

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

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

?!?

Future communication challenges



Ipsos MORI
Social Research Institute

Two traditional mindsets for data sharing

1. Commercial transactions: *'My data has financial value'*

Buying

Actively given



Doing



Passively taken

Wary mindset

Data is given as part of a **deal: consumer gets something in return**

Expectation it will be used and shared for financial gain by the collector

Two traditional mindsets for data sharing

2. Social contract mindset: *'We're all helping each other'*

Actively given

Open, vulnerable mindset

Service using



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

Being



Assumption that only **high-level data** is collected and for health purposes

Passively taken

Commercial access to health data constitutes 'context collapse'

Am I actively giving it?

Concern for vulnerable groups, risk of exploitation

Buying

Service using



Should I be wary?

Should I be a helpful citizen?

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

Doing

Being

Is it being passively taken?

What drives acceptability: four key tests

More acceptable



Less acceptable/red lines

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

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

3. WHAT

Aggregate data, passively collected

Aggregate but risk of jigsaw ID

Identifiable personal details with real world implications

Genetic data; uncertain future uses

4. HOW

Secure storage & regulation is assumed

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

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



Open to commercial interest
Accepting of private sector involvement in general

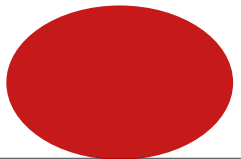


Abstract
Concern for human rights, social goods, and impact on everyone



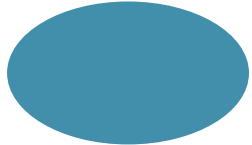
Less concerned with public benefit, risks to society; neutral stance towards commercial orgs (including marketing and insurance). Not worried/haven't really thought about security risks.

Fear large-scale negative impact on all society: do not trust commercial orgs. 'Big Brother' society where commercial use of data worsens social inequality.

