



Working together to shape the endometrial cancer research agenda: The top ten unanswered research questions

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HIGHLIGHTS

- Endometrial cancer (EC) is under-researched and there are many knowledge gaps.
- We used James Lind Alliance methodology to prioritise unanswered research questions in EC.
- The top 10 questions span EC risk prediction, diagnosis, treatment and survivorship.
- Tackling these issues through research will improve the lives of women affected by EC.

ARTICLE INFO

Article history:

Received 25 July 2016

Received in revised form 26 August 2016

Accepted 27 August 2016

Available online 1 September 2016

Keywords:

Endometrial cancer
Research priorities
Shared decision making
Collaborative
James Lind Alliance

ABSTRACT

Background. 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. We sought to engage patients, carers and healthcare professionals to identify the most important unanswered research questions in EC.

Methodology. The priority setting methodology was developed by the James Lind Alliance and involved four key stages: gathering research questions; checking these against existing evidence; interim prioritisation; and a final consensus meeting during which the top ten unanswered research questions were agreed using modified nominal group methodology.

Results. Our first online survey yielded 786 individual submissions from 413 respondents, of whom 211 were EC survivors or carers, and from which 202 unique unanswered research questions were generated. 253 individuals, including 108 EC survivors and carers, completed an online interim prioritisation survey. The resulting top 30 questions were ranked in a final consensus meeting. Our top ten spanned the breadth of patient experience of this disease and included developing personalised risk scoring, refining criteria for specialist referral, understanding the underlying biology of different types of EC, developing novel personalised treatment and prevention strategies, prognostic and predictive biomarkers, increasing public awareness and interventions for psychological issues.

Conclusion. Having established the top ten unanswered research questions in EC, we hope this galvanises researchers, healthcare professionals and the public to collaborate, coordinate and invest in research to improve the lives of women affected by EC.

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1. Introduction

Endometrial cancer (EC) is now the most common gynaecological malignancy in developed nations [1]. In the UK, age standardised incidence rates have increased by 25% in the last decade [2]. Although this trend has not been mirrored in the US where the age standardised rate of EC has remained stable, the latter statistic masks the rise in the absolute numbers of women being diagnosed with this condition. In 2016, 60,050 women will be diagnosed with EC in the US [3]. By 2030, this is expected to double to 122,000 cases, overtaking lung and colorectal cancer to become the third most common cancer affecting women in the US [4]. These trends can in large part be attributed to the increase in overweight and obesity and demographic shifts which mean that a greater proportion of our population is now over 65 [5]. These statistics also serve to mask the disproportionate increase in disease burden amongst minority populations. Black and Hispanic women have seen a 2.4% and 4.4% age-adjusted increase in EC incidence respectively [3].

The age standardised mortality rate for British women with EC has increased alongside incidence over the last decade [6]. Based on current data extrapolated from trends in the US, by 2030 this could mean an additional 30–40,000 deaths per year worldwide [4]. There is an urgent need to curb the escalating burden of EC through risk prediction and targeted prevention strategies. Since the majority of women are diagnosed with early stage disease and cured by hysterectomy, reducing the physical burden of treatment and addressing the psychological after-effects for survivors is also important.

Low public awareness of the disease [7,8] has been accompanied by a lack of interest amongst grant-awarding bodies and leading gynaecological oncology researchers. This is reflected in a smaller share of research funding than is warranted by the rising incidence and mortality; 0.7% (£3.3 million) of the UK's total budget [9] and one-fifth of that allocated to ovarian cancer research in 2012. This is mirrored in the US, where \$17.8 million was allocated to EC research in 2013 by the National Cancer Institute compared to \$100.6 million to ovarian cancer research [10]. Although some important practice changing evidence exists in surgery and radiotherapy, chronic underfunding compared to other cancers has meant that there are many knowledge gaps. In particular, there is a growing need to discover equitable, effective and cost-effective interventions to improve the prevention, detection and treatment of EC.

Traditionally, medical research questions have been developed and funded following academic peer review with minimal input from potential users of the research i.e. patients, carers and non-research active healthcare professionals. This model has been criticised as wasteful [11] and there are frequently considerable mismatches between the priorities of researchers and patients [12]. More recently, the advantages of involving patients and healthcare professionals in the identification of research priorities have been recognised [13]. This ensures the right questions are asked and that potential solutions are acceptable to patients. Major funders now mandate active patient and public involvement in the design and execution of the research they fund. To support this process, the James Lind Alliance (JLA) was established in 2004 to bring together patients, carers and clinicians to identify shared research priorities in various healthcare fields. The JLA advocates the development of consensus about research priorities through a series of surveys, stakeholder meetings and guided discussions. This approach provides a systematic, explicit and transparent process through which future health research can be commissioned.

The aim of this study was to engage EC survivors, carers and healthcare professionals in a dialogue to establish a consensus regarding the top ten unanswered research questions in EC.

2. Methodology

This study followed the JLA priority setting method [14]. This process is set out to ensure consistency between priority setting partnerships

and has been used to prioritise research priorities in over 60 healthcare fields [15]. Key stages in the process are described below.

2.1. Establishing a steering group

In 2014, we established the Womb Cancer Alliance to identify the most important unanswered research questions in EC through a broad-based consultative process. As part of the JLA process, all organisations that could reach and advocate for patients, carers and clinicians were invited to become involved in a Priority Setting Partnership (PSP). A steering group composed of representatives from these groups was then formed to ensure the study remained inclusive and fulfilled its aim to deliver and publicise a list of shared research priorities. This steering group was established from a purposive sample of individuals with patient experience of EC and healthcare professionals from primary care, obstetrics and gynaecology, gynaecological oncology, clinical/medical oncology, gynaecological cancer specialist nursing, as well as representatives from women's health and cancer charities. Groups with significant competing interests such as pharmaceutical companies were excluded. By employing a maximum variation approach in the selection of members to this steering group, we hoped to maximise the diversity of its frames of reference. An independent advisor from the James Lind Alliance was Chair of the steering group. This ensured that conflicts of interest were minimised.

Partner organisations that supported the alliance included the British Gynaecological Cancer Society, Macmillan Cancer Voices, National Forum of Gynaecological Oncology Nurses, James Lind Alliance (JLA), Womb Cancer Support UK, Womb Cancer Voice, Eve Appeal, Wellbeing of Women, Cochrane, National Institute of Health Research, Pelvic Obstetric and Gynaecological Physiotherapists, College of Radiographers and Allied Health Professionals Network.

2.2. The consultative process

The University of Manchester Research Ethics Committee 3 (ref. 14435) approved the study. The initial consultative phase formed the first part of a modified Delphi consensus making approach [16] whereby individuals were invited to provide their opinion through an anonymised survey. A website was created (<http://research.bmh.manchester.ac.uk/wombcanceralliance>) to advertise the initiative and link to the online survey. 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 organisations were sent electronic invitations.

2.3. Gathering uncertainties

The initial consultation was performed via an electronic questionnaire, which was also available on paper at request. Submissions were accepted between 23rd March 2015 and 31st May 2015. Non-probability sampling methods were used to maximise the diversity of opinions offered. In line with the aims of the JLA approach, this promoted inclusivity of all patients and professionals who might wish to contribute to the study. Sociodemographic data of the participants were monitored throughout the data gathering period and where particular groups appeared under-represented, targeted recruitment strategies were employed. These included providing paper copies of the survey with a self-addressed envelope for return of the completed questionnaire to elderly participants who were not comfortable submitting their questions online. Participants were asked 'What are the most important research questions in womb cancer?' and were provided with examples of

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