CASTING LONG SHADOWS

Phenotyping dementia and the making of the digital ageing subject

Natassia Brenman (University of Cambridge), Alessia Costa & Richard Milne (Wellcome Genome Campus)

EASST/4S 2020

How is the digital ageing subject 'figured' through data practices for the early detection of dementia?
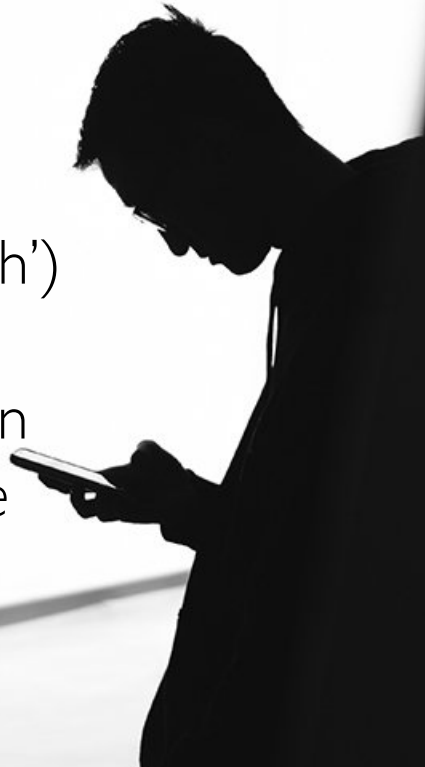
FIGURE/GROUND

What is the relationship between this 'figure' and the 'ground' on which it forms?
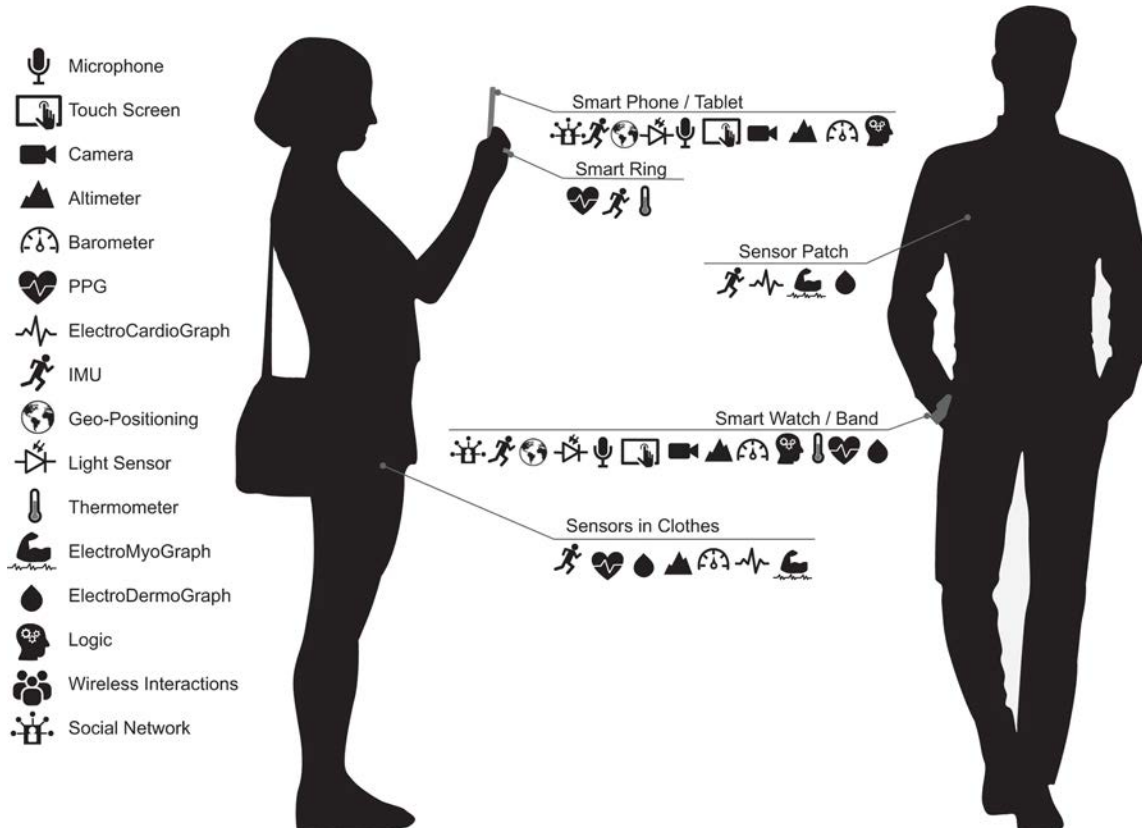
FIGURE/GROUND