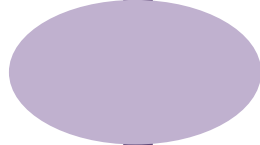


Wary of commercial interest
Sceptical of private sector involvement

Pragmatic
Concerned with impact of privacy at personal level

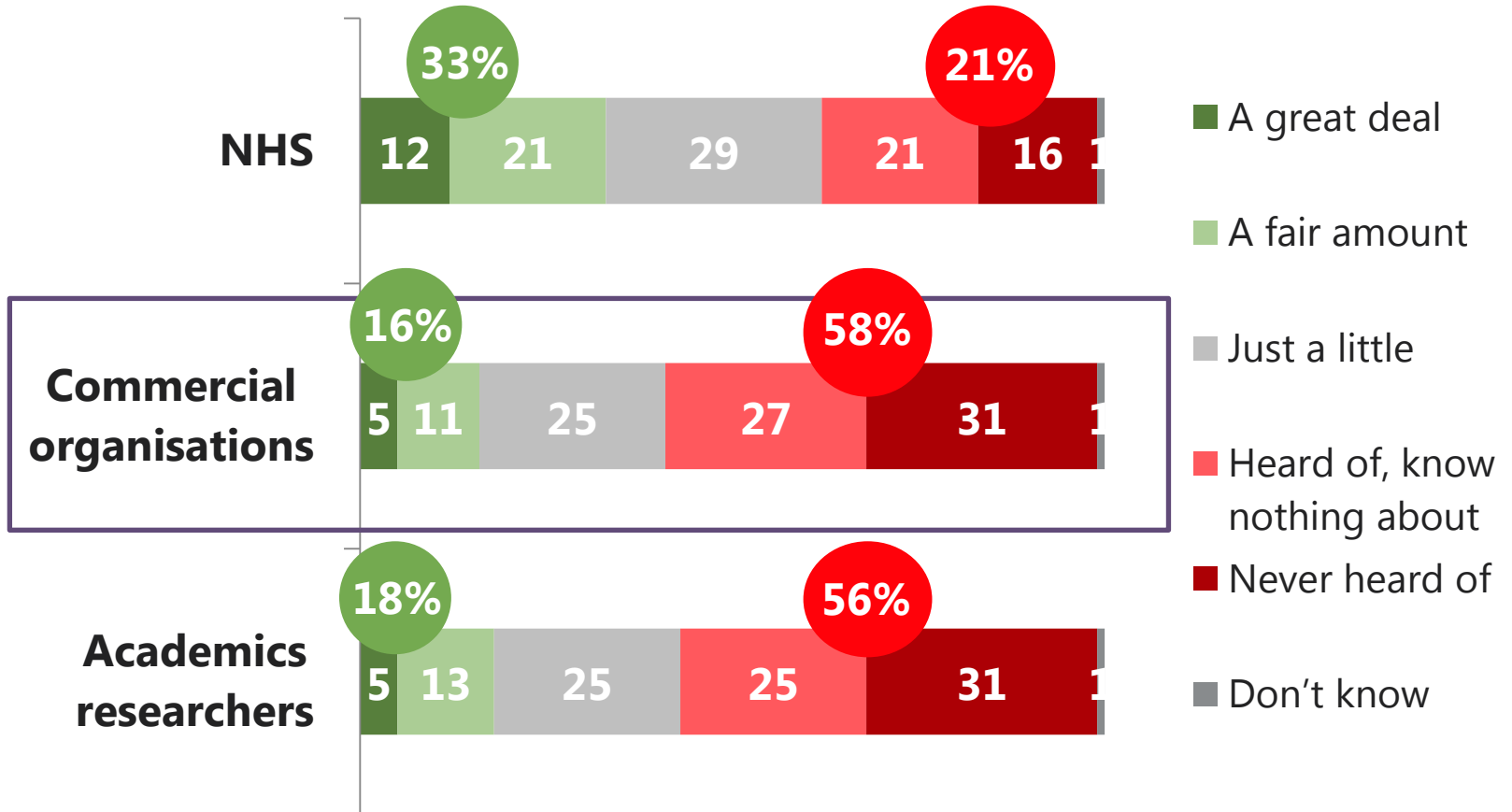


Sceptical of commercial motives and coexistence of public and private benefit. Lack faith in systems. Recognise benefits but commercial involvement is imperfect solution. Pro opt out.



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?*



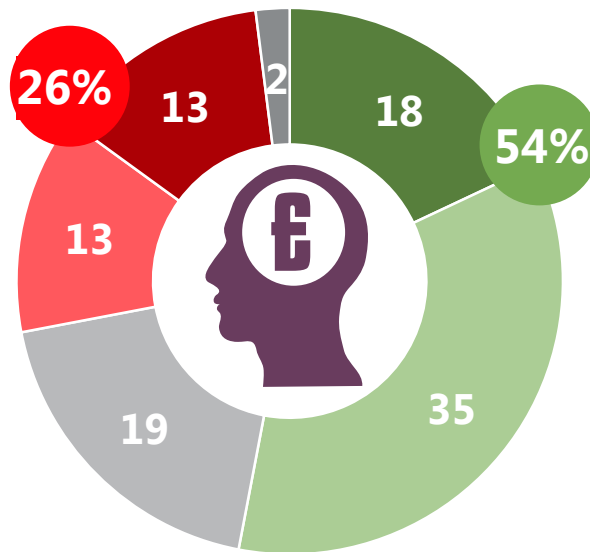
Base: 2,017 GB adults, aged 16+

*See report for full question wording

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



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%)

