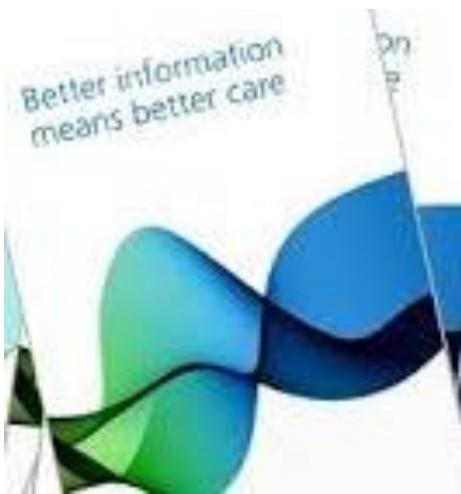


# **Public attitudes to commercial access to health data**

An Ipsos MORI study commissioned by the  
Wellcome Trust

Nicola Perrin

# Background



## Context

Public reaction to *care.data*

Concerns about surveillance culture and how data is collected and used

Increasing interest in 'big data' potential, especially in health

## Previous research

People are generally positive about personal health data use for research

**But**, wariness and low acceptability for commercial involvement

# Methods

- What:
- Qualitative workshops – 200+
  - Interim analysis
  - Quantitative survey – 2000+

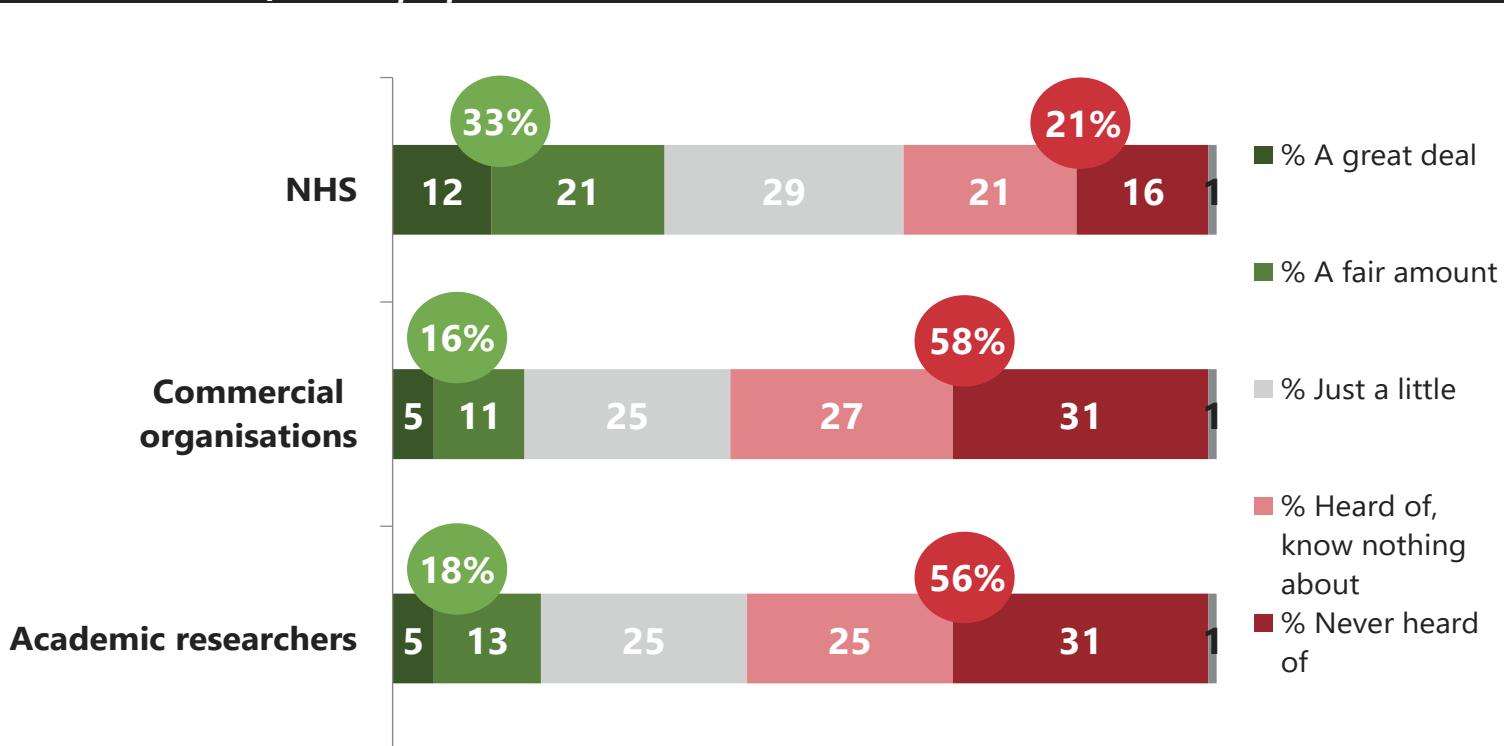
- Who:
- Public
  - Patients
  - Rare disease patients
  - GPs/hospital doctors
  - Research cohort members

