Ethical challenges in the data-driven detection of dementia

DR RICHARD MILNE AND DR ALESSIA COSTA

Something old, something new

Risk disclosure and the return of results

Social justice and algorithmic equity

Floridi, L., and Taddeo, M.. 2016. https://doi.org/10.1098/rsta.2016.0360.
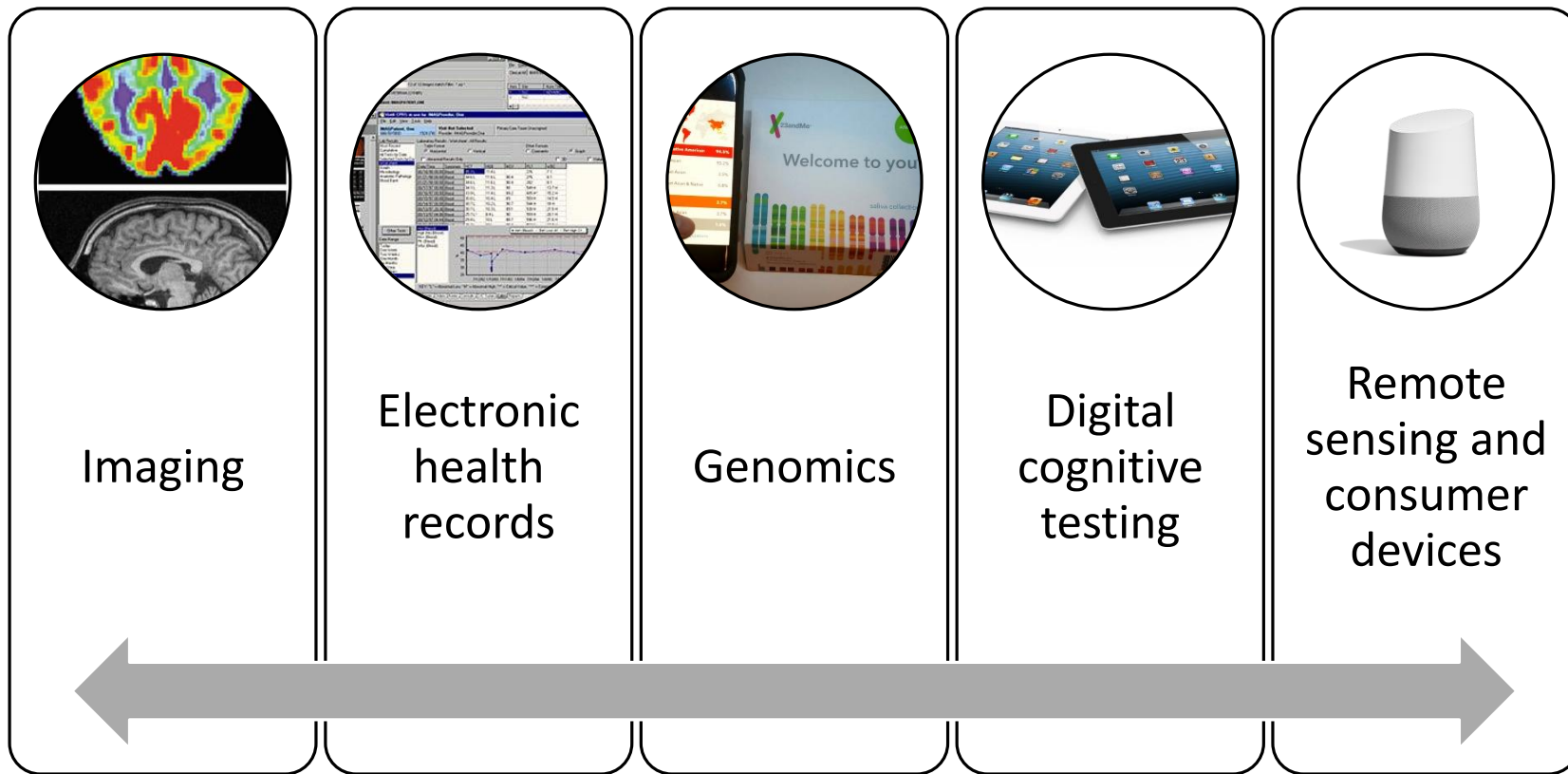
SPACE

