The Economics of Personal Data and Privacy

Personal Data in the Healthcare sector

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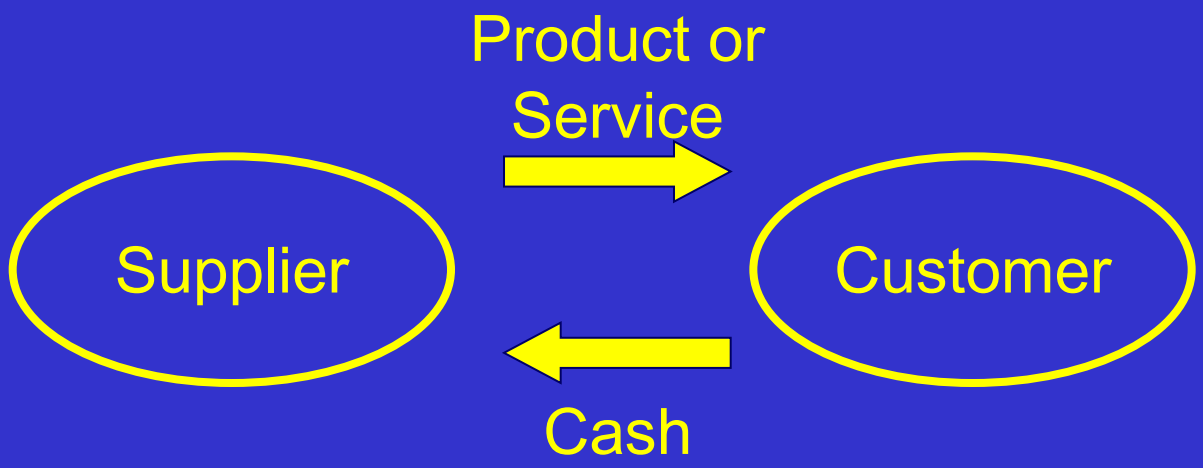
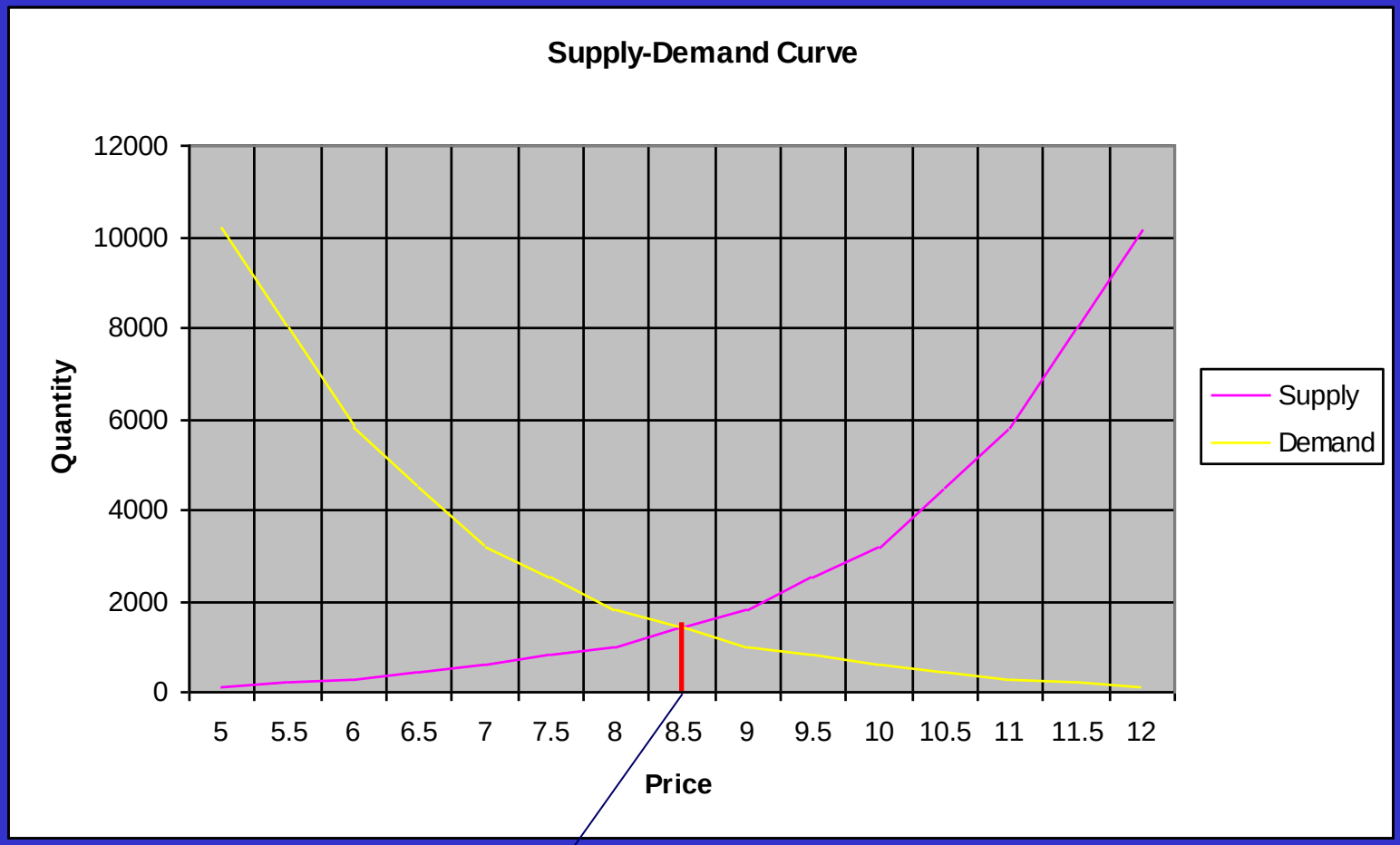
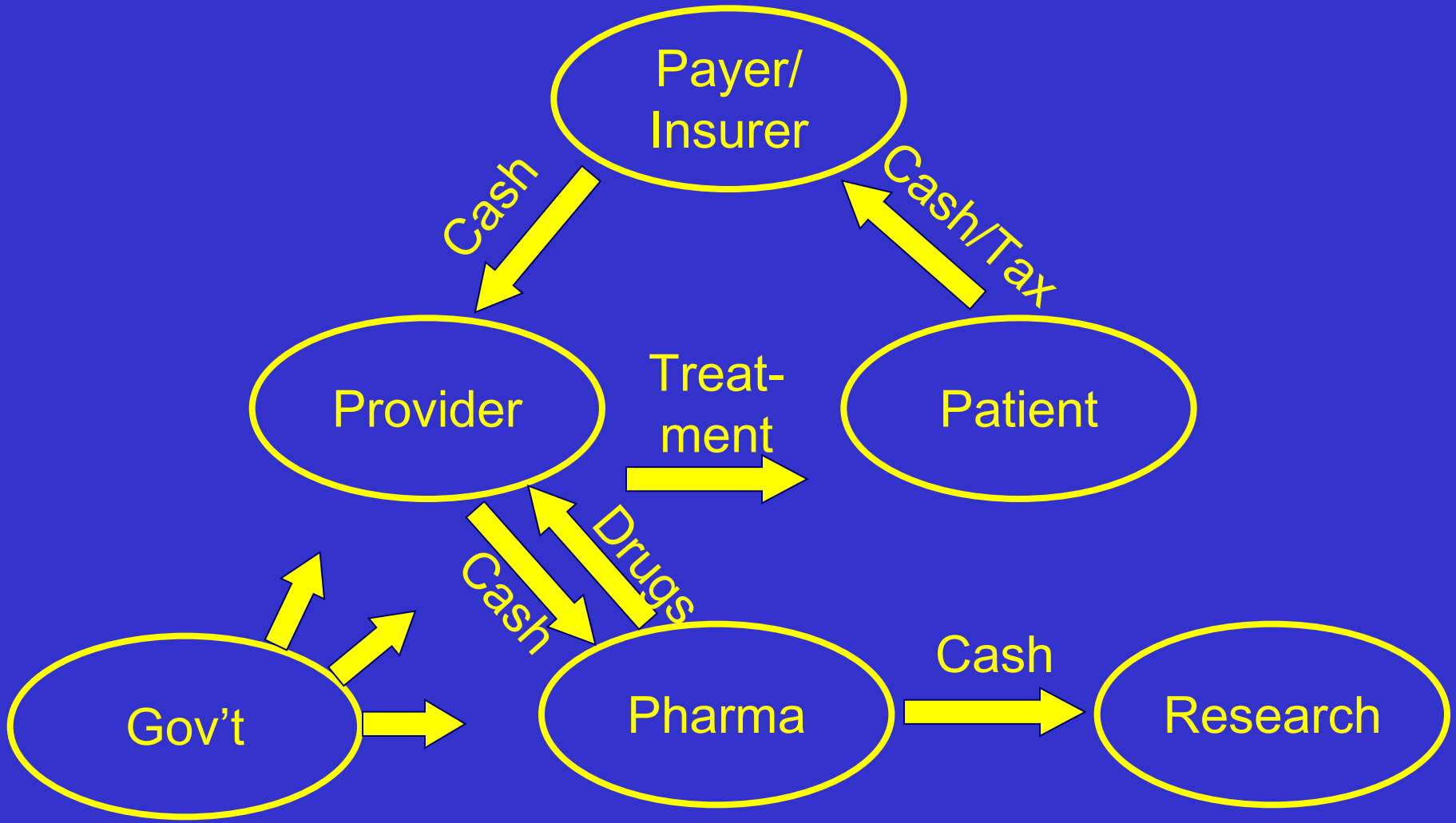
Classical two-party transaction



Relatively simple solutions



Healthcare transaction



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

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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?