- How
- Real life case studies and ‘what if’ scenarios
  - Range of different commercial organisations

# Key findings: Context and awareness

## Some awareness of health data usage, but little depth of understanding

*How much, if anything, would you say you know about how the following organisations use health data for these purposes?\**



Base: 2,017 GB adults, aged 16+



Ipsos MORI  
Social Research Institute

\*See appendices for full question wording

Source: Ipsos MORI/Wellcome Trust

# ‘Context collapse’

## Two traditional mindsets for data sharing

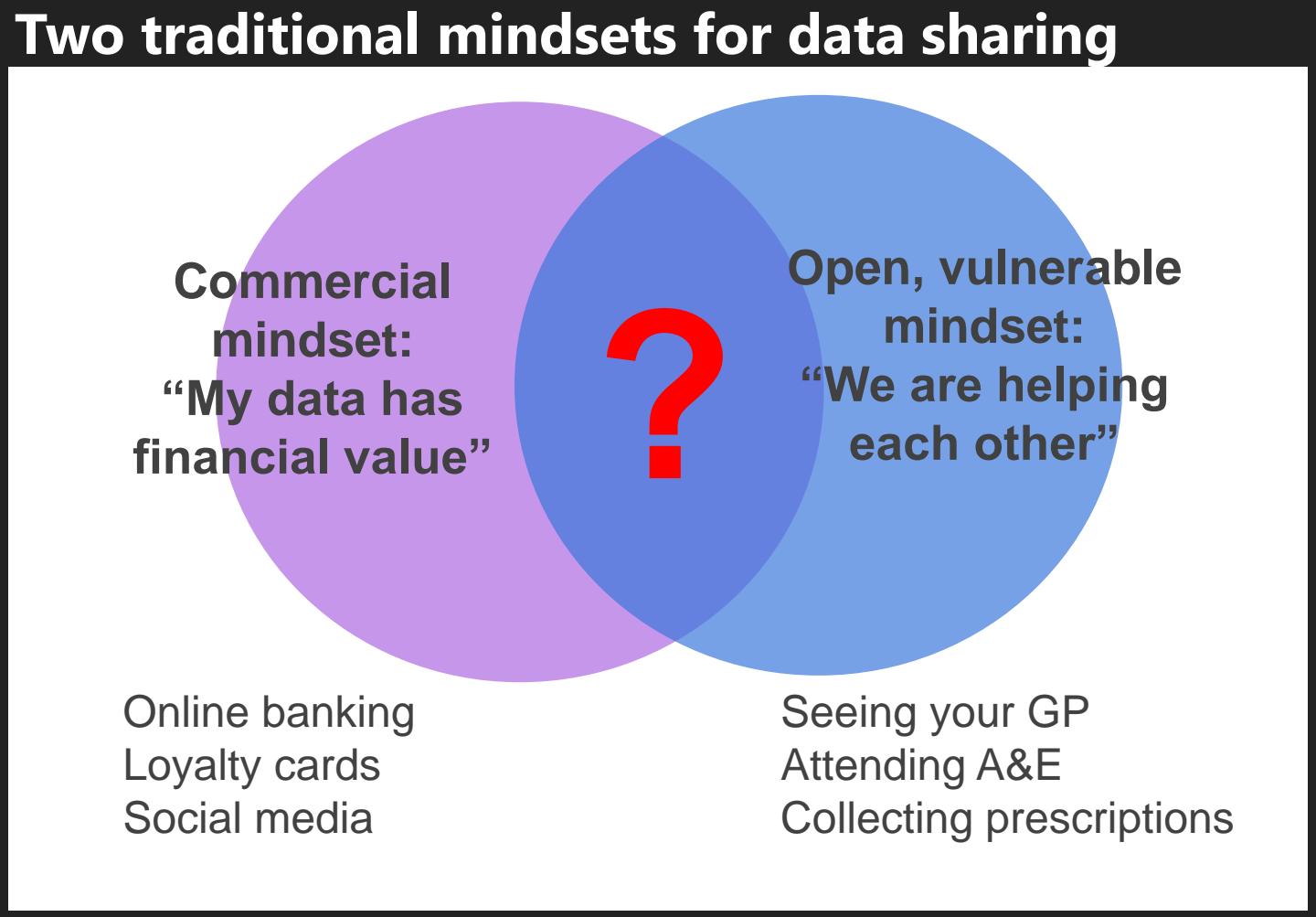
**Commercial  
mindset:**  
“My data has  
financial value”

