

Patient Information Sheet
CONSENT FORM

PID

West London Premature Ovarian Insufficiency Database

Investigator's Name: Mr Nick Panay
Investigator's Address: Queen Charlotte's and Chelsea Hospital
 Chelsea & Westminster Hospital
 Fulham Road
 Du Cane Road
 SW10 9NH
 W12 0HS

Please initial in the space below

1. I confirm that I have read and understood the information sheet dated July 2011. I had the opportunity to consider the information, ask questions and had these answered satisfactorily.	
2. I understand that that I am free to withdraw my permission to have my data stored at any time, without giving any reason and without my medical care or legal rights being affected.	
3. I understand that relevant sections of my medical notes and data collected may be looked at by individuals from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	
4. I understand that I will be given a copy of this signed and date consent form.	
5. I agree for my medical data to be gathered and stored in the database.	
6. I agree for my medical data to be used in an anonymous form for research purposes and understand that the data will be treated as fully confidential.	

Patient's signature: _____ Patient's name: _____

Date: _____

Person conducting the informed consent discussion: I have fully explained the details of this study to the above named patient including her freedom to withdraw at any time.

Investigator/Delegate Signature: _____

Investigator/Delegate Name: _____

Date: _____

Two copies to be completed. 1 copy is given to the patient and 1 copy is kept in the medical notes.
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Introduction

You are being asked whether your medical data can be stored for research purposes. Please take time to read the following information carefully.

Ask us if there is anything that is not clear, or if you would like more information.

What is the purpose of the database?

Premature Ovarian Insufficiency (POI), or premature menopause, is estimated to affect 0.3-1% of the population and it is becoming more common due to improved survival following cancer. POI has many important physical and psychological implications as it can affect fertility, bone density and risk of heart disease. Despite this, many aspects of POI remain poorly understood including the underlying causes and ideal treatments.

The aim of the West London POI database is to gather data which will allow us to study POI in a larger population. Observational research studies can be carried out on the data which will provide important information in terms of underlying causes and the long-term effects of different treatments. We hope it will provide women with much greater information on which to base their treatment decisions. Any research studies we do on this data will not require any extra participation from you.

What data will be collected?

We will collect your age at diagnosis, underlying cause, presenting symptoms, results of blood tests or scans and any treatments used. We will not collect any data which is not gathered as part of routine care and it will require no extra time during your appointment. No extra visits to hospital or investigations such as blood tests are required.

Will my data be kept confidential?

The data is collected and stored in an on-line database in an anonymous format. Access to the database is restricted and password protected. Any medical professional who wishes to access the data has to have permission from the Data Controller. Any research will only be done on fully anonymous data and you will not be identified in any report or publication.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your safety, rights, wellbeing and dignity.

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