



**Understanding
Patient Data**

Why do companies need patient data?

Nicola Perrin
October 2017

Thank you!



This work uses data provided by patients and collected by the NHS as part of their care and support.

[#datasaveslives](#)

With thanks to  for the hard work and letting us adopt it.

Insurance bosses buy medical records of all NHS hospital patients

By **Laura Donnelly, Health Correspondent**

THE medical records of every NHS hospital patient in the country have been sold to insurers. *The Daily Telegraph* can

by the Staple Inn Actuarial Society – a major organisation for UK insurers – details how it was able to use NHS data covering all hospital in-patient stays between 1997 and 2010 to track the medi-

were able to better calculate the likelihood of conditions, with “amazingly” clear forecasts possible for certain diseases, in particular lung cancer.

Phil Beath from privacy campaign

Why Google DeepMind wants your medical records

🕒 19 July 2016 | [Technology](#)

Boots, Tesco and Superdrug to get access to NHS medical records

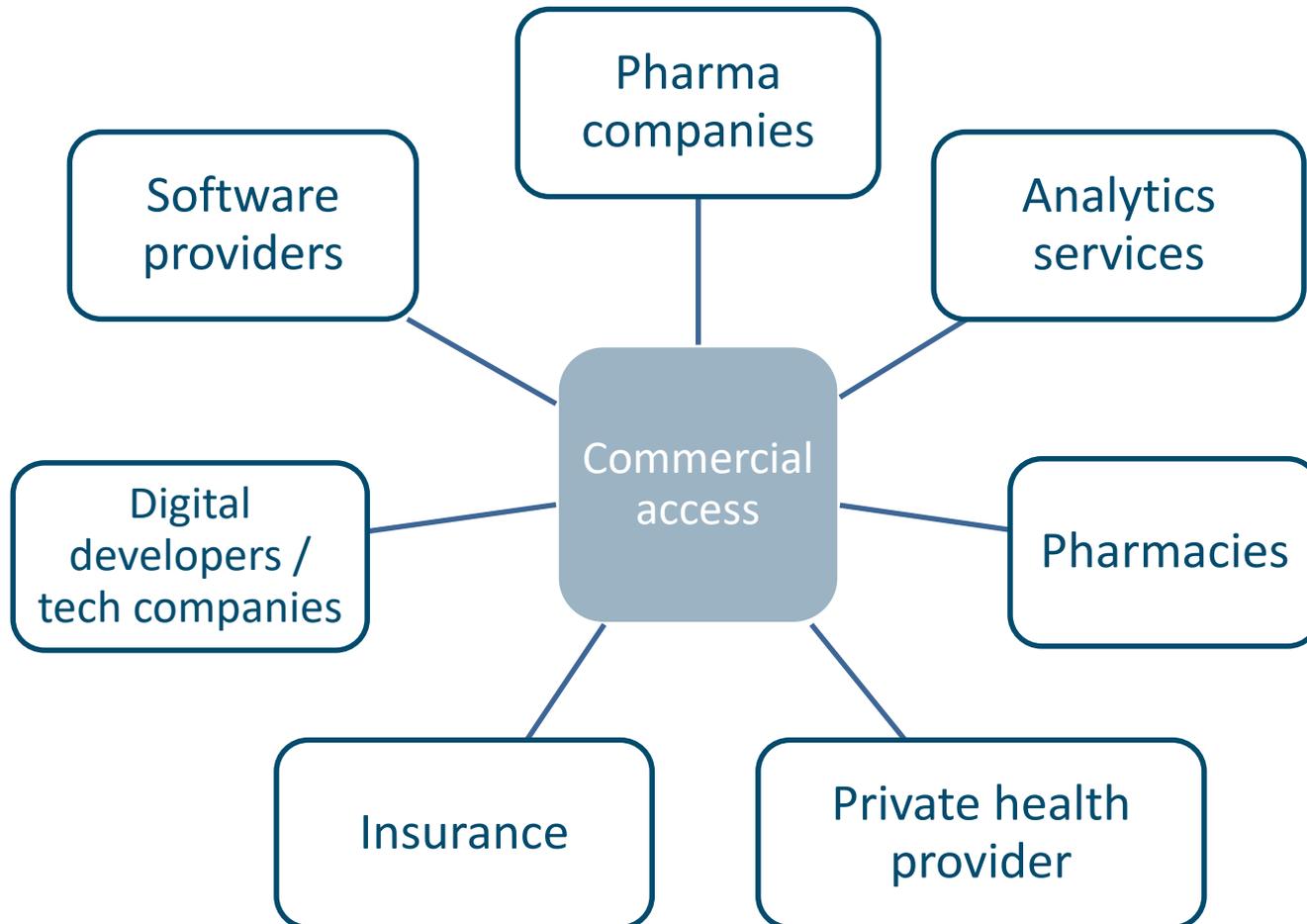
Your medical data is for sale, and there's nothing you can do about it

TECHNOLOGY NEWS 29 April 2016

Revealed: Google AI has access to huge haul of NHS patient data

A data-sharing agreement obtained by *New Scientist* shows that Google DeepMind's collaboration with the NHS goes far beyond what it has publicly announced

Many companies access health data





The context

How do people feel about companies using patient data?

