

## **Lancet correspondence: Top 10 UK and Ireland Research Priorities for Endometriosis**

Endometriosis is a chronic, incurable condition associated with debilitating pain and subfertility that affects ~176 million women worldwide (1,2). It is a complex, heterogeneous disorder of unknown aetiology defined by the presence of endometrial-like tissue (lesions) outside the uterus. Despite an estimated prevalence in women that mirrors that of diabetes, Crohn's disease and rheumatoid arthritis (3), the full socioeconomic impact of endometriosis is hugely underestimated. There are currently no accurate non-invasive diagnostic tests or biomarkers for endometriosis. Treatment options are inadequate and largely confined to surgical excision of the lesions which is associated with high recurrence rates, and ovarian suppressive drugs that have significant side-effects.

Endometriosis research is significantly underfunded relative to other diseases with high healthcare burdens. The Endometriosis Priority Setting Partnership (PSP) was formed with the objective of identifying the key questions about endometriosis that were most important to both patient and health care practitioners involved in their care. Using methods established by the James Lind Alliance ([www.jla.nihr.ac.uk](http://www.jla.nihr.ac.uk)), a shortlist of those considered priorities for research in the UK and Ireland by both women with endometriosis and healthcare practitioners was agreed. A PSP was established that included women with endometriosis, their supporters, key healthcare practitioners, endometriosis researchers, and representatives from organisations involved with women with endometriosis. Research questions were gathered from women with endometriosis, healthcare practitioners and researchers using surveys complemented by clinical guidelines and systematic reviews. Priority setting was carried out using data from (a) online surveys, (b) online voting, and (c) a facilitated workshop of equal numbers of women with endometriosis and healthcare practitioners.

In the first online survey, 4767 research questions ('uncertainties') were submitted by 1286 UK and Ireland respondents (75% women with endometriosis, 16% healthcare practitioners), and a further 111 research uncertainties identified from literature searches. After removing questions already addressed by systematic reviews, or ongoing research, and merging similar questions, 72 were listed in a second survey allowing participants to vote (rank) the questions. 1418 participants from UK and Ireland voted. From the 30 uncertainties which received most votes, 10 research priorities were agreed during the workshop (26 participants, held in London in April 2017) and are shown in the panel.

It is intended that these 10 priorities will provide a platform for researchers, funding bodies and the pharmaceutical industry to ensure that future research funding and research activities focus on questions that are important to women with endometriosis and to healthcare practitioners.

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## References

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2. Hickey M, Ballard K, Farquhar C. Endometriosis. BMJ 2014 348: 1-9.
3. Simoens S, Dunselman G, Dirksen C, et al. The burden of endometriosis: costs and quality of life of women with endometriosis and treated in referral centres. Hum Reprod 2012 27(5):1292-9.

## **Panel: Top XX UK research priorities for endometriosis**

*To be added after final London workshop on 25 April 2017*