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

Research Project: MR39 - SMOKING STUDY - MEN ATTENDING BUPA MEDICAL CENTRE

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 ORE

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/privacy

Research Project specific information we collect and why

Project Name: MR39 - SMOKING STUDY - MEN ATTENDING BUPA MEDICAL CENTRE

Project Details: The BUPA cohort recruited 22,000 men aged 35-64 who attended the British United Provident Association (BUPA) medical centre in London for a comprehensive medical examination between 1975 and 1982. Serum samples were collected from the men and have been stored in freezers. Information from death certificates and cancer registrations are received regularly from NHS Digital. This BUPA cohort study was set up to look at risk factors for cancer and cause specific mortality, with an emphasis on the risks of smoking. The data on mortality and cancers has been used to conduct both cohort and case control

studies resulting in over 32 papers being published in peer review journals. The areas of research covered have included the health effects of active and passive smoking, screening, cancer and nutrition, cancer and infection, serum cholesterol in relation to Ischaemic Heart Disease (IHD) and cancer, apolipoproteins, blood pressure and stroke, cardiovascular screening and osteoporosis. The BUPA study was originally funded by the Medical Research Council and BUPA. Currently no data processing is occurring, but if funds become available researchers at SGUL will conduct new research into risk factors for mortality, mainly from ischemic heart disease or cancer. 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 and ECG), Identifiable information such as Name and Date of Birth, Date of death and causes of death and cancer registration information

Contract Reference: CON-341863-L0X2Y

Project Reference: DARS-NIC-148331-5F2FS-v2.2

Funding: None at present

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-informationContact 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 BUPA study and then deleted.

What your rights are

The BUPA 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/