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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

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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…

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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? …

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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 …

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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

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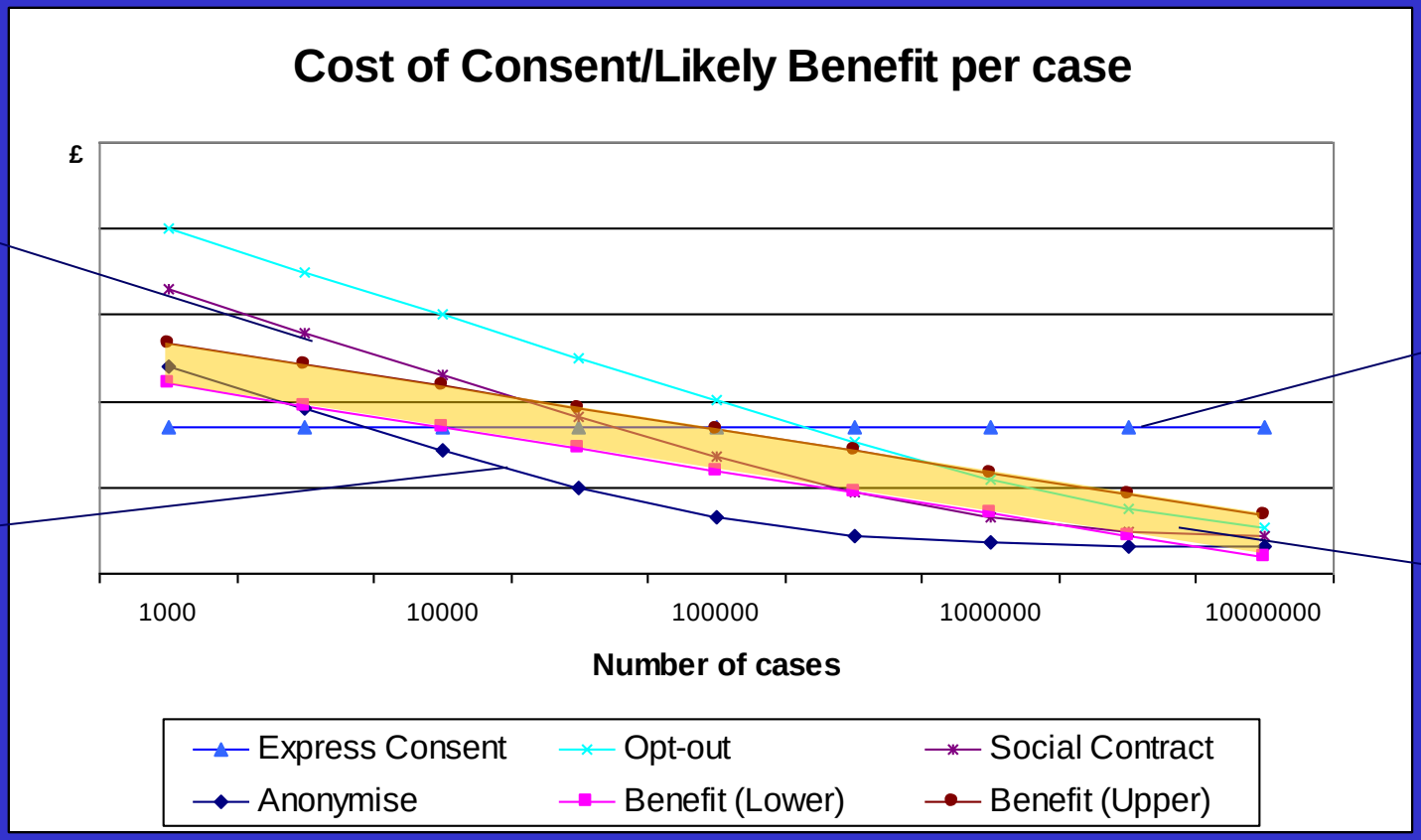
The opportunity cost of consent



'Social contract' – studies must be approved; can opt-out

Anonymising best overall, but not always possible

Express consent too expensive

Average benefit decreases as numbers increase, though 'power' of study increases

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

From Singleton, P and Wadsworth, M: *'Practical aspects of obtaining consent for the use of personal medical data in research'*, British Medical Journal, Jul 2006; 333: 255 - 258

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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

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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'

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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’

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“If you think education is expensive, try ignorance.”

- Automobile Bumper Sticker

Thank you.

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