

Public attitudes to commercial access to health data

An Ipsos MORI study commissioned by the Wellcome Trust

Workshop on Patients' Control over Patient Records
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Dr Natalie Banner
n.banner@wellcome.ac.uk
@natalie_banner

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

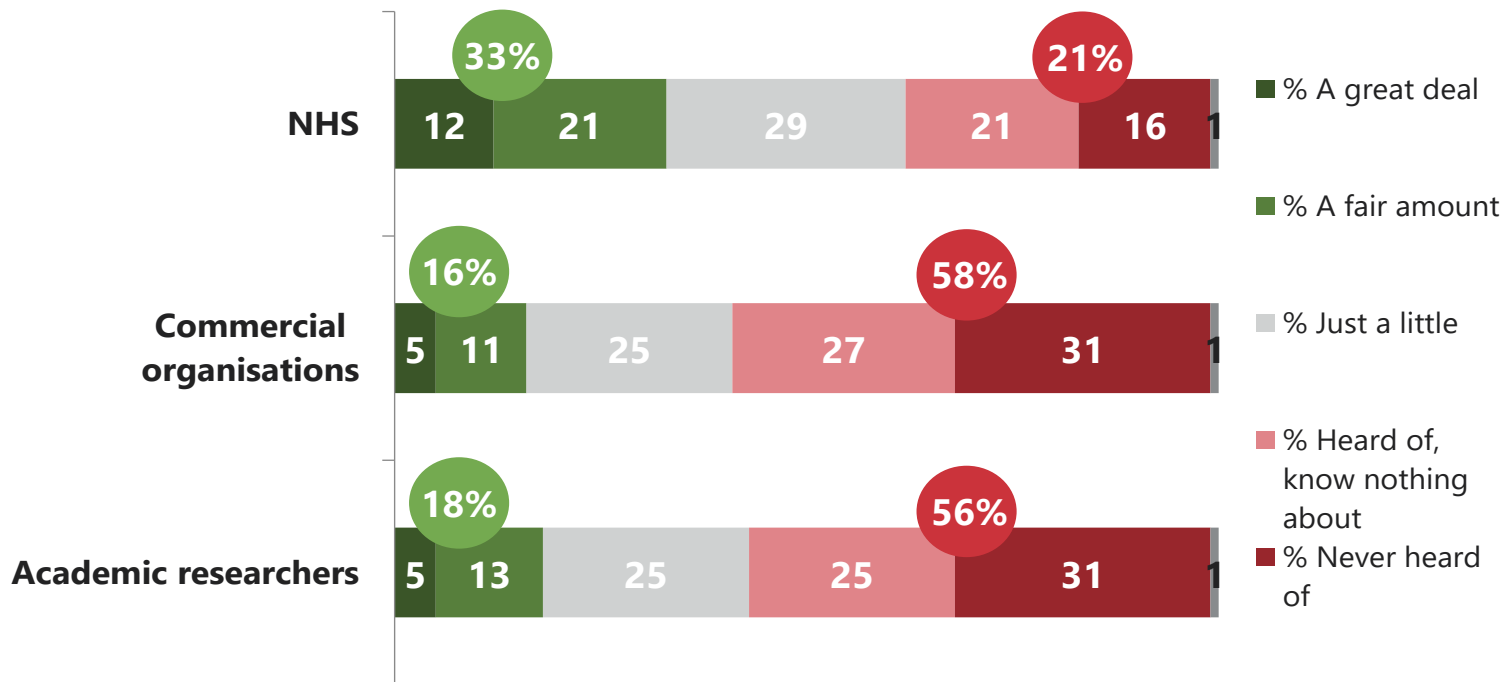
Methods

- What:
- Qualitative workshops – 200+ participants
 - 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?**

