

## DATA PROTECTION ACT 1998

In accordance with the above Act we have a responsibility to inform you of the following:

- All data pertaining to your participation in the United Kingdom Collaborative Trial of Ovarian Cancer Screening (UKCTOCS) will be stored under the auspices of University College London data registration, Registration number Z6364106.
- This data will be used solely for research purposes as detailed in the UKCTOCS information leaflet and as discussed at registration for the research trial.
- As outlined in the UKCTOCS information leaflet, data obtained as a result of your participation in UKCTOCS may be used for other research projects, for example investigations into heart disease or other cancers. In this event all personal details will be removed prior to the data being analysed by researchers so that you cannot be identified, that is your name, address and GP details will not be made available.
- The data will be stored for a minimum of 15 years after the end of the trial. At any stage during this time the records may be audited to validate the trial data.
- Routine follow-up will be regenerated and attendance monitored by the trial database. All abnormal results and referrals for surgical intervention will be performed manually by the trial medical team. The database will be audited regularly to ensure that all follow-up is appropriate and prompt.
- If during the course of the trial you have any queries regarding the storage of your data you should contact the Safety Officer, UKCTOCS, Gynaecological Cancer Research Centre, Institute of Women's Health, UCL, 1<sup>st</sup> Floor, Maple House, 149 Tottenham Court Road, London W1T 7DN.

I have read the above information and have had the opportunity to discuss the impact of the Data Protection Act 1998 on my participation in UKCTOCS. I am happy for my details to be managed in this manner.

Signature:

Witness:

Date:

Date:

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The Gynaecological Cancer Research Centre, based at University College London is co-ordinating the UKCTOCS trial. For the past 15 years much of the pioneering work to come out of this unit has been made possible as a direct result of grants provided by the charity "The Gynaecology Cancer Research Fund" known as The Eve Appeal, Registered charity number 1091708. The Gynaecology Cancer Research Fund undertakes fundraising events throughout the year in order to raise funds for research.

Please place a tick in the appropriate box.

I wish to receive information about the fund raising work of the Gynaecology Cancer Research Fund.

I do not wish to receive information about the fund raising work of the Gynaecology Cancer Research Fund.

Please be assured that your decision will not affect in any way your participation in UKCTOCS.

Signature:

Witness:

Date:

Date: