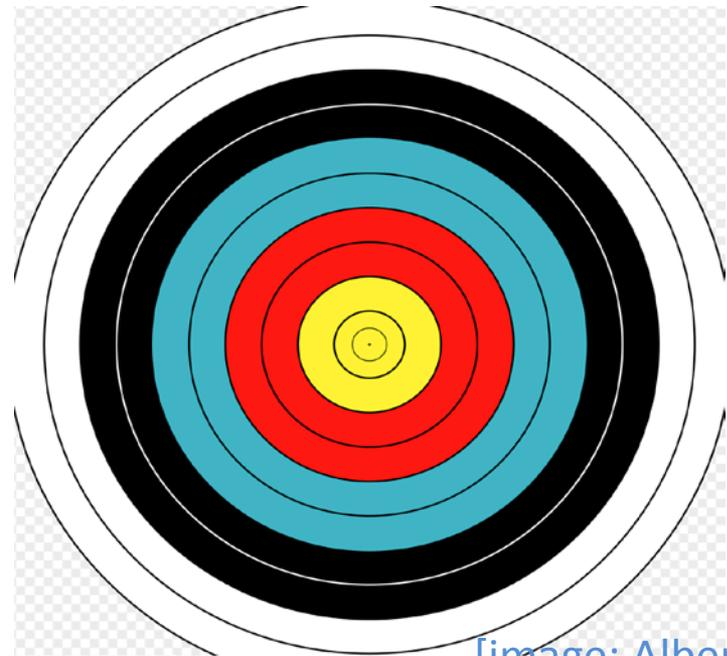


The datafication of everything?

Effects on convergence of forensic and medical bioinformation

Newcastle 23 November 2016

ESRC Seminar series on genetics, technology,
security and justice. Crossing, contesting and
comparing boundaries



[image: Alberto Barbati]

KING'S
College
LONDON

Barbara Prainsack
Global Health & Social Medicine
King's College London



[image: Gary Knight]

GPs' diagnostic skills could be obsolete within 20 years' time, says Hunt

6 October 2015 | By [Alex Matthews-King](#)



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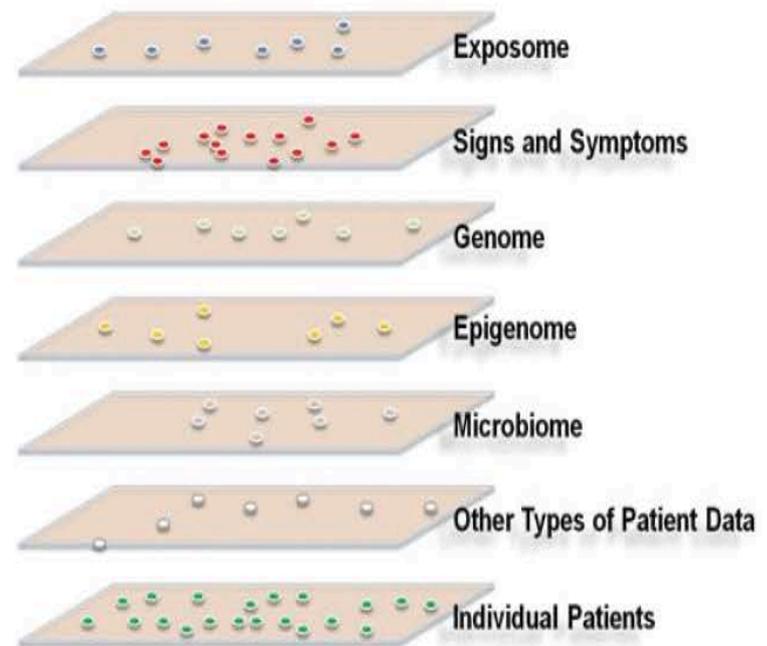
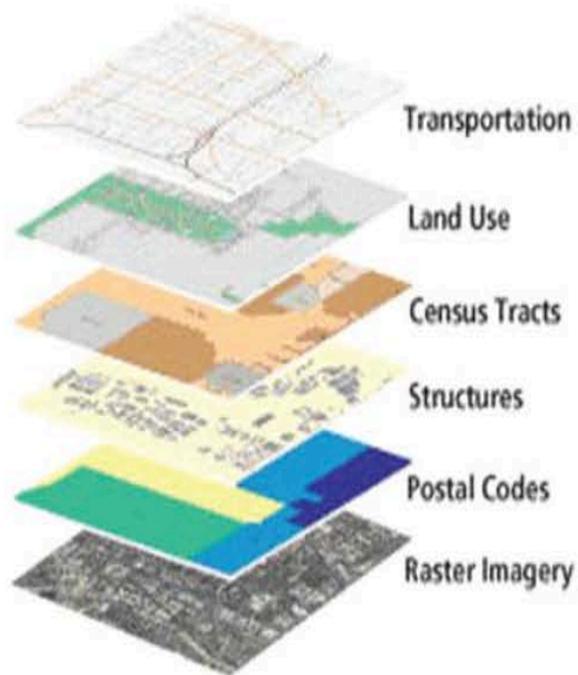
EMAIL TO A FRIEND



