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Public views on sharing anonymised patient-level data where there is a mixed public and private benefit

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Foreword

The NHS is increasingly being called on to provide patient data for purposes other than direct patient care. We know from previous research that people sometimes find it unacceptable when commercial organisations have access to their health data. However, commercial uses of patient data are varied and some commercial uses may be more acceptable than others.

In 2016, the Wellcome Trust carried out research into attitudes towards the commercial use of patient data. It showed that the factors driving acceptability relate principally to why the data is being used and by whom.¹ The research found that some uses of data tend to be acceptable; where the 'why' is a clear public benefit and the 'who' is a public health provider. It also found that some uses tend to be unacceptable; where the 'why' is a solely private benefit and the 'who' is a body with no link to improving public health. However, the research also found that, in-between these two extremes, there is a space where levels of acceptability are unclear; where the 'why' is a mix of public and private benefit and the 'who' is a for profit organisation in the health sector.

The research we present in this report investigates the acceptability of sharing patient data in this uncertain space; focussing on situations where there is a potential mixed public and private benefit. It identifies factors that influence people's attitudes towards sharing of anonymised patient-level data where disclosure is for both a public purpose (research for example) and a private benefit (commercial gain). Although people may have an instinctive reaction against the prospect of sharing anonymous patient-level data with commercial organisations, this research shows that views are nuanced where people learn about the role that commercial organisations might play in developing and delivering data-driven healthcare.

¹ The Wellcome Trust The One-Way Mirror: Public attitudes to commercial access to health data March 2016.

Executive summary

This research suggests that people readily accept NHS access to anonymous patient-level data for public benefit reasons other than the individual's direct care. However, people do not easily accept non-NHS access to this data. People found it particularly difficult to accept commercial organisations having access to this data.

However, we found that people's views change significantly if they are informed about the role that commercial organisations might play in developing data-driven services and products that might have a positive impact on healthcare. At the start of the deliberative workshops in this project 18% of participants felt that it would be acceptable to share anonymised patient-level data with commercial organisations for reasons other than direct care. After the deliberative workshop this figure had grown to 45%. When asked why there was such a change in views from the beginning to the end of the workshop, participants reported that the view at the beginning of the day indicated their 'gut reaction' and that they changed their mind when exposed to information and discussion about particular ways that commercial organisations might be involved in developing healthcare products and services.

However, participants unanimously felt that two conditions should apply where commercial organisations sought to access to patient data:

- the NHS should receive benefit in recognition of the role that the data played in the product's development.
- the NHS should be involved in the development of the product at all stages.

There were two main ways that people thought the NHS should benefit if the commercial organisations produced something of value. First, any product or service developed with patient data should be made available to the NHS at a preferential rate. Second, the NHS should have unlimited access to any new knowledge or insights which arise from the company's work with the patient data.

In terms of NHS involvement, people felt that this should not be tokenistic but should be end to end involvement from commissioning through development and endorsement. People spoke of a 'partnership'. NHS involvement enabled people to have greater trust in the project's ability to benefit the public and to safeguard the data accessed from the NHS.

Ensuring that these factors are built into the way that patient data is accessed by commercial organisations developing data-driven healthcare products will maximise the potential for people to have trust in and support the use of NHS data.

Project report

The objectives of this research were:

- To identify the factors that influence people's attitudes towards sharing of anonymised patient-level data where disclosure was purportedly for both a public (research or non-research) purpose and a private (commercial) benefit.
- To understand the conditions or characteristics of disclosure related to public confidence: evidence of what in an application for sharing would raise or lower levels of acceptability of any risk associated with such sharing.
- To explore the relationships between and relative importance of the influences identified by the participants.

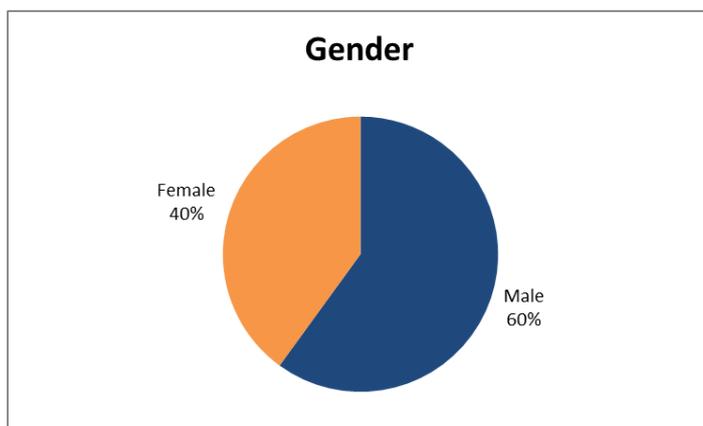
Recruitment

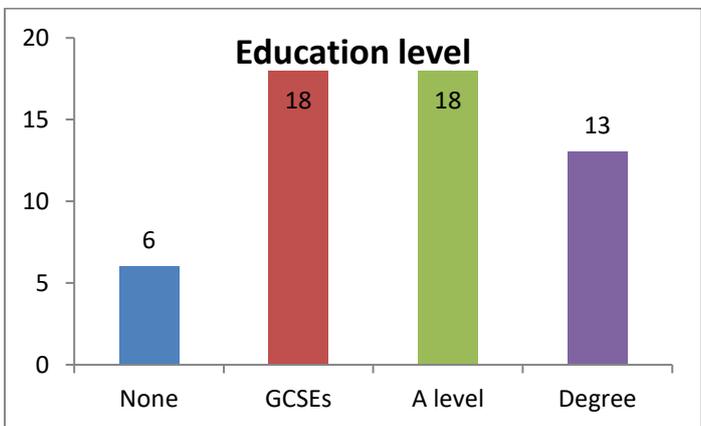
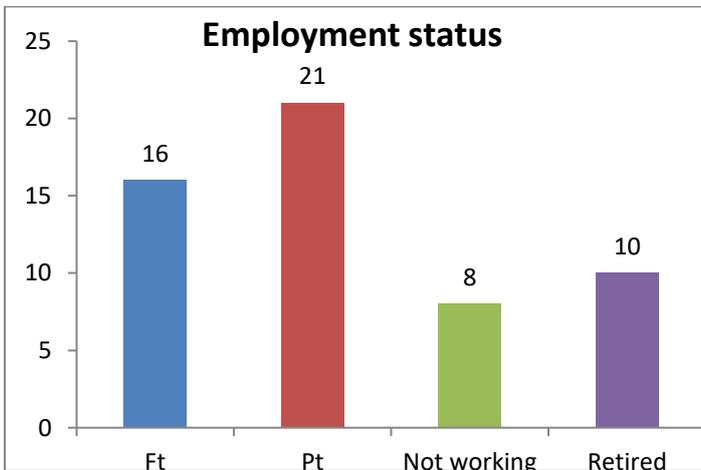
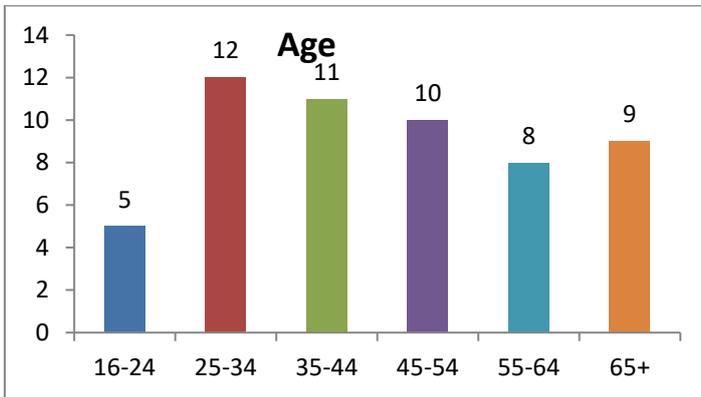
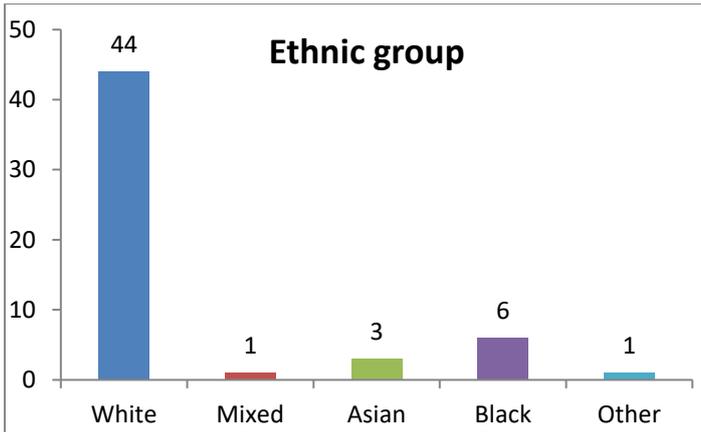
55 people attended the workshops. The publics were recruited by a market research company using a quota to be representative in terms of basic demographic criteria such as age, gender, ethnicity, and social class. Individuals were excluded if they worked in the NHS, health research, or the pharmaceutical industry. Patients were recruited via local NHS contacts and through the People in Research website. The participants in the public workshops were recruited to reflect the demographics of the local (South Yorkshire) population.

