**Participants and recruitment**

The Irish Census 2011 reported an estimated population of 6,560 people with an intellectual disabilities in the South East of Ireland. Approximately 1300 women with mild to moderate intellectual disabilities live in the region, and are supported by family and paid carers. Women with intellectual disabilities and their carers were purposively recruited for this study carried out between June and December 2013.

The researcher personally contacted the Service Managers at Intellectual Disability Services in the region. Information meetings, advertised by posters and letters to families were held at the intellectual disability service providers to explain the purpose of the study to the service provider, the women using these services and their families. Information packs with easy to read information and consent sheets, were distributed at the meetings.

**Design of the survey instrument**

The Cancer Awareness Measure and tumour specific Cancer Awareness Measures for breast and cervical cancer were used to assess baseline cancer and screening awareness levels. The study specific CAM survey used selected questions from the Cancer Awareness Measures. The questions selected are detailed below:

* Recognition of warning signs for breast and cervical cancer
* Recall of breast and cervical cancer risk factors
* Age related risk of breast and cervical cancer
* Confidence to notice and breast or cervical cancer symptom
* Frequency of breast self-examination
* Anticipated delay in medical help seeking on self-discovery of a breast or cervical cancer symptom
* Barriers to seeking medical advice on discovery a breast or cervical cancer warning sign
* Awareness about breast and cervical cancer-screening programmes, attendance at the breast screening programme and the Cervical Cancer vaccination programme
* Personal experience of cancer (self, family or friend)
* Demographic variables of interest such as age, carer status and residential status of women with mild to moderate intellectual disabilities

Two additional questions were added to the Cervical- CAM relating to the receipt of a cervical screen invite, and attendance at the cervical screening programme in the Republic of Ireland. The screening questions were amended to reflect the name of the programmes in Ireland, BreastCheck and CervcialCheck. In addition, just one set of the awareness of cancer risk factors questions were included in the CAM, as the inclusion of both could lead to self-prompting of the answer which could lead to a misleading assessment of awareness levels.

**CAM administration**

The CAM for the women with mild to moderate intellectual disabilities was administered as a face-to-face interview as participants’ literacy levels were acknowledged to be poor. The woman co-signed the accessible information consent form with the researcher and the carer where present, and provided GP details. The woman was reminded that the interview was being recorded and that she could withdraw from the interview at any time. Following the interview the woman’s GP was notified via post/fax of the woman’s participation in the study just in case the woman had any further queries following CAM completion.

The carer CAM was made available in two formats a self-administered postal version and an online version (Cancer Research UK, 2011). A detailed information sheet was provided with the CAM based on CAM toolkit guidance that discussed issues such as confidentiality and the advice to be followed should a cancer symptom be noticed following completion of the CAM. There was no consent form given, implied consent was presumed by self-completion of the CAM.

300 postal CAM’s were distributed throughout the participating intellectual disability service providers to paid and family carers. A self- addressed stamped envelope was provided with the print version in an effort to improve the response rate for the survey. The online version was distributed as an email attachment via the intellectual disability service provider.

*Data analysis procedures*.

Responses were coded as per the CAM Toolkit guidance using the numbers and correct SPSS variable names for recording the data. In the Excel file the variable names are provided in the top row as per this guidance e.g **Cervical\_vaginalbleedC.** In the women with intellectual disabilities SPSS files (20171014 WWID.sav) and the carer SPSS file (20171014.sav) ‘No’, ‘Don’t Know’ coded as either ‘1’, ‘2’ or ‘99’ depending on the question asked and ‘Prefer not to say’ coded as ‘98’ were collapsed into one variable for further statistical analysis.

**Results**

A total of 125 nurses, social care workers, health care assistants and family carers completed a self-administered English language version of the study specific CAM (124 postal; 1 online).

Initially 47 women were recruited following the information meetings during the time frame June to November 2013. Two women withdrew from the study during this time. Overall 45 women with mild to moderate intellectual disabilities participated in a face-to-face CAM interview.

Only the top recalled breast or cervical cancer risk factor was included in the analysis and a full list of the risk factors recalled is shown in Tables 1 and 2. In addition, verbatim responses collected for the questions about the things that might affect a woman’s chance of getting breast or cervical cancer, things that might put you off going to the doctor and anticipated delay in medical help seeking on self-discovery of a breast or cervical cancer symptom.

**Table 1.** Top recalled breast cancer risk factor

|  |  |  |
| --- | --- | --- |
| Breast\_risk01 | 1 | Previous breast cancer |
| 2 | HRT |
| 4 | Being overweight |
| 5 | Genetics |
| 6 | Having children late in life or not at all |
| 7 | Early menarche |
| 8 | Late menopause |
| 9 | Not doing enough exercise/ physical activity |
| 10 | Older age (unspecified) |
| 11 | Having gone through the menopause |
| 12 | Being a smoker |
| 13 | Diet (Unspecified) |
| 14 | Drinking alcohol |
| 15 | Chance |
| 16 | Hormone imbalance |
| 17 | Breastfeeding |
| 18 | Taking the oral contraceptive pill |
| 19 | Stress |
| 20 | Other |
| 21 | Nothing |
| 22 | Environmental factors |
| 23 | Spray deodorants |
| 24 | Lifestyle |
| 26 | Blow to the breast |
| 27 | Health history |
| 28 | Breast implants |
| 29 | Sun exposure |
| 30 | Childbirth- age not specified |
| 31 | Not checking breast |
| 32 | Unmarried women |
| 33 | Lack of awareness |
| 34 | Living location |
| 35 | Having a weakened immune system |
| 36 | Radiation for other cancers in local area |
| 37 | Medication |
| 38 | Early menopause |
| 39 | Working load |
| 40 | Personal hygiene |
| 41 | Sexual relationships |
| 98 | Prefer not to say |
| 99 | Don't know |

**Table 2.** Top recalled cervical cancer risk factor

|  |  |  |
| --- | --- | --- |
| Cervical\_risk01 | 1 | Infection with HPV |
| 2 | Smoking any cigarettes at all |
| 3 | Having a weakened immune system |
| 4 | Long term use of the contraceptive pill |
| 5 | Infection with Chlamydia |
| 6 | Having a sexual partner who is not circumcised |
| 7 | Starting to have sex at a young age (before the age of 17) |
| 8 | Having many sexual partners |
| 9 | Having many children |
| 10 | Having a sexual partner with many previous partners |
| 11 | Not going for regular smear (Pap) tests |
| 12 | Other |
| 13 | Nothing |
| 14 | Genetics |
| 15 | Environmental factors |
| 16 | Diet |
| 18 | Lifestyle |
| 19 | Exercise |
| 20 | Stress |
| 21 | Drinking alcohol |
| 22 | Sexual health |
| 23 | Medical conditions |
| 24 | Age |
| 25 | Chance |
| 26 | Hormone imbalance |
| 27 | Ovaries |
| 28 | Being overweight |
| 29 | Medical history |
| 30 | Unsafe sex |
| 31 | Early menarche |
| 32 | Nulliparity |
| 33 | Not taking the contraceptive pill |
| 34 | Personal hygiene |
| 35 | Persistent problems in that area |
| 36 | Lower social class |
| 37 | Not vaccinated against cervical cancer |
| 38 | Menopause |
| 39 | Too many cells in the womb |
| 98 | Prefer not to say |
| 99 | Don't know |

**Publications**

A paper on the breast cancer awareness of women with intellectual disabilities is currently under review in the British Journal of Learning Disabilities.