“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]

Precision Medicine



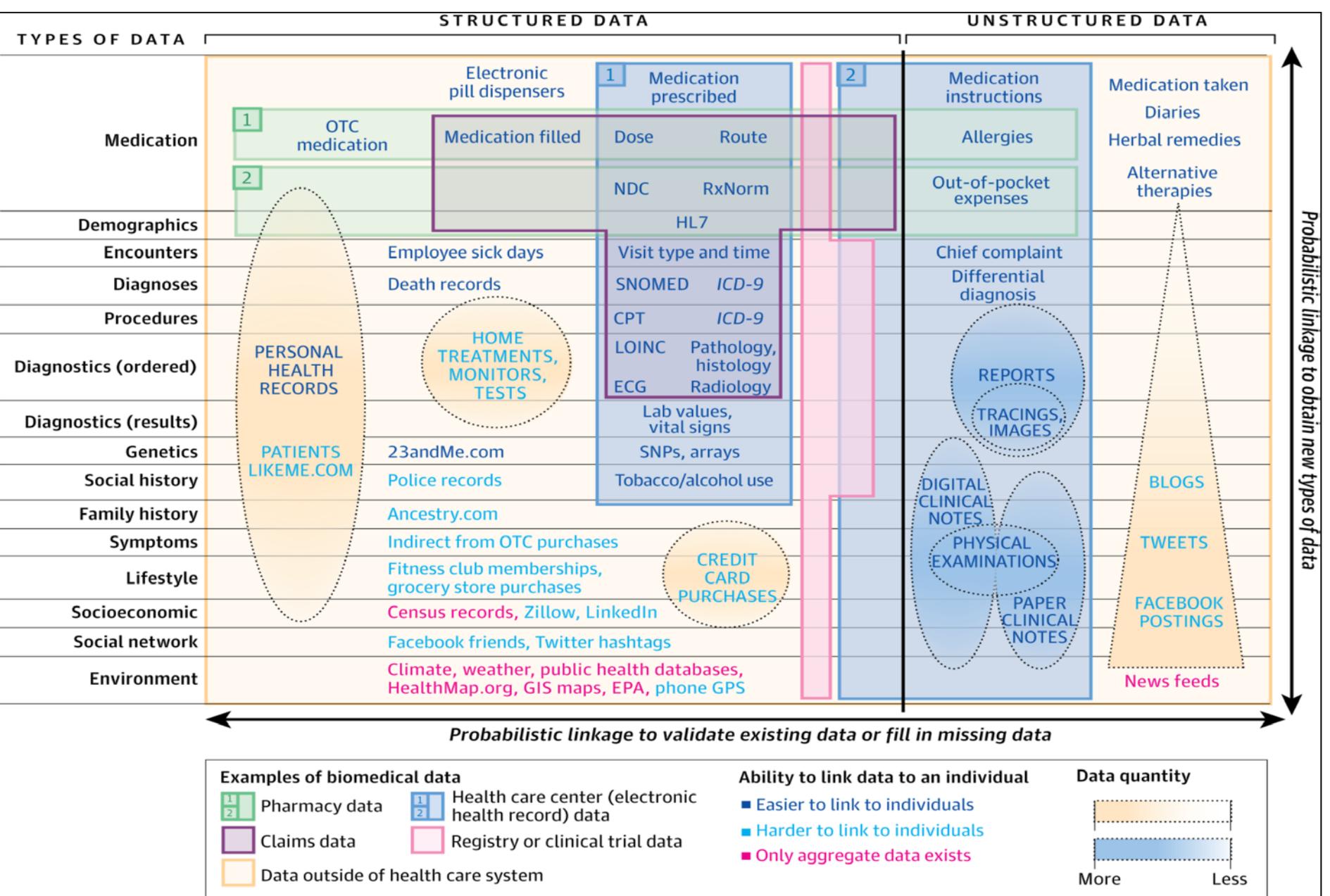
US National Academy of Sciences (NAS) (2011) *Toward Precision Medicine: Building a Knowledge Network for Biomedical Research and a New Taxonomy of Disease*. Washington, DC: NAS.]