Demographics

Whilst the general public groups were recruited to be demographically representative, the patient group was largely self-selected and there is a higher proportion of females in this group. The table 1 below shows the demographic breakdown of all the participants.

Demographic data





Method

Data collection

Three workshops were held in total; two with the public and one with patients. The public workshops were held on 6 and 7 September 2016, with 20 people at each workshop. The third workshop on 9 September was attended by 15 patients. Each lasted six hours.

The workshops adopted the same format. The participants were asked to give baseline views about commercial uses of health data (see Part one). The same survey was also conducted at the end of the workshop to identify any changes in attitude (see Part five).

Four educational presentations covering types of data, safeguards, regulation and the role of commercial organisations were delivered (see Appendix two for details of these presentations). The participants were asked to consider five scenarios where the proposal was that anonymised patient-level data would be disclosed to a commercial organisation for a reason which might lead to both private and public gain. Each scenario was presented individually (see Part two for the scenarios) and the participants then discussed their views in groups. The composition of the small discussion groups was changed following each scenario. The groups consolidated their views in writing. The facilitators then reviewed the notes to focus a discussion involving the whole group.

With participants' consent, these discussions were audio-recorded for transcription purposes. Following the discussion of each scenario, the participants were asked to record their personal view on whether the patient data should be disclosed to three different types of commercial organisation (see Appendix five for all five questionnaires).

Data analysis

Quantitative analysis

Data collected through questionnaires administered at the start and end of each day together with individual voting on each of the five scenarios was inputted into SPSS alongside demographic data. All identifiers were removed. Analysis took the form of basic frequencies and cross-tabulations. Differences noted in this paper were statistically significant at 0.05. Although this is clearly a small sample, percentages have been used to describe the findings to aid understanding.

Qualitative analysis

The recordings of the focus groups were transcribed then inputted to the qualitative data analysis software programme NVivo (version 11) for analysis. The analysis involved identifying, coding and categorising themes in order to establish primary, secondary and lower level frequency. We investigated the priority of those factors in determining people's attitudes and the coding strategy adopted reflects whether people's attitudes were (strongly) positive or (strongly) negative. As coding progressed, we were able to make and describe relationships between the safeguards in the use of patient data and their impact on attitudes to use of data (see Appendix four for details of the coding matrix). As coding progressed it became clear that people's general view on whether something was of public

benefit was conditional. As these conditions emerged the core concepts, identified in the initial coding, were fleshed out to reflect these conditional aspects.

The initial coding exercise identified many references to the commercial nature of the organisation under consideration. This was not a surprise as the work was designed to test views about commercial organisations' use of patient data. Following this initial coding the highlighted transcripts, with the frequent words also highlighted, were again analysed to determine a granular account of the factors which influenced people's attitudes towards particular commercial organisations having access to patient data.

Each of the factors which were identified as influencing attitudes were analysed to determine if other participants voiced opposition or agreement. In this way, the extent to which each factor might be said to represent a consensus was tested. Minority views were noted. This approach created a coding matrix which consisted of 14 parent nodes and 13 sub-nodes. These nodes fell under two main themes: factors which influenced attitudes to whether the use could be seen to be a public benefit, and factors which influenced attitudes to the acceptability of a particular type of commercial organisation having access to the data. The results of this analysis are presented under these two themes in Parts three and four of this report.

Structure of the report

This report is organised into five main parts.

- Part one reports the initial views of participants toward sharing of patient data with different kinds of organisation, including specifically commercial companies.
- Part two describes the scenarios and reports the individual responses to proposed sharing with different organisations in each of the scenarios.
- Part three considers what factors influence people's attitudes on whether they perceived there to be a sufficient public benefit in the intended use.
- Part four investigates the factors that influence attitudes to the acceptability of a particular type of commercial organisation having access to the data.
- Part five reports whether there was any change in the views of participants during the workshop.

Part one: initial views on sharing anonymous patient data

To assess baseline views at the start of the workshop, we asked the 55 workshop attendees:

‘Do you feel that it is acceptable for the following institutions to have access to your anonymised personal level health data for reasons other than your direct care?’

Table 1: Question 1 - Acceptability of different types of organisations having access to anonymised personal level health data at baseline (start of the day)

	Yes	No	Don't Know	Total
NHS	96%	2%	2%	100%
University	69%	11%	20%	100%
Local Authority	64%	17%	18%	100%
Medical Charity	55%	18%	27%	100%
Commercial Company	18%	40%	42%	100%

(See Appendix three for Question 1)

Initial views

A baseline assessment of participants' attitudes revealed that the clear majority of participants on the day (96%) were happy for the NHS to have access to their anonymised patient-level data for reasons other than direct care. 69% of participants supported universities in having access to the data and this fell slightly to 64% for local authorities. Just over half of participants supported medical charities having access, but only one in five supported access by commercial companies. If asked specifically about the acceptability of sharing anonymised patient-level data to a commercial organisation for both commercial and public health care improvement benefit, then exactly half of all workshop participants felt that it was acceptable. There were no significant differences between the views of the publics and patients at this point. At this point, that there had been no discussion of why different organisations might want access to health data, how it might be of public benefit, or the nature of commercial organisations that might have access to this health data.

At the same stage of the workshop participants were then asked:

‘Is it acceptable for anonymised person level health data to be given by the NHS to a commercial company when there is both a commercial and a public (e.g. health care improvement) benefit?’

Exactly half of all workshop participants felt that this was acceptable.

Table 2: Question 2 - Acceptability of sharing anonymised data with a commercial company at baseline

	General Public	Patients	All participants %
I feel very strongly that it is acceptable	2.5%	7%	4%
I feel that it is acceptable	47.5%	43%	46%
I don't know if it is acceptable	45%	43%	44%
I feel that it is NOT acceptable	5%	7%	6%
I feel very strongly that it is NOT acceptable	-	-	-
Total	100%	100%	100%

(See Appendix three for Question 2)

Men were slightly more inclined to regard the sharing of anonymised data as acceptable but this variation was not statistically significant. Respondents of an Asian origin were much less likely to regard the sharing of anonymised data as acceptable than people from other ethnic categories. There were no significant differences between the public and the patient groups.

Part two: scenarios

We asked participants to consider five scenarios where a commercial organisation would have access to anonymous person level data for a use that had both public and private benefit. In each scenario, we asked participants to consider three types of commercial organisation to determine if the type of organisation made a difference to the acceptability of the scenario.

Scenario 1

What is the purpose of the data access?

- The NHS wants to improve care to children with heart conditions
- To know if fewer children would die or suffer disability, if care was concentrated in specialist centres rather than general hospitals
- To compare individual level data from children in both settings, looking at what treatments they are given and how well they recover

What is the public benefit?

- The identification of the most safe and effective way to deliver care.
- Independent and high-quality specialist data analysis

What is the commercial benefit?

- A private company will charge the NHS for providing the data analysis

Who is involved?

- The NHS is considering contracting with one of three different companies:
 - A university spin-out company specialising in data analytics with no other products or services
 - A small or medium sized UK company with a wide range of products and services, including data analytics
 - A large well-known international company with expertise in wide range of data services including internet search and market research

Table 3: Support for Scenario 1

Scenario 1: Assessing care to children with heart conditions	Yes	No	Don't know	Total
1. University spin-out company specialising in data analytics with no other products or services	89%	4%	7%	100%
2. Small or medium sized UK company with a wide range of products and services, including data analytics	84%	2%	14%	100%
3. Large well-known international company with expertise in wide range of data services including internet search and market research	64%	18%	18%	100%

Support for Scenario 1 was high, particularly for smaller UK commercial organisations.

Support for data sharing with the University spin-out company varied significantly with social class, with less support from respondents in social class E. Older participants were less accepting of disclosing the data to a large well-known international company than younger people.

Scenario 2

What is the purpose of the data access?

- A company wants to pave the way for development of a new drug
- The new drug may treat asthma when current front-line drugs do not
- Development would require understanding individual characteristics of those people who do not benefit from current asthma drugs

What is the public benefit?

