

## COVID-19 Infection Survey

# Participant information sheet for Adults

(Including parents and carers)  
and Adolescents 16 years and older



Study Contact: **0800 085 6807**

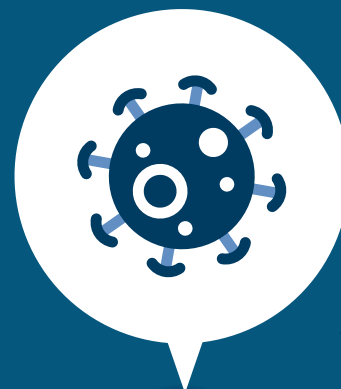
 [www.COVIDSurvey.ons.gov.uk](https://www.COVIDSurvey.ons.gov.uk)

 [www.ons.gov.uk/cis](https://www.ons.gov.uk/cis)

# COVID-19 Infection Survey

**We would like to invite you to take part in our research survey.**

Before you decide, it is important that you understand why the research is being done and what it would involve for you. Please take time to read this information and discuss it with others if you wish. If there is anything that is not clear, or if you would like more information, **please call 0800 085 6807.**



It is important to understand that this is a research study, and not a testing programme. We send participants their test results from the survey, but this may not happen as quickly as results used to come from the national testing programmes.

**[www.ons.gov.uk/cis](http://www.ons.gov.uk/cis)**

## What information is in this leaflet?

What is the purpose of the survey?	3	Useful links about your data	20
Why are we doing this research?	3	What will happen if I don't want to carry on with the survey?	20
How have I been invited?	4	What will happen if I move home?	21
Who can take part?	4	What happens at the end of the survey?	21
Do I have to take part?	5	What if we find something unexpected?	21
How do I take part?	5	What if there is a problem?	21
What will happen in my testing windows?	6	How have patients and the public been involved in this survey?	21
Booking a courier	9	Who is organising and funding the survey?	22
Damaged or missing kits	10	Who has reviewed the survey?	22
What will happen after my first testing window?	11	Your views are essential to us	22
What are the possible benefits of taking part?	12	Further information and contact details	23
Will I be told my results?	12		
What should I do if my test result is positive?	13		
What if I develop symptoms?	15		
Are there any possible disadvantages or risks from taking part?	15		
What do I get for taking part?	16		
Will my taking part in the survey be kept confidential?	17		
What will happen to the samples I give?	17		
What will happen to my data?	18		

## What is the purpose of the survey?

The coronavirus (COVID-19) pandemic has had a major impact at both a UK-wide and an individual country level. This survey aims to find out how many people of different ages:

- are still getting COVID-19, with or without symptoms
- previously had COVID-19, with or without symptoms
- still have a strong immune response to a COVID-19 vaccination

This is particularly important as more people are vaccinated against COVID-19 with “boosters” and more people get COVID-19. We need to monitor how many people are still testing positive for COVID-19, with or without symptoms and see how vaccinations and having had COVID-19 before affect our risk of getting COVID-19 in the future. We also need to work out who might need vaccinating in the future.

Although the vaccines work well, they do not completely stop people getting the virus, or getting it again, and neither does having had COVID-19 in the past. As individuals, we all respond differently to infections and vaccinations, and it is the impact of these differences that we are trying to understand. The information we get from people like you taking part in the survey will help scientists and the government work out how to deal with COVID-19.

## Why are we doing this research?

We test for current COVID-19 infection by using a swab taken from someone’s throat and nose. Once someone has completely recovered from the infection, the virus can no longer be found in their throat and nose. But one way the body fights infections like COVID-19 is by producing “antibodies”. It takes at least 2-3 weeks for the body to make enough of these antibodies to fight the infection. When someone gets better, these antibodies stay in their blood at low levels and give some protection against future infection. Getting vaccinated against COVID-19 is another way to help people develop antibodies that can protect them against getting COVID-19.

However, **not everybody develops the same number of antibodies.**

So scientists try to measure levels of both the virus and these antibodies to work out who has COVID-19 now (with or without symptoms) and who has had it in the past, or has developed antibodies against it after getting vaccinated.

However, it is very important to understand that we do not yet know what having different amounts of antibodies means in terms of exactly how likely you are to get COVID-19 again, particularly with different variants of coronavirus.

## How have I been invited?

If you live in England, Wales or Scotland, then for either this survey, or a previous survey run by the Office for National Statistics, your address was randomly selected from a database called AddressBase, which is maintained by the Ordnance Survey. It contains details for 40 million residential and business addresses.

If you live in Northern Ireland, for either this survey, or a previous survey run by the Northern Ireland Statistics and Research Agency (NISRA), such as the NISRA COVID Opinions Survey, your address was randomly selected from the NISRA Address Register primarily based on the Land and Property Services POINTER database.

Your household has been invited to have swab tests for virus from the throat and nose and to have blood tests for antibodies.

## Who can take part?

In this survey, we are asking for all adults, teenagers and children aged 2 years and over currently resident in your household to take part.

- By **"currently resident"**, we mean a person who typically stays overnight in the household address at least four nights out of seven.
- A **"household"** is defined as one person living alone; or a group of people (not necessarily related) living at the same address who share cooking facilities and share a living room or sitting room or dining area.

The only exception is adults who are not able to consent for themselves. Taking part will not affect the medical care you receive and there is no effect on any regular medication or other prescribed or over-the-counter medicines you might be taking. It is also fine to take part if you are involved in other research studies or surveys.

Please talk to any children and young people in your home about whether they would like to take part. Information Sheets written specifically for children can be found at [www.ndm.ox.ac.uk/covid-19/covid-19-infection-survey/protocol-and-information-sheets](http://www.ndm.ox.ac.uk/covid-19/covid-19-infection-survey/protocol-and-information-sheets) or requested by calling **0800 085 6807**.

## Do I have to take part?

No, taking part is your choice. Everyone in your home can make a different choice – it is not necessary for everyone to do the same. Anyone who takes part may withdraw from the survey at any time without giving a reason. Parents/carers may also withdraw their child from the survey at any time without giving a reason.

