

Department of Nursing and Healthcare

Waterford Institute of Technology

Doctoral Thesis Volume II

TITLE:

**Promoting Cancer and Screening Awareness in Women with
Intellectual Disabilities: A Mixed Methods Study.**

BY

Mary Reidy

STUDENT NUMBER

20032970

Academic Supervisors

Dr. Suzanne Denieffe

Ms Sinéad Foran

Dr. Martina Gooney

**Submitted as partial fulfilment of the
Requirements for the Doctor of Philosophy Degree**

June 2016

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Appendix III: Permissions to use materials and copyright

AIII.1 American Cancer Society

RE: Published Materials

American Cancer Society - Contact Us

<undl@emailcenter.cancer.org>

Mon 02/06/2014 17:18

TO: Mary Reidy <mreidy@wit.ie>;

If you reply to this message, please retain your serial number in the subject line. This reference, (THREAD ID:1-4PWYBQ8) (ACTIVITY ID:1-4Q29VLT) will assist us in locating your questions and answers.

Dear Mary,

Thank you for your interest in the American Cancer Society and contacting us for permission to use the information on our website. We truly appreciate your efforts to help educate others at your upcoming women's health education initiative. You are welcome to make one permanent printout of each page of the website to be used for personal, educational and noncommercial uses, which do not harm the reputation of the American Cancer Society.

If you wish to use or copy content from our website for commercial use, please submit your request to permissionrequest@cancer.org.

Please provide the following information with your request:

- > Information about the exact ACS material you propose to use or copy, including the title of the document, page numbers, section titles, and copyright dates. To use information from the ACS Web site, include the Web address (URL) and, if possible, attach a copy of the specific information you wish to use.
- > An explanation of how the ACS information will be used and/or distributed and whether reprinted materials will be sold
- > A description of the nature of your organization or business (for-profit, not-for-profit, etc.)
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You will receive an email response verifying receipt of the request within two business days. Please allow up to 14 business days for requests to be processed.

If your request is time sensitive, please send it by fax to: 404-417-5808 (Attention: "Reprints")

To learn more about permission to reprint web content, please view our Web Content Use guidelines at:

http://www.cancer.org/docroot/SU/content/SU_1_2_Usage_of_Content.asp?sitearea=SU

Thank you for helping the American Cancer Society in the global fight against cancer!

Ken

Online Cancer Information Specialist

If you have any questions, please contact us via <http://www.cancer.org> or call 1-800-ACS-2345. Information Specialists are available 24 hours a day, 7 days a week.

This e-mail message is not intended as medical advice, and should not be relied upon as a substitute for consultations with qualified health professionals who are familiar with your individual medical needs. The American Cancer Society makes no warranties of any kind regarding this e-mail message, including but not limited to any warranty of accuracy, completeness, currency, reliability, merchantability or fitness for a particular purpose and such warranties are expressly disclaimed.

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-----Original Message-----

From: mreidy@wit.ie
Sent: 5/30/2014 08:41:43 AM
To: <contactus@emailcenter.cancer.org>
Subject: Published Materials

To whom it may concern,
I am interested in using information from the American website to inform the content of a non commercial womens health education initiative about breast and cervical cancer awareness and screening in the Republic of Ireland. This programme forms part of my postgraduate degree. I wish to seek permission to use information from the website as part of this educational programme. Full copyright acknowledgement will be given to the American Cancer Society and the content will not be altered in any way. I hope you will consider my request favourably.

Thanking you in advance,
Mary Reidy,
Postgraduate Research Student,
Department of Nursing,
Waterford Institute of Technology,
051- 845593

AIII.2 Permission to use CAM in Ireland

RE: The use of CAM in research outside the UK

Anne Helme <Anne.Helme@cancer.org.uk>
Mon 26/11/2012 08:54

To: Mary Reidy <MREIDY@wit.ie>;
Dear Mary,

Thank you for your enquiry. I don't see that there would be any problems in using CAM in Ireland, but your best approach is probably to request the toolkit (http://www.cancerresearchuk.org/cancer-info/spotcancerearly/naedi/AboutNAEDI/Researchevaluationandmonitoring/naedi_cam/) using this survey: <https://survey.cancerresearchuk.org/Survey.aspx?s=c782eab2506841dfa5bade7e9a2b5647> - you can specify your location as being Ireland. If you have any further questions, please contact naedi@cancer.org.uk and my colleagues who oversee the CAM tool should be able to help.

Best wishes,
Anne

Dr Anne Helme

Research Funding Manager
Strategy and Research Funding

From: Mary Reidy [mreidy@wit.ie]
Sent: 23 November 2012 11:03
To: Anne Helme
Subject: The use of CAM in research outside the UK

Dear Dr. Helme.

I am in the early stages of a funded MSc by Research in Nursing at Waterford Institute of Technology, Waterford, Ireland. My research is funded by the Health Service Executive. My area of interest is cancer awareness in women with intellectual disabilities in the south east of Ireland. My query is whether CAM can be used outside the UK to measure cancer awareness and if so how is permission sought.

Thank you for your time.

Best Regards
Mary Reidy
BSc, RNID.

NOTICE AND DISCLAIMER

This e-mail (including any attachments) is intended for the above-named person(s). If you are not the intended recipient, notify the sender immediately, delete this email from your system and do not disclose or use for any purpose.

We may monitor all incoming and outgoing emails in line with current legislation. We have taken steps to ensure that this email and attachments are free from any virus, but it remains your responsibility to ensure that viruses do not adversely affect you.

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A company limited by guarantee. Registered company in England and Wales (4325234) and the Isle of Man (5713F).

Registered Office Address: Angel Building, 407 St John Street, London EC1V 4AD.

AIII.3: Change Picture Bank Licence

6. CHANGE Picture Bank Licence

6.1 Terms of the License

This section of the Terms applies:

- (i) if you are purchasing or purchased one of the CHANGE Picture Bank CD-ROMs and Licenses for use, whether a single or multiple user license; and/or
- (ii) if you download any individual CHANGE Pictures from our website.
(together "CHANGE Image Resources")

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The CHANGE Image Resources may only be run or otherwise operated by your employees on equipment owned by you. Any further use is prohibited.

You must only use pictures from CHANGE to make information accessible and easy to understand.

You must give due credit to CHANGE when using pictures from CHANGE including any of our Picture Banks. This can be via use of our Publisher's Mark (a copy of which can be obtained from us by writing to info@change-people.co.uk) or a short reference on the back cover of documents or at the bottom of web-pages. E.g. 'all pictures used are from CHANGE www.changepeople.co.uk'.

If you want to use the pictures from CHANGE to make money e.g. in a document or product that is going to be for sale through your organisation, you must write to us and ask our separate permission. We may charge you a commission fee on any reproduction of our work for commercial gain.

AIII.4 Channel 4 Embarrassing Bodies

Jane Reid from Channel 4, need a web form if going to embed info in any website. Form not needed if for information purposes

Jane Reid@ Channel 4 00443450760191 28th May 2014

AIII.5 Irish Cancer Society

RE: Permission for the dissemination of knowledge

Orla Sheils <osheils@irishcancer.ie>

Wed 28/05/2014 14:47

To: Mary Reidy <mreidy@wit.ie>;

Hi Mary

Thank you for your query.

That is absolutely fine, once the Society as referenced.

Best of luck with your research.

Kind regards
Orla

Orla Sheils | Assistant Communications Officer

Irish Cancer Society | 43-45 Northumberland Road, Dublin 4.

T: 01 231 0559 | Fax: +353 1 2310 555

E: osheils@irishcancer.ie

W: www.cancer.ie

National Cancer Helpline Freefone 1800 200 700

Registered in Dublin no. 20868 CHY 5863

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From: Mary Reidy [mailto:mreidy@wit.ie]

Sent: 28 May 2014 14:45

To: Communications

Subject: Permission for the dissemination of knowledge

To whom it may concern,

I am interested in using information from the Irish Cancer Society website to inform the content of a non commercial cancer awareness programme. This programme forms part of my postgraduate degree. I wish to seek permission to disseminate information from the ICS as part of this educational programme. Full credit will be given to the ICS and the content will not be altered in any way. I hope you will consider my request favourably.

Thanking you in advance,

Mary Reidy,

Postgraduate Research Student,

Department of Nursing,

Waterford Institute of Technology,

051- 845593

AIII.6 Jo's Cervical Cancer Trust

/To:

Thank you for your email. It sounds like a very interesting project that you are working on.

Our website is accessible to the general public and thus anyone can access the information. As you mentioned you will be referencing where you sourced the material I see no reason why you couldn't use our information within your study.

Do let us know how the study goes and if we can be of further assistance.

Best wishes

Claire

Claire Cohen Information and Education Manager

Jo's Cervical Cancer Trust - CAN Mezzanine, 49-51 East Road, London, N1 6AH | t. 020 7250 8311 | m. 07896717034 | w. www.jostrust.org.uk | **Helpline. 0808 802 8000**

Registered in England and Wales | Company Limited by Guarantee: 7111375 | Registered Charity Number: 1133542 | Registered Scottish Charity Number: SC041236

Help to raise awareness of cervical screening via our new Put Yourself In The Picture app. Join the campaign now.

From: Mary Reidy [mailto:mreidy@wit.ie]

Sent: 05 June 2014 14:52

To: Claire Cohen

Subject: Permission to use information

Dear Claire,

My postgraduate research study involves the development of a non commercial educational initiative for women with intellectual disabilities and their carers that aims to improve breast and cervical cancer awareness and screening uptake. This is intended to lead to the earlier diagnosis and treatment of cancer with better outcomes for the women.

I am interested in using information e.g. videos and cervical cancer information from Jo's Cervical Cancer Trust website to inform the content of the initiative. I wish to seek permission to use information from Jo's Cervical Cancer Trust website. Full copyright acknowledgement will be given to Jo's Cervical Cancer Trust and the content will not be altered in any way. I hope you will consider my request favourably.

Best regards,

Mary Reidy,
Postgraduate Research Student,
Department of Nursing,
Waterford Institute of Technology,
051- 84559

AIII.7 NHS Screening Programme

Information (call ref:SCH0145)

screeninghelpdesk (PUBLIC HEALTH ENGLAND)

<PHE.screeninghelpdesk@nhs.net>

Tue 20/05/2014 09:33

To: Mary Reidy <mreidy@wit.ie>;

Good Morning Mary

Thank you for contacting the NSC Screening Helpdesk.

We're happy for you to use the cancer screening information, as you request.

It's Crown Copyright so please just add the following statement to your paper:

"© Crown Copyright 2014. This information was originally developed by the UK National Screening Committee/NHS Screening Programmes (www.screening.nhs.uk) and is used under the Open Government Licence v2.0"

Further information on how you are allowed to use Crown Copyright materials can be found at

<http://www.nationalarchives.gov.uk/doc/open-government-licence/version/2/>

I hope this helps.

Linda Harrison

Screening Helpdesk Advisor

UK National Screening Committee/NHS Screening Programmes

Phe.screeninghelpdesk@nhs.net

0207 164 2014 / +44(0) 07810 525591

www.screening.nhs.uk

[@PHE_Screening](#)

[Public Health England](#) supports the UK National Screening Committee and is responsible for the NHS Screening Programmes

-----Original Message-----

From: UK NSC Enquiries [mailto:PHE.screeninghelpdesk@nhs.net]

Sent: 19 May 2014 12:17

To: screeninghelpdesk (PUBLIC HEALTH ENGLAND)

Subject: Screening Information

This message was sent from an email address external to NHSmail but gives the appearance of being from an NHSmail (@nhs.net) address. The recipient should verify the sender and content before acting upon information contained within.

The identified sender is phe.screeninghelpdesk@nhs.net

UK Screening Portal website contact enquiry

From: Mary Reidy

Role:

Email address: mreidy@wit.ie

Message:

I am a postgraduate student in the Republic of Ireland promoting cancer and screening awareness in women with intellectual disabilities. I am interested in using NHS cancer screening information with the women and wish to enquire if I need specific permission to use these excellent resources. Thank you for your kind attention to this matter

This message may contain confidential information. If you are not the intended recipient please inform the sender that you have received the message in error before deleting it. Please do not disclose, copy or distribute information in this e-mail or take any action in reliance on its contents: to do so is strictly prohibited and may be unlawful.

Thank you for your co-operation.

NHSmail is the secure email and directory service available for all NHS staff in England and Scotland
NHSmail is approved for exchanging patient data and other sensitive information with NHSmail and GSi recipients
NHSmail provides an email address for your career in the NHS and can be accessed anywhere

AIII.8 Women be Healthy

RE: Women be Healthy II curriculum

Mary Reidy

Tue 20/05/2014 10:05

To: Susan Parish <slp@brandeis.edu>;

Dear Susan,

Thank you so very much for your email. I am delighted that I can use the excellent resources on the website to encourage the women to become more active in their own healthcare.

Thanks

Best regards,

Mary Reidy,

Postgraduate Research Student,

Department of Nursing,

Waterford Institute of Technology,

051- 845593

From: Susan Parish <slp@brandeis.edu>

Sent: 19 May 2014 16:35

To: Mary Reidy

Cc: karenluken@gmail.com

Subject: Re: Women be Healthy II curriculum

Dear Mary,

Thank you so much for your interest in the WBH project. I will defer to Karen on the particulars; she has access to the various materials.

You are welcome to use the materials on the website- they are free and everyone is welcome to them. Here is a link to the revised curriculum:

<http://lurie.brandeis.edu/women/index.html>

The link for the curriculum itself is on the left side.

I would be interested in hearing Karen's thoughts, but I recommend that you have 3 sessions per week, each of one hour, in order to fit everything. In our previous work with 7 weekly sessions, we found that the curriculum wasn't effective, particularly in relation to Pap tests. It was moderately effective over the 7 weeks with regard to breast cancer.

I would love to hear more about your work and project as you move forward.

All the best,
Susan

Susan L. Parish, PhD, MSW
Nancy Lurie Marks Professor of Disability Policy
Director, Lurie Institute for Disability Policy
Associate Dean for Research
The Heller School for Social Policy and Management
Brandeis University
slp@brandeis.edu
781.736.3928



Visit the Lurie Institute online: <http://lurie.brandeis.edu/>

On Mon, May 19, 2014 at 11:10 AM, Mary Reidy <mreidy@wit.ie> wrote:

Dear Susan and Karen,

I contacted your team in late 2012 about using modules from the Women be Healthy 2 Educational Programme in the Republic of Ireland. Unfortunately due to delays in ethical approval and recruitment, the educational programme was subsequently delayed, and will now commence in the Summer of 2014. I have accessed the curriculum online and have identified some key areas of interest

1. The programme delivery in my study is limited to a six week time frame.
2. The field trips would most likely not be feasible nor would bringing radiography students or smartakers to the classes to meet the women.
3. Sexual health is a taboo subject in Ireland , so I am particularly interested in the DVD of the pelvic and breast exam to encourage the women to talk about breast and cervical health.
4. I am also interested in using the relaxation techniques with the women.
5. Your facebook page is an excellent resource, and I would like to use the clips to encourage the women in the group to take part in screening tests.

I think you and your team have done fantastic work with women with intellectual disabilities. I am a Registered Nurse Intellectual Disability and have 4 years experience in working with women with intellectual disabilities. I would be delighted if you would agree to facilitate my request to use sections of the WBH2 programme in my educational programme.

Best regards,

Mary Reidy,
Postgraduate Research Student,
Department of Nursing,
Waterford Institute of Technology,

AIII.9 Copyright acknowledgements

CAM Toolkits

Cancer Awareness Measure toolkit version 2.1 Updated 09.02.11 This survey instrument (CAM) was developed by Cancer Research UK, University College London, Kings College London, and University of Oxford in 2007-2008.

Cervical Cancer Awareness Measure Toolkit Version 2.1 Updated 09.02.11: This survey instrument (the Cervical CAM) was developed by the UCL Health Behaviour Research Centre, in collaboration with the Department of Health Cancer Team and The Eve Appeal, with funding from The Eve Appeal. It forms part of the Cervical Cancer Awareness and Symptoms Initiative (CCASI). It is based on a generic CAM developed by Cancer Research UK, University College London, King's College London and Oxford University in 2007-08.

Toolkit (version 2): This survey instrument (Breast CAM) was developed by Cancer Research UK, King's College London and University College London in 2009 and validated with the support of Breast Cancer Care and Breakthrough Breast Cancer.

CHANGE: 'all pictures used are from CHANGE www.changepeople.co.uk'.

EMBRACES-ID Cover Picture Credit: Heather Clements, 2013.

NHS Screening Programme: "© Crown Copyright 2014. This information was originally developed by the UK National Screening Committee/NHS Screening Programmes (www.screening.nhs.uk) and is used under the Open Government Licence v2.0"

Appendix IV Phase I Comprehensive Needs Assessment Documentation

AIV.1 E-mail to Intellectual Disability Service Providers Managers

Please find attached the following documents for the WIT/ HSE study ' Cancer awareness and screening in women with intellectual disabilities' as discussed in our recent telephone conversation.

- Invitation letter for families.
- Information sheet for Cancer Awareness Measure questionnaire for carers.
- Information sheet for interviews for carers of women with severe to profound intellectual disabilities.
- Accessible Cancer Awareness Measure information sheet for women with mild to moderate ID.
- Consent sheet for women with mild to moderate ID.
- Cancer awareness measure questionnaire.

The following sections provide further details about the people I would like to talk to during the study.

(a) **Women with mild to moderate ID** who are interested in participating would complete an adapted Cancer Awareness Measure (CAM) questionnaire with me. I would arrange to come to meet them at the day service- it takes about 10- 15 minutes. We would hope that **as many women with ID as possible** would participate as it is important to assess the cancer awareness and screening knowledge of women with ID and the women with ID are best placed to provide this information.

The inclusion criteria for the women with ID in the Adapted CAM interviews are to:

- have a diagnosis of mild to moderate ID;
- demonstrate an understanding of the project;
- have expressive language skills;
- 20 years and over.

(b) **Staff and families who support women with ID** are asked to complete a CAM questionnaire (around 10 minutes) anonymously to gather an awareness of staff and family knowledge about cancer awareness and screening. We would anticipate that **as many staff and families as possible** would participate. It is a key focus of this study to assess family awareness of cancer and screening programmes. The CAM is available in print version, online version and is also possible to complete over the phone with a member of the research team.

(c) **Staff and families supporting women with severe to profound intellectual disabilities** are invited to an individual interview offer their perspectives on issues relating to cancer awareness and screening participation for women with severe to profound ID. I would arrange a date to meet interested parties for a recorded interview.

I look forward to hearing from you in the near future.

AIV.2 Follow up invitation to Service Managers



Postgraduate Research Office,
Department of Nursing,
O' Connell- Bianconi Building,
Waterford Institute of Technology.
Cork Road,
Waterford City.
051- 845593
mreidy@wit.ie
(date).

To whom it may concern,

Waterford Institute of Technology/ HSE are carrying out research about breast and cervical cancer and screening awareness in women with intellectual disabilities in the South East. We would like to talk to women and their carers about breast and cervical cancer and screening awareness. The results will be used to develop education programmes for the women and their carers to increase screening uptake for women with intellectual disabilities. This is intended to lead to the earlier diagnosis and treatment of cancer with better outcomes for the women.

A Cancer Awareness Measure survey of staff and family members will help us to assess their personal cancer and screening awareness. The survey can be completed online, over the telephone or as a printed version, and should take about 20 minutes to complete.

Individual interviews will help us to assess the carer's views of the needs on women with severe to profound intellectual disabilities in relation to cancer awareness and screening. These carer interviews should take between 30-45 minutes.

Please do not hesitate to contact me if you have any further queries about this project. I look forward to working with you during this project.

Kind regards,
Mary Reidy,
Postgraduate Research Student.

AIV.3 Carers advertisement poster

Would you like to tell us what you know about breast and cervical cancer awareness and screening?



What's the project about?

Waterford Institute of Technology/ HSE are carrying out research about breast and cervical cancer awareness and screening in women with ID in the South East. We would like to talk to the women and their carers about breast and cervical cancer and screening awareness.

The results will be used to develop education programmes for the women and their carers to increase screening uptake for women with ID. This is intended to lead to the earlier diagnosis and treatment of cancer with better outcomes for the women.

What would I need to do?

(a) You would complete a questionnaire on breast and cervical cancer awareness and screening either online or over the telephone which takes about 20 minutes.

OR

(b) You would take part in an interview for around 45 minutes to explore the needs of the women about breast and cervical cancer awareness and screening.

Are you interested in taking part?

There will be an information session on dd/mm/yyyy where I will answer any questions you may have about the project. I'm also available to answer telephone or e-mail queries about the project.

Mary Reidy,
 Postgraduate Student,
 Postgraduate Research
 Unit,
 Department of Nursing,
 School of Health Science,
 WIT,
 Cork Road,
 Waterford

Your Name: Mary Reidy
 Phone: 051 845598
 E-mail: mreidy@wit.ie

Your Name: Mary Reidy
 Phone: 051 845598
 E-mail: mreidy@wit.ie

Your Name: Mary Reidy
 Phone: 051 845598
 E-mail: mreidy@wit.ie

Your Name: Mary Reidy
 Phone: 051 845598
 E-mail: mreidy@wit.ie

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 E-mail: mreidy@wit.ie

Your Name: Mary Reidy
 Phone: 051 845598
 E-mail: mreidy@wit.ie

Your Name: Mary Reidy
 Phone: 051 845598
 E-mail: mreidy@wit.ie

Your Name: Mary Reidy
 Phone: 051 845598
 E-mail: mreidy@wit.ie

AIV.4 Women with intellectual disabilities advertisement poster



My name is Mary. I am doing a course at WIT. I am doing a research project.



I would like to have a chat about what you know about cancer and the tests that check for cancer. I won't be doing any tests on you.



The chat will take no longer than half an hour.



You can say yes or no. It is up to you if you want you take part.



If you would like to know more about taking part:

I'll be here of dd/mm/yyyy to talk to people at the centre about the project.

You can phone me at 051 845593

AIV.5 Carers CAM information sheets (online and telephone version)



CARER (CAM) INFORMATION LEAFLET

Project Title: Cancer Awareness and Screening in Women with Intellectual Disabilities (ID)

You are being invited to take part in a research project. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully.

What is the purpose of the project?

Waterford Institute of Technology/ HSE are carrying out research about breast and cervical cancer and screening awareness in women with ID in the South East. We would like to talk to the women and their carers about breast and cervical cancer and screening awareness. The results will be used to develop education programmes for the women and their carers to increase screening uptake for women with ID. This is intended to lead to the earlier diagnosis and treatment of cancer with better outcomes for the women.

Why have I been invited to take part?

You have been invited to take part because you are a family member or work with a woman with ID. We would like to know about your own breast and cervical cancer and screening awareness to help us to develop the health education programmes.

Do I have to take part?

It is up to you whether you decide to take part, taking part is voluntary.

What would I have to do?

You would not be required to take part in any medical tests. If you decide to take part, you would complete a questionnaire about breast and cervical cancer awareness and screening. The questionnaire is available to complete online and returned to mreidy@wit.ie. It would be best to complete the questionnaire without checking the internet or books for the answers as we are interested in your opinion. Alternatively, the questionnaire can be completed over the telephone at a time that suits you. The research team will make arrangements to phone you at that time.

If you have any questions about symptoms you have had or other questions about cancer after completing the questionnaire, please speak to your GP.

Confidentiality

The answers you give will be given a specific code and it will not be possible for you to be identified from your answers. All the information that is collected will be anonymous and kept strictly confidential and your name will never be used with this information.

What happens to the information that is collected?

The answers you give will be given a specific code and it will not be possible for you to be identified from your answers. This coded information will be sent to the UK Data Archive. The archive will help us to build an understanding of public knowledge about cancer so that we can develop ways to improve communications and services that aim to improve cancer outcomes. More information about the archive can be found here: <http://www.datarchive.ac.uk/Introduction.asp>

Contact details for further information:

Mary Reidy
MSc by Research in Nursing Student,
Department of Nursing,
Waterford Institute of Technology.
Email: mreidy@wit.ie Phone: (051) 845593

Thank you for taking the time to read this information sheet.

AIV.6 Carers CAM information sheets (postal version)



CARER (CAM) INFORMATION LEAFLET



Project Title: Cancer Awareness and Screening in Women with Intellectual Disabilities (ID)

You are being invited to take part in a research project. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully.

What is the purpose of the project?

Waterford Institute of Technology/ HSE are carrying out research about breast and cervical cancer and screening awareness in women with ID in the South East. We would like to talk to the women and their carers about breast and cervical cancer and screening awareness. The results will be used to develop education programmes for the women and their carers to increase screening uptake for women with ID. This is intended to lead to the earlier diagnosis and treatment of cancer with better outcomes for the women.

Why have I been invited to take part?

You have been invited to take part because you are a family member or work with a woman with ID. We would like to know about your own breast and cervical cancer and screening awareness to help us to develop the health education programmes.