Study of stakeholder perspectives on ethical challenges of digital tools for the detection of cognitive decline

1. Mapping review of tools and technologies

2. Expert interviews and observations

3. Interviews with older adults on digital health monitoring, and changing perspectives as a result of the COVID-19 pandemic

WELLCOME GENOME CAM
CONNECTING
SCIENCE
SOCIETY+
ETHICS
RESEARCH

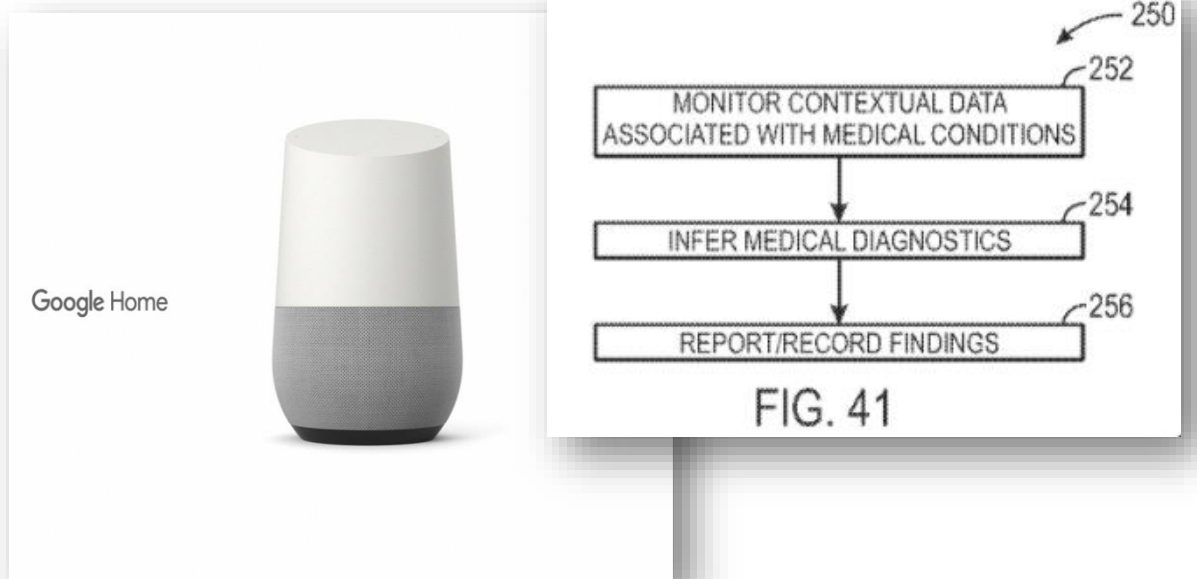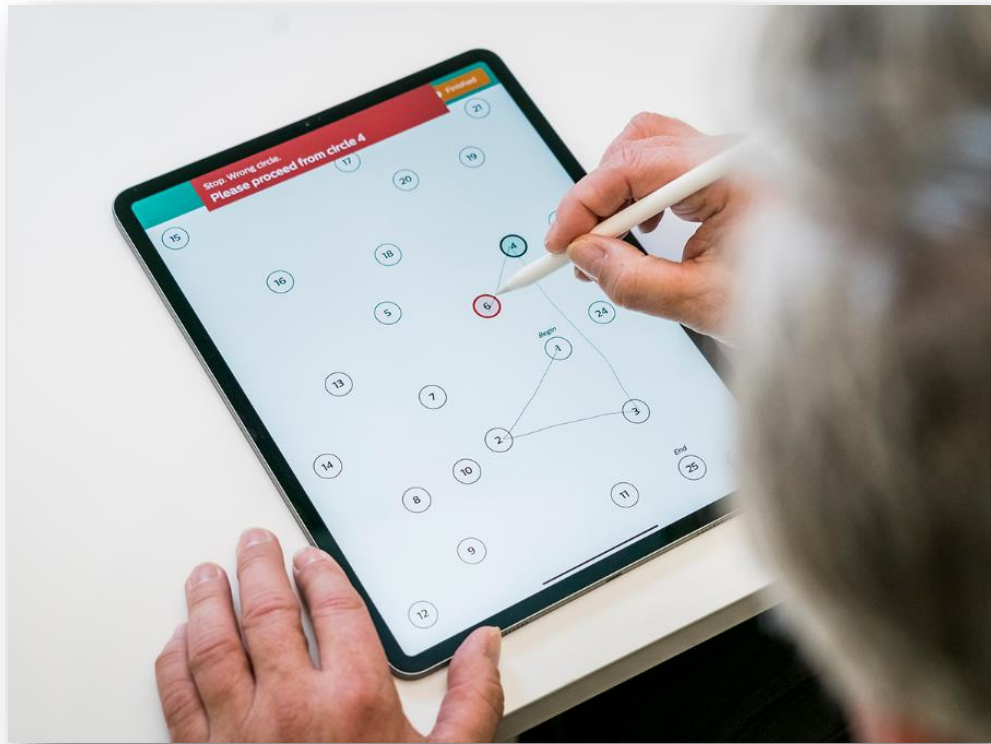SPACE