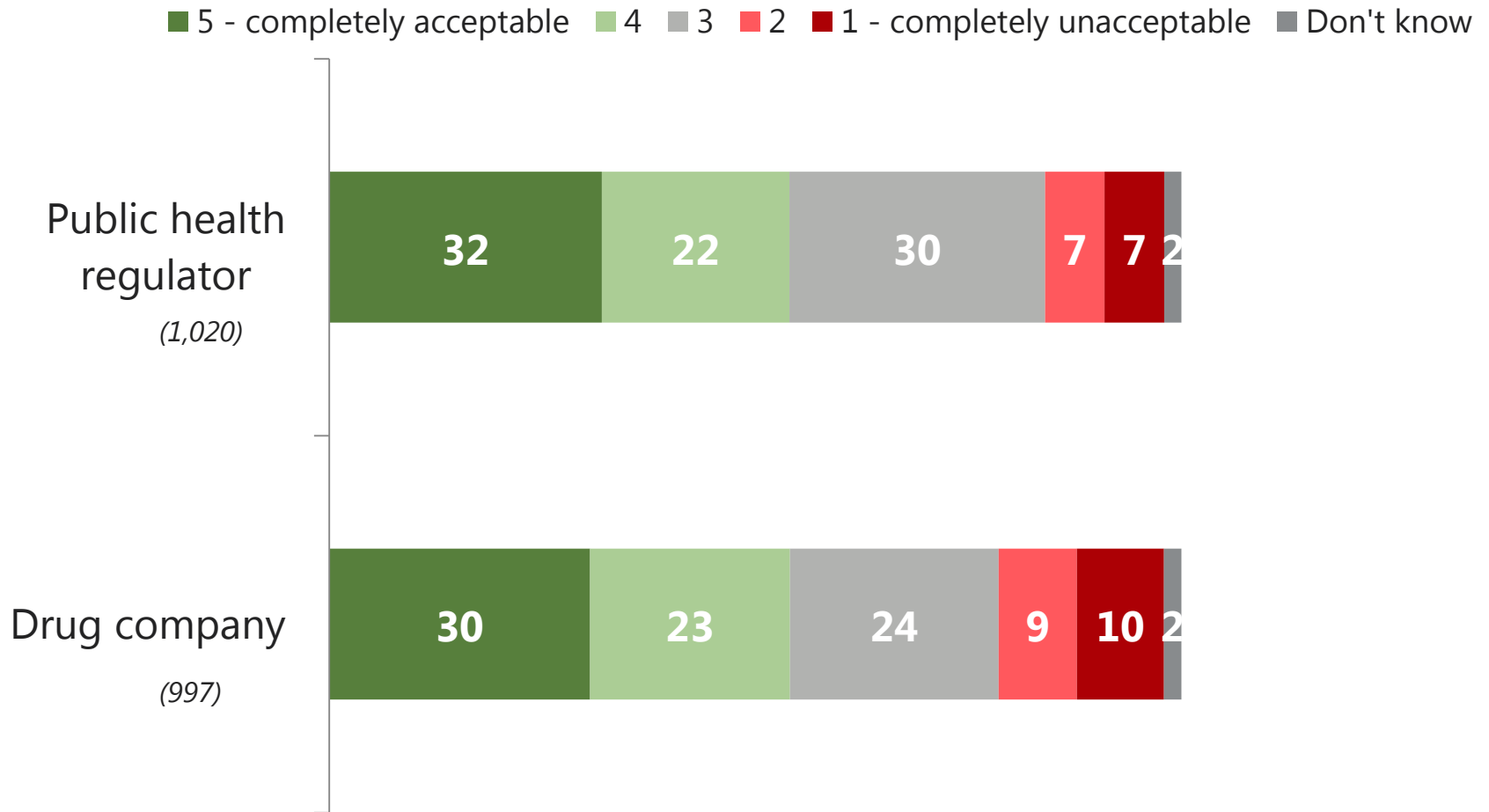
Data usage awareness:
Aware (56%-59%)
Not aware (45%-47%)

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?**

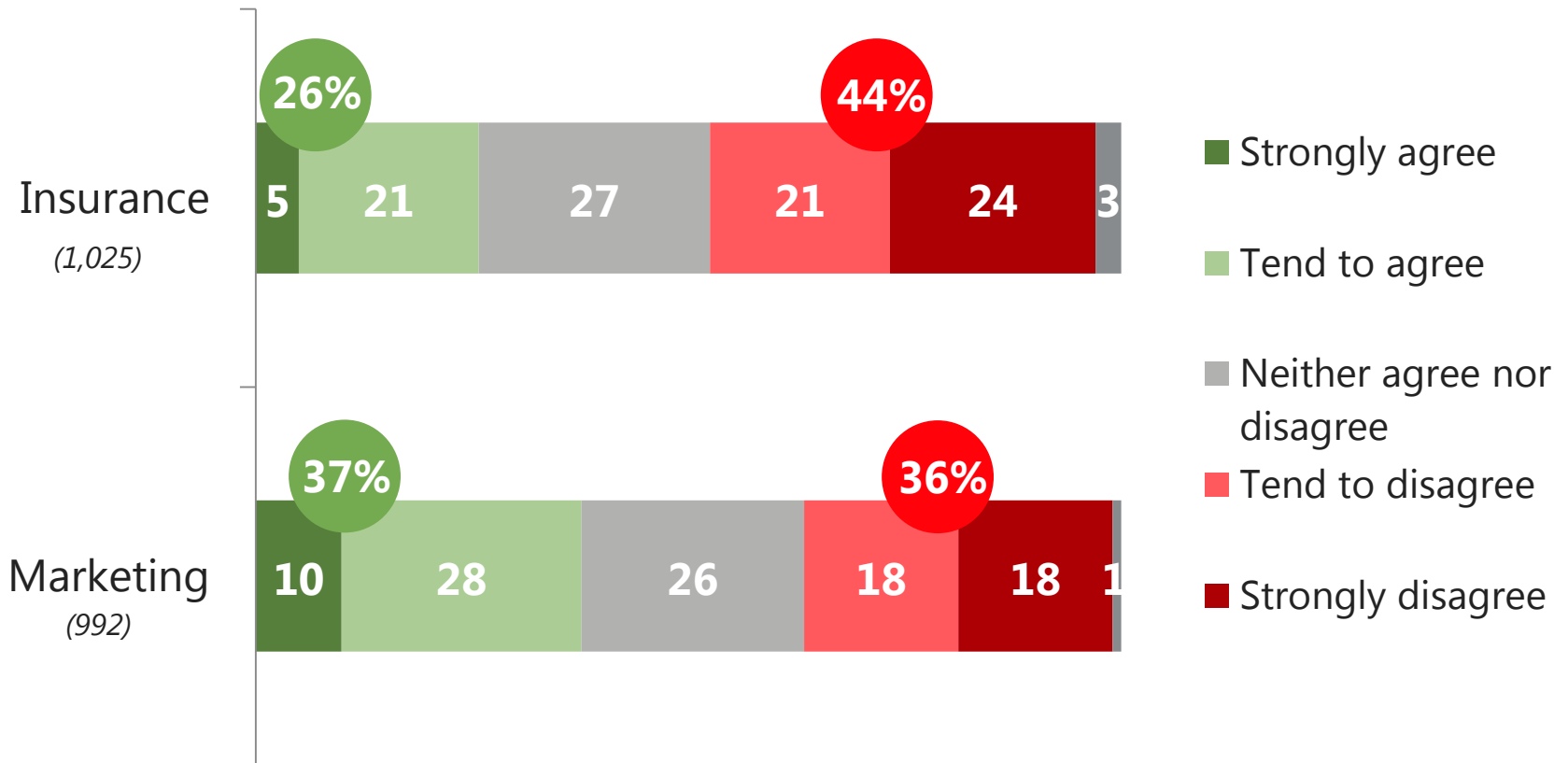


Base: split sample, bases on chart

...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?**



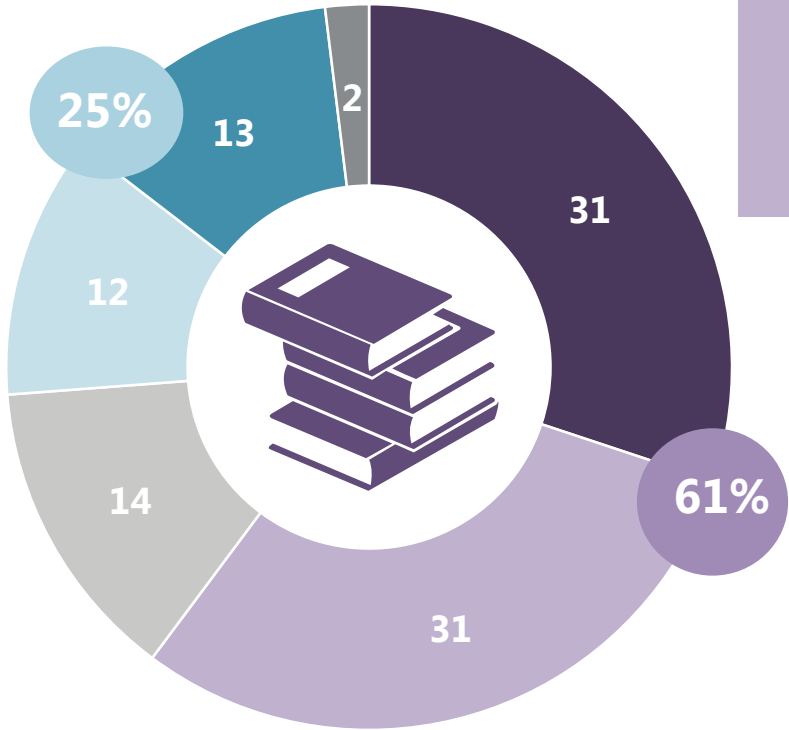
Base: split sample, bases on chart

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

Base: 974 GB adults, aged 16+

*See report for full question wording

Differences within differences – not all sceptics the same

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 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)

Source: Ipsos MORI/Wellcome Trust

We need a shared understanding of value

Aggregate

Recognised as a national resource, but with conditions

Long-term value to society, not just private interest/financial gain

Support for public goods e.g. NHS

Fair process – data shared when vulnerable 'service use mind set' so should not be exploited

Individual

Harder to grasp, questions of ownership and perverse incentives

Health data as currency – potential benefits for those without money

But worries over unintended consequences – What if the wealthier opt out leading to bad datasets? Will vulnerable groups be exploited for their data?

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