## How do I take part?

To register to take part in the survey, please call **0800 085 6807 for free**. You will need your household ID which you can find on your invite letter.

On this phone call, once you have had any questions you have answered, you will be asked to formally agree to take part – this is called ‘informed consent’. Everyone aged 16 or over will need to register and consent themselves. Parents or carers will need to register and consent on behalf of children under 16 years old.

If an older child or teenager (10-15 years) in your home wants to join the survey, we will also ask them whether they are happy to be in the survey when you call to register. For younger children aged 2-9 years, we will just ask their parent or carer to confirm this, although it is important that the child is also happy about this.

On the registration call, one person will be asked about the number and age of the people who live in the house who may also want to take part. We will also ask some questions about each person aged 2 years or older in your home who wants to take part, **including**:

- Sex
- Ethnicity
- Date of birth

You can call between 9am – 9pm Monday to Thursday, 9am – 8pm Friday, and 9am – 5pm Saturdays and Sundays. If the phone line is busy, we will aim to call you back as soon as possible.

If you have accessibility needs and require additional support, please call **0800 085 6807** or email **[iqvia.covid19survey@nhs.net](mailto:iqvia.covid19survey@nhs.net)**

**Ideally, everyone in your home who would like to take part should be available when you call.** If someone who wants to take part cannot be available when you call us, they will have 7 days after this to call themselves. If they do not call us within 7 days, they will not be able to take part. Once you have agreed to join the survey, the next time you will hear from us is when we securely send you a copy of your consent form, your unique participant ID, a step-by-step guide about what will happen in the survey, and guides on how to take your samples.

Your participant ID is a coded number that is unique to you and that the survey uses to link your test results and questionnaire data, without having to use your name.

We will post swab and blood test kits to everyone in your home who joins the survey. We will also ask each person who joins the survey to answer some questions online or over the telephone, depending on what they prefer, when they take their samples.

We will tell you when the test kits are about to be posted to you by email or letter, depending on what you prefer. We will also tell you when your **'testing window'** is. Your testing window is the number of days which you have to answer the questions in the questionnaire, and take and return your swab and blood samples. **Everyone in your home who joins the survey will have the same testing window.** We give you a testing window so that you can take part at a time that suits you.

We aim to start your first testing window around 16 days after the first person in your home registers, but it may take longer than this if lots of people register for the survey at the same time. This gives other people in your home time to call to join the survey themselves, and for us to give you enough notice of when your first testing window will be.

## What will happen in my testing windows?

We will ask everyone in your home aged 2 years and over who joins the survey to give a swab sample from their throat and nose using a kit that we will send to you in the post. The test kits fit through the letterbox.

At first, we will ask you to take your swab sample and complete your questionnaire once every week, for 4 weeks in a row. These first 4 testing windows will be 7 days long, because we will ask you to take your samples and complete the questionnaire once every week. If you agree, we would also like you to take a blood sample with your first swab sample. Having about a week between the days you take your samples and complete your questionnaire for these weekly testing windows means we can capture any changes in your test results better.

Then, we will ask you to take your swab and blood samples and complete your questionnaire once every month from your first testing window until the survey ends. These monthly testing windows will be 14 days long.

We will tell you by email or letter, depending on what you prefer, when the test kits are about to be posted to you and the dates of your testing window. Choosing to get this information by email is quicker, because you will not have to wait for the letter to be delivered. The email will come from **[noreply@medcomms.iqvia.com](mailto:noreply@medcomms.iqvia.com)**



Within each testing window, we will ask you to:

- ① First, take your swab and blood samples
- ② Then, complete and submit the questionnaire
- ③ Then, send your samples back to us

**You should do all three on the same day and within your testing window.**

**You can do this on a different day to anyone else in your home who is in the survey, as long as it is in the testing window.**

The swab will tell us whether you currently have COVID-19 - you should take your swab even if you think or know you have COVID-19 to make sure we know this. Taking the swab is easy; it is the same swab test that has been used in the national testing programmes. Anyone aged 12 years and over can take the swab themselves. We will ask the parent/carer to take the swab from children aged 2-11 years. The swabs are the same size as normally used for children.

We would also like **those aged 16 years or older** to take a blood sample to measure levels of antibodies. You will do this yourself by taking a small amount of blood (around 0.5ml) from a finger prick, using a kit that we will also send to you in the post.

You do not have to do this part of the survey if you do not want to. And you can always change your mind at each testing window.

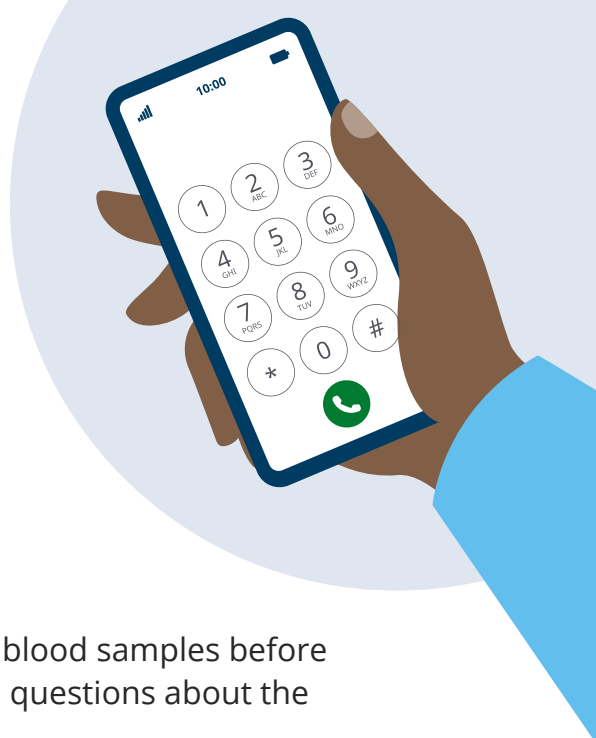
We will send you more information on how to take a swab and blood sample after you have called to join the survey. You can request a paper copy by calling **0800 085 6807** or you can view the guides online at **[www.ndm.ox.ac.uk/covid-19/covid-19-infection-survey/protocol-and-information-sheets](http://www.ndm.ox.ac.uk/covid-19/covid-19-infection-survey/protocol-and-information-sheets)**