Online banking  
Loyalty cards  
Social media

**Open, vulnerable  
mindset:**  
“We are helping  
each other”

Seeing your GP  
Attending A&E  
Collecting prescriptions

# 'Context collapse'

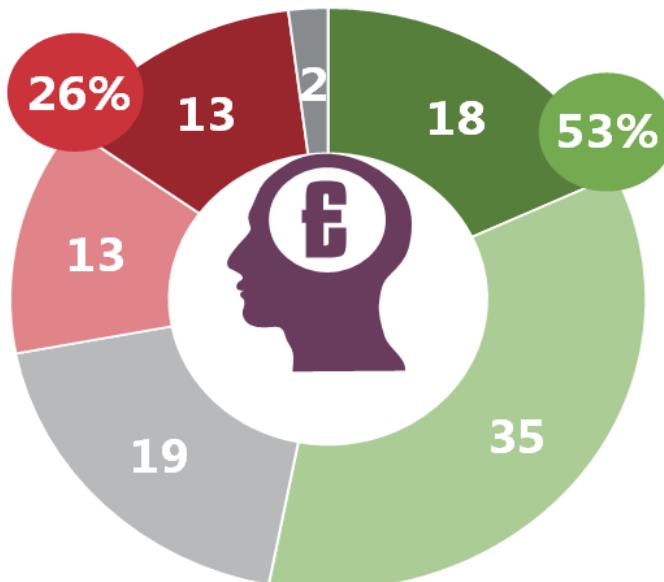


# Quantitative findings

## More support than oppose health data sharing for research

*To what extent, if at all, would you support your health data being accessed by commercial organisations if they are undertaking health research?\**

- % Strongly support
- % Tend to support
- % Neither support nor oppose
- % Tend to oppose
- % Strongly oppose
- % Don't know