- May ultimately result in the development of a new drug to treat asthma

What is the commercial benefit?

- A private company may profit from development of a commercially viable product

Who is involved?

- The NHS is considering contracting with one of three different companies:
 - Small specialist university spin-out company with no other products or services
 - Large UK-based pharmaceutical company
 - International pharmaceutical company with head office in USA

Table 4: Support for Scenario 2

Scenario 2: Improving care and treatment of asthma – drug development	Yes	No	Don't Know	Total
1. Small specialist university spin-out company with no other products or services	78%	9%	13%	100%
2. Large UK based pharmaceutical company	93%	2%	3%	98%*
3. International pharmaceutical company with head office in USA	60%	18%	18%	96%*

*some totals do not add up to 100% as some participants did not answer all the questions

Participants were more supportive of the larger pharmaceutical company having access to the data than they were of a small specialist university spin-out company. Some participants suggested larger companies may have greater information governance knowledge. There was also suggestion that larger companies would be better resourced and thus more able to deliver the project and its benefits.² This may also demonstrate a growing trust in the pharmaceutical sector following significant public discourse in the role of pharmaceutical companies in bringing drugs to market and corresponding scrutiny of the industry.³

There was no difference between the publics and patients in terms of their support for the spin-out company. However, in terms of the larger UK based pharmaceutical company there was significant difference between the publics and patients; 100% of the general public participants supported access by the large pharmaceutical company in comparison with 70% of the patient group.

Both groups showed the same level of support for an international pharmaceutical company with 60% across the board. Some participants were less concerned about data going overseas because there was less risk of someone who knew them accessing the data and therefore less risk of identification.

Male respondents were considerably more supportive of data sharing with a university spin out company than female participants. As with scenario 1, there was less support for data sharing with a university spin-out company from participants in social class E. Support for data sharing with a large UK based pharmaceutical company was consistently high across the board, regardless of social class.

² See paragraphs 83-88.

³ <https://yougov.co.uk/topics/consumer/articles-reports/2013/08/30/report-british-attitudes-pharmaceutical-industry>

Whilst there was overall less support data sharing with an international pharmaceutical company with a US based head office, older people were much less likely to support this scenario than younger people.

Scenario 3

What is the purpose of the data access?

- A company wants to develop a mobile phone app to be marketed direct to public through an app store
- The app provides early warning signs of asthma attacks to people who buy and use it
- Significant historical medical information such as peak flow rates and other individual characteristics associated with emergency asthma admission is needed to develop an effective app.

What is the public benefit?

- The aim is to help people better manage their asthma and reduce hospital admission

What is the commercial benefit?

- The opportunity to sell equipment (additional optional sensors to evaluate peak flow) to those who buy and use the app and to sell advertising space

Who is involved?

- The NHS is considering contracting with one of three different companies:
 - A small specialist university spin-out company with no other products or services
 - A large multi-national information technology company who will make the app open source
 - A well-known international company with broad range of products and services, including data services, such as internet search and market research

Table 5: Support for Scenario 3

Scenario 3: Improving care and treatment of asthma – App development	Yes	No	Don't Know	Total
1. Small specialist university spin-out company with no other products or services	66%	16%	18%	100%

2. Large multi-national information technology company who will make the app open source	62%	18%	20%	100%
3. Well-known international company with broad range of products and service, including data services, such as internet search and market research	49%	24%	27%	100%

Participants expressed scepticism about the ability of the app to provide tangible patient benefit. Consequently, some participants did not accept the notion of a public benefit in relation to the app development.

As with previous scenarios sharing data with a large international company with a head office outside of the UK, attracted less support.

Scenario 4

What is the purpose of the data access?

- A company wants to develop an insurance policy which encourages healthy choices to sell to particular people both new and existing customers
- To understand the relationship between exercise and reduced health risks for particular groups of people. This requires significant historical medical data related to individual characteristics
- The product will not (knowingly) to be sold directly to those whose data was used to develop the product

What is the public benefit?

- Those who take out the policy can enjoy subsidised gym membership, daily step counters, and fitness classes at a local health centre
- May reduce health risks

What is the commercial benefit?

- Increased revenue and potentially reduced insurances pay outs related to relevant health risks

Who is involved?

- The NHS is considering contracting with one of three different companies:
 - A specialist for profit insurance company with no other product or services
 - A not for profit charitable company providing insurance services and gyms
 - A company with a wide range of products and services, including providing insurance and gyms

Table 6: Support for Scenario 4

Scenario 4: Developing a health insurance product that promotes healthy choices	Yes	No	Don't Know	Total
1. Specialist for profit insurance company with no other product or services	34%	44%	22%	100%
2. Not for profit charitable company, providing insurance services and gyms	67%	18%	15%	100%
3. Company with a wide range of products and services, including providing insurance and gyms	42%	34%	24%	100%

The health insurance product scenario attracted the lowest levels of support of all the scenarios. However, support for access by the 'not for profit' charity was significantly higher than the other two company types. The views of the public were very different to those of patients in this scenario. The public was more supportive of the 'not for profit' charity having access to the data than the patients 77%:40% respectively. Nevertheless, there was still a significant lack of support from older participants.

Male participants were less supportive of data sharing with a company with a wide range of products and services including insurance and gyms than females.

Scenario 5

What is the purpose of the data access?

- There are health benefits linked with vitamin D supplements that might be more relevant to some groups of people.
- Understanding individual characteristics of vitamin D deficiency will allow a more effective public health message
- The product will not (knowingly) sold directly to those whose data was used to develop market access

What is the public benefit?

- Marketing can be targeted at those groups most likely to benefit

What is the commercial benefit?

- Selective marketing will reduce costs.
- More effective marketing that is based on evidence of need

Who is involved?

- The NHS is considering contracting with one of three different companies:

- A specialist company making and selling vitamin D supplements
- A large retail pharmacist on most high streets which also provides health advice
- A company with a wide range of products and services, including making and selling vitamin D

Table 7: Support for Scenario 5

Scenario 5: Targeted marketing of Vitamin D	Yes	No	Don't Know	Total
1. Specialist company making and selling vitamin D supplements	73%	16%	7%	96%*
2. Large retail pharmacist on most high streets which also provides health advice	82%	9%	5%	96%*
3. Company with a wide range of products and services, including making and selling vitamin D	64%	18%	14%	96%*

*some totals do not add up to 100% as some participants did not answer all the questions

Publics were more likely to consider the targeted marketing of vitamin D to be a public benefit regardless of the type of company. In relation to the specialist company making and selling vitamin D having access to data (88% of the general public were supportive compared to 33% of the patients – sig at 0.001).

There was a similar difference in attitudes between patients and publics in relation to sharing data with a large retail pharmacy (90% of the publics were supportive compared with 60% of the patients).

Male participants were more supportive of data sharing with a university spin out company than female participants.

Support for sharing data with a company with a wide range of products and services including making and selling vitamin D was considerably less amongst unemployed participants and highest amongst those working full time.

Scenario analysis

Scenarios 1 and 2 attracted the highest levels of overall support regardless of the type of company, followed closely by scenario 5. However, there was considerable disparity between the public and patients in terms of the level of support the specialist company making and selling vitamin D.

Scenario 3 attracted low support mainly because the participants were sceptical about the potential for public benefit which could not be evidence until after the data had been accessed to build the app.

Scenario 4 based on a health insurance example was ranked the lowest overall, mainly due to the perception of lack of public benefit. Nevertheless, there was considerable support from the publics for the access by the 'not for profit' charitable company.