You can watch a video that shows how to take your blood with a finger prick test at **[www.ndm.ox.ac.uk/covid-19/covid-19-infection-survey/guides](http://www.ndm.ox.ac.uk/covid-19/covid-19-infection-survey/guides)** and a video that shows how to take a swab at **[www.ndm.ox.ac.uk/covid-19/covid-19-infection-survey/guides](http://www.ndm.ox.ac.uk/covid-19/covid-19-infection-survey/guides)**

**The questionnaire we ask you to do in each testing window will ask you about:**

- any symptoms you may have now
- contacts with someone who had COVID-19
- contacts you have outside the home, including travel abroad
- occupation and questions about work, or school for those still at school
- whether you have had COVID-19 in the past, and symptoms you had then
- whether you have ongoing symptoms from having had COVID-19 (called “long COVID”)
- your health in general, including COVID-19 and flu vaccinations





If you take part, we will ask you to take your swab and blood samples before completing the questionnaire, as we will ask you some questions about the samples in it.

To complete the questionnaire, you will need your **participant ID**. This is a coded number that is unique to you and that the survey uses to link your test results and questionnaire data, without having to use your name. We will send you this if you agree to join the survey.

To make sure that the survey is being done properly, we will telephone a small number of participants to ask how their testing window went. You do not have to take these calls if you do not want to.

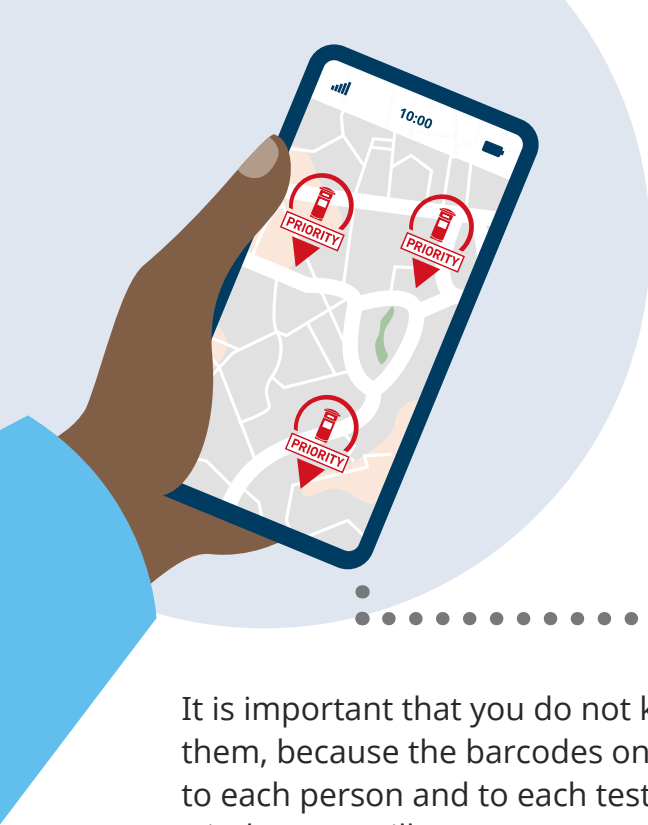
**To do the questionnaire online, you will go to [www.COVIDSurvey.ons.gov.uk](http://www.COVIDSurvey.ons.gov.uk) after taking your samples.**

If you are unable to do the questionnaire online, you can **complete the questionnaire over the phone by calling 0800 085 6807**.

You will need to call after taking your samples and between 9am – 9pm Monday to Thursday, 9am - 8pm Friday, and 9am – 5pm Saturdays and Sundays. If the phone line is busy, we will aim to call you back as soon as possible.

**If you will not be able to take your samples and complete the questionnaire during the testing window, or do not want to take part that time**, you will be able to let us know online at [www.COVIDSurvey.ons.gov.uk](http://www.COVIDSurvey.ons.gov.uk) or by calling **0800 085 6807**. You will have 4 days to let us know you will not be taking part each time. It is really important that you tell us if you cannot take your samples, so we can reduce waste and make sure we do not send you test kits that will not be used. If you would prefer not to take a blood sample at any testing window, you can choose to just take your swab sample and complete the questionnaire. If you let us know this means we will not send you a blood test kit that testing window. You can also decide on the day if you want to take a blood sample or not.

We understand that plans can change. If you do not let us know you cannot take your samples within 4 days, this is OK, but **you will need to throw your test kits away in your household bin**.



It is important that you do not keep the tests kits or let someone else use them, because the barcodes on the test kits we send you each time are specific to each person and to each testing window. If you do not take part for one testing window, we will contact you as usual when your next testing window is coming up. **Please do not return any unused test kits to us.**

We will ask you to return your samples via a **Royal Mail priority post box** wherever possible. A priority post box is a special type of post box that is collected from more often.

To make returning the samples as easy as possible for you, we have already paid the postage. You can find your nearest priority post box and the collection times on [www.royalmail.com/services-near-you#/](http://www.royalmail.com/services-near-you#/) If you cannot access the internet, we can search for your nearest priority post box when you call to let us know you would like to take part in the survey.

If you are unable to get to the priority post box yourself, someone else can take the samples to the post box for you. This can be someone from outside your home.

## Booking a courier

If you cannot find someone to help you, you can arrange a pre-paid courier to collect your samples. Couriers will be available Monday to Friday, and you may need to stay at home for up to 4 hours for the courier to collect your samples but this could be any time on that day.

You can **book a courier** to collect your samples if:

- There are no Royal Mail priority post boxes where you live
- You are classed as vulnerable or clinically extremely vulnerable
- You are too unwell to leave your home
- You find it difficult to get around
- You cannot get to a Royal Mail priority post box without using public transport

When you let us know you are happy to take part, we will ask if you or someone else can return your samples via a priority post box or if you need a courier and for which reason. We will remember your preference for each of your testing windows.

