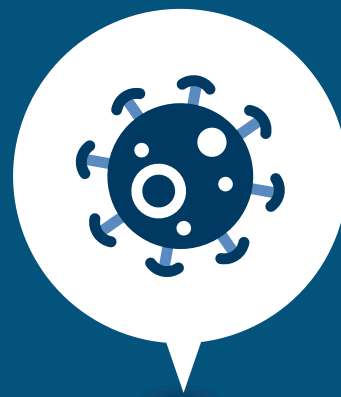


COVID-19 Infection Survey

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 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 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 also be in the survey.

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

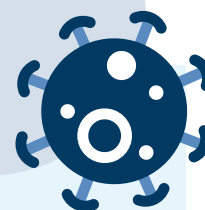
What is the purpose of the survey?

The coronavirus (COVID-19) pandemic has had a major impact across the UK. This survey aims to find out how many people of different ages:

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

This is particularly important as more people are vaccinated against COVID-19 and we start to monitor how well the vaccines work in the real-world.

Although the vaccines work very 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.

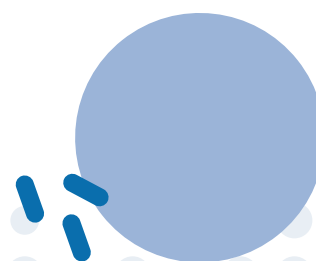


Why are we doing this research?

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 amount 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.



How 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.



At the moment, **people from over 240,000 homes from across the UK are taking part in the survey.**

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

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.

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. We aim to conduct your first appointment in the week after you register, but it may be longer than this if lots of people register for the survey at the same time. 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. 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. If the time isn't convenient for you, you can change it – we will try to find a time that works for you, including evenings or weekends. The reason for sending someone from the survey team to your home is so that you do not have to travel to take part in the survey.

What will happen on my first visit?

When the survey team member visits your home, they will:

- 1 check that you still want to take part
- 2 ask you to sign a consent form
- 3 ask you some questions about yourself
- 4 show you how to use a self-swabbing kit for you to take **a swab from your throat and nose**

⌵ This will take around **20 minutes per person**.

If an older child or teenager (10-15 years) in your home wants to join the survey, we will ask 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 ask everyone who wants to join the survey some questions about:

- any symptoms they may have now or have had in the past
- contacts with someone who had COVID-19
- and what kind of contacts they have outside the home

They will also ask about:

- sex
- ethnicity
- religion
- date of birth
- occupation and questions about work, or school for those still at school



i If any information gets missed accidentally, a member of the survey team will call you.

The swab will tell us whether you currently have COVID-19. 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 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. Taking the swabs yourself reduces the risk of spreading COVID-19 to the survey team member and the household. It also means the survey team member does not need to come into your home.

- ▶ To watch a video that shows how to take a swab, see www.ndm.ox.ac.uk/covid-19/covid-19-infection-survey/video-guides

The trained survey team member will bring all necessary equipment, including personal protective equipment (PPE) with them to your home for the 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 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.

Survey team members will still visit if anyone in your home is currently experiencing symptoms of COVID-19, self-isolating or shielding. 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 the survey questions from this distance. **It is important to visit these people to find out how many are infected or exposed to the virus.**

