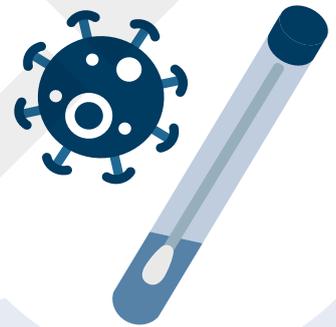


Participant information sheet for Adults

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



Study Contact:
0800 085 6807



COVID-19 Infection Survey

We'd 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 really 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 be as quick as getting results from the national testing programmes.

Everyone in the survey can receive a COVID-19 vaccination when they are eligible to do so – and people who have received a COVID-19 vaccination can be in the survey.



What is the purpose of the survey?

The coronavirus (COVID-19) pandemic has had a major impact across the UK. This survey aims to find out how many people are still getting COVID-19, or are likely to have had it even if they haven't realised it at the time. This is particularly important as more people start getting vaccinated against COVID-19. Although the vaccines work very well, they do not completely stop people getting the virus again and neither does having had COVID-19 in the past. We need to monitor how well the vaccines work in the real-world, and how well the combination of people having had COVID-19 before and getting vaccinated stops the virus spreading.

One way to find out whether a person has COVID-19 infection is to directly look for the virus. The main test we are using to diagnose COVID-19 at the moment uses 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 small particles in the blood called "antibodies". It takes 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 that people can get antibodies that can protect them against getting COVID-19. 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 know yet what having antibodies means in terms of exactly how likely you are to get COVID-19 again.

In this survey we want to find out how many people of different ages across the UK are still getting COVID-19, particularly with many people now returning to work or school and getting vaccinated, and how many have had COVID-19 in the past.

We will do this by testing for the virus in the throat and nose. In some people we will also measure levels of antibodies in their blood. We want to find out how many people have COVID-19 over the coming months – either with symptoms or without knowing they have the infection because they don't have any symptoms. We want to do this in a group of people that reflect the population of the UK – so in a range of ages and places where people live, and not just people with symptoms.

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 the coronavirus outbreak better over the next year.

Thank you for thinking about helping us.

Why have I been invited?

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 in the UK.



In this survey we are asking for **all adults, teenagers and children in your home aged 2 years or older to take part.**

Over the next year we plan to include **around 240,000 homes from across the UK.**

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

Do I have to take part?

Taking part is entirely your choice. **Everyone in your home can make a different choice to take part or not to take part – 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 and without any consequences. Parents/carers may also withdraw their child from the survey at any time without giving a reason.

What will happen if I decide to take part?

If you or anyone currently resident in your household would like to take part in the survey, then we will arrange for a member of the survey team to make an appointment to visit your home.

- 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.

To register to take part in the survey, please call 0800 085 6807. Once you have registered, the next time you will hear from us is when a member of the survey team contacts you the evening before your planned visit. If this time isn't convenient for you, you can change it – we will try to find a time that works for you, including at evenings or on the weekend. We aim to conduct your first appointment in the week after you register, but this may be delayed if lots of people try to register for the survey at the same time. The reason for sending someone from the survey team to your home is so that you do not have to travel to a health centre. Everyone working for the survey has received appropriate training. The survey team member will bring all necessary equipment, including PPE (personal protective equipment) with them to your home for the visit.

When the survey team member visits your home, they will first check that you still want to take part. They will ask you to sign a consent form. If an older child or teenager (10-15 years) in your home wants to join the survey, we will ask both them and their parent or carer to sign to say they are happy to be in the survey. For younger children aged 2-9 years, we will just ask their parent or carer to sign, although it is important that the child is also happy about this.

The survey team member will then ask everyone who wants to join the survey some questions about any symptoms they may have now or in the past, contacts with someone who had COVID-19, and what kind of contacts outside the home they have. They will also ask about gender, ethnicity, religion, date of birth and occupation. If any information gets missed accidentally, a member of the survey team will call you. The survey team member will also show everyone how to use a self-swabbing kit to take a swab from their throat and nose. This swab will tell us whether you currently have the COVID-19 virus.

