

The Womb Cancer Awareness Measure (WCAM): Development of a validated tool to assess public awareness of endometrial cancer

Supplementary Tables , Figures and Appendices

Table S1 Summary of items included in the Womb Cancer Awareness Measure validation studies

| Awareness section | Items included in Womb CAM | Maximum score |
|------------------------------|----------------------------|---------------|
| Warning signs and symptoms | 1 open item | 8 |
| | 8 prompted items | 8 |
| Risk factors | 1 open item | 10 |
| | 13 prompted items | 65 |
| Peak age of incidence | 1 item | 2 |
| Endometrial Cancer screening | 1 item | 1 |

Table S2 Sociodemographic characteristics of participants ($n = 65$) in the initial validation studies

| | Test-retest reliability ($n=22$) | Construct validity ($n=26$) | | Sensitivity to change ($n=43$) | |
|---|---------------------------------------|----------------------------------|-------------------------------------|-------------------------------------|----------------------------|
| | | Experts ($n=10$) | Non-medical academics ($n=16$) | Control ($n=21$) | Intervention ($n=22$) |
| Age, median (range) | 41 (24-65) | 46.5 (30-57) | 41.5 (20-65) | 23 (20-61) | 22 (19-58) |
| Education level, n (%) | | | | | |
| Secondary school (GCSE/ A Levels) | 2 (9) | - | 2 (13) | 9 (43) | 12 (55) |
| Undergraduate | 13 (59) | 1 (10) | 8 (50) | 7 (33) | 9 (41) |
| Postgraduate | 6 (28) | 9 (90) | 5 (32) | 5 (24) | 1 (5) |
| Other | 1 (5) | - | 1 (6) | - | - |
| Ethnicity, n (%) | | | | | |
| White British or Other White Ethnicity | 21 (95) | 9 (90) | 16 (100) | 16 (76) | 19 (86) |
| Black Ethnicity | - | - | - | - | 1 (5) |
| Asian | - | 1 (10) | - | 5 (24) | 1 (5) |
| Arab | - | - | - | - | 1 (5) |
| Mixed/Multiple ethnic groups | 1 (5) | - | - | - | - |

Table S3 Sociodemographic characteristics of participants in the Validation Study (UK Population Sample)

| | UK population sample, n (%) (n = 847) |
|---|--|
| Age, median (range) , years | 44 (19-80) |
| By age brackets, years | |
| 18-24 | 50 (6.3) |
| 25-34 | 139 (17.4) |
| 35-44 | 239 (30.0) |
| 45-54 | 229 (28.7) |
| 55-64 | 140 (17.6) |
| >65 | 50 (6.3) |
| Ethnicity, n (%) | |
| White British/Other | 800 (94.0) |
| Black African/Caribbean/ British | 6 (1.0) |
| Asian | 22 (3.0) |
| Arab | 1 (0.1) |
| Mixed/Multiple ethnic groups | 17 (2.0) |
| Other | 3 (0.5) |
| Education level, n (%) | |
| No educational qualifications | 21 (3.0) |
| GCSEs and A Levels or equivalent | 229 (27.0) |
| Undergraduate degree | 288 (34.0) |
| Postgraduate degree | 303 (36.0) |
| Other | 7 (1.0) |
| Previous womb cancer diagnosis*, n (%) | 266 (31.02) |
| Predisposing medical condition, n (%) | |
| Polycystic ovary syndrome | 51 (6.0) |
| Endometrial hyperplasia | 27 (3.2) |
| Type 2 diabetes | 15 (1.7) |
| Metabolic syndrome | 4 (0.6) |

*(either themselves or someone close to them)

Table S4 Prompted responses to womb cancer symptoms and risk factors

| Question | | Identified as risk factor, n (%) |
|--|---|----------------------------------|
| Endometrial cancer symptoms (n = 824) | Intermenstrual bleeding | 744 (90) |
| | Pelvic pain | 711 (86) |
| | Post-menopausal bleeding | 704 (85) |
| | Heavier periods | 589 (72) |
| | Pain during sex ^φ | 577 (70) |
| | Abnormal discharge | 542 (66) |
| | Weight loss | 537 (65) |
| | Anaemia | 347 (58) |
| Endometrial cancer risk factors* (n = 798) | Smoking ^φ | 757 (95) |
| | Family history | 709 (89) |
| | Combined oral contraceptive pill ^φ | 677 (85) |
| | Being overweight | 654 (82) |
| | Sedentary lifestyle | 558 (70) |
| | PCOS | 472 (59) |
| | Postmenopausal | 458 (57) |
| | Diabetes | 397 (50) |
| | Negative cervical smear ^φ | 373 (47) |
| | Nulliparity | 302 (38) |
| | Early menarche | 287 (36) |
| | Tamoxifen | 288 (36) |
| | Late menopause | 207 (26) |
| Hysterectomy ^φ | 181 (23) | |

*For risk factors, 'yes'=score of >4 (agree/strongly agree), 'no'=score of ≤3 (neutral/ disagree/ strongly disagree)

^φDistractor item

Table S5 Total knowledge scores of participants in general population sample

| | No prior experience (n = 519) | Endometrial cancer experience* (n = 224) | Physicians (n = 24) |
|---|--|---|--------------------------------|
| Total knowledge score, mean (SD) Max: 98 | 57 (7.2) | 59 (8.0) | 68 (8.0) |
| One way-Anova comparing three groups | | <0.001 | <0.001 |
| One way Anova comparing two groups | | | <0.001 |

*Participants who answered 'yes' the question 'Have you, a relative, or close friend ever been diagnosed with womb cancer?' p-values <0.05 are regarded as statistically significant.



