

The value*s of Precision Medicine

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Precision Medicine (PM): Layers of meaning



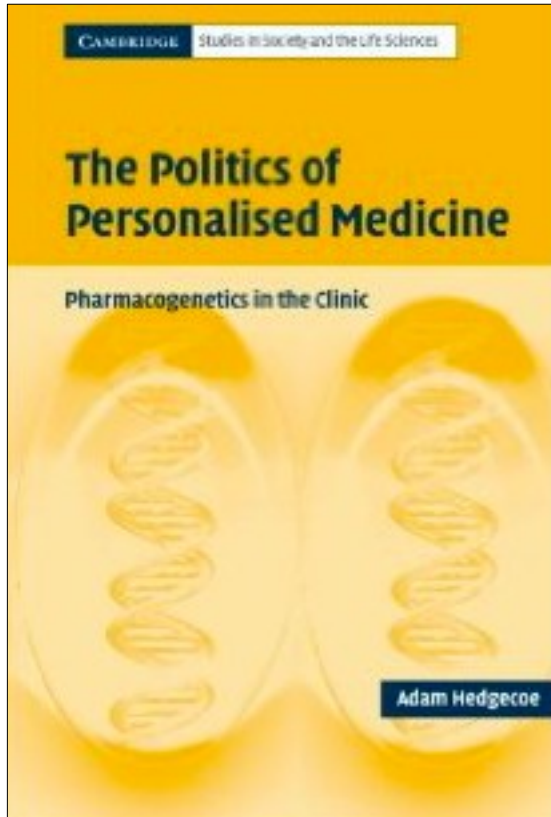
PM as a concept



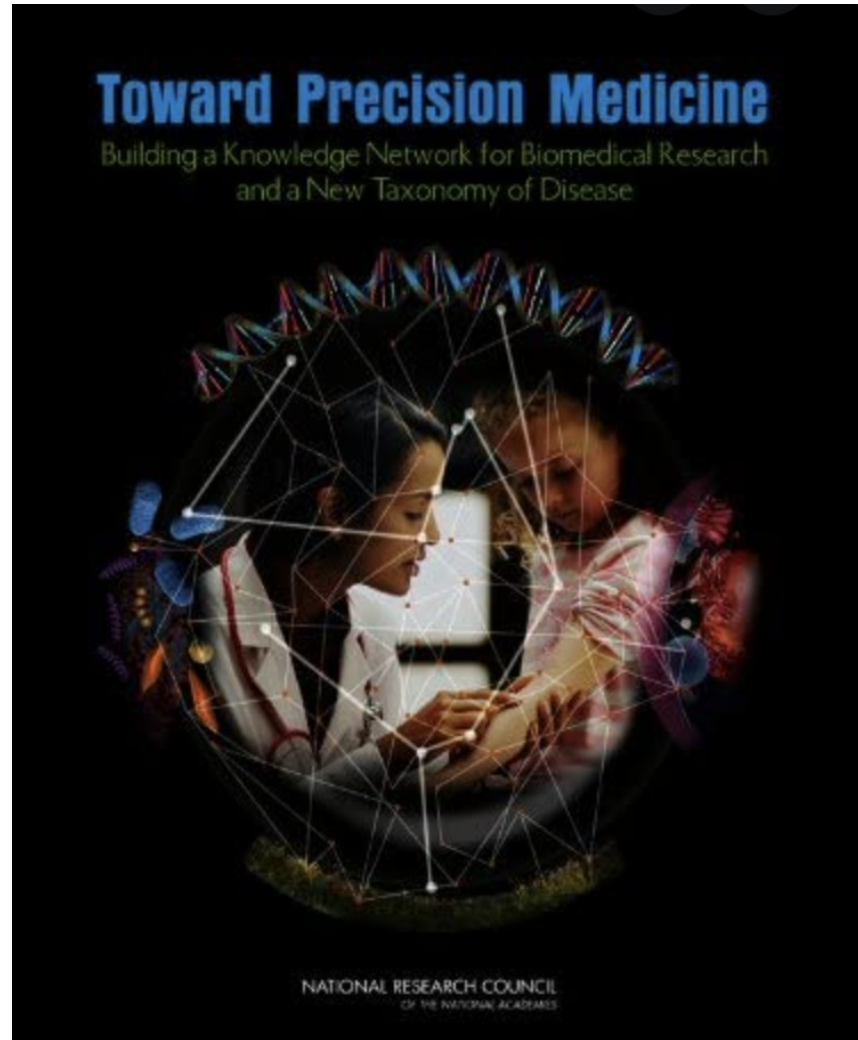
PM as a programme



PM in practice



2004



2011

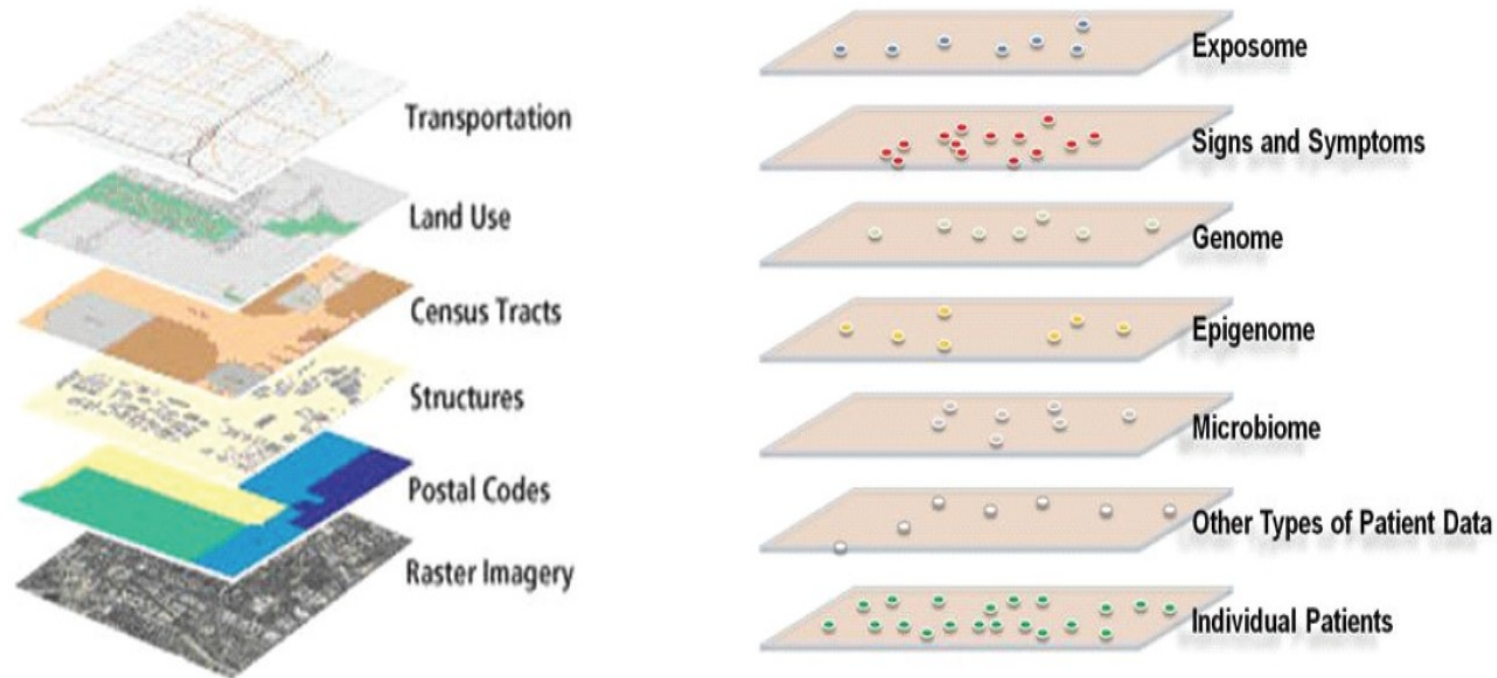
PM as a concept



2016

[<https://obamawhitehouse.archives.gov/>]

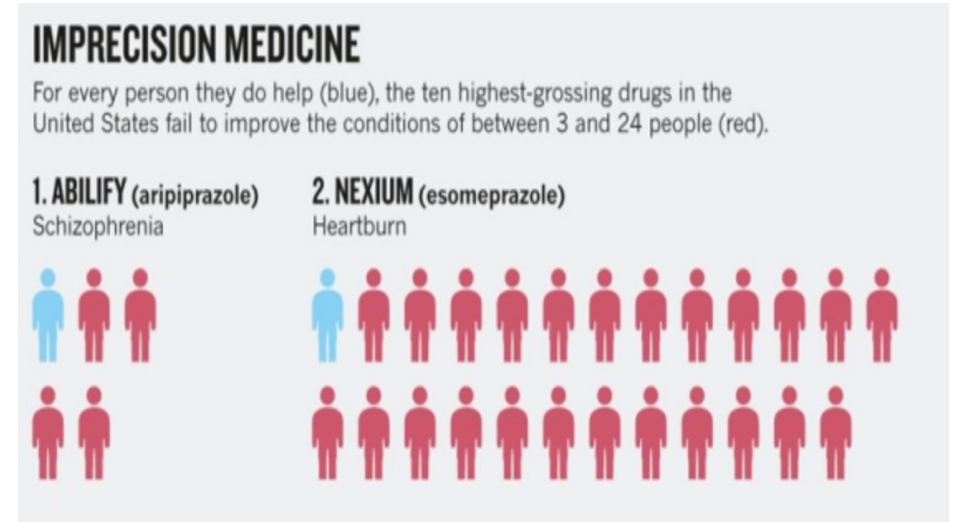
US: "Precision Medicine"



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.]

Key promises of PM

1. Systemic and multi-omic approaches
2. Closing the "actionability gap" between evidence-based medicine and individual patients
3. From symptomatic and "episodic" medicine → continuous and presymptomatic medicine



[Prainsack B (2015). Is personalized medicine different? *British Journal of Sociology* 66(1), 28-35.]

