

How do people feel about their data being shared by the NHS?

From 25 May 2018, people will be able to make a choice about how the NHS uses their confidential patient information for reasons other than their care. We polled over 2,000 people to find out more about their views and concerns on sharing their data.

People's patient records play a vital role in informing medical research and changes to health and social care. Advances in understanding diseases and developing treatments have been possible because of access to patient data, resulting in positive benefits to people. Today, with the help of technology, researchers are making huge advancements in areas such as genomics, which could revolutionise health and care for future generations.

However, a number of recent scandals involving the use of people's data have eroded public trust in the ability of organisations to hold data appropriately. Issues like the use of data collected by Cambridge Analytica and Facebook and the data breach at telecoms company TalkTalk have all kept the issue in the spotlight in recent years.

Data scandals have also hit the NHS. For example, the malicious 'Wannacry' hacking scandal in May 2017 affected around a third of hospitals across England, resulting in thousands of cancelled operations.

This comes at a time when more control than ever is being given to people as to how their data is used by others. On 25 May 2018 the European Union's General Data Protection Regulations (GDPR) will come in to force. On the same day the NHS too will give people the option to opt-out of their confidential information being used for anything other than direct care.

In order to understand more about people's attitudes towards how their data is used, in March Healthwatch England commissioned ComRes to survey 2,000 adults in the UK about their opinions. The survey found that:

- 3 in 4 people (73%) say they would be happy for the NHS to use their patient data to improve the healthcare treatment of others
 - The same proportion (77%) say they are confident in the ability of the NHS to protect their patient data, with the health sector the most trusted ahead of retail, banking and other public services.
 - Just over half (53%) report being more aware of data security issues than they were three years ago.
 - 85% said that they'd heard of the NHS 'Wannacry' hacking scandal, with half (53%) saying it negatively affected their confidence in the ability of the NHS to handle data.
 - People were much less aware of positive initiatives such as the NHS Genomics programme (25%)
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Understanding the issue

With the huge rise over the past few years in the amount of information transferred online on a daily basis, or stored digitally, it has never been more important that organisations are able to handle people's data appropriately.

The amount of available data has the potential to revolutionise the way in which services work for people. For example, the NHS is currently sequencing 100,000 whole human genomes, a project that will lead to better treatment for people with rare diseases.

However, recent scandals in the media around how data is used by organisations have led to the issue coming under increasing scrutiny.

Use of data within the NHS

In 2014, as part of the Five Year Forward View, NHS England committed to making the NHS paperless by 2020.

In October 2015, the Health Secretary outlined *the Government's vision for the use of technology* across the NHS, which included the aim that all doctors and nurses will be able to access the most up-to-date lifesaving information across GP surgeries, ambulance services and A&E departments, no matter where a patient is in England, by the end of 2018. By 2020 this will include the social care system as well.

This commitment built on some of the changes introduced in the 2012 Health and Social Care Act. In particular, the Act allowed for the Health and Social Care Information Centre (now NHS Digital) to collect and share confidential information from health records in order to create a national picture of health patterns so that health care can be improved in the future, called care.data.

However, with concerns raised around how care.data was being communicated to the public, the programme was paused, pending review by Dame Fiona Caldicott, the National Data Guardian.

Wider issues around data privacy have also been brought to public attention by commercial agreements made between the NHS and technology companies. For instance, the agreement made between the Royal Free Hospital NHS Trust and Google's Deep Mind programme to share 1.6m patient records in order to identify patients at risk of kidney disease was subsequently found by the Information Commissioner's Office to have not done enough to safeguard people's data.¹

While the NHS has subsequently worked hard to communicate data initiatives to the public, and has taken on board comments and concerns from a range of stakeholders, including Healthwatch England, it is clear that more needs to be done not only to maintain but strengthen public trust in the ways their data is handled and used.

¹ <http://www.bbc.co.uk/news/technology-40497020>

Our previous work on patient data

Care.data

Healthwatch England and the Healthwatch network have sought to understand people's attitudes towards the use of their confidential patient information since 2013, when care.data was introduced.

Care.data aimed to make better use of patient information to improve care in the future. However, people reported to us that they felt unable to make an informed decision about whether to opt out of the programme. Even if they wanted to opt out, it was not clear how to.

In 2014, after a quarter of the local Healthwatch network [*raised concerns over NHS England's attempts to explain the care.data programme*](#), the programme was paused.

Following the pause, 'pathfinder' projects were introduced in a number of areas of England in order to test out how clearly people were being communicated with about the initiative. Local Healthwatch in Hampshire, Blackburn with Darwen, Leeds, Somerset, Oxfordshire, Bedfordshire, Islington, and Surrey contributed to public engagement in these areas, while Healthwatch England supported activity at a national policy level.

National Data Guardian

At the end of 2014, Dame Fiona Caldicott was appointed as the first National Data Guardian (NDG), to advise the health and care system to help ensure that peoples' confidential information is safeguarded securely and used properly.

In early 2015 we ran a national poll to explore public attitudes on information sharing initiatives and to help inform the National Data Guardian's development of a data consent and opt-out policy. Respondents were broadly in favour of sharing data if it was anonymous, (66% of positive responses) and the majority trusted the NHS, with 58% indicating that they believe their rights as a patient are respected. Only a minority of respondents (22%) reported not being willing to share their data, even if anonymous.

We also published our [*10 principles for good data sharing*](#), and in December provided a [*summary of our conversations with the public*](#) as evidence to the National Data Guardian's review.

