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


Gynaecological Oncology Research Group, Institute of Cancer Sciences, Faculty of Medical and Human Sciences, University of Manchester, St Mary's Hospital, Oxford Road, Manchester M13 9WL, UK

Womb Cancer Alliance Priority Setting Partnership Study Group, UK

Trust Library, Central Manchester University Hospitals NHS Foundation Trust, Oxford Road, Manchester M13 9WL, UK

James Lind Alliance, National Institute for Health Research Evaluation Trials and Studies Coordinating Centre, Southampton, UK

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.

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
Questions relating to other healthcare concerns. Questions were also gathered from current EC guidelines from Europe and North America.

2.4. Data analysis and verifying uncertainties

Entries were grouped into themes. Each theme was analysed by two members of the steering group, one with patient experience of EC and the other a healthcare professional with an interest in this area; thus 7 pairs of reviewers contributed to the analysis of the dataset. This ensured that the exclusion of entries was less likely to be affected by researcher bias given the diversity of expertise amongst the steering group. To maximise the reproducibility of categorisation between reviewers, explicit criteria of how to categorise each entry were provided a priori. When both reviewers identified questions as duplicates, unanswerable by research, out of scope or personal stories rather than research questions, they were removed. Discrepancies were settled by independent review by two further reviewers. Every question was searched against existing literature and those that had already been answered by research were removed. Literature searches were performed by an independent team of health information specialists from the Central Manchester University Hospitals Foundation Trust and The Christie NHS Foundation Trust using systematic pre-agreed search criteria. Analysis of search results was performed by 3 clinical researchers from the study group. Searches deemed answered by research were defined as those with recent level 1 evidence [17] (systematic review with 3 years), where the review did not conclude that there was insufficient evidence.

2.5. Interim priority setting

Unanswered questions that had been asked by at least three independent participants were automatically taken forward to the prioritisation survey. It was agreed by the steering group that using this cut-off ensured that those questions asked the most frequently would be reflected in the second Delphi survey, irrespective of whether members of the steering group agreed with these opinions. Those asked less frequently were reviewed by the Womb Cancer Alliance steering group; questions that were ‘shared’ priorities, being asked by both patients and healthcare professionals, and those viewed as fundamentally important to improving EC care were also taken forward to the second survey which constituted the ranking phase of the modified Delphi technique. Between 19th October 2015 and 26th November 2015, the second online survey asked patients and healthcare professionals to select the two most important questions from each of 7 domains based on the initial thematic analysis. These were: aetiology/risk factors, prevention/screening, diagnosis, primary treatment, treatment of recurrent disease, survivorship, and patient support issues. Each domain contained between 8 and 10 questions. Questions were presented to each participant in a random order to reduce bias. Participants were required to make two selections from each domain in order to proceed to the next stage of the survey. To ensure transparency and minimisation of bias, this process was closely monitored by the JLA Advisor.

2.6. Final priority setting

Questions voted most or second-most important in each domain by at least 25% of survey participants were taken forward to the final face-to-face consensus meeting. Volunteers from partner organisations and individuals taking part in the online surveys were invited to attend. Attendees were split into three equal groups of individuals from different professional and lay backgrounds and asked to rank the questions through guided discussions using modified nominal group methodology facilitated by independent JLA Advisors. These rankings were

![Fig. 1. Study flow diagram showing the number of participants and submissions at each stage.](image-url)
reviewed a second time after the groups had been mixed and the rank-

ings from the small group discussions were aggregated to generate a

priority order for discussion amongst the whole group. The final top

ten most important unanswered research questions in EC were agreed

by the full group (Fig. 1).

3. Results

3.1. Question-gathering

A total of 413 participants took part in the question-gathering sur-

vey, including 211 (51%) patients, carers and individuals who identified

themselves as being at risk of EC. Participant demographics are shown

in Table 1. The first survey yielded 788 entries, which were grouped

into themes. Word clouds depicting the relative frequency with which

questions were proffered for each of the top ten themes are shown for

the lay and professional groups in Fig. 2. There was some mismatch

between the relative importance ascribed to each theme by the two

groups.

3.2. Verification of uncertainties

Duplicate entries, personal stories, questions that were out of scope

or unanswerable by research were removed, leaving 218 questions. A

further 29 were derived from professional guidelines from Europe and

North America. The resulting 247 questions were searched against

existing evidence. A summary of the existing evidence for each question

is given in Fig. 3 and the full search is available for download at http://

research.bmh.manchester.ac.uk/wombcancercollaboration. In total, 209

(85%) questions were considered unanswered by current research.

