

Working Together to Shape the Endometrial Cancer Research Agenda: The Top Ten Unanswered Research Questions

Wan et al. (2016)

<https://doi.org/10.1016/j.ygyno.2016.08.333>

For which topic were research priorities identified?

endometrial cancer

In which location was the research priority setting conducted?

Europe - United Kingdom

Why was it conducted at all?

Endometrial cancer (EC) is the most common gynaecological cancer in developed nations and its incidence is rising. As a direct consequence, more women are dying from EC despite advances in care and improved survivorship. There is a lack of research activity and funding, as well as public awareness about EC.

What was the objective?

to engage patients, carers and healthcare professionals to identify the most important unanswered research questions in endometrial cancer

What was the outcome?

a ranking list of 10 research questions

How long did the research prioritization take?

March 2015 - November 2015

Which methods were used to identify research priorities?

JLA method

How were the priorities for research identified exactly?

Step 1: setting up PSP: steering group established, stakeholders and partner organizations identified. Step 2: gathering research questions: participants were asked: What are the most important questions in womb cancer?, questions also gathered from current endometrial cancer guidelines, 788 suggestions made. Step 3: data processing: grouping into themes, check against evidence, resulting in 209 unanswered questions, unanswered questions that had been asked by at least three participants were automatically taken forward, questions asked less frequently were reviewed by steering group, questions that were shared priorities (being asked by both patients and healthcare professionals) and those viewed as fundamentally important to improving endometrial cancer care were also taken forward. Step 4: interim ranking: survey asking participants to select the two most important questions from each of 7 domains, each domain contained between 8 and 10 questions, resulting in 54 most important unanswered questions, the 30 questions that were ranked most or second most important within each of the 7 domains by 25% or more of the participants were taken forward. Step 5: final prioritization: workshop: small group discussions with nominal group technique and small group rankings, aggregate rankings, plenary discussions

Which stakeholders took part?

Ec survivors, carers, healthcare professionals. Survey: 413 participants: 211 patients. Interim ranking: 257 participants: 113 lay representatives. Workshop: 23 participants.

How were stakeholders recruited?

Prospective participants were invited to engage with the consultation process by advertisements sent through mailing lists of the stakeholder groups, social media and by national and local press releases. EC survivors were recruited from online peer support forums and informal networks supported by Womb Cancer Alliance patient partners and by direct invitation if enrolled in current ongoing clinical trials. Carers with an interest in EC were recruited through social media initiatives. Healthcare professionals on mailing lists of Womb Cancer Alliance partner organizations were sent electronic invitations.

Were stakeholders actively involved or did they just participate?

Stakeholders not only participated but were also actively involved in the research prioritization process: They were part of a steering group. The steering group consisted of individuals with patient experience of EC and healthcare professionals from primary care, obstetrics and gynecology, gynecological oncology, clinical/medical oncology, gynecological cancer specialist nursing and representatives from women's health and cancer charities. The members were involved in data processing and interim ranking.