

Top ten endometriosis research priorities in the UK and Ireland

Endometriosis is a chronic and incurable condition associated with debilitating pain and subfertility that affects approximately 176 million women worldwide.^{1,2} It is a complex, and 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, the full socioeconomic impact of endometriosis is considerably underestimated.³ 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 (a procedure that is associated with high recurrence rates) and ovarian suppressive drugs (which have important side-effects).

Endometriosis research is considerably underfunded relative to other diseases with high health-care 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 women with endometriosis and health-care practitioners involved in their care. Using methods established by the James Lind Alliance, a shortlist of those considered priorities for research in the UK and Ireland was agreed by both women with endometriosis and healthcare practitioners. A PSP was established that included women with endometriosis, their supporters, key health-care practitioners, endometriosis researchers, and representatives from organisations involved with women with endometriosis. Research questions were gathered from women with endometriosis, health-care practitioners, and researchers using surveys complemented by clinical guidelines and systematic reviews. Priority setting was carried out using data from online surveys, online voting, and a facilitated workshop of equal numbers of women with endometriosis and health-care practitioners.

In the first online survey, 4767 research questions (termed "uncertainties") were submitted by 1225 respondents from the UK and Ireland. Of these

respondents, 861 (70.3%) had a current or previous confirmed diagnosis of endometriosis; 247 (20.2%) were health-care practitioners, of whom 39 also had a diagnosis of endometriosis; 117 respondents (9.5%) did not belong to either category, with the majority being friends or family of women with endometriosis. A further 111 research uncertainties were 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) for the questions. 1418 participants from the UK and Ireland voted. From the 30 uncertainties that received the most votes, ten research priorities were agreed during the workshop that involved 26 participants and was held in London, UK, in April, 2017 (panel).

These ten priorities are intended to 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 health-care practitioners.

We declare no competing interests.

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Published Online
 May 19, 2017
[http://dx.doi.org/10.1016/S0140-6736\(17\)31344-2](http://dx.doi.org/10.1016/S0140-6736(17)31344-2)

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Panel: Top ten research priorities for endometriosis in the UK and Ireland

- 1 Can a cure be developed for endometriosis?
- 2 What causes endometriosis?
- 3 What are the most effective ways of educating health-care professionals throughout the health-care system resulting in reduced time to diagnosis and improved treatment and care of women with endometriosis?
- 4 Is it possible to develop a non-invasive screening tool to aid the diagnosis of endometriosis?
- 5 What are the most effective ways of maximising and/or maintaining fertility in women with confirmed or suspected endometriosis?
- 6 How can the diagnosis of endometriosis be improved?
- 7 What is the most effective way of managing the emotional and/or psychological and/or fatigue impact of living with endometriosis (including medical, non-medical, and self-management methods)?
- 8 What are the outcomes and/or success rates for surgical or medical treatments that aim to cure or treat endometriosis, rather than manage it?
- 9 What is the most effective way of stopping endometriosis progressing and/or spreading to other organs (eg after surgery)?
- 10 What are the most effective non-surgical ways of managing endometriosis-related pain and/or symptoms (medical/non-medical)?

See Online for appendix

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- 2 Hickey M, Ballard K, Farquhar C. Endometriosis. *BMJ* 2014; **348**: 1–9.
- 3 Simoons 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**: 1292–9.