Questions regarding aetiology and epidemiology were most common.

Over one third of these questions had already been answered by

research, supporting the need for better dissemination of research

findings.

3.3. Interim prioritisation

The 54 most important unanswered research questions in EC were

further prioritised through an online survey completed by 257 people,

including 113 lay participants (45%). 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 forwards to the final consensus

meeting. This cut-off balanced the need to retain as many questions as

possible to reduce the risk of excluding an important question whilst

limiting the questions to be taken forward for consideration at the

final consensus meeting to a manageable number. Decision making re-

search has shown that increasing the number of alternatives increases

the complexity of the decision, leading to increasing conflict and forcing

individuals to resort to deferring decisions, choosing the default option

or failing to make a decision altogether [18,19]. The proportion of partici-

pants who voted each question as most important across each of the 7

domains is shown in Fig. 4.

3.4. Final prioritisation

A group of 23 stakeholders discussed the ranking of the remaining

30 questions at the final face-to-face consensus meeting. The stake-

holders were provided with summary information regarding how

often each question had been prioritised by lay and professional partic-

ipants to help guide these discussions.

Thirteen questions were agreed as the most important unanswered

research questions (marked in Fig. 4). Six of these had significant over-

lap and were amalgamated to form 3 composite questions. The resulting

top ten unanswered research questions in EC are shown in Fig. 5. Al-

though the stakeholders were not constrained to choosing a certain

number of questions from each domain, questions from all domains

contributed to the final ten (see Fig. 4). The questions selected do not

only reflect the most frequently prioritised questions, but also reflect

questions where there were roughly equal proportions of lay and pro-

fessional participants who supported its prioritisation. In fact, those

questions where it was predominately prioritised by one or other

group were not prioritised in the final ten.

Table 1

Characteristics of lay and EC professionals in the question gathering survey.

<table>
<thead>
<tr>
<th>Demographic information</th>
<th>Number of lay participants (%)</th>
<th>Number of EC professional participants (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td></td>
<td></td>
</tr>
<tr>
<td>– Female</td>
<td>211 (100)</td>
<td>130 (64)</td>
</tr>
<tr>
<td>– Male</td>
<td>0</td>
<td>69 (34)</td>
</tr>
<tr>
<td>– Prefer not to say/no answer</td>
<td>0</td>
<td>3(2)</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>– 18–39</td>
<td>29(14)</td>
<td></td>
</tr>
<tr>
<td>– 40–49</td>
<td>47(22)</td>
<td></td>
</tr>
<tr>
<td>– 50–59</td>
<td>84(40)</td>
<td></td>
</tr>
<tr>
<td>– 60–69</td>
<td>45(20)</td>
<td></td>
</tr>
<tr>
<td>– 70–79</td>
<td>5(2)</td>
<td></td>
</tr>
<tr>
<td>– &gt;79</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>– Prefer not to say/no answer</td>
<td>3(1)</td>
<td></td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>– White (any background)</td>
<td>204 (98)</td>
<td></td>
</tr>
<tr>
<td>– Chinese</td>
<td>1 (0)</td>
<td></td>
</tr>
<tr>
<td>– Black Caribbean</td>
<td>1 (0)</td>
<td></td>
</tr>
<tr>
<td>– Mixed race – White &amp; Black</td>
<td>1 (0)</td>
<td></td>
</tr>
<tr>
<td>Caribbean</td>
<td></td>
<td></td>
</tr>
<tr>
<td>– Prefer not to say/no answer</td>
<td>4 (2)</td>
<td></td>
</tr>
<tr>
<td>Background</td>
<td></td>
<td></td>
</tr>
<tr>
<td>– Patient</td>
<td>177 (83)</td>
<td></td>
</tr>
<tr>
<td>– Carer</td>
<td>19 (10)</td>
<td></td>
</tr>
<tr>
<td>– At risk individual</td>
<td>15 (7)</td>
<td></td>
</tr>
<tr>
<td>– General practitioner</td>
<td>–</td>
<td>53 (26)</td>
</tr>
<tr>
<td>– Gynaec-oncology surgeon</td>
<td>–</td>
<td>51 (25)</td>
</tr>
<tr>
<td>– Nurse</td>
<td>–</td>
<td>24 (12)</td>
</tr>
<tr>
<td>– Allied health professional</td>
<td>–</td>
<td>18 (9)</td>
</tr>
<tr>
<td>– Clinical academic</td>
<td>–</td>
<td>12 (6)</td>
</tr>
<tr>
<td>– Medical/Clinical oncologist</td>
<td>–</td>
<td>9 (4)</td>
</tr>
<tr>
<td>– Diagnostic specialist</td>
<td>–</td>
<td>4 (2)</td>
</tr>
<tr>
<td>– Palliative care</td>
<td>–</td>
<td>3 (1)</td>
</tr>
<tr>
<td>– Other</td>
<td>–</td>
<td>25 (12)</td>
</tr>
<tr>
<td>– Prefer not to say/no answer</td>
<td>–</td>
<td>2 (1)</td>
</tr>
</tbody>
</table>