- More support (54%) than oppose commercial access to health data for research
 - Increases to 61% if no other way of research being conducted
- 17% do not want commercial access under any circumstances



March 2016

The One-Way Mirror: Public attitudes to commercial access to health data

Report prepared for the Wellcome Trust

How do people feel about companies using patient data?

- It depends on the purpose
 - if there is a **public benefit**, people are more willing to accept commercial involvement
 - if there is no other way of research being conducted, people are more accepting
- Concerns fall into two categories
 - harms to the individual or family
 - negative impact of commercial organisations on society
- The main concerns are about insurance and direct marketing

Red lines

1. WHY

Solely private benefit

2. WHO

No link to improving public health

3. WHAT

Identifiable personal details with real world implications

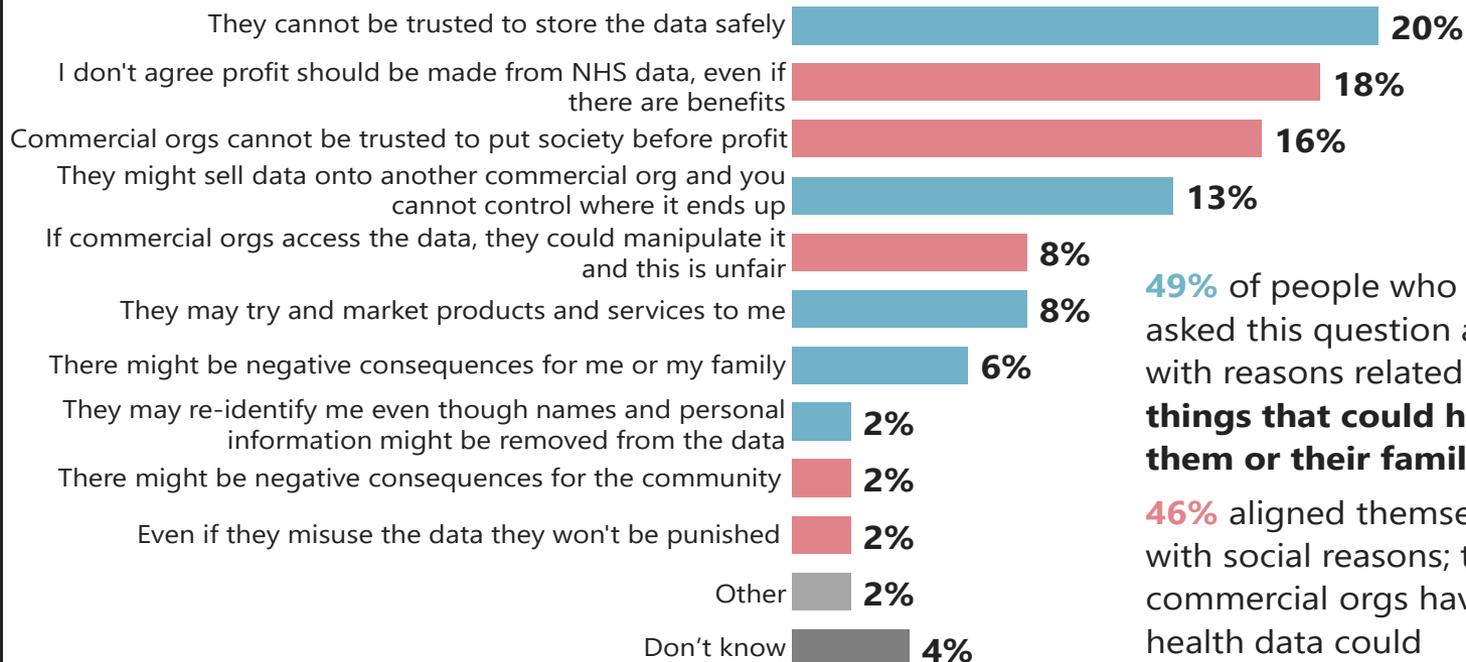
4. HOW

Secure storage & regulation is assumed

Unpacking the concerns

Those who do not want to see commercial orgs having access to health data fall evenly into two groups

