

Public attitudes to commercial access to health data

An Ipsos MORI study commissioned by the Wellcome Trust

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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

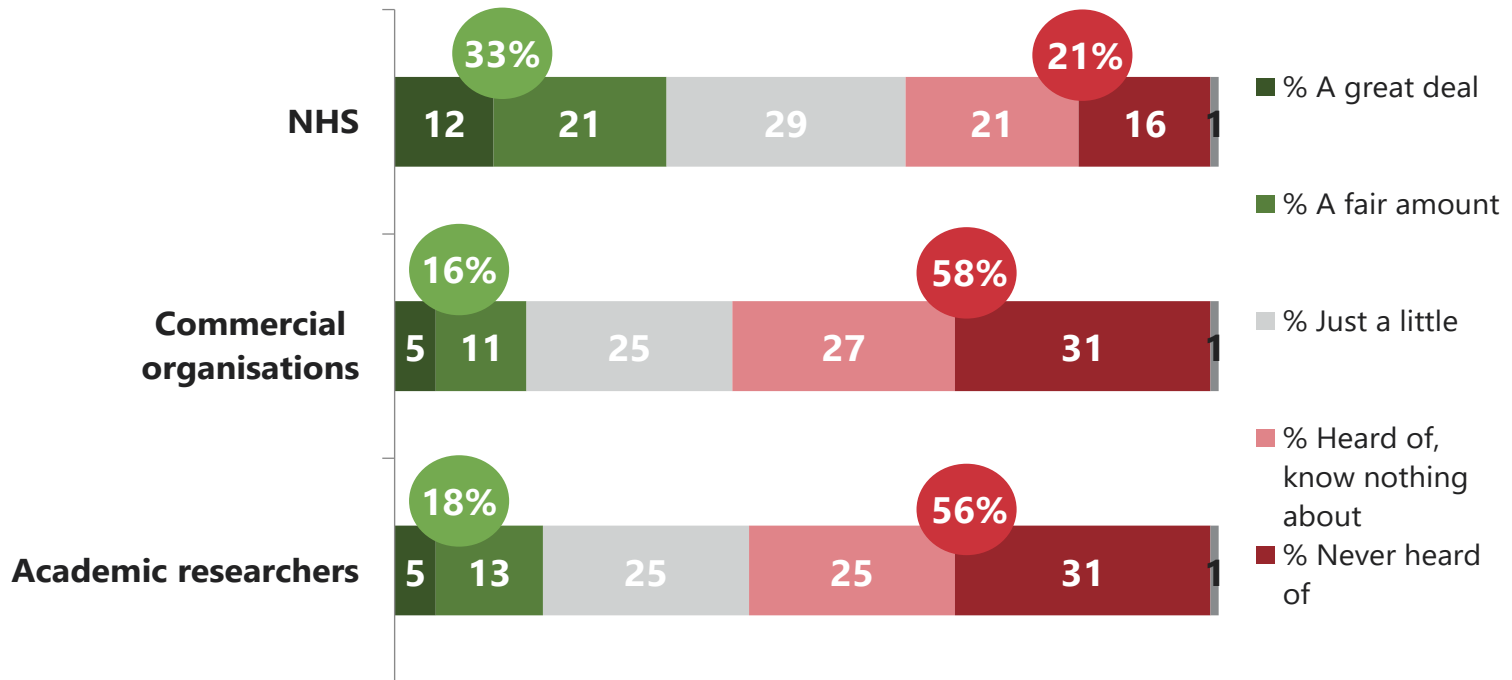
Methods

- 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+

‘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'