Table 8: Support for each scenario

Rank	Scenario	Mean level of support for data access
1	Scenario 1: Assessing care to children with heart conditions	79%
2	Scenario 2: Improving care and treatment of asthma – drug development	77%
3	Scenario 5: Targeted marketing of vitamin D	73%
4	Scenario 3: Improving care and treatment of asthma – App development	59%
5	Scenario 4: Developing a health insurance product that promotes healthy choices	48%

Table 9: Level of support for each scenario and type of commercial organisation

Rank	Scenario	Type of company	% supporting access
1	Scenario 2: Improving care and treatment of asthma – drug development	Large UK based pharmaceutical company	93%
2	Scenario 1: Assessing care to children with heart conditions	University spin-out company specialising in data analytics with no other products or services	89%
3	Scenario 1: Assessing care to children with heart conditions	Small or medium sized UK company with a wide range of products and services, including data analytics	84%
4	Scenario 5: Targeted marketing of vitamin D	Large retail pharmacist on most high streets which also provides health advice	82%

Rank	Scenario	Type of company	% supporting access
5	Scenario 2: Improving care and treatment of asthma – drug development	Small specialist university spin-out company with no other products or services	78%
6	Scenario 5: Targeted marketing of Vitamin D	Specialist company making and selling vitamin D supplements	73%
7	Scenario 4: Developing a health insurance product that promotes healthy choices	Not for profit charitable company, providing insurance services and gyms	67%
8	Scenario 3: Improving care and treatment of asthma – App development	Small specialist university spin-out company with no other products or services	66%
9	Scenario 1: Assessing care to children with heart conditions	Large well-known international company with expertise in wide range of data services including internet search and market research	64%
10	Scenario 5: Targeted marketing of Vitamin D	Company with a wide range of products and services, including making and selling vitamin D	64%
11	Scenario 3: Improving care and treatment of asthma – App development	Large multi-national information technology company who will make the app open source	62%
12	Scenario 2: Improving care and treatment of asthma – drug development	International pharmaceutical company with head office in USA	60%
13	Scenario 3: Improving care and treatment of asthma – App development	Well-known international company with broad range of products and service, including data services, such as internet search and market research	49%
14	Scenario 4: Developing a health insurance product that promotes healthy choices	Company with a wide range of products and services, including providing insurance and gyms	42%
15	Scenario 4: Developing a health insurance product that promotes healthy choices	Specialist for profit insurance company with no other product or services	34%

This shows the level of support for each scenario and type of company in rank order. Support for data access is not restricted to small university companies. Participants were equally, if not more, supportive of large UK based companies. However, international based companies attracted less support.

Insurance companies attracted little support, but even this was nuanced. Whilst there was limited support for 'for profit' insurance companies of any size, there was some support for sharing with a 'not for profit' charitable status organisation which provided insurance policies.

Part three: What factors influence people's perceptions on whether the use of data will have a public benefit?

In each of the scenarios people were asked to consider whether they perceived there to be a (potential) public benefit in the intended use. Those uses where participants perceived a direct benefit to patients through the NHS were seen as more valuable than those where the benefit was not available through the NHS, but something that had to be personally accessed or bought. Where people were less able to perceive a clear public benefit their perspective on risk shifted. They were less able to accept personal risk and were more concerned about risks to society.

The need for evidence

One of the major considerations influencing people's view of whether there was a public benefit in the use of the data was whether there was evidence that the alleged benefit would materialise. Within this context, people were concerned about the risks associated with the intended use. This was a multi-faceted issue. People were worried that the intended use itself might not be beneficial, and in some circumstances, might be harmful. In essence, people needed sufficient evidence of the benefit before they would consider there to be a public benefit in the intended use. Some strong views were expressed about the sufficiency of the evidence for public benefit in the patient group:

'Well that's very speculative isn't it? It says may reduce the risk of type two diabetes, for some people (female: patient)'

'I don't think that I would support any product that wasn't tested, it's just outrageous that it should be even considered (male: patient)'

This has implications where patient data is required for the development of a service or treatment since proof of concept can be difficult to demonstrate in the early stages. However, this indicates that there is likely to be support for the use of data where this is to determine the safety of a product which has been proven in the development phase.

A lack of evidence that a new product would work (the app scenario) led to concerns that data could be used for a product that could be harmful.

'I suppose my concern over whether trying to make a judgement on patient benefit is much more about the quality of the app, because the only way it's going to be of benefit if it's a good app. It could actually cause disbenefit, but because there isn't the regulation process that we get with drugs, then you've actually no way of knowing whether it's going to create patient benefit or not (female: patient)'

'You're really possibly putting people at risk, because no control goes into these apps (female: patient)'

'it should be treated in the same manner as you would do a pharmaceutical drug, it's got to have a clinical trial where you have patients with asthma, use the app, make sure it works, in a medical environment (male: public)'

However, some participants were more willing to support disclosures that concerned experimental projects on the basis that this would be the only way to determine whether a particular use could lead to a development that might have public benefit. This attitude was more prevalent in the public groups than the patient group:

'I think in terms of everyone's concerns about, you know, if it doesn't work, how are we ever going to find anything that does work and improve it if people aren't willing to be the test group for it, essentially? (male: public)'

'I'd still be saying yes, I'd give them the data because it is anonymous data, but knowing the perceived outcome of it, what they're intending to do, I don't think it would work, I don't think it's of benefit, but it wouldn't stop me saying yes OK take the data, go and see if you can make such an app (male: public)'

'Who are we to say whether they can or they can't or who's going to use it afterwards, or what's going to happen with it, that's further down the line. This is the stage where I'm saying yes they can have it and I'm saying all three can have it, get on with it please and make a good app (female: public)'

The individual's attitude to risk had an impact on how much evidence they needed to perceive a public benefit. Where the evidence that a public benefit would materialise was not clear, people were less content to accept risk, whether this was perceived as personal data risk or risk to society in terms of the risk of using the developed product or service.

Attitudes to running risk

Some people were much happier to accept risks associated with sharing anonymous personal level data than others.

'there's everything to gain and nothing to lose as far as I can see. We give the data to a commercial company, they run with it to devise a product which could have the benefit or, or benefit lots of people who've got asthma, if they use the anonymised data and they can't bring it to market, I'm not quite sure what we, as the collective, have actually lost there (male: public)'

'I feel a bit uncomfortable, not uncomfortable, unsure, but I think I'd take the risk, if it was up to me (male: patient)'

Risks associated with using the product or service

Concerns about risks to the end user were complex. Primarily the worry was that the product wouldn't work and the health of those who might rely on it could be adversely affected.

'what happens if the app don't work? What happens if it's faulty? what happens if, you know, you rely on that and then he's actually worse and you don't get to hospital in time? I don't see a benefit (female: public)'

'I think the potential for things to go wrong, and potentially not get to hospital in time...I just think that is not worth the risk at all (female: public)'

'It's too radical, I think it's moving too quick, technology with your health, technology, you know health should come first (female: public)'

Some people were supportive of the use of their data if they felt that the developed product would generate something new, in terms of new knowledge or treatments. This led to a widespread feeling that the healthy living products that the insurance company wanted to market were not a sufficient public benefit because the benefits of healthy living are already well known and will not be furthered by the access to the patient data.

‘this is a bit of a flimsy sort of premise to be accessing everybody’s information, like in this day and age if you don’t know the fairly obvious fact that unhealthy lifestyle is going to cut your life expectancy, increase your exposure to things like type two diabetes, all that sort of stuff, then you don’t want to know (male: public)’

‘I don’t think it could make a big enough difference. I don’t think it’s supplying anything new that’s not already out there. People already know, like, you’re meant to eat healthily and run a bit, erm, so I just think the public interest on this one wasn’t great enough for it to warrant the data being sent (female: patient)’

This indicates that people are more accepting of commercial access to patient data if it will be used to develop novel insights and treatments. This position sits awkwardly with the risk averse attitude identified where participants needed to see clear evidence that the intended product or service would be successful.⁴

Risks associated with disclosing data

Some participants were concerned about the personal risk in the disclosure of patient data to commercial organisations to develop products or services. This was a view that was exclusively expressed by the patient group.⁵

‘I don’t mind my data going to help people, it would depend on the risks to me that I might be worried about in terms of erm, confidentiality (female: patient)’

If the product required further information to be disclosed by the end user, albeit with their consent, the participants were concerned about the risk to the end user from misuse of their data. This feeling was particularly strong in relation to the scenario describing an app to help manage asthma. There was a view that young people might be at risk because they might not be aware of the implications of uploading health data to a commercial app:

‘all these young people who’s going to be on it, they’re going to be around for a long long time and all the information’s going here, there and everywhere. Not a good idea (female: public)’

The concern about risk to the data subject was amplified where the data was of a kind that might invite stigma. Again, this concern was exclusively expressed in the patient group.

‘we feel with children’s heart conditions, there’s not a huge amount of stigma attached to that, so that would be a much easier decision than something like people might place blame on (female: patient)’

⁴ See paragraphs 40141.

⁵ We saw less concern about risks to the data subject than might have been expected or than has been reflected in previous empirical work. See Royal Statistical Society Response to the Department of Health on Protecting Health and Care Information in England: A consultation on proposals to introduce new regulations August 2014; Wellcome Trust The One-Way Mirror: Public attitudes to commercial access to health data March 2016. This may have been because the opening presentation explained the safeguards that are in place to protect against data misuse and we asked participants to assume that these safeguards were in place in all of the scenarios.

NHS endorsement or partnership

Where there was a perceived risk that the product or service might not deliver a sufficient public benefit, involvement of the NHS in the project helped to alleviate fears associated with running the risk that the public benefit might not materialise.