[Schatz BR (2015). National Surveys of Population Health: Big Data Analytics for Mobile Health Monitors. *Big Data* 3/4: 219-229.]

[Schork NJ (2015). Personalized Medicine: Time for One-Person Trials. *Nature* 520: 609-611.

[Vogt H, Hoffman B, Getz L. (2016). The new holism: P4 systems medicine and the medicalization of health and life itself. *Medicine, Health Care and Philosophy* 19(2):307-23.]

Precision Medicine (PM): Layers of meaning



PM as a concept



PM as a programme

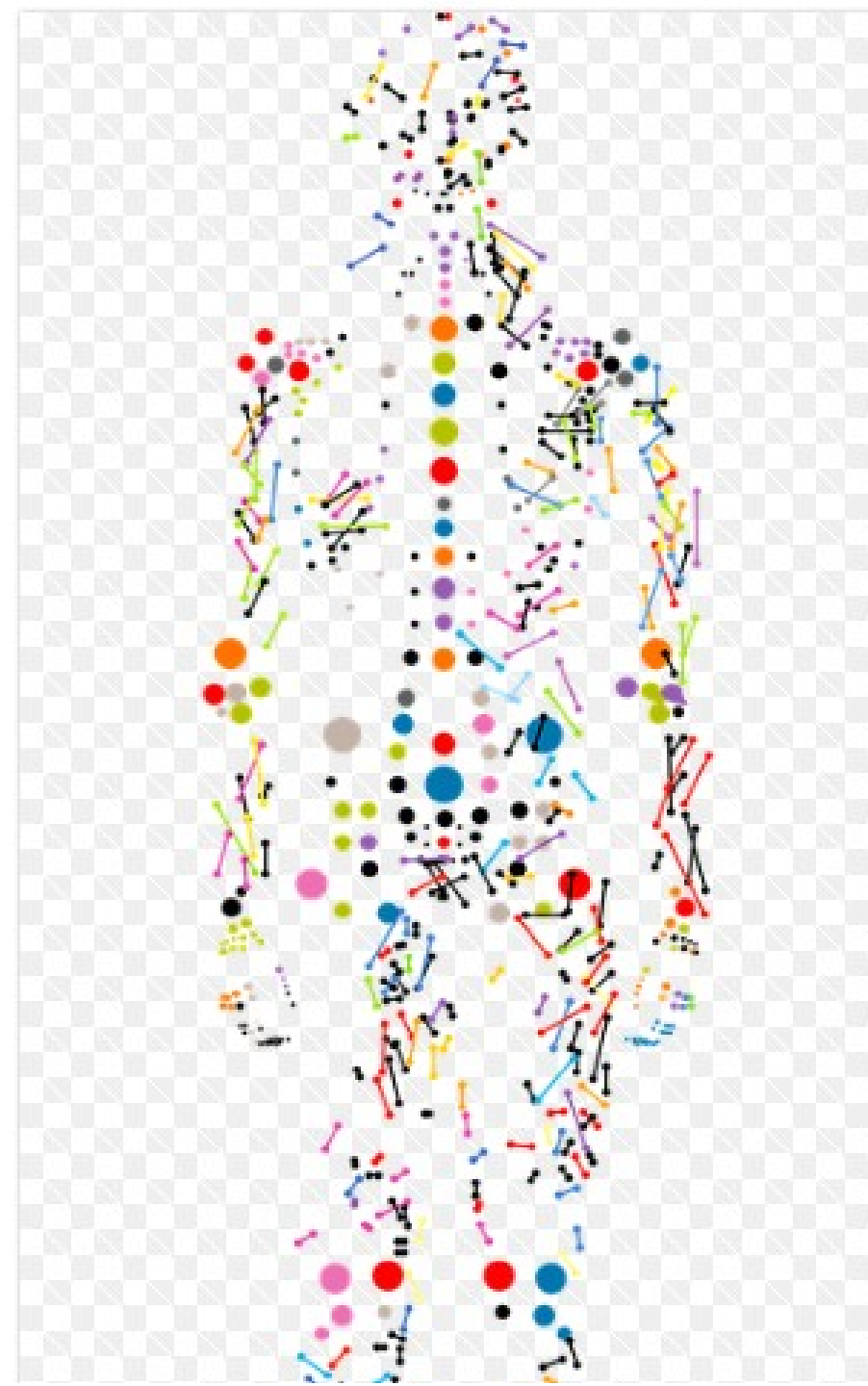


PM in practice

PM as a programme

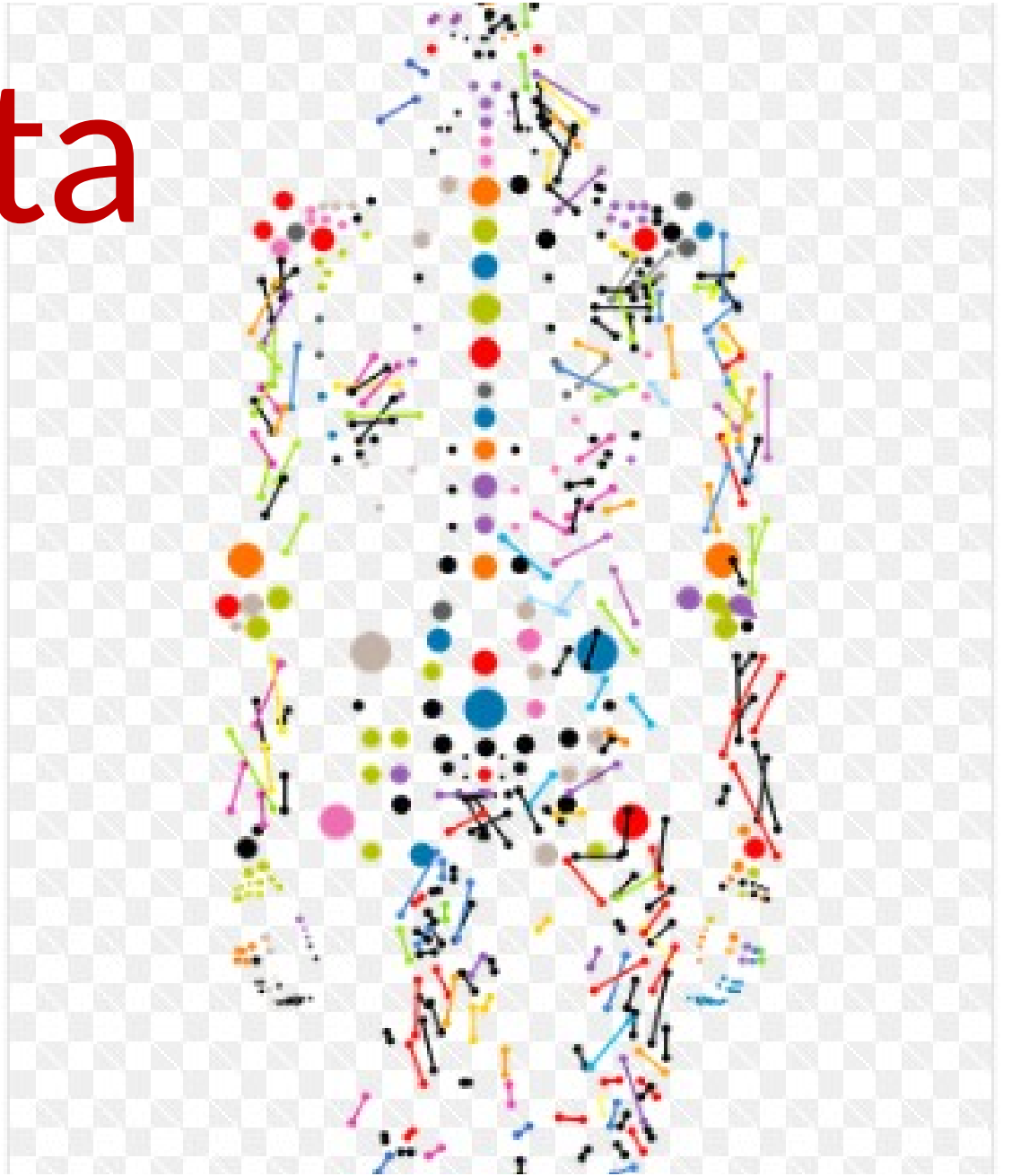
3 key commitments:

1. Technoscientific holism (Vogt et al. 2016)
2. Crowding-out of experiential knowledge with standardised, machine-generated knowledge (Kuch et al. 2020)
3. “Epistemic coloniality” (C. Friese)





