

*Detecting value(s): moral  
economies of digital innovation  
in early disease detection*

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# The SPACE project

- Stakeholder Perspectives on ethical Aspects of data-driven Cognitive Evaluation (SPACE)
- Study in empirical ethics (Cribb 2019, Petersen 2013)
- Ethnographic fieldwork

Interviews with experts (n=24) and members of the public

Observations

Documentary analysis

# Digital Innovation

- Early diagnosis and the creation of “preclinical” Alzheimer’s Disease
- “Unleashing the power of Big Data” (OECD, 2017)
- The “disruptive impact” of digital data:
  - From the clinic to the “real world”
  - “Take the diagnosis way back, even 10 to 15 years”

# Detecting Value(s)

“I can produce algorithms which could diagnose dementia possibly as accurately as a clinician. But **I haven't worked out what the value of that is yet.**”

*(Senior academic, interview with RM)*

- How actors imagine, articulate and justify the value(s) of data-driven early detection.
- Values as enacted in practice (Dussage et al, 2015; Sharon, 2015)

1. In clinical and research settings

*“We were always very clear that we did not want to develop tools for self-diagnosis. **And I think this is where the field really divides at the moment.** But some people do. [They are] developing these apps and tools for potentially self-diagnose of people. And I think that's quite **tricky.**” (Senior academic, interview with RM)*

2. Direct user engagement through self-assessment and self-tracking

*“I’m not trying to make an app. What our group is interested in doing is to actually look at...a set of fundamental unknowns about **how you activate people, how you motivate [them], how you return agency.**” (S. Friend, Turing Lecture)*

# Autonomy as “control”

“Because I **empower you to take control of your own cognition**, you could download a reliable, valid, sensitive methodology, test yourself, and that data would be private to you by definition. So, you own that data... If you let people test your cognition for you, then you can probably weave your privacy goodbye very quickly. If you could do that independently, then **you can retain the data and preserve your privacy**. I think the market will provide solutions to these issues.”

*(Senior academic/Free-lance company consultant, interview with AC)*

- Drawing on discourses on self-tracking practices as **enhancing users' autonomy** (Sharon 2015; Lanzing 2016)
- “**Soft resistance**” against stigma and medicalization (cf. Nafus and Sherman 2014)
- Users aspiring to being **in charge of their own health** (cf. Shcüll 2016)
- Data “curious **ability to animate**, to act, to produce effects dramatic and subtle ” (Bennet 2014, cited in Lupton 2018)

“We want to make this feedback a lot **faster**, so that... and if you take those wrong lifestyle choices, you can instantly see the impact of those choices, and you can correct those before it’s too late [...] So visualising this data is **like a little nudge** that can send you back to the right track, and also the fact that our tool...is **very sensitive**, it can give you micro measurements, it can give you little improvements that you’ve made, and this is very powerful as well...



...I'll give you again another analogy: if I asked you to lose five kilograms in the next six months, you'd probably lose one or two kilograms in the next two months, but then it comes back because your brain doesn't get rewarded, you haven't got to the point that you see that your goal is achieved, but if I ask you to lose 50 grams every week, you probably can keep your goal for six months because **your brain gets rewarded** every time you lose the 50 grams, so you can continue that path, and that's what our tool is capable of providing, **very little micro measurements of the improvement.**"

*(Company CEO, interview with AC)*

“We don't give people like the raw score... We give people those **rough categories**”

(Company research, interview with AC)

“I think we gave them access to either five or seven days of data...But even just those **short periods of trend lines**, and also we were very sure that many people were screen-shotting or otherwise keeping track over months.”

(Senior researcher, not-for-profit organization, interview with AC)

“Even saying you can detect [something] is difficult. Because **if you can truly detect it, are you not a diagnostic device?** And then, there is definitely a lot of regulation going on. So, it’s detection more, detection of risks or is it real detection in which case it’s probably diagnostic in some sense?”

*(Company CEO, interview with RM)*

# Autonomy as the right (not) to know

“Is there a case for detection? I.e. diagnosis in **somebody that presents with a problem**? The answer is yes... If somebody has a problem, you have a discussion about what the options are, what you might do to do a diagnosis, to what extent do they want me just to wait and see how things are in a year. Because often I’ll say: “I’m not sure, it could be. But I don’t think there’s anything here that is going to change dramatically.” We’ve excluded some things, and **that’s people’s choice of how to manage it.**”

*(Senior clinician, interview with AC)*

- Experience of illness and health vs placing individual on disease trajectory
- Right not to know information that have limited clinical utility and might cause psychological harm
- Patient and family's choices inform rather than follow the medical diagnosis

# Conclusions

- In both cases, autonomy is enacted in specific ways to imagine and justify different ways of organizing and regulating data flows.
- In both cases autonomy was part of enacting the disease in contextually specific ways.
- Caution against extrapolating arguments about value of digital health data from other contexts.

Thank you!

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