Investigating the material dimension of ethics

SOCIAL AND ETHICAL IMPLICATIONS OF AI ASSISTED DIGITAL SELF-MONITORING FOR CARDIOVASCULAR DISEASE



Mignon Hagemeijer – Institute for Science in Society (ISiS) Mignon.Hagemeijer@ru.nl



Quick introduction

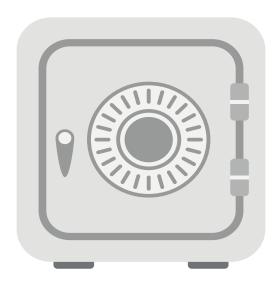
Research consortium

- Cardiologists
- AI & data scientists

Research: use of AI models to predict and prevent Cardiovascular Disease (CVD)

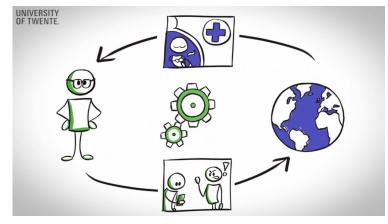
- Personal health platform (PGO)
- Basis for 'MyDigiTwin' app

My research: ethical & societal implications



Mediation theory: a philosophy of technology

- 1. Technology mediates how we experience the world
- In turn technology also shapes how we act upon the word (e.g., by steering our actions & influencing our interactions)
- 3. Designing and creating technologies is one way of doing ethics



https://ppverbeek.org/mediation-theory/

But then how could we study this material dimension of the ethics of things?

Scripts

Creating a technology is like creating a movie or theatre script

1. When designing you're making decisions:

"framework of **action** together with the **actors** and the **space** in which they are supposed to act" (Akrich, 1992, p. 208).

- 2. Informed by biases & world views of the developers
- 3. Mismatch between technology-developers and the users' world views and assumed roles

Connecting to mediation theory

- 1. Look at the design of a technology and how it might steer certain people actions, and people's interactions
- 2. Look at how people in turn use the technology in their own specific context and setting.



1. Stetting the scene and actors

 Set a scene you describe place, time, actors (human & nonhuman), what they are doing

1. Stetting the scene and actors

Setting: where and when

(on-human) actors: who EXT. SHIRE LANE - DAY The cart rattles along a leafy lahe, driven by a stooped figure in GREY. INTERCUT WITH: SHOTS OF FRODO RUNNING ... CAREENING DOWN A HILL ... JUMPING OVER LOGS ... DODGING TREE BRANCHES. ANGLE ON: The shambling OLD PONY snorts and rears as ... SUDDENLY FRODO appears on the bank above the cart. FRODO (human) actors: who You're late. CLOSE ON: GANDALF glowers at the young HOBBIT... GANDALF A wizard is never late, Frodo Baggins, nor is he early. He arrives precisely when he means to. They look at each other for a moment ... then both start laughing as FRODO'S face breaks into a smile and he leaps on to the front seat of the cart. FRODO

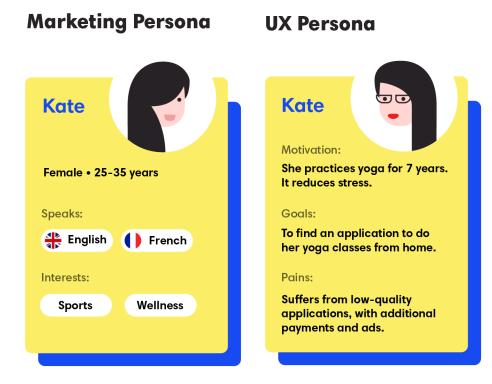
It's wonderful to see you, Gandalf!

1. Setting the scene and actors

Technology development:

- 1. Explicitly
- 2. Implicitly





Source: Sara Eldebissy on Behance

Source: Qubstudio on **qubstudio.com**

2. implicit & explicit assumptions

When developing a technology, developers (consciously or unconsciously) make some hypothesis about the world and the users of the technology.







3. Role of user's

- world views technology developers =/= world views of users
- Users are not merely passive agents
- Technology can get a new or different meaning

Movie script: actors can also read a script and give their own spin or meaning to it.

Moment of big drama → moment of shock & realism



https://www.youtube.com/watch?v=5TQARRckm6U

Technology development: quantified self movement & self-tracking gadgets (Ha, 2017)

- Create an app self tracking based on medical information, goals and guidelines
- Some users: own goals and guidelines, distrust medical system



Scripts: what has this to do with ethics?

In this process technology developers are:

- 1. Excluding/including certain people
- What are your (implicit assumptions about people) you have in your technological script?
- How does this allow different people to reap the benefits?
- When designing a technology, what values are counting most severely?

Developer making value assessments with imperfect data:

"So are you allowed to save 100 more men from a heart infarct if you loose 3 women because they will not be detected anymore?"

- Priorities highly accuracy vs. equality?



Scripts: what does this have to do with ethics?

In this process technology developers are

- 1. Excluding/including certain people
- 2. Ascribing certain roles and subsequent responsibility to people
- New roles → new responsibilities
- New roles & responsibilities → new/changed experiences



Patient's experience of health shifts with the new role of being a data collector:

"(...) with all those hospital equipments in my home, everytime again, in the bathroom there is a confrontation with "ow yeah my illness". Because I have to weight en measure, and those kinds of nasiness because of heartcondition."

[earlier they told me they stopped collecting data]



Scripts: what has this to do with ethics?

In this process technology developers are:

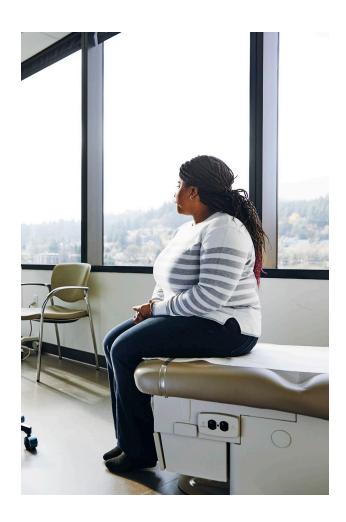
- 1. Excluding/including certain people
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Developer making value assessments with imperfect data:

"So are you allowed to save 100 more men from a heart infarct if you loose 3 women because they will not be detected anymore?" - Priorities highly accuracy vs. equality?

Foot note talking about roles:

Whose responsibility is it to collect accurate data that is not biased?



The Scripts Under Development

- Implicit & explicit assumptions?
- Excluding/including certain people
- What actors are placed in what roles and subsequent responsibility to people

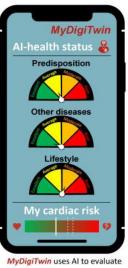
Digital Twin or simulator to see how one could influence the risk score

Idea: compare own health data with existing guidelines

User has a PGO through that provides their data



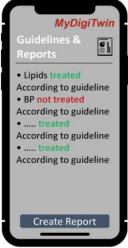
User provides own data and indicators into MyDigiTwin



health status



User can run an Al-simulation on his/her DigiTwin of modifying indicators



User can use MyDigiTwin to create comprehensivereports to discuss management with the GP/cardiologist



Patients can use MyDigiTwin to manage their levels of consent to participate in this and other studies, and which data they wish to share with the platform, in real-time

Dynamic consent for data sharing

AI that calculates a risk core

Take at home message

When developing a technology developers are writing a script:

"framework of action together with the actors and the space in which they are supposed to act"

- Informed by worldviews and values
- Do not always match that of users

In this process technology developers are

- 1. Excluding/including certain people
- 2. Ascribing certain roles and subsequent responsibility to people