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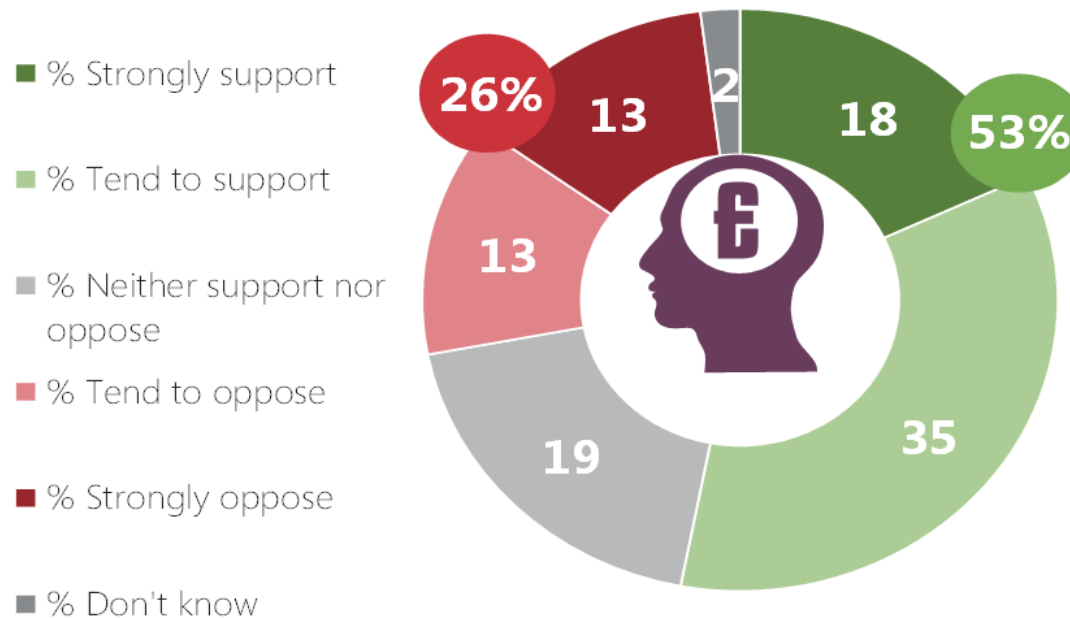
Open, vulnerable mindset:
"We are helping each other"

Seeing your GP
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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?**

