

Commercial access to patient data



The
University
Of
Sheffield.



Health Research
Authority



Juliet Tizzard
Director of Policy
5 December 2019

Purpose of the research

To gain a greater understanding of attitudes to sharing anonymised individual level data with commercial organisations where there is both a public and a private benefit

Method used

We involved 55 people in three workshops in September 2016:

- 2 with members of the public (South Yorkshire demographic)
- 1 with patient representatives



Method used

At the beginning of the workshop, they were asked to give their general views about the use of health data

And asked to complete a questionnaire



Questionnaire views: start of day

Is it acceptable for anonymised personal level health data to be given by the NHS to a commercial company where there is both a commercial and a public benefit?

	Start of day	End of day
I feel very strongly that it is acceptable	4%	
I feel that it is acceptable	46%	
I don't know if it is acceptable	44%	
I feel that it is NOT acceptable	6%	
I feel very strongly that it is NOT acceptable	-	

Scenarios presented for discussion

1. Assessing care to children with heart conditions
2. Improving care and treatment of asthma – drug development
3. Improving care and treatment of asthma – app development
4. Developing a health insurance product that promotes healthy choices
5. Targeted marketing of vitamin D

1: Assessing care to children with heart conditions

What is the purpose of the data use?

- To improve care for children with heart conditions
- To know if fewer children would die or be disabled if care was in specialist centres instead of general hospitals
- To compare individual level data from children in both settings

What is the public benefit?

- Not knowing may put some children at higher risk of poor care
- Knowing will identify the most safe and effective way to deliver care
- A company can provide independent and high quality specialist analysis

What is the commercial benefit?

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

1: Assessing care for children with heart conditions

	Yes	No	Don't know	Total
1. University spin out company specialising in data analytics (with no other products/services)	89%	4%	7%	100%
2. Small or medium sized UK company with a wide range of products and services, incl. data analytics	84%	2%	14%	100%
3. Large well known international company with expertise in wide range of data services including e.g. internet search and market research	64%	18%	18%	100%

2: Improving care and treatment of asthma – drug development

What is the purpose of the data use?

- Development of a new drug to help 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 improve treatment of asthma

What is the commercial benefit?

- Company benefits from development of a commercially viable product
- This drug could be sold to NHS for prescription to individual patients
- Payment would be from NHS to company

2: Improving care and treatment of asthma – drug development

	Yes	No	Don't know	Total
1. Small specialist university spin off (with no other products/services)	78%	9%	13%	100%
2. Large UK based pharmaceutical company	93%	2%	3%	98%*
3. International pharmaceutical company with head office in U.S.A.	60%	18%	18%	96%*

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

5: Targeted marketing of vitamin D

What is the purpose of the data use?

- There are health benefits linked with vitamin D supplements for some people
- Knowing who would most benefit will allow more effective public health messages

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
- Describing a particular group of people or area as vitamin D deficient may increase sales

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 (and providing 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 participant did not answer all the questions

3: Improving care and treatment of asthma – app development

What is the purpose of the data use?

- to develop an app to be sold direct to public
- to provide early warning signs of crisis to people who use it
- to assess historical medical information (eg, 'peak flow' rates and other individual characteristics associated with emergency admission)

What is the public benefit?

- to help people better manage their asthma and reduce A&E admissions

What is the commercial benefit?

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

3: Improving care and treatment of asthma – app development

	Yes	No	Don't know	Total
1. Small specialist university spin off (with no other products/services)	66%	16%	18%	100%
2. Large multi-national information technology company who will make 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%

4: Developing a health insurance product that promotes healthy choices

What is the purpose of the data use?

- to develop an insurance policy which encourages healthy choices to sell to new and existing customers
- to understand the relationship between exercise and reduced health risks for particular groups of people

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 risk of type 2 diabetes for some people

What is the commercial benefit?

- It increases revenue and, if it reduces pay-outs related to type 2 diabetes, reduce costs

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 products/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%

Questionnaire views: end of day

Is it acceptable for anonymised personal level health data to be given by the NHS to a commercial company where there is both a commercial and a public benefit?

	Start of day	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%

What influences the public benefit test?

1. **The need for evidence**
2. Attitudes to running risk
3. Risk associated with using the product or service
4. Risk associated with disclosing the data
5. NHS endorsement or partnership

'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.'
(female: patient)

What influences the public benefit test?

1. **The need for evidence**
2. Attitudes to running risk
3. Risk associated with using the product or service
4. Risk associated with disclosing the data
5. NHS endorsement or partnership

‘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)

What influences the public benefit test?

1. The need for evidence
2. Attitudes to running risk
3. Risk associated with using the product or service
4. Risk associated with disclosing the data
5. **NHS endorsement or partnership**

‘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)

What influences the public benefit test?

6. Regulation
7. Not against our interests
8. **Relieving the burden on the NHS**
9. Obligation to make benefits available to NHS
10. Universality of public benefit

***‘if that’s preventing A&E admissions and reducing the number of prescriptions and GP appointments... it is benefitting the NHS which is why I personally think it is in the public benefit to have something like that’
(female: patient)***

What influences the public benefit test?

6. Regulation
7. Not against our interests
8. Relieving the burden on the NHS
9. Obligation to make benefits available to NHS
- 10. Universality of public benefit**

'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)

What influences the public benefit test?

6. Regulation
7. Not against our interests
8. Relieving the burden on the NHS
9. Obligation to make benefits available to NHS
- 10. Universality of public benefit**

‘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)

What influences views on sharing?

1. The size of the commercial organisation
2. Conflicts of interest
3. Internationality

What influences views on sharing?

1. **The size of the commercial organisation**
2. Conflicts of interest
3. Internationality

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

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

What influences views on sharing?

1. The size of the commercial organisation
2. Conflicts of interest
3. **Internationality**

'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)

What influences views on sharing?

1. The size of the commercial organisation
2. Conflicts of interest
3. **Internationality**

***‘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)***

Overall findings

- Where there is a public and private benefit attitudes to acceptability of sharing with commercial organisations are nuanced
- Profit is acceptable if it doesn't undermine public benefit
- There is also nuance about the kind of commercial organisation
- There is suspicion of insurance companies but not of others

Thank you for listening

@juliet_tizzard

juliet.Tizzard@nhs.net

Follow us on Twitter **@HRA_Latest**

Sign up for our monthly newsletter at **www.hra.nhs.uk**