Base: 2,017 GB adults, aged 16+



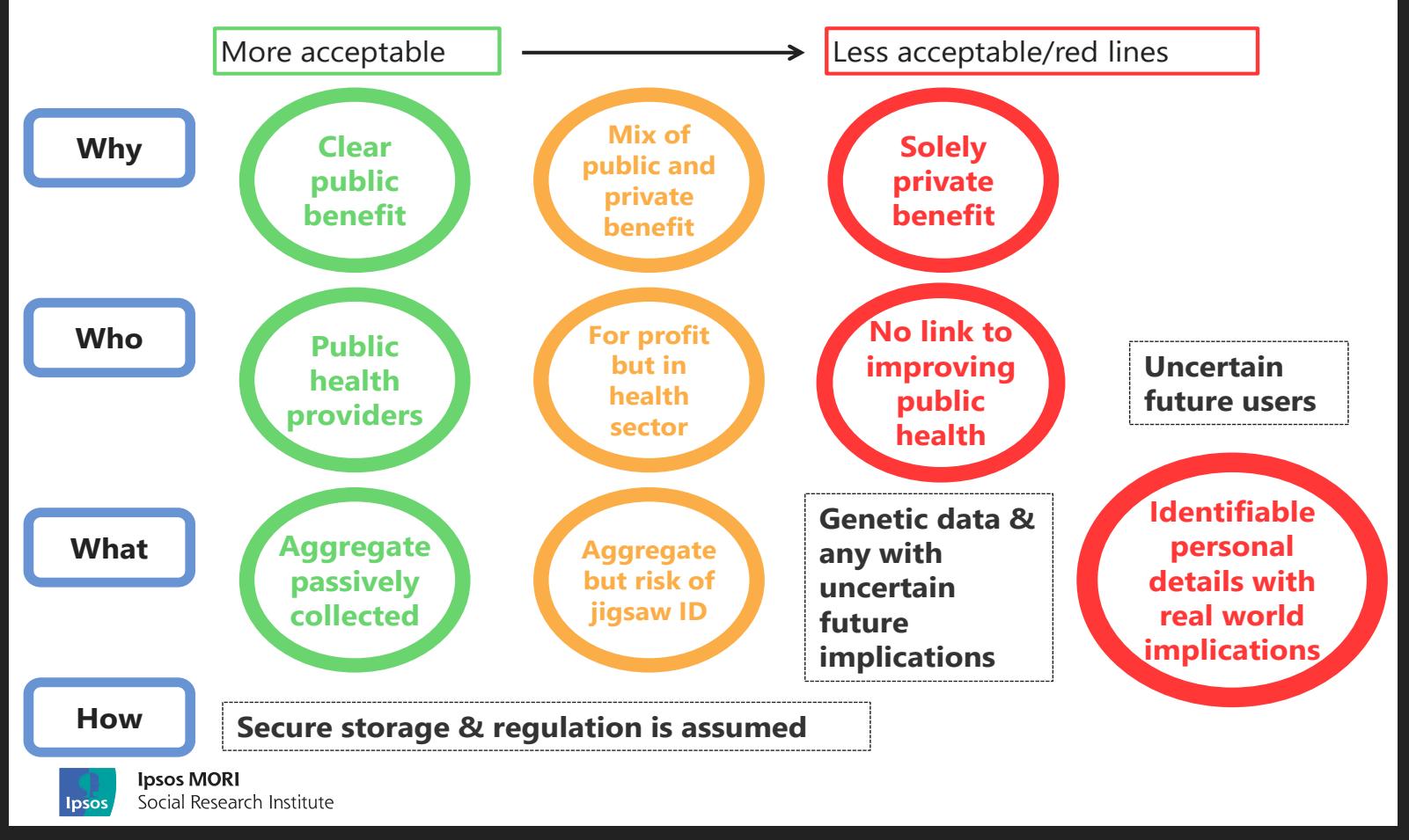
Ipsos MORI  
Social Research Institute

\*See appendices for full question wording

Source: Ipsos MORI/Wellcome Trust

# Key findings: Factors and ‘key tests’

## What drives acceptability: in summary



# Case studies

Data linking and analysis in the NHS

Monitoring safety of drugs and medicines

Calculating insurance premiums

Pharmacists using Summary Care Records

Using genetic data in care and research

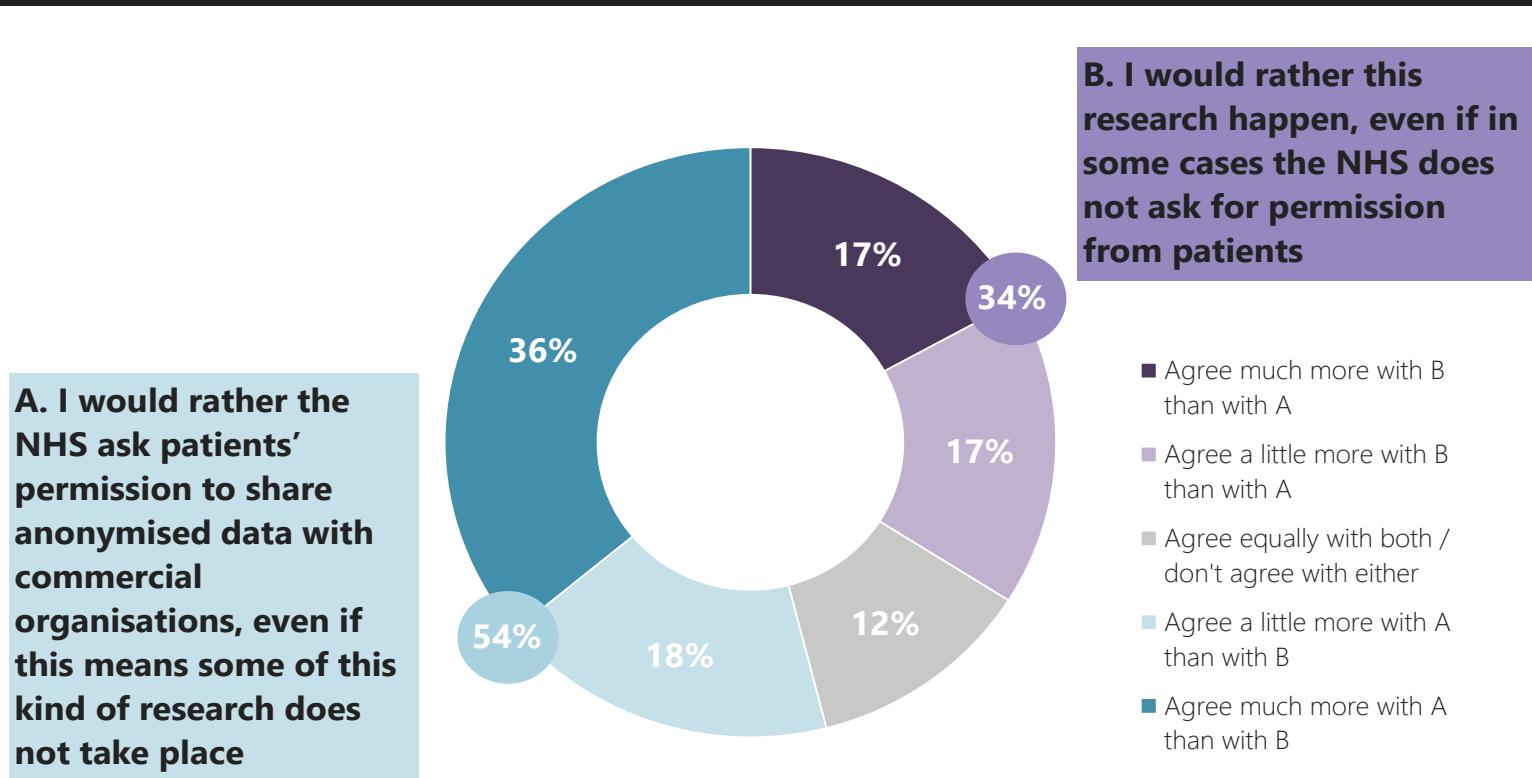
Crowdsourcing to provide support for patients

