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OPTIMISING CLINICAL MANAGEMENT OF POI USING A GLOBAL REGISTRY

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Premature ovarian insufficiency (POI) has traditionally been estimated to affect about 1% of women younger than 40. However, as the cure rates of cancers in childhood and young women continue to improve, it is likely that the incidence of iatrogenic prematurely menopausal women will rise rapidly. In a study at Imperial College London, of 4968 participants, 370, or 7.4%, had either spontaneous or medically induced POI.

POI remains poorly understood and under-researched. Controversy persists over nomenclature with terms such premature ovarian failure / dysfunction and "primary ovarian insufficiency" still in usage. Women with POI require integrated care to address physical, psychosocial and reproductive health as well as preventative strategies to maintain long term health. There is still debate as to the the best type of hormone replacement for these young women.

For many aspects of POI research, a prospective international database recruiting many thousands of cases is the only realistic way in which meaningful data will be gathered to answer many of the questions for which there is only speculation at present. As is the case with a number of other centres, we have been collecting data from our cohort of women with POI for a number of years. We have over 800 subjects to date registered in our Imperial College London database https://poiregistry.net

The next step is to fully amalgamate these data with those of our colleagues globally. 45 UK and international collaborators have already signed up to the POI registry and some have started contributing their data. The registry has already demonstrated that delay in making a diagnosis of POI and instituting treatment leads to lower bone mineral density.

We hope the registry will ultimately lead to better understanding of the presentation and causes of the condition. Fully evidence based management will facilitate the targeted care of young women with POI to optimize both their short and long term outcomes.

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