

UKCTOCS/UKLWC PRIVACY NOTICE

1. Introduction

UKCTOCS (UK Collaborative Trial of Ovarian Cancer Screening) is the ovarian cancer screening trial which recruited 202,638 participants between 2001 and 2005. UKLWC (UKCTOCS Longitudinal Women's Cohort) is the bioresource comprising the serum samples donated by the UKCTOCS participants and the accompanying data for ethically approved research studies. The UKCTOCS/UKLWC trial 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 17th June 2019.

2. About us

The UKCTOCS/UKLWC trial team is part of the MRC Clinical Trials Unit (MRC CTU), Institute of Clinical Trials and Methodologies (ICTM) at University College London (UCL). Until 2018 we were based at the Institute for Women's Health at 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.);
- The names and other details about third parties who are involved in the issues we are helping you with.

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 UKCTOCS trial.** At recruitment you consented to participate in the UKCTOCS trial, a trial designed to investigate whether screening for ovarian cancer would save lives, granting us access to your medical records; or
- **To use your donated samples and data (now referred to as UKLWC).** Your stored serum samples and data may be used in ethically approved research studies if you consented to allow this at recruitment to UKCTOCS. Some examples of such studies (full list available on [UKLWC website](#)) include, investigation of new markers (in both the blood and genes) to improve detection of ovarian, breast, colorectal (bowel) and pancreatic cancer, using genetic data to discover new treatments; or
- **To collect further information about your health by linking to your electronic health records and postal 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 clinical consent at any time by contacting us using the details set out on the Participant Info tab 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.

Anonymised data 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, NCRAS (National Cancer Registration and Analysis Service) at Public Health England (PHE), NHS Wales and N. 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 this 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 in order to correctly identify your cancer/death registrations and hospital episodes and return this data to us, the UKCTOCS team at UCL. NCRAS take great care to keep the information they hold about you confidential, and as with other medical records, strict ethical and security safeguards are in place, and access is strictly controlled. Information about NCRAS including why information about you and your cancer is recorded, how this information is used, and how, if you wish, you can see your information or have it removed can be found here www.NDRS.nhs.uk.

Additionally, in the past, we have shared your name and address data with a printing service company in order to send you a health-related questionnaire.

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 European Economic Area (EEA).

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 will keep your personal data according to the [Records Retention Schedule](#). Currently, we have ethical permission from the Health Research Authority, North West – Haydock Research Ethics Committee, to hold your data until 2024. However, for clinical trials, it is expected that the data will be held for 15 years after the end of the trial which is expected at end 2020. This is mainly for the purpose of allowing an independent investigator to reproduce any of the findings that come out of the trial.

It is likely we will ask the Research Ethics Committee for permission to keep your data until 2035 or longer for use in secondary research studies.

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

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](#).