wellcome

Imaging

Electronic health records

Genomics

Digital cognitive testing

Remote sensing and consumer devices

Clinical settings

Domestic settings

Google Home

MONITOR CONTEXTUAL DATA
ASSOCIATED WITH MEDICAL CONDITIONS — 252

INFER MEDICAL DIAGNOSTICS — 254

REPORT/RECORD FINDINGS — 256

250

FIG. 41

Next, based upon the monitored contextual data, an inference may be made regarding medical diagnosis of one or more occupants of the household. For example, when an occupant's movement patterns match those of the movement patterns associated with Alzheimer's disease, the system may infer a higher probability that the household occupant has the disease. Further, upon attributing coughs and/or sniffing, for example, by a household occupant, the system may infer that the occupant is acquiring a cold and/or influenza. The inference may be reported and/or recorded for subsequent use in the system.

Risk disclosure and returning results

On Not Jumping the Gun: Ethical Aspects of APOE Gene Testing for Alzheimer's Disease[a]

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Sunday Review

What if You Knew Alzheimer's Was Coming for You?

Simple blood tests may soon be able to deliver alarming news about your cognitive health.
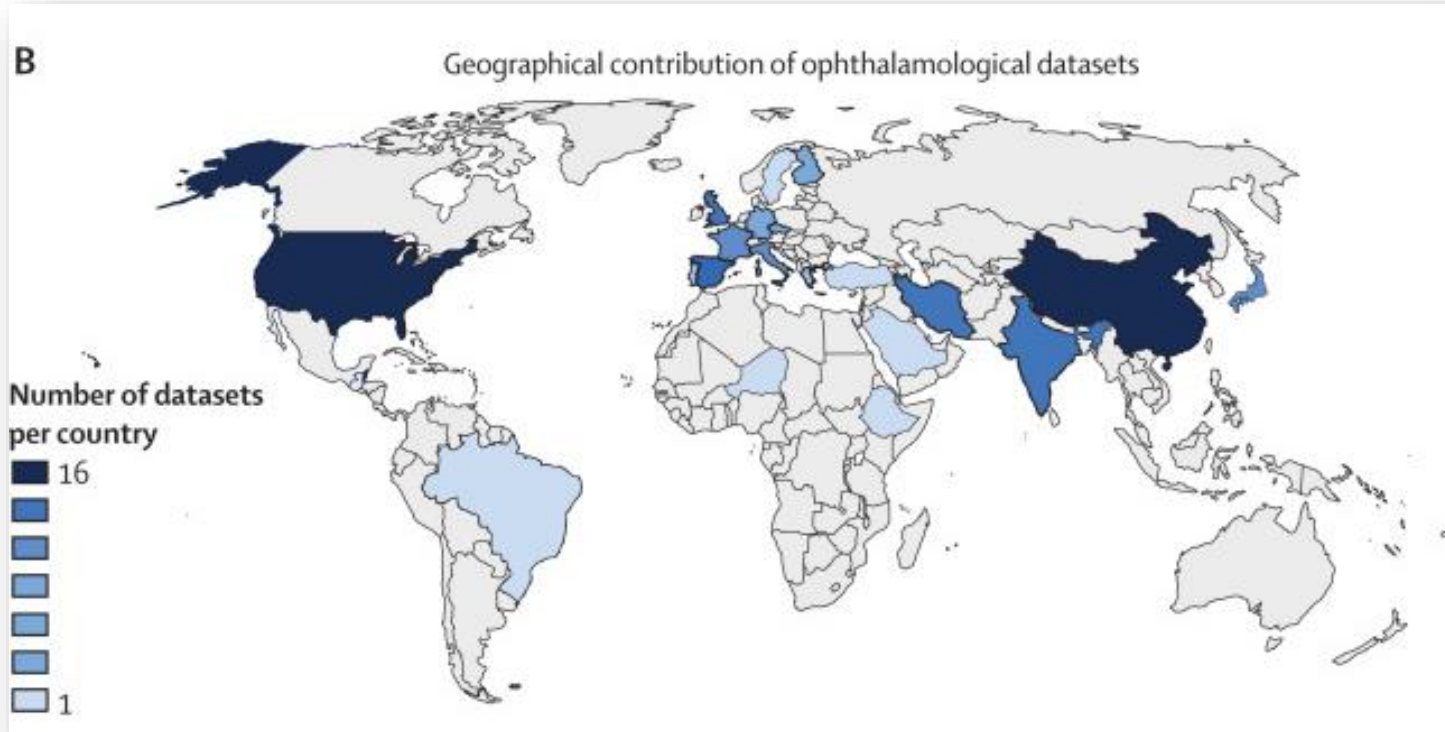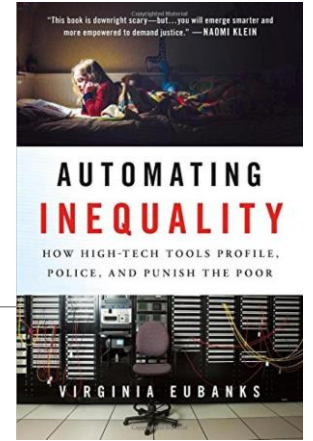
By PAGAN KENNEDY   NOV. 17, 2017

