

Top Ten Endometriosis Research Priorities in the UK and Ireland

Horne et al. (2017)

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For which topic were research priorities identified?

endometriosis

In which location was the research priority setting conducted?

Europe - Ireland; Europe - United Kingdom

Why was it conducted at all?

Endometriosis is a chronic and in curable condition associated with debilitating pain and subfertility that affects approximately 176 million women worldwide. It is a complex, and heterogeneous disorder of unknown aetiology defined by the presence of endometrial-like tissue (lesions) outside the uterus. Endometriosis research is considerably underfunded relative to other diseases with high healthcare burdens.

What was the objective?

to identify the key questions about endometriosis that were most important to both women with endometriosis and health care practitioners involved in their care

What was the outcome?

a ranking list of 10 research questions

How long did the research prioritization take?

No information provided.

Which methods were used to identify research priorities?

JLA method

How were the priorities for research identified exactly?

Step 1: survey: research questions collected via survey, 4767 research questions submitted, additionally literature reviewed, further 111 research uncertainties identified. Step 2: data processing: merging similar questions, check against literature. Step 3: interim ranking: list of 72 questions, participants were asked to vote for their most important questions, top 30 questions moved forward. Step 5: final prioritization: workshop: small group discussions and small group rankings, followed by plenary session to achieve consensus on top 10

Which stakeholders took part?

Women with endometriosis, healthcare practitioners, researchers. Survey: 1225 participants: 861 (70.3%) had a current or previous confirmed diagnosis of endometriosis, 247 (20.2%) were healthcare practitioners, of whom 39 also had a diagnosis of endometriosis, 117 participants (9.5%) did not belong to either category, with the majority being friends or family of women with endometriosis. Interim ranking: 1418 participants. Workshop: 26 participants.

How were stakeholders recruited?

No information provided.

Were stakeholders actively involved or did they just participate?

Stakeholders were mere participants of the research prioritization process; they were not actively involved in the process.