competence
- Principle 2.3 - Law
- Principle 2.4 - Professional review
- Principle 2.5 - Thoroughness
- Principle 2.6 - Responsibility
- Principle 2.7 - Public understanding
- Principle 2.8 - Avoid unauthorized access

Sketching the Ethics in Big Data Ecosystem in Biomedicine

Effy Vayena (UZH) & Urs Gasser Berkman Center (Harvard Law School), in Mittelstadt & Floridi (Ed.) The Ethics of Biomedical Big Data [3]

Work in progress, the authors propose three main elements

- Ethical Use and Privacy
- Data Governance
- Transparency and Accountability

Proposed moral duties for computer professionals handling health data in a Big Data context

- Have the persons behind the data in mind, protect their rights and prevent doing harm towards them
- Have always a professional approach and be aware what you are doing; analyse and mitigate risks on a daily base
- Define and shape best practices
- Speak up, when ethical aspects are neglected

➡ Act as responsible and accountable professional, be aware that moral duties cannot be delegated

Literature

1. Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics*, (Oxford: Oxford Press 2013[7])
2. Ronald E. Anderson, Deborah G. Johnson, Donald Gotterbarn, and Judith Perrolle, “Using the New ACM Code of Ethics in Decision Making”, *Comm. ACM* 36, 2 (1993), 98–107 and
   Bo Brinkman, Catherine Flick, Don Gotterbarn, Keith Miller, Kate Vazansky, Marty J. Wolf, “Listening to Professional Voices: Draft 2 of the ACM Code of Ethics and Professional Conduct”, *Comm. ACM*, Vol. 60, 5 (2017), 105-111
3. Effy Vayena and Urs Gasser, “Strictly Biomedical? Sketching the Ethics of the Big Data Ecosystem in Biomedicine”, in, *The Ethics of Biomedical Big Data*, Brent D. Mittelstadt, Luciano Floridi, (Springer 2016), 17-39