Figure S1 Word cloud representing common misconceptions about the symptoms of endometrial cancer warning signs based on unprompted responses.



Figure S2 Word cloud representing common misconceptions about the risk factors for endometrial cancer based on unprompted responses

Appendix S1 The Womb Cancer Awareness Measure

Part 1: Firstly, we would like to know a little about you. This information helps us to build a picture of your background and analyse the results.

1. What age are you now?

years old

2. Which of the following describes the highest level of education you achieved?

| | |
|--|--|
| <input type="checkbox"/> No qualifications | <input type="checkbox"/> Postgraduate qualification e.g., Postgraduate Diploma or Master's Degree |
| <input type="checkbox"/> CSE/GCSE/O-Levels/Intermediate GNVQ | <input type="checkbox"/> Doctorate/PhD |
| <input type="checkbox"/> A levels/ Advanced GNVQ/BTEC National Diploma | <input type="checkbox"/> Other, please specify : <input type="text"/> |
| <input type="checkbox"/> Degree level e.g., BA, BSc and/or Higher National Diploma | |

3. What is your current occupation (or most recent occupation, if you are retired)?

4. How would you describe yourself? (Please select **one**)

White:

English/Welsh/Scottish/Northern Irish/
British

Irish

Other White background, please specify:

Black/African/Caribbean/Black British

African

Caribbean

Any other Black/African/Caribbean
background, please specify:

Asian:

Indian

Pakistani

Bangladeshi

Chinese

Any other Asian background, please specify:

Mixed/multiple ethnic groups:

White and Black Caribbean

White and Black African

White and Asian

Any other Mixed/ multiple ethnic
background, please specify:

Arab

Any other ethnic background, please specify:

5. What is your current height and weight?

Height ____ft ____ inches OR ____ cm **Weight** ____stone OR ____lbs OR ____kg

6. Have you or a relative/close friend ever been diagnosed with womb cancer?

Yes No

7. Have you ever been diagnosed with any of the following conditions? (Please select **ALL** that apply)

Polycystic ovary syndrome

Type 2 Diabetes

Metabolic Syndrome

Endometrial hyperplasia (thickening of the womb lining)

Part 2: Womb Cancer Awareness Measure

6. There are several warning symptoms and symptoms of womb cancer. Name as many as you can think of:

| |
|--|
| |
|--|

7. Some of the following could be symptoms of womb cancer. Tell us which you think are SYMPTOMS OF WOMB CANCER:

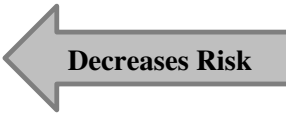

| | Yes | No | Don't know |
|---|--------------------------|--------------------------|--------------------------|
| Bleeding in between your periods? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Having heavier periods than normal? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Vaginal bleeding after the menopause? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Bloody or pink and watery vaginal discharge? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Pain or discomfort in the pelvic area? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Pain during sex? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Having a low blood or iron count (i.e., anaemia)? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Weight loss? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

8. If you had a symptom you thought could be a sign of womb cancer, how soon would you make an appointment with your doctor about it?

| |
|--|
| |
|--|

| 9. In the next year, who is most likely to develop womb cancer? | |
|--|--------------------------|
| A woman aged 30 years | <input type="checkbox"/> |
| A woman aged 50 years | <input type="checkbox"/> |
| A woman aged 70 years | <input type="checkbox"/> |
| A woman aged over 80 years | <input type="checkbox"/> |
| Womb cancer is not related to age | <input type="checkbox"/> |

| 10. What things do you think increase a woman's chance of developing womb cancer? |
|--|
| |

| 11. There are some things that can increase a woman's chance of developing womb cancer. How much do you agree that each of these things can INCREASE the risk of developing womb cancer? | | | | | |
|---|--|--------------------------|---|--------------------------|--------------------------|
| |  Decreases Risk | | Increases Risk  | | |
| | Strongly disagree | Disagree | Neutral | Agree | Strongly Agree |
| Not having children | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Starting periods at a young age | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Having gone through the menopause | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Having a late menopause | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Having a close relative with womb cancer | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Having had a hysterectomy (womb removed) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Having a negative cervical smear test | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Having polycystic ovary syndrome | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Having diabetes | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Being overweight (BMI over 25) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Living a sedentary lifestyle (i.e., not being physically active) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Being a smoker | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Taking the combined (two hormones) contraceptive pill | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Using tamoxifen (medication) for breast cancer treatment or prevention | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