- Controversial ‘what if...’ scenarios included

# Permission

## Support for research without permission being sought

*Which of the following statements comes closest to your view of commercial organisations seeking to access this kind of anonymised health data?\**



Base: 1,043 GB adults, aged 16+



Ipsos MORI  
Social Research Institute

\*See appendices for full question wording

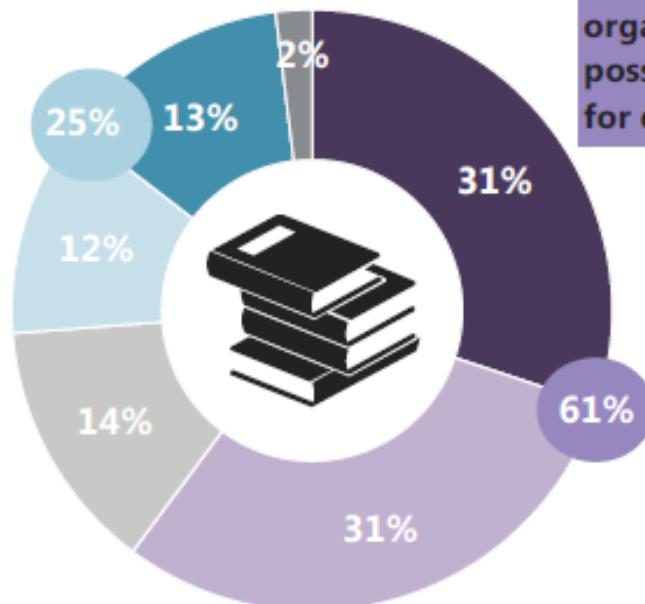
Source: Ipsos MORI/Wellcome Trust

# Commercial involvement in research

## Support for commercial access if research at risk

*Which of the following statements comes closest to your view of health data being shared with commercial organisations?\**

**A. I would not want commercial organisations to have access to anonymised health data, even if this means the research does not take place**



**B. The research should be conducted by commercial organisations if there is a possibility of new treatments for diseases being developed**

- Agree much more with B than with A
- Agree a little more with B than with A
- Agree equally with both / don't agree with either
- Agree a little more with A than with B
- Agree much more with A than with B
- Don't know

