

# [NDG poll findings: public attitudes to organisations innovating with NHS data](#)

Dame Fiona Caldicott, the National Data Guardian for Health and Social Care (NDG) is calling for a public debate to shape the future of commercial relationships between the NHS, universities and private companies. She today releases the results of a poll on public attitudes to NHS organisations working with partners to use data to develop new medicines and technologies to improve health. The NDG commissioned the polling to inform [her own priority setting for the coming year](#).

The poll of more than 2,220 people in England tested what the public thought would be fair when partnerships with universities or private companies result in valuable new discoveries that could be traded commercially. It presented a range of benefits that result from such partnerships, including improved care for patients, financial benefits for the NHS and profits being made by partner organisations.

The polling found strong support for the idea that NHS and patients should benefit from such partnerships. Around seven in ten approved of partnerships resulting in benefits such as access to new technologies at a reduced cost and improved patient care. Around half agreed that it is fair that a partner university or private companies make a profit, with slightly higher proportions supporting the propositions in which the NHS benefited financially. Among those who said they were already aware that such collaborations take place, there was stronger agreement that it was fair that partners and the NHS make a profit.

It was striking that significant proportions of respondents said they neither agreed nor disagreed with whether the range of benefits was fair. More than a third did not give views on questions about profits being made by partners or by the NHS.

The National Data Guardian believes this may be because these are issues that have not been discussed sufficiently with the public and that exploration and discussion with patients is necessary. She welcomes that a first step in this is being taken by [Understanding Patient Data working alongside the Ada Lovelace Institute](#) and NHS England to commission research to find out what people think and feel about different partnership models between the NHS and private companies wishing to use NHS data. She also welcomes work by the [Office for Life Sciences to develop a framework](#) to realise the benefits for patients and the NHS where data underpins innovation.

The National Data Guardian said:

“Great benefits can be reaped for all of us if we can use the rich information that is held by the health and care system safely, carefully and with the agreement of the public and patients. The NHS cannot do this alone. We need to work with universities and the private sector to find new

medicines, develop cutting-edge technologies, uncover insights from our data.

“Some of the public clearly are beginning to have views about how benefits from patient data can be shared for the benefit of the NHS. Supporting and extending this public conversation is crucial if we are to gain from the rich information held safely in the health and care system and retain public trust.”

The poll showed:

## **NHS benefits**

- More than half agree that it is fair that the NHS shares in a profit with a partner university (58%) or partner private company (56%).
- Nearly one in ten (9%) disagree with the NHS sharing in a profit with a partner private company and 6% disagree with the NHS doing this with a partner university.
- However, more than a third did not give a view and said that they neither agreed or disagreed with the NHS sharing in profit (36% for the NHS doing this with a partner university and 35% with a partner private company).
- Half (50%) were happy to support the idea of the NHS receiving a one-off payment from the partner university or company for using NHS data.
- Benefits other than profit garnered even more support. A large majority (73%) agreed that the NHS should benefit in other ways, for example, by getting access to new technologies or medicines at a reduced cost. A large majority (77%) agreed that “The main benefit for NHS patients is improved care and treatment”.

## **Partners making profits**

- Half of people strongly agree or agree that it is fair that a profit is made by a partner university (49%) or a partner private company (51%).
- Nearly one in ten (9%) disagree to a partner university doing this, and slightly more (13%) to a partner private company.
- A significant proportion neither agreed or disagreed that it is fair that a profit is made by a partner university (41%) or a partner private company (36%).

## Breakdowns by groups

- Among those who are aware that such collaborations take place: 59% agree that it is fair that universities make a profit; 60% agree that it is fair that companies do this; 66% agree that it is fair that the NHS shares in a profit with a partner university and 65% agree that it is fair that the NHS shares in a profit with a partner company.
- Among those who are not aware: 39% agree that it's fair for partner universities to make a profit; 38% for partner companies; and 49% agree that it is fair that the NHS shares in a profit with a partner university and 46% agree that it is fair that the NHS shares in a profit with a partner company.
- Men are more likely to agree than women that it is fair that a profit is made by a partner university (55% of men agree versus 44% of women) private company (57% of men versus 44% of women) or that the NHS shares in profit (60% of men versus 55% of women) with a partner university and with a partner company (60% of men versus 53% of women).
- There is also a difference by social grade: 53% in those classed as ABC1 and 45% in C2DE agree that it is fair that a profit is made by a partner university; 54% in ABC1 and 47% in C2DE agree that a profit is made by a partner private company; 62% in ABC1 and 52% in C2DE agree in the NHS sharing in profit with a partner university; 61% in ABC1 and 51% in C2DE agree in the NHS sharing in profit with a partner private company.
- Looking at responses by region, Londoners are most likely to agree that it is fair that a profit is made, with 61% agreeing where the partner is a university and 64% when it is a company. Those in the South West are the least likely, 40% agreeing where the partner is a university and 45% when it is a company.

## Notes to editors

1. Polling was conducted by Kantar in England via OnLineBus, an Internet omnibus survey on a sample size of 2,201. 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+.
2. A variety of case studies on the use of data to develop new technologies and improve care – including in partnership with universities and private companies [has been published by Understanding Patient Data](#).
3. The full polling results tables are published on this page. The poll

asked two questions:

### **Question 1**

Whenever we go to a doctor or a hospital, they collect data about us which is recorded and stored in our patient record. It may include information such as height and weight, what aches, pains or infections we've got, what medications we are taking, results of blood tests etc.

The NHS therefore holds a lot of information about patients. When data from many patients is linked up and put together, it can be used by researchers and scientists to spot patterns so that they can develop new ways to predict, diagnose or treat illness. This linked information is often anonymous so that individuals cannot be identified. There are rules to stop patient information being used by insurers or marketing companies without patients' consent.

NHS organisations do not always have the expertise needed to do the work of linking and analysing large amounts of data on their own. So they sometimes work in collaboration with researchers, scientists and inventors in universities or private companies. New medicines and technologies can then be developed to treat patients. Are you aware that some NHS organisations work in partnership with private companies and universities to use NHS patient data to develop new medicines and technologies to improve health?

Yes

No

Not sure

### **Question 2**

Sometimes these partnerships result in valuable discoveries that could be traded commercially in this country and abroad. For instance, an NHS organisation might use the information it has about patients to work with if a university or technology company. The result could be a new medicine or a new computer programme that spots disease faster. It could be possible to make a profit from this discovery and help the NHS provide better care.

To what extent do you agree with these statements:

It is fair that when partnerships between the NHS and universities or private companies lead to valuable new discoveries:

- A profit is made by a partner university
- A profit is made by a private company
- The NHS shares in profit with a partner university

- The NHS shares in profit with a private company
- The NHS receives a one-off payment by the partner university or company for using NHS data
- The NHS benefits by receiving additional data analysis that it can use in the future for other research
- The NHS benefits in other ways, for example, by getting access to new technologies or medicines at a reduced cost
- The main benefit for NHS patients is improved care and treatment

Strongly agree

Agree

Neither agree nor disagree

Disagree

Disagree strongly

### **Polling results tables**

The spreadsheet below provide a full statistical breakdown for the survey.

[NDG polling results breakdown by question](#) (MS Excel Spreadsheet, 731KB)

[NDG polling results breakdown by question](#) (ODS, 371KB)