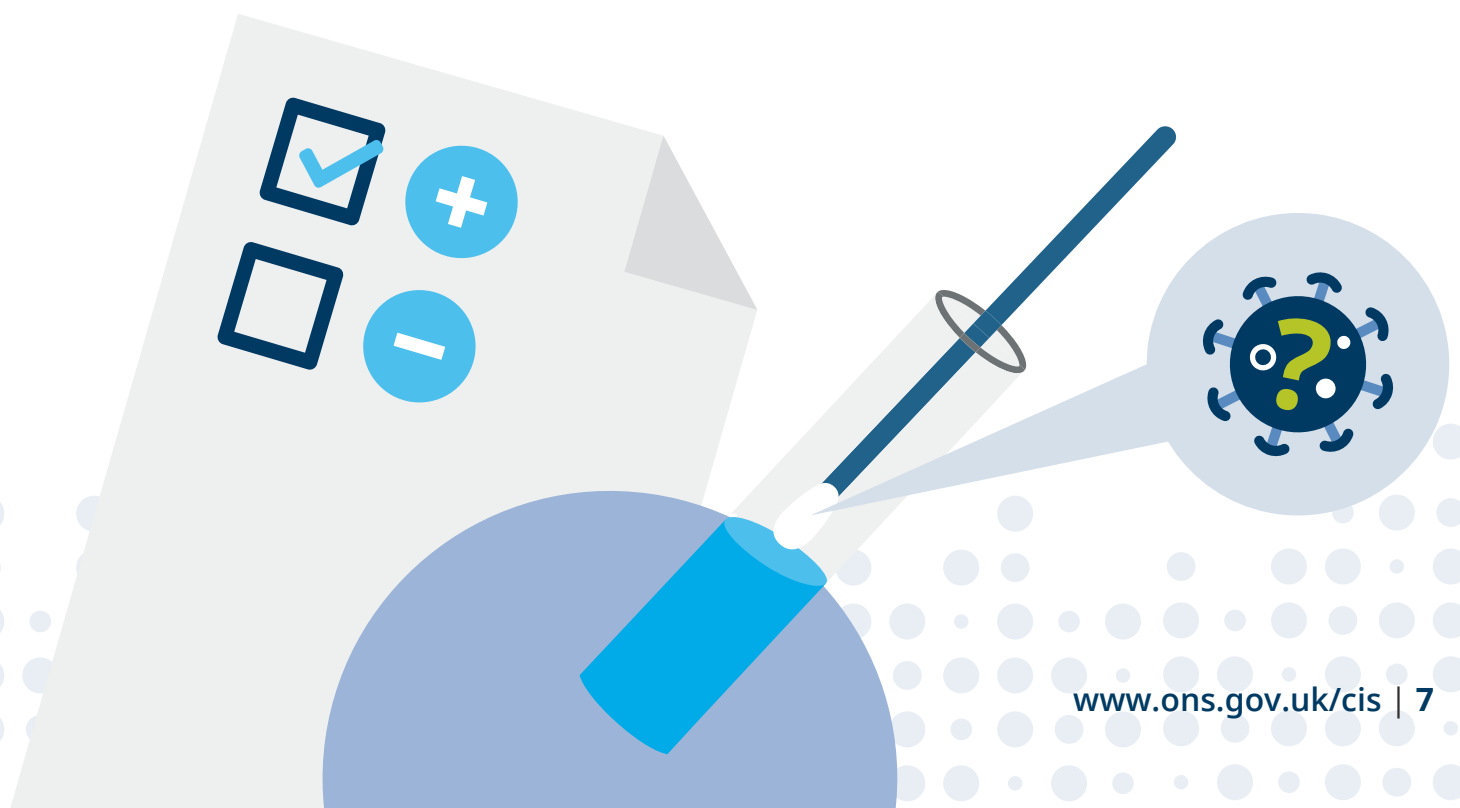
What will happen after my first visit?

We will ask whether you or anyone in your home would be interested in further visits. This is so that we can see how COVID-19 infection 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, and then monthly visits until the survey finishes (at least 6 visits in total). At the moment, the survey is running until April 2022. We will let you know if this changes.

You do not have to agree to more visits. These repeat visits should take around 15 minutes per person. Each visit involves the same questions and a throat and nose swab.



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.

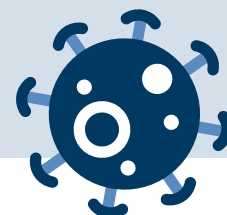
If you would be happy for us to do so, we will send you information about other studies that have been approved by a Research Ethics Committee or programmes that have been approved by the Department of Health and Social Care so that you could contact them if you would be interested in taking part in 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 covid.genomicc.org

What are the possible benefits of taking part?

Taking part in this survey will help us to understand more about COVID-19 and vaccinations. This information is very useful in helping the country recover from COVID-19 and work out how we are going to manage it in the coming years.

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. 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.

The COVID-19 Infection Survey is a research study, not a testing programme. Our swab tests are mostly with people without COVID-19 symptoms. These take lower priority than tests from the national testing programmes and clinical service.

As this is a research study, you may not get these results as quickly as in the main national testing programmes. In the research study, it takes a day 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 to the research study.

