

This Ipsos MORI and Imperial College London survey and your personal data: REACT COVID-19 testing research study (22-010641-01)

Ipsos MORI and Imperial College London are inviting you to take part in this research on behalf of the Department for Health and Social Care (DHSC), to help the Government measure the prevalence of COVID-19 and to understand the interaction with influenza (flu).

This Privacy Notice explains who we are, the personal data we collect, how we use it, who we share it with, and what your legal rights are.

About the Department of Health & Social Care, Imperial College London and Ipsos MORI

- The Department of Health & Social Care is responsible for government policy on health and adult social care in England. You can find more information about DHSC at <https://www.gov.uk/government/organisations/department-of-health-and-social-care>
- Imperial College London is a leading university closely involved in the COVID-19 response. You can find out more about Imperial College London at <https://www.imperial.ac.uk/medicine/research-and-impact/groups/react-study/>
- Market & Opinion Research International Limited is a specialist research agency, commonly known as “Ipsos MORI”. Ipsos MORI is part of the Ipsos worldwide group of companies, and a member of the Market Research Society. As such we abide by the Market Research Society Code of Conduct and associated regulations and guidelines.

How did you get my contact details?

- Ipsos MORI is contacting you on behalf of DHSC. Names were chosen at random from the NHS list of patients registered with a GP in England. NHS Digital has shared a limited amount of your personal data so that Ipsos MORI can invite you to take part in this research. This data consists of:
 - Your name and address
 - Your mobile number
 - Your NHS number
 - Your gender and month and year of birth
- Ipsos MORI will keep your data confidential and will only use your contact details to send you this survey invitation and information about this study. If you agree to take part in the study, we will then send you a further letter containing the swab and instructions.
- Ipsos MORI may use your telephone number to contact you to remind you to register for the study.
- If you take part in the study, your data will be shared with the research team at Imperial College London who will keep your data confidential and will be doing the analysis of the data.
- If you complete the swab test and survey, some of the data you provide will be shared with NHS Test and Trace. Please go to “How will Imperial College London and Ipsos MORI use any personal data including survey responses you provide?” for further information.

- Once the survey is finished, Ipsos MORI will securely destroy your contact details. Imperial College London will keep your data for up to 20 years.

What will happen with the information I provide?

- The Department for Health and Social Care (DHSC) and Imperial College London are joint data controllers for the processing of personal data for this survey, which means that they are responsible for ensuring that the processing complies with the General Data Protection Regulation (GDPR). You can access DHSC's Privacy Notice at https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/800049/Privacy_Note_v2_.pdf and Imperial's Privacy Notice at <https://www.imperial.ac.uk/medicine/research-and-impact/groups/react-study/>.
- Ipsos MORI is a data processor, acting on behalf of DHSC and Imperial College London. They will only keep your data in a way that can identify you for as long as is necessary to support the research project and findings. By the end of April 2022 for Round 18 (access codes starting with LL) and May 2022 for Round 19 (access codes starting with MM), Ipsos MORI will delete your personal contact data from their systems.
- If you consent to being contacted for future research, and/or for the results of this study being linked to other health information that the NHS holds about you, Imperial College London, may keep your data for up to 20 years in order to support this research. That includes the contact details you provide to Ipsos MORI. If you have consented to data linkage, we may receive your contact details from the NHS and, if you have consented to be contacted for future studies, we may use them to contact you.
- If you agree to data linkage, identifiable data may be shared outside the two research teams (Ipsos MORI and Imperial College London) and NHS Test and Trace for the purposes of data linkage only. It will not be possible to identify you in any published results.
- If you agree to data linkage, your survey answers will NOT be provided to your healthcare provider.
- Researchers who wish to access the data from this study and/or to contact participants about future research will have to apply to a data access committee composed of at least 3 of the study investigators and at least one public representative.
- Ipsos MORI has a legal obligation to pass on your COVID-19 and flu test result (whether positive, negative or inconclusive) and a small amount of additional data about you to NHS Test and Trace. A full list of the data that will be provided can be found on the gov.uk website on <https://www.gov.uk/guidance/covid-19-and-influenza-point-of-care-testing-results-how-to-report#what-to-report>.
- This change in law has been made to improve the overall understanding of how COVID-19 is spreading and to improve the actions taken in response to the COVID-19 pandemic.

What is our legal basis for processing your personal data?

- We use personally-identifiable information collected in this study to conduct research to improve health, care and services.
- DHSC and Imperial College are the data controllers for the processing of personal data for this study. This means that they are responsible for ensuring that the processing complies with the General Data Protection Regulation (GDPR) and related legislation.
- The Department of Health and Social Care, who are the data controller for this study, have the following legal duty under the Health and Social Care Act 2012 and are conducting this research in order to discharge that duty, to generate incidence and prevalence rates in relation to COVID-19 and to understand the impact of influenza on COVID-19.

