



Ethical imperatives for personalized medicine

A costly promise?

Joshua Hordern

Associate Professor of Christian Ethics
Oxford Healthcare Values Partnership

Faculty of Theology and Religion, University of Oxford, UK

[@oxfordhvp](http://www.healthcarevalues.ox.ac.uk)

joshua.hordern@theology.ox.ac.uk



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]

This work is supported by a UK Arts and Humanities Research Council grant, *Compassion in Healthcare: Practical Policy for Civic Life*. Thanks to Liz Morrell, Tim Maughan, Therese Feiler, Kezia Gaitskell, Rob Horne, Alastair Kent and Bowel Cancer UK for input. Thanks to FEAM for this invitation and to the European Alliance for Personalised Medicine (Denis Horgan and Mark Lawler). For more info:

www.healthcarevalues.ox.ac.uk Oxford Healthcare Values Partnership @oxfordhvp