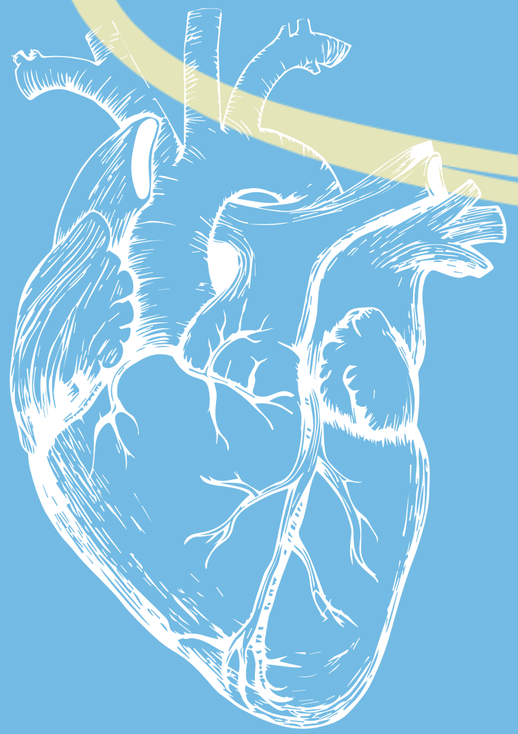
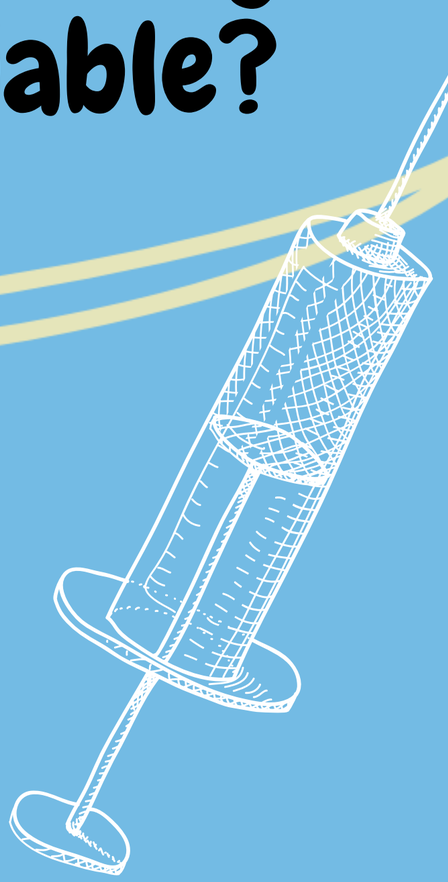
Digital Transformation: Technically Feasible AND Ethically Justifiable?





PRESENTED BY

JESSICA MORLEY

@jessRmorley

www.healthdatanerd.org

Digital Transformation Drivers

PRESENTED BY
JESSICA MORLEY

1

- Policymakers signal the need for more efficient, cost-effective care to achieve the "triple aim"
- Incentivise the adoption of AI and Telehealth to achieve "P4 medicine"

2

- Investment in digital, data, AI industry booms
- Unvalidated, unregulated "solutions" flood the market

3

- Technical 'epistemic' community gains influence
- Assumes 1st order change
- Pushes narrative regulation stifles innovation
- Encourages tech deterministic attitude

NOT "JUST" DATA-DRIVEN

PRESENTED BY
JESSICA MORLEY

20th Century Model of Care

- Evidence-Based
- Patient-Centric
- 1:1
- Narrow Trust

21st Century Model of Care

- Algorithm-Based
- Automated & 'Digital Twin Centric'
- Many: Many
- Distributed Trust

THIS IS HAPPENING INSIDE A LARGELY UNGOVERNED BLACK BOX

PRESENTED BY
JESSICA MORLEY

PRESENTED BY
JESSICA MORLEY

All existing modes of Governance have been disrupted

The law is woefully outdated

Data protection law, medical device law, consumer protection law, discrimination law, liability law