Precision medicine (NAS 2011; ESF 2012)

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



[image: Torbak Hopper]



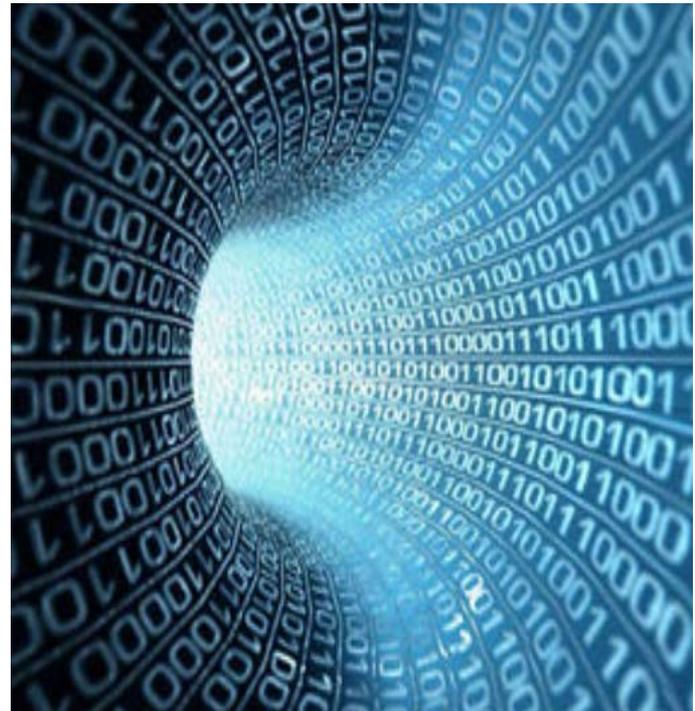
Probabilistic linkage to obtain new types of data

[Weber, G.M., Mandl, K.D., and Kohane, I.S. (2014) Finding the missing link for big biomedical data. *The Journal of the American Medical Association* 331/24: 2479-2480].

“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”

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

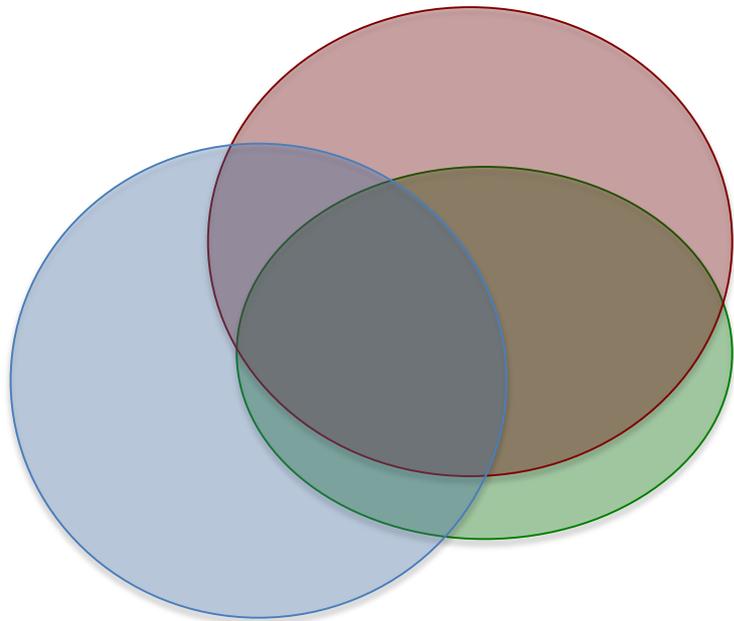
Insurer's algorithm analyses social media usage to identify safe drivers in unprecedented use of customer data



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:

