Ethics of Research in Evaluation of Health Information Systems

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prelude:

- I focus on *research in* instead of *research on*
- The topic inherits a lot from its parent concepts, the focus here is its peculiarities
- It is hard to find a crisp boundary for the definition of health information systems

Initialization:
Perspective and Problematization

- Positivists vs interpretivists: what to evaluate?
  - For example: measuring *patient waiting time* vs evaluating the *whole experience*
  - What if positivistic approach is more a response to our need (researcher) for stability, simplicity, and order, or even, better reviewers-acceptable/citable papers/fund-applications?

Experiments:
Invasive Evaluation

- Invasive evaluation in the mission critical HIS (mostly in prospective researches)
  - MRI vs Biopsy (for body) => X vs Y (for health setting)
  - Examples (negative): interruption of service, altering accessibility, exclusion of users or discriminating between them (similar to placebo trials), lowering safety standards, or degrading the effectiveness
  - Examples (positive): replace an older method, upgrade to a newer system

Experiments:
Side-effects of Non-Invasive Evaluations

- Non-critical (many of m-health) and/or non-invasive (e.g. tracking consumables in the operation theatre)
- When: low-risk, highly-hazardous, in large population
- Example: is using social networks safe? What if we evaluate a *health behavior* intervention?

Experiments:
Double Faceted Experiments

- No experiment on other living organisms in HIS evaluation (Example: brain stimulation reward) => Adverse effects are not clearly anticipated

- Adherence or Addiction?

  "*kinds of persistently repeated maladaptive behaviour that are not secondary to a recognized psychiatric syndrome, and in which it appears that the patient is repeatedly failing to resist impulses to carry out the behaviour. There is a prodromal period of tension with a feeling of release at the time of the act.*" ICD-10

Experiments:
Informed Consent

- What is *informed consent* when we are not sure about the impact aspects of a technology
  - Example: Tele-medicine instead of face-to-face, what are possible negative impacts?
    - Risk to independence and autonomy
    - Vulnerability to manipulation
    - Weaker trust relationship
    - Weaker social interactions

Experiments:
Training against wrong usage

- Consuming vs using
- Example hazards:
  - Confidentiality and anonymity breach
  - Over confidence in the reliability of the system
  - Over confidence in the certainty of the results
  - Wrong interpretation of the results

Observation:
Vagueness of Consent in Analytics

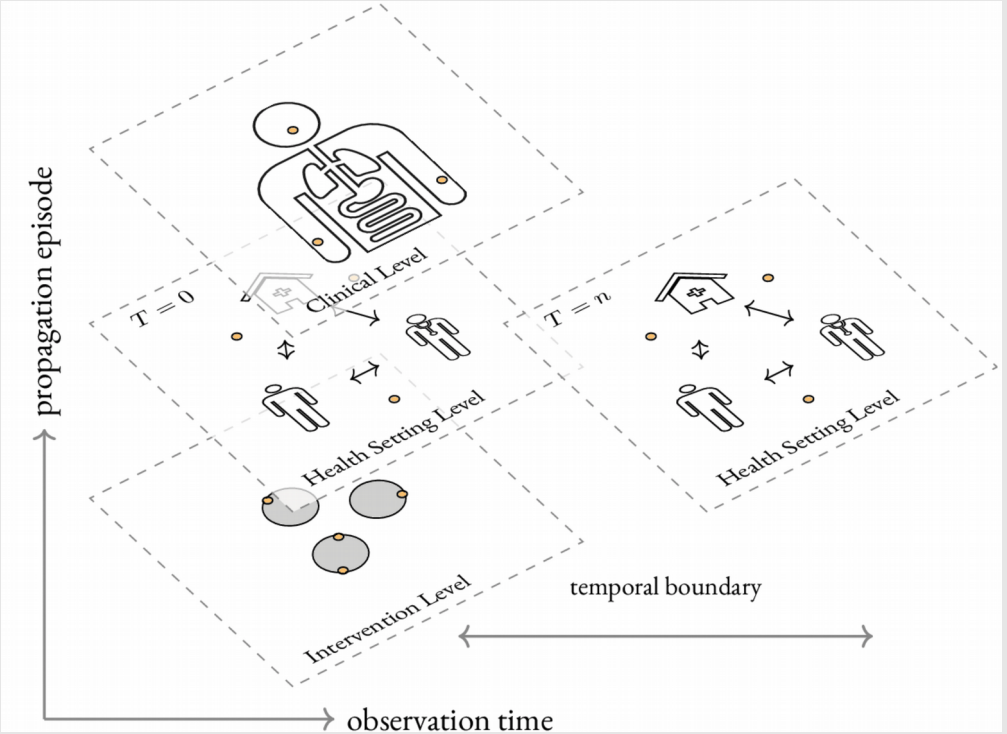
- General Terms
- Prospective combining of data for *some good intentions*

Observation/Reporting:
Third-party Induced Bias

- Who has access to:
  - The patients
  - The log files
  - Implementing/calling/showing the evaluation code/window
- Possible misconducts:
  - Hiding the results not confirming the quality
  - Hiding adverse or unfavorable events
  - Mishandling the research protocol (especially when it is ratified by the ethics committee)

Reporting:
Comparable Evaluation Results

- What is the problem
- The missing QALYs and DALYs => low efficiency in policy and budgeting



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Reporting and Storing:
Data Challenges

- Publication of anonymized data that can be combined for a possible deanonymization
  - Current regulations vs future algorithms/events
- Storing data
  - Rules for retention period exist but not for *degrees of specification* rules

Thanks!

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