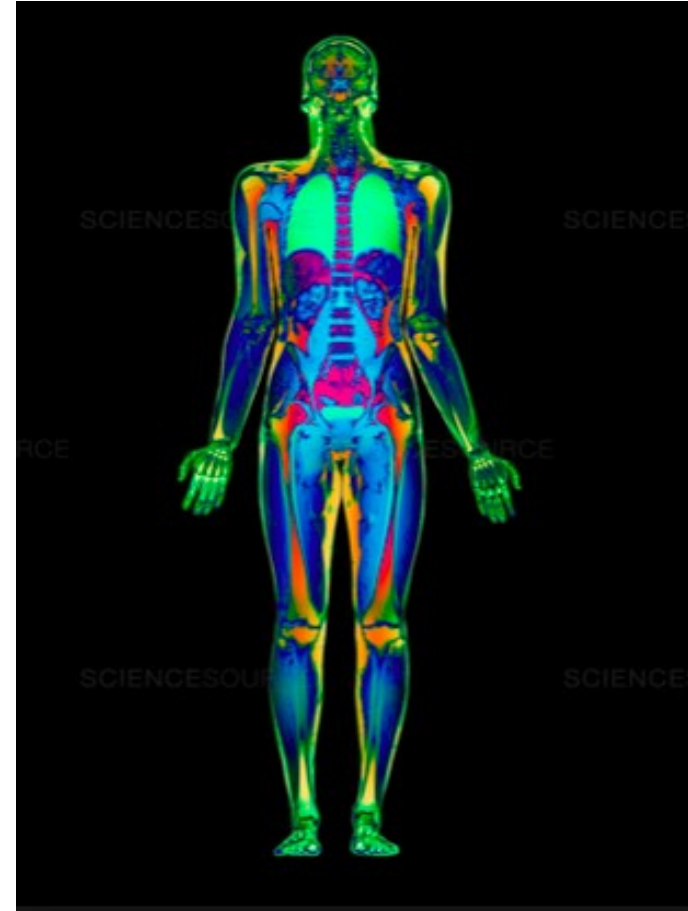
data



“Techno-scientific holism” (Vogt et al. 2016)

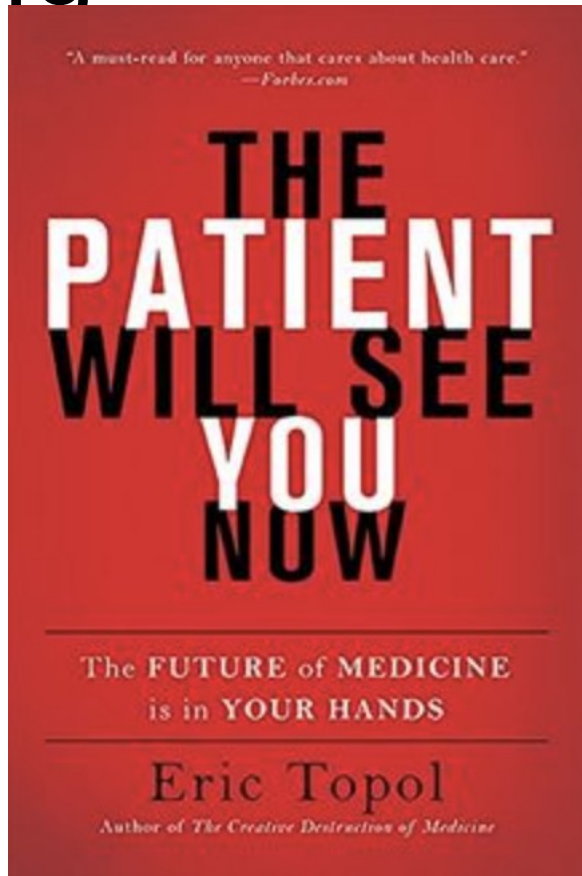
”Each person’s whole life process is defined in biomedical, technoscientific terms as quantifiable and controllable and underlain a regime of medical control that is holistic in that it is *all-encompassing*”

[Vogt H, Hofmann B, Getz L. 2016. The New Holism: P4 Systems Medicine and the Medicalization of Health and Life Itself. *Medicine, Health Care and Philosophy*, 19/2: 307-23.]



[Image: sciencesource.com]

Human experience gives way to other forms of knowing



The rhetoric of the cost-effectiveness of precision conceals a deeper change in economic and political rationales as well as personal practices (Kuch et al. 2020)

[Juengst ET, McGowan ML. 2018. Why does the shift from “personalized medicine” to “precision health” and “wellness genomics” matter? *AMA Journal of Ethics* 20/9: 881-890]

2018

[Kuch D, Kearnes M, and Gulson K. 2020. The promise of precision: datafication in medicine, agriculture and education. *Policy Studies* 41/5: 527-546]

2020

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

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

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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]

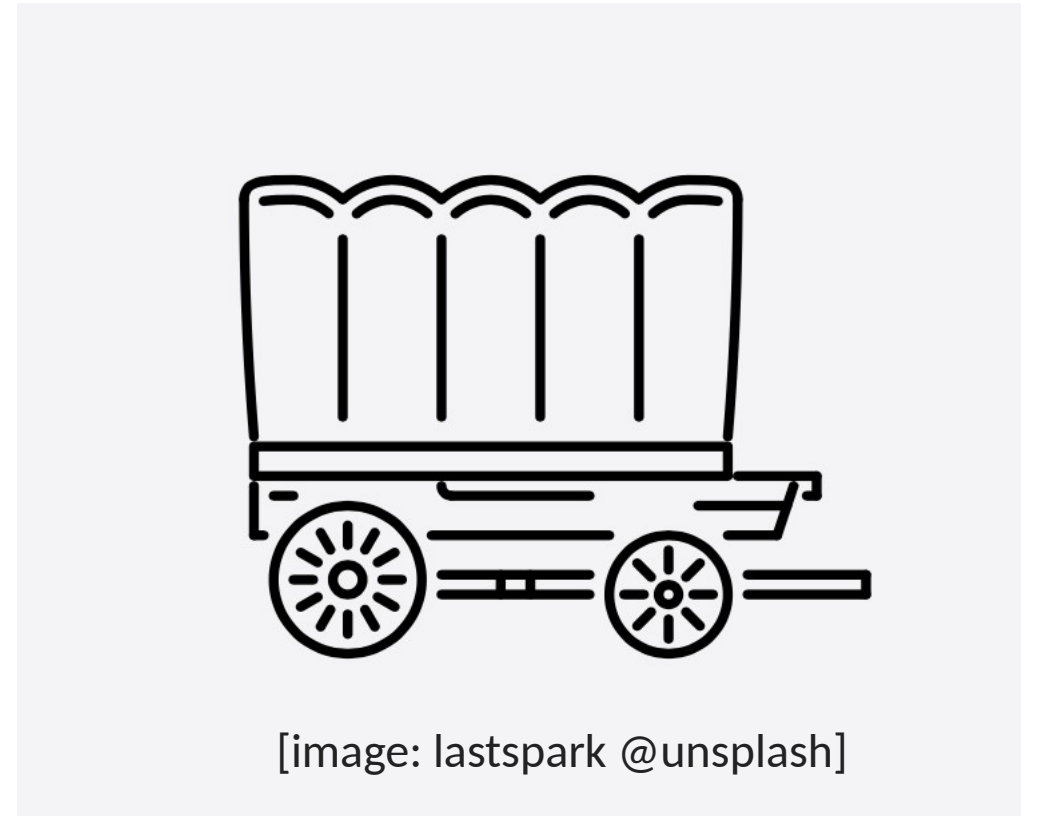
“Epistemic coloniality”