**If you have told us you need a courier to collect your samples, you will need to follow these steps at each testing window:**

- Once we tell you when your testing window begins, you should book a courier to arrive on a **specific day between Monday and Friday** within your testing window.
- To do this online go to **www.COVIDSurvey.ons.gov.uk** or you can call **0800 085 6807** between 9am – 9pm Monday to Thursday, 9am – 8pm Friday, and 9am – 5pm Saturdays and Sundays.
- **You must wait to take your samples and complete the questionnaire until the day your courier will arrive, but please do this before your courier arrives.**
- You will book a day for the courier to collect your samples. Nearer the day you will get a slot of up to 4 hours but this may be at any time on that day, depending on the courier. Someone will need to be at your home during this time to give the courier your samples.

You **will not** be able to rebook your courier slot if you miss it, so it is important to make sure someone is available during the timeslot.

If you usually return your samples by priority post box, but for one testing window something changes and you need a courier, please call **0800 085 6807**.

## **Damaged or missing kits**

**If either your swab or blood kit arrives damaged**, but the other kit is not damaged, you will still get a voucher, if you chose to get one, if you complete your questionnaire and take either a swab or blood sample within your testing window. In the unlikely event that both of your test kits arrive damaged or with parts missing, please let us know so we can improve things for you and others in the future. You can let us know via the questionnaire at **www.COVIDSurvey.ons.gov.uk** or by calling **0800 085 6807**. Unfortunately, we will not have time to send you replacement test kits within your testing window and so you will not be able to take your samples or be eligible for a voucher this time.

## What will happen after my first testing window?

- At first you will have a 7-day testing window every week for 4 weeks in a row.
- Then you will have 14-day testing windows every month from your first testing window until the survey ends.

If you agree to give blood the first time, we would like you to give blood again every month, but not at weeks 1, 2 or 3. **You can decide on the day whether or not you want to give blood each time.**

We will link information from you in this survey to health data from the NHS, the UK Health Security Agency and ONS, or the equivalent national bodies in Wales, Northern Ireland and Scotland, to check your health status, whether you have visited hospital or a GP, or had another test for COVID-19 somewhere else. This is to try to work out what we need to do to keep the NHS going during this pandemic and over the coming years. We will do this for up to 15 years after your last testing window. We will use your name, address, date of birth and sex to do this. We will do this from January 2016 onwards. The reason for this is because it is not clear whether having had COVID-19, with or without symptoms, could make people more likely to get other long-term conditions like diabetes, heart disease or dementia in the future.

Because we test people every month in the survey, we have a very good idea of who has had COVID-19 and who has not – whether they knew it at the time. This makes the survey one of the best studies to look at whether people develop other conditions in the future. The reason for linking data back to January 2016 (4 calendar years before the start of the COVID-19 epidemic) is to make sure we account properly for conditions that people had before they joined the survey, because we do not ask questions about this as part of the survey. This linkage would be done both during the survey – for example, to find out the impact of having COVID-19 or being vaccinated on how often people have to go into hospital or visit their GP – and after people stop taking part in the survey.

If you would be happy for us to do so, we will send you information about other studies that have been approved by a Research Ethics Committee, or programmes that have been approved by the UK Health and Security Agency or Department of Health and Social Care so that you could contact them if you would be interested in taking part in their studies too. You do not have to agree to take part in this survey, and you do not have to take part in any other studies we send you information about.

You can find a list of these research studies and approved programmes on [www.ndm.ox.ac.uk/covid-19/covid-19-infection-survey/other\\_studies](http://www.ndm.ox.ac.uk/covid-19/covid-19-infection-survey/other_studies) For example, a study led by Genomics England is trying to find out whether there are genetic factors that mean that some people experience severe symptoms of COVID-19 whilst others experience only mild symptoms.

If you have a positive swab test, you can register for this yourself on [covid.genomicc.org/](https://covid.genomicc.org/) You can also join this survey if your blood test is positive for antibodies to COVID-19.

## What are the possible benefits of taking part?

Taking part in this survey will help us to understand more about COVID-19 and the effect of vaccinations, and having had COVID-19 before, on the risk of getting COVID-19 in the future. This information is very useful in helping the country recover from COVID-19 and work out how we are going to manage it over the long term. You will be told the results of your swab and blood tests, which you would not otherwise have done.

## Will I be told my results?

Yes, you will be told your results. You can choose whether this is by email or letter. Parents/carers will get results for their children.

The COVID-19 Infection Survey is a research study, not a testing programme. This means that you may not get these results as quickly as results used to come from the main national testing programmes. In the survey, it takes 2-3 days to get the swab to the labs, and then it can take up to 3-4 days to do the tests. Results are sent back every weekday morning from the labs. Once results come back, they are matched to participants through a sample barcode and emails or letters are then sent out. So it typically takes at least a week by email and at least 9-10 days by letter before people get their swab test results. It typically takes at least a week before people get their blood test results by email or at least two weeks by letter. Your antibody result will be returned as positive or negative in line with the approval for the test if the test does not fail.

If your result is positive, we will tell you whether there is the standard or a higher concentration of antibodies. The standard antibody threshold was worked out before the coronavirus (COVID-19) vaccines were developed. Our bodies respond to infection and to vaccination in slightly different ways. Having had a COVID-19 infection before usually gives a stronger immune response than vaccination. To get a similar level of protection from vaccination alone, a higher level of antibodies is needed. Based on all the blood tests people in the survey have done, we have now worked out just how much higher.

We compared how the risk of new COVID-19 infections changes across different antibody levels for the Delta variant, which was the most common variant at the time this research was done. The higher antibody level gives a 67% lower risk of getting a new COVID-19 infection with the Delta variant after two vaccinations, compared with someone who was unvaccinated and had not had COVID-19 before [www.nature.com/articles/s41591-022-01721-6](https://www.nature.com/articles/s41591-022-01721-6).