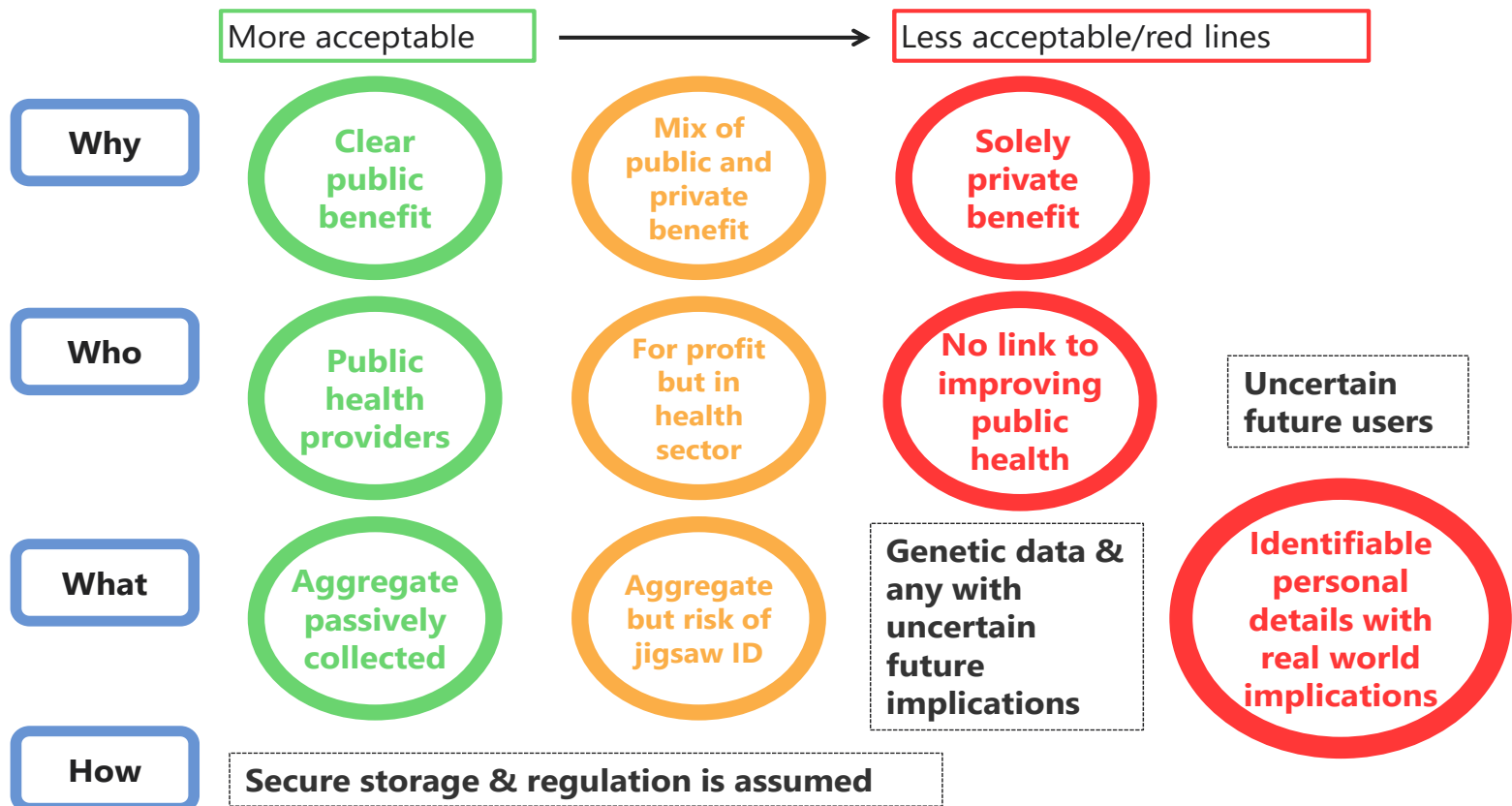


Base: 2,017 GB adults, aged 16+

*See appendices for full question wording

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

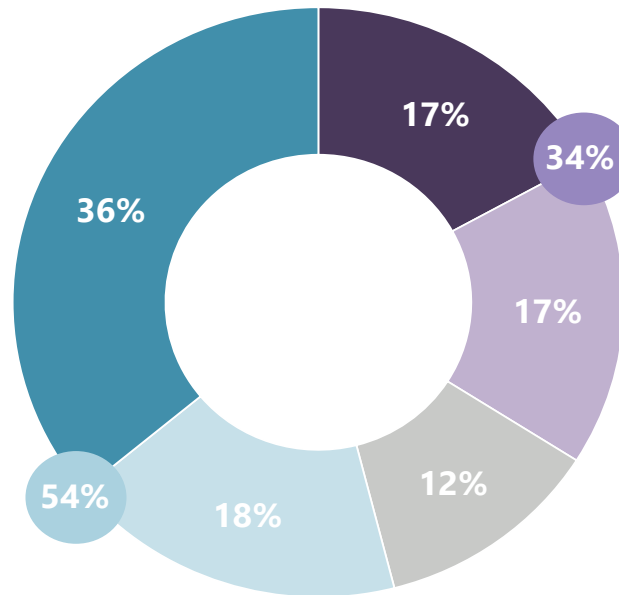
Permission

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?*

A. I would rather the NHS ask patients' permission to share anonymised data with commercial organisations, even if this means some of this kind of research does not take place