Which of the following views, if any, comes closest to why you do not want commercial organisations to have access to health data under any circumstances?*



49% of people who were asked this question aligned with reasons related to **things that could harm them or their family**

46% aligned themselves with social reasons; that commercial orgs having health data could **negatively impact society**

Base: All those who do not want commercial organisations to have access to health data under any circumstances (356)

Questions to address

- **Why** do companies need patient data?
- Will companies **market** products to me because of my health condition
- Will **insurance companies** discriminate against me?
- Does the **NHS sell patient data**?
- Can companies **make a profit** from patient data?
- Can companies **be trusted** to store the data safely?



Why do companies need access
to patient data?

Type of company

Pharma companies



Pharmacies



Software providers



Digital developers / tech companies



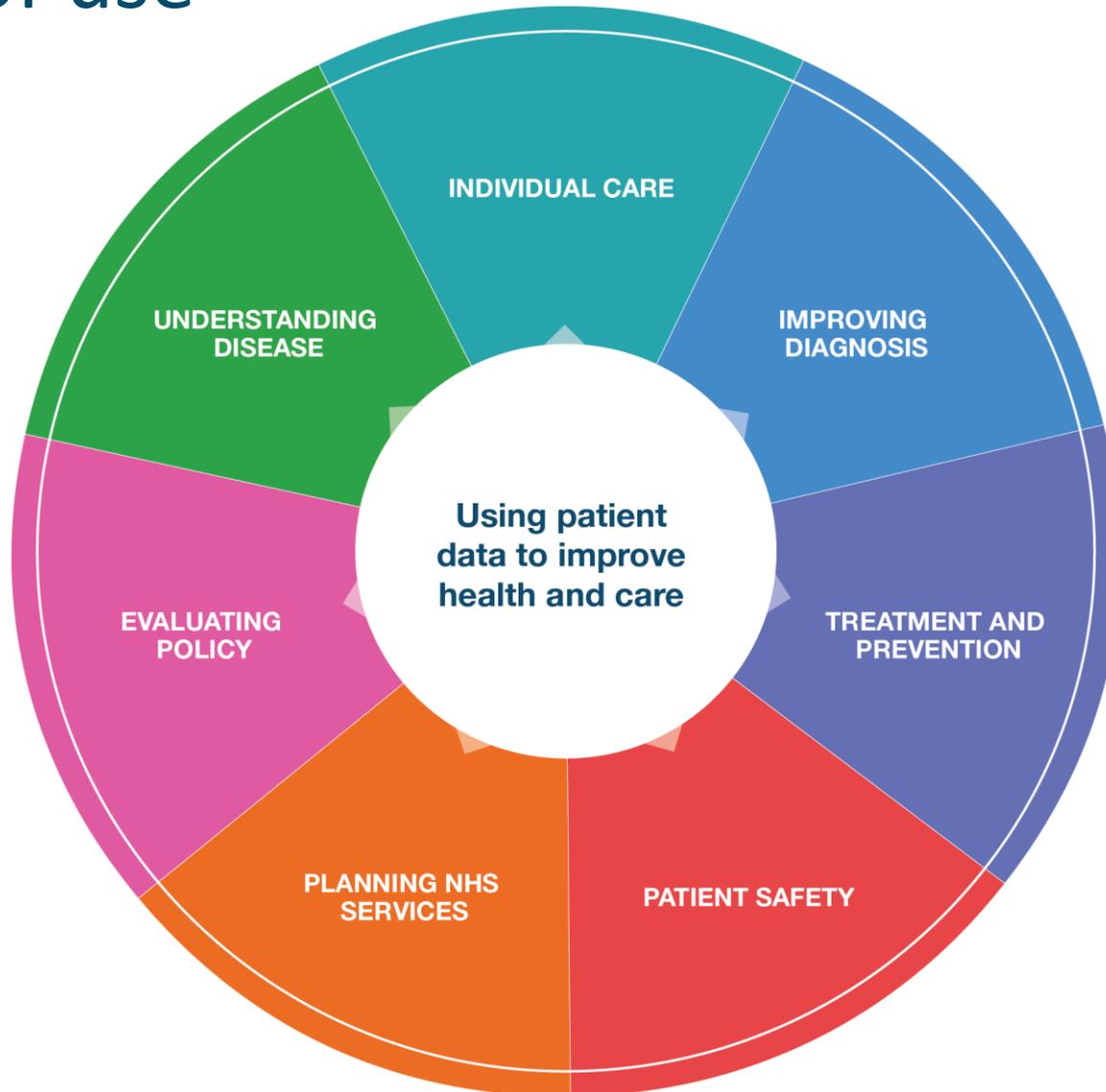
Analytics services



Insurance



Type of use



Individual care



- provide software for electronic patient records at your GP surgery and in hospital
- patient-facing services allow you to access your patient records and book appointments online