Taking the swab is easy: it is the same swab test that is being used in the drive through testing centres. **Anyone aged 12 years or older can take the swab themselves.** We will ask the parent/carers to take the swab from children aged 2-11 years, after they have tried it themselves. The swabs are the same size as used normally for children. **The reason for asking people to swab themselves is to protect the survey team in case people have COVID-19 and don't know it.**

Each person will need to spend around 20 minutes with the survey team member for the first visit. The survey team member will use all the recommended precautions that protect against the virus.

In particular, the survey team member will not enter your home, and will pass you the self-swabbing kits whilst staying at least 2m away from everyone in the home. They will ask questions from this distance. If you prefer, they can also call you from their car to ask you the questions.

We will also ask whether you or anyone in your home would be interested in further visits so that we can see how infection with COVID-19 changes over time. **You could agree to:**

- A** the first visit only
- B** the first visit and a visit every week for one month **(5 visits in total)**
- C** the first visit, a visit every week for one month, then 11 monthly visits **(16 visits in total over 1 year)**

You do not have to agree to more visits, even if you agree to the first visit. **These repeat visits should only take around 15 minutes,** because each involves the same questions, and throat and nose swab every time.

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.

We will link information from you in this survey to health data from the NHS, Public Health England 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. We will do this for one year after your last visit. We will use your name, address, date of birth and sex to do this.

If you would be happy for us to do so, we would send you information about other studies that have been approved by a Research Ethics Committee or programmes that have been approved by the Department of Health and Social Care (e.g. for convalescent plasma) 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/information-for-participants/other-studies-you-may-be-interested-in. 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 www.genomicsengland.co.uk/covid-19/.

What should I consider?

Anyone aged 2 years or older can take part in this survey. 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.

What are the possible benefits of taking part?

The samples that you take from your throat and nose will be tested at a national testing laboratory for the COVID-19 virus. These are the same laboratories doing the tests for the national testing programmes. You will get your test results, and you would not usually get these tests done. However, because this is a research study, you may not get these results as quickly as in the main national testing programmes. **There is more information about this under “Will I be told my results?” below.** So it is very important that if you develop symptoms of COVID-19 you follow the usual guidance on self-isolation on <https://www.nhs.uk/conditions/coronavirus-covid-19/symptoms-and-what-to-do/>.