Adler, Ken (1995), 'A revolution to measure: The political economy of the metric system in France', in M.N. Wise (ed), *The values of precision*, Princeton, NJ, Princeton University Press, pp. 39-71.]

PM is a bandwagon where
'large numbers of people,
laboratories, and
organizations commit their
resources to one approach
to a problem'

(Au & da Silva 2021 see also
Fujimura 1988: 261)



[Fujimura, J.H. (1988). 'The molecular biological bandwagon in cancer research: Where social worlds meet', *Social Problems*, **35**(3), 261-283.]

[Au, L. and da Silva, R.G.L. (2021), 'Globalizing the Scientific Bandwagon: Trajectories of Precision Medicine in China and Brazil', *Science, Technology, & Human Values*, **46**(1), 192-225]

Precision Medicine (PM): Layers of meaning



PM as a concept



PM as a programme



PM in practice



Clinicians

Ontological,
epistemological,
institutional aspects

Data-centredness

Patients

[image: Timon Studler@unsplash]

Precision and the person (PI: Alex Broom)

Is it worthwhile?

What are the costs?

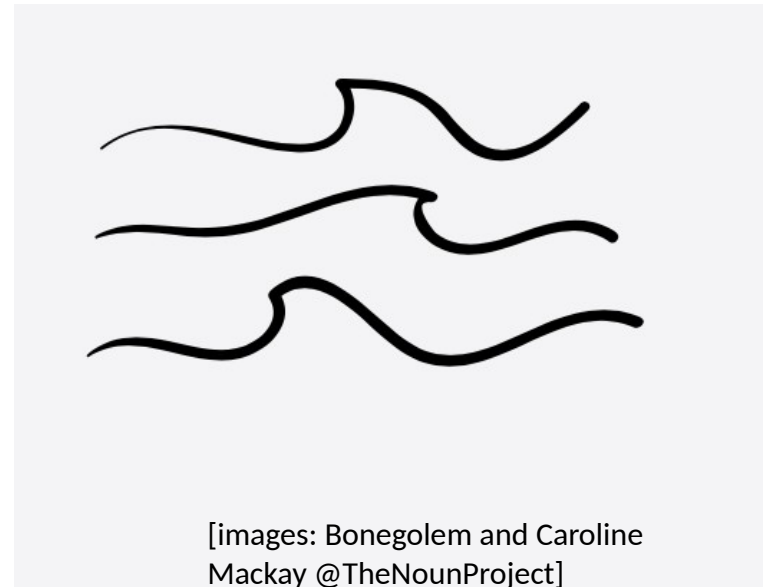
Can I withdraw?

Who gets to decide?

[Broom, A., Kenny, K., Veazey, L.W., Page, A., Prainsack, B., Wakefield, C.E., Khasraw, M., Itchins, M. and Lwin, Z., 2022. Living (well) with cancer in the precision era. *SSM-Qualitative Research in Health*, 2, p.100096]

[Steinberg, D.L., 2015. The bad patient: Estranged subjects of the cancer culture. *Body & society*, 21(3), pp.115-143.]

[Jain, S.L., 2007. Living in prognosis: Toward an elegiac politics. *Representations*, 98(1), pp.77-92.]