Do I have to take part?

It is up to you whether you decide to take part, taking part is voluntary.

What would I have to do?

You would not be required to take part in any medical tests. If you decide to take part, you would complete a questionnaire about breast and cervical cancer awareness and screening. The questionnaire should be returned to Ms. Mary Reidy in the stamped addressed envelope provided. It would be best to complete the questionnaire without checking the internet or books for the answers as we are interested in your opinion. Alternatively, the questionnaire can be completed over the telephone at a time that suits you. The research team will make arrangements to phone you at that time.

If you have any questions about symptoms you have had or other questions about cancer after completing the questionnaire, please speak to your GP.

Confidentiality

The answers you give will be given a specific code and it will not be possible for you to be identified from your answers. All the information that is collected will be anonymous and kept strictly confidential and your name will never be used with this information.

What happens to the information that is collected?

The answers you give will be given a specific code and it will not be possible for you to be identified from your answers. This coded information will be sent to the UK Data Archive. The archive will help us to build an understanding of public knowledge about cancer so that we can develop ways to improve communications and services that aim to improve cancer outcomes. More information about the archive can be found here: <http://www.datarchive.ac.uk/Introduction.asp>

Contact details for further information:

Mary Reidy
MSc by Research in Nursing Student,
Department of Nursing,
Waterford Institute of Technology.
Email: mreidy@wit.ie Phone: (051) 845593

Thank you for taking the time to read this information sheet

AIV.7 Carers of women with severe to profound intellectual disabilities information sheets



Forbairneacht na Seirbhíse Sláinte
Health Service Executive



Waterford Institute of Technology
WATERFORD TECHNOLOGICAL UNIVERSITY

CARER INFORMATION LEAFLET

Project Title: Cancer Awareness and Screening in Women with Intellectual Disabilities

You are being invited to take part in a research project. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully.

What is the purpose of the study?

Waterford Institute of Technology/ HSE are carrying out research about breast and cervical cancer awareness and screening in women with ID in the South East. We would like to talk to the women and their carers about breast and cervical cancer awareness and screening. The results will be used to develop education programmes for the women and their carers to increase screening uptake for women with ID. This is intended to lead to the earlier diagnosis and treatment of cancer with better outcomes for the women.

Why have I been invited to take part?

You have been invited to participate because you work with/ or are a family member of a woman with severe to profound intellectual disabilities. We would like to talk to you about what you think are the women's needs about breast and cervical cancer awareness and screening.

Do I have to take part?

It is up to you whether you decide to take part, taking part is voluntary. You are free to withdraw at any time without giving a reason.

What would I have to do?

If you do decide to take part, you would take part in a taped interview to gather information on your views of the needs of the women about breast and cervical cancer awareness and screening. The information gathered would be used to design the education programme for the women and their carers. You would not be required to take part in any medical tests.

Confidentiality

All the information that is collected will be kept strictly confidential your name will never be used with this information. Only the research team will have access to the information.

Contact details for further information:

Mary Reidy
MSc by Research in Nursing Student,
Department of Nursing,
Waterford Institute of Technology
Email: mreidy@wit.ie
Phone: (051) 845593

Thank you for taking the time to read this information sheet

AIV.8 Women with intellectual disabilities Adapted CAM information sheets



Feilmeannacht na Scríbhne Síne
Health Service Executive



Waterford Institute of Technology
WATERFORD

INFORMATION LEAFLET: Cancer Awareness and Screening in Women with ID.



My name is Mary. I am doing a course at WIT. I am doing a research project.



I would like to hear about what you know about cancer and the tests that check for cancer. I won't be doing any tests on you.



The two of us would have a chat about what you know about cancer and the tests to check for cancer.



If you have any questions about symptoms you have had or other questions about cancer, you can talk to the nurse educator at your centre. You and the nurse educator can also



arrange a chat with your GP.

I will let your GP know that you have taken part in the project.



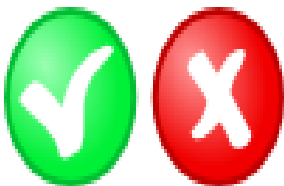
To help other people doing projects about cancer and tests, your answers will be put in a computer. Don't worry nobody will know the answers are from you.



You can ask for our chat to stop at any time.



The chat will take no longer than half an hour.



You can say yes or no. It is up to you if you want you take part.



If you do want to take part, please ask your keyworker or family to help you read the consent form.



If you would like to talk to me, you should sign the consent form with Mary and your keyworker.



If you would like to know more about the project, please ring me at (051) 845593.



Thank you for taking the time to read this information leaflet.

AIV.9 Carers interview consent form



Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive



Waterford Institute of Technology
WATERFORD INSTITUTE OF TECHNOLOGY

CARER CONSENT FORM

Project Title: Cancer Awareness and Screening in Women with Intellectual Disabilities

Please insert your initials in the box opposite each statement:

I have read and understand the information leaflet for the study and have had the opportunity to ask questions all of which have been satisfactorily answered.

I understand that taking part in the study is voluntary and that I am free to leave the study at any time without giving a reason.

I agree to take part in the study.

I agree to the interview being tape recorded.

I understand that all information I give will be confidential.

I understand my name or information which might identify me will not be used in any publications.

Participants Signature

Date

Name in block capitals

Researchers Signature

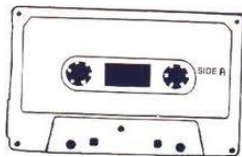
Date

Name in block capitals

**AIV.10 Women with intellectual disabilities Adapted CAM consent form
CONSENT FORM**

Cancer Awareness and Screening in Women with ID.

If I talk to Mary about her project “Cancer Awareness and Screening in Women with ID”



I understand that the chat with Mary will be recorded.



I understand that the chat with Mary will be in private.



I understand that I can stop the chat with Mary at any time.

If you understand these three sentences, you now can decide if you would like to take part in the project.

I have decided that I would like to talk to Mary about her project “Cancer awareness and screening in women with ID”

Please put a circle around Yes or No.



Yes



No

Please print your name.....

Keyworker’s signature.....

Researcher’s signature.....

GP name and telephone number.....

Date.....

AIV.11 Carers invitation to the information meeting



Postgraduate Research Office,
Department of Nursing,
O' Connell- Bianconi Building,
Waterford Institute of Technology.
Cork Road,
Waterford City.
051- 845593
mreidy@wit.ie
(date).

To whom it may concern,

Waterford Institute of Technology/ HSE are carrying out research about breast and cervical cancer and screening awareness in women with intellectual disabilities in the South East. We would like to talk to women and their carers about breast and cervical cancer and screening awareness. The results will be used to develop education programmes for the women and their carers to increase screening uptake for women with intellectual disabilities. This is intended to lead to the earlier diagnosis and treatment of cancer with better outcomes for the women.

An information meeting for women with intellectual disabilities, their families, and members of staff at the (name of service) will be held at (time) on (date). The meeting will be held in (where). Two posters are available for your centre to advertise the meeting. An invitation letter to the meeting for the families is also included, so it would be great if you could arrange for this letter to be distributed to the families.

I look forward to meeting with you on the night to answer any questions you may have about the project.


Kind regards,
Mary Reidy,
Postgraduate Research Student.

AIV.12 Powerpoint Presentation for Information Meetings




Information Meeting
Brothers of Charity, Waterford
11th June 2013


The two of us would have a chat about what you know about cancer and the tests to check for cancer.




If you would like to talk to me, you should sign the consent form with me and your keyworker or family.



My name is Mary. I am doing a research project at Waterford Institute of Technology.




The chat will take no longer than half an hour.



I would like to hear about what you know about cancer and the tests that check for cancer.

I won't be doing any tests on you.



You can say yes or no. It is up to you if you want you take part.



AIV.13 Media advertisements

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Lifestyle

Cancer awareness and screening in women with intellectual disabilities

Wednesday, 2nd October 2013

Invitation to families to participate in a research study exploring cancer awareness and screening in women with intellectual disabilities

What is the research about?

Waterford Institute of Technology in collaboration with the HSE-SE are carrying out research about breast and cervical cancer awareness and screening in women with intellectual disabilities in the South East region.

The members of the research team are Dr. Suzanne Denieffe, Ms. Sinéad Foran and Ms Mary Reidy from the Department of Nursing at Waterford Institute of Technology.

As part of this research study we are inviting the families of women with intellectual disabilities to participate in a survey about cancer awareness and screening. The results of this survey will be used to develop education programmes to improve screening uptake for women with intellectual disabilities. This may lead to the earlier diagnosis and treatment of cancer with better outcomes for the women.

What would you need to do?

There are no medical tests involved. If you decide to take part you would complete a questionnaire on cancer awareness and screening. The questionnaire takes about 15 minutes to complete.

You can complete the questionnaire over the telephone at a time that suits you. The research team will make arrangements to phone you at that time.

Or if you would rather complete a paper copy of the questionnaire, we will send you a copy, as well as a stamp addressed return envelope.

You also have the option of completing an online version of the questionnaire which is available from mreidy@wit.ie

Confidentiality

All the information that is collected will be anonymous and kept strictly confidential and your name will never be used with this information.

If you are interested in taking part in this research, please contact Ms. Mary Reidy, at the Department of Nursing at Waterford Institute of Technology.

E-mail: mreidy@wit.ie Phone: (051) 845593

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Reasons for Hope

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Union Kitchen - blending the best o...

we need a Website

talk to the experts...

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- Web Design
- Graphic Design
- Online Marketing

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WEB & GRAPHIC DESIGN STUDIO

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Invitation to families to participate in a research study exploring cancer awareness and screening in women with intellectual disabilities.



What is the research about?

Waterford Institute of Technology in collaboration with the HSE-SE are carrying out research about breast and cervical cancer awareness and screening in women with intellectual disabilities in the South East region.



The members of the research team are Dr. Suzanne Deniette, Ms. Sinead Foran and Ms Mary Reidy from the Department of Nursing at Waterford Institute of Technology.

As part of this research study we are inviting the families of women with intellectual disabilities

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to participate in a survey about cancer awareness and screening. The survey will begin in early October and finish in mid December 2013. The results of this survey will be used to develop education programmes to improve screening uptake for women with intellectual disabilities. This may lead to the earlier diagnosis and treatment of cancer with better outcomes for the women.

What would you need to do?

There are no medical tests involved. If you decide to take part you would complete a questionnaire on cancer awareness and screening. The questionnaire takes about 15 minutes to complete.

You can complete the questionnaire over the telephone at a time that suits you. The research team will make arrangements to phone you at that time.

or

If you would rather complete a paper copy of the questionnaire, we will send you a copy, as well as a stamp addressed return envelope.

or

You also have the option of completing an online version of the questionnaire which is available from mreidy@wit.ie

Confidentiality

All the information that is collected will be anonymous and kept strictly confidential and your name will never be used with this information.

If you are interested in taking part in this research, please contact Ms. Mary Reidy, at the Department of Nursing at Waterford Institute of Technology. E-mail: mreidy@wit.ie
Phone: (051) 845593

AIV.14 Carers CAM

Project Title: Cancer Awareness and Screening in Women with Intellectual Disabilities.

Please complete the Cancer Awareness Measure (CAM) for this project online. It should take 20 minutes. Your opinion is important to us.

Please do not alter the CAM questions in any way.

It would be best to complete the survey without checking the internet or books for the answers as we are interested in your opinion.

The questionnaire is comprised of four sections.

Section A: Breast Cancer Awareness Measure.

Section B: Cervical Cancer Awareness Measure.

Section C: Cancer Awareness Measure.

Section D: Demographic Questions.

Please remember to save your answers after each section of the CAM.

Please remember to attach the completed CAM questionnaire to the email.

Please return the completed CAM questionnaire to mreidy@wit.ie by dd/mm/yyyy.

Your email address will be deleted on receipt of the completed CAM questionnaire by Mary Reidy so that your answers remain confidential.

Thank you for your time.

Section A: Breast Cancer Awareness Measure

Toolkit (version 2)

This survey instrument (Breast CAM) was developed by Cancer Research UK, King's College London and University College London in 2009 and validated with the support of Breast Cancer Care and Breakthrough Breast Cancer.

Instructions for completion of the Breast- CAM

1. Please do not alter any of the information in the CAM questionnaire.
2. Please answer each question in the CAM, we are interested in your opinion.

Q1: The following may or may not be warning signs for breast cancer. We are interested in your opinion. Please indicate your answer with an X.

	Yes	No	Don't know
Do you think a lump or thickening in your breast could be a sign of breast cancer?			
Do you think a lump or thickening under your armpit could be a sign of breast cancer?			
Do you think bleeding or discharge from your nipple could be a sign of breast cancer?			
Do you think the pulling in of your nipple could be a sign of breast cancer?			
Do you think a change in the position of your nipple could be a sign of breast cancer?			
Do you think a rash on or around your nipple could be a sign of breast cancer?			
Do you think redness of your breast skin could be a sign of breast cancer?			
Do you think a change in the size of your breast or nipple could be a sign of breast cancer?			
Do you think a change in the shape of your breast or nipple could be a sign of breast cancer?			
Do you think pain in one of your breasts or armpit could be a sign of breast cancer?			
Do you think dimpling of the breast skin could be a sign of breast cancer?			

Q2a. How often do you check your breasts? Please indicate your answer with an X.

Rarely or never	At least once every 6 months	At least once a month	At least once a week

Q2b. Are you confident you would notice a change in your breasts? Please indicate your answer with an X.

Not at all confident	Not very confident	Fairly confident	Very confident

Q2c. Have you ever been to see a doctor about a change you have noticed in one of your breasts? Please indicate your answer with an X.

Yes	No	Never noticed a change in one of my breasts

Q3. If you found a change in your breast, how soon would you contact your doctor to make an appointment to discuss it? Please type your answer below.

Q4. In the next year, who is most likely to develop breast cancer? Please indicate your opinion with an X	
A 30 year old woman	
A 50 year old woman	
A 70 year old woman	
A woman of any age	

**Q5. What things do you think affect a woman's chance of developing breast cancer?
Please type your answer in this box.**

Q6a. As far as you are aware is there a national breast screening programme in Ireland? Please indicate your answer with an X.

Yes	No	Don't know

If your answer to Q. 6a was yes, please answer the following two questions, otherwise please go to Q 6b

If yes, at what age are women first invited for breast screening?

Age	Don't know

If yes, at what age are women last invited for breast screening?

Age	Don't know

Q6b. Have you ever been invited for breast screening on the national breast screening programme? Please indicate your answer with an X.

Yes	No	Don't know

6c. Have you ever had breast screening on the national breast screening programme? Please indicate your answer with an X.

Yes	No	Don't know

Section B: Cervical Cancer Awareness Measure

Cervical Cancer Awareness Measure Toolkit Version 2.1 Updated 09.02.11

This survey instrument (the Cervical CAM) was developed by the UCL Health Behaviour Research Centre, in collaboration with the Department of Health Cancer Team and The Eve Appeal, with funding from The Eve Appeal. It forms part of the Cervical Cancer Awareness and Symptoms Initiative (CCASI). It is based on a generic CAM developed by Cancer Research UK, University College London, King's College London and Oxford University in 2007-08.



Working in partnership with



Instructions for completion of the Cervical- CAM

1. Please do not alter any of the information in the CAM questionnaire.
2. Please answer each question in the CAM, we are interested in your opinion.

Q1. The following may or may not be warning signs for cervical cancer. We are interested in your opinion: Please indicate your answer with an X.

	Yes	No	Don't know
Do you think vaginal bleeding between periods could be a sign of cervical cancer?			
Do you think persistent lower back pain could be a sign of cervical cancer?			
Do you think persistent vaginal discharge which smells unpleasant could be a sign of cervical cancer?			
Do you think discomfort or pain during sex could be a sign of cervical cancer?			
Do you think menstrual periods that are heavier or longer than usual could be a sign of cervical cancer?			
Do you think persistent diarrhoea could be a sign of cervical cancer?			
Do you think vaginal bleeding after the menopause could be a sign of cervical cancer?			
Do you think persistent pelvic pain could be a sign of cervical cancer?			
Do you think vaginal bleeding during or after sex could be a sign of cervical cancer?			
Do you think blood in the stool or urine could be a sign of cervical cancer?			
Do you think unexplained weight loss could be a sign of cervical cancer?			

Q2. How confident are you that you would notice a cervical cancer symptom? Please indicate your answer with an X.

Not at all confident	Not very confident	Fairly confident	Very confident

Q3. If you had a symptom that you thought might be a sign of cervical cancer how soon would you contact your doctor to make an appointment to discuss it? Please type your answer below.

Q4. In the next year, who is most likely to develop cervical cancer? Please indicate your answer with an X	
A woman aged 20-29 years	
A woman aged 30-49 years	
A woman aged 50-69 years	
A women aged 70 or over	
Cervical cancer is unrelated to age	

**Q5. What things do you think affect a woman's chance of developing cervical cancer?
Please type your answer in this box.**

Q6a. As far as you are aware is there a national cervical screening programme in Ireland? Please indicate your answer with an X.

Yes	No	Don't know

If your answer to Q. 6a was Yes, please answer the next question, otherwise please go to Q 6b

If yes, at what age are women first invited for cervical screening?

Age	Don't know

Q6b. Have you ever been invited for cervical screening on the national cervical screening programme? Please indicate your answer with an X.

Yes	No	Don't know

6c. Have you ever had cervical screening on the national cervical screening programme? Please indicate your answer with an X.

Yes	No	Don't know

Q6a. As far as you are aware is there is there a national vaccination programme to protect against cervical cancer? Please indicate your answer with an X.

Yes	No	Don't know

If yes, at what age is this first offered?

Age	Don't know

Section C: Cancer Awareness Measure

Cancer Awareness Measure toolkit version 2.1 Updated 09.02.11

This survey instrument (CAM) was developed by Cancer Research UK, University College London, Kings College London, and University of Oxford in 2007-2008.

Instructions for completion of the CAM

1. Please do not alter any of the information in the CAM questionnaire.
2. Please answer each question in the CAM, we are interested in your opinion.

Q1. Sometimes people put off going to see the doctor, even when they have a symptom that they think might be serious. Could you say if any of these might put you off going to see the doctor?

	Yes Often	Yes sometimes	No	Don't know
I would be embarrassed				
I would be scared				
I would be worried about wasting the doctor's time				
My doctor would be difficult to talk to				
It would be difficult to make an appointment with my doctor				
I would be too busy to make time to go to the doctor				
I have too many other things to worry about				
It would be difficult for me to arrange transport to the doctor's surgery				
I would be worried about what the doctor might find				
I wouldn't feel confident talking about my symptom with the doctor				
Other (please specify)				

Section D:

Demographic Questions

We would now like to ask you a few questions about yourself. This will help us to analyse the results of the survey. The data collected will help us to identify specific age or demographic groups of people who are in need of more information about cancer. You will not be asked your name and all of your answers will be kept strictly confidential and anonymous. Your personal data will be held in accordance with the Data Protection Act 1988-2003.

1. What is your age?	
	Prefer not to say

2. What is your gender?		
Male	Female	Prefer not to say

3: What is your carer status?	
Family Carer	
Health Care Assistant	
Nurse	
Social Care Worker	
Other	
Prefer not to say	

4. Have you, your family or close friends had cancer?

	Yes	No	Don't know	Prefer not to say
You				
Partner				
Close family member				
Other family member				
Close friend				
Other friend				

Thank you for taking the time to complete this questionnaire.

AIV.15 Adapted CAM women with mild to moderate intellectual disabilities

**Project Title: Cancer Awareness and Screening in
Women with Intellectual Disabilities.**

Adapted CAM

**Section A: Breast Cancer
Awareness
Measure**

Toolkit (version 2)

This survey instrument (Breast CAM) was developed by Cancer Research UK, King's College London and University College London in 2009 and validated with the support of Breast Cancer Care and Breakthrough Breast Cancer.

Instructions for completion of the Breast- CAM

3. Please do not alter any of the information in the CAM questionnaire.
4. Please answer each question in the CAM, we are interested in your opinion.

Q1: The following may or may not be warning signs for breast cancer. We are interested in your opinion. Please indicate your answer with an X.

	Yes	No	Don't know
Do you think a lump or thickening in your breast could be a sign of breast cancer?			
Do you think a lump or thickening under your armpit could be a sign of breast cancer?			
Do you think bleeding or discharge from your nipple could be a sign of breast cancer?			
Do you think the pulling in of your nipple could be a sign of breast cancer?			
Do you think a change in the position of your nipple could be a sign of breast cancer?			
Do you think a rash on or around your nipple could be a sign of breast cancer?			
Do you think redness of your breast skin could be a sign of breast cancer?			
Do you think a change in the size of your breast or nipple could be a sign of breast cancer?			
Do you think a change in the shape of your breast or nipple could be a sign of breast cancer?			
Do you think pain in one of your breasts or armpit could be a sign of breast cancer?			
Do you think dimpling of the breast skin could be a sign of breast cancer?			

Q2a. How often do you check your breasts? Please indicate your answer with an X.

Rarely or never	At least once every 6 months	At least once a month	At least once a week

Q2b. Are you confident you would notice a change in your breasts? Please indicate your answer with an X.

Not at all confident	Not very confident	Fairly confident	Very confident

Q2c. Have you ever been to see a doctor about a change you have noticed in one of your breasts? Please indicate your answer with an X.

Yes	No	Never noticed a change in one of my breasts

Q3. If you found a change in your breast, how soon would you contact your doctor to make an appointment to discuss it? Please type your answer below.

Q4. In the next year, who is most likely to develop breast cancer? Please indicate your opinion with an X	
A 30 year old woman	
A 50 year old woman	
A 70 year old woman	
A woman of any age	

**Q5. What things do you think affect a woman's chance of developing breast cancer?
Please type your answer in this box.**

Q6a. As far as you are aware is there a national breast screening programme in Ireland? Please indicate your answer with an X.

Yes	No	Don't know

If your answer to Q. 6a was yes, please answer the following two questions, otherwise please go to Q 6b

If yes, at what age are women first invited for breast screening?

Age	Don't know

If yes, at what age are women last invited for breast screening?

Age	Don't know

Q6b. Have you ever been invited for breast screening on the national breast screening programme? Please indicate your answer with an X.

Yes	No	Don't know

6c. Have you ever had breast screening on the national breast screening programme? Please indicate your answer with an X.

Yes	No	Don't know

Section B: Cervical Cancer Awareness Measure

Cervical Cancer Awareness Measure Toolkit Version 2.1 Updated 09.02.11

This survey instrument (the Cervical CAM) was developed by the UCL Health Behaviour Research Centre, in collaboration with the Department of Health Cancer Team and The Eve Appeal, with funding from The Eve Appeal. It forms part of the Cervical Cancer Awareness and Symptoms Initiative (CCASI). It is based on a generic CAM developed by Cancer Research UK, University College London, King's College London and Oxford University in 2007-08.



Working in partnership with



Instructions for completion of the Cervical- CAM

3. Please do not alter any of the information in the CAM questionnaire.
4. Please answer each question in the CAM, we are interested in your opinion.

Q1. The following may or may not be warning signs for cervical cancer. We are interested in your opinion: Please indicate your answer with an X.

	Yes	No	Don't know
Do you think vaginal bleeding between periods could be a sign of cervical cancer?			
Do you think persistent lower back pain could be a sign of cervical cancer?			
Do you think persistent vaginal discharge which smells unpleasant could be a sign of cervical cancer?			
Do you think discomfort or pain during sex could be a sign of cervical cancer?			
Do you think menstrual periods that are heavier or longer than usual could be a sign of cervical cancer?			
Do you think persistent diarrhoea could be a sign of cervical cancer?			
Do you think vaginal bleeding after the menopause could be a sign of cervical cancer?			
Do you think persistent pelvic pain could be a sign of cervical cancer?			
Do you think vaginal bleeding during or after sex could be a sign of cervical cancer?			
Do you think blood in the stool or urine could be a sign of cervical cancer?			
Do you think unexplained weight loss could be a sign of cervical cancer?			

Q2. How confident are you that you would notice a cervical cancer symptom? Please indicate your answer with an X.

Not at all confident	Not very confident	Fairly confident	Very confident

Q3. If you had a symptom that you thought might be a sign of cervical cancer how soon would you contact your doctor to make an appointment to discuss it? Please type your answer below.

Q4. In the next year, who is most likely to develop cervical cancer? Please indicate your answer with an X	
A woman aged 20-29 years	
A woman aged 30-49 years	
A woman aged 50-69 years	
A women aged 70 or over	
Cervical cancer is unrelated to age	

**Q5. What things do you think affect a woman's chance of developing cervical cancer?
Please type your answer in this box.**

Q6a. As far as you are aware is there a national cervical screening programme in Ireland? Please indicate your answer with an X.

Yes	No	Don't know

If your answer to Q. 6a was Yes, please answer the next question, otherwise please go to Q 6b

If yes, at what age are women first invited for cervical screening?