Even higher thresholds may be needed to give equivalent protection against the Omicron variant. We are still learning about antibodies and COVID-19, and we will be using the blood samples people give to work out what levels may be needed to give similar protection against the Omicron variant.

You do not need to do anything differently in response to your antibody results. This is because antibodies are only one part of the way that our bodies fight infection. Other parts of our immune system, like T-cells, also help. Antibody levels can also change over time – this is a normal part of how our immune systems work.

Like all tests, the throat and nose swab test is not perfect, so both “false positives” (the test result is positive but you don’t have the infection) and “false negatives” (the test result is negative but you do have the infection) are possible. However, the swab test we are using has a false-positive rate of under 0.005%, meaning that fewer than 1 in 20,000 people who don’t have the infection will wrongly get a positive test result. The chance that any individual positive result is right depends on other things that affect the chance that you really have COVID-19 (such as how many other people are infected at the time, whether you have any symptoms and whether you know you have been in contact with someone else with COVID-19, even if you don’t know it). But the very low false positive rate means that if you get a positive test result it is extremely likely that you were infected with COVID-19 when we collected the swab. Whatever the results, it is also essential to keep following government guidance.

## What should I do if my test result is positive?

**If one of your throat and nose swabs test positive**, as soon as we receive the result back from the labs, we immediately pass the result onto the relevant national public health bodies. They may then contact you by text, email or phone, and this may be before you get this positive result back from the survey. **Please follow their advice.**

**If your throat and nose swab is positive**, then you and everyone in your home should follow the guidance **found at:**

England: **[www.nhs.uk/conditions/coronavirus-covid-19/symptoms-and-what-to-do/](https://www.nhs.uk/conditions/coronavirus-covid-19/symptoms-and-what-to-do/)**

Wales: **[gov.wales/contact-tracing-if-you-have-tested-positive](https://gov.wales/contact-tracing-if-you-have-tested-positive)**

Scotland: **[www.nhsinform.scot/illnesses-and-conditions/infections-and-poisoning/coronavirus-covid-19](https://www.nhsinform.scot/illnesses-and-conditions/infections-and-poisoning/coronavirus-covid-19)**

Northern Ireland: **[www.publichealth.hscni.net/covid-19-coronavirus/covid-19-information-public](https://www.publichealth.hscni.net/covid-19-coronavirus/covid-19-information-public)**

Around half the people in the survey with positive tests do not report having symptoms, so **please do not assume the test is wrong.**



Please be aware that some people can carry on being positive on a throat and nose swab for several weeks after they first test positive. This does not mean that they are still infectious; studies have only been able to grow live virus from people in the first 1-2 weeks after they get COVID-19.

**Please follow the latest guidance in your country:**

England: [www.nhs.uk/conditions/coronavirus-covid-19/symptoms-and-what-to-do/](https://www.nhs.uk/conditions/coronavirus-covid-19/symptoms-and-what-to-do/)

Wales: [gov.wales/contact-tracing-if-you-have-tested-positive](https://gov.wales/contact-tracing-if-you-have-tested-positive)

Scotland: [www.nhsinform.scot/illnesses-and-conditions/infections-and-poisoning/coronavirus-covid-19](https://www.nhsinform.scot/illnesses-and-conditions/infections-and-poisoning/coronavirus-covid-19)

Northern Ireland: [www.publichealth.hscni.net/covid-19-coronavirus/covid-19-information-public](https://www.publichealth.hscni.net/covid-19-coronavirus/covid-19-information-public)

As required by law, if you test positive in any country, or if you test negative in England, we will share a small amount of your personal data (including your name, contact details, postcode and ethnicity) with:

UK Health Security Agency: [www.nhs.uk/conditions/coronavirus-covid-19/self-isolation-and-treatment/](https://www.nhs.uk/conditions/coronavirus-covid-19/self-isolation-and-treatment/)

Public Health Wales: [gov.wales/contact-tracing-if-you-have-tested-positive/](https://gov.wales/contact-tracing-if-you-have-tested-positive/)

Public Health Agency: [www.publichealth.hscni.net/covid-19-coronavirus/testing-and-tracing-covid-19](https://www.publichealth.hscni.net/covid-19-coronavirus/testing-and-tracing-covid-19)

NHS Inform: [www.nhsinform.scot](https://www.nhsinform.scot)

**By taking part in this survey you agree to this disclosure taking place.**

It is important to remember that the throat and nose swab is a test for whether you currently have COVID-19. A positive antibody test means that you have been exposed to COVID-19 at some point in the past or have been vaccinated against COVID-19 at some point in the past.

**i** It does not necessarily mean you are infected with the virus now, although if you have had a positive swab test recently, the positive antibody test probably relates to this infection.



## What if I develop symptoms?

It is very important that if you develop symptoms of COVID-19 you follow the guidance on self-isolation found at:

England: [www.nhs.uk/conditions/coronavirus-covid-19/symptoms-and-what-to-do/](https://www.nhs.uk/conditions/coronavirus-covid-19/symptoms-and-what-to-do/)

Wales: [gov.wales/contact-tracing-if-you-have-tested-positive/](https://gov.wales/contact-tracing-if-you-have-tested-positive/)

Scotland: [www.nhsinform.scot/illnesses-and-conditions/infections-and-poisoning/coronavirus-covid-19](https://www.nhsinform.scot/illnesses-and-conditions/infections-and-poisoning/coronavirus-covid-19)

Northern Ireland: [www.publichealth.hscni.net/covid-19-coronavirus/covid-19-information-public](https://www.publichealth.hscni.net/covid-19-coronavirus/covid-19-information-public)

Even if you have had a recent swab test done in this survey and have developed symptoms, do not wait for its results before following the guidance.

