



## **WHITEHALL II STUDY PRIVACY NOTICE**

### **1. Introduction**

The Whitehall II Study is a closed occupational cohort. At recruitment in 1985 it included 10,308 participants, all employees of the British Civil Service; 3,413 women and 6,895 men. To date there have been 13 data collection waves, 8 of which have involved a clinical assessment. The Whitehall II Study team (“we” “us”, or “our”) respects your privacy and is committed to protecting your personal data.

Please read this Privacy Notice carefully – it describes why and how we collect and use personal data and provides information about your rights. It applies to personal data provided to us, both by individuals themselves or by third parties and supplements the following wider [UCL privacy notice\(s\)](#):

- [General privacy notice](#) when you visit UCL’s website
- [Research participants for health and care purposes privacy notice](#)

We keep this Privacy Notice under regular review. It was last updated on 10<sup>th</sup> December 2021.

### **2. About us**

The Whitehall II Study team is part of the Research Department of Epidemiology and Public Health, Institute of Epidemiology and Health Care (IEHC) at University College London (UCL).

UCL, a company incorporated by Royal Charter (number RC 000631), is the entity that determines how and why your personal data is processed. This means that UCL is the ‘controller’ of your personal data for the purposes of data protection law.

### **3. Personal data that we collect about you**

Personal data, or personal information, means any information about an individual from which that person can be identified. It does not include data where the identity has been removed (anonymous data).

We may collect, use, store and transfer different kinds of personal data about you. This may include:

- Your name and contact details;

- ‘Special category’ data about you (this may include details about your race or ethnicity, religious or philosophical beliefs, sexual orientation, political opinions, trade union membership, information about your health etc.);

#### **4. How we use your personal data**

We will only use your personal data when the law allows us to. Most commonly, we will use your personal data in the following circumstances:

- **As part of the Whitehall II Study.** At recruitment you consented to participate in the Whitehall II Study. The study is a longitudinal cohort study established in 1985 to investigate the relationship between socioeconomic status, stress and cardiovascular disease; or
- **To use your donated samples and data.** Your stored samples and data may be used in ethically approved research studies if you consented to allow this at recruitment to Whitehall II Study. Examples of such studies can be found on our [Impact of Research](#) page on our website,; or
- **To collect further information about your health by linking to your electronic health records and follow-up questionnaires.** Depending on the circumstances, this may include special category personal data such as diseases, medical conditions and treatments. We obtained your informed consent for this at recruitment, for clinical purposes, however the legal basis for processing this data is set out in section 6 below.

You have the right to withdraw your consent at any time by contacting us using the details set out on the [Data Processing F&Q page](#) of our website. Please note that this will not affect the lawfulness of processing based on “Public task” as set out in section 6 below. Your rights as a participant in health and care research are detailed [here](#).

We may also use anonymised data, meaning data from which you cannot be identified, for the purposes of:

- Education and research; or
- Fundraising and promotional purposes.

Aggregate, group data, which is anonymous may also be used in published reports or journals and at conferences.

#### **5. Who we share your personal data with**

Your personal data will be collected and processed primarily by our staff and UCL (Access to your personal information is limited to staff who have a legitimate need to see it for the purpose of carrying out their job at UCL). We may have to share your personal data with the parties set out below for the purposes outlined in section 4:

NHS Digital, NHS Wales, NHS Scotland and Northern Ireland Social Care Agency provide us with cancer registration data (cancer diagnosis and date of diagnosis), hospital episode data (diagnosis, operations/treatment and dates of hospital episodes) and, in the case of your death, date, place and cause of death. In order to receive these data we share with the agencies data that you provided at recruitment (name, date of birth, NHS number and postcode). These agencies use the data we share with them to correctly identify your cancer/death registrations and hospital episodes and return this data to us, the WHII team at UCL.

Additionally, we may share your name and address data with a field work service provider (NatCen) company to facilitate the home visits for a clinical assessment as part of the Whitehall II study.

We require all third parties to respect the security of your personal data and to treat it in accordance with the law. We do not allow our third-party service providers to use your personal data for their own purposes – we only permit them to process your personal data for specified purposes and in accordance with our instructions.

## **6. Lawful basis for processing**

Data Protection Legislation requires that we meet certain conditions before we are allowed to use your data in the manner described in this notice, including having a "lawful basis" for the processing. The basis for processing will be as follows:

- Public task. The processing of your personal data may be necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in us. **I.e. The medical research that we carry out using your information is considered a worthwhile task that is in the public interest.**

For special category personal data, the following lawful bases for processing will be used:

- **As above, the medical research that we carry out using your information is considered a worthwhile task that is in the public interest.** Specifically, Article 9(2)(j) of the GDPR: processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes in accordance with Article 89(1) based on Union or Member State law which shall be proportionate to the aim pursued, respect the essence of the right to data protection and provide for suitable and specific measures to safeguard the fundamental rights and the interests of the data subject.

## **7. International transfers**

We do not transfer your identifiable personal data outside the UK.

## **8. Information security**

We have put in place appropriate security measures to prevent your personal data from being accidentally lost, used or accessed in an unauthorised way, altered or disclosed. We have established procedures to deal with any suspected personal data breach and will notify you and any applicable regulator of a breach where we are legally required to do so.

## **9. Data retention**

We will only retain your personal data for as long as necessary to fulfil the purposes we collected it for, including for the purposes of satisfying any legal, accounting, or reporting requirements.

We have ethical permission from the Health Research Authority, London - Harrow Research Ethics Committee will keep your personal data for 20 years according to the [Records Retention Schedule](#).

## **10. Your rights**

Under certain circumstances, you may have the following rights under data protection legislation in relation to your personal data:

- Right to request access to your personal data;
- Right to request correction of your personal data;
- Right to request erasure of your personal data;
- Right to object to processing of your personal data;
- Right to request restriction of the processing your personal data;
- Right to request the transfer of your personal data; and
- Right to withdraw consent.

If you wish to exercise any of these rights, please contact the [Data Protection Officer](#).

## **Contacting us**

You can contact UCL by telephoning +44 (0)20 7679 2000 or by writing to: University College London, Gower Street, London WC1E 6BT.

Please note that UCL has appointed a Data Protection Officer. If you have any questions about this Privacy Notice, including any requests to exercise your legal rights, please contact our Data Protection Officer using the details set out below:

Data Protection & Freedom of Information Officer  
[data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk)

## **11. Complaints**

If you wish to complain about our use of personal data, please send an email with the details of your complaint to the [Data Protection Officer](#) so that we can look into the issue and respond to you.

You also have the right to lodge a complaint with the Information Commissioner's Office (**ICO**) (the UK data protection regulator). For further information on your rights and how to complain to the ICO, please refer to the [ICO website](#).