Age	Don't know

Q6b. Have you ever been invited for cervical screening on the national cervical screening programme? Please indicate your answer with an X.

Yes	No	Don't know

6c. Have you ever had cervical screening on the national cervical screening programme? Please indicate your answer with an X.

Yes	No	Don't know

Q6a. As far as you are aware is there is there a national vaccination programme to protect against cervical cancer? Please indicate your answer with an X.

Yes	No	Don't know

If yes, at what age is this first offered?

Age	Don't know

Section C: Cancer Awareness Measure

Cancer Awareness Measure toolkit version 2.1 Updated 09.02.11

This survey instrument (CAM) was developed by Cancer Research UK, University College London, Kings College London, and University of Oxford in 2007-2008.

Instructions for completion of the CAM

3. Please do not alter any of the information in the CAM questionnaire.
4. Please answer each question in the CAM, we are interested in your opinion.

Q1. Sometimes people put off going to see the doctor, even when they have a symptom that they think might be serious. Could you say if any of these might put you off going to see the doctor?

	Yes Often	Yes sometimes	No	Don't know
I would be embarrassed				
I would be scared				
I would be worried about wasting the doctor's time				
My doctor would be difficult to talk to				
It would be difficult to make an appointment with my doctor				
I would be too busy to make time to go to the doctor				
I have too many other things to worry about				
It would be difficult for me to arrange transport to the doctor's surgery				
I would be worried about what the doctor might find				
I wouldn't feel confident talking about my symptom with the doctor				
Other (please specify)				

Section D:

Demographic Questions

We would now like to ask you a few questions about yourself. This will help us to analyse the results of the survey. The data collected will help us to identify specific age or demographic groups of people who are in need of more information about cancer. You will not be asked your name and all of your answers will be kept strictly confidential and anonymous. Your personal data will be held in accordance with the Data Protection Act 1988-2003.

1. What is your age?	
	Prefer not to say

2. What is your gender?		
Male	Female	Prefer not to say

3: What is your carer status?	
Family Carer	
Health Care Assistant	
Nurse	
Social Care Worker	
Other	
Prefer not to say	

4. Have you, your family or close friends had cancer?

	Yes	No	Don't know	Prefer not to say
You				
Partner				
Close family member				
Other family member				
Close friend				
Other friend				

Thank you for taking the time to complete this questionnaire.

Section A: Breast Cancer Awareness Measure

Toolkit (version 2)

This survey instrument (Breast CAM) was developed by Cancer Research UK, King's College London and University College London in 2009 and validated with the support of Breast Cancer Care and Breakthrough Breast Cancer.

1. The following may or may not be warning signs for breast cancer. We are interested in your opinion:

	Yes	No	Don't know
Do you think a lump or thickening in your breast could be a sign of breast cancer? Picture 1 : Lump or thickening in your breast	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think a lump or thickening under your armpit could be a sign of breast cancer? Picture 2: Lump or thickening in your armpit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think bleeding or discharge from your nipple could be a sign of breast cancer? Picture 3: Any liquid leaking from your nipples	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think the pulling in of your nipple could be a sign of breast cancer? Picture 4: Pulling in of nipple	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think a change in the position of your nipple could be a sign of breast cancer? Picture 5: Nipple in different place	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think a rash on or around your nipple could be a sign of breast cancer? Picture 6: Rash on nipple	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think redness of your breast skin could be a sign of breast cancer? Picture 7: Changes to skin on breast – redness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think a change in the size of your breast or nipple could be a sign of breast cancer? Picture 8: Change in size/shape breast	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think a change in the shape of your breast or nipple could be a sign of breast cancer? Picture 9: Changes in shape of breast/ nipple	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think pain in one of your breasts or armpit could be a sign of breast cancer? Picture 10: Pain in one breast or armpit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think dimpling of the breast skin could be a sign of breast cancer? Picture 11: Changes to skin on breast- dimpling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2a. When do you check your breasts? (Picture 12)

Rarely or never	At least once every 6 months	At least once a month	At least once a week
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2b. How confident are you that you would notice a change in your breast?

Not at all confident	Not very confident	Fairly confident	Very confident
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2c. Have you ever been to see a doctor about a change you have noticed in one of your breasts?

Yes	No	I have not noticed a change in my breast
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. If you did notice a change in your breast, how soon would you go to talk to the doctor? (Picture13)

<p>3. If you did notice a change in your breast, how soon would you go to talk to the doctor? (Picture13)</p>

4. In the next year, who is more likely to get breast cancer? (Picture 14)	
A 30 year old woman	<input type="checkbox"/>
A 50 year old woman	<input type="checkbox"/>
A 70 year old woman	<input type="checkbox"/>
A woman of any age	<input type="checkbox"/>

5. What things do you think affect a woman's chance of getting breast cancer?

	Yes	No	Don't know
6a. As far as you are know is there a national breast screening programme in Ireland?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If yes, at what age are women first invited for breast screening? Age:____			<input type="checkbox"/>
If yes, at what age are women last invited for breast screening? Age:____			<input type="checkbox"/>
6b. Have you ever been invited for breast screening on the national breast screening programme?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6c. Have you ever had breast screening on the national breast screening programme?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Section B: Cervical Cancer Awareness Measure

Cervical Cancer Awareness Measure Toolkit Version 2.1 Updated 09.02.11

This survey instrument (the Cervical CAM) was developed by the UCL Health Behaviour Research Centre, in collaboration with the Department of Health Cancer Team and The Eve Appeal, with funding from The Eve Appeal. It forms part of the Cervical Cancer Awareness and Symptoms Initiative (CCASI). It is based on a generic CAM developed by Cancer Research UK, University College London, King's College London and Oxford University in 2007-08.



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1. The following may or may not be warning signs for cervical cancer. We are interested in your opinion:

	Yes	No	Don't know
Do you think vaginal bleeding between periods could be a sign of cervical cancer? Picture 1: Bleeding between periods	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think persistent lower back pain could be a sign of cervical cancer? Picture 2: Lower back pain that doesn't go away for 3 weeks or longer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think persistent vaginal discharge which smells unpleasant could be a sign of cervical cancer? Picture 3: Smelly discharge from your vagina that doesn't go away or 3 weeks or longer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think discomfort or pain during sex could be a sign of cervical cancer? Picture 4: Pain during sex	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think menstrual periods that are heavier of longer than usual could be a sign of cervical cancer? Picture 5: Heavier periods that last longer than normal periods	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think persistent diarrhoea could be a sign of cervical cancer? Picture 6: Runny poo that doesn't go away for 3 weeks or longer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think vaginal bleeding after the menopause could be a sign of cervical cancer? Picture 7: Any bleeding after the menopause	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think persistent pelvic pain could be a sign of cervical cancer? Picture 8: Pain in your pelvis that doesn't go away for 3 weeks or longer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think vaginal bleeding during or after sex could be a sign of cervical cancer? Picture 9: Bleeding during or after sex	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think blood in the stool or urine could be a sign of cervical cancer? Picture 10: Blood in poo or wee	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you think unexplained weight loss could be a sign of cervical cancer? Picture 11: If you lose weight but don't know why	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. How confident are you that you would notice a cervical cancer symptom?

Not at all confident	Not very confident	Fairly confident	Very confident
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. If you had a symptom that you thought might be a sign of cervical cancer how soon would you go to your doctor to talk about it? (Picture 12)

4. In the next year, who is most likely to get cervical cancer? (Picture 13)	
A woman aged 20-29 years	<input type="checkbox"/>
A woman aged 30-49 years	<input type="checkbox"/>
A woman aged 50-69 years	<input type="checkbox"/>
A women aged 70 or over	<input type="checkbox"/>
Cervical cancer is unrelated to age	<input type="checkbox"/>

5. What things do you think affect a woman's chance of getting cervical cancer?

	Yes	No	Don't know
6a. As far as you know , is there a national cervical screening programme in Ireland? (Picture 14)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If yes, at what age are women first invited for cervical screening? Age: _____			<input type="checkbox"/>
6b. Have you ever been invited for cervical screening on the national cervical screening programme?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6c. Have you ever had cervical screening on the national cervical screening programme?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Yes	No	Don't know
7. As far as you know, is there a national vaccination programme to protect against cervical cancer? (Picture 15)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If yes, at what age is do you get it? Age: _____			<input type="checkbox"/>

Section C: Cancer Awareness Measure

Cancer Awareness Measure Toolkit version 2.1 Updated 09.02.11

This survey instrument (CAM) was developed by Cancer Research UK, University College London, Kings College London, and University of Oxford in 2007-2008.

1. Sometimes people put off going to see the doctor, even when they have a symptom that they think might be serious. Could you say if any of these might put you off going to see the doctor?

	Yes Often	Yes sometimes	No	Don't know
I would be embarrassed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I would be scared	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I would be worried about wasting the doctor's time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My doctor would be difficult to talk to	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It would be difficult to make an appointment with my doctor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I would be too busy to make time to go to the doctor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have too many other things to worry about	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
It would be difficult for me to arrange transport to the doctor's surgery	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I would be worried about what the doctor might find	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I wouldn't feel confident talking about my symptom with the doctor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify)				

Section D: Demographic Questions

We would now like to ask you a few questions about yourself. This will help us to analyse the results of the survey.

1. What is your age?	
<input type="checkbox"/> <input type="checkbox"/>	Prefer not to say <input type="checkbox"/>

2. What is your gender?		
Male	Female	Prefer not to say
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3: Where do you live?	
With my parents	<input type="checkbox"/>
In a residential home	<input type="checkbox"/>
In the community	<input type="checkbox"/>
Other	<input type="checkbox"/>
Prefer not to say	<input type="checkbox"/>

4. Have you, your family or close friends had cancer?

	Yes	No	Don't know	Prefer not to say
You	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Close family member	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other family member	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Close friend	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other friend	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Thank you for your time.

AIV.16 Carers Interview Topic Guide

Question 1: What is your own understanding of breast cancer awareness and screening?

Question 2: What is your own understanding of cervical cancer awareness and screening?

Question 3: Have you had to deal with issues such as participation in screening with the women?

Question 4: What do you think would be useful to help you assist women with severe to profound ID in relation to breast and cervical cancer awareness?

Question 5: What do you think would be useful to help you assist women with severe to profound ID in relation to participate in screening programmes?

AIV.17 GP letter for women with mild to moderate intellectual disabilities completing the Adapted CAM

Postgraduate Research Office,
Department of Nursing,
School of Health Sciences,
Waterford Institute of Technology.

(051) 845593

Date.

Dear Dr. x

Waterford Institute of Technology/ HSE are carrying out research about breast and cervical cancer awareness and screening in women with intellectual disabilities in the South East. We are talking to the women with intellectual disabilities and their carers about breast and cervical cancer awareness and knowledge of screening programmes. The results will be used to develop education programmes for the women and their carers to increase cancer awareness and improve screening uptake. This is intended to lead to the earlier diagnosis and treatment of cancer with better outcomes for the women.

Your patient, x, (service name) Waterford, has completed a questionnaire about breast and cervical cancer awareness and screening programmes. x has been advised to contact her GP in collaboration with the nurse educator in her services should she have any concerns about breast or cervical cancer following her participation in this study. This is in accordance with the requirements of the HSE- South Research Ethics Committee approval for this study.

Yours sincerely,

Mary Reidy, Postgraduate Research Student.

mreidy@wit.ie

Appendix V: Phase II Feasibility Testing of the EMBRACES-ID intervention documentation

AV.1 EMBRACES-ID Adapted CAM Pictorial Prompts

EMBRACES-ID (Early Monitoring of Breast and Cervical Cancer Signs & Screening in Intellectual Disabilities)



An Education Programme for Women with Intellectual Disabilities, Staff and Family Carers

Pictorial Prompts for Women with Mild to Moderate Intellectual Disabilities

YES



NO



DON'T KNOW



Section A: Breast Cancer Awareness Measure

Toolkit (version 2)

This survey instrument (Breast CAM) was developed by Cancer Research UK, King's College London and University College London in 2009 and validated with the support of Breast Cancer Care and Breakthrough Breast Cancer.



Picture1: Lump or thickening in your breast



Picture 2: Lump or thickening in your armpit



Picture 3: Any liquid leaking from your nipples



Picture 4: Pulling in of nipple



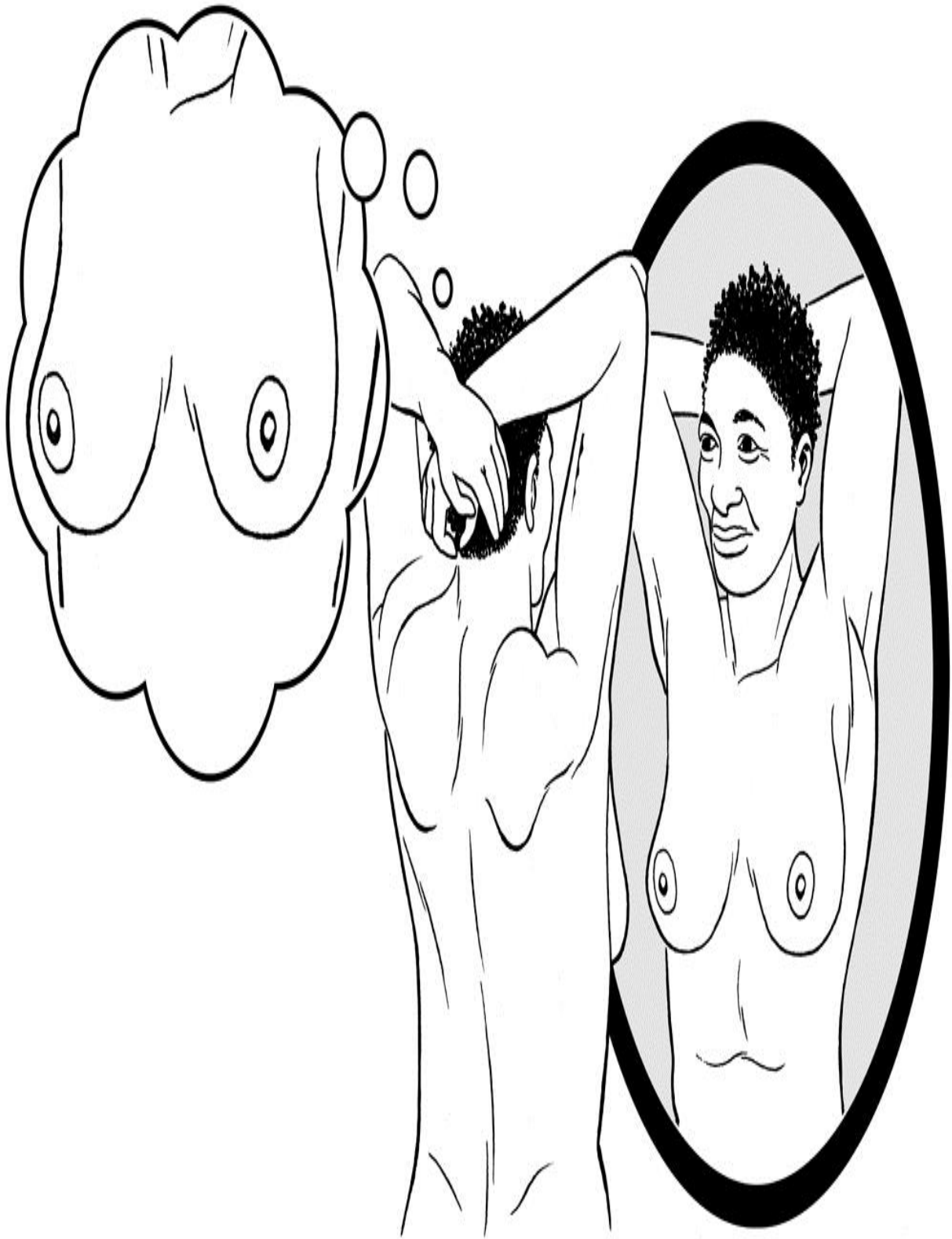
Picture 5: Nipple in different place



Picture 6: Rash on nipple



Picture 7. Changes to skin on breast – redness



Picture 8: Change in size/shape breast



**Picture 9: Changes in shape of breast/
nipple**



Picture 10: Pain in one breast or armpit



Picture 11: Changes to skin on breast-dimpling



Picture 12: When do you check your breasts?



Picture13: If you did notice a change in your breast, how soon would you go to talk to the doctor?



Picture 14: In the next year, who is most likely to develop breast cancer?



Picture 15: Is there a national breast screening programme in Ireland?

Section B: Cervical Cancer Awareness Measure

Cervical Cancer Awareness Measure Toolkit Version 2.1 Updated 09.02.11

This survey instrument (the Cervical CAM) was developed by the UCL Health Behaviour Research Centre, in collaboration with the Department of Health Cancer Team and The Eve Appeal, with funding from The Eve Appeal. It forms part of the Cervical Cancer Awareness and Symptoms Initiative (CCASI). It is based on a generic CAM developed by Cancer Research UK, University College London, King's College London and Oxford University in 2007-08.



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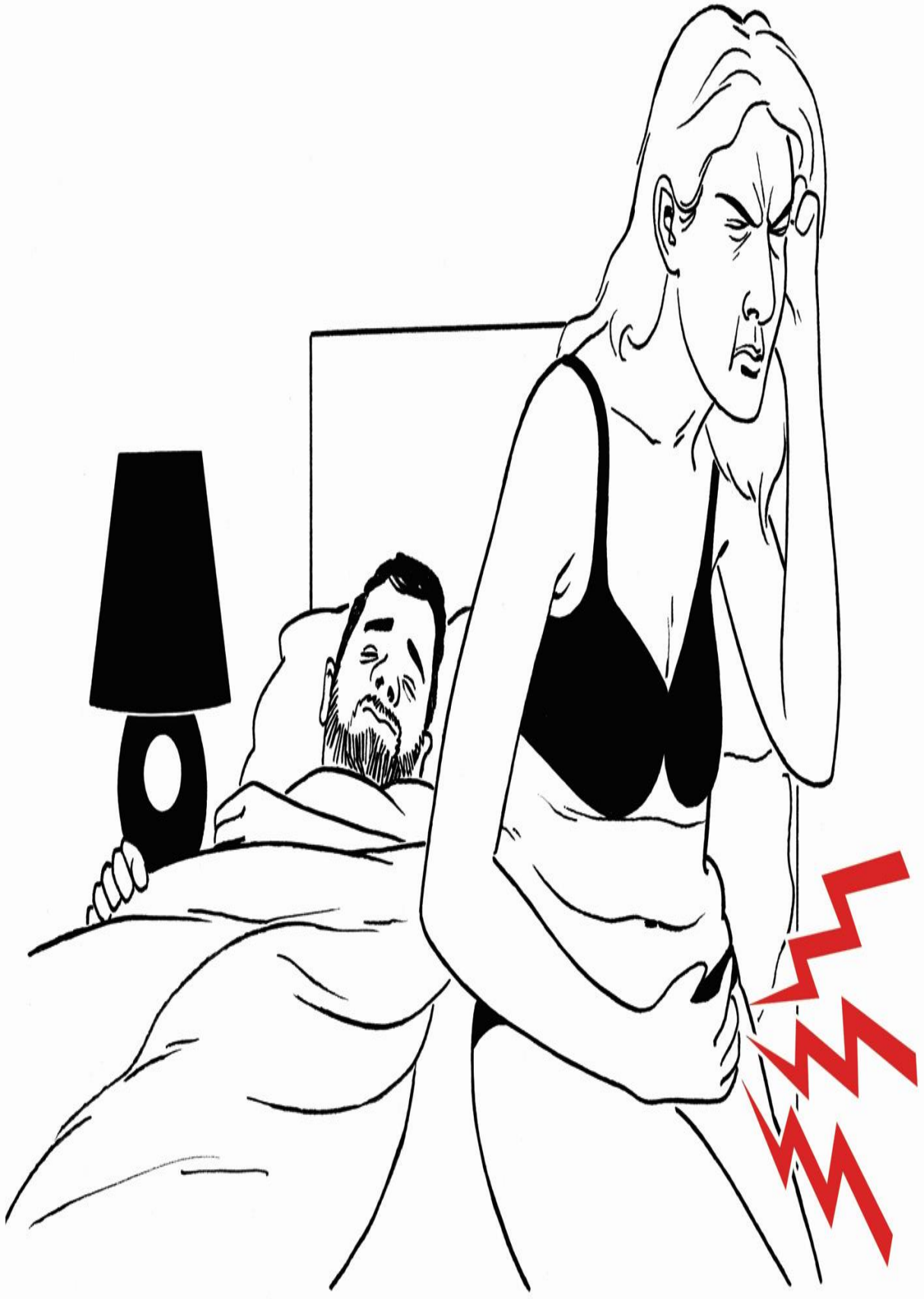
Picture 1: Bleeding between periods



Picture 2: Lower back pain that doesn't go away for 3 weeks or longer



Picture 3: Smelly discharge from your vagina that doesn't go away for 3 weeks or longer



Picture 4: Pain during sex



Picture 5: Heavier periods that last longer than normal periods



Picture 6: Runny poo that doesn't go away for 3 weeks or longer



Picture 7: Any bleeding after the menopause



Picture 8: Pain in your pelvis that doesn't go away for 3 weeks or longer



Picture 9: Bleeding during or after sex



Picture 10: Blood in poo or wee



Picture 11: If you lose weight but don't know why?



Picture 12: If you had a symptom that you thought might be a sign of cervical cancer how soon would you go to your doctor to talk about it?



Picture 13: In the next year, who is most likely to get cervical cancer?



Picture 14: Is there a national cervical screening programme in Ireland?

AV.2 Introductory email for intellectual disability service providers:

EMBRACES-ID

A research team based at the Department of Nursing and Health Care at Waterford Institute of Technology Dr. Suzanne Denieffe, Ms Sinéad Foran and Ms Mary Reidy in collaboration with the HSE are carrying out research about cancer awareness and screening in women with intellectual disabilities in the South East. We have talked to the women, staff and family carers about breast and cervical cancer awareness and screening. The results were used to develop a cancer awareness programme.

We would like invite your service to take part in **EMBRACES-ID** (**Early Monitoring of Breast and Cervical Cancer Signs & Screening in Intellectual Disabilities**), a four week programme designed for women with mild to moderate intellectual disabilities, staff and family carers. The programme aims to raise the awareness of

- a) cancer warning signs;
- b) risk factors;
- c) screening programmes;
- d) promote early help seeking on discovery of a symptom of breast or cervical cancer.

The group programme will be delivered by Ms. Mary Reidy in a supportive learning environment at your day centre. All materials for the programme will be provided. Each woman with an intellectual disability who is willing and able to participate would be accompanied by the same staff/family member to each of the four two- hour education sessions. There are no medical tests involved.

In order to help us to evaluate the programme, each participant is also invited to attend short interviews. These interviews will take place the week before the programme starts; at the end of the programme and again 3 months post completion of the programme.

The training will commence in mid -September 2014. Recruitment to the programme is now open. We look forward to hearing from you.

AV.3 Carers poster advertisement



EMBRACES-ID (Early Monitoring of Breast and Cervical Cancer Signs & Screening in Intellectual Disabilities)

What's the project about?

EMBRACES-ID is a programme designed for women with intellectual disabilities, staff and family carers.

The programme aims to raise the awareness of

- ⇒ cancer warning signs
- ⇒ risk factors
- ⇒ screening programmes
- ⇒ promote early help seeking on discovery of a symptom of breast or cervical cancer.



What would I need to do?

Staff, family carers and women using the service would participate in a weekly group training session for four weeks. Each training session lasts for two hours. The sessions are run at the service and will begin in September 2014.

AND

You would help us evaluate the training by taking part in interviews before and after the training and again 3 months after the training has ended.

Are you interested in taking part?

Contact: Mary Reidy
Phone: (051) 845593 or e-mail mreidy@wit.ie

Mary Reidy,
PhD Candidate,
Postgraduate Research
Unit,
Department of Nursing,
School of Health Science,
WIT,
Cork Road,
Waterford

Mary Reidy
Phone: 051 845593
E-mail: mreidy@wit.ie

Mary Reidy
Phone: 051 845593
E-mail: mreidy@wit.ie

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Mary Reidy
Phone: 051 845593
E-mail: mreidy@wit.ie


AV.4 Women with intellectual disabilities poster advertisement



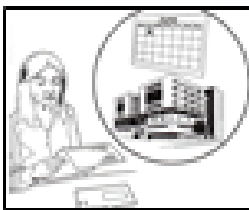
Healthcare in the Home
Health Service Executive



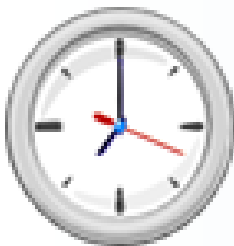
Widening of Training




My name is Mary. I am doing a course at WIT.
I am doing a research project.




I am going to give classes about cancer and the tests to check for cancer.
These classes are for the women using the service, their families and staff.



There are 4 classes.
Each class takes 2 hours a week.