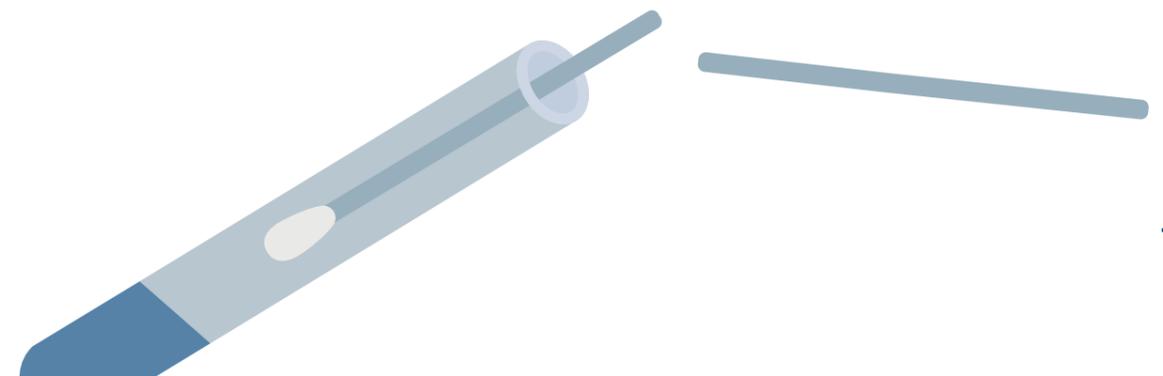
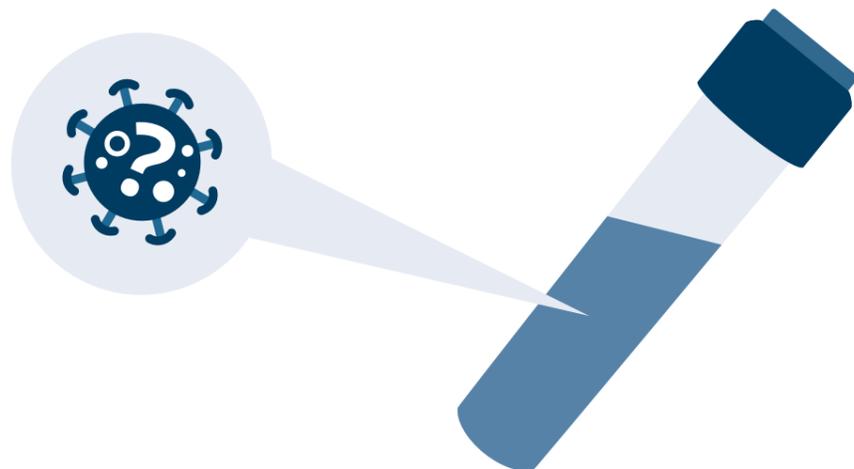
Even if you have had a recent test done in this survey and have developed symptoms, do not wait for its results before self-isolating. If you have not had a recent test in the survey, please follow the guidance on getting a test <https://www.gov.uk/guidance/coronavirus-covid-19-getting-tested>. Like all tests, this 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 test we are using has a false-positive rate of under 0.005%, meaning that only around 1 in 20,000 positives will be wrong. Whatever the results, it is also essential to keep following government guidance.

An electronic version of this information sheet which you can just click on the hyperlinks is on <https://www.ndm.ox.ac.uk/covid-19/covid-19-infection-survey/protocol-and-information-sheets>

Will I be told my results?

Yes, **you will be told your results.** At first this will be by letter. We are working hard on being able to text or email you your results if you are happy to give us your mobile number or email address. Parents/carers will get results for their children.

However, **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.



- 1 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.** 
- 2 Results are sent back every weekday morning from the labs to the research study. 
- 3 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.** 
- 4 **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. 
- 5 They will then contact you, by text, email or phone call, **and this will almost certainly be before you get this positive result back from the study.** Please follow their advice. 

As required by law, at the moment we will share your swab test results and personal data (including your name, contact details, postcode and ethnicity) with Public Health England for referral to the NHS Test and Trace system <https://contact-tracing.phe.gov.uk/>. You will shortly receive all your swab test results through the national tracing programme, rather than by letter, 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.**

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

If your throat and nose swab is positive, then you and everyone in your home should follow guidance and isolate even if you don't have any symptoms. It is important to know that around **half the people in the survey with positive tests do not report having symptoms, so please do not assume the test is wrong.**

It is important to know 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. People only need to complete one period of self-isolation from their first positive test – they do not need to self-isolate every time. People only need to isolate again if they test positive 3 months later.