DATA SHADOWS

Distortions (good to 'think with')

Characterised by what they can
do – more than how things *are*

DEMENTIA 'DATA SHADOWS'

- Eye movement,
- Navigation skills,
- Gait,
- Tone of voice,
- Verbal fluency,
- Executive functions,
- Tremor,
- Facial movements and expressions,
- Latency, accuracy & speed to complete cognitive tests,
- Interactions with smartphones, such as taps, swipes & clicks.

Source: Kourtis, L.C. et al. Digital biomarkers for Alzheimer's disease: the mobile/wearable devices opportunity. npj Digital Med 2, 9 (2019)

FIGURE/GROUND

DIGITAL PHENOTYPING IN THE 'REAL WORLD'

Tracking "lifestyle, including social skills, level of activity and dietary habits…"
Mindstrong Patent

THE VALUE OF 'ECOLOGICAL VALIDITY'

''At the simplest level, [this type of data] has its own intrinsic value. It tells us about what it is to be a human being with this brain interacting with the world. And I think that's very interesting.''
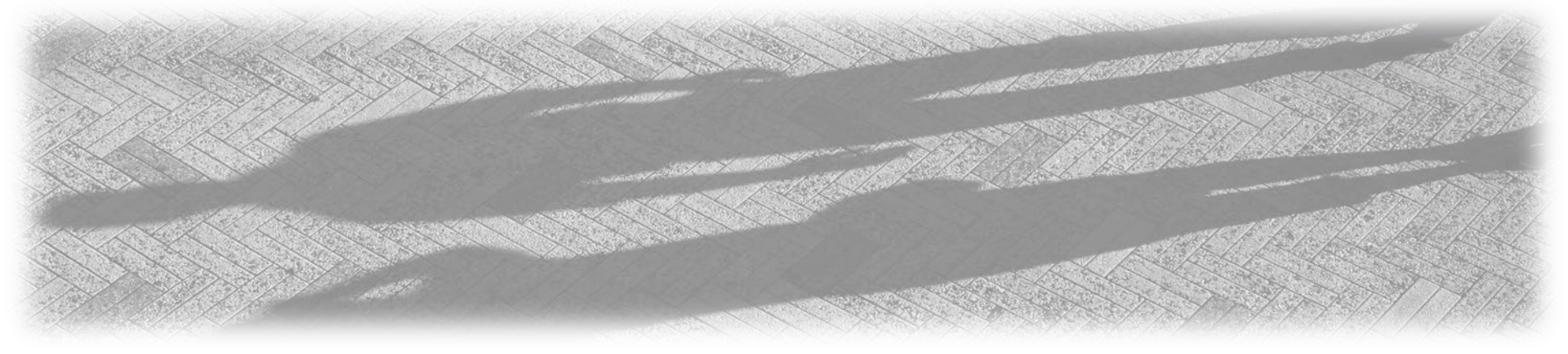(Senior clinical academic, interview with AC)

''the performance data of a natural person, obtained while operating and moving in a day-to-day environment…''
(Altoida patent).

FIGURE/GROUND

CASTING LONG SHADOWS

In the practical application of these technologies: a return to the **narrow**, casting **long** into the future…

CASTING LONG SHADOWS

NARROW: From 'ecologies' to individual biomarkers

… a paradox of scale (cf M'charek, 2016)

CASTING LONG SHADOWS

LONG: ''you are getting older; you do have a risk of developing a form of dementia. It's looming larger in your mind ''
(phenotyping study participant, interview with NB)

CONCLUSIONS

Thinking with shadows…

Ways of seeing figure/ground in a new light with different distortions.

- - Imaginary of capturing totality/'real life'
- - Reproduction of the bounded individual
- - The promise of present data capture and future prediction

THANK YOU

Natassia Brenman: nkf23@cam.ac.uk
Alessia Costa: alessia.costa@wgc.org.uk
Richard Milne: richard.milne@wgc.org.uk