Commercial access to health data

Key findings
April 2016
Recap of methodology

16 qualitative workshops across GB, 246 individuals

- 8 x general public
- 3 x GPs and hospital doctors
- 4 x long-term health conditions
- 1 x cohort members

Quantitative survey of 2,017 GB adults

Quantitative research run as follow-up to qualitative work
Face-to-face interviews
Qualitative context
Lots of initial uncertainty and wariness

Lack of understanding around current data-use and sharing

Most haven’t thought about private sector/academic/charities’ involvement in NHS

Individual-level data thought of as ‘my data’. Aggregate data as ‘statistics’ (instinctively more benign)

Little knowledge of safeguards and how datasets are handled

Most assume rules are in place
Two traditional mindsets for data sharing

1. Commercial transactions: ‘My data has financial value’

- **Actively given**
  - Buying
    - Wary mindset
      - Data is given as part of a deal: consumer gets something in return
  - Doing
    - Expectation it will be used and shared for financial gain by the collector

- **Passively taken**
Two traditional mindsets for data sharing

2. Social contract mindset: ‘We’re all helping each other’

Actively given

Service using

Open, vulnerable mindset

Data is given in confidence in exchange for a service, assumption it will be used for that purpose only

Being

Passively taken

Assumption that only high-level data is collected and for health purposes
Commercial access to health data constitutes ‘context collapse’

Am I actively giving it?

Buying

Service using

Doing

Being

Concern for vulnerable groups, risk of exploitation

Should I be wary?

Tendency to revert to assumptions and prejudices e.g. ‘private companies cannot be trusted’

Should I be a helpful citizen?

Is it being passively taken?
What drives acceptability: four key tests

1. WHY
   - Clear public benefit
   - Mix of public and private benefit
   - Solely private benefit

2. WHO
   - Public health providers
   - For profit but in health sector
   - No link to improving public health

3. WHAT
   - Aggregate data, passively collected
   - Aggregate but risk of jigsaw ID
   - Identifiable personal details with real world implications

4. HOW
   - Secure storage & regulation is assumed

More acceptable

Less acceptable/red lines

Uncertain future users – e.g. ‘sharing on’ with third party
Genetic data; uncertain future uses
The public can see opportunities

1. WHY

Clear public benefit

Primary driver: without this, majority say data shouldn’t be shared

2. WHO

Public health providers

NHS, Charities, Academic researchers and partnerships involving them

3. WHAT

Aggregate data

Aggregate data, passively collected (i.e. no personal details ever attached) less risky

4. HOW

Secure storage & regulation is assumed

Transparency, independent scrutiny, sanctions and fines for misuse reassure
But they also have concerns

1. WHY
   Mix of public and private benefit
   For some acceptable: WHO becomes more important – is the organisation trusted?

2. WHO
   For profit but in health sector
   e.g. analytics company working with NHS. Some fears about ‘big pharma’ & retail – makes regulation more important

3. WHAT
   Aggregate but risk of jigsaw ID
   If originally taken from identifiable data - potential risk to the individual

4. HOW
   Secure storage & regulation is assumed
   Doubts generally linked to WHO is handling the data and whether they are trusted; regulation helps reassure
…and some red lines

1. WHY

**Solely private benefit**

If no clear public benefit, sharing is unacceptable to most

2. WHO

**No link to improving public health**

Insurance companies, marketing companies; never benefit public, motivated by profit

Uncertain future users – e.g. ‘sharing on’ with third party

3. WHAT

**Identifiable personal details with real world implications**

Concerns about impact on employment prospects, insurance premiums etc.

Genetic data; uncertain future uses

4. HOW

**Secure storage & regulation is assumed**

No regulation/scrutiny to ensure data is used for intended purpose and not passed on
Seven mindsets influence views

**Abstract**
Concern for human rights, social goods, and impact on everyone

- **Open to commercial interest**
  Accepting of private sector involvement in general

- **Pragmatic**
  Concerned with impact of privacy at personal level

- **Wary of commercial interest**
  Sceptical of private sector involvement

- **Sceptical of commercial motives and coexistence of public and private benefit. Lack faith in systems. Recognise benefits but commercial involvement is imperfect solution. Pro opt out.**

- **Commercial access necessary for social development; public benefits worth risk to personal privacy. Duty to share health data?**

- **Less concerned with public benefit, risks to society; neutral stance towards commercial orgs (including marketing and insurance). Not worried/haven’t really thought about security risks.**

- **Fear large-scale negative impact on all society: do not trust commercial orgs. ‘Big Brother’ society where commercial use of data worsens social inequality.**
Quantitative context
Awareness is an initial stumbling block to 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>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>NHS</td>
<td>33%</td>
<td>21%</td>
<td>29%</td>
<td>21%</td>
<td>16%</td>
<td>1%</td>
</tr>
<tr>
<td>Commercial organisations</td>
<td>16%</td>
<td>58%</td>
<td>27%</td>
<td>31%</td>
<td>1%</td>
<td>1%</td>
</tr>
<tr>
<td>Academics researchers</td>
<td>18%</td>
<td>56%</td>
<td>25%</td>
<td>31%</td>
<td>1%</td>
<td>1%</td>
</tr>
</tbody>
</table>