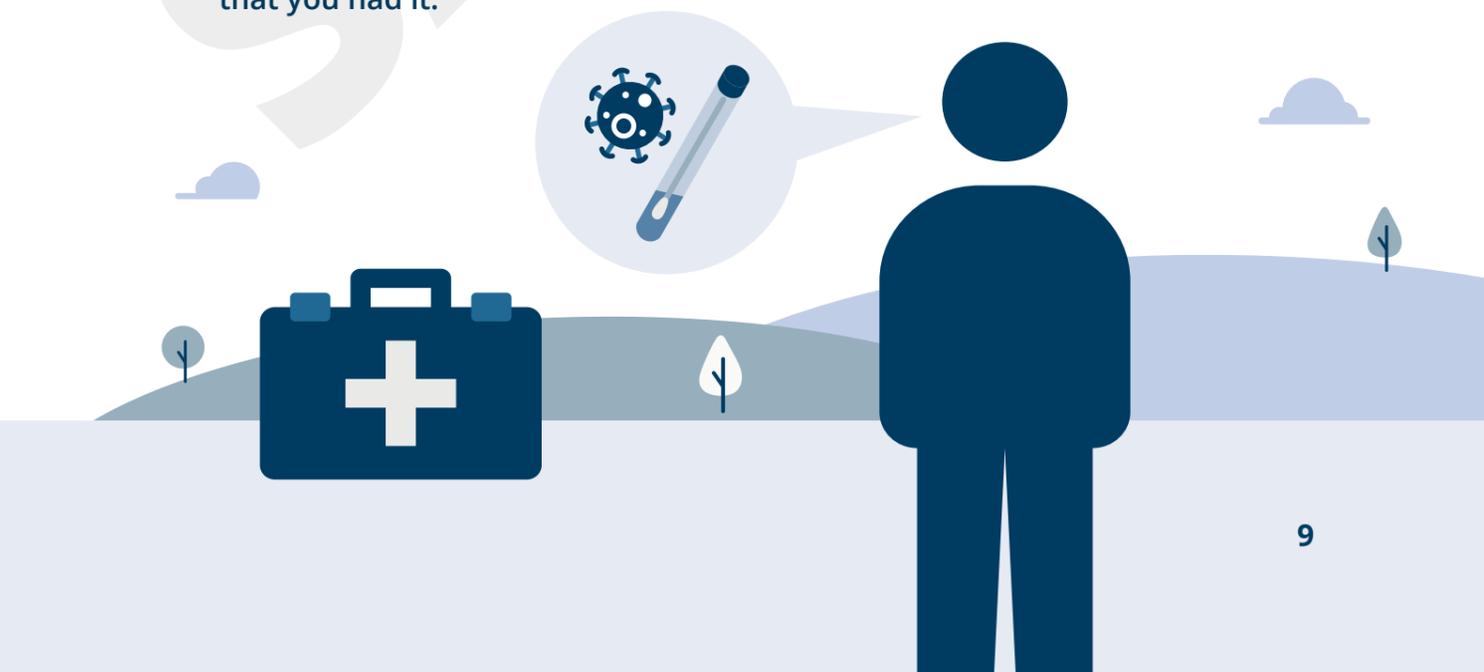
If anyone in your home tests positive for COVID-19 on a throat and nose swab, we would like to ask you whether you and any other adult aged 16 years or older in your home would be happy to give a blood sample to measure levels of antibodies at your survey visits. This will be done either from a vein, like having a blood test at your local GP, or from a finger prick. We will take about 1 teaspoon (5mls) of blood from a vein, or you will take a much smaller amount (around 0.5ml) from a finger prick yourself, using a kit that we will provide for you for each visit. How we take the blood sample will depend on what survey team members are available, although we aim to use a finger prick whenever possible and eventually use finger pricks in everyone giving blood. Taking blood from a finger prick also means that the survey team member does not need to come into your home. You do not have to do this part of the survey if you do not want to, and neither does anyone in your home. The only difference would be that the survey team member would need to come into your home if they take blood from a vein, and would do so using appropriate PPE; everything else about the visits would be the same. When blood is taken there is a small risk of bruising and/or fainting – the survey team members are qualified to reduce this risk. 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.

Are there any possible disadvantages or risks from taking part?

The main disadvantage to taking part is the time and inconvenience of having a member of the survey team visit your home. However, they will try to make appointments for a convenient time, including the evening or weekend.

The survey has been designed to make the risk of catching COVID-19 as low as possible – that is why the survey team member will use the recommended precautions and PPE and avoid entering your home. However, even with this, it is possible that there is still a small risk of getting COVID-19 from the survey team member (or a survey team member getting it from someone in the survey).

- ! You may find out that you have had COVID-19 when you did not realise that you had it.



What do I get for taking part?