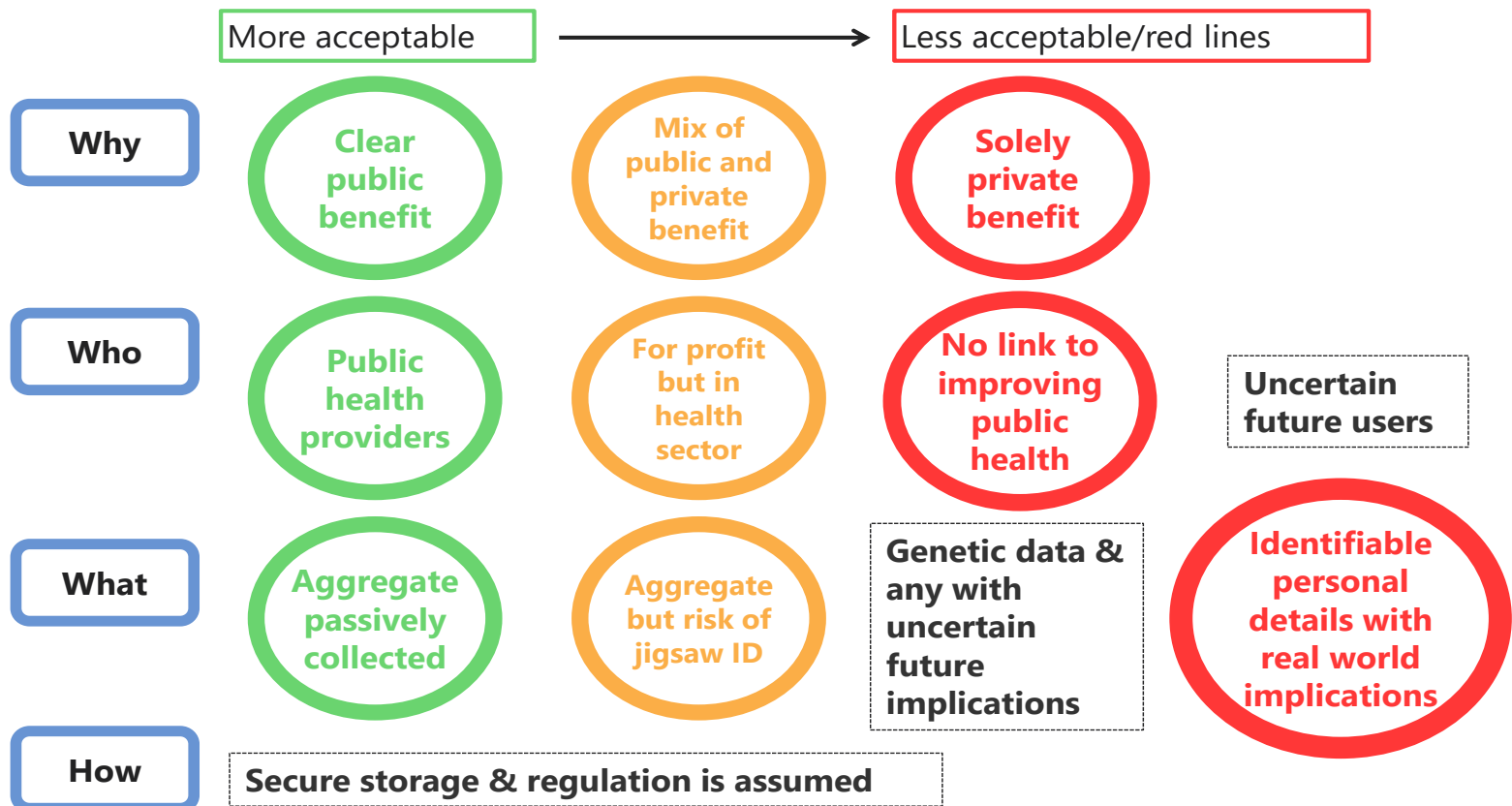


Base: 2,017 GB adults, aged 16+

*See appendices for full question wording

Key findings: Factors and 'key tests'

What drives acceptability: in summary



'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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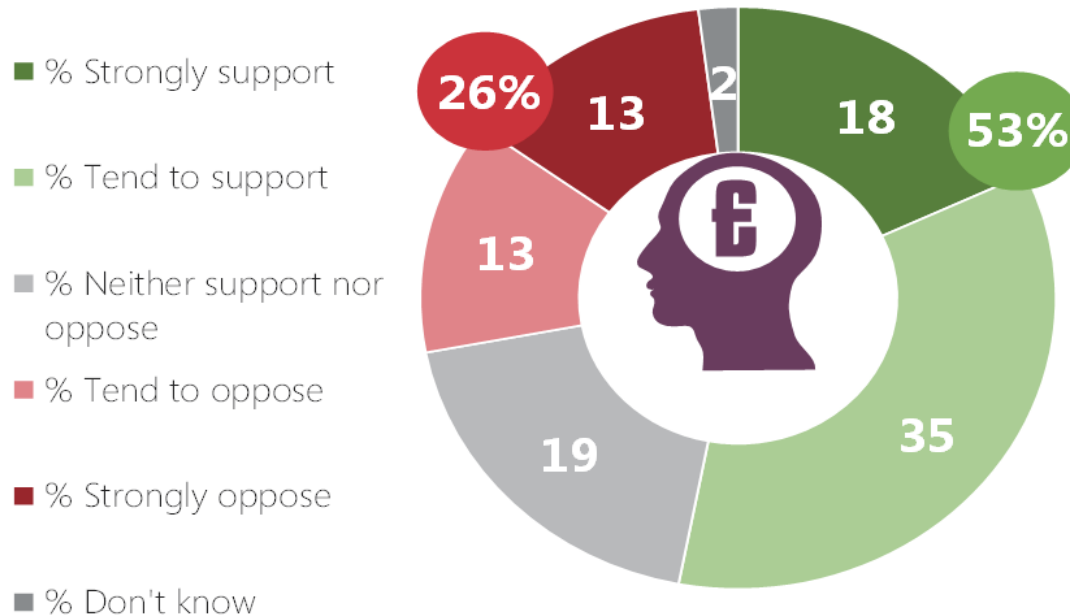
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"We are helping each other"

