

# Transparency and public engagement are essential to demonstrating that data is being used for public benefit

News story

Today we are publishing the findings of a dialogue with more than 100 members of the public about how to make sure health and care data is used in ways that benefit people and society.



Today we are [publishing the findings of a dialogue](#) with more than 100 members of the public about how to make sure health and care data is used in ways that benefit people and society.

The National Data Guardian (NDG) will use the insights to develop guidance to support people making decisions about access to data for research and innovation.

The report is part of the Putting Good into Practice project, which is co-funded by the National Data Guardian for Health and Care, [Understanding Patient Data](#) (UPD) and UK Research and Innovation's [Sciencewise](#) programme.

## **Key findings of the report include:**

1. Transparency cannot be separated from public benefit. It is not an add-on or nice to have. Public benefit can only be demonstrated if the value of using data is explained to society.
2. To demonstrate public benefit, transparency is required throughout the whole data life cycle. This includes during collection, storage, assessment and use of data, not just at the point of an application or decision being made to use data.
3. Public benefit is undermined if authentic public engagement is not

integrated into decisions about use of data. This means engaging people from a cross-section of society in assessing how data is used.

### **Areas that matter most to dialogue participants:**

1. Being ambitious for the use of health and care data in research and innovation. Public benefit can be achieved through using data for collaboration, exploratory research, and new developments, such as drugs, treatments and services.
2. Identifiable and sensitive data should be treated with the utmost care. If it is, it has the potential to bring public benefits.
3. The benefits from the use of health and social care data must be fairly distributed, with protections against discrimination and unjustified geographic disparities.
4. Safeguards are needed to protect society from data manipulation, especially where data could be used to achieve political or financial ends.
5. Public benefit must outweigh profit, with profitable uses of data rigorously scrutinised before data is used.

Previous research has shown that 'public benefit' is the crucial condition for most members of the public to support the use of health and care data for purposes beyond their own individual care. However, what exactly is meant by public benefit is often not clear, so the NDG and UPD wanted to find out more, with a view to producing practical guidance that would help organisations evaluate public benefit. The guidance will encourage greater consistency for decisions about whether health and care data should be used for research, planning and innovation.

The public dialogue was designed and managed by deliberative engagement specialists [Hopkins Van Mil](#) and supported by Sciencewise. It involved 112 participants recruited in a 50-mile radius from four locations: Great Yarmouth, Stockport, Plymouth and Reading. Each participant attended five online dialogue events, with the opportunity to interact and discuss the topic with policymakers and specialists before coming to their own conclusions and recommendations. The dialogue was independently evaluated by [3KQ](#).

A cross section of the original dialogue participants will reconvene this summer as the NDG develops the new statutory guidance. Participants will discuss the draft guidance with data users, data custodians and policymakers to check it meets their expectations.

[Read the report.](#)

Published 14 April 2021

---

## [Statement by Minister Duddridge on the Somalia elections: 13 April 2020](#)

Press release

Statement by James Duddridge on the decision of the Lower House of the Somali Parliament to extend the mandates of Mohamed Farmajo as President and of the Somali Parliament by two years.



We are dismayed by the decision of the Lower House of the Somali Parliament to extend the mandates of Mohamed Farmajo as President and of the Somali Parliament by two years. This is not a solution to the ongoing impasse on the electoral process, but instead a move that undermines the credibility of Somalia's leadership and risks the safety and future of the Somali people.

We have consistently opposed any initiatives leading to a parallel process, partial election or an extension of prior mandates. We urge Somalia's leaders to refrain from any further unilateral actions that may escalate political tensions or violence. It is vital that all parties remain calm and protect Somalia's stability and security.

Constructive dialogue between Somali leaders is central to ensuring implementation of the 17 September agreement on the electoral model. That agreement is the only legitimate basis for elections. Now is the time for Somalia's leaders to look beyond narrow self-interest and uphold their responsibilities to the people of

Somalia. We urge Somalia's leaders to return to talks immediately to find practical solutions and reach agreement on remaining issues, demonstrating restraint and compromise.

In the absence of consensus leading to inclusive and credible elections being held without further delay, the international community's relationship with Somalia's leadership will change. The UK will work with its international partners on a common approach to re-evaluate our relationship and the nature of our assistance to Somalia.

Published 13 April 2021

---

## [PM call with King Abdullah II of Jordan: 13 April 2021](#)

Press release

The Prime Minister spoke to His Majesty King Abdullah II of Jordan this afternoon.



