This Ipsos MORI and Imperial College London survey and your personal data: COVID-19 home testing research study (20-046047-01)

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.

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 email address
  - Your NHS number
  - Your gender and date of birth
- Ipsos MORI will keep your data confidential and will only use your contact details to send you this survey invitation. If you agree to take part in the survey, we will then send you a further letter containing the swab and instructions.
- If you take part in the survey, 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.
- 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 is our legal basis for processing your personal data?

- DHSC and Imperial College are the data controllers for the processing of personal data for this survey. This means that they are responsible for
ensuring that the processing complies with the General Data Protection Regulation (GDPR) and related legislation.

- This research is being carried out to help the Government develop its approach to COVID-19 testing. 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’. This means that DHSC and Imperial College London can use the personal data they hold about you for research with appropriate safeguards in place. 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.


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 how you found taking part in the test, as well as questions about you and your health.

Are national data opt-outs applied to this survey?

- No. The Department of Health and Social Care has confirmed that the National Data Opt-out only applies when confidential patient information is being used for purposes other than care for the individual. Confidential patient information includes clinical data about the individual (such as any medical conditions, prescriptions or care received), and any information about the individual that has been accessed via the individual’s medical record. This survey only uses demographic data and contact details drawn from patient registration records to select and contact individuals to take part. This personal data is not classified as confidential patient information as no clinical information is used or accessed. 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.

Have you got access to my health data?

- Ipsos MORI has only been given your NHS number, name, address, day, month and year of birth, and gender. DHSC have not given Ipsos MORI any information about your health.
• Ipsos MORI are given your NHS number so that they can identify you if you have previously opted-out from the survey to ensure they do not contact you again. Your contact details are used to contact you regarding the survey.
• Information about date 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.
• 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 how you found taking the test. 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. We will also ask some questions about you and your health.

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 Policy.
• 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.
• Ipsos MORI will use your personal data and responses solely for this research.
• If you consent, 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.
• No identifiable data will be shared outside the two research teams (unless you agree to data linkage), and it will not be possible to identify you in any published results.

Who your personal data is shared with?

• 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:
  o Print and despatch (Adare and Formara)
• Royal Mail: distribution
• Online data collection (Questback)
• The Delivery Group (courier who collects your kit)
• Text local (to send text messages if you provide a mobile number)

• These suppliers are approved and compliant with the General Data Protection Regulations.
• If you test positive, we will inform NHS Test and Trace so that they can contact you.
• 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.
• Both Ipsos MORI and Imperial College London have regular internal and external audits of their information security controls and working practices and are accredited to the International Standard for Information Security, ISO 27001.

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. 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 courier.
- We would also like you to answer some questions online about how you or your child found taking the test. 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. This is really important to help us understand your experience with the test so that we can make it better in future. We will also ask some questions about you and your health/your child and their health. This questionnaire will take about 10-15 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 picked up by courier and returned to a laboratory.
- The laboratory will share the results of the test with Ipsos MORI and Imperial College London. The results from the test will be sent by Ipsos MORI to you by email and text message, if you have provided these contact details and by letter.

**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 Policy.
- 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.
- No identifiable data will be shared outside the two research teams, and it will not be possible to identify you in any published results.

**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 obtained the research data, we will securely remove your personal, identifying data from our systems.
- For this project we will securely remove your personal data from our systems by December 2020.
- 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.
• 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.
• 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.
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:** compliance@ipsos.com with “COVID-19 home testing (20-046047)” in the email subject line

**Post:** COVID-19 home testing (20-460427)  
Data Protection Officer, Compliance Department  
Market and Opinion Research International Limited  
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United Kingdom