

Polling indicates growing public understanding about importance of using health and care data

The National Data Guardian for Health and Social Care (NDG) (1) has conducted polling (2) which indicates that the public understands that data is vital for tackling the COVID-19 coronavirus pandemic, but also wants to know more about what is happening and still expects people's confidentiality to be protected.

More than half of survey respondents (56%) agreed that during the coronavirus pandemic, they have learned more about how health and care data can be used to monitor public health and for research (3). Among those working in health and social care this was higher at 69%.

We asked people whether what they have learned during the pandemic has made them more accepting of the need for sharing health and care data. Nearly two thirds (63%) agreed and among health and care workers this was 73%.

Around eight in ten people (78%) agreed that during a public health emergency such as coronavirus, it is more important than usual that health and care data is shared with all those involved in the emergency response. When asked if they would like to know more about how information about them can be used to tackle the coronavirus pandemic, 71% of respondents said they would. Among people working in health and care, 81% would like more information.

A majority (64%) said that they would trust government agencies to use information about them such as coronavirus test results. However, a further 17% did not agree with this and 19% were not sure, showing that it is essential that there is an ongoing focus to build public trust in the use of their information to manage the pandemic.

Looking ahead to how data sharing should take place after the pandemic, seven in ten people (70%) said that, data sharing rules should return to what they were before, with around just one in twenty (7%) disagreeing with this and 23% neither agreeing or disagreeing. At the same time 60% agree that after the pandemic, organisations such as local authorities, university and hospital researchers, and private companies should be allowed to carry on using health and care data to improve care (for all people, not just coronavirus patients).

Dame Fiona Caldicott, the National Data Guardian, said: "By building people's understanding about how their health and care data can be used safely and appropriately for their own individual benefit and for the wider public good, we build public trust for the use of that data.

"During the pandemic we have seen members of the public taking a more active part in discussions that were formerly the domain of experts – such as how

data can be used to track disease spread, show us who is most at risk and reveal what treatment is effective. People have been able to see the immediate relevance and need for data to be used.

“This is encouraging but we should remember that trust is hard-won and easily lost. It is essential that clear reasons and explanations are given to the public if their data is to be used. Appropriate safeguards must be in place to protect confidentiality and data security.

“In the first few months of the pandemic, I was pleased to see emergency measures put into place to ensure data could be used when and where it was needed. As we move into the next phase, it will be important to examine which of these needs to continue and what needs changing. By doing this openly and transparently, we can build on what we are seeing about the readiness for people to allow their data to be used in ways that benefit themselves, their families and others both now and in the future.”

Comparisons with previous surveys

Some of the questions we polled had been previously included in comparable polls.

- We polled levels of trust in the NHS and local authorities. In our July 2020 poll 57% of respondents said they would trust the NHS with data about them and 32% trust local authorities. This compares to 59% and 36% respectively when we polled this question in February 2020.
- Awareness about the National Data Opt-out (NDOP) increased between February and July. We asked survey respondents whether they thought individuals could opt out of sharing their confidential information for medical research and planning. When this question was polled in the weeks the launch of the NDOP in May 2018, 57% said yes. This dropped to 33% in February 2020, and then climbed in our latest poll to 41%.
- After being told about the opt-out, 25% said they were likely to opt-out. This compares to 26% in February 2020 and just 20% May 2018, when a significantly greater proportion said they knew about it. Among those working in health and care, likelihood to opt-out remains much higher – it was 46% in July 2020.

Notes to editors

1. The National Data Guardian for Health and Social Care (NDG) is Dame Fiona Caldicott. The NDG is a statutory role which provides advice and guidance on the use of health and care information. The NDG’s aim is to make sure that the public can trust their confidential information is securely safeguarded and make sure that it is used to support care and

to achieve better outcomes from health and care services.

2. The NDG commissioned a survey of 2,114 adults in England which was carried out by Kantar between July 30 and August 6 and included a variety of breakdowns, including individuals who work in health and social care. Polling was conducted by Kantar in England via OnLineBus, an Internet omnibus survey on a sample size of between July 30 and August 6 2020. Interviewing was conducted by online self-completion from 25/04/2019 – 02/05/2019. The sample has been weighted to represent the adult population of England 16+.
3. A further 18% disagreed and 26% neither agreed nor disagreed.
4. Where numbers do not add up to 100, this is due to rounding.
5. For further information contact Jenny Westaway, Head of the Office of the National Data Guardian on j.westaway@nhs.net or 07827 955 604