

Privacy Notice - St George's University of London - Health and Social Care Research

Research Project: *Helicobacter pylori* screening study: a randomised stomach cancer prevention trial

Who we are

St George's, University of London (SGUL) is the 'Data Controller' of personal data provided directly or indirectly to us and are registered with the Information Commissioner's Office (ICO) for the purposes of UK data protection legislation, registration number Z5770328.

How to contact us

The University has a Data Protection Officer who can be contacted at:

Email: dataprotection@sgul.ac.uk
Tel: 020 8725 0668
Address: Data Protection Officer, Information Services, St George's University of London, Cranmer Terrace, LONDON SW17 0RE

What research information we collect from you and why

As an active healthcare university with research at the core of our activity we use personally-identifiable information to conduct health and social care research with the aim of improving healthcare and related services. As a publicly-funded organisation, we have to ensure that it is in the public interest when we use the personally-identifiable information of people who have agreed to take part in one of our research projects, either provided directly by those individuals or from a 3rd party source such as NHS Digital or ONS. This means that when you agree to take part in a research study we are leading or collaborating in, we will use your data in the ways needed to conduct and analyse the research study.

Health and social 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. For SGUL general research privacy notice please see:

https://www.sgul.ac.uk/images/about/Policies/Privacy_Notice_Research_SGUL.pdf

Research Project specific information we collect and why

Project Name: *Helicobacter pylori* screening study: a randomised stomach cancer prevention trial

Project Details: Lifelong infection of the stomach with the bacterium *Helicobacter pylori* (H Pylori) increases the risk of stomach cancer. The aim of this trial was to determine whether screening and treatment of H Pylori infection in middle age can reduce the risk of stomach cancer. 62,454 men and women attending ten BUPA Wellness Centres in Britain from 1997 to 2006 for a medical examination were recruited and randomly allocated into equally sized screened and control groups according to week of attendance. Those attending in screened weeks were offered serological testing for H pylori and, if they were positive, a one-week course of eradication treatment. Blood

was collected and the serum stored from all participants (screened and control). Information from death certificates and cancer registrations are received regularly from NHS Digital on all trial participants. When over 120 participants have developed stomach cancer (estimated to occur in 2022, after about 25 years follow-up) the serum samples from all persons who developed stomach cancer will be tested for H. pylori. The final comparison will be between the incidence of stomach cancer in the screened and control groups among H pylori positive persons only (rather than all persons). If the trial showed that all, or a substantial part of the excess risk of stomach cancer due to H Pylori infection can be reduced it would mean that most cases of stomach cancer in the world could be prevented – a major public health finding. No automated decision-making, including profiling, will be performed on this data.

Category of personal data collected relates to: Primary source data (i.e. medical questionnaire responses), Identifiable information such as Name and Date of Birth, Date of death and causes of death and cancer registration information

Contract Reference: CON-315125-P6G9X

Project Reference: DARS-NIC-147843-8NKTW-v2.2

Funding: CRUK

Data Controller(s): St George's, University of London - DPA Registration Number Z5770328

Legal Basis:

- a. Article 6(1)(e) of the General Data Protection Regulation (GDPR) provides the legal basis for public authorities (e.g. universities and NHS organisations) to process personal data for research purposes.
- b. Additionally, article 9(2)(j) of the GDPR provides the legal basis for processing special categories of (sensitive) personal data which includes data concerning health and ethnicity for scientific research purposes.

Data Source: National Health Service (NHS) Digital are the national information and technology partner to the health and social care system using digital technology to transform the NHS and social care. Details on NHS Digital's responsibilities regarding looking after your health and care information can be found at: <https://digital.nhs.uk/about-nhs-digital/our-work/keeping-patient-data-safe/how-we-look-after-your-health-and-care-information>Contact details NHS Digital Data Protection Officer: Email: enquiries@nhsdigital.nhs.uk Tel: 0300 303 5678

Who we share your information with

Data will not be shared with anyone outside the immediate research team

How long we keep your information for

Your information will be retained for a period of 24 months after completion of the Helicobacter pylori screening study and then deleted.

What your rights are

The *Helicobacter pylori* screening study is a research project carried out in the public interest. Therefore your rights to access, change or move your information are limited, as we need to manage the data in specific ways in order for the research to be reliable and accurate. If you withdraw your consent to participate in a research project, this will not mean we will have to remove all data as well. We will keep the information about you that we have already obtained to ensure research integrity is maintained in the public's interest. To safeguard your rights, we will strive to use the minimum personally-identifiable information possible.

How to make a complaint

If you are unhappy with the way in which your personal data is being processed you may, in the first instance, lodge a complaint with the University Data Protection Officer using the contact details above.

If you continue to have concerns thereafter you have the right to contact the Information Commissioner for a decision. The Information Commissioner can be contacted as below

Helpline: 0303 123 1113

Website: <https://ico.org.uk/for-the-public/raising-concerns/>