DUTY: Protection of public health	Under section 11 of the Health and Social Care Act 2012, the Department of Health and Social Care has a statutory duty to protect ‘the public in England from disease or other dangers to health’ including conducting research ‘for advancing knowledge and understanding’
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- This research is being carried out to help the Government develop its approach to COVID-19 testing and help the NHS prepare for the autumn and winter. The lawful basis for processing is Article 6(1) (e) - “*processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller and Article 9(2) (j) ‘processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes’.*” For the COVID-19 testing research study this means that the Department of Health and Social Care are not relying on consent as a basis for obtaining contact details or for processing the data provided voluntarily by those completing it. The DHSC and Imperial College London can use the personal data they hold about you for research with appropriate safeguards in place. For this study they have shared a limited amount of information with the research team at Ipsos MORI in order to invite a random selection of patients to take part in the testing research.
- Health and care research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following the [UK Policy Framework for Health and Social Care Research](#). Ipsos MORI is the data processor acting on instructions of DHSC to deliver the survey.
- You can access DHSC’s Privacy Notice at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/800049/Privacy_Note_v2_.pdf
- Ipsos MORI is required by law to provide information to NHS Test and Trace under The Health Protection (Notification) (Amendment) Regulations 2020 and The Health Protection (Notification) (Amendment) (Coronavirus) Regulations 2020. You can find what information is provided under “what will happen with the information I provide” section on this Privacy Notice or at

<https://www.gov.uk/guidance/covid-19-and-influenza-point-of-care-testing-results-how-to-report#what-to-report>.

Do I have to take part?

- Taking part is entirely voluntary and registering to take part and then completing the swab test and any answers you give to the online survey, are given with your consent.
- The survey will include questions about you and your health.

Are national data opt-outs applied to this survey?

- No. NHS Digital have stated that the information shared with Ipsos MORI from the Personal Demographics Service, for the purpose of the REACT 1 study, should be classed as Confidential Patient Information. NHS Digital has shared a limited amount of your personal data so that Ipsos MORI can invite you to take part in this research. This data consists of:
 - Your name and address
 - Your mobile number
 - Your NHS number
 - Your gender and month/year of birth
- Ipsos MORI has not been given access to clinical data about any individual (such as any medical conditions, prescriptions or care received), nor any information from an individual's medical record.
- The Secretary of State for Health and Social Care has issued NHS Digital with a Notice under Regulation 3(4) of the Health Service (Control of Patient Information) Regulations 2002 (COPI) to require NHS Digital to share confidential patient information with organisations entitled to process this under COPI for COVID-19 purposes. These data have been provided to Ipsos MORI under this COPI regulation and, as such, the National Data Opt-out does not apply.
- Imperial College London asks for your consent to link the study data to other health information that the NHS holds about you. Since we would only do this with your consent the national data opt-out would not apply.

Has Ipsos MORI got access to my health data?

- Ipsos MORI has been given your NHS number, name, address, month and year of birth, mobile number, and gender. DHSC have not given Ipsos MORI any information about your health.
- Ipsos MORI is given your NHS number so that we can, as far as possible, avoid selecting people for more than one round of the study. Your contact details are used to contact you regarding the study.
- Information about month and year of birth and gender will be used to make sure that the anonymised survey data matches the profile of the population as closely as possible.
- We will ask your consent for Imperial College London to link data held by NHS Digital and other NHS bodies to your survey data, but you can refuse consent or withdraw this consent at any point.

What will I be asked to do?

- We are initially asking you to register your interest to complete a swab self-test that may show whether you currently have the COVID-19 virus.
- The swab will also be tested for flu.
- If you agree to take part, we will send you a swab test and some instructions. Please be aware that the test is not 100% accurate at an individual level.
- We would also like you to answer some questions online about you and your health. We would like you to do this regardless of whether you were able to take the test or if you think the test has not worked.

How will Imperial College London and Ipsos MORI use any personal data including survey responses you provide?