The Prime Minister spoke to His Majesty King Abdullah II of Jordan this afternoon.

He congratulated the King on the occasion of Jordan's centenary, noting the close relationship between our two countries over the last 100 years and hopes to strengthen that partnership even further in the future.

King Abdullah also passed on his deepest condolences on the death of HRH the Duke of Edinburgh, a long-standing friend and supporter of Jordan.

The leaders agreed to continue working together to ensure regional stability and prosperity. The Prime Minister commended Jordan's constructive role in

the Middle East Peace Process and custodianship of the holy sites in Jerusalem.

They also discussed the global response to Covid-19, as well as climate change and efforts to protect biodiversity in the Middle East ahead of COP26.

Published 13 April 2021

---

## [Surge testing to be deployed in Southwark](#)

Press release

NHS Test and Trace is providing additional testing in a targeted area within Southwark, South London where the variant first identified in South Africa has been found.



Working in partnership with the local authority, NHS Test and Trace is providing additional testing and genomic sequencing in a targeted area within SE16 in Southwark where an additional confirmed case of the variant first identified in South Africa has been found.

Genomic sequencing results indicate that this case is linked to the cluster identified in Lambeth and Wandsworth. The confirmed case is self-isolating and their contacts have been identified.

This targeted approach will contact certain households in Southwark, due to lower confirmed case numbers. These households will either get a leaflet asking them to get a test from a specially deployed mobile testing unit, or be asked to complete a home kit by a door-to-door team. Everybody aged 11 years and over in this area who is contacted and invited to take part is strongly encouraged to take a COVID-19 PCR test, whether they are showing symptoms or not.

Enhanced contact tracing is used for individuals testing positive with a variant of concern. This is where contact tracers look back over an extended period in order to determine the route of transmission.

By using PCR testing, positive results can be sent for genomic sequencing at specialist laboratories, helping us to identify variant of concern cases and their spread. People in this area should continue using twice-weekly rapid testing alongside the PCR test as part of surge testing.

People with symptoms should book a free test online or by phone so they can get tested at a testing site or have a testing kit sent to them at home. Those without symptoms should visit the local authority website for more information: <https://www.southwark.gov.uk/>

Dr Kevin Fenton, Regional Director, PHE London and Regional Director of Public Health, NHS London:

The cluster of cases in parts of South London – predominantly the Lambeth and Wandsworth areas but also in Southwark – of the variant first identified in South Africa is significant. It's really important people in the local area play their part in stopping any further spread within the local community.

PCR testing is now available for all and I would strongly encourage everyone in Southwark who is invited to take part to get tested, even if they don't have any symptoms of coronavirus.

Around 1 in 3 people with COVID-19 don't show any symptoms. By taking part you can protect yourselves and your loved ones and help us identify any possible new cases that would otherwise be missed, preventing further transmission and saving lives.

Published 13 April 2021

---

## **Remaining university students to return to campus from Step 3 of the roadmap, no earlier than 17 May**

- All students to return to in-person teaching from Step 3 of the Government's roadmap, no earlier than 17 May
- New home testing kits provided to students to increase testing uptake and help limit virus transmission

All university students who have not yet returned to campus and in-person teaching will be able to do so from 17 May, at the earliest, the Government has confirmed today (Tuesday 13 April).

The timing aligns with Step 3 of the Government's roadmap, where restrictions on social contact and indoor mixing will be further eased, and aims to limit potential public health risks associated with student populations moving across the country.

Progression to Step 3 of the roadmap will be dependent on a review of the latest data and the impact of Step 2 on the four key tests.

Creative and practical students started returning from the 8 March, with an estimated 49 per cent of students already eligible to return to in-person teaching, subject to decisions by their institutions, and remaining students have received online provision throughout the term.

Upon return, all students and staff are encouraged to take three supervised tests (3 to 5 days apart) at an asymptomatic testing site on campus, where this is available.

After this, students will also have access to home testing kits throughout the summer term through both the Government's offer of free rapid LFD tests twice weekly to everyone in England, and 'University Collect' services, under which universities will distribute tests from communal locations on campus, such as libraries. This is in addition to the onsite testing already offered.

All tests will be free, and all students and staff who test positive from an LFD test will need to self-isolate for 10 days, unless they receive a negative PCR test within two days.

The Government has made available an additional £15 million in hardship funding to support those students most in need, such as those struggling to pay accommodation costs due to the pandemic. International and postgraduate students will be eligible for this funding along with domestic undergraduates.