* Data regarding age and ethnicity of EC professionals was not collected as it was felt that this was unlikely to affect responses.
4. Discussion

This study highlights the paucity of evidence that underpins many aspects of care of women with EC. Of the 247 research questions generated in this study, we found only 15% of these had been answered by level 1 evidence. To begin to tackle this problem, we have developed a consensus of the top ten unanswered research questions in EC shared by both clinicians and patients, using an inclusive decision making approach. The top ten questions span disease risk stratification, diagnosis, treatment, management and survivorship that cover the breadth of...
patient experience of this disease. Identification of these questions is the first step to accelerating research that will maximise health benefits to women, both at risk of EC and those who have already been diagnosed with the disease. The next steps are to secure funding for these research areas and to disseminate the findings of this study and those resulting from it in an attempt to address the mismatch between disease burden and research activity.

At the forefront of both patient and clinicians’ priorities is the development of personalised risk prediction. Over 40% of EC are thought to be preventable [20]. Risk stratification offers the opportunity for women to understand their underlying risk and engage in targeted risk modification and/or screening, with the aim of reducing the incidence of EC. These aims demonstrate a shift in paradigm from a reactive to a more proactive approach known as ‘predictive, personalised, preventative and participatory (P4) medicine’. This focus on prevention will provide us with the opportunity to turn the tide on the rising numbers of women diagnosed with, and dying from, this potentially preventable disease. Our finding that risk prediction is the most important priority challenges the belief that societal barriers will be the most difficult obstacle to achieving P4 medicine [21]. The incorporation of EC within the 100,000 Genomes Project in England [22] and the ForeCee project [23] will provide researchers with a wealth of data to begin building algorithms that are not only based on lifestyle and behaviour, but also incorporate genetic predisposition. The challenge going forward is to combine this knowledge with evidence-based prevention strategies.

Coupling prevention with earlier diagnosis may provide the best opportunity to save lives. Women diagnosed with early stage disease benefit from longer disease-specific survival and avoid the long term complications associated with adjuvant therapy. A focus on educating the public about early signs of disease and providing tools for primary care physicians to better identify women with EC and pre-cancer from within a cohort of symptomatic women represent ways in which both earlier detection and improvements in the experience of being diagnosed can be achieved. The Eve Appeal National Gynaecological Cancer survey revealed that whilst 71% women had experienced one or more symptoms of a gynaecological cancer, 20% had dismissed these symptoms as normal for someone of their age [8].

For those women diagnosed with EC, the challenges lie in personalising care and improving quality of life following treatment. Therefore, we need to prioritise research into developing therapies that are not only effective but also have minimal side effects, and identifying and avoiding harmful treatments in women who would otherwise receive no benefit. Additionally, recognising that a diagnosis of EC and its treatment has psychological, as well as physical, effects will pave the way for much needed research into interventions to improve the psychological wellbeing of patients. More research is also needed in non-drug interventions that empower women to improve their overall health and reduce the risk of recurrence, thus prolonging overall survival.

In our study, the lay participants predominantly identify as white and under 60 years old. It is notable that individuals of Asian (i.e. people identifying as of Indian, Pakistani, Bangladeshi or other South Asian ethnicity) and Black ethnicity and older women who make up a substantial proportion of women diagnosed with EC are underrepresented. A consultation process such as this will inevitably reach patients who are already engaged in lobbying and policy change. These individuals are often younger women with rarer forms of the disease. Other researchers have demonstrated that younger women are more likely to perceive that their healthcare needs are inadequately met [24]. This may also account for the disproportionate number of younger women responding to our survey. In order to ensure that views of older women were represented during the initial consultation phase and the final consensus meeting, we specifically invited several women over 65 years of age to participate over and above those recruited from generic call out.