You can say yes or no. It is up to you if you want you take part.



If you would like to know more about taking part:

You can phone me at 051 845593

You can email me at mreidy@wit.ie

AV.5 Carers information sheet



CARER INFORMATION LEAFLET



EMBRACES-ID (Early Monitoring of Breast and Cervical Cancer Signs & Screening in Intellectual Disabilities).

You are being invited to take part in a research project. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully.

What is the purpose of the study?

Waterford Institute of Technology/ HSE are carrying out research about breast and cervical cancer awareness and screening in women with intellectual disabilities in the South East. We talked to the women and their carers about breast and cervical cancer awareness and screening. The results were used to develop an education programme for the women and their carers to raise cancer awareness. This is intended to lead to the earlier diagnosis and treatment of cancer with better outcomes for the women.

Why have I been invited to take part?

You have been invited to participate because you work with/ or are a family member of a woman with mild to moderate intellectual disabilities. We would like to invite you to take part in the educational programme about breast and cervical cancer awareness and screening programmes.

Do I have to take part?

It is up to you whether you decide to take part, taking part is voluntary. You are free to withdraw at any time without giving a reason.

What would I have to do?

If you do decide to take part

- You would participate in a weekly group training session for four weeks. Each session lasts for two hours.
- You would help us evaluate the training by taking part in interviews before and after the training and again 3 months after the training has ended.
- You would not be required to take part in any medical tests.

If you have any questions about symptoms you have had or other questions about cancer, please speak to your GP.

Confidentiality

All the information that is collected will be kept strictly confidential your name will never be used with this information. Only the research team will have access to the information.

What happens to the information that is collected?

The answers you give will be given a specific code and it will not be possible for you to be identified from your answers. This coded information will be sent to the UK Data Archive. The archive will help us to build an understanding of public knowledge about cancer so that we can develop ways to improve communications and services that aim to improve cancer outcomes. More information about the archive can be found here: <http://www.datarchive.ac.uk/Introduction.asp>

Contact details for further information:

Mary Reidy
PhD Candidate,
Department of Nursing,
Waterford Institute of Technology
Email: mreidy@wit.ie
Phone: (051) 845593

Thank you for taking the time to read this information sheet.

AV.6 Women with Intellectual Disabilities Information Sheet



Ídhlmeasacht na Saoibhóir Síne
Health Service Executive



Waterford Institute of Technology
WATERFORD INSTITUTE OF TECHNOLOGY

INFORMATION LEAFLET: EMBRACES-ID (Early Monitoring of Breast and Cervical Cancer Signs and Screening in Intellectual Disabilities)



My name is Mary. I am doing a course at WIT. I am doing a research project.



I am going to give some classes at _____ about cancer and the tests to check for cancer.



The two of us would have a chat about what you know about cancer and the tests to check for cancer.



If you have any questions about symptoms you have had or other questions about cancer, you can talk to _____ at your centre. You and



_____ can also arrange a chat with your GP.

I will let your GP know that you have taken part in the project.



To help other people doing projects about cancer and tests, your answers will be put in a computer. Don't worry nobody will know the answers are from you .



You can ask for our chat to stop at any time.



The chat will take no longer than half an hour.



I will be giving 4 classes at _____ about

cancer and the tests to check for cancer to women.



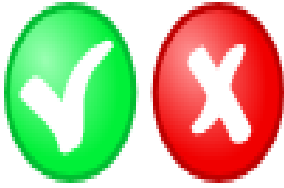
After all the classes are over I will have two more chats with you to see what you know about cancer and the tests to check for cancer.



After the classes are finished if you have any questions about symptoms you have had or other questions about cancer, you can talk to _____ at your centre. You and _____ can also arrange a chat with your GP.



I will let your GP know that you have taken part in the project.



You can say yes or no. It is up to you if you want you take part.



If you do want to take part, please ask your keyworker or family to help you read the consent form.



If you would like to talk to me, you should sign the consent form with Mary and your keyworker.



If you would like to know more about the project, please ring me at (051) 845593.



Thank you for taking the time to read this information leaflet.

AV.7 Carers Consent Form



CARER CONSENT FORM



Project Title: EMBRACES-ID (Early Monitoring of Breast and Cervical Cancer Signs and Screening in Intellectual Disabilities)

Please insert your initials in the box opposite each statement:

I have read and understand the information leaflet for the study and have had the opportunity to ask questions all of which have been satisfactorily answered.

I understand that taking part in the study is voluntary and that I am free to leave the study at any time without giving a reason.

I agree to take part in the study.

I agree to the interview being tape recorded.

I understand that all information I give will be confidential.

I understand my name or information which might identify me will not be used in any publications.

Participants Signature

Date

Name in block capitals

Researchers Signature

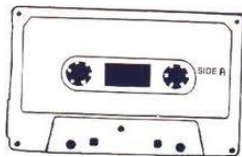
Date

Name in block capitals

AV.8 Women with Intellectual Disabilities Consent Form



If I talk to Mary about her project “EMBRACES-ID (Early Monitoring of Breast and Cervical Cancer Signs and Screening in Intellectual Disabilities)”



I understand that the chats with Mary will be recorded.



I understand that the chats with Mary will be in private.



I understand that I can stop the chats with Mary at any time.



I understand that I can
stop going to Mary's
classes about cancer and
the tests to check for
cancer if I want to.

If you understand these sentences, you now can decide if you
would like to take part in the project.

I have decided that I would like to talk to Mary about her project “EMBRACES-ID (Early Monitoring of Breast and Cervical Cancer Signs and Screening in Intellectual Disabilities)”

Please put a circle around Yes or No.



Yes



No

I have decided that I would like to take part in the classes that Mary is giving about cancer and the tests to check for cancer.

Please put a circle around Yes or No.



Yes



No

Please print your name.....

Keyworker’s signature.....

Researcher’s signature.....

GP name and phone number.....

Date.....

EMBRACES-ID (Early Monitoring of Breast and Cervical Cancer Signs & Screening in Intellectual Disabilities)



An Education Programme for Women with Intellectual Disabilities, Staff and Family Carers

Cancer Awareness Measure

Please complete the Cancer Awareness Measure (CAM) for this project. It should take 20 minutes. Your opinion is important to us.

Please do not alter the CAM questions in any way.

It would be best to complete the survey without checking the internet or books for the answers as we are interested in your opinion.

The questionnaire is comprised of four sections.

Section A: Breast Cancer Awareness Measure.

Section B: Cervical Cancer Awareness Measure.

Section C: Cancer Awareness Measure.

Section D: Demographic Questions.

Please return the completed CAM questionnaire to Ms Mary Reidy.

Thank you for your time.

Section A: Breast Cancer Awareness Measure

Toolkit (version 2)

This survey instrument (Breast CAM) was developed by Cancer Research UK, King's College London and University College London in 2009 and validated with the support of Breast Cancer Care and Breakthrough Breast Cancer.

Instructions for completion of the Breast- CAM

5. Please do not alter any of the information in the CAM questionnaire.
6. Please answer each question in the CAM, we are interested in your opinion.

Q1: The following may or may not be warning signs for breast cancer. We are interested in your opinion. Please indicate your answer with an X.

	Yes	No	Don't know
Do you think a lump or thickening in your breast could be a sign of breast cancer?			
Do you think a lump or thickening under your armpit could be a sign of breast cancer?			
Do you think bleeding or discharge from your nipple could be a sign of breast cancer?			
Do you think the pulling in of your nipple could be a sign of breast cancer?			
Do you think a change in the position of your nipple could be a sign of breast cancer?			
Do you think a rash on or around your nipple could be a sign of breast cancer?			
Do you think redness of your breast skin could be a sign of breast cancer?			
Do you think a change in the size of your breast or nipple could be a sign of breast cancer?			
Do you think a change in the shape of your breast or nipple could be a sign of breast cancer?			
Do you think pain in one of your breasts or armpit could be a sign of breast cancer?			
Do you think dimpling of the breast skin could be a sign of breast cancer?			

Q2a. How often do you check your breasts? Please indicate your answer with an X.

Rarely or never	At least once every 6 months	At least once a month	At least once a week

Q2b. Are you confident you would notice a change in your breasts? Please indicate your answer with an X.

Not at all confident	Not very confident	Fairly confident	Very confident

Q2c. Have you ever been to see a doctor about a change you have noticed in one of your breasts? Please indicate your answer with an X.

Yes	No	Never noticed a change in one of my breasts

Q3. If you found a change in your breast, how soon would you contact your doctor to make an appointment to discuss it? Please write your answer below.

Q4. In the next year, who is most likely to develop breast cancer? Please indicate your opinion with an X

A 30 year old woman	
A 50 year old woman	
A 70 year old woman	
A woman of any age	

Q5. How much do you agree that each of these can increase the chance of developing breast cancer?

Please indicate your answer with an X

	Strongly disagree	Disagree	Not sure	Agree	Strongly agree
Having a past history of breast cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Using HRT (Hormone Replacement Therapy)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Drinking more than 1 unit of alcohol a day	<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"/>
Having a close relative with breast cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having children later on in life or not at all	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Starting your periods at an early age	<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"/>
Doing less than 30 mins of moderate physical activity 5 times a week	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q6a. As far as you are aware is there a national breast screening programme in Ireland? Please indicate your answer with an X.

Yes	No	Don't know

If your answer to Q. 6a was yes, please answer the following two questions, otherwise please go to Q 6b

If yes, at what age are women first invited for breast screening?

Age	Don't know

If yes, at what age are women last invited for breast screening?

Age	Don't know

Q6b. Have you ever been invited for breast screening on the national breast screening programme? Please indicate your answer with an X.

Yes	No	Don't know

6c. Have you ever had breast screening on the national breast screening programme? Please indicate your answer with an X.

Yes	No	Don't know

Section B: Cervical Cancer Awareness Measure

Cervical Cancer Awareness Measure Toolkit Version 2.1 Updated 09.02.11

This survey instrument (the Cervical CAM) was developed by the UCL Health Behaviour Research Centre, in collaboration with the Department of Health Cancer Team and The Eve Appeal, with funding from The Eve Appeal. It forms part of the Cervical Cancer Awareness and Symptoms Initiative (CCASI). It is based on a generic CAM developed by Cancer Research UK, University College London, King's College London and Oxford University in 2007-08.



Working in partnership with



Instructions for completion of the Cervical- CAM

5. Please do not alter any of the information in the CAM questionnaire.
6. Please answer each question in the CAM, we are interested in your opinion.

Q1. The following may or may not be warning signs for cervical cancer. We are interested in your opinion: Please indicate your answer with an X.

	Yes	No	Don't know
Do you think vaginal bleeding between periods could be a sign of cervical cancer?			
Do you think persistent lower back pain could be a sign of cervical cancer?			
Do you think persistent vaginal discharge which smells unpleasant could be a sign of cervical cancer?			
Do you think discomfort or pain during sex could be a sign of cervical cancer?			
Do you think menstrual periods that are heavier or longer than usual could be a sign of cervical cancer?			
Do you think persistent diarrhoea could be a sign of cervical cancer?			
Do you think vaginal bleeding after the menopause could be a sign of cervical cancer?			
Do you think persistent pelvic pain could be a sign of cervical cancer?			
Do you think vaginal bleeding during or after sex could be a sign of cervical cancer?			
Do you think blood in the stool or urine could be a sign of cervical cancer?			
Do you think unexplained weight loss could be a sign of cervical cancer?			

Q2. How confident are you that you would notice a cervical cancer symptom? Please indicate your answer with an X.

Not at all confident	Not very confident	Fairly confident	Very confident

Q3. If you had a symptom that you thought might be a sign of cervical cancer how soon would you contact your doctor to make an appointment to discuss it? Please write your answer below.

Q4. In the next year, who is most likely to develop cervical cancer? Please indicate your answer with an X

A woman aged 20-29 years	
A woman aged 30-49 years	
A woman aged 50-69 years	
A women aged 70 or over	
Cervical cancer is unrelated to age	

Q6The following may or may not increase a woman's chance of developing cervical cancer. How much do you agree that each of these can increase a woman's chance of developing cervical cancer?

Please indicate your answer with an X

	Strongly disagree	Disagree	Not sure	Agree	Strongly agree
Infection with HPV (human papillomavirus)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Smoking any cigarettes at all	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having a weakened immune system (e.g. because of HIV/AIDS, immunosuppressant drugs or having a transplant)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Long term use of the contraceptive pill	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Infection with Chlamydia (a sexually transmitted infection)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having a sexual partner who is not circumcised	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Starting to have sex at a young age (before age 17)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having many sexual partners	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having many children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having a sexual partner with many previous partners	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not going for regular smear (Pap) tests	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q6a. As far as you are aware is there a national cervical screening programme in Ireland? Please indicate your answer with an X.

Yes	No	Don't know

If your answer to Q. 6a was Yes, please answer the next question, otherwise please go to Q 6b

If yes, at what age are women first invited for cervical screening?

Age	Don't know

Q6b. Have you ever been invited for cervical screening on the national cervical screening programme? Please indicate your answer with an X.

Yes	No	Don't know

6c. Have you ever had cervical screening on the national cervical screening programme? Please indicate your answer with an X.

Yes	No	Don't know

Q6a. As far as you are aware is there is there a national vaccination programme to protect against cervical cancer? Please indicate your answer with an X.

Yes	No	Don't know

If yes, at what age is this first offered?

Age	Don't know

Section C: Cancer Awareness Measure

Cancer Awareness Measure toolkit version 2.1 Updated 09.02.11

This survey instrument (CAM) was developed by Cancer Research UK, University College London, Kings College London, and University of Oxford in 2007-2008.

Instructions for completion of the CAM

5. Please do not alter any of the information in the CAM questionnaire.
6. Please answer each question in the CAM, we are interested in your opinion.

Q1. Sometimes people put off going to see the doctor, even when they have a symptom that they think might be serious. Could you say if any of these might put you off going to see the doctor?

	Yes Often	Yes sometimes	No	Don't know
I would be embarrassed				
I would be scared				
I would be worried about wasting the doctor's time				
My doctor would be difficult to talk to				
It would be difficult to make an appointment with my doctor				
I would be too busy to make time to go to the doctor				
I have too many other things to worry about				
It would be difficult for me to arrange transport to the doctor's surgery				
I would be worried about what the doctor might find				
I wouldn't feel confident talking about my symptom with the doctor				
Other (please specify)				

Section D:

Demographic Questions

We would now like to ask you a few questions about yourself. This will help us to analyse the results of the survey. The data collected will help us to identify specific age or demographic groups of people who are in need of more information about cancer. You will not be asked your name and all of your answers will be kept strictly confidential and anonymous. Your personal data will be held in accordance with the Data Protection Act 1988-2003.

1. What is your age?	
	Prefer not to say

2. What is your gender?		
Male	Female	Prefer not to say

3: What is your marital status?		
Single	<input type="checkbox"/>	Widowed <input type="checkbox"/>
Married/ living with partner	<input type="checkbox"/>	Civil partnership <input type="checkbox"/>
Separated/ divorced	<input type="checkbox"/>	Prefer not to say <input type="checkbox"/>

4: Which of the following best describes	your working status?	
Employed full-time	<input type="checkbox"/>	Full time homemaker <input type="checkbox"/>
Employed part-time	<input type="checkbox"/>	Retired <input type="checkbox"/>
Unemployed	<input type="checkbox"/>	Student <input type="checkbox"/>
Self-employed	<input type="checkbox"/>	Prefer not to say <input type="checkbox"/>

5: What is the highest level of educational qualification you have obtained?			
Primary School or equivalent	<input type="checkbox"/>	Ordinary Degree (Level 7)	<input type="checkbox"/>
Group Certificate	<input type="checkbox"/>	Honours Degree (Level 8)	<input type="checkbox"/>
Inter/Junior Certificate or equivalent	<input type="checkbox"/>	Postgraduate Degree	<input type="checkbox"/>
Leaving Certificate or equivalent	<input type="checkbox"/>	Higher Degree	<input type="checkbox"/>
FETAC Level 5 or equivalent	<input type="checkbox"/>	Other	<input type="checkbox"/>
FETAC Level 6 or equivalent	<input type="checkbox"/>	Prefer not to say	<input type="checkbox"/>
Diploma/ Certificate	<input type="checkbox"/>		

6: What is your carer status?	
Family Carer	
Health Care Assistant	
Staff Nurse- Please indicate register division e.g RNID	
Clinical Nurse Manager- Please indicate register division and grade e.g. RNID/ CNM1	
Social Care Worker	
Other	
Prefer not to say	

7. Have you, your family	or close	friends had	cancer?	
	Yes	No	Don't know	Prefer not to say
You				
Partner				
Close family member				
Other family member				
Close friend				
Other friend				

Thank you for taking the time to complete this questionnaire.

AV.10 EMBRACES-ID Adapted CAM women with mild to moderate intellectual disabilities

EMBRACES-ID (Early Monitoring of Breast and Cervical Cancer Signs & Screening in Intellectual Disabilities)



An Education Programme for Women with Intellectual Disabilities, Staff and Family Carers

Adapted Cancer Awareness Measure

Section A: Breast Cancer Awareness Measure

Toolkit (version 2)

This survey instrument (Breast CAM) was developed by Cancer Research UK, King's College London and University College London in 2009 and validated with the support of Breast Cancer Care and Breakthrough Breast Cancer.

Instructions for completion of the Breast- CAM

7. Please do not alter any of the information in the CAM questionnaire.
8. Please answer each question in the CAM, we are interested in your opinion.

Q1: The following may or may not be warning signs for breast cancer. We are interested in your opinion. Please indicate your answer with an X (Pictures 1-11).

	Yes	No	Don't know
Do you think a lump or thickening in your breast could be a sign of breast cancer?			
Do you think a lump or thickening under your armpit could be a sign of breast cancer?			
Do you think bleeding or discharge from your nipple could be a sign of breast cancer?			
Do you think the pulling in of your nipple could be a sign of breast cancer?			
Do you think a change in the position of your nipple could be a sign of breast cancer?			
Do you think a rash on or around your nipple could be a sign of breast cancer?			
Do you think redness of your breast skin could be a sign of breast cancer?			
Do you think a change in the size of your breast or nipple could be a sign of breast cancer?			
Do you think a change in the shape of your breast or nipple could be a sign of breast cancer?			
Do you think pain in one of your breasts or armpit could be a sign of breast cancer?			
Do you think dimpling of the breast skin could be a sign of breast cancer?			

Q2a. How often do you check your breasts? Please indicate your answer with an X (Picture 12).

Rarely or never	At least once every 6 months	At least once a month	At least once a week

Q2b. Are you confident you would notice a change in your breasts? Please indicate your answer with an X.

Not at all confident	Not very confident	Fairly confident	Very confident

Q2c. Have you ever been to see a doctor about a change you have noticed in one of your breasts? Please indicate your answer with an X.

Yes	No	Never noticed a change in one of my breasts

Q3. If you found a change in your breast, how soon would you contact your doctor to make an appointment to discuss it? Please write your answer below (Picture 13).

Q4. In the next year, who is most likely to develop breast cancer? Please indicate your opinion with an X (Picture 14).

A 30 year old woman	
A 50 year old woman	
A 70 year old woman	
A woman of any age	

5. What things do you think affect a woman's chance of getting breast cancer?

5. What things do you think affect a woman's chance of getting breast cancer?

Q6a. As far as you are aware is there a national breast screening programme in Ireland? Please indicate your answer with an X (Picture 15).

Yes	No	Don't know

If your answer to Q. 6a was yes, please answer the following two questions, otherwise please go to Q 6b

If yes, at what age are women first invited for breast screening?

Age	Don't know

If yes, at what age are women last invited for breast screening?

Age	Don't know

Q6b. Have you ever been invited for breast screening on the national breast screening programme? Please indicate your answer with an X.

Yes	No	Don't know

6c. Have you ever had breast screening on the national breast screening programme? Please indicate your answer with an X.

Yes	No	Don't know

Section B: Cervical Cancer Awareness Measure

Cervical Cancer Awareness Measure Toolkit Version 2.1 Updated 09.02.11

This survey instrument (the Cervical CAM) was developed by the UCL Health Behaviour Research Centre, in collaboration with the Department of Health Cancer Team and The Eve Appeal, with funding from The Eve Appeal. It forms part of the Cervical Cancer Awareness and Symptoms Initiative (CCASI). It is based on a generic CAM developed by Cancer Research UK, University College London, King's College London and Oxford University in 2007-08.



Working in partnership with



Instructions for completion of the Cervical- CAM

7. Please do not alter any of the information in the CAM questionnaire.
8. Please answer each question in the CAM, we are interested in your opinion.

Q1. The following may or may not be warning signs for cervical cancer. We are interested in your opinion: Please indicate your answer with an X. (Pictures 1-11)

	Yes	No	Don't know
Do you think vaginal bleeding between periods could be a sign of cervical cancer?			
Do you think persistent lower back pain could be a sign of cervical cancer?			
Do you think persistent vaginal discharge which smells unpleasant could be a sign of cervical cancer?			
Do you think discomfort or pain during sex could be a sign of cervical cancer?			
Do you think menstrual periods that are heavier or longer than usual could be a sign of cervical cancer?			
Do you think persistent diarrhoea could be a sign of cervical cancer?			
Do you think vaginal bleeding after the menopause could be a sign of cervical cancer?			
Do you think persistent pelvic pain could be a sign of cervical cancer?			
Do you think vaginal bleeding during or after sex could be a sign of cervical cancer?			
Do you think blood in the stool or urine could be a sign of cervical cancer?			
Do you think unexplained weight loss could be a sign of cervical cancer?			

Q2. How confident are you that you would notice a cervical cancer symptom? Please indicate your answer with an X.

Not at all confident	Not very confident	Fairly confident	Very confident

Q3. If you had a symptom that you thought might be a sign of cervical cancer how soon would you contact your doctor to make an appointment to discuss it? Please write your answer below. (Picture 12)

Q4. In the next year, who is most likely to develop cervical cancer? Please indicate your answer with an X (Picture 13)

A woman aged 20-29 years	
A woman aged 30-49 years	
A woman aged 50-69 years	
A women aged 70 or over	
Cervical cancer is unrelated to age	

5. What things do you think affect a woman's chance of getting cervical cancer?

Q6a. As far as you are aware is there a national cervical screening programme in Ireland? Please indicate your answer with an X. (Picture 14)

Yes	No	Don't know

If your answer to Q. 6a was Yes, please answer the next question, otherwise please go to Q 6b

If yes, at what age are women first invited for cervical screening?

Age	Don't know

Q6b. Have you ever been invited for cervical screening on the national cervical screening programme? Please indicate your answer with an X.

Yes	No	Don't know

6c. Have you ever had cervical screening on the national cervical screening programme? Please indicate your answer with an X.

Yes	No	Don't know

Q6a. As far as you are aware is there is there a national vaccination programme to protect against cervical cancer? Please indicate your answer with an X.

Yes	No	Don't know

If yes, at what age is this first offered?

Age	Don't know

Section C: Cancer Awareness Measure

Cancer Awareness Measure toolkit version 2.1 Updated 09.02.11

This survey instrument (CAM) was developed by Cancer Research UK, University College London, Kings College London, and University of Oxford in 2007-2008.

Instructions for completion of the CAM

7. Please do not alter any of the information in the CAM questionnaire.
8. Please answer each question in the CAM, we are interested in your opinion.

Q1. Sometimes people put off going to see the doctor, even when they have a symptom that they think might be serious. Could you say if any of these might put you off going to see the doctor?

	Yes Often	Yes sometimes	No	Don't know
I would be embarrassed				
I would be scared				
I would be worried about wasting the doctor's time				
My doctor would be difficult to talk to				
It would be difficult to make an appointment with my doctor				
I would be too busy to make time to go to the doctor				
I have too many other things to worry about				
It would be difficult for me to arrange transport to the doctor's surgery				
I would be worried about what the doctor might find				
I wouldn't feel confident talking about my symptom with the doctor				
Other (please specify)				

Section D:

Demographic Questions

We would now like to ask you a few questions about yourself. This will help us to analyse the results of the survey. The data collected will help us to identify specific age or demographic groups of people who are in need of more information about cancer. You will not be asked your name and all of your answers will be kept strictly confidential and anonymous. Your personal data will be held in accordance with the Data Protection Act 1988-2003.

1. What is your age?	
	Prefer not to say

2. What is your gender?		
Male	Female	Prefer not to say

3: What is your marital status?	
Single <input type="checkbox"/>	Widowed <input type="checkbox"/>
Married/ living with partner <input type="checkbox"/>	Civil partnership <input type="checkbox"/>
Separated/ divorced <input type="checkbox"/>	Prefer not to say <input type="checkbox"/>

4: Which of the following best describes	your working status?
Employed full-time <input type="checkbox"/>	Full time homemaker <input type="checkbox"/>
Employed part-time <input type="checkbox"/>	Retired <input type="checkbox"/>
Unemployed <input type="checkbox"/>	Student <input type="checkbox"/>
Self-employed <input type="checkbox"/>	Prefer not to say <input type="checkbox"/>

5: What is the highest level of educational qualification you have obtained?

