wellcome trust

Public attitudes to commercial access to health data

The information held in patient records has huge potential to help advance health and medical research. But if this data is going to be used for research purposes, it is essential that the public and patients have confidence in the way that their data is managed and assurance over how it will be used.

Existing research into public attitudes about health data shows that, in general, people are happy for their personal data to be used for research, but it is equally clear that many people feel uncomfortable if a commercial organisation is involved.

The Wellcome Trust, an independent health research foundation, wanted to explore this issue further and find out what people in the UK think about commercial access to health data. In particular, they were interested to see people's perceptions of different types of commercial organisations accessing health data, and what might help make systems for collecting and using their data more trustworthy.

Wellcome therefore commissioned Ipsos MORI to undertake a major piece of social research to examine these questions, involving workshops with more than 200 participants, and a survey of over 2000 people across the UK.

Key factors

The study found that people were largely unaware of how data is already being used within the NHS, let alone by academic researchers, charities and commercial organisations. There was also confusion about whether data is, or could be, identifiable and what anonymisation means in practice.

In workshops, participants learned about several real and potential scenarios involving the use of health data. For example:

- A healthcare analytics company working with an NHS Trust to identify patterns in health outcomes in its hospitals.
- A pharmaceutical company conducting an observational study to look at the long-term effects in the population of a drug they've developed.
- A private health insurance company using anonymised hospital records to help refine their premiums for critical illness cover.

Participants reacted to the idea of these organisations having access to health data very differently. In each case, before accepting the idea of their own data being used, people applied four tests, in the following order:

A strong case for public benefit is the most important factor for many people: without it, data use by any organisation is rarely acceptable.

‘Context collapse’

It was clear from the study that commercial involvement in health research settings creates a new context that people are unsure how to negotiate. We are used to giving doctors information because we expect better care as a result. We are also used to giving information to commercial companies, through transactions or other activities that generate data, as long as we gain services that we value in return. These are distinct, well-established contexts for data sharing, and we have a different mindset in each.

When commercial companies are involved in the health service and in health research, the distinction between these contexts collapses. Unsure whether we are using a service or making a transaction, we find it harder to assess the risks and benefits of our data being made accessible. In these situations, participants in the research were often cautious about the idea of commercial access to their data but struggled to articulate why; they simply had an intuitive sense of discomfort. This suggests traditional norms and paradigms are being challenged, with uncertain consequences.

Survey findings

The survey showed that a slight majority (53%) of people would be happy for their data to be used by commercial organisations if it was for research. Over 60% would rather that commercial research organisations have access to health data than society miss out on the benefits these companies could potentially create. Academic researchers, charities and organisations working in partnership with the public sector were considered the most acceptable users of health data.

Overall, the research showed that most people were extremely wary of insurance and marketing companies using anonymised health data. These companies were seen to be acting against the interests of individuals, motivated by their own private interest with little or no public benefit.

Safeguards and regulation provide reassurance to people but there is no single safeguard or restriction that increases acceptability for everyone. Prevention of third party access to data was cited by 53% of those surveyed as an essential condition for allowing commercial access to health data.

A significant minority of people (17%) objected to private companies having access to health data under any circumstances. This finding has implications for thinking about whether an opt-out should be available for those who do not wish their health data to be used in this way.

Communication

The research also showed that the more informed people were, the more likely they were to approve of their health data being used for other purposes, including by commercial companies. This may explain why findings from the survey did not always match the findings from the workshops: in the workshops, participants learned more about how data is used in and beyond the health service.

The Wellcome Trust believes it is vitally important to engage the public in a wider debate about health data and to explain how people’s data can be used for research. This new report is a contribution to that debate, which could help to determine broadly acceptable practices in the collection, use and sharing of personal data for the future.

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