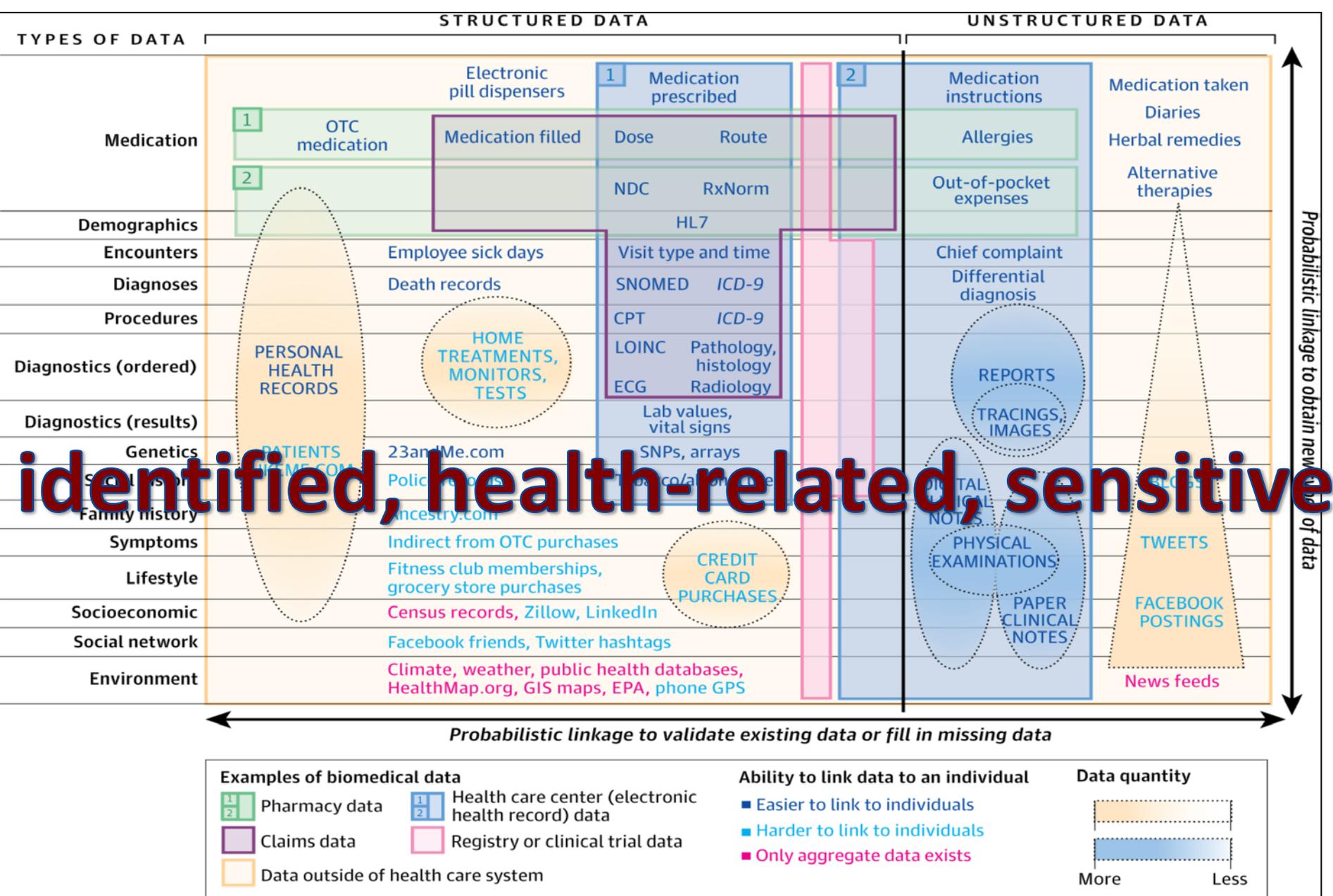
Identified v.
anonymous/anonymised/pseudo
nymous data

Health-related v. non-health-
related

sensitive v. non-sensitive

Medical v. forensic data (etc.)