If you have not had a recent swab test in the survey, please follow the guidance on getting a test:

England: [www.gov.uk/guidance/coronavirus-covid-19-getting-tested](https://www.gov.uk/guidance/coronavirus-covid-19-getting-tested)

Wales: [www.gov.wales/apply-coronavirus-covid-19-test](https://www.gov.wales/apply-coronavirus-covid-19-test)

Scotland: [www.gov.scot/publications/coronavirus-covid-19-getting-tested/pages/arrange-a-test/](https://www.gov.scot/publications/coronavirus-covid-19-getting-tested/pages/arrange-a-test/)

Northern Ireland: [www.publichealth.hscni.net/covid-19-coronavirus/testing-and-tracing-covid-19](https://www.publichealth.hscni.net/covid-19-coronavirus/testing-and-tracing-covid-19)

## Are there any possible disadvantages or risks from taking part?

The disadvantages are:

- The time and inconvenience of having to take the samples and complete the questionnaire and either return them to a priority post box or organise a courier collection at your home.
- You may find out that you have had COVID-19 when you did not realise that you had it.
- When blood is taken from a finger prick, you may need to prick several fingers to get enough blood and your fingers may be sore for a few days afterwards.

- There is a small risk of fainting; only do the blood test if you feel well on the day. If you start to feel unwell, please stop straight away and if possible have someone else from your home stay with you. If you have fainted with a blood test before, it is fine not to do the blood test. Things you can do to make the risk of fainting smaller when you do the test.
  - Make sure you have drunk enough water and that you have eaten.
  - Sit down when you do the test and if you feel unwell at any point (dizzy, sick, lightheaded, or sweating) stop the test immediately. Stay sitting down or lie down flat with your legs lifted up against a chair or against a wall until you begin to feel better.

## What do I get for taking part?

To reflect the time and inconvenience of taking part in the survey, every person in your home who joins the survey (regardless of how old they are) can choose to be compensated with a £20 voucher for every testing window they complete. They will need to **both** fully complete the questionnaire and take a sample in their testing window to get the £20 voucher. People can choose not to receive vouchers, if they prefer.

If you get to the end of the questionnaire and take your sample, you will be eligible for a voucher. If you do not press submit at the end of the questionnaire, your data will still be used as part of this survey.

Vouchers will just be for testing windows where you both fully complete the questionnaire and take a sample within your testing window. If you skip your samples and questionnaire one testing window, you will not receive a voucher. You will still be eligible for a voucher as usual for any testing window after that where you take a sample and complete your questionnaire. If the survey is stopped, or you decide to leave the survey, you will not continue to receive vouchers.

If we do not receive your samples three times and you have told us you have taken them, we will contact you to try to find out what has happened.

You may not receive further vouchers if we do not receive your samples when you have told us you have taken them.

If you would like to receive vouchers, we can get vouchers to you more quickly by email, or we can post them if you prefer. It may still take at least 20 working days to receive vouchers. Vouchers can be spent in many stores online but some will only accept them in store. We will also email you updates on results and news about the survey.

**! Please note we will never ask for your bank details. The vouchers will only ever be issued by email or post.**

## **Will my taking part in the survey be kept confidential?**

Yes. We will only use name, address, date of birth and sex where this is absolutely necessary to link to your other healthcare records, and where we are required by law to pass these data (and ethnicity) on to the national public health bodies to help the country manage COVID-19. We will use your postcode to try to work out how COVID-19 is spreading around the country and in your local area. All samples and survey records will be identified only by a code for your home and for each person in it joining the survey, together with month and year of birth (not actual date). Information which can identify you will only be held by ONS and IQVIA and specific other providers listed under "What will happen to my data" for the purposes of the survey.

Responsible members of the University of Oxford may be given access to data for monitoring and/or audit of the survey to ensure that the research is complying with applicable regulations.

## **What will happen to the samples I give?**

Your throat and nose swabs will be tested for COVID-19 at one of the laboratories in the government accredited testing network and you will be sent the results. In future, the same swab sample may also be tested for other viruses and microbes that cause infections in the nose, throat and lungs. You will be sent the results of any validated tests that are done. The throat and nose swabs will be destroyed once tests are done. Any blood samples will be tested by scientists at the University of Oxford.

They will look for antibodies against COVID-19 and you will be sent the results. We would like to keep any blood that is not used for the antibody test for future research, including for future tests related to COVID-19. Your samples will be used mainly by researchers in the UK. Ethically approved research projects may take place in hospitals, universities, non-profit institutions or commercial laboratories worldwide.

The blood sample will only be identified by a code that will not personally identify you. We will ask your permission for this – you do not have to agree to this part of the survey. If you do agree to this part of the survey, your blood samples will either be used or destroyed after 5 years.

## What will happen to my data?

Data protection regulation requires that we state the legal basis for processing information about you. In the case of research, this is "a task in the public interest." The University of Oxford and the ONS are Joint Data Controllers and are responsible for looking after your information and using it properly. IQVIA will organise the testing windows and will work in partnership with other select partner organisations. **The companies involved in running the survey will not pass information about you to anyone not involved in the survey.**

This survey uses information from you and NHS Digital, the UK Health Security Agency and ONS, and equivalent national databases in Wales, Northern Ireland and Scotland. We will use the minimum personally identifiable information possible. IQVIA will keep identifiable information about you from this survey for up to 5 years after the survey has finished. The ONS has the statutory objective to promote and safeguard the production of official statistics that serve the public good. For us to produce statistics, we may link the data we obtain through this survey with other survey and administrative data that we hold. All our uses of data will comply with UK Statistics Authority's ethical framework.

The ONS will continue to hold the data collected through this survey for as long as it remains useful for statistical research and production. Data will also be shared with the relevant organisations in Wales, Northern Ireland and Scotland for statistical purposes only where it is lawful and ethical to do so, specifically the Welsh Government, the Northern Ireland Statistics and Research Agency (NISRA), the Scottish Administration (see section 53a of the Statistics and Registration Service Act). The ONS and the relevant organisations from the Devolved Administrations may give access to de-identified data to accredited processors and researchers for accredited research purposes, where it is lawful and ethical to do so. When making this de-identified data available the ONS and the relevant organisations from the Devolved Administrations may link the data we obtain through this survey with other survey and administrative data that they hold. Access will only be given to support valuable new research insights about UK society and the economy that are considered to be in the public good.