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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?**



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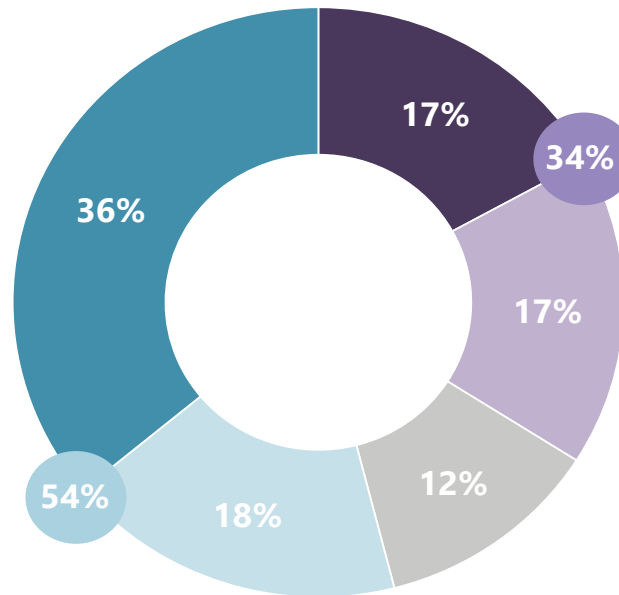
*See appendices for full question wording

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

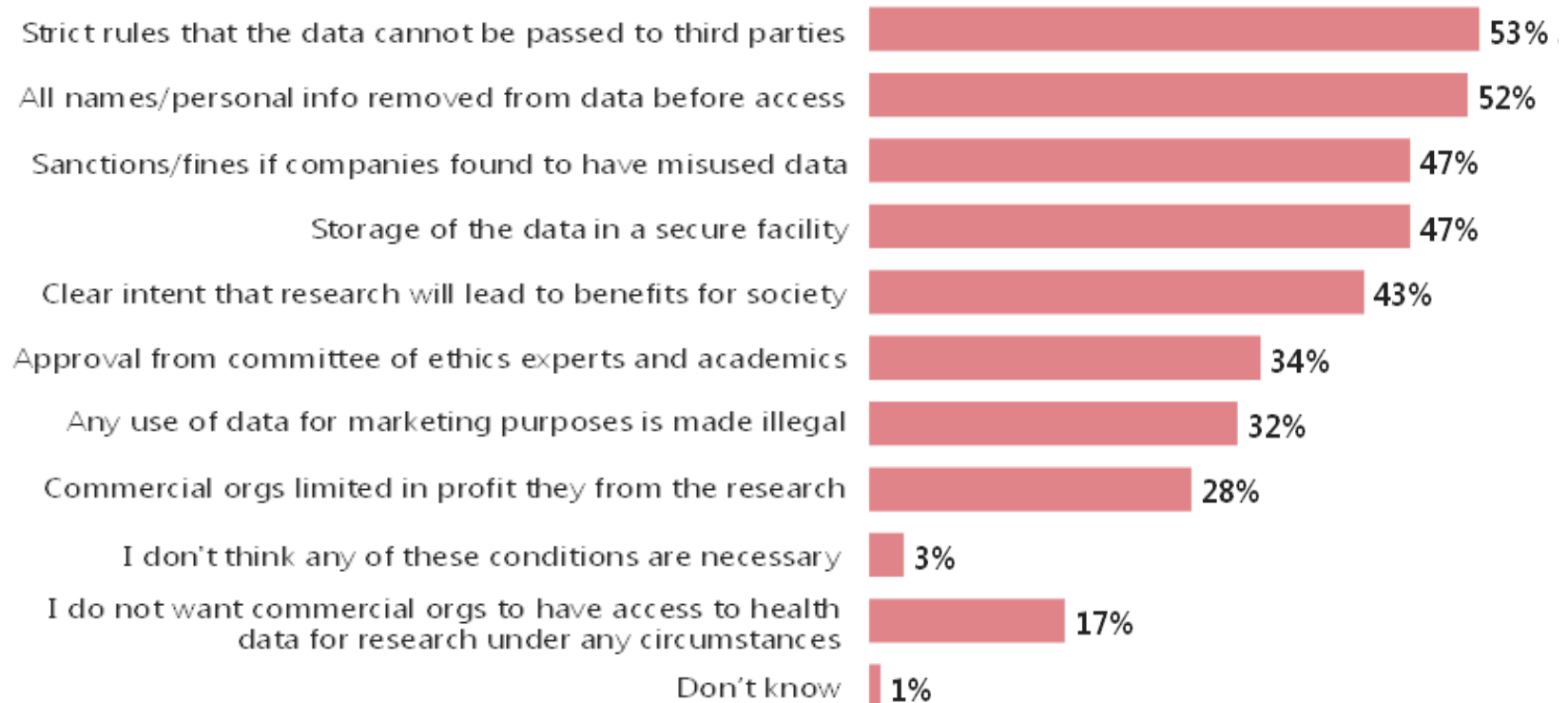
- Agree much more with B than with A
- Agree a little more with B than with A
- Agree equally with both / don't agree with either
- Agree a little more with A than with B
- Agree much more with A than with B