To reflect their time, inconvenience of having a survey worker come to your home, and having to donate throat and nose swabs, **every person in your home (regardless of how old they are) who joins the survey will be compensated with a £50 voucher for the first home visit they complete. For every further visit that they complete, they will be compensated with a £25 voucher.** These will just be for visits that are completed; for example, if the survey is stopped you would not receive compensation for visits that don't happen. If you are happy to give us your email address, we can get vouchers to you more quickly, or we can post them if you prefer. However, it may still take at least 20 days to receive vouchers. Whilst vouchers can be spent in many stores online, they can only be spent for grocery shopping in person. 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 in some cases by post.**

Will my taking part in the survey be kept confidential?

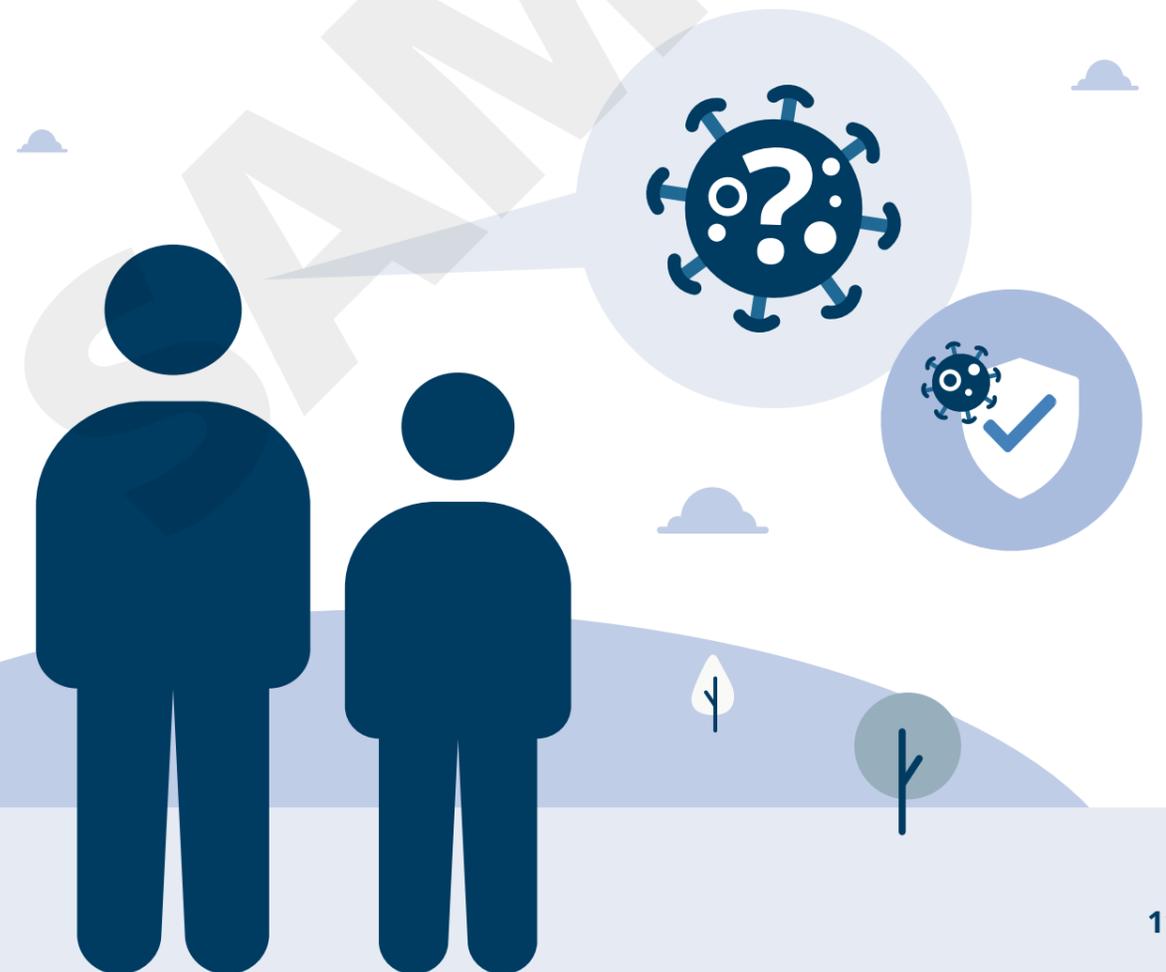
Yes. We will only use name, address, date of birth and sex where this is absolutely necessary to link to your other healthcare records, and where we are required by law to pass these on to the national public health bodies to help the country manage the pandemic. We will use your postcode to try to work 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 at one of the national Lighthouse laboratories, either at the National Biosample Centre, Milton Keynes, Glasgow, or Alderley Park, Liverpool, using the standard test to find out if someone currently has COVID-19. The throat and nose swabs will be destroyed once the test is done.