Primary School or equivalent	<input type="checkbox"/>	Ordinary Degree (Level 7)	<input type="checkbox"/>
Group Certificate	<input type="checkbox"/>	Honours Degree (Level 8)	<input type="checkbox"/>
Inter/Junior Certificate or equivalent	<input type="checkbox"/>	Postgraduate Degree	<input type="checkbox"/>
Leaving Certificate or equivalent	<input type="checkbox"/>	Higher Degree	<input type="checkbox"/>
FETAC Level 5 or equivalent	<input type="checkbox"/>	Other	<input type="checkbox"/>
FETAC Level 6 or equivalent	<input type="checkbox"/>	Prefer not to say	<input type="checkbox"/>
Diploma/ Certificate	<input type="checkbox"/>		

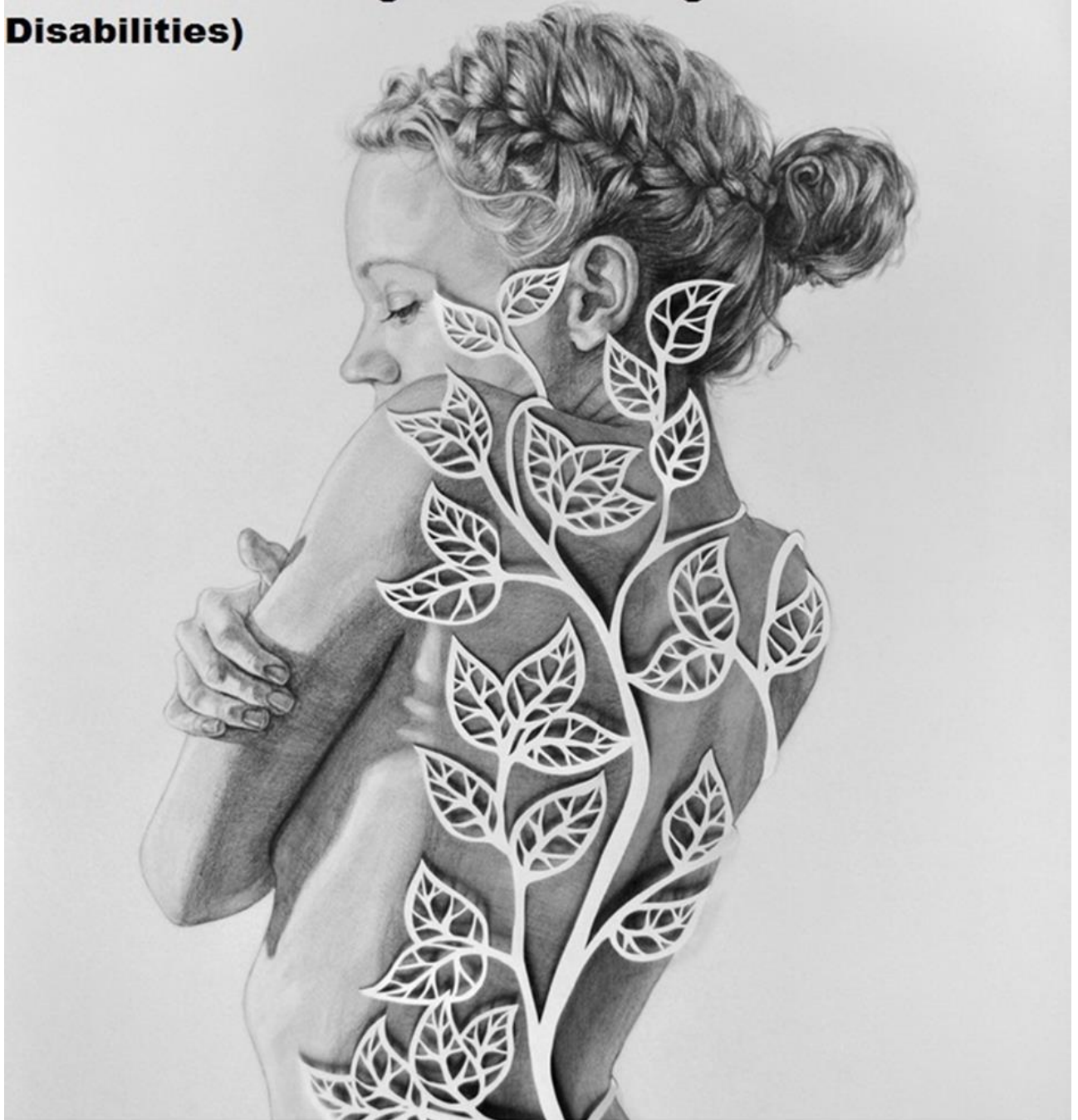
6: Where do you live?

With my parents	<input type="checkbox"/>
In a residential home	<input type="checkbox"/>
In the community	<input type="checkbox"/>
Other	<input type="checkbox"/>
Prefer not to say	<input type="checkbox"/>

7. Have you, your family	or close	friends had	cancer?	
	Yes	No	Don't know	Prefer not to say
You				
Partner				
Close family member				
Other family member				
Close friend				
Other friend				

Thank you for taking the time to complete this questionnaire.

EMBRACES-ID (Early Monitoring of Breast and Cervical Cancer Signs & Screening in Intellectual Disabilities)



An Education Programme for Women with Intellectual Disabilities, Staff and Family Carers

INTERVIEW PROTOCOL

EMBRACES-ID (Early Monitoring of Breast and Cervical Cancer Signs & Screening in Intellectual Disabilities).

You are being invited to take part in a research project. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully.

What is the purpose of the study?

Waterford Institute of Technology/ HSE are carrying out research about breast and cervical cancer awareness and screening in women with intellectual disabilities in the South East. We talked to the women and their carers about breast and cervical cancer awareness and screening. The results were used to develop an education programme for the women and their carers to raise cancer awareness. This is intended to lead to the earlier diagnosis and treatment of cancer with better outcomes for the women.

Why have I been invited to take part?

You have been invited to participate because you work with/ or are a family member of a woman with mild to moderate intellectual disabilities. We would like to invite you to take part in the educational programme about breast and cervical cancer awareness and screening programmes.

Do I have to take part?

It is up to you whether you decide to take part, taking part is voluntary. You are free to withdraw at any time without giving a reason.

What would I have to do?

If you do decide to take part

- You would participate in a weekly group training session for four weeks. Each session lasts for two hours.
- You would help us evaluate the training by taking part in interviews before and after the training and again 3 months after the training has ended.
- You would not be required to take part in any medical tests.

If you have any questions about symptoms you have had or other questions about cancer, please speak to your GP.

Confidentiality

All the information that is collected will be kept strictly confidential your name will never be used with this information. Only the research team will have access to the information.

What happens to the information that is collected?

The answers you give will be given a specific code and it will not be possible for you to be identified from your answers. This coded information will be sent to the UK Data Archive. The archive will help us to build an understanding of public knowledge about cancer so that we can develop ways to improve communications and services that aim to improve cancer outcomes. More information about the archive can be found here: <http://www.datarchive.ac.uk/Introduction.asp>

Contact details for further information:

Mary Reidy
PhD Candidate,
Department of Nursing,
Waterford Institute of Technology
Email: mreidy@wit.ie
Phone: (051) 845593

Thank you for taking the time to read this information sheet

Project Title: EMBRACES-ID (Early Monitoring of Breast and Cervical Cancer Signs and Screening in Intellectual Disabilities)

Please insert your initials in the box opposite each statement:

I have read and understand the information leaflet for the study and have had the opportunity to ask questions all of which have been satisfactorily answered.

I understand that taking part in the study is voluntary and that I am free to leave the study at any time without giving a reason.

I agree to take part in the study.

~~I agree to the interview being tape recorded.~~

I understand that all information I give will be confidential.

I understand my name or information which might identify me will not be used in any publications.

Participants Signature

Date

Name in block capitals

Researchers Signature

Date

Name in block capitals

Instructions for the completion of the survey

Please answer the following nine questions about cancer prevention, cancer screening and your own personal experience of breast self examination.

Please do not alter the questions in any way

It would be best to complete the survey without checking the internet or books for the answers as we are interested in your opinion.

Please return the completed survey to Ms Mary Reidy in the stamped addressed envelope provided on or before / /

Q1: Can you tell me how much you know about breast cancer prevention?

Q2: Can you tell me how much you know about cervical cancer prevention?

Q3: Do you think breast cancer screening could reduce the chance of dying from breast cancer? Why?

Q4: Do you think cervical cancer screening could reduce the chance of dying from cervical cancer? Why?

Q5: How do you feel about women with intellectual disabilities having access to breast cancer screening opportunities that are available to women?

Q6: How do you feel about women with intellectual disabilities having access to cervical screening opportunities that are available to women?

Q7: How do you feel about women with intellectual disabilities obtaining the recommended screening to prevent cancer?

Q8: I would be interested in knowing how confident you are at performing breast self examination?

Q9. I would be interested in knowing how often have you performed BSE in past year?

Thank you for taking the time to complete this survey.

AV.12 EMBRACES-ID Programme Evaluation

EMBRACES-ID (Early Monitoring of Breast and Cervical Cancer Signs & Screening in Intellectual Disabilities)



An Education Programme for Women with Intellectual Disabilities, Staff and Family Carers

EVALUATION FORM

Instructions for the completion of the Evaluation Form

Please answer the following four questions about the programme.

Please do not alter the questions in any way.

AV.13 GP letter for women with intellectual disabilities participating in the intervention

Private and Confidential

Subject: Cancer Awareness and Screening in Women with Intellectual Disabilities

To: Dr.

Fax No.:

From: Mary Reidy,

Postgraduate Research Office,

Department of Nursing,

School of Health Sciences,

Waterford Institute of Technology.

Total no. of pages: 2

Postgraduate Research Office,
Department of Nursing,
School of Health Sciences,
Waterford Institute of Technology.

(051) 845593

Date.

Dear Dr. x

Waterford Institute of Technology/ HSE are carrying out research about breast and cervical cancer awareness and screening in women with intellectual disabilities in the South East. Last year we surveyed women with intellectual disabilities and their carers about cancer awareness and knowledge of screening programmes. The results of the survey were used to develop an education programme for the women and their carers.

Your patient, x, (name of service), is participating in the education programme. x has been advised to contact her GP in collaboration with the nurse educator in her services should she have any concerns about breast or cervical cancer following her participation in this study. This is in accordance with the requirements of the HSE- South Research Ethics Committee approval for this research. Please do not hesitate to contact me should you require further information about the research.

Yours sincerely,

Mary Reidy,

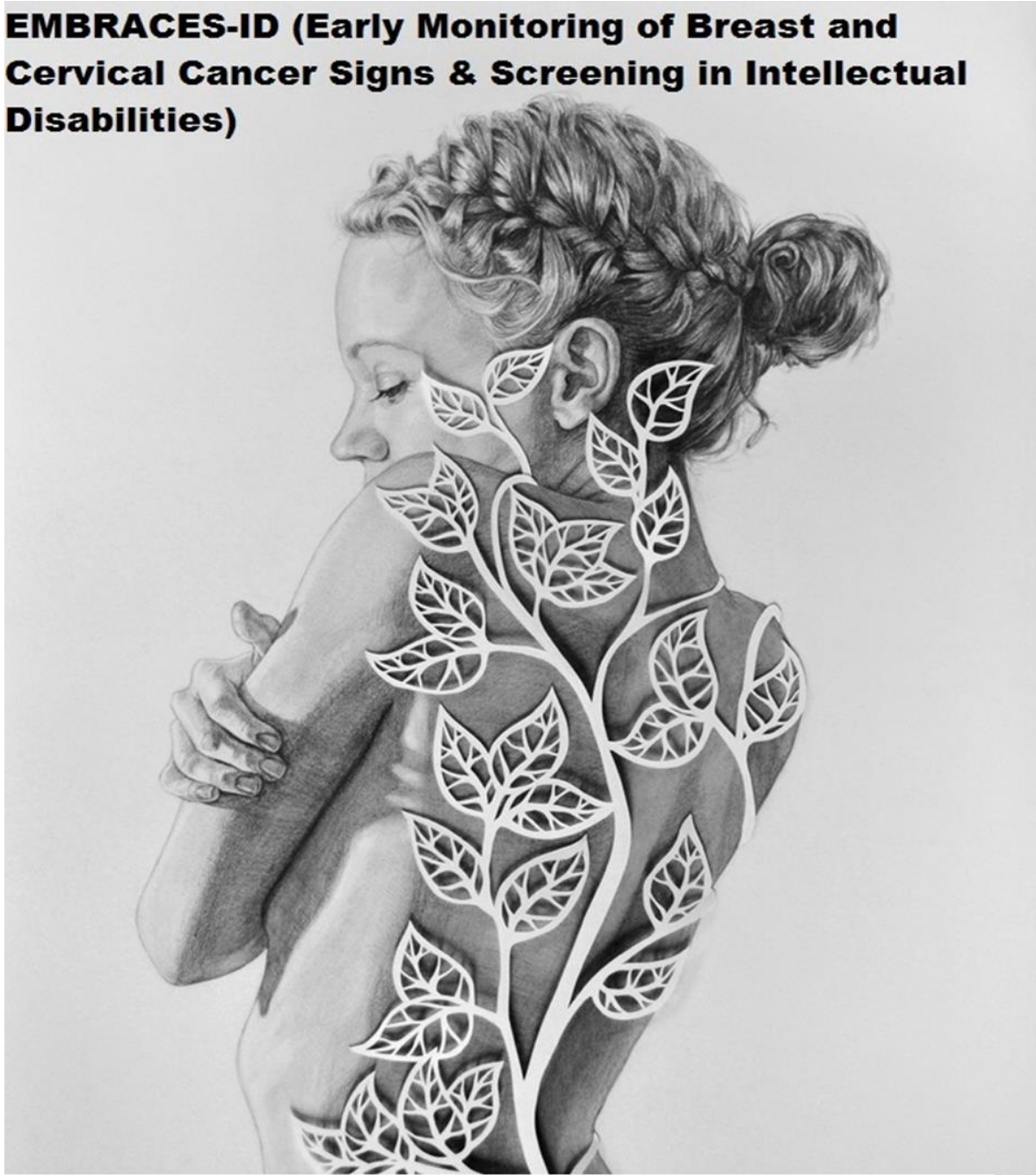
Postgraduate Research Student

mreidy@wit.ie

Appendix VI EMBRACES-ID Programme Material

AVI.1 EMBRACES-ID Programme Booklet

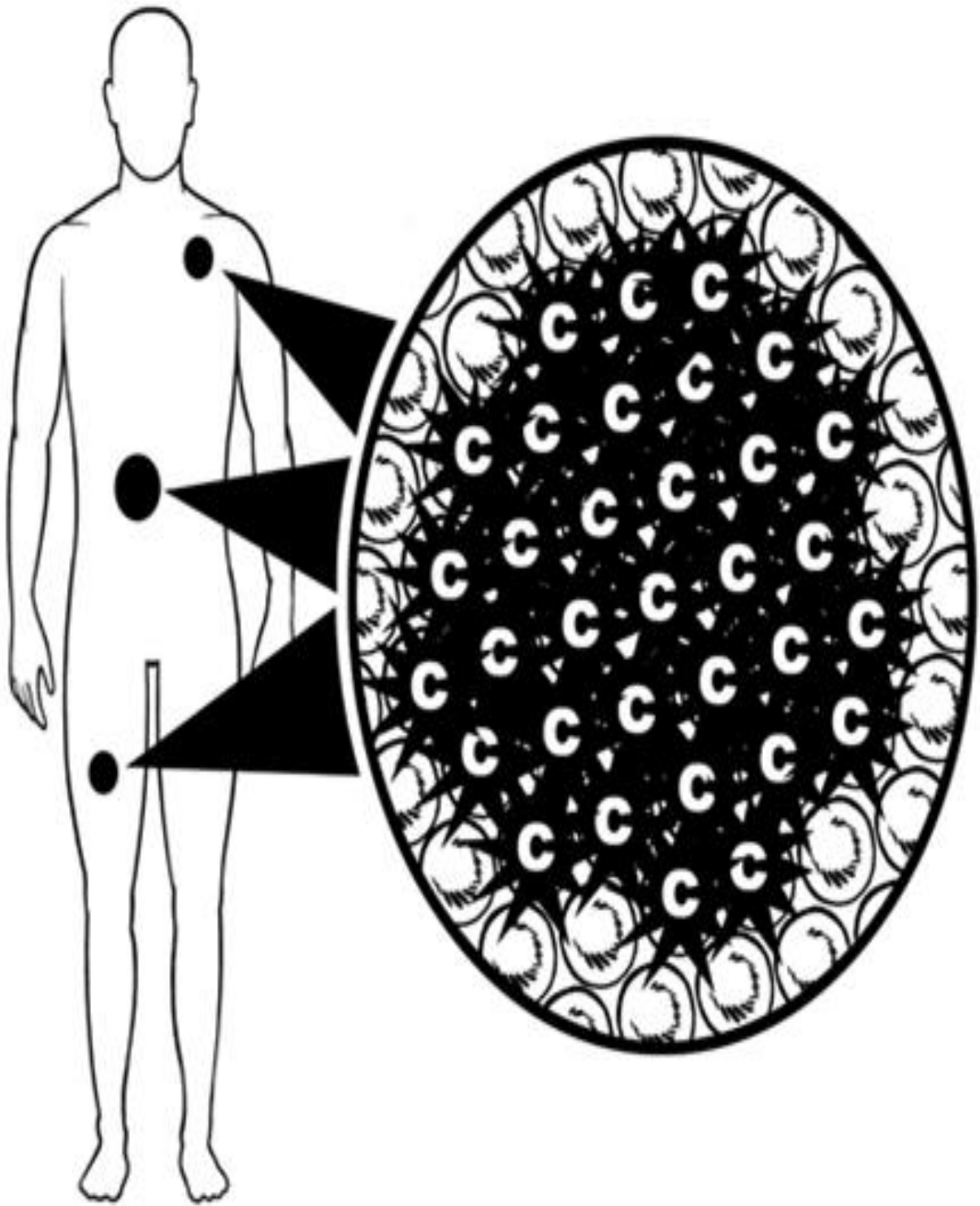
EMBRACES-ID (Early Monitoring of Breast and Cervical Cancer Signs & Screening in Intellectual Disabilities)



An Education Programme for Women with Intellectual Disabilities, Staff and Family Carers

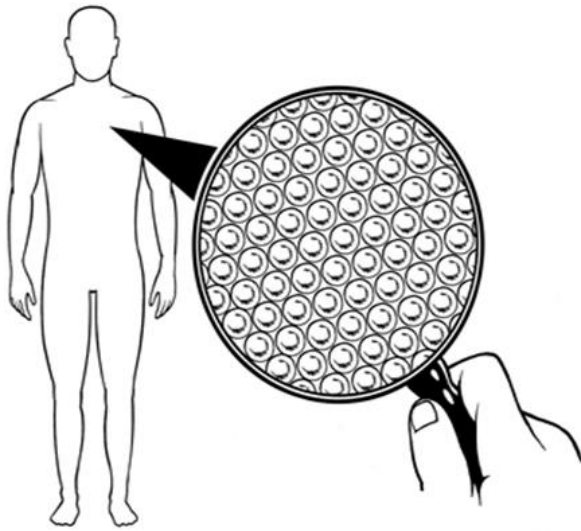
Contents	Page
What is cancer?.....	4
Spotting cancer early.....	12
Staying Healthy.....	15
Breast Cancer.....	23
What affects my risk of getting breast cancer?.....	25
Breast care- self checking.....	30
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Programme
Activities.....

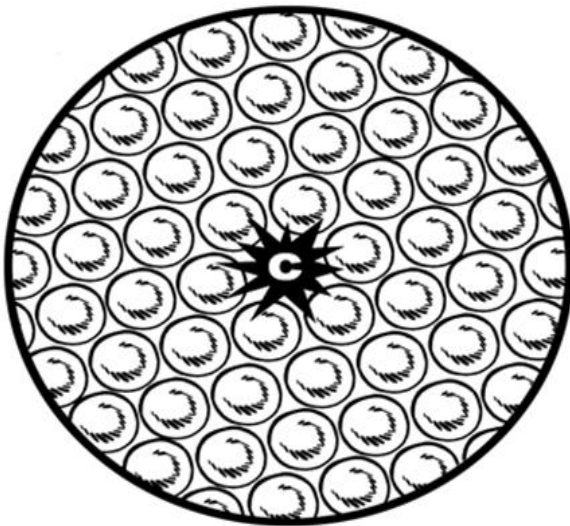


What is cancer?

What is cancer?



Your body is made up of lots of tiny pieces called cells.

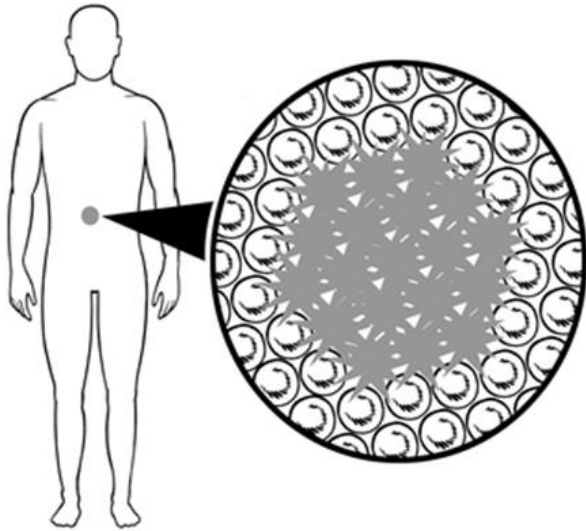


Sometimes these cells can go wrong.

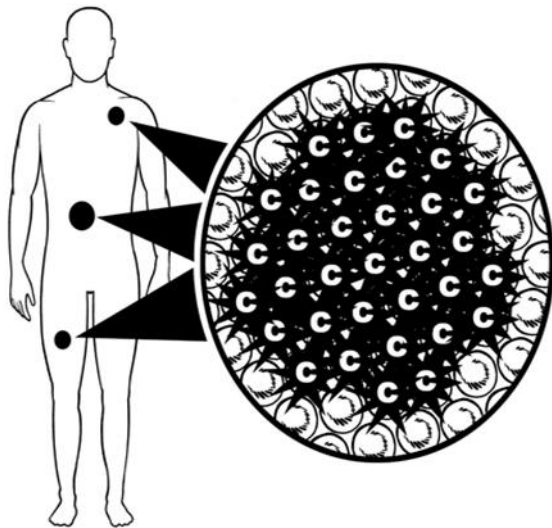


One cell might go wrong which can affect other cells and turn into a lump. This is called a **tumour**.

What is cancer?



Some tumours are '**benign**'. This means they are not cancer.



'**Malignant**' tumours grow and their cells spread to different parts of the body.



This is called **cancer**. **Cancer** can make you feel unwell.

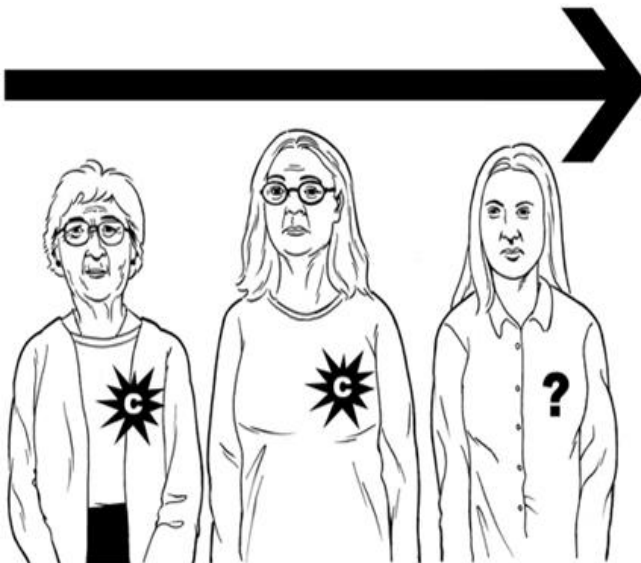
What is cancer?



More than **one in three** people are diagnosed with cancer in their lives.



You can't catch cancer from anyone or give it to anyone either.



This means you are more likely to get some types of cancer if there is a history of cancer in your family.

What is cancer?



You might feel worried about getting cancer because of this. Talk to your doctor about your worries.



Make sure you go for any screening you are offered and annual health checks.



Keep a look out for any changes in your body that are different from usual.

What is cancer?



It is important that any changes are checked by your doctor as soon as possible.