Base: 974 GB adults, aged 16+



Ipsos MORI  
Social Research Institute

\*See appendices for full question wording

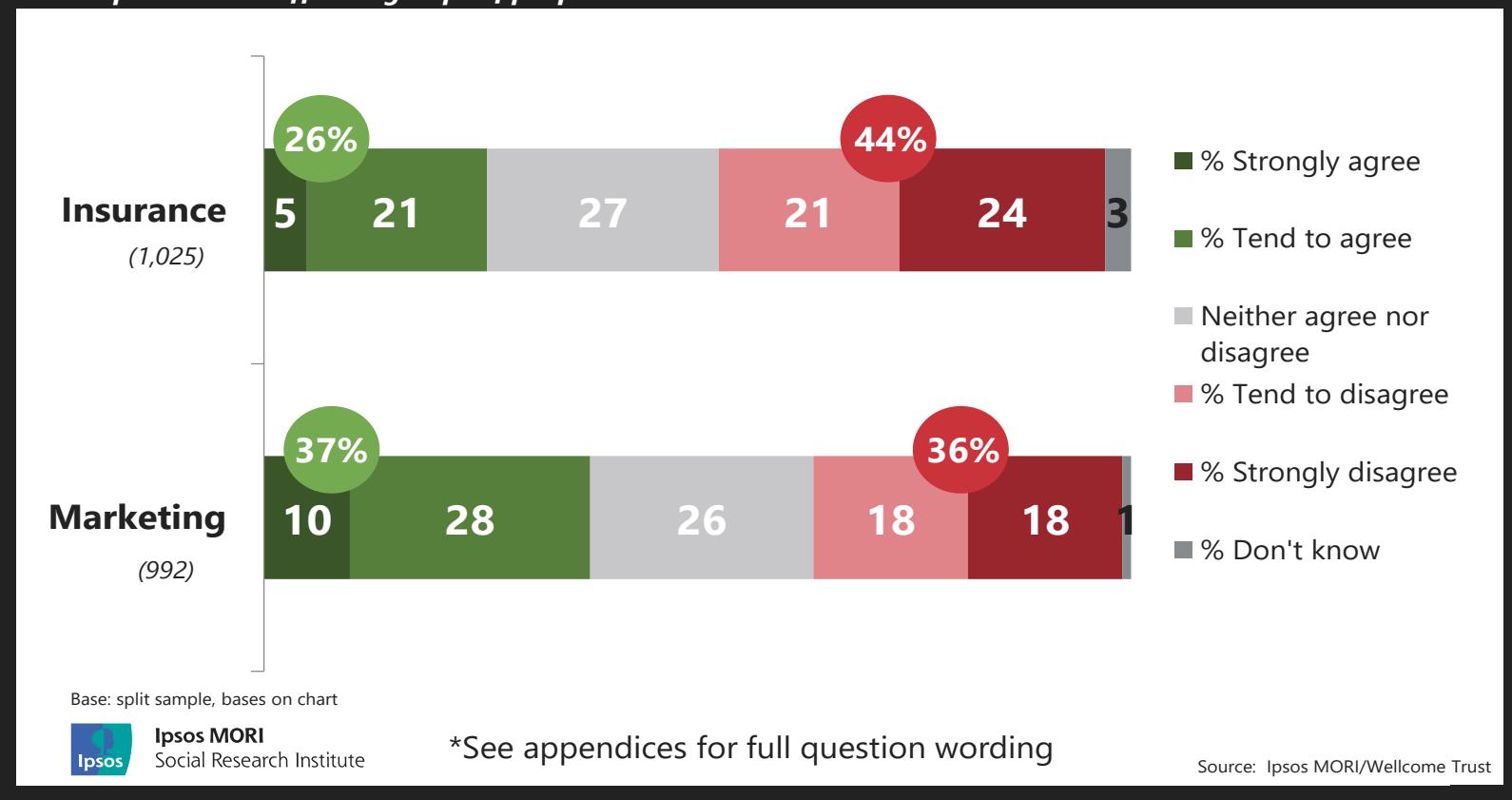
Source: Ipsos MORI/Wellcome Trust

# Insurance and marketing

## Insurance purposes compared with marketing purposes

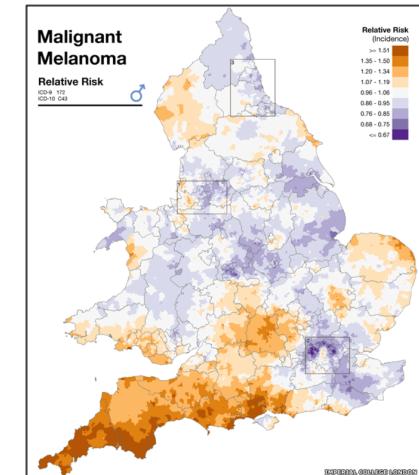
*To what extent, if at all, would you support insurance companies using health data collected in the NHS to further develop their health insurance prices?\**