The factor that seemed to give most assurance in the context of NHS involvement was if the NHS had commissioned the use.

‘And the NHS are asking aren’t they? They want to save lives (female: public)’

‘it weren’t a third party company asking for it to be done, it’s actually the NHS, that it was a bit more, erm, you know, justified (female: public)’

However, people were also reassured if, even though the NHS had not specifically commissioned the use, it had endorsed the end product or service.

‘when you get somebody endorsing it, like the NHS or the government that leaves you as a consumer, or customer, that level of assurance (male: public)’

‘I would have no problem with an app being developed commercially if it was endorsed by the NHS or any society, because it would be a useful tool which would obviously help people counteract symptoms (male: public)’

Some people gave a deeper explanation of what they felt NHS endorsement would consist of. Some emphasised the importance of the NHS approval of the final product, whereas others emphasised the importance of the NHS in the *process* of the development of the product or service. Where endorsement related to the final product, people felt that NHS involvement might prevent commercial organisations from making false claims about the product or service.

‘working with the NHS, advertising standards, erm, when they are actually selling the tablets they’re not making any false claims (male: public)’

‘They’ve got to have the leadership from the NHS so they don’t go overboard in their claims (male: public)’

In focussing on the involvement of the NHS in the process of developing the product or service, people were specific about how the NHS should be involved. Many people spoke of a ‘partnership’ between the NHS and the commercial organisation.

‘A potential partnership rather than something that’s mutually exclusive (female: patient)’

‘it’s got to be a partnership, led by the NHS it’s got to be companies who going to put resources in because they want to sell it, but they’re going to be getting that basic information which could be led by the NHS, it’s got to be nationwide (male: public)’

The reassurance of an NHS/commercial organisation partnership was particularly prevalent in relation to the app development scenario. People described two main ways that they thought this partnership might function. First, they felt that involvement from clinicians and charities representing the particular condition (asthma in this instance) would give them reassurance that the app could be beneficial for potential users.

‘asthma groups or whatever, and they, assuming that they’ve got their own mechanisms to establish whether there’s a benefit before they endorse something (male: public)’

‘you’d want consultation with doctors and things like that to be able to inform (public: female)’

Second, people felt that an NHS app site where apps could be uploaded when they had met some NHS defined criteria would give them some assurance that the product was beneficial to health.

‘I do think the long term answer is an NHS app site where it’s a totally trustable site from which you download apps that conform to certain standards (male: patient)’

‘the answer to that is just having NHS sites and saying yeah we’ve approved this one (female: patient)’

Regulation

The existence of regulation influenced people’s concerns about the safety of the app in the third scenario. One common theme was that people perceived the area of health app development to be lacking regulation but did not perceive such a lack of regulation in the other scenarios. People’s concerns about the lack of regulation were primarily focused on the safety of the intended product or service as opposed to the security of their data. This may be because in the educational presentations at the beginning of the workshops we asked people to assume that the following data safeguards were in place in each of the scenarios:

- Adequate technical and organizational security
- Data will not be passed on to third parties
- Data will be destroyed at end of contract period
- Noncompliance with Data Sharing Agreement can result in contractual action and no more data
- Fines can be applied by regulator (ICO) in case of unlawful re-identification of individuals.

People’s desire for greater regulation did not focus on the need for additional data governance safeguards⁶, rather concerns focused on unscrupulous commercial organisations which might not adhere to the regulations that *are* in place. Where there were concerns about lack of regulation, they focused on quality assurance. People were well aware of the need to demonstrate evidence of benefit of medical products and the fact that medical apps need not demonstrate such quality before they could be listed on the app store, which thereby made people less willing to support the use of data to develop an app.

‘my concern over whether trying to make a judgment on patient benefit is much more about the quality of the app, because the only way it’s going to be of benefit if it’s a good app. It could actually cause disbenefit, but because there isn’t the regulation

⁶ In addition to the safeguards described in the presentation at the beginning of the day.

process that we get with drugs, then you've actually no way of knowing whether it's going to create patient benefit or not (female: patient)'

'I don't think it's regulated enough to develop an app that somebody could look at and say 'oh I'm not having an attack, I don't need an A&E admission (female: public)'

'if it's not regulated, it's not endorsed then you're just trusting what the app developer said and they might not have followed criteria to help somebody with asthma (male: public)'

There was a feeling that the rigorous regulatory process that applies to drug development should apply to medical apps:

'it should be treated in the same manner as you would do a pharmaceutical drug, it's got to have a clinical trial where you have patients with asthma, use the app, make sure it works, in a medical environment who will then say it's actually been endorsed by a board or a charity who have monitored it and then it goes to the app store (male: public)'

Thus, people want new products to undergo testing and regulation before they are made available to the public and would be less keen to allow their data to be used in the developments of these products and services if they are not so regulated.

Not against our interests

Despite the cautious attitude to use of data for purposes where the intended public benefit is not clear, or there is a risk that it will be ineffective or harmful, there was also a more liberal attitude which accepted that some level of uncertainty, experiment and risk should not prevent the use of the data.

'I think also in regard to public benefit, something we came out with is that even if the drug completely failed or they couldn't develop it, just doing the research in the first place would be public benefit (male: patient)'

Two factors influenced this attitude; the trust in the efficacy of safeguards that are in place to protect the anonymity of patient data and a sense of altruism that influenced people to trade off what they saw as a relatively low risk of re-identification to themselves, against the chance, even if this was perceived to be a slim chance, that the disclosure might improve healthcare for others.

'if it's going to help people then personally I don't really think it matters, like I wouldn't mind my data being used to help somebody else because I don't think it really matters where the data comes from if it's going to help people (female: patient)'

'Yeah. If you could be sure with all the safeguards that the risks of sharing the data in the first place, then you're not really losing anything are you? You might gain something but, so you might as well give them the data (male: patient)'

'I think in all three scenarios I'd still be saying yes, I'd give them the data because it is anonymous data, but knowing the perceived outcome of it, what they're intending to do, I don't think it would work, I don't think it's of benefit, but it wouldn't stop me saying yes OK take the data (male: public)'

Relieving the burden on the NHS

People were prepared to think broadly about the ways in which a public benefit might be conceived. The Wellcome Trust research found that 'In examples where the public value or benefit is not clear, participants found it hard to weigh up public good against personal risk. The context collapse made these new data transactions hard to define'.⁷ However, in our public dialogue some people could perceive a use of data to be of public benefit even where they could not visualise a clear and direct benefit to individuals, if there was potential for that use to ease the burden on the NHS. People predominantly interpreted benefit to the NHS in terms of cost saving. There were two ways that people felt such a cost saving could be made; First, it would be a public benefit if commercial organisations helped the NHS to spread a particular health promotion message because this might allow the NHS to make savings:

'I mean it might be used as a bit of a marketing tool but...people and lifestyle, making lifestyle changes is really difficult. It's been proved that facilitating some of those lifestyle changes, behaviour change, often helps if you're actually making money or there's some financial incentive into it. So if what we're doing is increasing financial incentive and that's actually making people healthier, or taking healthier options, then that translates into healthy people and less pressure on the NHS (female: patient)'

'I just think that basically companies are doing the governments marketing for them for free, so why not? (female: patient)'

Second, even if people could not see a direct tangible benefit to individuals from the particular use, if the ability to access a benefit elsewhere prevented them from accessing NHS services, this was seen as a benefit to the NHS:

'there was a public benefit if it meant that X number of people no longer ended up going to A&E, or having an acute asthma attack or whatever, that there was a cost benefit to that to the NHS and that could be re-invested in other services that the NHS provide (male: public)'

'if that's preventing A&E admissions and reducing the number of prescriptions and GP appointments, all the costs of those admission and appointments add up and end up saving money for the public generally...it is benefitting the NHS which is why I personally think it is in the public benefit to have something like that (female: patient)'

'The trouble is, the health service, NHS is in crisis and it needs all the help it can get and that's got to be through pharmacies doing their bit to take the pressure off them to treat things that are even more serious or acute, (female: public)'

'That sentence there you just said 'the NHS is in crisis' that is probably the most truthful thing anybody's said all day, because that's what this is all about isn't it? (male: public)'

As well as seeing a benefit in preventing people from needing to access the NHS, people saw a corresponding benefit to the individual, if he or she could access services other than through the NHS. Where the commercial organisation was one which generally enjoyed a high degree of trust and was easier to access than the NHS, people felt that it would be a

⁷ Wellcome Trust The One-Way Mirror: Public attitudes to commercial access to health data March 2016 P.9

benefit to be able to access services from this commercial organisation instead of the NHS. This view was particularly expressed with regard to accessing advice about vitamin D deficiency from a pharmacy as opposed to a GP and so had particular relevance to the fifth scenario.