Although meaningful analysis of themes by age could not be conducted in our study due to the small numbers in each age group, other researchers have noted that older women in general are more concerned with preventing disability rather than specific diseases, being treated holistically and feeling validated in their relationship with their healthcare provider [24]. Our top ten research priorities do include research questions which look to prevent the morbidity associated with treatment and consider psychological and lifestyle issues. Involving older women and women of black and minority ethnicity remains difficult and going forward we will need to seek to ensure the involvement of these cohorts, since they form a significant proportion of women with EC, in the design of any research commissioned as a result of this study.

Ultimately, the strength of this work is the involvement of a broad base of different stakeholders throughout the decision-making process, to develop much needed priorities for research in this under-recognised condition. The involvement of healthcare professionals, patients and carers not only increases the credibility and transparency of the final output as has been recognised in many other prioritisation processes [25,26] but also ensures that these priorities are relevant and feasible. It was clear that there were disparities in the research themes proposed by the patient and healthcare professional groups but this reflected their differing experiences of EC. For the patients, risk factors, causality, lack of public awareness and survivorship were the predominant themes. For the healthcare professionals, risk prediction and prevention, diagnostic pathways and treatment were more pertinent. The final prioritisation workshop enabled all contributing groups to voice their opinions, thus shaping the order of the top ten to reflect these different, but equally important perspectives. Without such strong patient

<table>
<thead>
<tr>
<th>Top ten research questions for endometrial cancer (EC) that emerged from broad-based engagement</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Is it possible to develop a personalised score which reflects a woman’s individual risk of developing EC?</td>
</tr>
<tr>
<td>2. Which women with abnormal vaginal bleeding should be referred for specialist review?</td>
</tr>
<tr>
<td>3. What are the most effective treatments currently available for advanced EC and what key molecular pathways should be targeted when developing new treatments?</td>
</tr>
<tr>
<td>4. Can we predict which women will benefit from adjuvant chemotherapy or radiotherapy and avoid ineffective treatments?</td>
</tr>
<tr>
<td>5. Are blood tests, including markers like CA125, useful in predicting duration of survivorship and/or recurrent disease?</td>
</tr>
<tr>
<td>6. What ways of raising public awareness about EC are the most effective and cost effective?</td>
</tr>
<tr>
<td>7. What are the psychological issues surrounding diagnosis and treatment of EC and what interventions might be helpful?</td>
</tr>
<tr>
<td>8. What are the underlying causes of different types of EC and how do they develop?</td>
</tr>
<tr>
<td>9. Can we predict at the time of diagnosis which endometrial cancers and precancerous lesions will respond to hormone treatments?</td>
</tr>
<tr>
<td>10. Do changes in lifestyle, including weight loss, reduce the risk of recurrence and improve survival in women who have been treated for EC?</td>
</tr>
</tbody>
</table>

Fig. 5. Final top ten unanswered research questions in EC.
involvement, it is unlikely that the questions relating to public awareness, psychological consequences or lifestyle change following treatment for EC would have ranked so highly, and yet these aspects of being diagnosed with EC and living with the consequences of treatment really matter to patients. As a group, our common experience of this condition, as both patients and healthcare professionals, is at the time of treatment, and this is reflected in the large proportion of our research priorities focusing on this aspect of care. Nonetheless, our highest priority is prevention. We recognise that this primary focus, if successfully delivered, will save lives for potentially a smaller investment than research into treatment alone [27].

Highlighting a list of top ten unanswered research questions does not obviate the need for research in other areas. Indeed, a limitation of agreeing the final top ten within a much smaller group than was involved in the broader consultation is the risk that the final set of priorities and their order is biased by the participants involved on the day. This list of priorities should, therefore, serve only to focus discussion on how limited funding could be distributed to best meet needs and not be used as an absolute list. We hope, by sharing the remaining list of uncertainties, researchers with areas of expertise outside this top ten will continue to address the many other issues that affect EC patients and the healthcare professionals who care for them.

Perhaps the most important part of this process has been the strengthening of relationships between partner organisations, patients and clinicians. As a result, we have developed a list of core aims to be worked on collaboratively to deliver improvements in the lives of women who have been diagnosed with EC and those at risk.

Contribution to authorship

All authors contributed to study design, data interpretation and manuscript preparation. All authors reviewed and agreed the final version of the manuscript.

Conflicts of interest

The authors report no conflicts of interest.

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