"If you just give someone a score, I mean, you can't tell someone on an app that they have Alzheimer's or they're going to get Alzheimer's disease. … it's **ethically questionable**." (Company data scientist)

"… those questions around, why would you want to know early? What level of accuracy? How difficult is it to do that? I think those are the bigger and different questions for dementia" (clinical researcher)
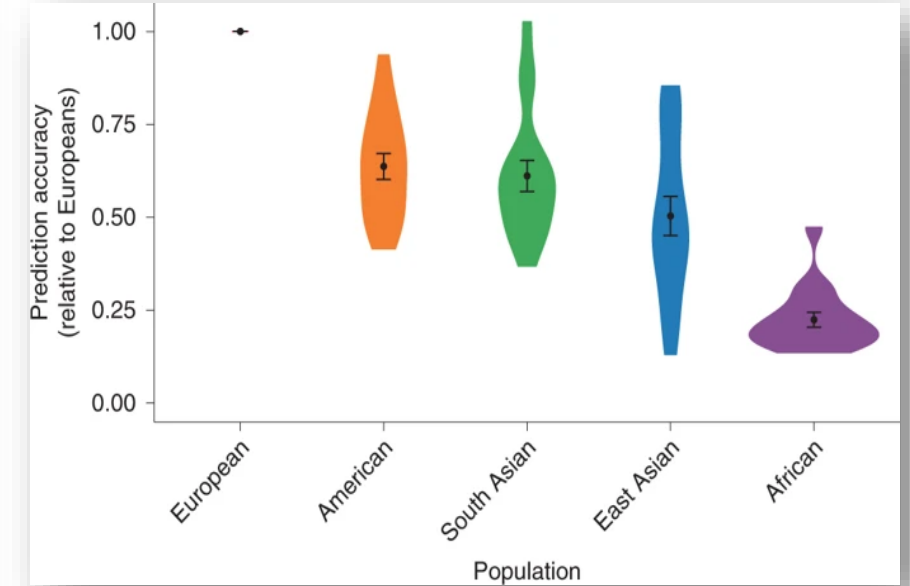
"it's always good to have a professional having a look at … whether the **whole picture of you** is potentially showing the first signs of a disease." (senior clinical researcher A)