‘a lot of people now have got busy lifestyles haven’t they? And they don’t want to be sat in the doctor’s surgery for a five o’clock appointment and don’t see the doctor till six and you’d rather go to the chemist (male: public)’

‘People want a bit more speed don’t though, even though the GP has more expertise they’d rather go elsewhere (male: public)’

‘I can’t get an appointment at my doctors, so I don’t know how they’re going to give me vitamin D. It takes about three weeks (female: public)’

This difference reflects the choice to be able to access treatment elsewhere as opposed to denial of treatment on the basis of ability to pay.

Obligation to make the benefits available to the NHS

The view that the NHS should benefit if the commercial organisation produced something beneficial to health was the most strongly stated view across all three workshops. There were two ways that people thought the NHS should benefit from commercial developments that were based on the use of patient data. First, they felt that any product of service that was developed with NHS patient data should be made available to the NHS at a preferential rate:

‘the commercial company involved would end up necessarily making a product which they would benefit from in the long term, and if that was directly attributable to the data sets that were provided from our people, that therefore when they came with a product to market, that that should have a direct consequence on the price that it charges the NHS (male: public)’

‘Data is supplied by the public and it’s been gathered by the NHS then there should be, for our benefit, a return in terms of percentage of the drug profits going back into the NHS to improve services and perhaps the cost of the drug should be minimal (female: patient)’

‘if they do develop a product based on the data that we’ve shared, or the NHS have shared, that they get preferential rate on the cost of the final product (male: public)’

Second, people felt that the NHS should have unlimited access to any new knowledge or insights which arise from the company’s work with the patient data:

‘I’d like to see the company giving their further analysis back to the NHS rather than just using it for marketing (female: patient)’

‘the factor would be whether or not the erm, analysis that the marketing company did of the data given to them would be given back to the NHS, if it was new information then I’d want it given back (female: patient)’

Universality of public benefit

Even though participants recognised less tangible public benefits than previous research,⁸ they became less convinced that there was a sufficient public benefit where the perceived benefit would not be universally available to all who might need it.

Some people expressed this as a matter of first principles. Even though something could be of benefit to some, if access could be perceived as discriminatory, the disbenefit of discrimination outweighed the benefit that might accrue to those who could access the service or product:

'We don't want it to be divisive do we? (male: public)'

'If they think that it were that good that if someone that needed it and wanted it couldn't have it purely on cost, if it was a good product but I think we are an NHS society though so it flies in the face of... (male: public)'

Some people were concerned that the cost of the product or service might affect its universal availability to those in need:

'Because when you're looking at population public benefit, OK an asthma app is not going to benefit every individual, but if there is sort of a collective benefit then it's in the public interest. If you could only access it if you were signed up to BUPA, for example, then that's, I think that's not of collective public benefit, it's quite a specialised benefit (female: patient)'

'because it's just for people who've got insurance (female: public)'

People also expressed the view that the product or service had the capacity to be divisive if it were inaccessible to those who lacked technical capabilities.

'not all of them are going to use an app, not all of them are going to be the right age range to have a phone that you can put an app on, you know, erm, and it varies from person to person because if you're quite old and you've got asthma then like I say, you're not going to go on to the app whereas teenagers, younger people will. So saying that you've got so many thousand people with asthma doesn't mean that they're all going to use it (female: public)'

'it's good for the young ones but the older people can't rely on technology because some of them haven't even got computers or mobile phones (female: public)'

However, some people felt that a product or service could be of sufficient benefit to the public even if it could only be accessed by a minority. This position was underpinned by the view that other intangible benefits could accrue to those unable to afford/use the service or product, if those who could afford/use it did so:

'things are developed that are expensive and they're used, they're popular and often it is people who can afford things in the first place, that's the nature of capitalism, people that can afford things in the first instance pay for those things, they then become population and then by default, sort of going bigger, it becomes cheaper (female: patient)'

⁸ Wellcome Trust The One-Way Mirror: Public attitudes to commercial access to health data March 2016.

'even if only so many people can afford it, if that's preventing A&E admissions and reducing the number of prescriptions and GP appointments, all the costs of those admission and appointments add up and end up saving money for the public generally. So even if only, I don't know, 20% of the asthma population can afford an app, and apps aren't normally that expensive, that in turn, like third party, is benefitting the NHS which is why I personally think it is in the public benefit to have something like that (female: patient)'

'I don't think they have to have very many people to benefit to call it a public benefit really (male: public)'

Whilst lack of universal access can prevent perception of a public benefit, we also found that people think it is a benefit to the NHS if people can choose to access healthcare elsewhere, thereby relieving the burden on the NHS.⁹ This difference in opinion reflects the ability to choose where to access service as opposed to denial on the basis of the ability to pay.

⁹ See paragraphs 69-72.

Part four: What factors influence people's attitudes to the acceptability of a particular type of commercial organisation having access to NHS patient data?

We know from previous research¹⁰ that people are less accepting of commercial organisations having access to healthcare data than other organisations. Generally, people did not want insurance or marketing companies to have access to their data, but they were more accepting of pharmaceutical and data analytics organisations having access to anonymous patient data.¹¹ Of course, this discussion of the acceptability of the commercial organisation accessing the data cannot be divorced from the discussion of whether the use of the data would lead to a sufficient public benefit which was addressed in Part three. However, the perception of a public benefit may decrease as the public perception of the commercial organisation is more unfavourable. In considering the acceptability of commercial organisations accessing patient data the scenarios introduced a number of factors which might influence the participants' ability to trust the particular type of commercial organisation.

In each scenario, we asked participants whether it would be acceptable to share anonymised patient-level data with three different commercial organisations for the stated purpose. The characteristics of the commercial organisations were varied according to the substantive situation under consideration. Variations were made based on company size, type of business, whether it was profit making and whether it was a national or international company. The word 'company' was the fourth most frequent word in the transcripts of the focus groups. A further search of companies and commercial allowed us to identify a number of themes that influenced people's views on the particular commercial organisation's use of patient data.

Whether the commercial organisation could be said to be trustworthy had an impact on whether people felt it was acceptable for the particular commercial organisation to use their data. This need to feel trust had two elements. People needed to be able to trust the organisation to protect their data and they also needed to be able to trust that the organisation would remain committed to the public benefit element of the produced product or service developed on the basis of access to the data. Five themes were identified as affecting trust in these ways:

- The size of the commercial organisation
- Conflicts of interest
- Portfolio of services
- Track record
- International dimension

¹⁰ Wellcome Trust Summary Report of Qualitative Research into Public Attitudes to Personal Data and Linking Personal Data July 2013; Royal Statistical Society Response to the Department of Health on Protecting Health and Care Information in England: A consultation on proposals to introduce new regulations August 2014; Wellcome Trust The One-Way Mirror: Public attitudes to commercial access to health data March 2016.

¹¹ Wellcome Trust The One-Way Mirror: Public attitudes to commercial access to health data March 2016 p 10-11.

The size of the commercial organisation

People had different views on how size affected trust. Some felt that larger organisations were less trustworthy because the large and transient workforce might increase the potential for data breach.

‘companies getting involved, and the larger ones getting involved then there becomes more of a security risk (male: public)’

‘More people you’ve got I mean the more risk of information leaking out isn’t there? If you’ve got a thousand people and you get a leak (male: public)’

Some people put more trust in a small specialist company:

‘I would always be happier with a smaller team of specialists (female: public)’

Significant emphasis was placed on the presentation from the software developer from epiGenesys, a University of Sheffield spin-out company, in articulating attitudes to trusting small specialist companies. People were motivated by the fact that a spin-out company might be offering other benefits to a section of the community such as training for students:

‘That puts a different perspective on it. The reason I also prefer the spin-out company was that it’s providing training, training to students who in the long run there is I think a greater good happening here (female: patient)’

‘What influenced me was that I would prefer the university spin-off company because there are other benefits to be gained (female: patient)’

However, people did not feel that this should mean that smaller or university spin-out companies should be able to access the data under a lower threshold:

‘I expect there to be a minimum threshold that all companies, whether they’re university or elsewhere, because I would be worried that, I mean universities mess up as well so, just because it’s a university company I don’t rate it any differently (male: public)’

On the other hand, some people felt more able to put more trust in larger organisations ability to protect their data, on the basis that they may have better organisation data protection.

