Public attitudes to commercial access to health data

An Ipsos MORI study commissioned by the Wellcome Trust

Workshop on Patients’ Control over Patient Records
10 March 2016

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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+ 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?*

<table>
<thead>
<tr>
<th>Organisation</th>
<th>% A great deal</th>
<th>% A fair amount</th>
<th>% Just a little</th>
<th>% Heard of, know nothing about</th>
<th>% Never heard of</th>
</tr>
</thead>
<tbody>
<tr>
<td>NHS</td>
<td>12</td>
<td>21</td>
<td>29</td>
<td>21</td>
<td>16</td>
</tr>
<tr>
<td>Commercial organisations</td>
<td>5</td>
<td>11</td>
<td>25</td>
<td>27</td>
<td>31</td>
</tr>
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<td>Academic researchers</td>
<td>5</td>
<td>13</td>
<td>25</td>
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<td>31</td>
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</table>

Base: 2,017 GB adults, aged 16+

*See appendices for full question wording

Source: Ipsos MORI/Wellcome Trust
Key findings: Factors and ‘key tests’

What drives acceptability: in summary

- **Why**
  - Clear public benefit
  - Mix of public and private benefit
  - Solely private benefit

- **Who**
  - Public health providers
  - For profit but in health sector
  - No link to improving public health
  - Uncertain future users

- **What**
  - Aggregate passively collected
  - Aggregate but risk of jigsaw ID
  - Genetic data & any with uncertain future implications
  - Identifiable personal details with real world implications

- **How**
  - Secure storage & regulation is assumed

Commercial access to health data

Ipsos MORI Social Research Institute
‘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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Commercial access to health data
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: 26%
- % Tend to support: 13%
- % Neither support nor oppose: 18%
- % Tend to oppose: 13%
- % Strongly oppose: 2%
- % Don’t know: 53%

Base: 2,017 GB adults, aged 16+

*See appendices for full question wording

Source: Ipsos MORI/Wellcome Trust
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

36% Agree much more with A than with B
17% Agree a little more with B than with A
17% Agree equally with both / don’t agree with either
12% Agree a little more with A than with B
18% Agree much more with B than with A

Source: Ipsos MORI/Wellcome Trust

Base: 1,043 GB adults, aged 16+

*See appendices for full question wording*
## 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?*

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<td>Strict rules that the data cannot be passed to third parties</td>
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<tr>
<td>All names/personal info removed from data before access</td>
<td>52%</td>
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<td>Sanctions/fines if companies found to have misused data</td>
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<tr>
<td>Storage of the data in a secure facility</td>
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<tr>
<td>Clear intent that research will lead to benefits for society</td>
<td>43%</td>
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<tr>
<td>Approval from committee of ethics experts and academics</td>
<td>34%</td>
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<tr>
<td>Any use of data for marketing purposes is made illegal</td>
<td>32%</td>
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<td>Commercial orgs limited in profit they from the research</td>
<td>28%</td>
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<td>I don't think any of these conditions are necessary</td>
<td>3%</td>
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<tr>
<td>I do not want commercial orgs to have access to health data for research under any circumstances</td>
<td>17%</td>
</tr>
<tr>
<td>Don’t know</td>
<td>1%</td>
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Source: Ipsos MORI/Wellcome Trust

Base: 2,017 GB adults, aged 16+
What safeguards and conditions?

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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?*

- They cannot be trusted to store the data safely: 20%
- I don't agree profit should be made from NHS data, even if there are benefits: 18%
- Commercial orgs cannot be trusted to put society before profit: 16%
- They might sell data onto another commercial org and you cannot control where it ends up: 13%
- If commercial orgs access the data, they could manipulate it and this is unfair: 8%
- They may try and market products and services to me: 8%
- There might be negative consequences for me or my family: 6%
- They may re-identify me even though names and personal information might be removed from the data: 2%
- There might be negative consequences for the community: 2%
- Even if they misuse the data they won't be punished: 2%
- Other: 2%
- Don’t know: 4%

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)

*See appendices for full question wording*

Source: Ipsos MORI/Wellcome Trust
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
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www.wellcome.ac.uk/publicattitudes