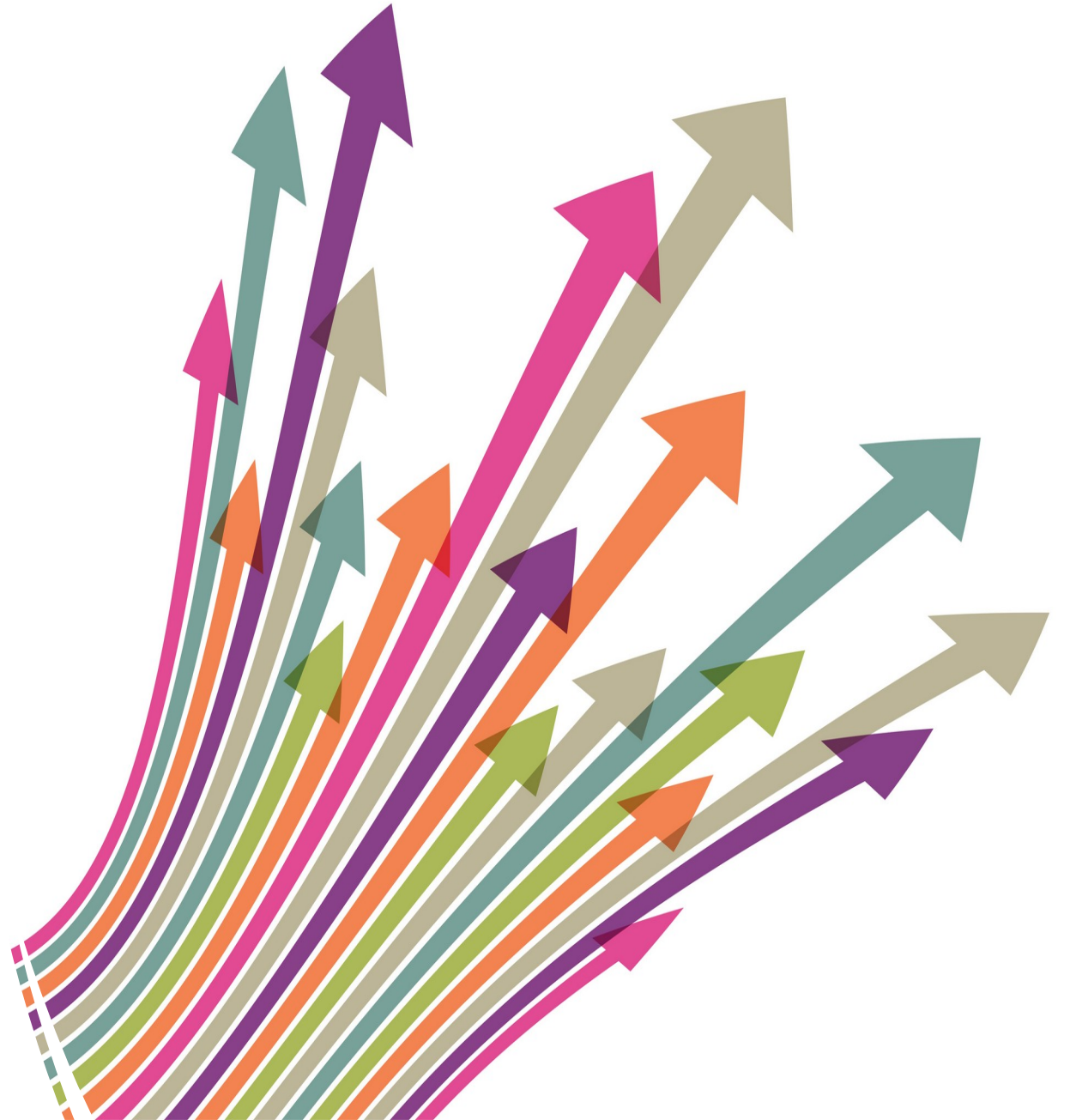


[images: Bonegolem and Caroline Mackay @TheNounProject]