*See report for full question wording

Source: Ipsos MORI/Wellcome Trust
Base: 2,017 GB adults, aged 16+
But 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: 35%
Strongly oppose: 2%
Don't know: 19%

Knowledge factors influence support

Educational attainment:
- Degree (59%)
- A-level (57%)
- GCSE (52%)
- No qualifications (43%)

Social grade:
- AB (62%)
- C1 (53%)
- C2 (53%)
- DE (46%)

Internet access:
- Daily users (56%)
- Less frequent (52%)
- No access (39%)

Data usage awareness:
- Aware (56%-59%)
- Not aware (45%-47%)

Source: Ipsos MORI/Wellcome Trust

Base: 2,017 GB adults, aged 16+

*See report for full question wording
Drug companies aren’t deal-breakers...

[INTRODUCTION about public health regulator OR drug company running tests on a new drug] ...On a scale of 1-5, how acceptable, if at all, do you find this use of data?*

*See report for full question wording

Base: split sample, bases on chart

Source: Ipsos MORI/Wellcome Trust
...but insurance and marketing purposes might be...

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?*

<table>
<thead>
<tr>
<th>Insurance</th>
<th>Strongly agree</th>
<th>Tend to agree</th>
<th>Neither agree nor disagree</th>
<th>Tend to disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1,025)</td>
<td>26%</td>
<td>44%</td>
<td>21%</td>
<td>27%</td>
<td>5%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Marketing</th>
<th>Strongly agree</th>
<th>Tend to agree</th>
<th>Neither agree nor disagree</th>
<th>Tend to disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>(992)</td>
<td>37%</td>
<td>36%</td>
<td>26%</td>
<td>18%</td>
<td>10%</td>
</tr>
</tbody>
</table>

*See report for full question wording

Base: split sample, bases on chart

Source: Ipsos MORI/Wellcome Trust
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

*See report for full question wording

Source: Ipsos MORI/Wellcome Trust
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?*

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

49% of people 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.

*See report for full question wording

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

Source: Ipsos MORI/Wellcome Trust
Implications for communications and public engagement
We need a shared understanding of value

<table>
<thead>
<tr>
<th>Aggregate</th>
<th>Individual</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recognised as a national resource, but with conditions</td>
<td>Harder to grasp, questions of ownership and perverse incentives</td>
</tr>
<tr>
<td>Long-term value to society, not just private interest/financial gain</td>
<td>Health data as currency – potential benefits for those without money</td>
</tr>
<tr>
<td>Support for public goods e.g. NHS</td>
<td>But worries over unintended consequences – What if the wealthier opt out leading to bad datasets? Will vulnerable groups be exploited for their data?</td>
</tr>
<tr>
<td>Fair process – data shared when vulnerable ‘service use mind set’ so should not be exploited</td>
<td></td>
</tr>
</tbody>
</table>

Communications need to take into account how the public conceive of different types of data
And a new social contract

Public question if commercial access is consistent with ‘promotion of health’

Care Act 2014 – data can be shared for provision of care or promotion of health

Scepticism towards commercial interest leading to socially beneficial outcomes

Even the more pragmatic lack awareness of the role commercial interests play in health (e.g. provide essential services/drug trials)

New innovations mean new challenges

Rise of wearables, passive data collection without full consent (e.g. small print Ts and Cs) links to questions of ownership and ethics

Individuals unaware of potential autonomy to shape own care

Communications need to:

• Tackle scepticism and low awareness of commercial access
• Signal potential benefits and risks of data and tech innovations
Currently, “no job description for being a citizen”

- Public don’t currently know enough to be guardians of their own health data
  - They have low awareness of the “quantified self”, many expect practitioners to make decisions for them
  - And low understanding of consent models, implications of ‘opt-out’ on accuracy

- There is space for a further conversation about future healthcare delivery: role of state, commerce, big data and individual citizens

- Shared learnings will be key: Academy of Medical Sciences, ‘Exploring a new social contract for medical innovation’, Royal Society’s work on Machine Learning, Cabinet Office on Data Science Ethics
What next?

Think about *how* commercial access is managed not just how it is communicated – fair processes and appropriate safeguards will play an important part in driving or hindering trust.

Safeguards help but there is much leg work to do before this – need to establish public benefit and tackle scepticism.

Consider terminology and public understanding of word ‘commercial’ – being specific will help remove public biases.

Identify public information needs (cf. other research). E.g. technical terms about data/data science/data collection, safeguards, consent options and role of commerce in health.
Rather put the brakes on now...

Public clearly concerned about commercial access and broader implications of a data-rich world.

If health data is a national resource then how it is handled now will impact future opportunities.

Done well, could drive trust in government and create optimism around future health data-sharing and role of commerce in health.

But done poorly, could lead to ‘confidence collapse’ and jeopardise future public support.
Q & A

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