

Department of Health & Social Care Other logos from Devolved Administrations as appropriate

# **COVID-19 Infection Survey**

Dear participant,

Thank you for your continued participation in the COVID-19 Infection Survey. With more than 1.5 million swab samples gathered so far, your household is one of many thousands providing vital information to help the response to the virus in communities across the UK. You can see the latest findings on www.ons.gov.uk and www.ndm.ox.ac.uk/covid-19/covid-19-infection-survey/results.

We've have been listening to participants and addressing issues they've raised with us. It's led to some important changes to how we conduct the survey. This short update summarises these changes.

### GPs

We no longer pass your results onto your GP. If you joined the study from October, we no longer tell your GP that you are in the survey.

## Getting results back

We now send your results directly back to you. At the moment this is done by letter. Parents/carers will get letters for children.

The COVID-19 Infection Survey is a research study, not a testing programme. Tests from this research study have to take lower priority than tests from the national testing programmes and clinical service. This is because our positivity rates are lower, because we are testing people in the community as part of research, rather than testing people with symptoms. Our tests, which are mostly on people without COVID-19, cannot be prioritised over testing those with symptoms, where the percentage positive is much higher and so will identify more positive individuals overall.

In the research study, it takes a day to get the swab to the labs, then it can take up to 3-4 days to do the tests. Results are sent back every weekday morning from the labs to the research study. Once results come back, they are matched to participants through a sample barcode and letters sent out. So it typically takes at least a week before people get their test results.

If one of your throat and nose swab tests positive, as soon as we receive the result back from the labs (but still with the delay above) we immediately pass the result onto the national tracing programme. They will then contact you, **and this will almost certainly be before you get this positive result back from the study**. Please follow their advice.

Because of this delay, it is very important that if you develop symptoms of COVID-19 you follow the usual guidance on self-isolation for where you live. Even if you have had a recent test done in this survey and have developed symptoms, do not wait for its results before self-isolating. Please follow the guidance on getting a test for your area and do not wait for the results from any test done in the survey.

As required by law, at the moment we will share your positive swab test result and personal data (including your name, contact details, postcode and ethnicity) with [AMEND AS APPROPRIATE BASED ON COUNTRY] Public Health England for referral to the NHS Test and Trace system/Public Health Wales for referral to the NHS Wales Test, Trace, Protect system/the Public Health Agency for referral to the HSC Northern Ireland's Test and Contact Tracing programme/ NHS Inform for referral to the Test and Protect system ([DELETE AS APPROPRIATE BASED ON COUNTRY] https://contact-tracing.phe.gov.uk/ https://gov.wales/contact-tracing-if-you-havetested-positive/ https://www.publichealth.hscni.net/covid-19-coronavirus/testingand-tracing-covid-19 https://www.nhsinform.scot/campaigns/test-and-protect).

[ENGLAND] However, the law has changed, which means that we need to update information related to confidentiality and sharing of your personal information as part of this research study. The UK Government's Health Protection (Notification) (Amendment) (Coronavirus) Regulations 2020 require that, from 23 November 2020, all results of laboratory and point of care tests for COVID-19 and Influenza must be reported to Public Health England. This is an expansion of the 2010 regulations, which required only notification of positive cases.

Positive, negative, unclear or void results must be reported with the following information from the survey:

•	first name
•	surname
•	sex
•	date of birth

ethnicity

current address (including postcode)

 telephone number (only for SARS-CoV-2 (COVID-19) positive or unclear results)

email address (only for SARS-CoV-2 (COVID-19) positive or unclear results)

The regulation is at

https://www.legislation.gov.uk/uksi/2020/1175/regulation/4/made

with further explanation at

https://www.legislation.gov.uk/uksi/2020/1175/memorandum/contents

Your participation in this research is voluntary. If this requirement to share data changes your willingness to participate in this research, please discuss this with the study team.

[WALES/NORTHERN IRELAND/SCOTLAND] However, the law is in the process of changing. When it does we will share this small amount of personal data with the national tracing programmes for all the tests done in the study.

You will then receive all your swab test results through the national tracing programme, and this should be faster. This will happen through the national NPex system which is a secure infrastructure provided by the NHS. **By taking part in this survey you agree to this disclosure taking place.** 

#### **Arranging visits**

Visits will be arranged by a survey team member calling you the evening before they plan to conduct each visit at your home. You will be able to say whether or not this is convenient and change the time as needed. Your visit is not confirmed until you have received the phone call from the survey team member **so please do not wait in if you have not heard from them**.

### How we use your data

Please note that if you signed up to take part in the study before 21 July 2020 there has been a small change to the way in which information from participants in the COVID-19 Infection Survey is to be used by the Office for National Statistics (ONS). The ONS and [WALES the Welsh Government/NORTHERN IRELAND the Northern Ireland Statistics and Research Agency (NISRA)/ SCOTLAND the Scottish Administration (see section 53a of the Statistics and Registration Service Act)] intend to link data from the survey to other survey and administrative data sets it/they holds, where it is lawful and ethical to do so. This will be beneficial in providing more in-depth analysis, which in turn will enable us to better understand the impact and nature of COVID-19 and answer critical questions to assist public health authorities and policy makers in better responding to the pandemic in the months ahead. This analysis is not part of the Infection Survey itself. Such linkage will continue for as long as there is value for statistical research and analysis.

The ONS and the relevant organisations from the Devolved Administrations may provide access to this data to accredited processors and researchers for accredited research purposes via accredited processing environments, where it is lawful and ethical to do so, and where the research is considered to be in the public good. It will not be possible to identify individuals from this data. Data will only be used for statistical research and analysis purposes and will not be shared with anyone else (other than access by accredited researchers). A full list of accredited processors is available at https://uksa.statisticsauthority.gov.uk/digitaleconomyact-researchstatistics/better-access-to-data-for-research-information-for-processors/list-ofdigital-economy-act-accredited-processing-environments/.

# Thank you for taking part.

The most up to date versions of the study information sheets and the protocol are available on <u>https://www.ndm.ox.ac.uk/covid-19/covid-19/covid-19-infection-survey/protocol-and-information-sheets</u>

You can find all the latest results on <u>https://www.ndm.ox.ac.uk/covid-</u> <u>19/covid-19-infection-survey/results</u>