Any blood samples will be tested by scientists at the University of Oxford. They will look for the levels of antibodies against COVID-19 using a test developed in Oxford and manufactured by a company called Thermofisher which has CE certification for testing blood from both veins and finger pricks. We will send you the results from this test. However, it is very important to understand that we do not know yet what it means to have antibodies in the blood in terms of exactly how likely you are to get COVID-19 again: that is one of the reasons that we are doing the research. 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 that may be better. Your de-identified samples will be used mainly by researchers in the UK, but ethically approved research projects may take place in hospitals, universities, non-profit institutions or commercial laboratories worldwide. We will ask your permission for this – you do not have to agree to this to be part of the survey. Your blood samples will either be used up 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 survey visits and will work in partnership with survey workers from other select partner organisations. The companies involved in running the survey will only use information about you for this survey – they will not pass it on to anyone not involved in the survey.

To do this survey, we will be using information from you and NHS Digital, Public Health England 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. In order for us to produce statistics we may link the data we obtain through this survey with other survey and administrative data that we hold. Further information on what we use data for is available at <https://www.ons.gov.uk/aboutus/transparencyandgovernance/datastrategy>. All our uses of data will comply with UK Statistics Authority's ethical framework. Further information on the ethical framework is available at <https://uksa.statisticsauthority.gov.uk/about-the-authority/committees/national-statisticians-data-ethics-advisory-committee/>. The ONS will continue to hold the data collected through this survey for as long as it remains useful for statistical research and production. The ONS may provide access to de-identified data to accredited processors and researchers for accredited research purposes via accredited processing environments, where it is lawful and ethical to do so. A full list of accredited processors is available at <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/>. When making this de-identified data available the ONS may link the data we obtain through this survey with other survey and administrative data that we hold. Access will only be provided to support valuable new research insights about UK society and the economy that are considered to be in the public good. Further information on how we provide access to data for research purposes is available at <https://uksa.statisticsauthority.gov.uk/digitaleconomyact-research-statistics/>.

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. To find out more about each service provider's commitment while they are handling your information, please visit their websites.

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

- **sending a thank you gift:** our service provider for this is Sodexo: further information on <https://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 and Serco: further information on <https://www.hhglobal.com/uk/privacy-policy>, <https://granicus.com/privacy-policy/>, and <https://www.serco.com/privacy-policy>.

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, you may **contact us at 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 Public Health England for referral to the NHS Test and Trace system.

Data protection regulation provides you with 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. Further information about your rights with respect to your personal data is available at <https://compliance.web.ox.ac.uk/individual-rights>. 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 (no names or addresses or full postcodes or date of birth).

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 (<https://www.ons.gov.uk/aboutus/transparencyandgovernance/dataprotection>). 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.

The Data Protection Officer at ONS can be contacted at DPO@Statistics.gov.uk.

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 and without consequences. This includes after you have arranged an appointment for a member of the survey team to visit your home 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 across the UK. 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 Public Health England 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. **The survey is based on a representative sample of addresses and so if you move house, 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 in the UK over the next year – you can find a summary on <https://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.

What if we find something unexpected?

None of the tests done in this survey are likely to find anything unexpected. They are only looking very specifically for the COVID-19 virus, or for antibodies to it.