‘I have a lot more faith in large companies’ attitudes towards data protection (male: public)’

‘bigger companies have better security than smaller companies (male: public)’

There was also a view that it would be more acceptable to share data with larger companies because they would be more likely to have a dedicated team who would be able to do a more efficient and cheaper job:

‘we thought that the larger company would probably have a dedicated team (male: public)’

‘bigger company, more staff, quicker than a smaller one? (female: public)’

‘larger company they have more money so they can come in with a lower bid and still provide the same service that the other two can (female: public)’

Conflicts of interest

Irrespective of the size of the company, the existence of any conflict of interest which indicated that the company might prioritise its own commercial gain over the public benefit in relation to the particular use had a significant impact on trust.

Some types of commercial organisation were associated with purely, and sometimes ruthlessly, maximising commercial gain:

'I thought on this particular occasion the commercial interest aspect seemed to me to outweigh what could be expected to be some public benefit, it was clearly weighted towards the commercial aspect of it for the company and I think that was my concern (male: public)'

'I think those people are distrustful and the motives surrounding companies like insurance companies because it will ultimately be used, as it was in that scenario, for their benefit and not anybody else's (male: public)'

'I'm very sceptical about insurance companies expanding their markets into areas of health, under false promises. They're selling an insurance policy; do not believe they're selling anything else (male: patient)'

Portfolio of services

People felt less able to trust larger companies with a portfolio of services because the company might take the opportunity to use the data across its other services even if this was not been the intention in the data sharing agreement. There was a worry here that additional uses by a different branch or department within the same company might not serve any public benefit even though the initial use could be said to serve a public benefit:

'larger company I think there's a greater risk of them using that data for things other than what they said they were going to use it for (female: public)'

'conflicts of interests before which are important for me, to look at all your bits which I feel large organisations could, if they can use that for something else (male: public)'

'anything that has a wider range of products I have a bit less trust in because they've got too many products (male: public)'

However, some people saw commercial gain in the health care sector as being part of what might drive technology and innovation. People who had this attitude were less concerned if the commercial gain seemed to precede the public benefit because they felt that this was a necessary part of achieving the public benefit:

'I think in the long run it would be beneficial to, it might cut the burden down on the NHS, but yeah, another company is going to making big profit from that, but it's making technology which might not be accessible to all, kinda out there (male: public)'

'so in reality their expertise although its usually for nefarious reasons, they could turn a good hand to help with something worthwhile like this, so that's my thinking on why a bigger multi-national company would be good for it (male: public)'

Track record

Where there might be conflicts of interest, organisations could offset the negative effect that this might have on trust if they had a good track record.

'I think a big issue for me with all three would be the reputation of the company, whether it's a spin-out company, or the large one or the medium or the small one, you know, what's been their past experience and record, how have they handled other contracts (female: patient)'

'I think track record, it's been highlighted but I think that's really the thing because I have the same kind of concern as James about erm, you know, sending out to international companies, erm, but if this was, had a very good reputation, we knew it had security, we knew there hadn't been past history of bad stuff then it would be the track record that was the number one consideration for me. And then if it wasn't track record it would just be general biases and assumptions about reputation (female: patient)'

'It's very very difficult because how do you know what these companies are up to? And what things they've done in the past (male: public)'

Track record positively influenced people's ability to be able to trust a commercial organisation with their data, particularly if that organisation already had a good track record in accessing data in the healthcare context. This feeling was particularly prevalent in relation to scenario five where one of the companies was a large retail pharmacist. People saw pharmacies as more trustworthy because of their track record in dealing with personal information in prescriptions:

'Because I always the same pharmacist, because it's where I live, near where I live, they've got my data anyway because my prescriptions are sent electronically so they have my personal information so I'm not bothered about them, that pharmacy, even though they maybe buy the product from another company, but I would be, I'm quite happy to buy it, if you see what I mean, from the pharmacist (female: public)'

'I think with pharmacists they do work very closely with the NHS, I mean there is pharmacists inside NHS hospitals so you probably would kind of go more towards a pharmacist than an actual shop (female: public)'

International dimension

People felt less able to trust international companies. There was a particular feeling that US companies could not be easily trusted. The key reason behind this seemed to be that people felt that they could not be confident that their data would be accorded the same level of protection in the US as it enjoys in the UK:

'They've got different legislation over there (USA) (male public)'

'if it's overseas there are no privacy laws in the united states are there? And the individual company policies about data can be rather generous (female: patient)'

Those who did not trust US companies and their regulation of personal data did not report the same lack of trust in European commercial organisations.

'American law and their rules and commerce is pretty notorious for letting companies run random really, because they have a much more heavy lobbying culture and things like that so, now you mention it, maybe. I'd be a lot more in favour of a European company, as they'd be a lot more stricter in terms of regulations (male: public)'

If a commercial organisation was going to make a commercial gain from using NHS patient health data, people felt that this gain should be made by a UK company:

'And we're the NHS, you know, it's what, we should be proud of it, you know, the NHS is Britain you know, so we should have the resources to be able to, in this country, to make this and to produce this medicine for our country, why do we need to go out to another country (female: public)'

'I think it's the fact that if the data's been gathered from the British public it should definitely stay with the UK based company, not going international (male: public)'

'I do feel that if it's gathered here it should stay here rather than going to a different company, or country (male: public)'

Some of the participants did not share the lack of trust in US commerce and regulation.

'I think the UK people, or UK as a whole are pretty insular and anything outside the UK is not trusted. They might trust Europe more than the USA but as long as it's outside the UK, they are always going to be nervous. I can't really imagine America being much different to the UK, we're both supposed to be civilised societies, so in a lot of respects I think a lot of the concerns are pretty unfounded really. You need to have it abroad based to actually bring it to a fulcrum if you like, to bring it to a point. It's like any other technology, you can't keep it to yourself, you've got to share and you've got to spread it, or else it's not going to develop. That's the way I look at it. So people are like saying they don't want it to be USA, but at the end of the day, the USA is a massive resource, and what's to say, you don't, anybody in this room, erm attached to a UK company, you don't actually know who owns that company. It might be America, it might be China, it might be German. You're just making the assumption that it's British but basically, it's not necessarily so (male: public)'

'Personally, I don't think you should be excluding them because you might be excluding potentially a better company to come up with a better product, (male: public)'

'I think let it go as far as it can. The company that can come up with the best cure, data doesn't come into it. When you're saving lives and making a lot of people happier and healthier (female: public)'

Part five - Change in views across the day

At the end of each workshop we repeated the assessment of the participants' attitudes towards sharing NHS data using the same questions administered at the start of the day to assess if there had been any change in opinion over the course of the day. As before, we asked:

'Do you feel that it is acceptable for the following institutions to have access to your anonymised personal health data for reasons other than your direct care?'

Participants were asked to state who they felt could have access from a list of five different types of organisations. The Table below sets out the workshop attitudes towards data sharing at baseline.

Table 10: Acceptability of different types of organisations having access to anonymised personal level health data at end of the workshop

	Yes	No	Don't Know	Total %	Total number
NHS	100%	-	-	100%	53
University	81.5%	7.5%	11%	100%	54
Local Authority	72%	19%	9%	100%	53
Medical Charity	70%	15%	15%	100%	54
Commercial Company	45%	30%	25%	100%	53

Change in views across the day

The opinion of the NHS remained consistently high with 100% of participants supporting access to anonymised patient data. Support for all other groups had grown over the day with much higher levels of support expressed in the exit questionnaire. At baseline roughly half of all participants supported sharing anonymised patient level data with a commercial company where there was both a public and a private benefit. By the end of the workshop, this percentage had increased to almost three quarters of all participants.

The findings show a large increase in support for commercial access to data as the day progressed and the significant shift in opinion is statistically significant (t-test significant at 0.003). Interestingly, opinion moved in both directions with 2% feeling very strongly that it is not acceptable to share anonymised data at the end of the workshop and a significant reduction in the number of people saying that they don't know. Looking at the shift of opinion at an individual level - of the 24 people who said they did not know if it is acceptable at the beginning of the day, 14 had moved to an acceptable position by the end of the day. Similarly, the three people who had made up the not acceptable category at the start of the day had all moved to an acceptable position by the end.

Table 11: Comparison: supporting access to anonymised patient level data for reasons other than direct care - baseline and end of day

	% Yes baseline	% Yes at end
NHS	96%	100%
University	69%	81.5%
Local Authority	64%	72%
Medical Charity	55%	70%
Commercial Company	18%	45%

Participants were then asked:

‘Is it acceptable for anonymised person level health data to be given by the NHS to a commercial company when there is both a commercial and a public (e.g. health care improvement) benefit?’