"you get into a hotter and hotter water the **more responsibility you take away** from the clinician" (senior clinical researcher B)
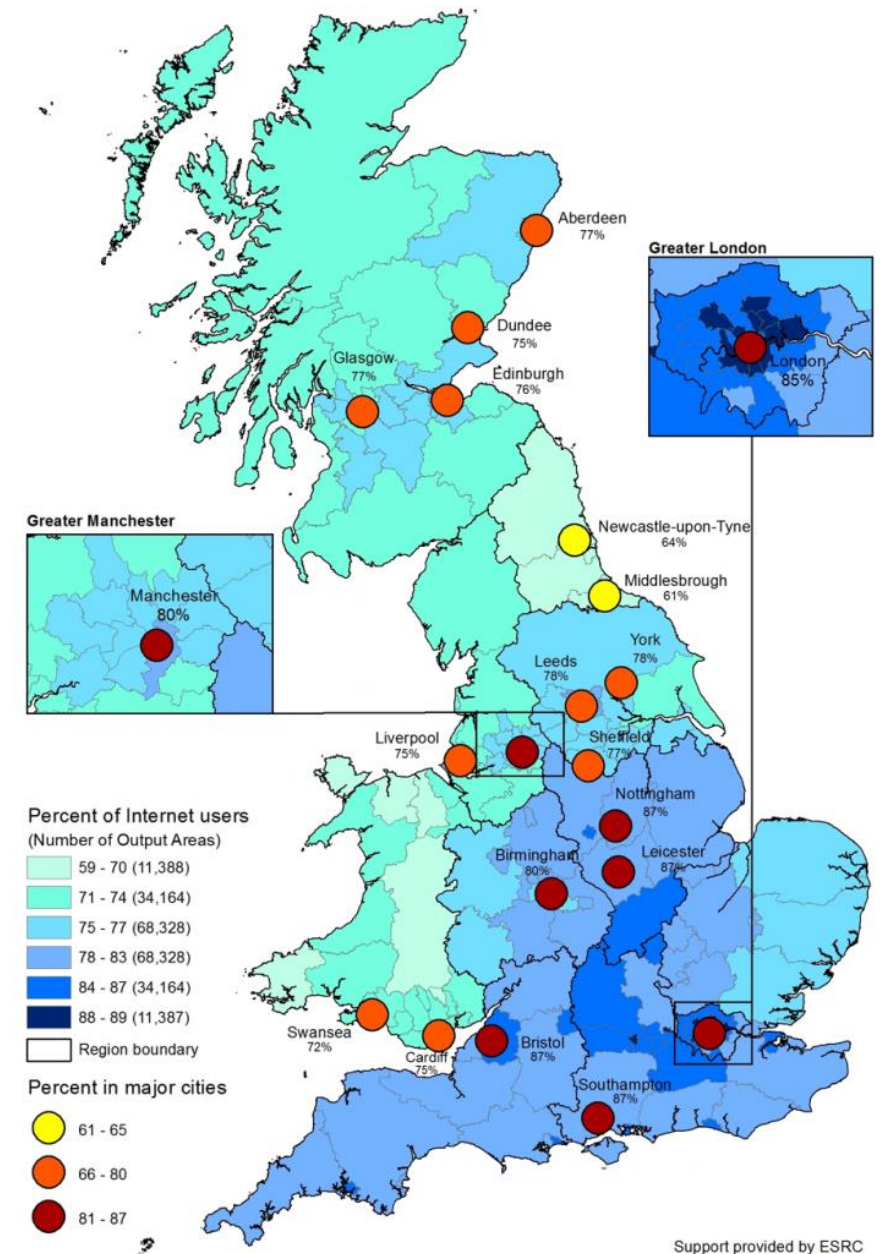
Bias and equity

Geographical contribution of ophthalamological datasets

Number of datasets per country: 16 ... 1

Khan et al. 2020. *The Lancet Digital Health*, October 2020. https://doi.org/10.1016/S2589-7500(20)30240-5.

Prediction accuracy relative to European-ancestry individuals across 17 quantitative traits and 5 continental populations in the UKBB. (Martin et al. 2019)

"… some people believe that there are gender biases, ethnic biases in the diagnoses, and if that's true and we develop a 100% accurate classifier, I'm concerned that at extreme you could say we've developed a racist algorithm" (senior clinical researcher A)

Blank, G., Graham, M. and Calvino, C. 2018. "Local Geographies of Digital Inequality." *Social Science Computer Review* 36 (1): 82–102. https://doi.org/10.1177/0894439317693332.

Conclusions

Clarity   **H**umility   **E**quity   **S**uitability   **S**upport