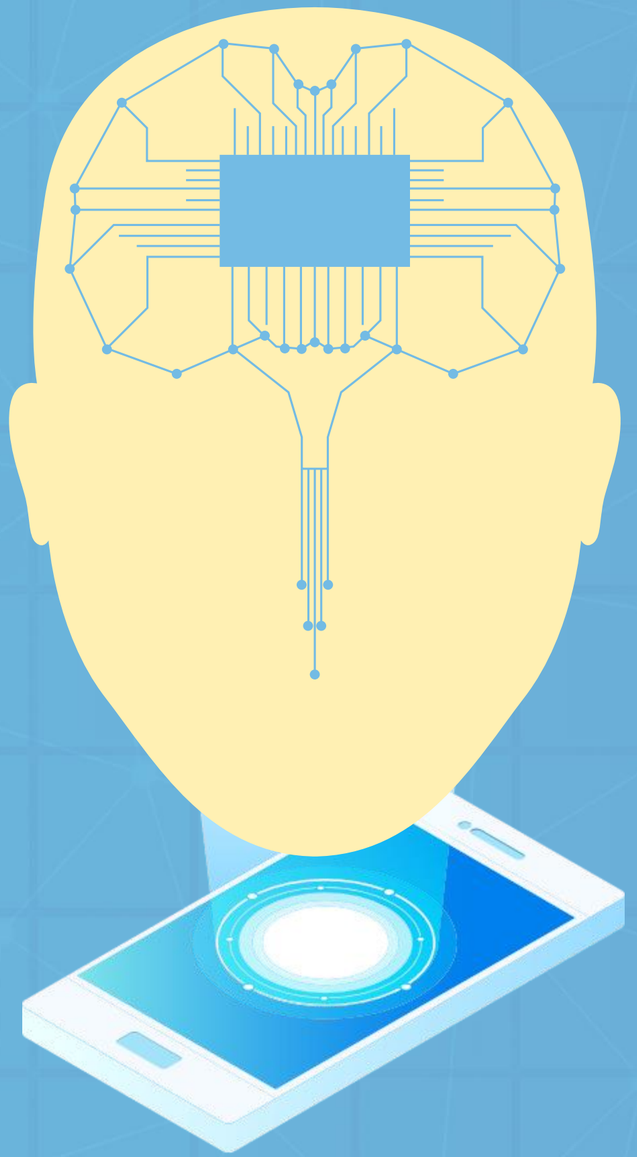
Medical ethics are not fit-for-purpose

Medical ethics 1:1 not many:many
Statistical accuracy is not clinical efficacy

Necessary skills are lacking

Automation bias, loss of autonomy, no means of challenging 'decisions'

AND CAUSING A FUNDAMENTAL SHIFT



Why is this shift occurring?

OUTSOURCING KNOWLEDGE ABOUT THE BODY

- Changing what counts as evidence of illness (and its absence)
- Undermining the right not to know

DISRUPTING THE FUNDAMENTALS OF CARE

- New power dynamics
- Devaluing the ethics of care
- Challenging accountability

UNIVERSAL COVERAGE =! EQUITABLE ACCESS

- Baked in existing bias
- New sources of bias

PRESENTED BY
JESSICA MORLEY

PRESENTED BY
JESSICA MORLEY

Creating the inverse data quality law

The availability of high quality medical or social care data tends to vary inversely with the need of the population served.

The Consequence is Personalised Unwellness

TWO TIER SYSTEM

- Worried well
- Ignored sick

HEALTH =! ABSENCE OF ILLNESS

- A constant state of improvement
- Fuelled by private, algorithms & black-boxes
- Changing the dynamic of 'sick role'

CHANGING PATTERNS OF RESPONSIBILITY

- All become responsible for their own health
- Who can be a good patient?
- Who gains social health capital

PRESENTED BY
JESSICA MORLEY

To rebrand digital transformation, we must...

Recognise that the infosphere is a social determinant of health.

Recognise that digital health is public health not personalised health.

Focus the system's attention on information **Needs** rather than information **Wants.**

PRESENTED BY
JESSICA MORLEY

By paying attention to the quality of...

PRESENTED BY
JESSICA MORLEY

Indirect-to-Patient Information

- User-generated content inc social media
- Online information inc websites & targeted adverts

Direct-to-Patient Information

- Apps
- Wearables
- LLMs
- Personalised recommender systems

Indirect-to-Clinician Information

- Medical Research
- Medical Insurance

Direct-to-Clinician Information

- Clinical Decision Support Software
- Medical recommender systems

Direct-to-Policy Information

- Public health surveillance
- Service analytics

Thank You

PRESENTED BY
JESSICA MORLEY

www.healthdatanerd.org

@jessRmorley