

## POI: progress through a global registry

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### Premature Ovarian Insufficiency

International registry to improve diagnosis and treatment

**CONTEXT:** Premature ovarian insufficiency (POI) remains poorly understood and under researched. Recent published guidelines from ESHRE, IMS, EMAS and NICE UK have been developed using data largely from observational and short term randomised studies. The POI registry <https://poiregistry.net> has been developed at Imperial College London, UK using a British Research Council grant to collect national and international data in an effort to avoid fragmented research and improve our understanding of this relatively uncommon but important disease.

**OBJECTIVE:** Retrospective and prospective registry analysis of women with POI.

**METHODS:** Data collected on women diagnosed with POI younger than 40 years have been entered onto an online registry utilising the semantic web. The data were subsequently extracted and analysed at Imperial College London by patient ages, aetiology, ethnicity, time to diagnosis, symptom profile and bone mineral density (BMD).

**RESULTS:** More than 60 centres have registered to enter data globally thus far. Many of the centres are in the UK but also include investigators in Australia, Canada, Chile, Italy, Russia, Spain and South Africa. Retrospective (legacy) data have been entered for 484 women and prospective data for 343 women with POI thus far. A further 250 patients have been entered into a Chinese translation of the registry at Beijing O & G Hospital, Capital Medical University and will soon be uploaded onto the main database. Data entry include demographics, diagnosis, presentation, management and outcomes such as bone mineral density. Collaborative work is planned to facilitate biobanking for genetic and biomarker analyses. A key finding from early data analyses is that delay to diagnosis results in lower bone mineral density. These and other data on diagnosis, presentation and management of POI will be presented.

**CONCLUSIONS:** The POI registry has already proved successful in data collection as shown by the number of centres registered and the number of patients entered thus far. By encouraging more healthcare professionals to engage with data collection, we aim to optimize the quality and quantity of data. It is particularly hoped that a long and successful collaboration with our international colleagues will be achieved to improve the diagnosis and treatment of premature ovarian insufficiency.

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