Base: 1,043 GB adults, aged 16+

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

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?*

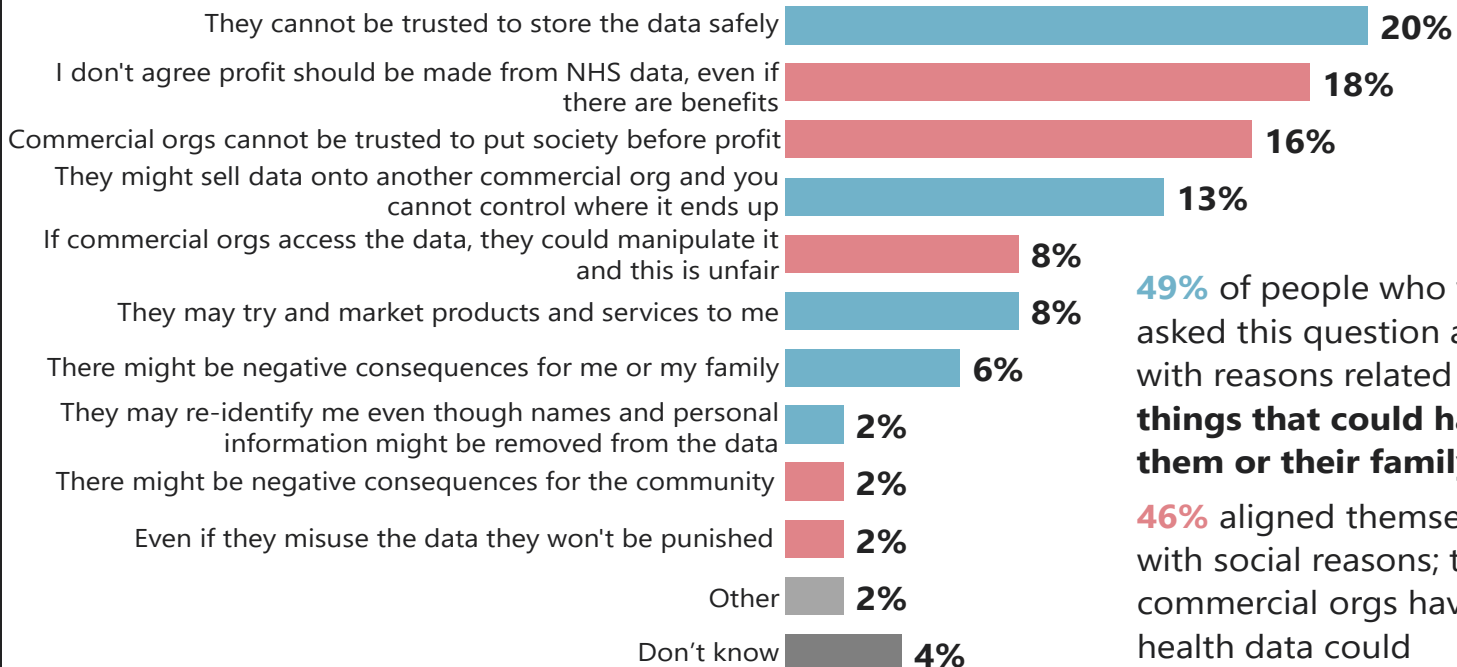


Base: 2,017 GB adults, aged 16+

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

- Low awareness and understanding how health data can be used even within the NHS – let alone beyond
 - Difficulty relating abstract research purposes to personal health data
- Confusion about identifiable/ de-identified/ anonymised/ 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 about how data can be used in practice, including:
 - Clear purpose, with public benefit
 - Description of what kinds of data, including honesty about risks
 - Robust ‘red lines’ – including for anonymised data
 - Safeguards and protections
 - Opt-out for those objecting

Follow up

Panel discussion:

Tuesday 19 April

Wellcome Trust, Euston Road

London

09:30-12:30

Contact me for more information

n.banner@wellcome.ac.uk

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