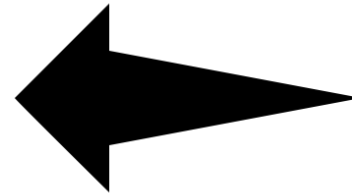
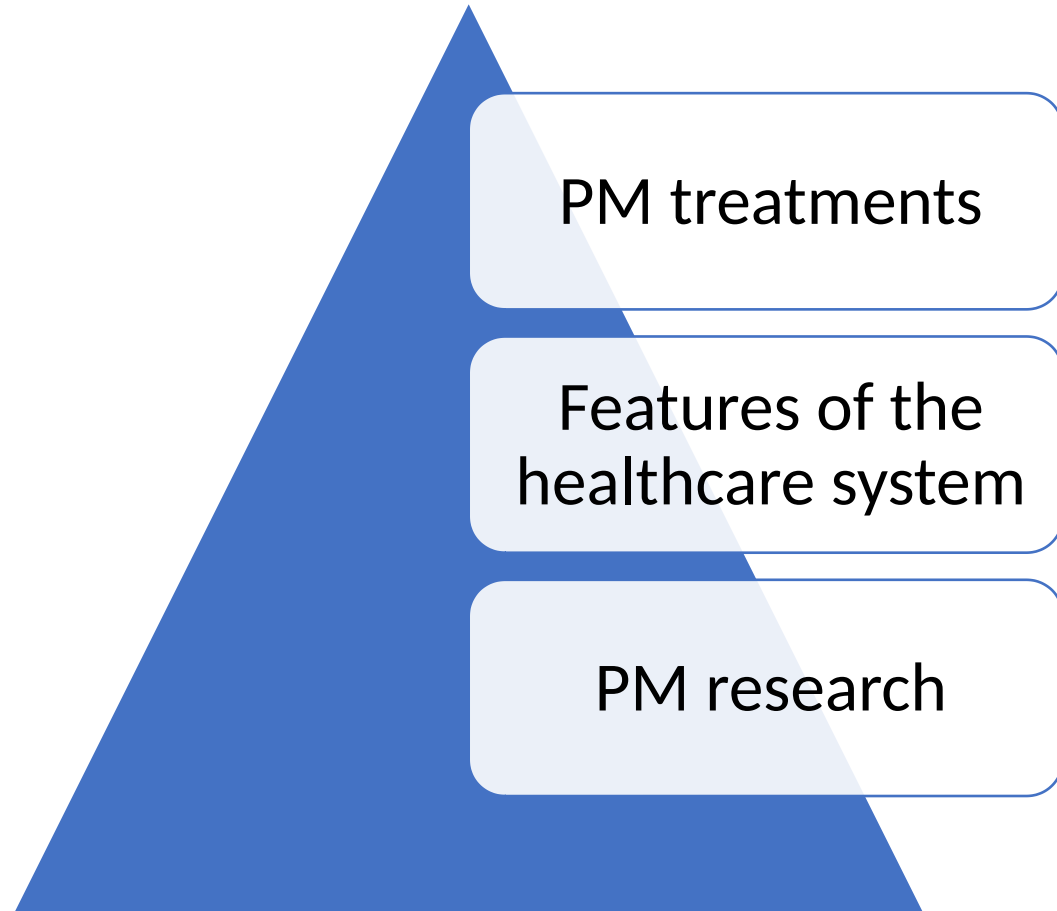
The many values of precision

[Kenny, K., Broom, A., Page, A., Prainsack, B., Wakefield, C.E., Itchins, M., Lwin, Z. and Khasraw, M., 2021. A sociology of precision-in-practice: The affective and temporal complexities of everyday clinical care. *Sociology of Health & Illness*, 43(9), pp.2178-2195.]

[Dam, M.S., Green, S., Bogicevic, I., Hillersdal, L., Spanggaard, I., Rohrberg, K.S. and Svendsen, M.N., 2022. Precision patients: Selection practices and moral pathfinding in experimental oncology. *Sociology of Health & Illness*, 44(2), pp.345-359.]



How the political economy of PM shapes equity effects



[Vogt, Henrik, and Bjørn Hofmann. "How precision medicine changes medical epistemology: A formative case from Norway." *Journal of Evaluation in Clinical Practice* (2022).]

[Green, S., Prainsack, B., and Sabatello, M. Precision Medicine and the Problem of Structural Injustice. Work in progress.]

Conclusions

[P]recision values always have another face, often hidden, the face that reveals the culture in which instruments of particular kinds are important, because the quantities they determine are valued.

M. Norton Wise 1995: 4.

precision (n.) 1630s, from Fr. précision (16c.), from L. praecisionem (nom. praecisio) 'a cutting off'

etymology.en-academic.com/28283/precision



Precision Medicine (PM): Layers of meaning

 PM as a concept

 PM as a programme

 PM in practice



1. Consider what and who the way we see and treat patients leaves out (to avoid the pitfalls of technoscientific holism; Vogt et al.); include social biomarkers
2. Acknowledge the value of interpretation

Are we interpreting the right data?

More emphasis on (personal and social) meaning, value, experience.

- Metrics, indicators and incentives that
 - (a) are outcome-based
 - (b) systematically consider personal and social value and meaning
- Patient-reported outcome/experience measures (PROM/PREM)
- “Realistic Medicine” (NHS Scotland)
- “Health information counsellors” (Fiske, Buyx, Prainsack)

[Mulley A et al. (2017). New approaches to measurement and management for high integrity health systems. *British Medical Journal* 356: j1401]

[NHS Scotland (2016). *Realising Realistic Medicine: Chief Medical Officer’s Annual Report 2015-2016*]

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Health Information Counselors: A New Profession for the Age of Big Data

Fiske, Amelia, PhD; Buyx, Alena, MD, PhD, MA; Prainsack, Barbara, PhD, MPhil

Academic Medicine: August 7, 2018 - Volume Publish Ahead of Print - Issue - p

doi: 10.1097/ACM.0000000000002395

Perspective: PDF Only

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PAP

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PM as a concept



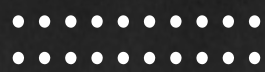
PM as a programme



PM in practice



1. Consider what and who the way we see and treat patients leaves out (to avoid the pitfalls of technoscientific holism; Vogt et al.); include social biomarkers
2. Acknowledge the value of interpretation
3. High touch is important as high tech



A divided future?

- Resources, cost, allocation, equity, reimbursement
- ▮ Automated & digital medicine for the masses, boutique medicine for the rich?

[image: drian Swancar @unsplash]



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