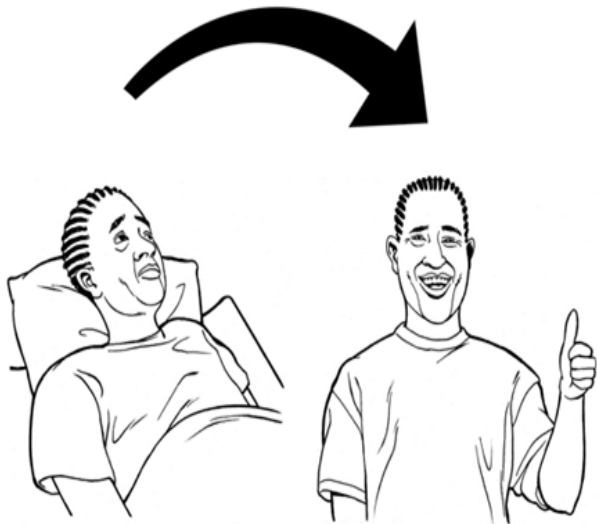


You might be worried about seeing your doctor.



You might be worried that if you have cancer you will die.

What is cancer?



Cancer is a serious illness but there are lots of people who make a full recovery.

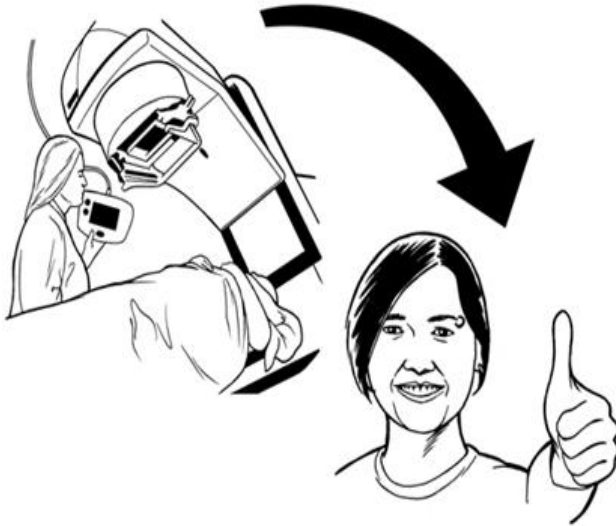


However, some people who get cancer do die.



When a person gets cancer they will need to go to a hospital for treatment.

What is cancer?



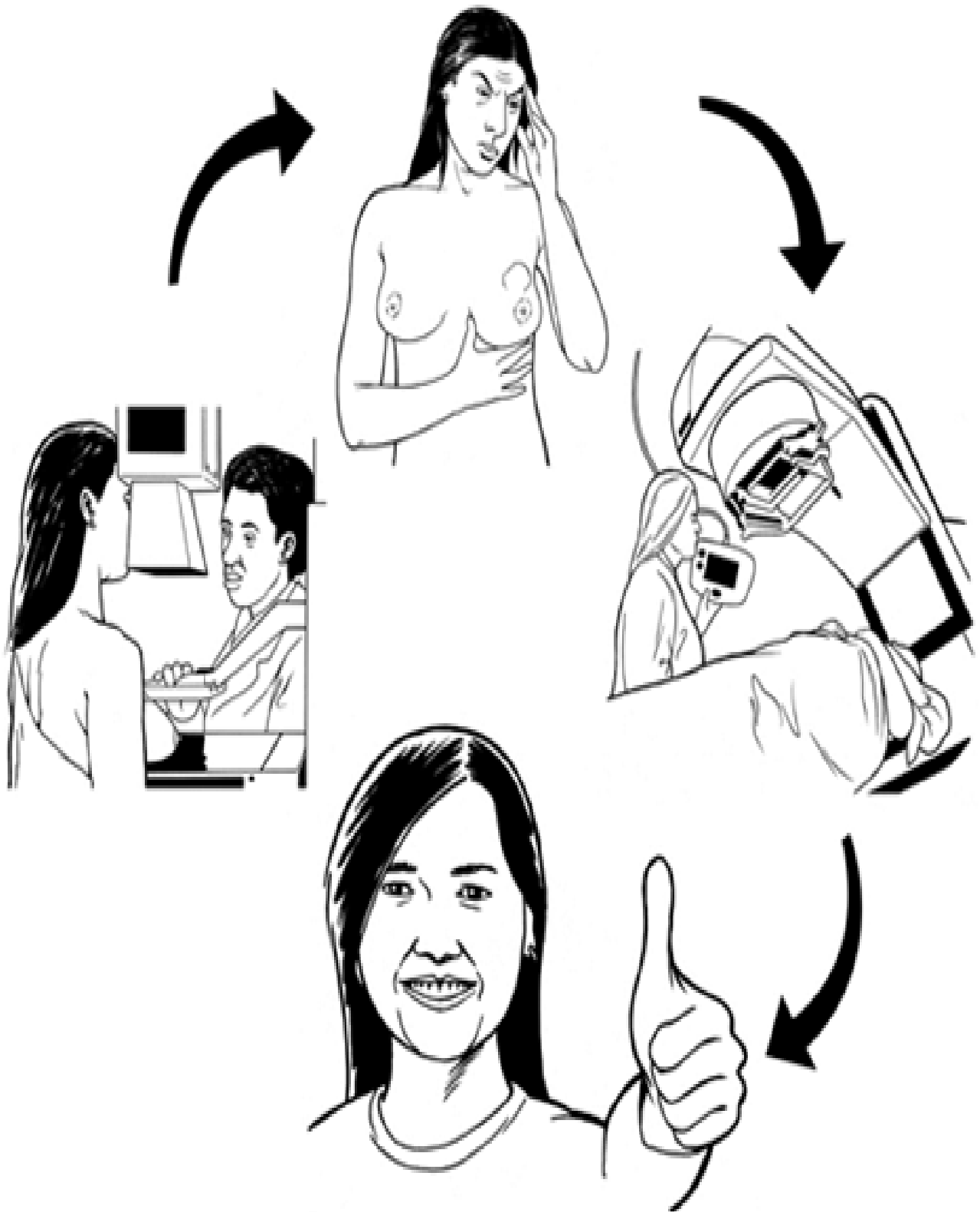
Sometimes the treatment will make them better.



Sometimes the treatment will help them to live longer.



Sometimes the treatment will help them to feel more comfortable and have less pain.



Spotting cancer early

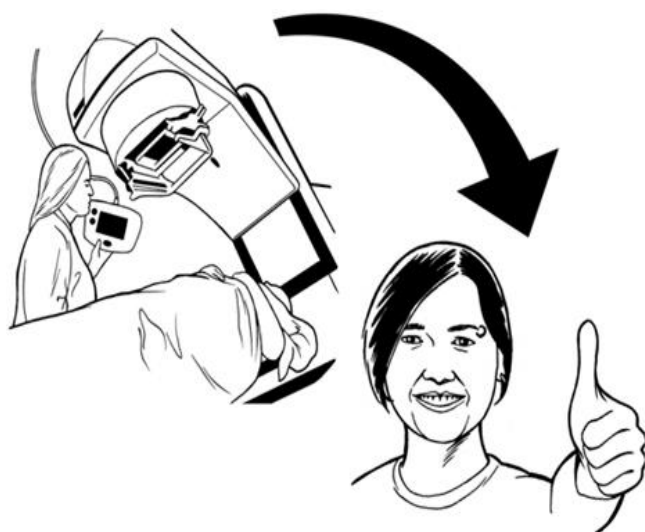
Spotting cancer early



There are special tests called screening that can pick up the signs of cancer early.

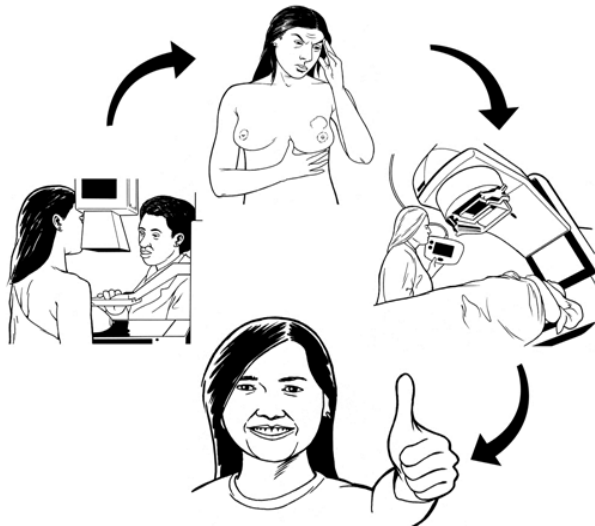


It is very important to go for regular screening even if you feel healthy and have no symptoms.



Choosing to go for screening you are offered is part of staying healthy.

Spotting cancer early



Spotting cancer early gives you the best chance of treating the disease and getting well again.



There are signs and symptoms to look out for that can be caused by cancer.



Sometimes these signs and symptoms are caused by other illnesses. It is important that you go to have them checked.



Staying healthy

Changes you can make to stay healthy



You can reduce your risk of getting cancer by making changes to how you live your life.



There are certain things you can do to keep yourself healthy. These are:

Changes you can make to stay healthy



Stop smoking.
Smoking is the biggest cause of cancer in the world.

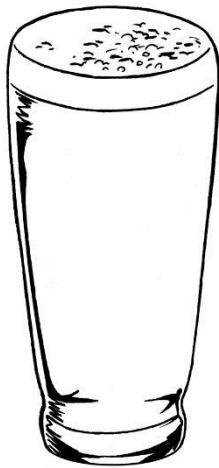


Cut down on the amount of alcohol you drink.



All types of alcohol including: **beer**, **wine** and **spirits** increase your risk of getting cancer.

Changes you can make to stay healthy



Do not drink more than one standard drink per day. For example, **one** glass of beer is a standard drink.



If you are overweight you increase your risk of getting cancer.



The more active you are the more you reduce your risk of cancer.

Changes you can make to stay healthy



So it is important for you to exercise and keep fit.



Walking



Swimming

Changes you can make to stay healthy



Eating a healthy diet can help keep you fit and reduce your risk of cancer.

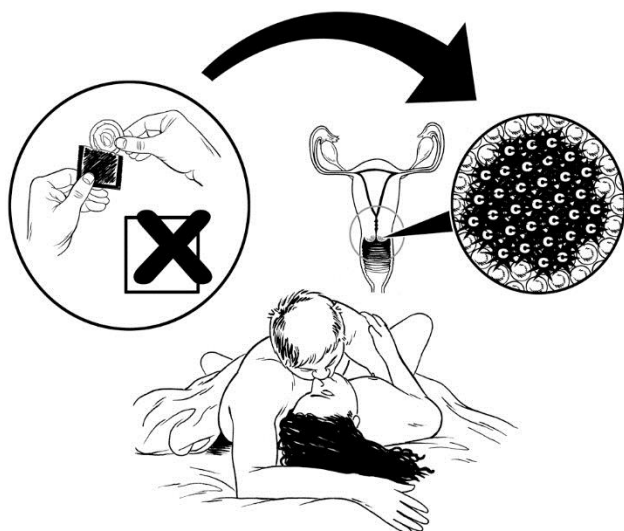


It is important to eat a balanced diet with plenty of fibre, fruit and vegetables.

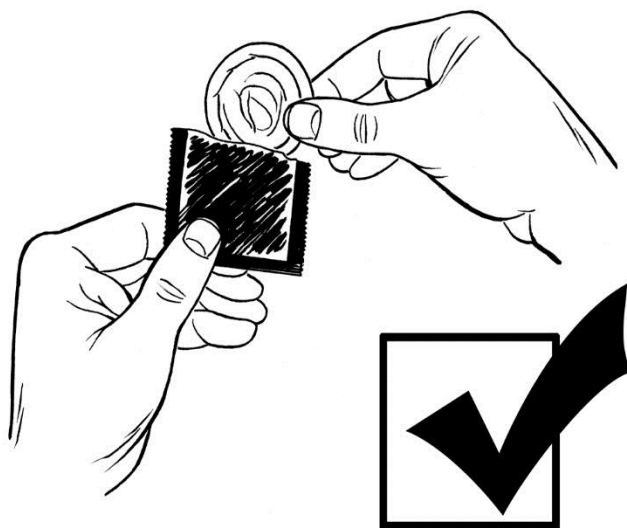


Cut down on eating red meat and foods with lots of fat, salt and sugar in them.

Changes you can make to stay healthy



Some infections are passed on by having unprotected sex.



It is best to always use a condom.

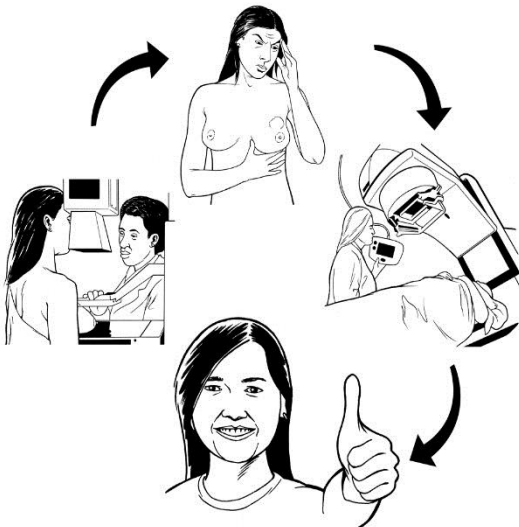


Girls aged between 12 and 18 are offered a vaccine which protects against 2 types of HPV.

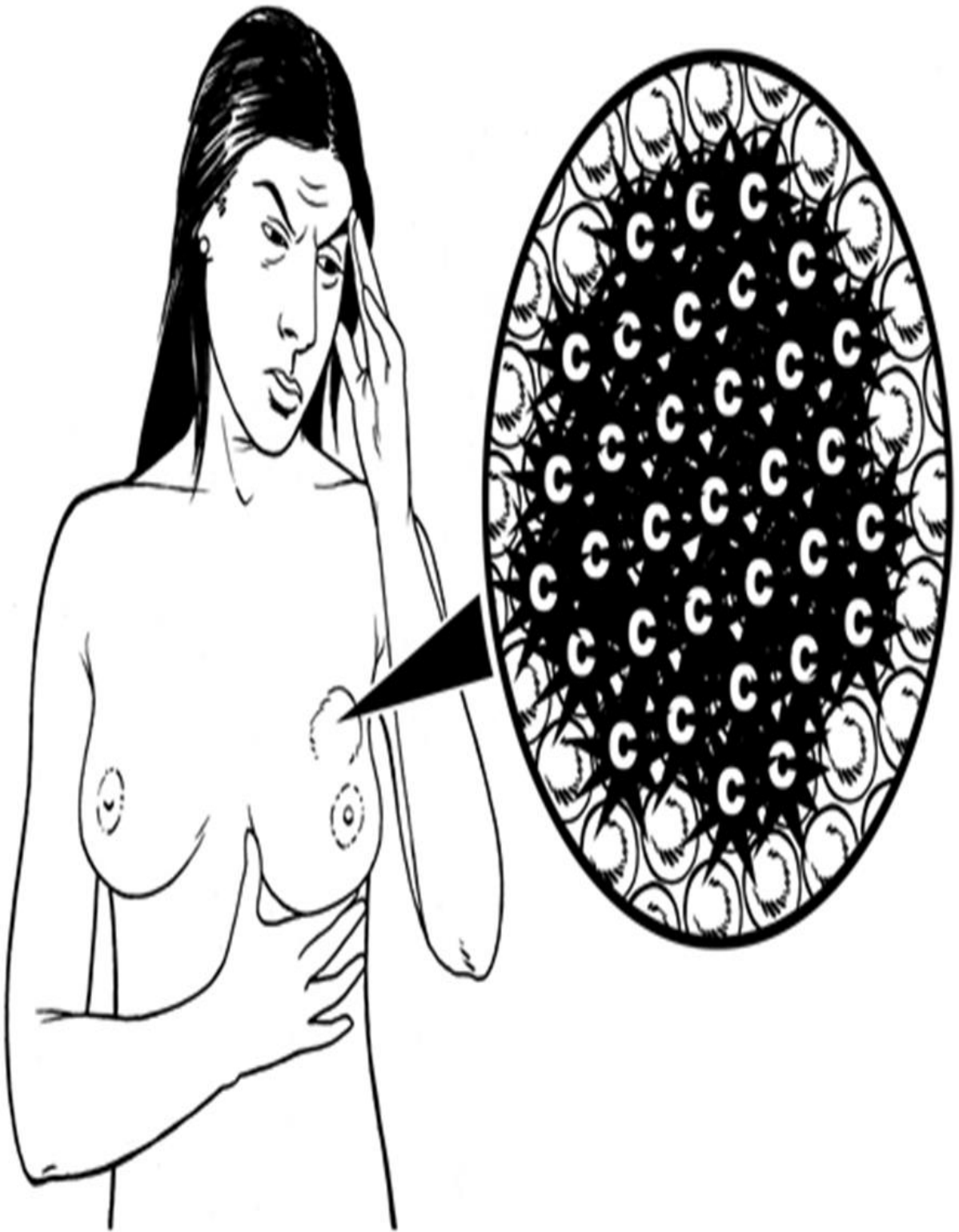
Changes you can make to stay healthy



There are special tests called screening that can pick up signs of cancer early.

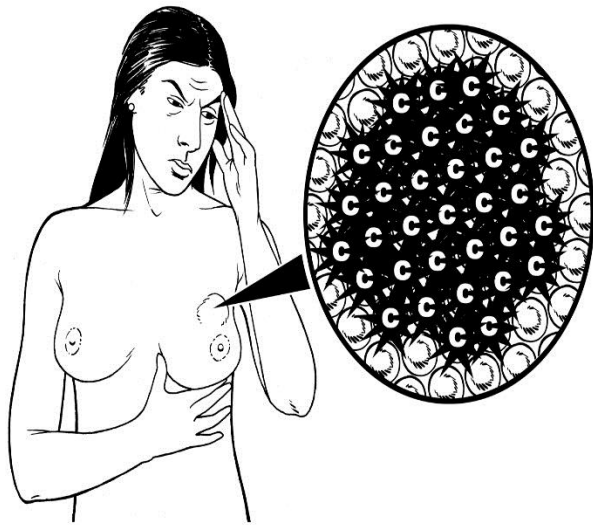


It is important to go for regular screening. Finding out early could save your life.

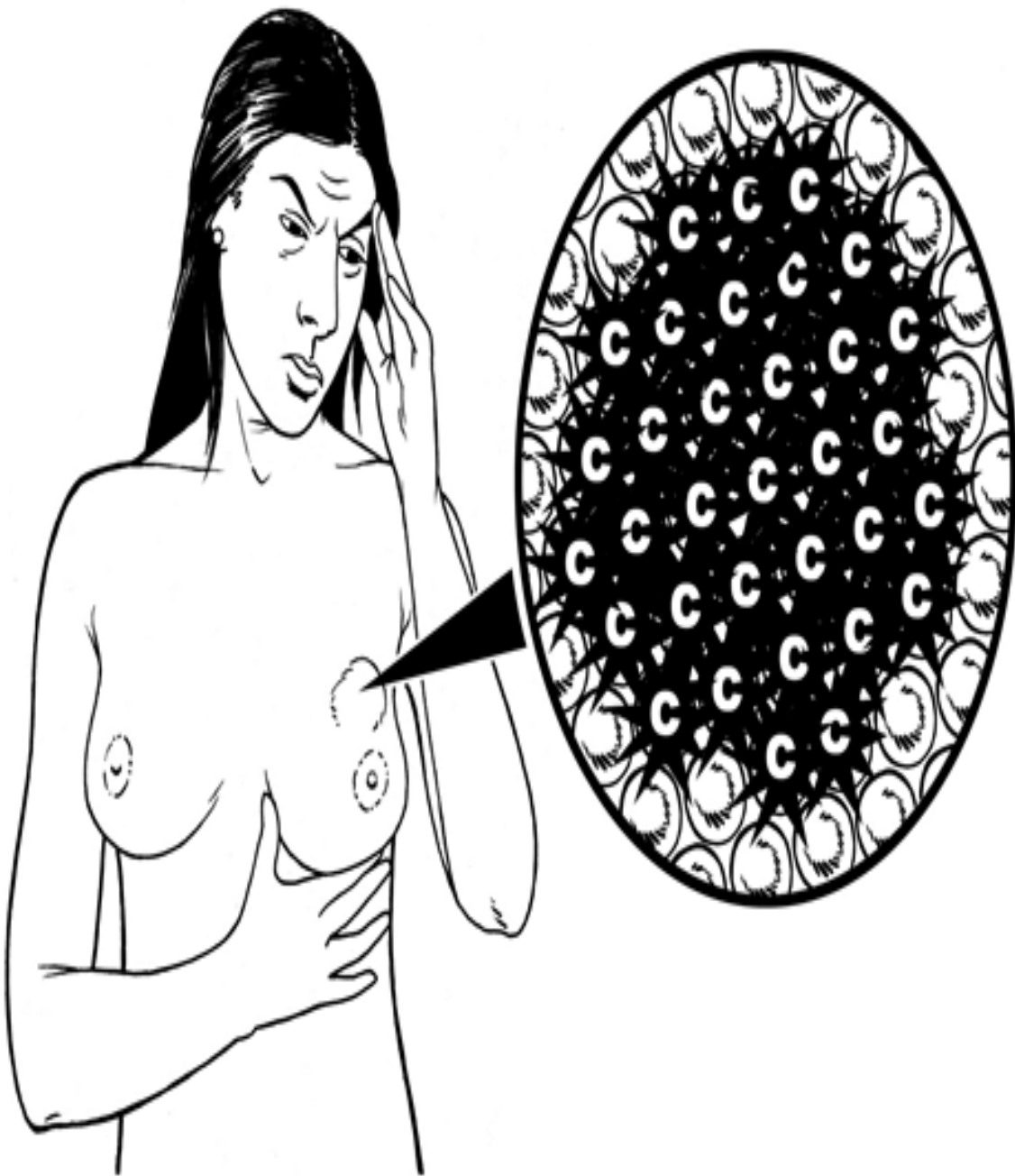


Breast cancer

Breast cancer



The most common cancer for women is **breast cancer.**



What affects my risk of getting breast cancer?

What affects my risk of getting breast cancer?

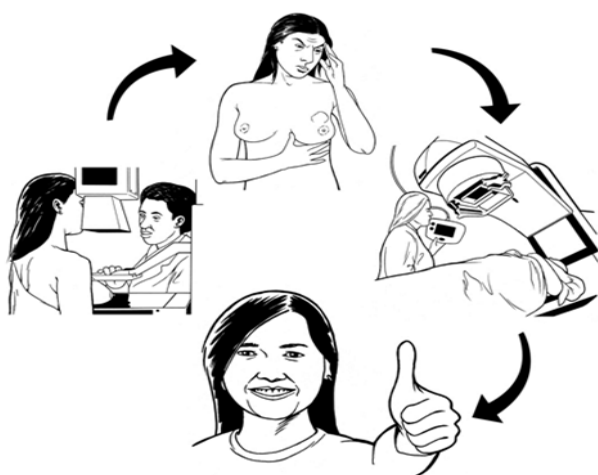


Women of any age can get breast cancer.

The risk is higher when you are **over 50 years of age**.



Women whose mother, aunts or sisters have had breast cancer may have a higher risk of getting breast cancer.



If you had breast cancer already.

What affects my risk of getting breast cancer?



Taking the pill.



Using HRT.



Starting your periods
at an early age

What affects my risk of getting breast cancer?



Having a late
menopause



Having no children or
having children later in
life.

What affects my risk of getting breast cancer?