Table 12: Comparison: supporting access to anonymised patient level data with a commercial company - baseline and end of day

	All participants % baseline	All participants % at end of day
I feel very strongly that it is acceptable	4%	11%
I feel that it is acceptable	46%	63%
I don't know if it is acceptable	44%	18%
I feel that it is NOT acceptable	6%	6%
I feel very strongly that it is NOT acceptable	-	2%
Total	100% (N=55)	100% (N=54)

At baseline almost half of all participants supported sharing anonymised patient level data with a commercial company. By the end of the workshop, this percentage had increased to almost three quarters of all participants. The findings show a large increase in support for commercial access to data as the day progressed and the significant shift in opinion is statistically significant (t-test significant at 0.003). Interestingly, opinion has moved in both directions with 2% now feeling very strongly that it is not acceptable to share anonymised data and a significant reduction in the number of people saying that they don't know.

Looking at the shift of opinion at an individual level - of the 24 people who said they did not know if it is acceptable at the beginning of the day, 14 had moved to an acceptable position by the end of the day. Similarly, the three people who had made up the not acceptable category at the start of the day had all moved to an acceptable position by the end.

Conclusion

This research builds on the position identified in previous work that people are less accepting of commercial organisations accessing and using anonymous patient health data than other organisations.¹² However, previous work has also highlighted that there is low understanding of the kind of commercial organisation that might seek to use patient data and why they might want to access this data. The Wellcome Trust reports a gulf between how people think the NHS is likely to use patient data and reality. This research considers the access to, and use of, anonymous patient-level data by commercial organisations.

The main aim of this research is to inject granularity and specificity into the debate about commercial access to health data in a way that it might not have been seen previously. The types of commercial use of patient data vary enormously and in some the benefit to publics and patients might be more keenly appreciated than others. If this is the case, it is important that the involvement of commercial organisations is not approached in a way which reflects the range or purposes and types of commercial organisation that might seek access to patient data for a project that incorporates public benefit. Thus, the research addresses the views of publics and patients on a range of patient data uses that might be undertaken by commercial organisations, where there are both public and private benefits.

In addition, this research investigates how the attitudes of patients and publics attitudes might shift in line with a number of variables that relate to the type, size and location of the organisation. This approach has shown that most people do not have a one size fits all view on commercial access to patient data but are motivated primarily by the degree of public benefit in the data use. It also demonstrates that people are more willing to trust those commercial organisations that have proved themselves to be scrupulous.

In order to examine nuances in attitudes relating to a range of factors involved in commercial access to health data, people need to know about particular uses and who might use the data in those ways. The Wellcome Trust reports a lack of understanding around why the NHS would want or need to allow commercial access to data, or how companies contribute to healthcare. This report shows that as people learn about the role of commercial organisations in delivering data-driven applications which have the capacity to benefit human health, they become more accepting of the company's access to data.

This willingness to recognise that it might be appropriate for commercial organisations to access anonymised patient-level data where there is both a public and a private benefit goes hand in hand with some very strong views about how public benefits should be realised where commercial organisations have access to that data. Primarily, participants felt that the NHS should get preferential treatment if access to the benefits derived from the use of data in commercial projects. People also felt very strongly that the NHS should be involved in all stages of the project from commission through to development and endorsement. These messages should be at the forefront of the NHS's strategy in working with commercial organisations in data-driven developments. If the NHS assures the public of its ability to ensure that data-driven developments are preferentially available to the NHS, public trust is much more likely to be gained and maintained.

¹² https://understandingpatientdata.org.uk/sites/default/files/2018-08/Public%20attitudes%20key%20themes_0.pdf slide 13.

Appendix one: effect of demographics on attitudes

Gender

At the baseline measurement, men were more likely to accept data access than women. At the final measurement, only women felt that data access was not acceptable.

Age

All of those who felt that data access was not acceptable were all in the 55 plus age bracket. At scenario level, often the greatest objections to data sharing came from those aged 55 years plus or retired. In particular, those in the oldest age band objected most to data sharing with large international companies with a head office based outside of the UK.

Employment status

Analysis shows very clearly that support for data access was higher amongst those in employment and support was much lower amongst those not working. This was reflected in some of the scenarios and is supported by feedback from general public omnibus surveys commissioned by the HRA which indicate that confidence and trust in health research and the use of their data is directly associated with social grading and inequality.

Education

There was no significant variation in support for data sharing by education level.

Ethnicity

There was no significant variation in support for data sharing by ethnicity.

Appendix two: Presentations

Significant time was spent at the beginning of the workshop explaining the concept of patient level anonymised data and existing safeguards so that we could spend time with participants discussing the variables of *why* the data was requested and by who. We deliberately did not seek to test any non-commercial scenarios as we want to focus on the nuances of both commercial and public benefit across a range of commercial organisations.

The concepts of anonymization, pseudonymisation, aggregation and identifiability were explained. Participants were shown examples of identifiable, potentially identifiable and anonymised patient level data together with aggregate data and informed that in this focus group we would be considering only the anonymised kind of data at a patient level as opposed to identifiable or aggregate data. (Amanda Hunn)

The participants also heard a presentation which explained the safeguards that are currently in place to prevent misuses of potentially identifiable data. Here the focus was on unlawful re-identification of individuals or uses which were not covered by the data sharing agreement. (Dr Mark Taylor)

Participants heard a presentation about the types of commercial organisation which might request access to patient health data. (Dr Victoria Chico and Robert White, Senior Software Developer from epiGenesys a software development company which is a wholly owned subsidiary of the University of Sheffield)

Appendix three: beginning and end of workshop questionnaire

Do you feel that it is acceptable for the following institutions to have access to your anonymised personal health data for reasons other than your direct care?

	Yes	No	Don't Know
NHS			
Local Authority			
University			
Medical Charity			
Commercial Company			

Is it acceptable for anonymised person level health data to be disclosed by the NHS to a commercial company when there is both a commercial and a public (e.g. health care improvement) benefit?

	Please tick one.
I feel very strongly that it is acceptable	
I feel that it is acceptable	
I don't know if it is acceptable	
I feel that it is NOT acceptable	
I feel very strongly that it is NOT acceptable	

Appendix five: post-scenario questionnaires

Example 1: Assessing care to children with heart conditions

Would it be acceptable for person level anonymised personal health data to be used by 1, 2 AND 3 for this purpose?

Scenario 1: Assessing care to children with heart conditions	Yes	No	Don't know
1. University spin-out company specialising in data analytics with no other products or services			
2. Small or medium sized UK company with a wide range of products and services, including data analytics			
3. Large well known international company with expertise in wide range of data services including internet search and market research			

PLEASE TICK ALL APPROPRIATE ANSWERS

Example 2: Improving Care and Treatment of Asthma – drug development

Would it be acceptable for person level anonymised personal health data to be used by 1, 2 AND 3 for this purpose?

Scenario 2: Improving care and treatment of asthma – drug development	Yes	No	Don't Know
1. Small specialist university spin off company with no other products or services			
2. Large UK based pharmaceutical company			
3. International pharmaceutical company with head office in USA			

PLEASE TICK ALL APPROPRIATE ANSWERS

Example 3: Improving Care and Treatment of Asthma – App development

Would it be acceptable for person level anonymised personal health data to be used by 1, 2 AND 3 for this purpose?

Scenario 3: Improving care and treatment of asthma – App development	Yes	No	Don't Know

1. Small specialist university spin off company with no other products or services			
2. Large multi-national information technology company who will make the app open source			
3. Well known international company with broad range of products and service, including data services, such as internet search and market research			

PLEASE TICK ALL APPROPRIATE ANSWERS

Example 4: Developing a health insurance product that promotes healthy choices

Would it be acceptable for person level anonymised personal health data to be used by 1, 2 AND 3 for this purpose?

Scenario 4: Developing a health insurance product that promotes healthy choices	Yes	No	Don't Know
1. Specialist for profit insurance company with no other product or services			
2. Not for profit charitable company, providing insurance services and gyms			
3. Company with a wide range of products and services, including providing insurance and gyms			

PLEASE TICK ALL APPROPRIATE ANSWERS

Example 5: Targeted marketing of Vitamin D

Would it be acceptable for person level anonymised personal health data to be used by 1, 2 AND 3 for this purpose?

Scenario 5: Targeted marketing of Vitamin D	Yes	No	Don't Know
1. Specialist company making and selling vitamin D supplements			
2. Large retail pharmacist on most high streets which also provides health advice			
3. Company with a wide range of products and services, including making and selling vitamin D			

PLEASE TICK ALL APPROPRIATE ANSWERS