

Commercial access to health data quantitative strand – Final 24th November

MQ01. Health data collected from patients in hospitals and GP practices can also be used for research into diseases and treatments, and for planning healthcare services. When used in this way, health data has personal information removed, such as patients' name and address. How much, if anything, would you say you know about how the following organisations use health data for these purposes?

1. The NHS
2. Commercial organisations, such as drug companies and medical equipment manufacturers
3. Academic researchers

A great deal

A fair amount

Just a little

Heard of, know nothing about

Never heard of

Don't know

MQ02. As you may know, the NHS and other health services collect data about individuals, for example GP records and hospital visits. This data is used for the direct care of patients, but it can also be useful for hospitals, commercial organisations, researchers and others. Allowing access to data can bring benefits, such as enabling research to find more effective medical treatments for example. However, some people worry that allowing others access to health data will be a risk to their privacy and security, for example if it is possible to re-identify individuals. Overall, which of the following statements is closest to your view?

SPLIT SAMPLE A – OPTING OUT

a) "We should share all the data we can because it benefits health services and me – as long as I can opt out if I choose"

b) "We should not share data, even if I have the right to opt out, as the risks to people's privacy and security outweigh the benefits"

SPLIT SAMPLE B – ANONYMITY

a) "We should share all the data we can because it benefits health services and me – as long as the data is anonymised and I can't be identified as an individual"

b) "We should not share anonymised data as the risks to people's privacy and security outweigh the benefits"

SPLIT SAMPLE C – CONTROLLED ACCESS

a) "We should share all the data we can because it benefits health services and me – as long as there are strict controls on who can access the data and how it is used"

b) "We should not share data even with strict controls as the risks to people's privacy and security outweigh the benefits"

SPLIT SAMPLE D – GOVERNANCE/ENFORCEMENT

a) "We should share all the data we can because it benefits health services and me – as long as there are heavy fines and possible prison sentences for anyone caught misusing the data"

b) “We should not share data even with heavy fines and possible prison sentences for anyone caught misusing the data as the risks to people’s privacy and security outweigh the benefits”

SPLIT SAMPLE E – CONTROL QUESTION

a) “We should share all the data we can because it benefits health services and me.”

b) “We should not share data as the risks to people’s privacy and security outweigh the benefits.”

Agree much more with a than with b
Agree a little more with a than with b
Agree equally with both / don’t agree with either
Agree a little more with b than with a
Agree much more with b than with a
Don’t know

MQ03. To what extent, if at all, would you support your health data being accessed by commercial organisations if they are undertaking health research? By health data, we mean information that is routinely gathered about individuals by the NHS when they receive care. The information given to the organisation would NOT include your name and address or any contact details.

Strongly support
Tend to support
Neither support nor oppose
Tend to oppose
Strongly oppose
Don’t know

MQ04. To what extent do you agree or disagree with the following statements?

- 1. “My health data currently has financial value to others in that it can be used to save or make them money.”**
- 2. “My health data currently has a value to society in that it can be used to help improve things for people other than me.”**

Strongly agree
Tend to agree
Neither agree nor disagree
Tend to disagree
Strongly disagree
Don’t know

PRE-SCREEN: For the next question, imagine you have been asked to give guidance on whether access to people’s health data should be permitted or not in these situations. You can give a score from 1-5 where 1 is completely unacceptable and 5 is completely acceptable.

MQ05A. TESTING ‘PHARMA’

A drug company wants to run further tests on an approved drug to see whether the drug has had any unwanted side effects in the long term. The company requests information from a central government collection of medical records, which have had names, addresses and other personal information removed. The company covers the costs of doing this analysis.

MQ05B.

A public health regulator wants to run further tests on an approved drug to see whether the drug has had any unwanted side effects in the long term. The regulator requests information from a central government collection of medical records, which have had names, addresses and other personal information removed. The regulator covers the costs of doing this analysis.

On a scale of 1-5, how acceptable, if at all, do you find this use of data?

1. Completely unacceptable
 - 2.
 - 3.
 - 4.
 5. Completely acceptable
- Don't know

MQ06A. SPLIT SAMPLE 1: 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? This would be done using data with personal information removed, such as name and address. This would mean health insurance prices can be tailored to reflect the risk of ill-health for people living in different areas.

MQ06B. SPLIT SAMPLE 2: To what extent, if at all, would you support companies using health data collected in the NHS for marketing purposes, for example to target health products at different groups of people? This would be done using data with personal information removed, such as name and address. This could mean, for example, products such as low-fat margarine being promoted in areas where there is a higher risk of heart disease.

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

MQ07. SPLIT SAMPLE A. Research using health data can have many benefits, such as developing treatments for diseases or making health services more efficient. However, sometimes this research needs to be done by a commercial organisation who may make a profit out of the research. The information given to the organisation would not include names, addresses or any contact details.

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

MQ07. SPLIT SAMPLE B. Some commercial data analysis companies are interested in looking at a large number of hospital records, which do not contain names and addresses. Using many records allows analysts to see patterns that enable them to provide analysis to the NHS on how to improve services. However, due to the large numbers, it is not possible for the NHS to ask permission from patients each time a request is made to access the health data.

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

MQ08a. 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? If you do NOT want commercial organisations to have access to health data please say so.

Approval from an independent oversight committee of ethics experts and academic researchers
All names and personal information removed from the data before access
Clear intent that the research will lead to benefits for wider society
Any use of the data for marketing purposes is made illegal
Storage of the data in a secure facility
Commercial organisations to be limited in the amount of profit they can earn from the research
Strict rules that the data cannot be passed on to third parties
Criminal sanctions/ heavy fines if companies are found to have misused data
Other (specify)
I don't think any of these conditions are necessary
I do not want commercial organisations to have access to health data for research under any circumstances (GO TO MQ08B)

MQ08b. 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?

I don't agree any profit should be made from people's NHS health data, even if there are health and society-wide benefits from the commercial organisation's activities as well.

Commercial organisations cannot be trusted to put the interests of society before profitmaking

They may re-identify me even though names and personal information might be removed from the data

They might sell the data onto another commercial organisation and you cannot control where it ends up

They cannot be trusted to store the data safely

They may try and market products and services to me

There might be negative consequences for the community (e.g. lead to the NHS being charged more for certain drugs)

There might be negative consequences for me or my family in the future (e.g. information about my medical history are leaked)

Even if they misuse the data, they won't be punished

If commercial organisations access the data, they could manipulate it for their own benefit and this is unfair

Other (specify)