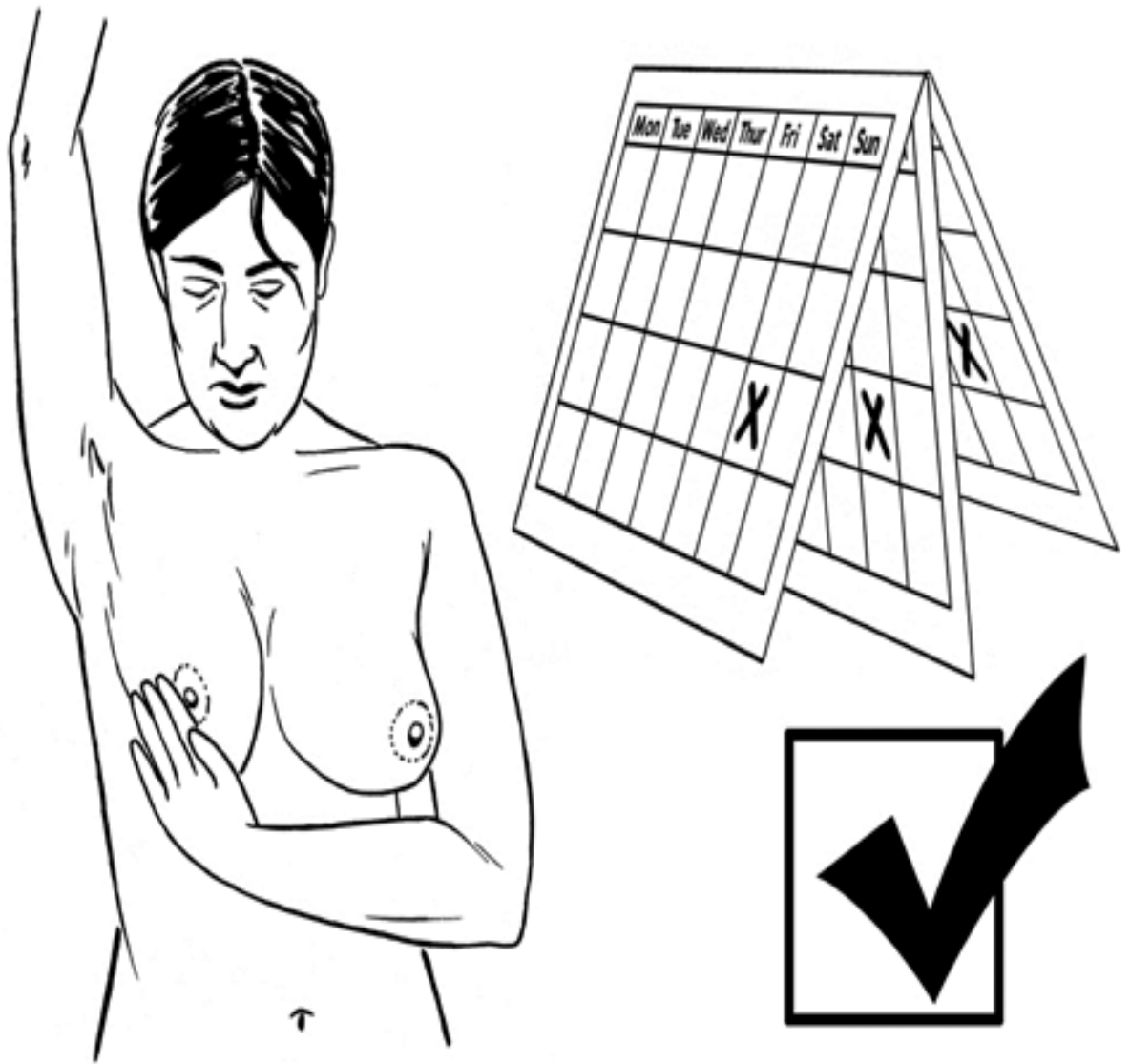
Drinking more than one standard drink per day.



If you are overweight with a BMI of over 25.

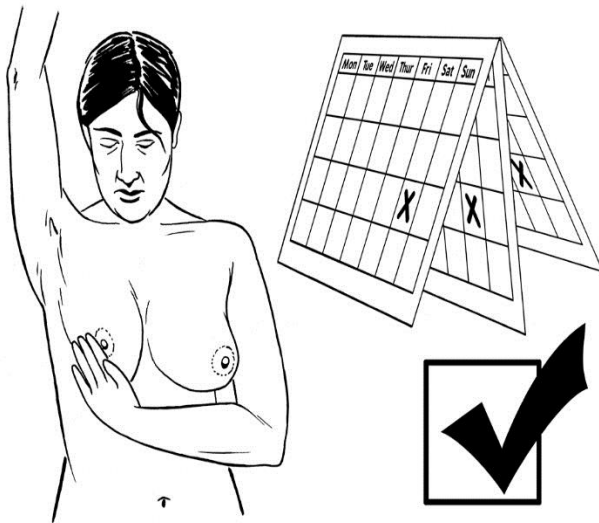


Doing less than 30 minutes of physical activity 5 times a week.

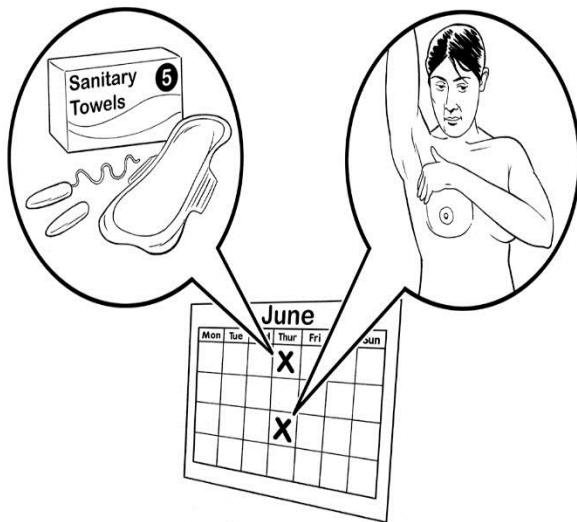


Breast care- self checking

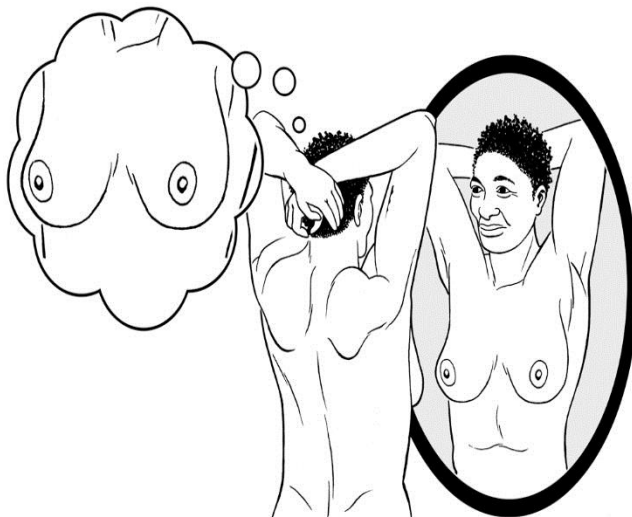
Breast care- self checking



It is very important that women check what their breasts feel like at different times of the month.

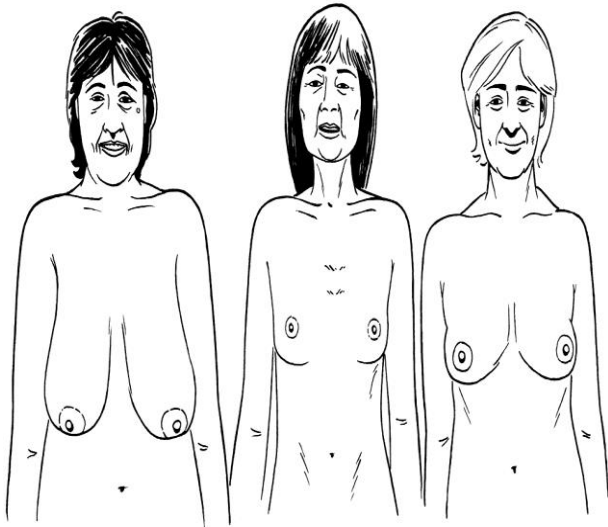


This is because the menstrual cycle makes changes in the breasts.

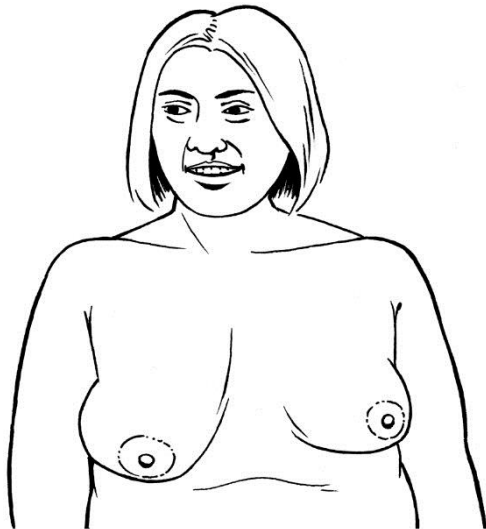


You need to know what is normal for you so you will notice any changes.

Breast care- self checking



Every woman's body is different.

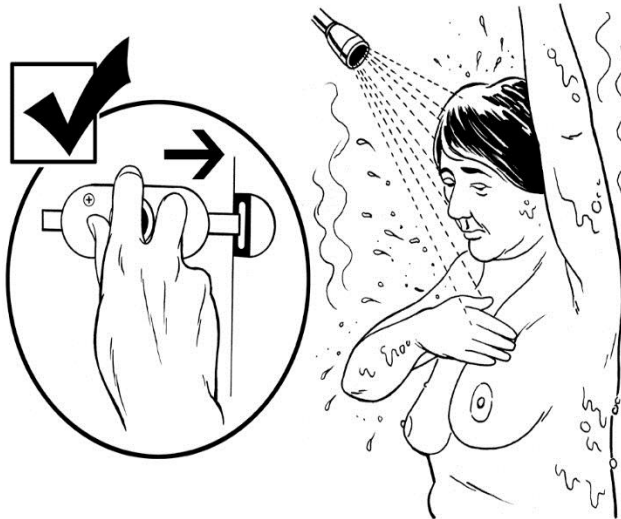


Some women have one breast larger than the other- this is ok.



It is best to check your breasts whilst looking in the mirror to see if anything looks different.

Breast care- self checking



Check your breasts while you are somewhere private like in the shower.



How to check your breasts

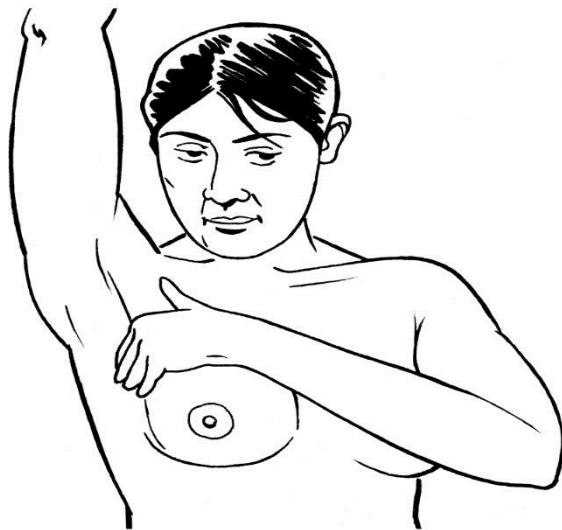
How to check your breasts



Feel all over the breast.



Then feel around the nipple area.



Then feel under your arms.



Changes to look out for

Changes to look out for



If you find changes in your breasts it is very important to see your doctor at once.



You can ask to see a female doctor if you prefer.

Changes to look out for



Lump or thickening in your breast.



Lump or thickening in your armpit.



Any liquid leaking from your nipples.

Changes to look out for



Pulling in of nipple.



Nipple in different place.



Rash on nipple.

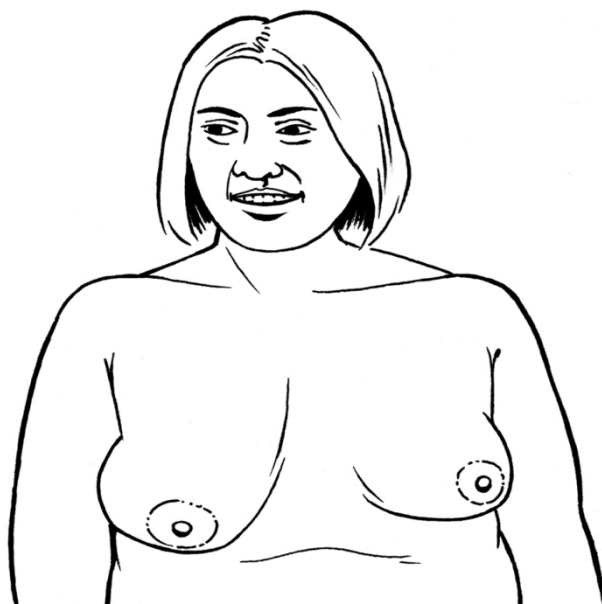
Changes to look out for



Changes to skin on breast – redness.



Change in size or shape of breast.



Changes in shape of breast or nipple.

Changes to look out for



Pain in one breast or armpit.



Changes to skin on breast- dimpling.

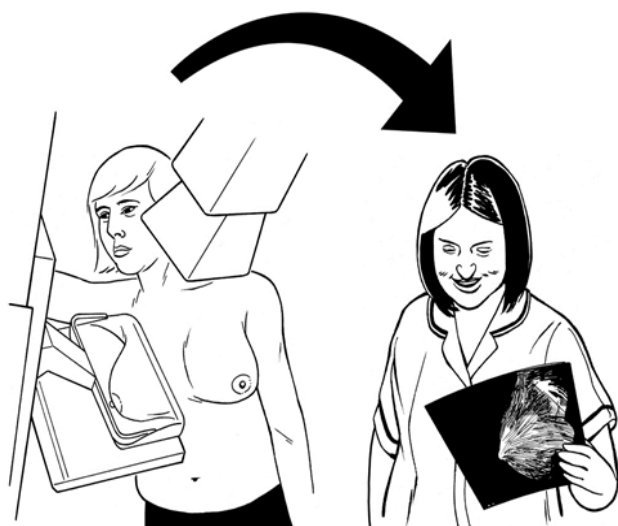


Breast screening

Breast screening



Women aged over **50** will be sent a letter from BreastCheck to invite them to come for a mammogram.

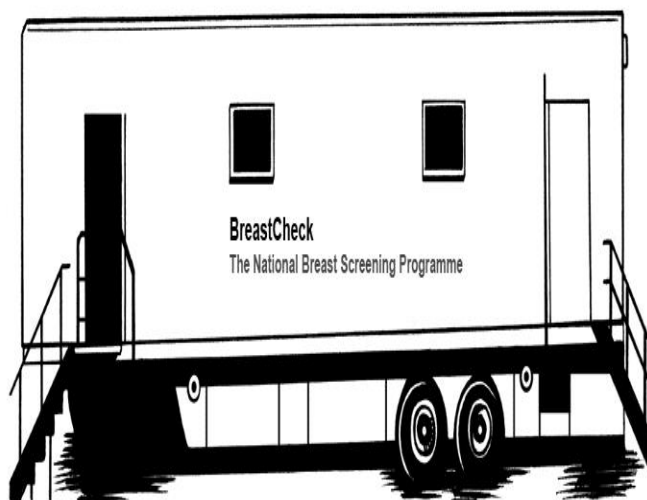


A mammogram is an x-ray of your breasts. This will check if your breasts are healthy.

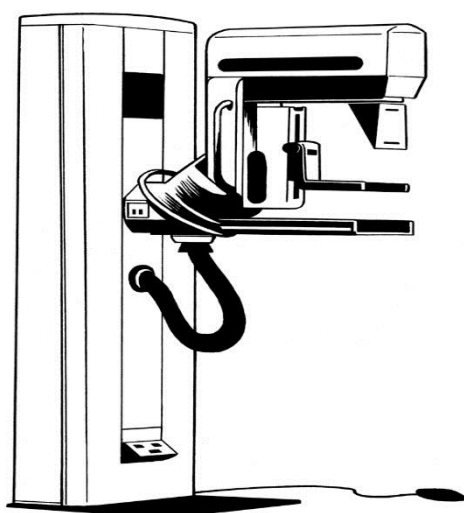


It is your choice if you want to go for a mammogram or not.

Breast screening



Mammograms can take place at hospitals or mobile units.



This is the mammography equipment used to take the x-rays of your breasts.



The radiographer is the person who takes the x-ray.



Mammogram

What happens?

Mammogram- what happens?



It is always female staff who do the mammogram.

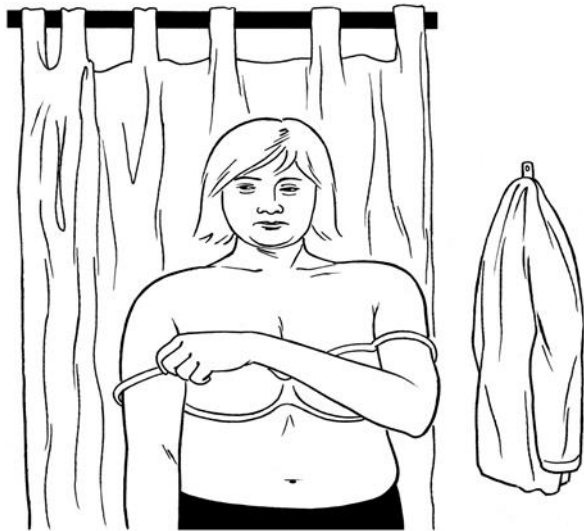


You can bring someone along to support you.



The radiographer will talk to you about the mammogram.

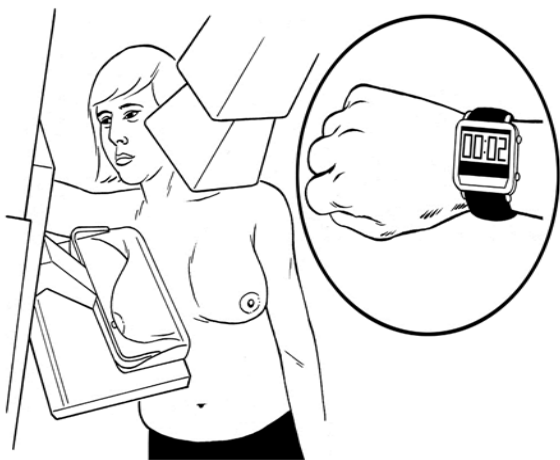
Mammogram- what happens?



You will be asked to undress from the waist up.



The radiographer will put your breasts one at a time between the plates and take the x-rays.



The mammogram will only take a few minutes.

Mammogram- what happens?



The radiographer will go behind a glass screen when the x-rays are being taken.



Some women find it painful or uncomfortable.



What happens next?

What happens next?



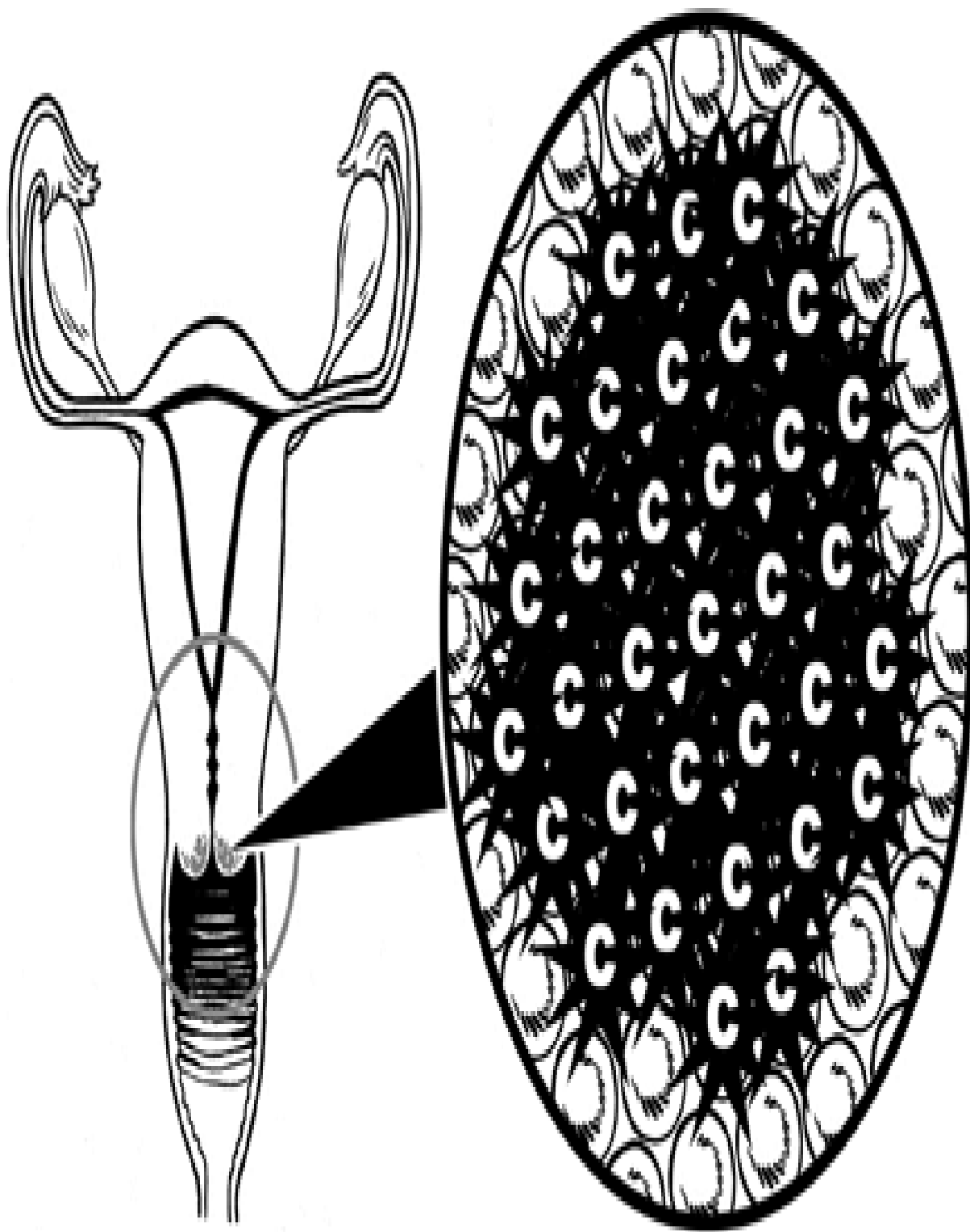
You will be sent a letter to tell you the results after a few weeks.



Sometimes you will be asked to come back for another mammogram.

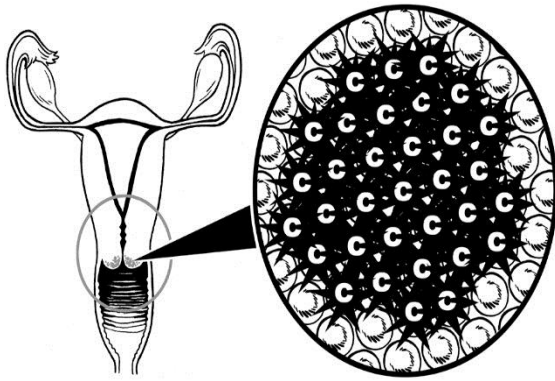


Ask for support to find out why you have to have another test.

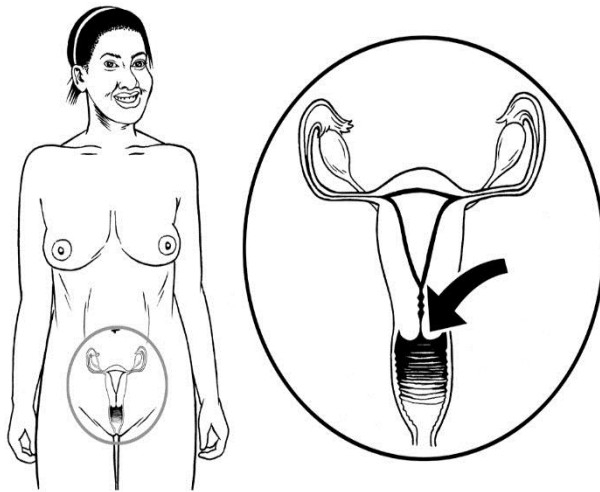


Cervical Cancer

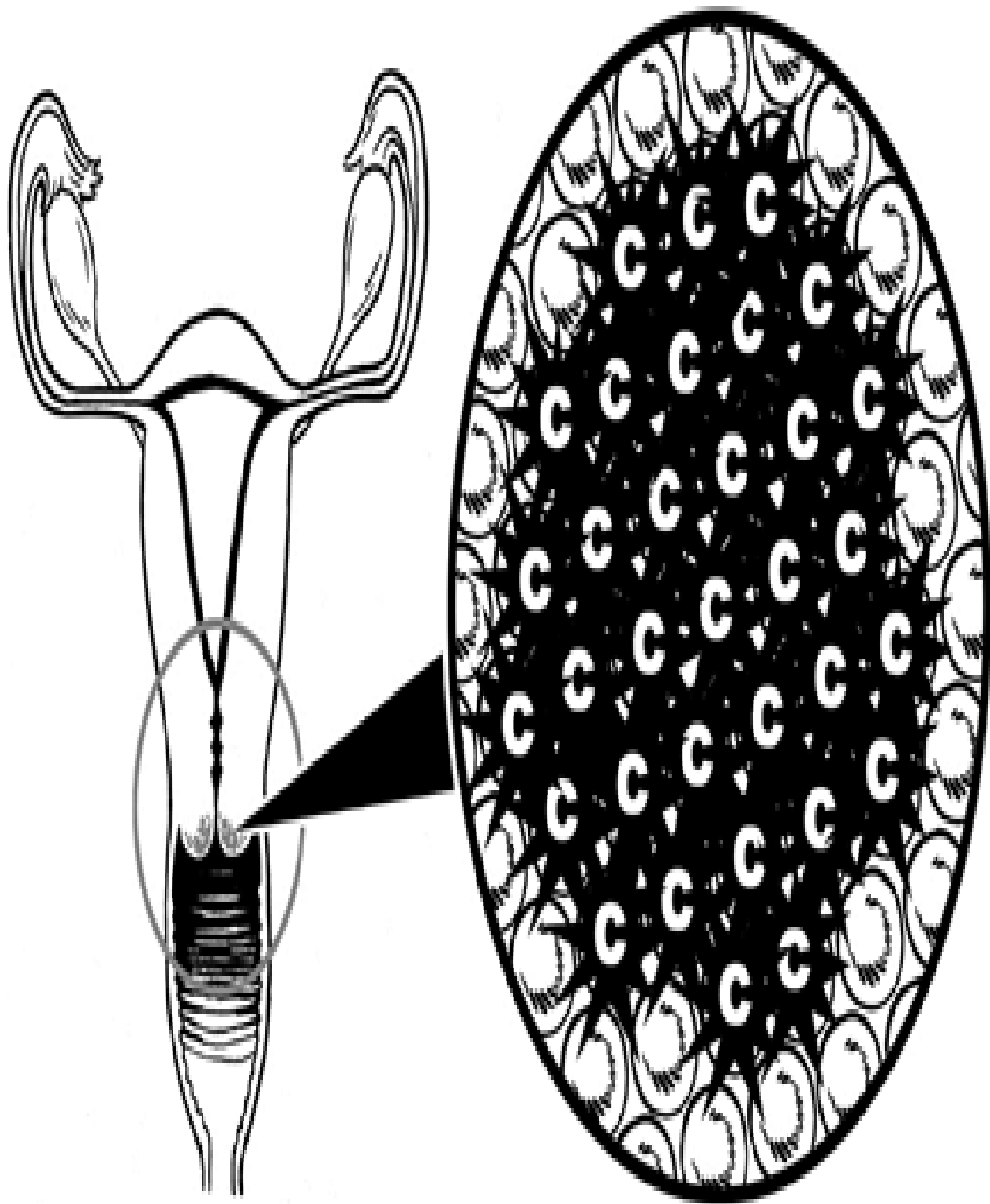
Cervical cancer



Women can get cancer of the cervix.