ONS and IQVIA sometimes share selected information with their service providers to help run very large studies like this one. They only share the personal details that are needed for the survey, and they are not used by service providers for any other purpose.

In this survey, we work with other organisations to provide the following services:

- **Sending a thank you voucher: our service provider for this is Sodexo:** further information on [www.sodexo.com/home/legal--privacy/online-data-protection-policy.html](http://www.sodexo.com/home/legal--privacy/online-data-protection-policy.html)
- **Helping us get in touch:** our service providers for this are HH Global, GovDelivery, GoInspire and Capita: further information on [www.hhglobal.com/privacy-policy](http://www.hhglobal.com/privacy-policy), [granicus.com/privacy-policy/](http://granicus.com/privacy-policy/), [www.goinspire.co.uk/privacy-policy/](http://www.goinspire.co.uk/privacy-policy/), [www.capita.com/privacy-notice](http://www.capita.com/privacy-notice)
- **Sending test results by email:** our service providers for this are the NHS Business Services Authority: further information on [www.nhsbsa.nhs.uk/our-policies/privacy](http://www.nhsbsa.nhs.uk/our-policies/privacy)
- **Sending test results by letter:** our service providers for this are Eight Days: further information on [www.eightdaysaweekprintsolutions.com/privacy-policy](http://www.eightdaysaweekprintsolutions.com/privacy-policy)
- **Sending out test kits:** the test kits will be made up and posted to you by a company called Thriva. They will need your name, address and participant ID to do this. Further information is on [thriva.co/privacy](http://thriva.co/privacy)
- The companies involved in the survey may sub-contract out specific services but any sub-contractors will be bound by the same duty of confidentiality and security arrangements.

Some of IQVIA's offices are located outside the UK, therefore IQVIA will sometimes need to process your information at a destination outside the European Economic Area.

Such transfers will only take place with appropriate safeguards in place to ensure the confidentiality and security of your personal information. If you require any information about these safeguards, please call **0800 085 6807**.

As required by law, we will share a small amount of your personal data (including your name, contact details, postcode and ethnicity) with the UK Health Security Agency and relevant public health bodies in Wales, Northern Ireland and Scotland.

Data protection regulation gives you control over your personal data and how it is used. When you agree to your information being used in research, however, some of those rights may be limited in order for the research to be reliable and accurate.

The information we find out from this survey may be useful for others. The survey is funded by the UK government, and so the data that we collect may be shared with researchers and organisations, inside or outside the UK. We would only share information that could not identify you directly (no names or addresses or full postcodes or date of birth). ONS takes their responsibilities to keep your personal information secure very seriously.

As such, they take every reasonable precaution to ensure your information is protected from loss, theft or misuse. These precautions include appropriate physical security of our offices, controlled access to computer systems, and use of secure, encrypted internet connections when collecting personal information.

## Useful links about your data

- Further information on what we use data for is available at [www.ons.gov.uk/aboutus/transparencyandgovernance/datastrategy](https://www.ons.gov.uk/aboutus/transparencyandgovernance/datastrategy)
- Further information on the ethical framework is available at [uksa.statisticsauthority.gov.uk/about-the-authority/committees/national-statisticians-data-ethics-advisory-committee/](https://uksa.statisticsauthority.gov.uk/about-the-authority/committees/national-statisticians-data-ethics-advisory-committee/)
- A full list of accredited processors is available at [uksa.statisticsauthority.gov.uk/digitaleconomyact-research-statistics/better-access-to-data-for-research-information-for-processors/list-of-digital-economy-act-accredited-processing-environments/](https://uksa.statisticsauthority.gov.uk/digitaleconomyact-research-statistics/better-access-to-data-for-research-information-for-processors/list-of-digital-economy-act-accredited-processing-environments/)
- Further information on how we provide access to data for research purposes is available at [uksa.statisticsauthority.gov.uk/digitaleconomyact-research-statistics/](https://uksa.statisticsauthority.gov.uk/digitaleconomyact-research-statistics/)
- The Data Protection Officer at ONS can be contacted at [DPO@Statistics.gov.uk](mailto:DPO@Statistics.gov.uk)
- If you have a question about how the ONS processes your personal data or want to find out more about your rights under data protection legislation, please see the ONS's data protection page [www.ons.gov.uk/aboutus/transparencyandgovernance/dataprotection](https://www.ons.gov.uk/aboutus/transparencyandgovernance/dataprotection)
- Further information about your rights with respect to your personal data is available at [compliance.web.ox.ac.uk/individual-rights](https://compliance.web.ox.ac.uk/individual-rights)

## What will happen if I don't want to carry on with the survey?

You can choose to withdraw from the survey at any time if you change your mind, without giving a reason. This includes after you have received the test kits in the post and if you have already given a swab from your throat and nose or a blood sample.

If the tests have already been done when you change your mind, we will still use the data from them because it is very important for our survey to get a good picture of who has had COVID-19. But if you no longer wish for any leftover blood to be stored, we will destroy it. You can also decide that you do not want us to get any more information about you from the NHS, ONS or UK Health Security Agency or other equivalent databases in Wales, Northern Ireland and Scotland if you leave the survey. We will use the data collected up to the time you leave the survey.



## What will happen if I move home?

The survey is based on a representative sample of addresses and so if you move home, your participation in the survey will finish.

## What happens at the end of the survey?

The results from this survey are already being used to help the government work out the best way to manage the COVID-19 pandemic at both a UK-wide and an individual country level. You can find a summary on [www.ndm.ox.ac.uk/covid-19/covid-19-infection-survey/results](http://www.ndm.ox.ac.uk/covid-19/covid-19-infection-survey/results)

We will also email you updates on results and news about the survey. The results of this survey may also be presented at academic meetings and may be published in medical journals. Any data presented will not identify any individuals. You can choose not to receive these updates, even if you have given us your email to use to receive information about your 'testing window' and test results. However, if you choose to receive information about your 'testing window' and test results by email, you cannot unsubscribe from these emails. This is because we need to be able to contact you with this important information, and with information about how the survey is run that has been approved by the Research Ethics Committee.

