



# Ethical imperatives for personalized medicine

## *A costly promise?*

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# A costly promise?



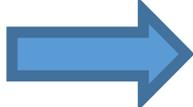
- the cost *to lives lived* amidst an ethos of promise
- in light of *our* finitude, promises always involve uncertainty
- tendency for promise to become distorted into hype
- immodest, incautious promises can be costly to people personally
- promises shape how people live: hope, fear, consent to clinical pathways, commitment to careers
- personal costs...
  - hopes raised then dashed; fears alleviated then renewed; pathways which turn out to be dead-ends; work which becomes all-consumed.
- reasons to bear costs willingly: hoped-for outcomes for self/neighbours...
  - Unnecessarily heavy costs?



# Cost to patients



## Unstratified patients

- Exclusion/disappointment  need for qualitative research on perception of risk/future
- Pressure to participate in other trials...to rejoin the narrative of promise.

## Stratified patients

- Evidence of disintegration *not* personalisation [breast cancer care – Imperial, London]

‘staff and patients alike find themselves in pieces, scattered along the pathway and struggling to put the parts together.’ [cost of sequencing  complexity of sense-making 

Day, S. et al. ‘Stratified, precision or personalised medicine? Cancer services in the ‘real world’ of a London hospital’ *Sociology of Health & Illness* Vol. 39 No. 1 2017 pp. 143–158, p.154

- With rising complexity, compassionate companionship suffers; disintegration of patient journey
- Although pathways cease/fragment, journeys/pilgrimages through life towards death go on
- Disintegration  de-personalisation  temptations to exert pressure harder to resist



# Cost to researchers



## **The promise of precision**

- ...captivates researchers – their imagination, their vision, their energy
- ...creates ‘Stockholm syndrome’ – ‘being taken hostage’
- ...a felt requirement
  - to make history turn out right
  - to ensure that the trial doesn’t fail
- ...captivity of vocation to the promise of precision/historical inevitability
- ...costs of the reduction of emotional ‘distance’ from bench to bedside

## **Exact science exacts a cost on scientists**

- a cost willingly borne?
- an unnecessarily heavy cost?



# Cost to society



## Attractiveness of the promise of precision to government

- *seemingly* bypassing intractable problems in societal health
- *seemingly* independent of patient behaviour/environmental factors

[reality: prevention *through* precision?...discouraging evidence on behaviour change; Hordern, J. 'Self-knowledge and risk in stratified medicine', *The New Bioethics* 23.1, April 2017, pp.55-63 ]

## (Over-)enthusiasm of government?

- UK's 100K Genome project – incautious optimism of policy-makers?
- Samuel & Farsides: The UK's 100,000 Genomes Project: manifesting policymakers' expectations, *New Genetics and Society*, 2017 p.1-18; Feiler, 'The Ontology of Personhood: Distinguishing Sober from Enthusiastic Personalised Medicine' *Studies in Christian Ethics* (2017); Parker et al. CMO for England and Wales Report 'Generation Genome' (2016) critiquing 'excessive assumptions' (ch.16 p.4)

## Opportunity cost

- Attention/funding distracted from the seemingly intractable grind of behaviour change, patient responsibility, environmental improvement etc.



# A costly promise



- The cost of exclusion, pressure, disintegration to patients
- The cost of captivity/low morale to researchers
- The (opportunity) cost to society's health systems/staff of diverting attention/funding from other challenges/approaches
- So what?
  - These costs may threaten the attractiveness of the 'genomic citizenship' upon which genomic medicine depends (*Generation Genome* CMO for England & Wales 2016 report ch.16, p.4)
  - Ethnographic, psycho-social and ethical reflection **may** [reduce hype] improve the ethos/policy of 'personalised' medicine



# Ethical imperatives for 'personalized' medicine...



- Whether or not pathways cease, **remember** that journeys/pilgrimages continue
- Amidst trials, **resist** temptations to captivity and coercion
- As complexity grows, **renew** compassionate companionship/collegial celebration
- In precision medicine *and* ethics, **reduce** hype

Feiler, Gaitskell, Maughan, Hordern (eds), Personalised Medicine: the Promise, the Hype and the Pitfalls, *The New Bioethics* (Apr 2017) [Open Access]

Hordern, Maughan, Feiler, Morrell, Horne, Sullivan, The 'molecularly unstratified' patient: a focus for moral, psycho-social and societal research' *Biomedicine Hub* (November 2017) [Open Access]

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