Proposals for a patient opt-out

Following the National Data Guardian developing a proposal, we ran an online poll to explore what people thought of it. Those who responded to our survey had mixed views about the level of choice the proposed opt out offered and how confident they were that care services will be able to keep their data safe. One of the most common questions people raised was around the use of anonymised data and what this would mean in practice.

These findings were further reinforced by a national poll of 2,044 UK adults we conducted in early 2016 which showed:

- Two thirds of people agree that if it can help others they are happy to have their data shared.
- When asked well over a third of people agreed that they already identify themselves as 'data donors'.
- However, they want reassurance that their information will be appropriately anonymised and that taking part will not have a negative impact on them.

- Only 1 in 5 said they feel sufficiently informed about how their data will be used, with more than half fearing that they may regret giving permission.
- People told us they wanted the right to opt-out of data initiatives at any point.

Wider work on data

Healthwatch England has also contributed to other national programmes in order to share our insight around people's attitudes to the use of their data. In particular, we took part in the development of the National Information Board's *vision for patients, carers and service users*.

Based on these conversations, we know that there is a real opportunity for the NHS to capitalise on people's openness to granting access to their data. Others, such as the Wellcome Trust's *Understanding Patient Data* project, have found similar things. What is crucial is that services are transparent about when, how and why people's information will be shared.

What people told us

In March 2018, we commissioned ComRes to poll 2,072 people to find out more about their views and concerns on sharing their data.

We asked people a number of questions, including how confident they felt in the ability of the NHS to protect their confidential patient information, how aware they were of a range of data security issues and how happy they would be to have their data used to help improve care for others.

Are people happy to share their patient data?

Overall, most people are positive about sharing their confidential patient information. 73% of adults told us they would be happy for the NHS to use their confidential patient information to improve the healthcare treatment of others.

When compared with other sectors including banking, retail and government, the health sector is also seen as the most trusted in terms of keeping people's data safe and the most likely to use data appropriately.

However, the NHS often needs to bring in the expertise of other organisations to help process and make sense of all the data collected. Whilst the practical need to do this is clear, it still gives rise to concern with two thirds of people telling us they thought they may later regret their confidential patient information being shared with organisations such as technology companies and universities.

More people are aware of data security issues

Just over half of the people we polled (53%) said they were more aware of data security issues than they were three years ago. Similarly 57% also said they were more concerned about how their data generally is being used.

Yet greater awareness does not directly link to greater concern. The research showed that whilst younger people in particular were more likely to be aware of data security issues they were also less likely to be concerned about how their data is used, with 55% of 18-34 year olds concerned compared to 62% of those aged 55+.

Did the hacking of NHS computers in 2017 have an impact on public trust?

The majority of respondents (85%) said they had heard of the hacking scandal that hit the NHS in May last year. More than half (53%) of people who had heard about this told us it made them less confident in the ability of the NHS to protect their confidential patient information.

So whilst overall confidence in the NHS remains high, it is clear that specific crises run the risk of eroding public trust over time.

In contrast, positive data initiatives like the ground breaking Genomics programme, which is seeking to map 100,000 genomes of people with rare diseases, had much lower levels of awareness (25% of adults). They also seemed to have less impact in terms of improving people's perceptions of how data is used.

In focus: The Great North Care Record

Last year Healthwatch Darlington, in partnership with the Connecting Health Cities and Teesside University, led a piece of work across the North East and Cumbria with their neighbouring 12 Local Healthwatch to gain an understanding of people's views on data sharing.

The project informed the Great North Care Record, a programme covering 3.6m people in the North East and North Cumbria that looks to join up patient records so that the NHS, Local Authorities, Universities and other health and care related organisations can work to identify trends and improve people's experiences.

In 2017 they ran a number of focus groups to hear what over 300 people felt was important when sharing health and social care data. People told them that the following issues were important to them:

- People said they want a say in how their data is used, by whom and for what purposes.
 - People recognised the benefits of sharing data for improving health and social care for themselves and others in the community. They said they would like to have access to information held about them, both to see what is in the record and to add additional information that might help their care, like organ donor preferences.
 - People expect to be informed about how their data may be used and to be able to access further information on GNCR and data sharing as and when required. People want governance of data sharing to be managed by both experts and citizens.
 - People expect communication and decision making about data sharing (including information about what data they are happy to share) to be accessible to all regardless of an individual's class, education and literacy, disability, ethnicity, mental health status.
 - People expect institutions handling their data to act in a trustworthy manner and that trust is easily breached. They said health and research institutions are the most trusted institutions; commercial and for-profit organisations the least trusted.
 - People expect their privacy to be maintained, except where they have specifically agreed to share personal information. They recognise privacy as central to the preservation of an individual's sense of self (identity) and that it should not be violated.
 - People expect an even higher level of care for data sharing about potentially stigmatising issues like mental health, reproductive health and sexuality.
 - People want to know that their data is secure and that their preferences are upheld.
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About us

Healthwatch is the independent champion for people who use health and social care services. We exist to ensure that people are at the heart of care.

We listen to what people like about services, and what could be improved, and we share their views with those with the power to make change happen. We also help people find the information they need about services in their area.

We have the power to ensure that people's voices are heard by the government and those running services. As well as seeking the public's views ourselves, we also encourage services to involve people in decisions that affect them. Our sole purpose is to help make care better for people.

Role of local Healthwatch

There is a local Healthwatch in every area of England. They provide information and advice about publicly-funded health and care services. They also go out and speak to local people about what they think of local care, and share what people like and what could be improved with those running services. They share feedback with us at Healthwatch England so that we can spot patterns in people's experiences, and ensure that people's voices are heard on a national level.

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