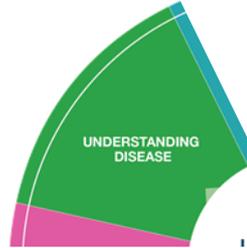


- to prepare prescription medicines for patients
- to target services to patients (with consent)



- apps to help patients self-manage conditions
- fitness and health trackers
- to develop IT systems to monitor a patient and alert the clinician if condition changes

Understanding disease



- to identify therapeutic targets
[depersonalised]
- to identify patients that are more likely to get a disease, or respond to a type of drug
[depersonalised]



- to understand the burden of disease, and assess the size of the market for a new drug or device
[anonymous]

Improving diagnosis



- to develop better diagnostic tests
[depersonalised / personally identifiable with consent]



- clinical decision support tools to help diagnosis
- using software to analyse MRI or retinal scans
[data used depends whether it is to provide individual care or for research / development of algorithm]

Developing new treatments

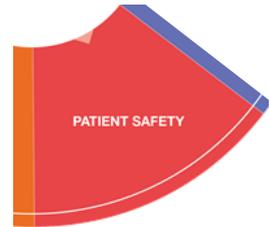


- recruiting people to take part in clinical trials
[personally identifiable – with consent]
- testing new treatments in real-world conditions
[personally identifiable – with consent]
- assessing effectiveness of a new medical device
[de-personalised]



- automated drug delivery systems / stoma bags
[personally identifiable – with consent]

Monitoring patient safety



- monitoring the safety of drugs + devices
(e.g. long-term follow up of side-effects)
[depersonalised – depending on condition]



- remote monitoring
(e.g. glucose monitoring,
telehealth for dementia)