*To what extent, if at all, would you support companies using health data collected in the NHS to help target health products at different groups of people?\**



# Calculating insurance premiums

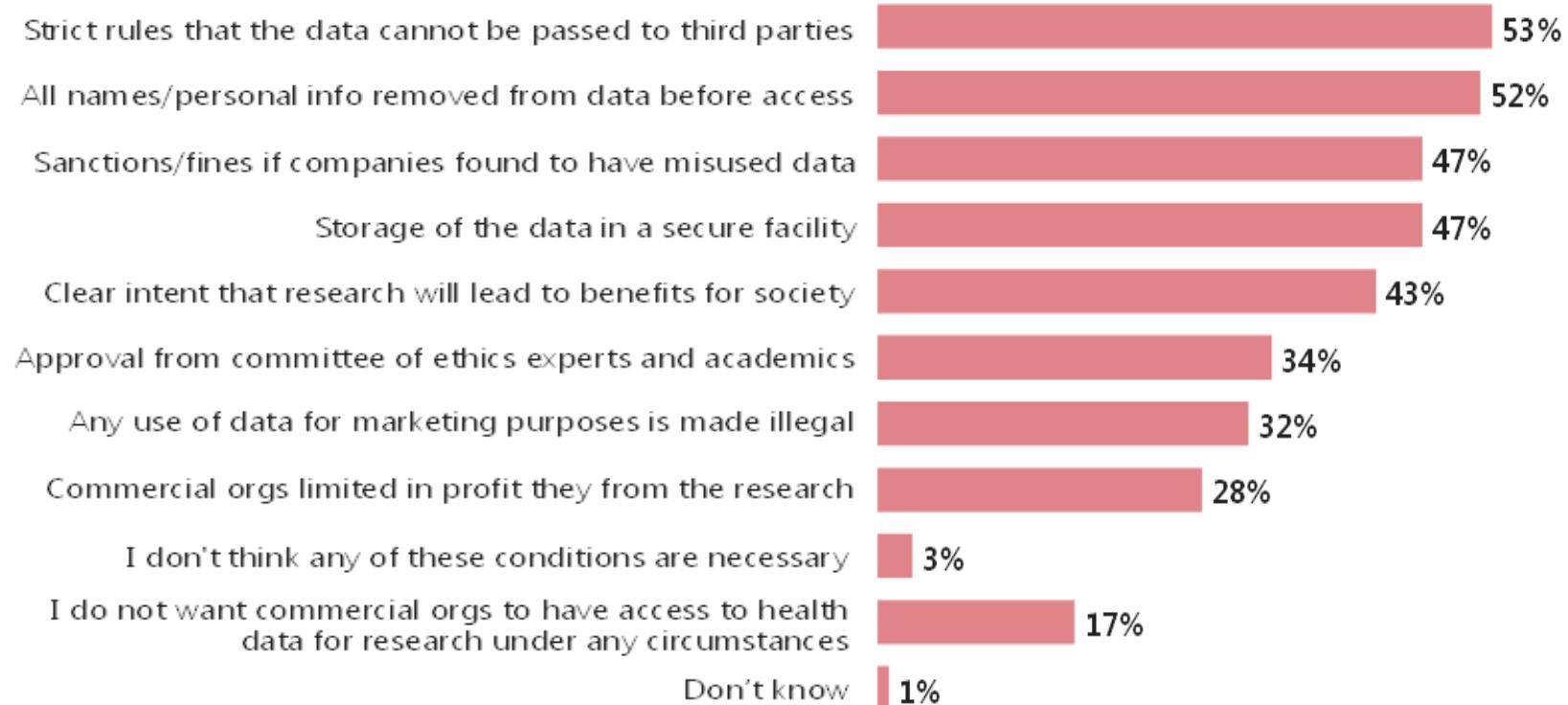
- Private health insurance companies want to have a good indicator of how likely different customers are to develop a critical illness, so that they set the right premium levels
- They want to know whether regional or economic differences make a difference to this health risk
- They use individual level Hospital Episode Statistics (HES) to link these with different types of demographic data.
- They discovered that in areas of lower deprivation there are lower rates of critical illness
  - but that this varies a lot by individual illness type.



