The datafication of everything?
Effects on convergence of forensic and medical bioinformation

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“You can get 300,000 biomarkers from a single drop of blood, so why would you depend on a human brain to calculate what that means when a computer can do it for you?”

[Health Secretary Jeremy Hunt, quoting Technology developers in California]
1. Systemic and multi-omics approaches

1. overcoming the “actionability gap” of evidence-based medicine at the individual level

1. Episodic & symptomatic
→ continuous & presymptomatic medicine
“Datafication”

taking “information about all things under the sun – including ones we never used to think of as information at all, such as person’s location, the vibrations of an engine, or the stress on a bridge – and transforming it into a data format to make it quantified”

(Mayer-Schönberger & Cukier 2013: 15)
Datafication

• is an ideology as much as it is a technological practice
• Establishes an implicit hierarchy between the action and expertise of humans and machines
• Often the aim is to make human judgement entirely obsolete

Mark Zuckerberg: “Identifying the truth is complicated”
'Extreme surveillance' becomes UK law with barely a whimper

Investigatory Powers Act legalises range of tools for snooping and hacking by the security services
“Extreme surveillance”

The Scoring of America: How Secret Consumer Scores Threaten Your Privacy and Your Future

By Pam Dixon and Robert Gellman
April 2, 2014

Admiral to price car insurance based on Facebook posts

Insurer’s algorithm analyses social media usage to identify safe drivers in unprecedented use of customer data

Admiral says its firstcarquote initiative is aimed at first-time drivers or car owners. Photograph: Image Source/Rex Features

One of the biggest insurance companies in Britain is to use social media to analyse the personalities of car owners and set the price of their insurance.
Solutions: Governing *data use*

Conventional risk-based data nomenclature:

- **Identified** v. anonymous/anonymised/pseudonym data
- **Health-related** v. non-health-related
- **Sensitive** v. non-sensitive
- Medical v. forensic data (etc.)

[see also: P Ohm, A Pentlandt et al.]
identified, health-related, sensitive
What we need:
From risk-based regulation to enhancing public benefits and mitigating harms

Data use **not** in the public interest

Data use in the public interest
• Introduction of *harm mitigation funds* (Prainsack & Buyx 2013; in press)

• Acceptance of rights and interest of secondary data subjects (e.g. M Taylor; G Laurie; H Widdows, B Mittelstadt, J Cohen)


Prainsack B, Buyx A. *Solidarity in Biomedicine and Beyond*. Cambridge, UK: Cambridge University Press.

Thank you very much for your attention
General Data Protection Regulation (GDPR) (EU)

Problems:

- Treats all data controllers/processers the same irrespective of the goal of data use (with the exception of consent requirements)

- Criterion that profiling “significantly affects the individual” (in which natural persons have a right not to be profiled) is not practicable

- “Personal” data are seen to relate to the individual they came from
Solidarity-based framework

Tier 1 (interpersonal level):
manifestations of willingness to carry costs to assist others; similarity in relevant respect

Tier 2 (group practices): manifestations of collective commitment to carry costs to assist others; communities of risk

Tier 3 (contractual level):
legal provisions and contractual norms

Reciprocity