

<http://www.mrc-cu.cam.ac.uk/research/rebecca-fitzgerald>

## **OCCAMS study: How we handle person-identifiable data**

We handle OCCAMS participants' data in line with the General Data Protection Regulations 2018. The patient information sheet given to all participants states that they may withdraw from the study at any time without reason and no further data or research will be collected once that participant has withdrawn. They should contact the Study Coordinator, Nicola Grehan on 01223 348667 or [nicola.grehan@addenbrookes.nhs.uk](mailto:nicola.grehan@addenbrookes.nhs.uk) or the study PI Rebecca Fitzgerald on 01223 763287 or [RCF29@MRC-CU.cam.ac.uk](mailto:RCF29@MRC-CU.cam.ac.uk) if they wish to withdraw. Please rest assured that the standard of care you will receive if you choose to withdraw will not be affected in any way.

Participants should first contact the study PI if they wish to complain. If they remain unsatisfied about any aspect of the way the study was conducted they may also contact Cambridge University Hospitals NHS Foundation Trust Patient Advice and Liaison Service (PALS) on 01223 216 756 or [pals@addenbrookes.nhs.uk](mailto:pals@addenbrookes.nhs.uk) to lodge a formal complaint at any time.

All OCCAMS participants are encouraged to maintain contact with their study nurse and inform them of any change to contact details as well as any significant health events. Based on patient consent and ethical approval, NHS registries are being used to supplement and confirm events reported by the trial. Existing registries will be providing data on cancer incidence and mortality. Further data will also be collected via the Hospital Episode Statistics (HES) which utilises in-patient, out-patient and A&E data.

The process for receiving healthcare data will involve the study management team at Cambridge and Genomics England, sending a list of the cohort's NHS linkage information which will include NHS Number, surname, forename, date of birth, sex and a unique identifier to Public Health England (PHE) and NHS digital. Once matched with records held by PHE and NHS digital information including HES, cancer registry and mortality data will be sent back to the study team who will update the cohort data which is securely stored on a server

The data from any participants who have withdrawn from participation of the study will not be sent to these third parties for any data linkages.

In the event of your death, mortality data (or civil registration data) will be supplied by Public Health England and NHS digital on behalf of the Office of National Statistics. Should we become aware of your death via ONS or from your trust research nurse, we will no longer request data about you from these bodies but may continue to store personal identifiable data in line with the overall retention period of the study.

Data Protection Act 2019 <http://www.legislation.gov.uk/ukpga/2018/12/contents> General Data Protection Regulation <https://eur-lex.europa.eu/eli/reg/2016/679/oj>

For further information, including on how we handle your personal identifiable data in this study, please contact Nicola on 01223 348667 or via [nicola.grehan@addenbrookes.nhs.uk](mailto:nicola.grehan@addenbrookes.nhs.uk).