B. I would rather this research happen, even if in some cases the NHS does not ask for permission from patients



- 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

Base: 1,043 GB adults, aged 16+

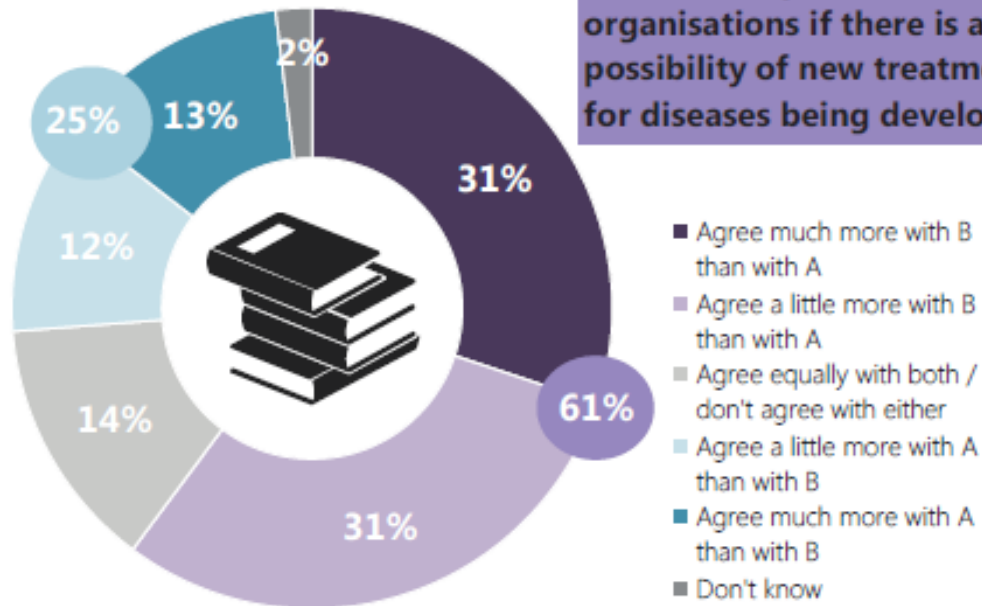
Commercial involvement in research

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



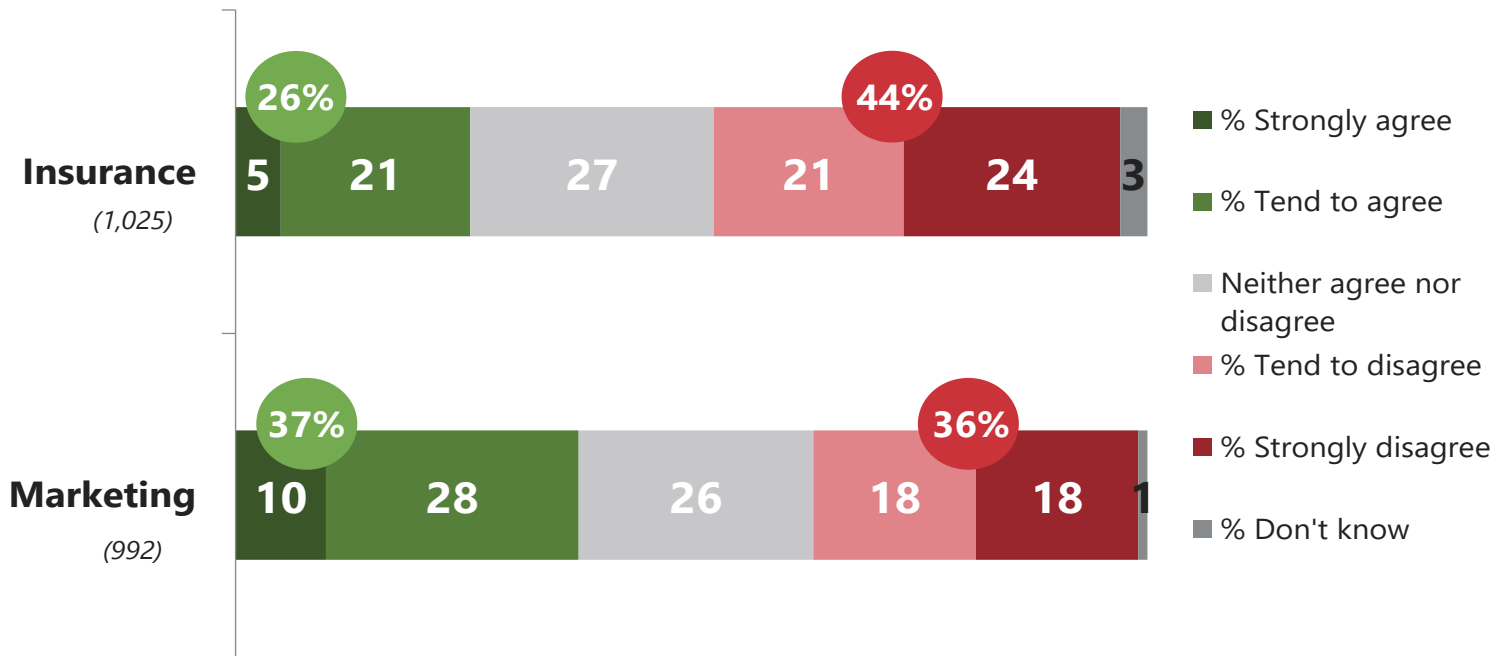
Base: 974 GB adults, aged 16+

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?*

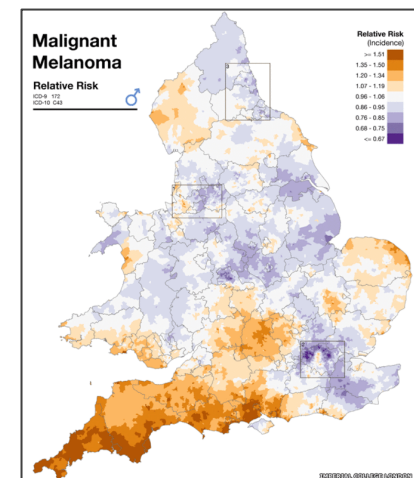