- Imperial College London and Ipsos MORI will keep your personal data and responses in strict confidence in accordance with this Privacy Notice.
- Your name and address will be kept separate from your answers and will only be shared with the research team at Ipsos MORI and Imperial College London.
- If you take part, Ipsos MORI has a legal obligation to pass on your COVID-19 and flu test result (whether positive, negative or inconclusive) and a small amount of additional data about you to NHS Test and Trace. A full list of the data that will be provided can be found at <https://www.gov.uk/guidance/covid-19-and-influenza-point-of-care-testing-results-how-to-report#what-to-report>.
- Ipsos MORI will use your personal data and responses solely for this research.
- If you consent in the follow up questionnaire, Imperial College London may use your personal data to contact you about participating in future research. DHSC may ask Imperial College London to share your data with another organisation who is acting under their instructions, this organisation in turn may contact you about participating in further research.
- Contact information may also be obtained through data linkage, but only if you consent to both data linkage and for Imperial College to contact you about further research. You will be asked if you consent in the follow up questionnaire.
- In the registration questionnaire we will ask if you give permission for Imperial College London to link health data held by NHS Digital and other NHS bodies to your survey data. This linkage would be done by the NHS. If you agree to data linkage in the follow up questionnaire, identifiable data may be shared outside the two research teams and NHS Test and Trace for the purposes of data linkage only. It will not be possible to identify you in any published results.

Who is your information shared with and for what purpose?

- Ipsos MORI is working with a number of supplier organisations to assist us in running this COVID-19 testing research. As part of the research, we will need to disclose your personal data to these supplier organisations for that purpose. These supplier organisations are:

- Formara: despatching testing kits (name and address)
 - Adare: printing letters to contact you about the study (name and address)
 - Royal Mail: distribution
 - Tivian: online data collection (name, month/year of birth and gender)
 - Textlocal: to contact you by text about the study, including the COVID-19 result of your test (mobile phone number)
- These suppliers are approved and compliant with the General Data Protection Regulations.
 - If you complete the swab test, we will inform NHS Test and Trace of all COVID-19 and flu test results (positive, negative and inconclusive), to improve the overall understanding of how COVID-19 is spreading and to improve the actions taken in response to the COVID-19 pandemic. For further information please visit <https://www.gov.uk/guidance/covid-19-and-influenza-point-of-care-testing-results-how-to-report#what-to-report>. The flu test is for research and monitoring purposes only, allowing us to estimate how many people in England are currently infected with the flu virus. We will send the COVID-19 swab test result to those who takes part but not the flu test result (which is for research and monitoring purposes only).
 - If you consent to be re-contacted, Imperial College may share your personal data with certain third parties, including other College employees, agents, contractors and service providers (for example, suppliers of printing and mailing services, email communication services or web services, or suppliers who help us carry out any of the activities described above). Our third-party service providers are required to enter into data processing agreements with us. We only permit them to process your personal data for specified purposes and in accordance with our policies.

How will Ipsos MORI and Imperial College London ensure my personal information is secure?

- Ipsos MORI and Imperial College London take their information security responsibilities seriously and apply various precautions to ensure your information is protected from loss, theft or misuse. Security precautions include appropriate physical security of offices and controlled and limited access to computer systems.
- Ipsos MORI has regular internal and external audits of its information security controls and working practices and is accredited to the International Standard for Information Security, ISO 27001.
- Similar processes are in place at Imperial College London where a database to carry out statistical analyses of the data at postcode level will be established in an ISO 27001 environment.

Does this survey use Cookies or similar code?

- Some online surveys collect information through the use of 'cookies'. These are small files stored on your computer. These files are used as sparingly as possible and only for quality control, validation and, more importantly, to prevent us sending you reminders for an online survey you have already

completed. It is possible for you to delete 'cookies' or to prevent their use by adjusting the browser settings on your computer.

- We also automatically capture information about your operating system, display settings and browser type in order to ensure that the survey questionnaire is delivered in a form suited to the software your computer is using. We do not capture any other information from your computer.

What will I be asked to do/what will my child be asked to do?

- We are initially asking you to register your interest to complete a swab test to show whether you may have the COVID-19 virus or the influenza (flu) virus. If your child has been selected, we would like you to confirm that they would be willing to complete a swab test. You will be asked to complete a short online survey (about 5 minutes), collecting some brief information.
- If you or your child agree to take part, we will send you a test and some instructions by post and would like you or your child to take the test and return it to the laboratory by post using your local priority postbox.
- We would also like you to answer some questions online about you and your health/ your child and their health. We would like you to do this regardless of whether you or your child were able to take the test or if you think the test has not worked. The survey is a really important part of the study, as it provides information about you and your health/your child and their health. This questionnaire will take about 15 minutes.
- We will also ask if you are happy for Imperial College London to link health data held by NHS Digital and other NHS bodies to your survey data. This linkage would be done by the NHS.

What happens to my test?

- The swab test will be returned to a laboratory by post using your local priority postbox.
- The laboratory will share the results of the test with Ipsos MORI and Imperial College London.
- The COVID-19 results from the test will be sent by Ipsos MORI to you by email and text message, if you have provided these contact details. The COVID-19 result will be sent by letter if you have tested positive or if you have not provided your email address and mobile telephone number.
- The flu swab test is for research and monitoring purposes only so we will not provide the result of the flu test to you.

And what happens to the answers I give online?