# What safeguards and conditions?

## Conditions for health data sharing with commercial organisations

*Which of the following conditions, if any, would you have in place before a commercial organisation, such as a drug company or medical technology manufacturer, could access NHS health data for research purposes?\**



Base: 2,017 GB adults, aged 16+



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Social Research Institute

\*See appendices for full question wording

Source: Ipsos MORI/Wellcome Trust

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Base: 2,017 GB adults, aged 16+



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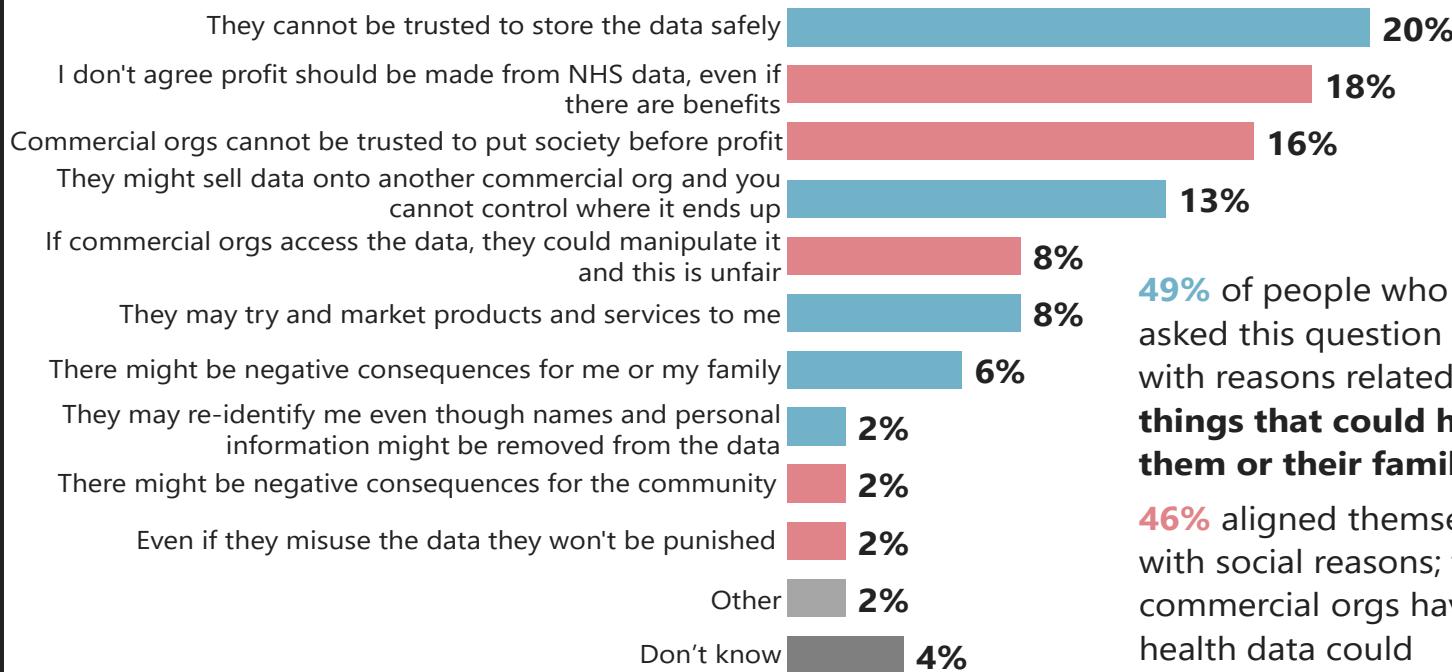
\*See appendices for full question wording

Source: Ipsos MORI/Wellcome Trust

# No commercial access

## 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?\**



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

**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**



**Ipsos MORI**  
Social Research Institute

\*See appendices for full question wording

Source: Ipsos MORI/Wellcome Trust

# Conclusions

- Little awareness and understanding how health data can be used, even within the NHS – let alone beyond.
- Confusion about identifiable, de-identified, anonymised or aggregate data
  - Anything individual-level perceived as ‘my’ data
- In general, more information leads to greater acceptance if there is a clear public benefit
- A significant minority object to commercial access under any circumstances
- Strong need to develop accessible narratives or case studies about how data can be used in practice, including:
  - Clear purpose, with public benefit
  - Description of what kinds of data, including honesty about risks
  - Clear, robust red lines
  - Safeguards and protections

# Follow up

Input into:

- Caldicott Review
- HRA public dialogues to inform CAG advice

Independent Taskforce on  
conversations about patient data – in  
development

Contact me for more information

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[www.wellcome.ac.uk/publicattitudes](http://www.wellcome.ac.uk/publicattitudes)



March 2016

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

Report prepared for the Wellcome Trust