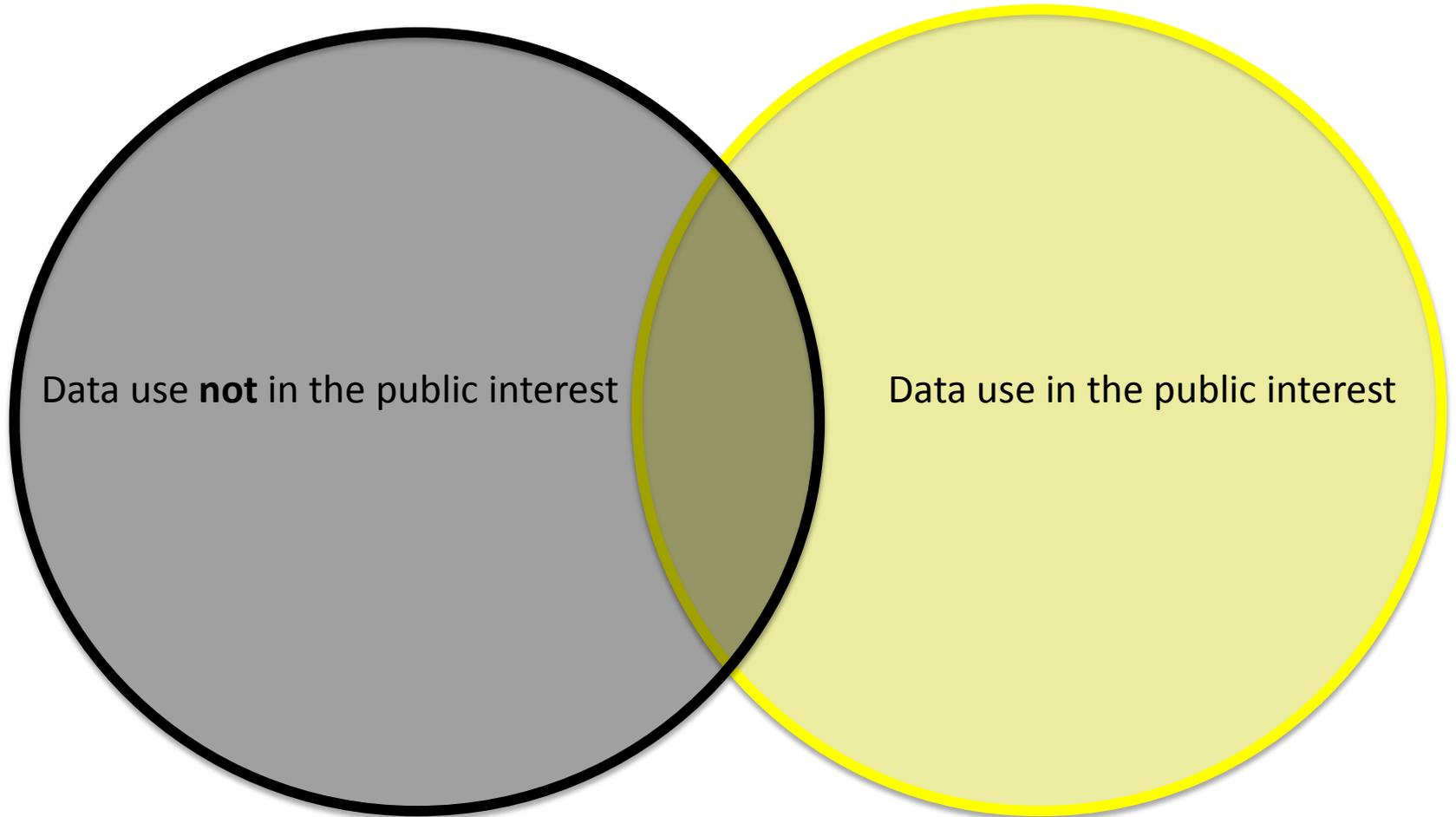
[see also: P Ohm, A Pentlandt et al.]



[Weber, G.M., Mandl, K.D., and Kohane, I.S. (2014) Finding the missing link for big biomedical data. *The Journal of the American Medical Association* 331/24: 2479-2480].

What we need:

From risk-based regulation to enhancing public benefits and mitigating harms



- 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 (2013). A solidarity-based approach to the governance of research biobanks. *Medical Law Review* 21(1): 71-91.

Lunshof JE, Church GM, Prainsack B (2014). Raw personal data: Providing access. *Science* 343(6169): 373-374.