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.**

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

This survey follows government and WHO 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 Department of Health and Social Care, 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 appointments, managing participants taking their own throat and nose swabs, and taking blood samples in some households, and sending results to participants. IQVIA may sub-contract some visits to survey workers from other select partner organisations.
- The Lighthouse Laboratories at the National Biosample Centre, Milton Keynes, Glasgow and Alderley Park, Liverpool, are responsible for storing and 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 Lighthouse Laboratories at the National Biosample Centre, Milton Keynes, Glasgow and Alderley Park, Liverpool, in collaboration with the University of Oxford.
- NPex will manage test results and personal data from the survey in the same way as it does for the national testing programmes for the NHS.

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.



Contact details

To take part you will need to register with the company running the survey for the government by phoning **0800 085 6807**.

The telephone adviser will register you onto the survey and a member of the survey team will then contact you. A contact email is available for those who are unable to telephone, for example due to hearing or speech impairment **iqvia.covid19survey@nhs.net**. If you are able to use the telephone, it would help us if you could do so.

Opening times are:

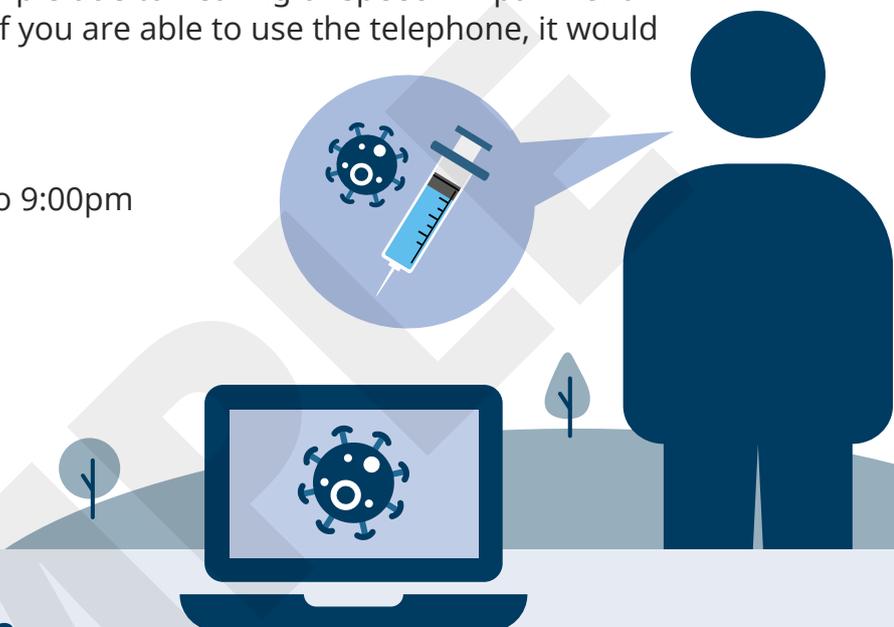
Monday to Thursday - 9:00am to 9:00pm

Friday - 9:00am to 8:00pm

Saturday - 9:00am to 5:00pm

Sunday - 9:00am to 5:00pm

Thank you for considering taking part.



Further information

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: <https://coronavirusexplained.ukri.org/en/>
- Government guidelines: www.gov.uk/coronavirus
- NHS advice: <https://www.nhs.uk/conditions/coronavirus-covid-19/>
- What taking a nose and throat swab is like <https://www.gov.uk/government/publications/covid-19-guidance-for-taking-swab-samples>
- Samaritans - Emotional support for everyone: www.samaritans.org
- Mind - Advice and support for anyone with a mental health problem www.mind.org.uk

<https://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 <https://www.ndm.ox.ac.uk/covid-19/covid-19-infection-survey/protocol-and-information-sheets>

Participant Information Sheet – adults and adolescents 16 years and older

COVID-19 infection survey | Version 7.0 Date: 1 February 2021

Ethics Ref: 20/SC/0195 | IRAS Project ID: 283248

Chief Investigator: Professor Ann Sarah Walker