## What if we find something unexpected?

None of the tests done in this survey are likely to find anything unexpected. They are only looking for the COVID-19 virus, or for antibodies to it. If you are happy to, we would like to record your telephone number so we can contact you, for example, if something goes wrong with one of your tests, or you miss a testing window without letting us know three times or more.

## What if there is a problem?

The University of Oxford, as Sponsor, has appropriate insurance in place in the unlikely event that you suffer any harm as a direct consequence of your participation in this survey.

If you wish to complain about any aspect of the way in which you have been approached or treated, or how your information is handled during the course of this survey, please contact our dedicated team on [COVID-19@ons.gov.uk](mailto:COVID-19@ons.gov.uk)

## How have patients and the public been involved in this survey?

This survey follows government and World Health Organisation advice, and its conduct is based on best practice, which has been informed by patients, service users and members of the public.



Members of the public have looked at this information sheet and teenagers have also looked at the shorter version. We are grateful for their helpful feedback which has been included.

## Who is organising and funding the survey?

This survey is funded by the UK Health Security Agency with in-kind contributions from the Welsh Government, the Department of Health on behalf of the Northern Ireland Government, and the Scottish Government. The research is being undertaken by ONS, IQVIA and the University of Oxford. It is sponsored by the University of Oxford.

- IQVIA are responsible for arranging testing windows, managing participants taking their own throat and nose swabs, taking blood samples in some households, and sending results to participants. IQVIA may sub-contract some aspects of the survey to other select partner organisations.
- The laboratories in the government accredited testing network (the Glasgow Lighthouse Laboratory and the Rosalind Franklin Laboratory, Leamington Spa) are responsible for testing the throat and nose swabs.
- Scientists at the University of Oxford are responsible for storing and testing the blood samples.
- ONS will analyse the data provided by the University of Oxford and the government accredited laboratories, in collaboration with the University of Oxford.

## Who has reviewed the survey?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect participants' interests. This survey has been reviewed and given favourable opinion by the Berkshire B Research Ethics Committee.

## Your views are essential to us

Finding out what you think about the survey is extremely important to us. We will therefore be offering you the chance to give some short feedback if you contact us to let us know you would like to join the survey, then again if you want to opt out of your first 'testing window', and after you complete your first questionnaires and send back your first samples. Questions can be answered online or over the telephone. You do not have to give this feedback, it is completely up to you.

We will also be contacting some participants to see if they would be happy to talk to us for around 30-45 minutes about how they found taking samples and completing questionnaires in the survey. These interviews will be audio recorded, and a £20 voucher would be offered to reflect the time taken. Again, no one has to agree to an interview, it is completely up to you.

## Further information and contact details

To take part, you will need to register with the company who are conducting the survey on behalf of ONS and Oxford. To register, call **0800 085 6807**. The telephone adviser will answer any questions you have and will take consent to join the survey, if you want to. You can call between 9am – 9pm Monday to Thursday, 9am – 8pm Friday, and 9am – 5pm Saturdays and Sundays.

If you have accessibility needs and require additional support, please call **0800 085 6807** or email [iqvia.covid19survey@nhs.net](mailto:iqvia.covid19survey@nhs.net)

You can watch a video that shows how to take your blood with a finger prick test at [www.ndm.ox.ac.uk/covid-19/covid-19-infection-survey/guides](http://www.ndm.ox.ac.uk/covid-19/covid-19-infection-survey/guides) and a video that shows how to take a swab at [www.ndm.ox.ac.uk/covid-19/covid-19-infection-survey/guides](http://www.ndm.ox.ac.uk/covid-19/covid-19-infection-survey/guides)

### Thank you for considering taking part.

If you are affected by any of the issues raised in this information sheet or are looking for information on COVID-19 (coronavirus) please visit:

Coronavirus explained: [coronavirusexplained.ukri.org/en/](http://coronavirusexplained.ukri.org/en/)

Government guidelines:

- England: [www.gov.uk/coronavirus](http://www.gov.uk/coronavirus)
- Wales: [gov.wales/coronavirus](http://gov.wales/coronavirus)
- Scotland: [www.gov.scot/collections/coronavirus-covid-19-guidance/](http://www.gov.scot/collections/coronavirus-covid-19-guidance/)
- Northern Ireland: [www.nidirect.gov.uk/campaigns/coronavirus-covid-19](http://www.nidirect.gov.uk/campaigns/coronavirus-covid-19)

NHS advice:

- England: [www.nhs.uk/conditions/coronavirus-covid-19/](http://www.nhs.uk/conditions/coronavirus-covid-19/)
- Wales: [gov.wales/coronavirus](http://gov.wales/coronavirus)
- Scotland: [www.nhsinform.scot/illnesses-and-conditions/infections-and-poisoning/coronavirus-covid-19](http://www.nhsinform.scot/illnesses-and-conditions/infections-and-poisoning/coronavirus-covid-19)
- Northern Ireland: [www.nidirect.gov.uk/articles/coronavirus-covid-19-overview-and-advice](http://www.nidirect.gov.uk/articles/coronavirus-covid-19-overview-and-advice)
- What taking a nose and throat swab is like [www.gov.uk/government/publications/covid-19-guidance-for-taking-swab-samples](http://www.gov.uk/government/publications/covid-19-guidance-for-taking-swab-samples)
- Samaritans - Emotional support for everyone: [www.samaritans.org](http://www.samaritans.org)
- Mind - Advice and support for anyone with a mental health problem [www.mind.org.uk](http://www.mind.org.uk)

[www.ndm.ox.ac.uk/covid-19/covid-19-infection-survey](http://www.ndm.ox.ac.uk/covid-19/covid-19-infection-survey)

The most up to date versions of this information sheet and the protocol are available on [www.ndm.ox.ac.uk/covid-19/covid-19-infection-survey/protocol-and-information-sheets](http://www.ndm.ox.ac.uk/covid-19/covid-19-infection-survey/protocol-and-information-sheets)