To what extent, if at all, would you support companies using health data collected in the NHS to help target health products at different groups of people?*



Base: split sample, bases on chart

Calculating insurance premiums

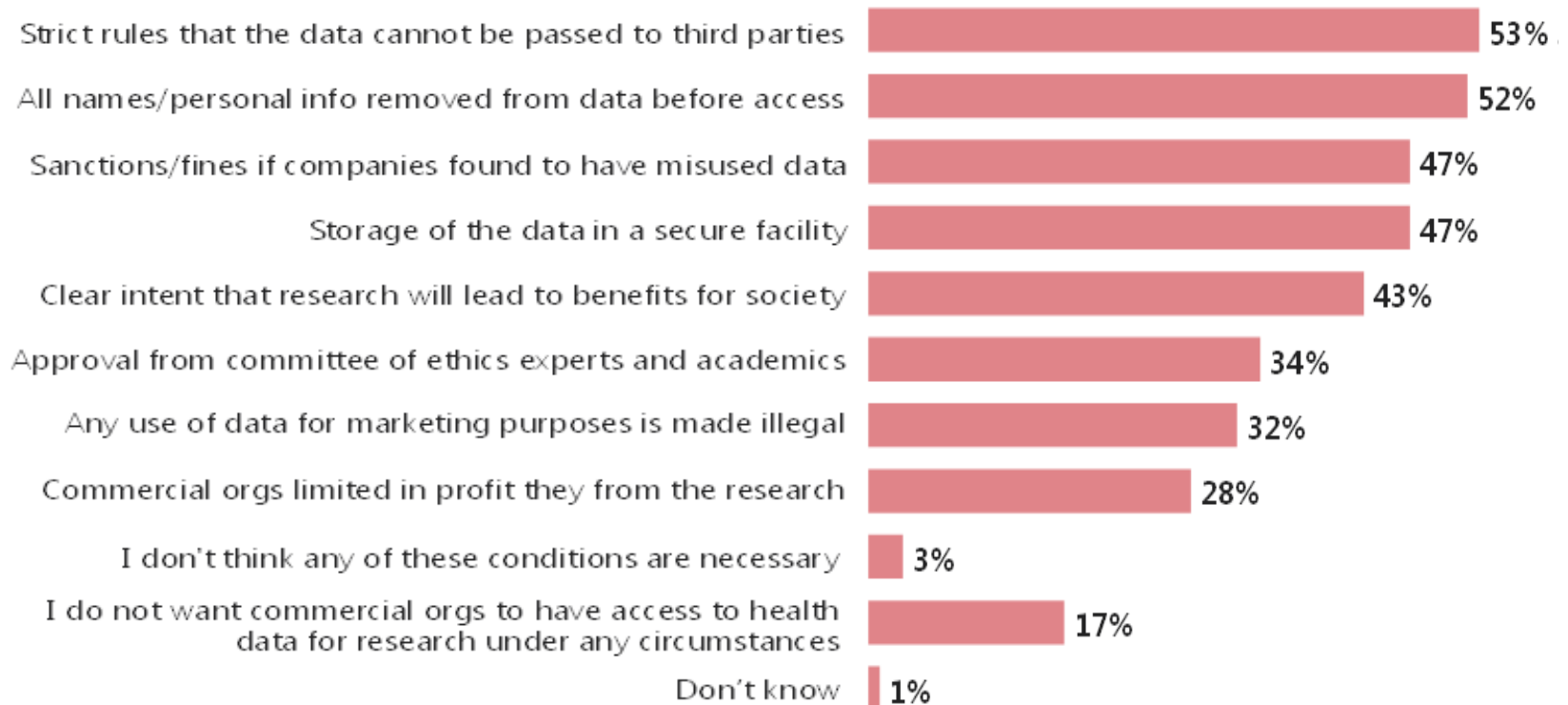
- Private health insurance companies want to have a good indicator of how likely different customers are to develop a critical illness, so that they set the right premium levels
- They want to know whether regional or economic differences make a difference to this health risk
- They use individual level 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+