| 12. Womb cancer diagnosis and management. Can you tell us which of the following statements are TRUE or FALSE? | | | |
|---|--------------------------|--------------------------|--------------------------|
| | True | False | Don't know |
| Womb cancer is uncommon (i.e. less than 1 in 20 women will develop it in their lifetime) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Womb cancer is usually diagnosed at an early stage (before it has spread)? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Womb cancer is easily treated? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Womb cancer has a poor prognosis (outlook)? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Womb cancer can run in families? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

| 13. NHS Cancer Screening Programmes. | | | |
|---|--------------------------|--------------------------|--------------------------|
| | Yes | No | Don't Know |
| 13a. Is there an NHS womb cancer screening programme? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| If yes, what age does screening start? _____ | | | |
| 13b. Is there an NHS cervical cancer screening programme? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| If yes, what age does screening start? _____ | | | |
| 13c. Is there an NHS breast cancer screening programme? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| If yes, what age does screening start? _____ | | | |
| 13d. Is there an NHS bowel cancer screening programme? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| If yes, what age does screening start? _____ | | | |

| 14. How confident are you that you would notice a womb cancer symptom? | | | |
|---|--------------------------|--------------------------|--------------------------|
| Not at all confident | Not very confident | Fairly confident | Confident |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

This is the end of the Womb CAM. Please note that this awareness measure is about womb cancer, also known as endometrial or uterine cancer.

Appendix S2

Calculation of Knowledge Scores

Warning symptoms and risk factors

When analysing responses to the unprompted items, one point was given for each warning sign or risk factor that corresponded to an item in the prompted list. Scores were totalled to give a range of 0-8 for warning symptoms and 0-10 for risk factors.

The prompted warning sign items were scored as either 0 (no/don't know) or 1 (yes). The potential score range was 0-8. Prompted risk factor items were scored from 1 (strongly disagree) to 5 (strongly agree) for the true items and 1 (strongly agree) to 5 (strongly disagree) for the protective items. This resulted in a score range of 13-65. Higher scores indicated greater womb cancer awareness.

Womb Cancer Warning Symptoms and Symptoms

Unprompted Warning symptoms and symptoms (1 point each)

- Heavy/ irregular menstrual bleeding
- Abnormal vaginal bleeding – i.e. intermenstrual or postcoital bleeding
- Postmenopausal bleeding
- Abnormal vaginal discharge
- Pelvic or back pain
- Weight loss
- Haematuria
- Anaemia

These are NOT scored as warning symptoms

- Pain during sex
- Pain on urination

Prompted warning symptoms (1 point each)

- Intermenstrual bleeding
- Heavier periods
- Postmenopausal bleeding
- Bloody discharge
- Pelvic pain
- Anaemia
- Weight loss

Incorrect

- Pain during sex

Womb Cancer Risk and Protective Factors**Unprompted risk factors**

- Age or postmenopausal status
- Sedentary lifestyle (low physical activity)
- Genetics and/or family history
- Diabetes And/or Insulin resistance and/or Metabolic Syndrome
- Obesity
- Nulliparity
- Oestrogen only HRT
- High oestrogen- early menses/ late menopause
- Polycystic ovary syndrome
- Tamoxifen

These are NOT scored as risk factors

- Radiation
- Hypertension
- Hypothyroidism

Prompted Risk Factors

Score 1 to 5, 1 strongly disagree to 5 strongly agree

- Nulliparity
- Early Menarche
- Postmenopausal
- Late Menopause
- Close Relative with Womb Cancer
- Polycystic Ovary Syndrome
- Diabetes
- Overweight
- Sedentary lifestyle
- Tamoxifen use

Prompted Protective Factors

Score 1 to 5, 1 strongly agree to 5 strongly disagree

- Previous hysterectomy
- Combined oral contraceptive pill (COCP)

Age-related risk

This item was scored as 2 (correct) if a participant thought that womb cancer is most likely to develop at age 70 or 80 years, 1 (partially correct) if the response was 50 years, and 0 (incorrect) for the response '30 years old' or 'womb cancer is not related to age.' The rationale for this scoring system was that the peak age of incidence for womb cancer is 75-79, although being postmenopausal (considered over 50) increases risk.²

Womb cancer screening

One point was given to participants who knew that there is not an NHS womb cancer screening programme.

Total knowledge

A total knowledge score was calculated by adding the scores for items on unprompted and prompted warning symptoms and risk factors items, age-related risk, and awareness of screening (Table 1). This produced a scale where higher scores indicated greater overall awareness of womb cancer (maximum score 94).

Adaptions to scoring system for test-retest reliability analysis

The kappa statistic method used for the test-retest reliability analysis required variables to be binary. Thus, aspects of the scoring system were adapted: a participant was considered to recognise a prompted item to be a risk factor if they achieved a score greater than 4 both times when completing the Womb CAM. For the total knowledge score, it was decided that scoring 80% of the maximum score demonstrated sufficient awareness of womb cancer.

For the test-retest analysis, the kappa statistic method required variables to be binary. The prompted risk factor scoring system therefore had to be adapted so that participants were only considered to be aware of risk/protective factors if they achieved a score greater than or equal to 4, which correlated to a response of 'agree' or 'strongly agree' for risk factors, and 'disagree' or 'strongly disagree' for protective factors.