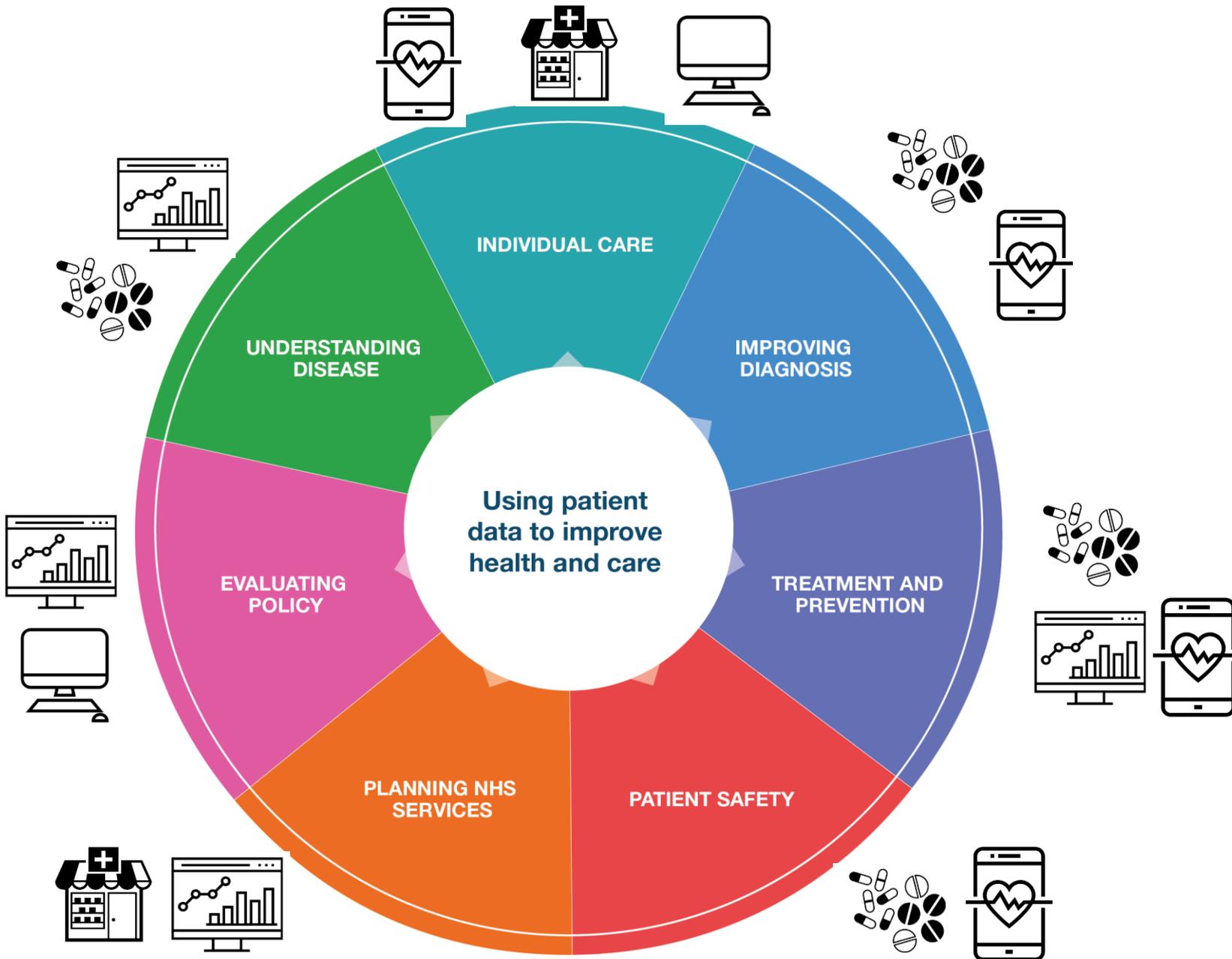
Planning NHS services



- To understand more about individual patient pathways, identify variation and design more efficient services
- Linking data across the system to help inform commissioning decisions + benchmarking [*depersonalised*]



- to ensure appropriate supply of medicines, by knowing numbers of people with a condition. [*anonymous*]



Why do insurance companies want data?



- Individual applications for insurance
 - e.g. life insurance cover
 - you will always be asked for permission before insurer can access information direct from your GP
 - moratorium on using genetic information
- Setting insurance premiums
 - use data about health and lifestyle to help understand and predict risk, in order to work out how much insurance cover will cost
 - only given access to anonymised data about large groups
 - can lead to higher or lower premiums depending on your situation

Questions to address

- **Why** do companies need patient data?
- Will **insurance companies** discriminate against me?
- Will companies **market** products to me because of my health condition
- Does the **NHS sell patient data**?
- Can companies **make a profit** from patient data?
- Can companies **be trusted** to store the data safely?

Will companies **market** products to me because of my health condition?

- Companies will never be given name or contact details of an individual
- Pharmaceutical companies have to follow strict rules about marketing, and they are not allowed to advertise prescription medicines to patients in the UK
- Pharmacies wanting to market services to patients have to ask for consent first
- You are more likely to receive targeted advertising as a result of internet searches.
 - 1 in every 20 google searches are health-related

Does the NHS sell patient data?

- NHS Digital does not sell data, but operates on a cost recovery basis
 - They are allowed to charge for the cost of processing and delivering the service, but not for data itself.
 - The charge depends on the type of application, amount of data requested, and the amount of work that NHSD will need to do.
- There needs to be more discussion about how the NHS can benefit from the value of data, for the benefit of patients
 - Where patient data has been used to develop a service, should the NHS get access to that service at a reduced rate?
 - The most appropriate business models and actual commercial value of the data are not yet fully understood.

Can companies make a profit from patient data?

- The NHS can't do all of this on their own
 - The NHS does not have the expertise or resource to make sense of large and complex datasets, or to develop new drugs in-house, and so they need to partner with companies to provide these services.
- Any access to data is strictly controlled, whoever the user.
 - All users have to sign contracts that set out what they can and cannot do with the data.
 - Personally identifiable patient data cannot be used for insurance or marketing purposes without consent.

Can companies be trusted to store data safely?

- There are strict rules regarding use of patient data
 - All users have to sign contracts setting out what they can and cannot do with the data, including limits on passing data to third parties.
 - Data must be stored securely, with controlled access and robust up-to-date IT systems to keep data safe.
- Companies are often more likely to have the resource, expertise and incentive to ensure they keep data safe



Any other questions?

Will companies make a profit from patient data?

Will my data be sold on to third parties, with no control?

Does the NHS sell my data?

Is it a slippery slope to privatising the NHS?

Feedback from today

- What are the key things you would tell someone, based on what you've heard today?
- What has surprised you most?
- Are you reassured or more concerned?
- Have we identified the right questions to answer?
- How much detail should we include in a resource?



**Understanding
Patient Data**

For further information

www.understandingpatientdata.org.uk

n.perrin@understandingpatientdata.org.uk

@NMRPerrin / @Patient_Data