What safeguards and conditions?

Conditions for health data sharing with commercial organisations

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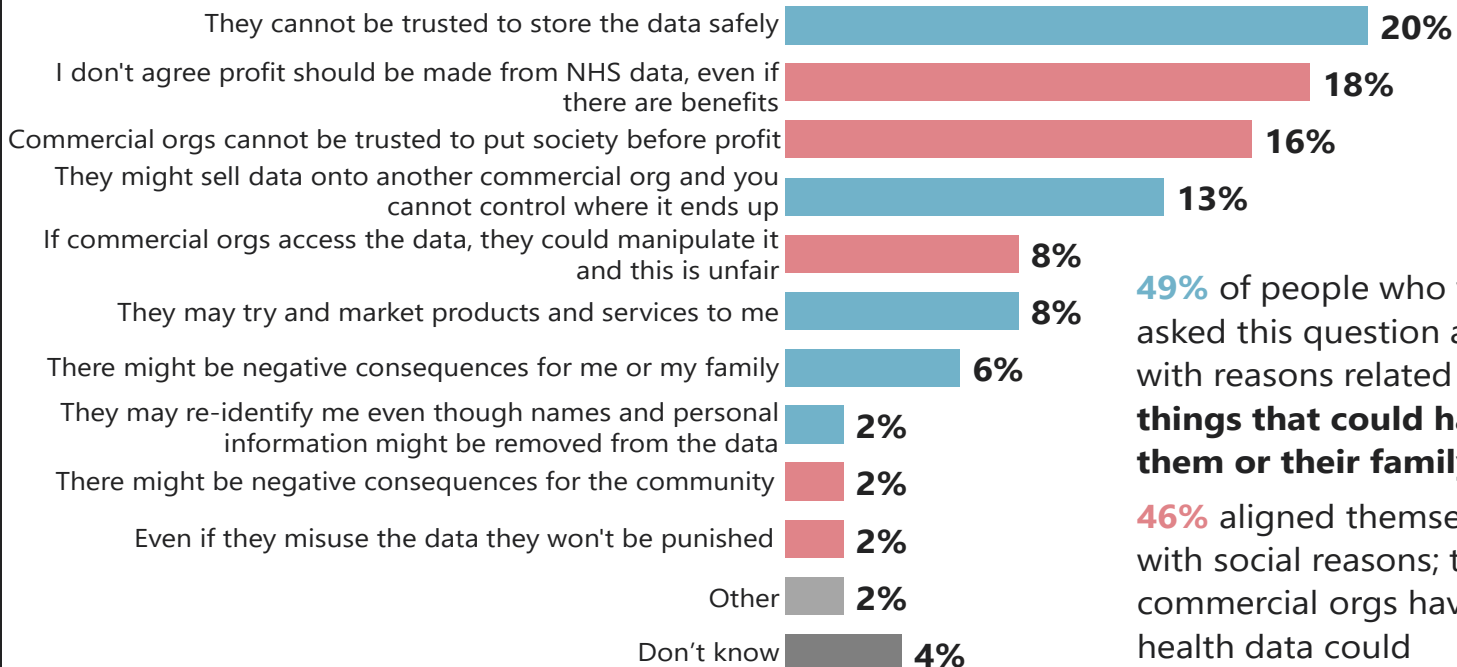


Base: 2,017 GB adults, aged 16+

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?*



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)

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



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

Report prepared for the Wellcome Trust