- Ipsos MORI will keep all personal data collected for the survey and responses in strict confidence in accordance with this Privacy Notice.
- Your name and address will be kept separate from your answers and will only be shared with the research team at Ipsos MORI and Imperial College London.
- Some of your responses will be shared with NHS Test and Trace when we receive your COVID-19 test result. Otherwise no identifiable data will be shared outside the two research teams. It will not be possible to identify you in any published results.

- We will also ask if you are happy for Imperial College London to link your answers and the results of your swab test to your NHS record. If you agree to this, Imperial College London may also link your survey answers to other health information that the NHS holds about you both now and in the future using your NHS number. This linkage would be done by the NHS and returned to Imperial College London.

How long will Ipsos MORI retain my personal data and identifiable responses?

- Ipsos MORI will only retain your data in a way that can identify you for as long as is necessary to support the research project and findings. In practice, this means that once we have satisfactorily captured the data and transferred the database to Imperial College London, we will securely remove your personal, identifying data from our systems.
- For the current study we will securely remove your personal data from our systems by the end of April 2022 for Round 18 (access codes starting with LL) and May 2022 for Round 19 (access codes starting with MM).
- In addition, Ipsos MORI adheres to the Market Research Society code of research ethics, and the contact information you provide will not be used by Ipsos MORI for anything other than the purpose of this survey.

How long will Imperial College London retain my personal data and identifiable responses?

- Imperial College London will only retain your data in a way that can identify you for as long as is necessary to support the research project and findings.
- If you consent to Imperial College contacting you about future research, your data may be held for up to 20 years. That includes the contact details you provide to Ipsos MORI.
- If you consent to data linkage, Imperial College London may link the results to other health information that the NHS holds about you. This linkage would be done by the NHS. If you consent to data linkage, retention may be up to 20 years.
- Imperial College London will maintain its database for up to 20 years to allow it to undertake studies of possible long-term health outcomes.
- Researchers (under the supervision of Imperial College London or DHSC) who wish to access the data from this study and/or to contact participants about future research will have to apply to a data access committee composed of at least 3 of the study investigators and at least one public representative.

Has the survey received ethical approval?

- This study has received formal ethical approval from South Central - Berkshire B Research Ethics Committee.

Your rights and the General Data Protection Regulation (GDPR)

- Once you have submitted your response to the survey your usual statutory rights to access, change or move your information are limited, because of

exceptions applicable to some types of research, and also because we need to manage your information in specific, lawful ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

- You have the right to request access to your personal data within the period that Ipsos MORI or Imperial College London holds it.
- If you want to exercise your rights, please contact us at the Ipsos MORI or Imperial College London address below.
- We must generally respond to requests in relation to your rights within one month, although there are some exceptions to this.
- Providing responses to the study's surveys is entirely voluntary and is done so with your consent. You have the right to withdraw your consent to our processing of your personal data at any time before the data is processed for reporting in March 2022 for Round 18 (access codes starting with LL) and April 2022 for Round 19 (access codes starting with MM).
- You have the right to lodge a complaint with the Information Commissioner's Office (ICO) or another data protection regulator, if you have concerns on how we have processed your personal data. You can find details about how to contact the Information Commissioner's Office at <https://ico.org.uk/global/contact-us/> or by sending an email to: casework@ico.org.uk.

The ICO does recommend that you seek to resolve matters with the data controller first before involving the regulator. Please see the contact details below.

Where will my personal data be held and processed?

- All of your personal data used and collected for this survey will be stored by Ipsos MORI and Imperial College London in data centres and servers within the United Kingdom and EEA. Where your personal data is stored by Ipsos MORI and Imperial College London in data centres and servers within the EEA, an agreement, based on the Standard Contract Clauses issued by the European Commission, is in place to ensure the transfer of data between the EEA and the UK takes place with appropriate legal safeguards.

How can I contact Ipsos MORI and Imperial College London about this survey and/or my personal data?

- If you have any questions about the research, please contact our helpline on FREEPHONE **0800 157 7818** or email UK-Covid-swab-research@ipsos.com.
- If you wish to raise a complaint on how we have handled your personal data, please contact:

DHSC:

Email: data_protection@dhsc.gov.uk

Post: Department of Health and Social Care
1st Floor North
39 Victoria Street
London
SW1H 0EU

Imperial College London:

Email: Data Protection Officer at: dpo@imperial.ac.uk

Post: Data Protection Officer
Imperial College London
Exhibition Road
South Kensington
London SW7 2BU

Ipsos MORI:

Email: UK-Covid-swab-research@ipsos.com

Post: REACT1 COVID-19 testing (22-010641-01)
Data Protection Officer, Compliance Department
Market and Opinion Research International Limited
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London E1W 1YW,
United Kingdom