The Economics of Personal Data and Privacy

Personal Data in the Healthcare sector

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Classical two-party transaction

Supplier → Product or Service → Customer

Supplier → Cash → Customer
Relatively simple solutions

Supply-Demand Curve

Equilibrium price point
Healthcare transaction

- **Payer/Insurer**
  - Cash
  - Cash/Tax

- **Provider**
  - Treatment
  - Drugs
  - Cash

- **Patient**
  - Treatment
  - Cash

- **Gov’t**
  - Cash

- **Pharma**
  - Cash

- **Research**
  - Cash
Healthcare economics

- Doctors have incentives to over-treat patients – paid by activity not outcomes
- ‘Medicalisation’ of normal conditions
- Improving quality of care may reduce income – fewer re-admissions
- Pharma has incentive to ameliorate chronic conditions rather than seek a cure or prevention – longer-term income
- Diseases affecting those too poor to pay tend to be ignored – little or no profit, so no R&D
- Politics: may not be acceptable to close failing hospitals & incentives for quick fixes
Personal data in Healthcare

- Demographics – to make contact
- Entitlement/insurance – will we get paid?
- Consultation notes – aide memoire & legal defence
- Clinical comms.: requests, results – to get it done
  - Checklists & protocols – for quality of care
  - Pathways/treatment plans – to join up care
- Treatments/interventions – to get paid for care
- Prescriptions – someone else supplies
  - Outcomes – did it work or didn’t it?
- Orders, invoices – usual financial stuff
  - Comparative performance – what works best?
Common Myths & Misconceptions

Patients have a ‘family doctor’ looking after them
• Teams of doctors, nurses and other professions provide complex care to patients

Doctors know what they are doing
• Medicine is developing faster than we can handle

Medicine is high-tech & sophisticated
• Doctors take 17 years on average to adopt a new proven technology; many use the medicine they were taught as students

Research is just for academics
• Research is almost the only quality feedback loop in healthcare

Patients ‘own’ their medical record
• Many parties need to use medical record – clinicians, regulators, auditors, trainees - patients are often last in line

The cost of healthcare is ever increasing
– we need to find new ways of doing things better
21st Century Healthcare

- Uses industrial methods, reviewing what works and what doesn’t
- Needs to provide feedback to professionals, institutions, and patients about health and healthcare delivery
- Needs to recognise genetic and family factors; needs to respond to social and psychological facts
- Needs ‘to get more personal’
- Needs to use its information better for all concerned

... means using data more not less...
OECD DP Principle 4:  
*Use Limitation Principle*

Personal data should not be disclosed, made available or otherwise used for purposes other than those specified [at or before data collection] except:

- a) with the consent of the data subject; or
- b) by the authority of law.

... *Easier said than done* ...

... *how specific and thorough?* ...

... *what if not known/foreseen?* ...
Consent vs. Choice

• EU Directive and DP laws place great emphasis on ‘consent’, which is only the expression of choice – leads to over-emphasis on bureaucratic solutions

• Henry Ford supported consent but not choice (‘any color as long as it is black’)

• Choice focuses on what individual would want, not what clinicians or lawyers want

• People must understand the choices and the consequences of their choice
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… too much to explain …
Public Attitudes to Privacy in Healthcare

Public attitudes are *not uniform* and they are often either *ill-informed* or *unformed*

- Attitudes vary from the completely unconcerned to a small proportion of the public that has strong views on privacy.
- It is clear that the public (and the professions!) are unclear on the potential uses of medical records in modern healthcare.
- People will express concerns if questioned about ‘concerns’, but will readily trade these ‘concerns’ for health or other benefits, even altruistic ones.
- The majority seem to trust in clinicians and the healthcare system.

*Literature Review for the UK General Medical Council*

Available at: www.gmc-uk.org/GMC_Privacy_Attitudes_Final_Report_with_Addendum.pdf_27007284.pdf
The opportunity cost of consent

The chart attempts to compare the costs of different consent approaches with the likely benefit (gold band) from a research study. Exact values are not material, but shows that 'express consent' or opt-in approaches will render large-scale data research infeasible.

The Social Contract

• Information should be the lifeblood of medicine – drugs and surgery are dangerous – we need to know what works well and what doesn’t

• Privacy of health data is important, but for most people it is secondary to health itself

• We need to agree what healthcare we want and understand the implications of those choices – not sharing information may mean poor care
The Social Contract

• Must describe WHY we need to share data
• Must describe HOW we will protect the data and patients’ interests
• Must detail WHAT choices patients can make and how this may affect their treatment – and everyone else
• Must recognise reality – and possible costs of choices
• Needs to have a ‘default’ position that helps medicine improve – it must be ‘opt-out’
Summary

- Safe cost-effective healthcare requires better use of personal data
- Privacy and choice are not ‘free goods’; choices have consequences
- Can we find ways to balance risks for individuals with benefits to wider community?
- Privacy is a social, not just a legal, question
- ‘Stewardship' is crucial; as is ‘trust'
“If you think education is expensive, try ignorance.”

- Automobile Bumper Sticker
Thank you.
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