Once results come back, they are matched to participants through a sample barcode and letters are then sent out. So it typically takes at least a week before people get their swab test results.

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 only around 1 in 20,000 positives will be wrong. 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 national tracing programme. They will then contact you by text, email or phone, **and this will almost certainly 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: www.nhs.uk/conditions/coronavirus-covid-19/symptoms-and-what-to-do/** **You should isolate even if you don’t have any symptoms.** 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. People usually 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 will ask whether you and any other adult aged 16 years and over in your home would be happy to give a blood sample to measure levels of antibodies at your survey visits. This will be done from a finger prick that you will do yourself. You will take a small amount of blood (around 0.5ml) from a finger prick, using a kit that we will provide. You do not have to do this part of the survey if you do not want to, and neither does anyone in your home. 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.

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 **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 if I develop symptoms?

It is very important that if you develop symptoms of COVID-19 you follow the usual guidance on self-isolation found at www.nhs.uk/conditions/coronavirus-covid-19/symptoms-and-what-to-do/

Even if you have had a recent swab 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 swab test in the survey, please follow the guidance on getting a test www.gov.uk/guidance/coronavirus-covid-19-getting-tested

Are there any possible disadvantages or risks from taking part?

The disadvantages are:

- The time and inconvenience of having a survey team member visit your home
 - You may find out that you have had COVID-19 when you did not realise that you had it
 - It is possible that there is a small risk of getting COVID-19 from the survey team member or a survey team member getting it from someone in the survey
- i** 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 not enter your home.

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) **will be compensated with a £50 voucher for the first home visit. For every further visit, they will be compensated with a £25 voucher.**

These will just be for completed visits. If the survey is stopped, or you decide to leave the survey, you will not receive compensation for visits that don't happen.

If you give us your email address, we can get vouchers to you more quickly, 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. For grocery shopping they can only be used 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 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 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 at one of the national Lighthouse laboratories and you will be sent the results. **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 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 survey visits and will work in partnership with survey workers from 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, 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. 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. 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. 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.

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
- **helping us get in touch:** our service providers for this are HH Global, GovDelivery, Serco (through to July 2021) and Capita (from July 2021): further information on www.hhglobal.com/uk/privacy-policy, granicus.com/privacy-policy/, www.serco.com/privacy-policy and www.capita.com/privacy-notice

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.

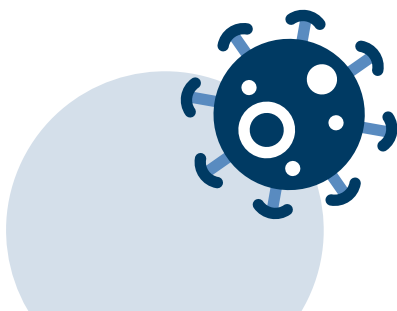
Data protection regulation provides you with control over your personal data and how it is used. When you agree to your information being used in research, however, some of those rights may be limited in order for the research to be reliable and accurate. The information we find out from this survey 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
- Further information on the ethical framework is available at 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/
- Further information on how we provide access to data for research purposes is available at uksa.statisticsauthority.gov.uk/digitaleconomyact-research-statistics/
- The Data Protection Officer at ONS can be contacted at 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
- Further information about your rights with respect to your personal data is available at 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 arranged an appointment for a survey team member 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.

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 in the UK. You can find a summary on 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 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 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 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, 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 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 who are conducting the survey on behalf of ONS and Oxford. To register, call **0800 085 6807**.

The telephone adviser will register you onto the survey and a member of the survey team will then contact you. If you are able to contact us by telephone in the first instance, it would help us if you could do so. If you are unable to contact us by telephone, for example if you have a hearing or speech impairment, please email iqvia.covid19survey@nhs.net

- ▶ To watch a video that shows how to take a swab, see www.ndm.ox.ac.uk/covid-19/covid-19-infection-survey/video-guides

Opening times are:

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

Friday - 9:00am to 8:00pm

Saturday & 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:

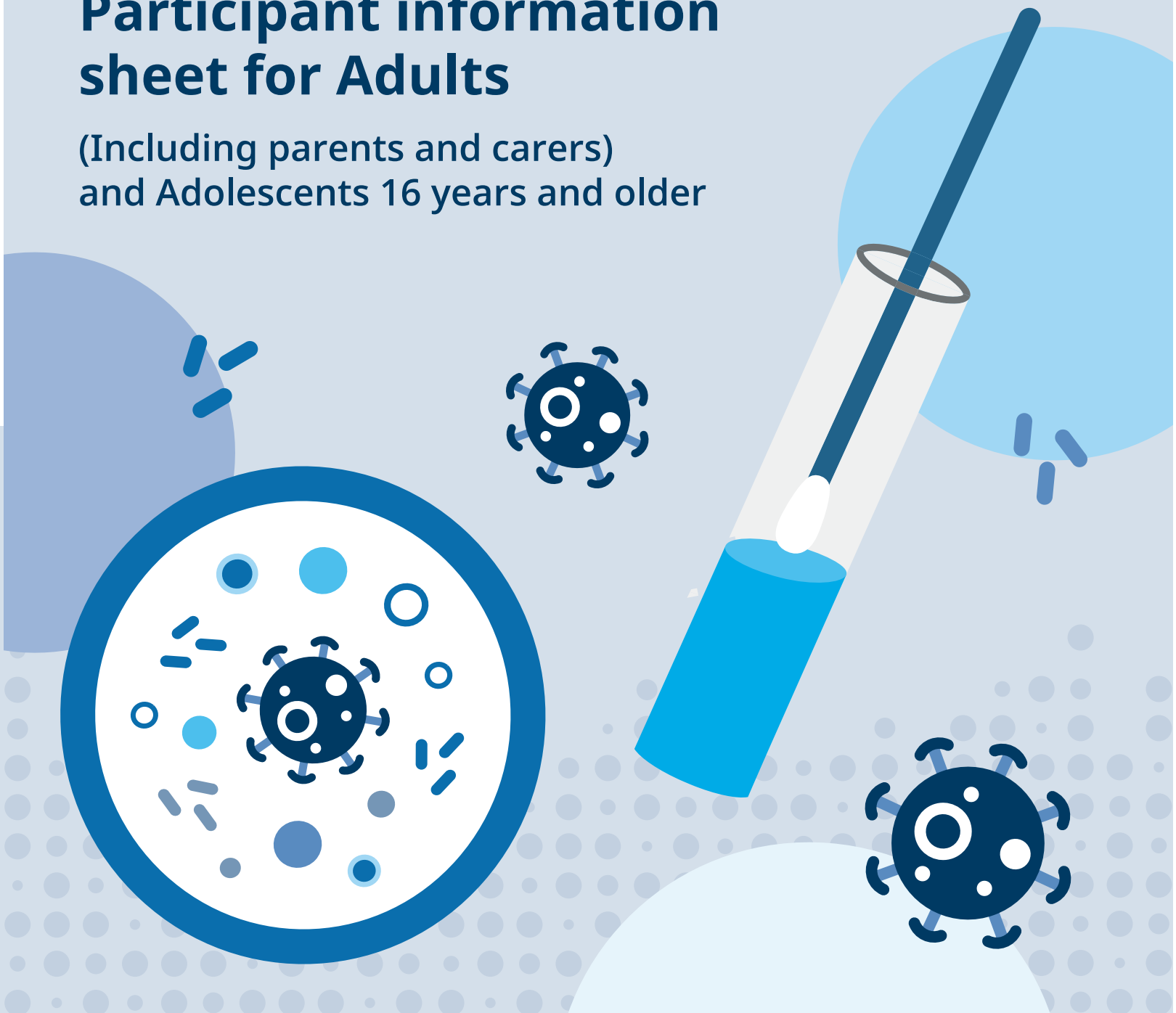
- Coronavirus explained: coronavirusexplained.ukri.org/en/
- Government guidelines: www.gov.uk/coronavirus
- NHS advice: www.nhs.uk/conditions/coronavirus-covid-19/
- What taking a nose and throat swab is like: www.gov.uk/government/publications/covid-19-guidance-for-taking-swab-samples
- Samaritans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

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

Participant information sheet for Adults

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



Study Contact:
0800 085 6807