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

Kelly SE, Spector TD, Cherkas LF, Prainsack B, Harris JM (2015). Evaluating the Consent Preferences of UK Research Volunteers for Genetic and Clinical Studies. *PLOS ONE* 10/3: e0118027]

Thank you very much for your
attention

General Data Protection Regulation (GDPR) (EU)

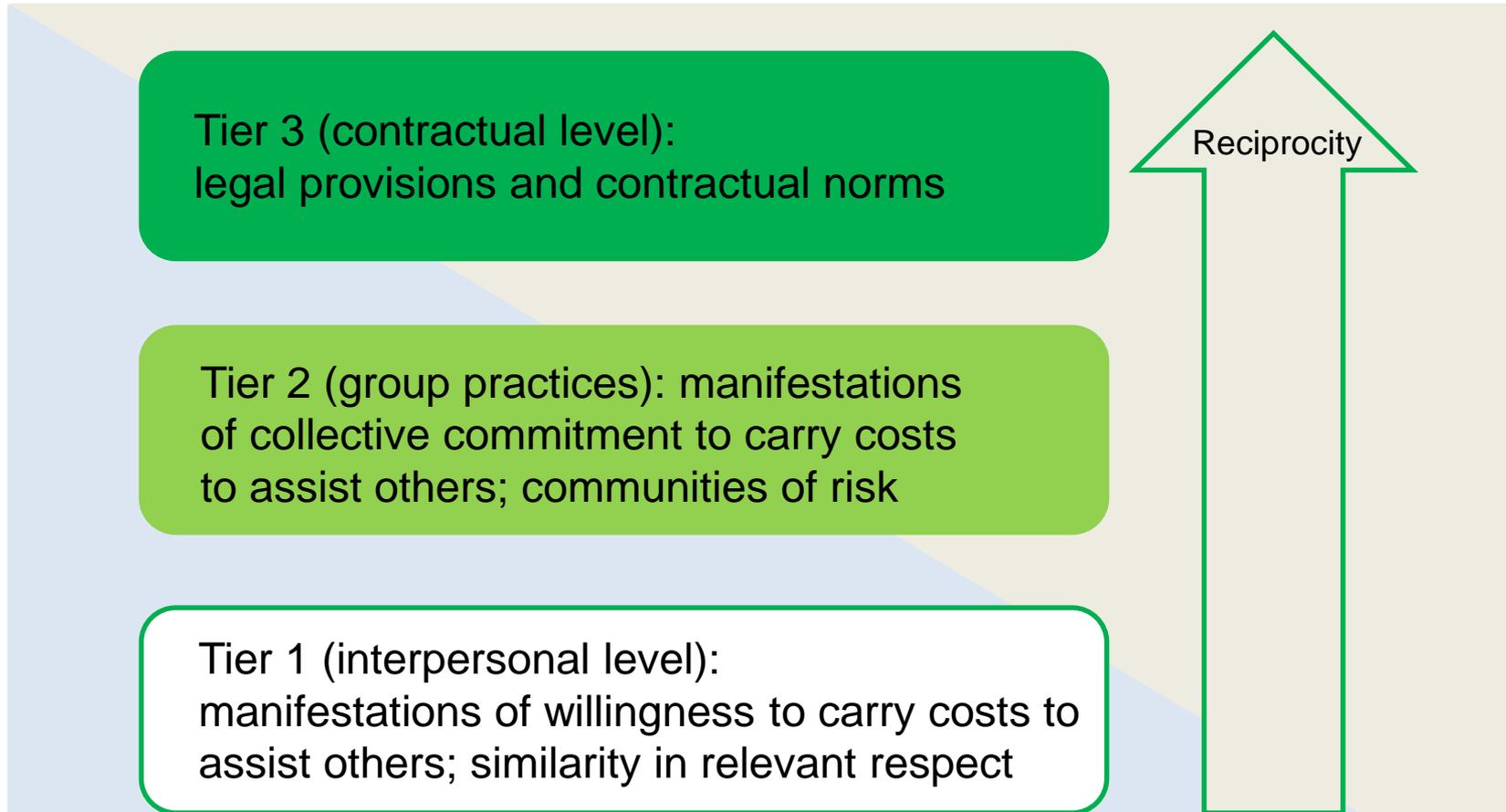
Problems:

- Treats all data controllers/processors 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

blue: practices

grey: institutionalisation



[Prainsack B, Buyx A. *Solidarity in biomedicine and beyond*. Cambridge, UK: Cambridge University Press (in press, 2016)]