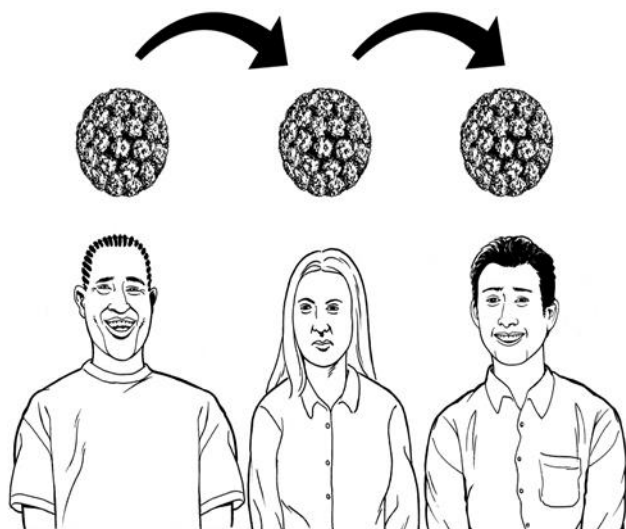


The cervix is the opening at the bottom of your womb inside the vagina.



What affects my risk of getting cervical cancer?

What affects my risk of getting cervical cancer?



Human Papilloma Virus (HPV) is a very common infection that is passed on during sex.



If you smoke, it can prevent the infection clearing up.



Not having regular smear tests.



Cervical screening

Cervical screening



All women between the ages of 25 and 60 are asked to go for a smear test.



You will be sent a letter inviting you to make an appointment for a smear test at your G.P.



It is your choice if you want to go for a smear test or not.

Cervical screening



If you are aged between 25 and 44 it is a good idea to have a smear test every 3 years.



If you are aged between 45 and 60 it is a good idea to have a smear test every 5 years.



The smear test will be done by a nurse or a doctor.

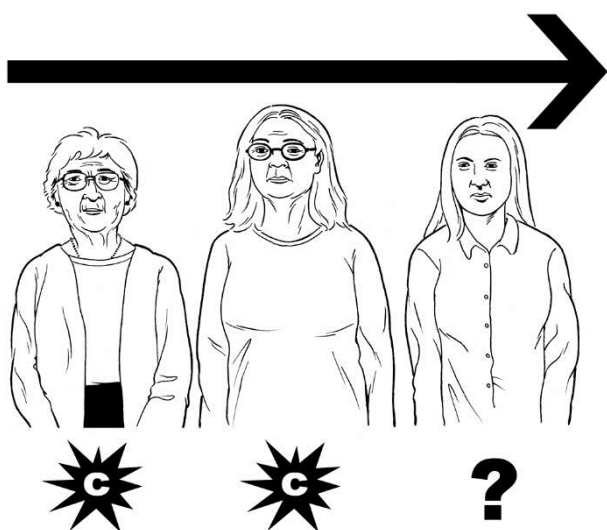
Cervical screening



You can ask for a female nurse or doctor if you are embarrassed.



You can bring someone to support you as well.



If there is a history of cervical cancer in your family you should have a smear test regularly.



Smear test – what happens?

Smear test – what happens?



The doctor or nurse will talk to you about your health.



They will then ask you to take off your pants.

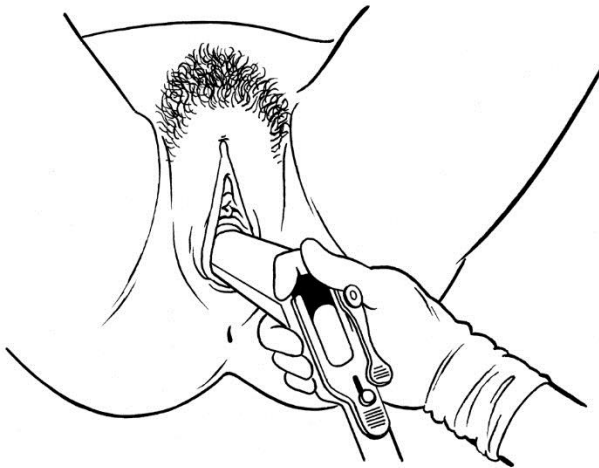


And then ask you to lie down on the examination bed.

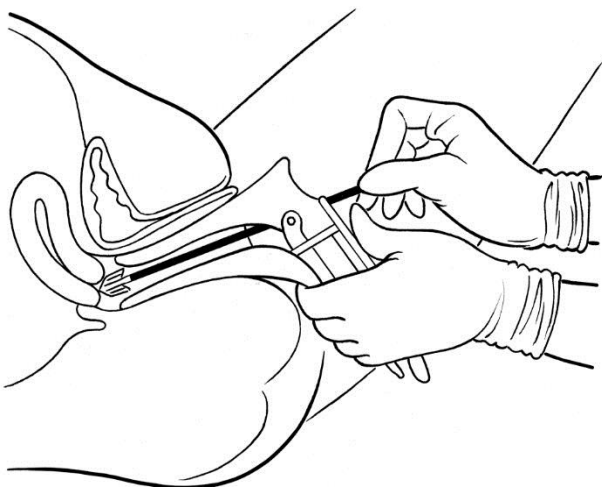
Smear test – what happens?



It is very important to try to relax and not worry during the smear test.



The doctor or nurse will use a **speculum** to open up your vagina so that they can see your cervix.

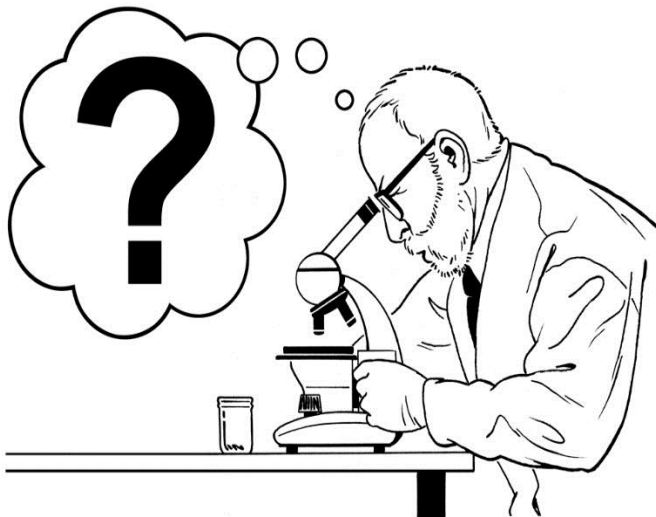


The doctor or nurse will use a small brush to take a sample of cells from your cervix.

Smear test – what happens?



That is it! You will be asked to get dressed again.



The cells that are collected on the brush will be sent for testing.



What happens next?

What happens next?



You will be sent a letter to tell you the results after a few weeks.

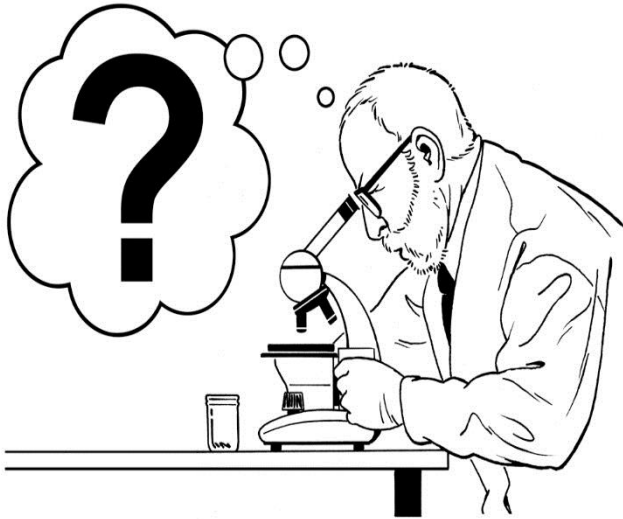


The letter may tell you that the test showed that everything is OK.

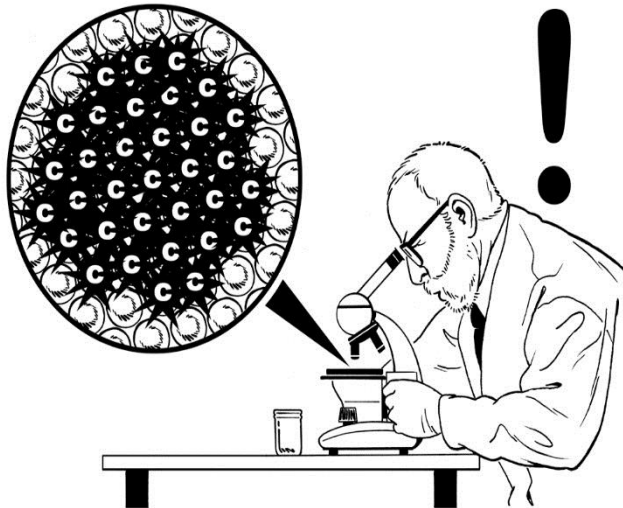


Sometimes you will be asked to come back for another test.

What happens next?



This might be because the test did not work properly.



Or it might be because the test shows that something is wrong.



Ask for support to find out why you have to have another test.



Changes to look out for

Changes to look out for



You need to go to your doctor as soon as possible if you have any of these symptoms:



Bleeding between periods.



Thick or smelly discharge from your vagina.

Changes to look out for



Pelvic pain.



Bleeding or pain during or after sex.



Any bleeding after you have had the menopause.



Useful contacts and resources

Useful contacts

BreastCheck- The National Breast Screening Programme

Freephone Information line: 1800 45 45 55

Email: info@breastcheck.ie

Additional help for people with disabilities can be arranged by phoning 01 8659300 or by sending an email to the BreastCheck Access Officer access@breastcheck.ie

See more at: www.breastcheck.ie

Cervical Check- The National Cervical Screening Programme

Freephone Information line: 1800 45 45 55

Email: info@cervicalcheck.ie

Additional help for people with disabilities can be arranged by phoning 1800 45 45 55 or by sending an email to the CervicalCheck Access Officer access@cervicalcheck.ie

See more at: www.cervicalcheck.ie

Irish Cancer Society

Provides information on cancer types, tests, treatments, side-effects and how to cope with a cancer diagnosis.

Call the National Cancer Helpline on Freephone 1800 200 700.

The Helpline is open Monday to Thursday from 9am-7pm; Friday from 9am-5pm.

See more at: <http://www.cancer.ie>

Useful resources

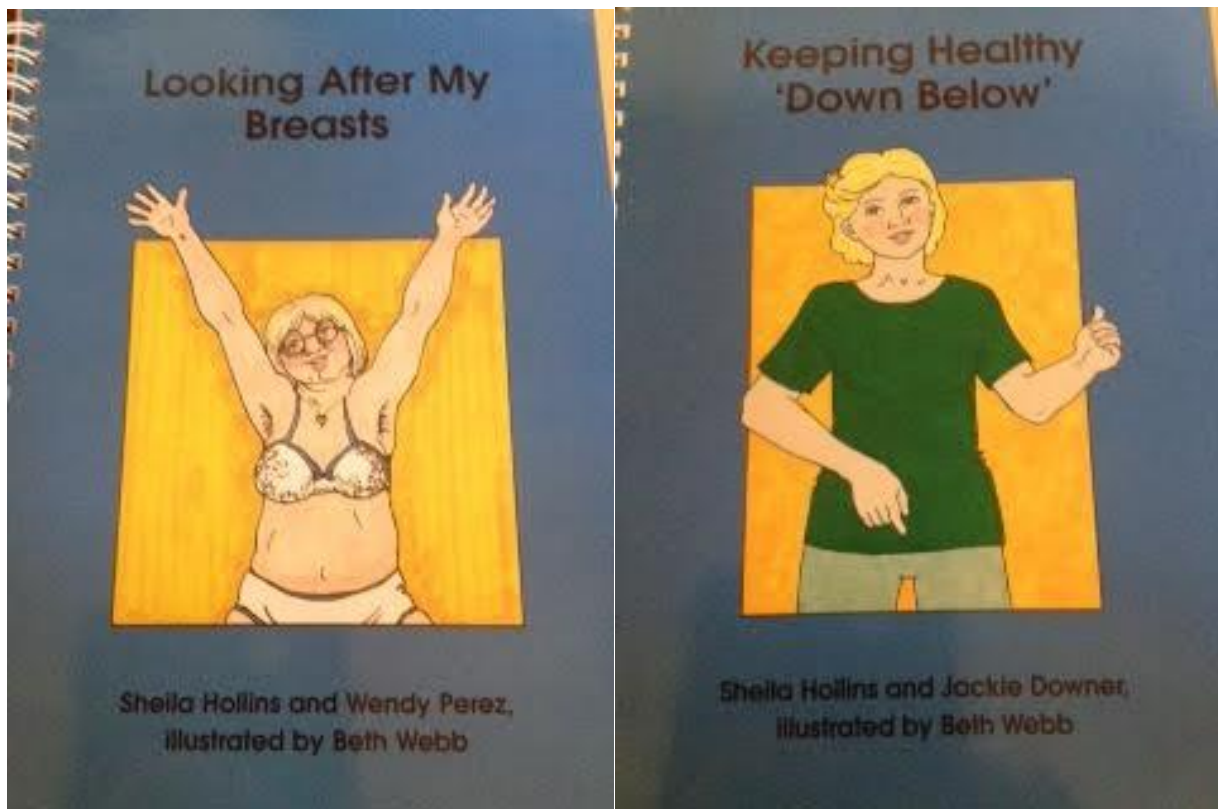
Books Beyond Words

Books beyond Words use pictures to tell stories that engage and empower people, on themes such as health. Each Books Beyond Words title has written information, guidelines and resources for readers, families, supporters and professionals.

The two books related to this programme are:

Looking after my breasts

Keeping Healthy 'Down Below'



See more at: www.booksbeyondwords.co.uk

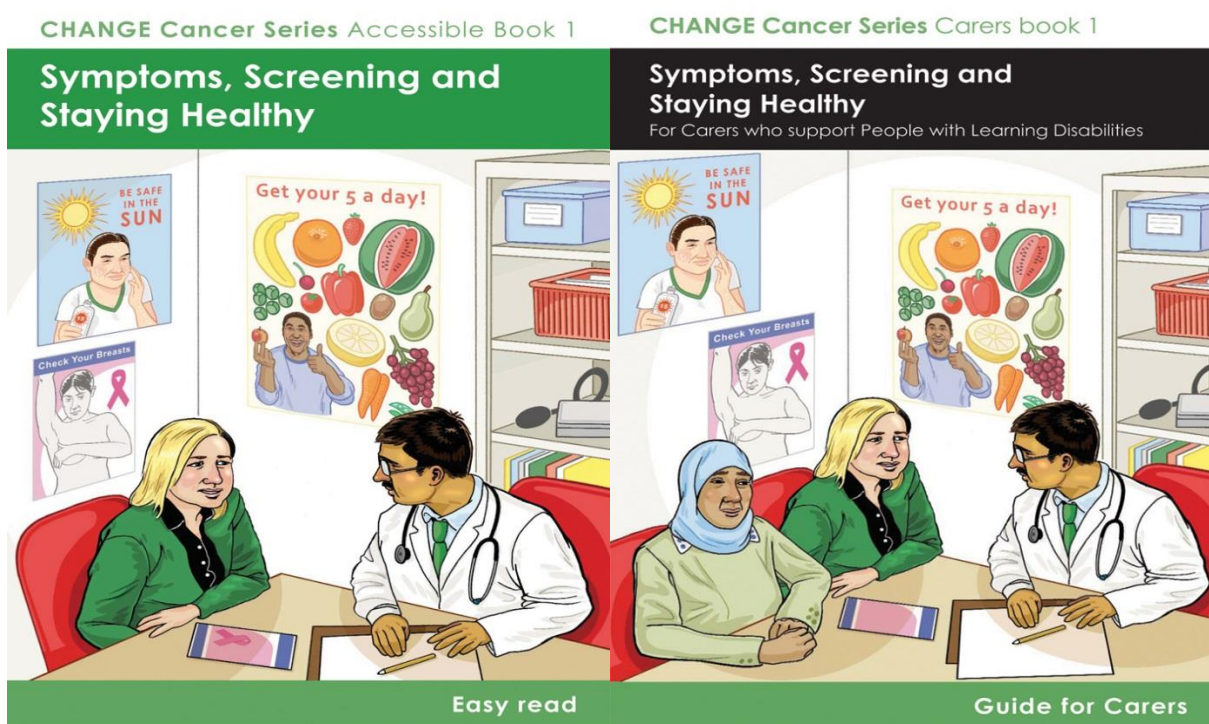
Useful resources

The CHANGE Cancer Series of books were produced by CHANGE, a leading Human Rights organisation led by disabled people. Macmillan Cancer Support and CHANGE work together to make cancer services more accessible.

There are 6 accessible books in the CHANGE Cancer Series

Book 1: Symptoms, Screening and Staying Healthy

Book 1: Symptoms, Screening and Staying Healthy for Carers




Useful resources

Book 2: Diagnosis and Treatment

Book 2: Diagnosis and Treatment for Carers

CHANGE Cancer Series Accessible Book 2 **CHANGE Cancer Series Carers book 2**

Diagnosis and Treatment **Diagnosis and Treatment**
For Carers who support People With Learning Disabilities through cancer



The book cover features several circular illustrations: a surgical team performing an operation, a patient in a hospital bed being scanned by a machine, a patient sitting in a chair with a medical monitor, and a carer sitting in a red chair reading a book. The main illustration shows a man in a yellow shirt sitting in a red chair reading a book, with another man in a green shirt sitting next to him pointing at the book.


Easy read Guide for Carers

Book 3: Palliative Care, End of Life Care and Bereavement

Book 3: Palliative Care, End of Life Care and Bereavement for Carers

CHANGE Cancer Series Accessible Book 3 **CHANGE Cancer Series Carers book 3**

Palliative Care, End of Life Care and Bereavement **Palliative Care, End of Life Care and Bereavement**
For Carers supporting People with Learning Disabilities



The book cover features two illustrations of a carer supporting a patient in a wheelchair. The main illustration shows a man in a red shirt supporting a woman in a purple shirt and a blue headscarf in a wheelchair. The smaller illustration shows a man in a blue shirt supporting a woman in a purple shirt and a blue headscarf in a wheelchair, with another man in a yellow shirt standing next to them.

Easy read Guide for Carers

Acknowledgements

All pictures used in this booklet are from the CHANGE Picture Banks© www.changepeople.co.uk'

The programme activities have been adapted from the Women be Healthy© programme.

This educational programme is part of a study taking place by the HSE and Waterford Institute of Technology.

Programme Activities

Week 1: Keeping yourself healthy

I will practice relaxing and think of something nice to say to myself when I have to visit the doctor.

Mark an X on the chart below each day you practice relaxing.

Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday



Programme Activities

Week 2: Keeping yourself healthy

I will practice relaxing and think of something nice to say to myself when I have to visit the doctor.

Mark an X on the chart below each day you practice relaxing.

Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday



Programme Activities

Week 3: Keeping yourself healthy

I will practice relaxing and think of something nice to say to myself when I have to visit the doctor.

Mark an X on the chart below each day you practice relaxing.

Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday



Programme Activities

Week 4: Keeping yourself healthy

I will practice relaxing and think of something nice to say to myself when I have to visit the doctor.

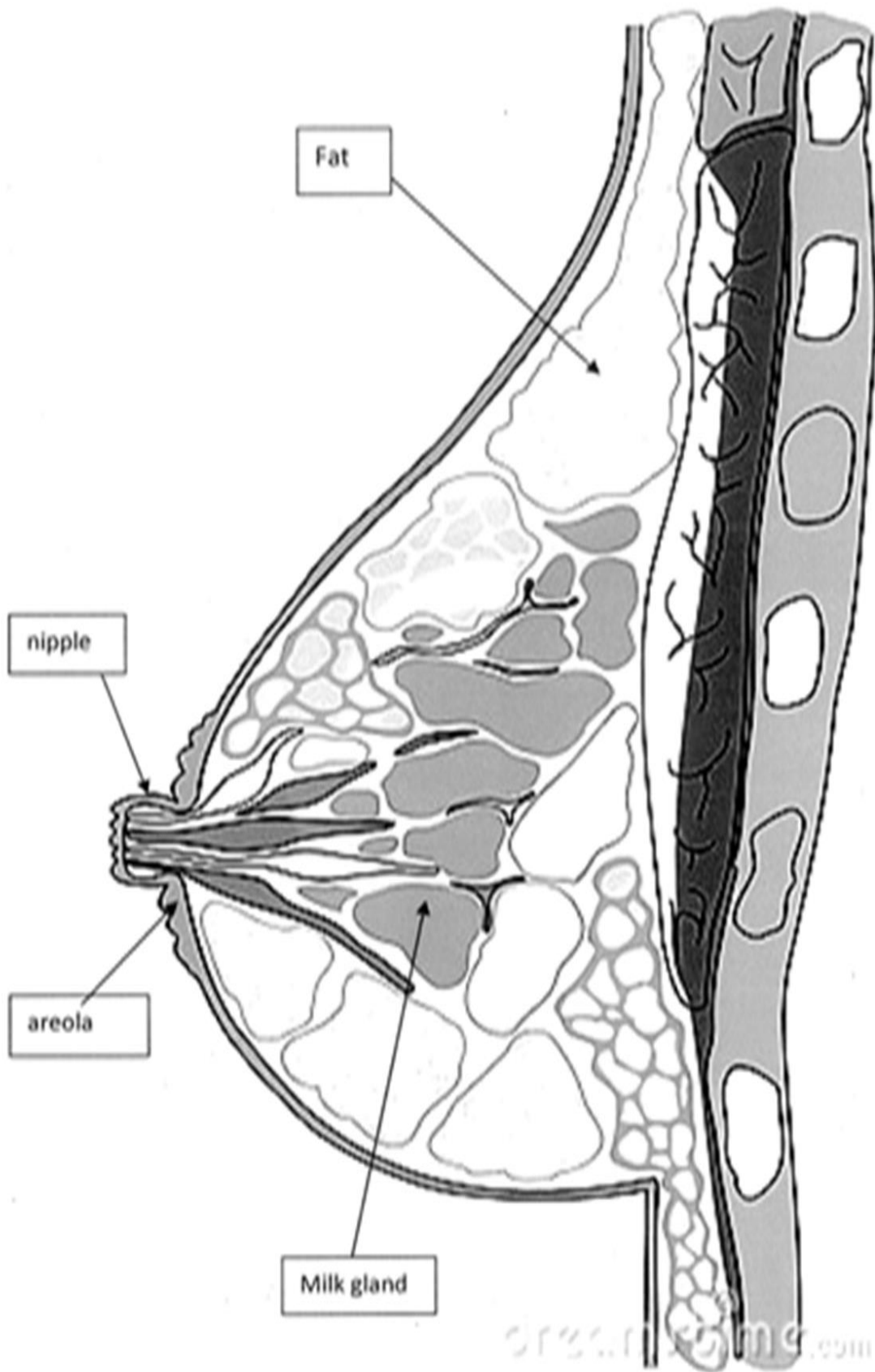
Mark an X on the chart below each day you practice relaxing.

Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday



Programme Activities

Week 2: Colour the female breast.



Programme Activities

Week 3:

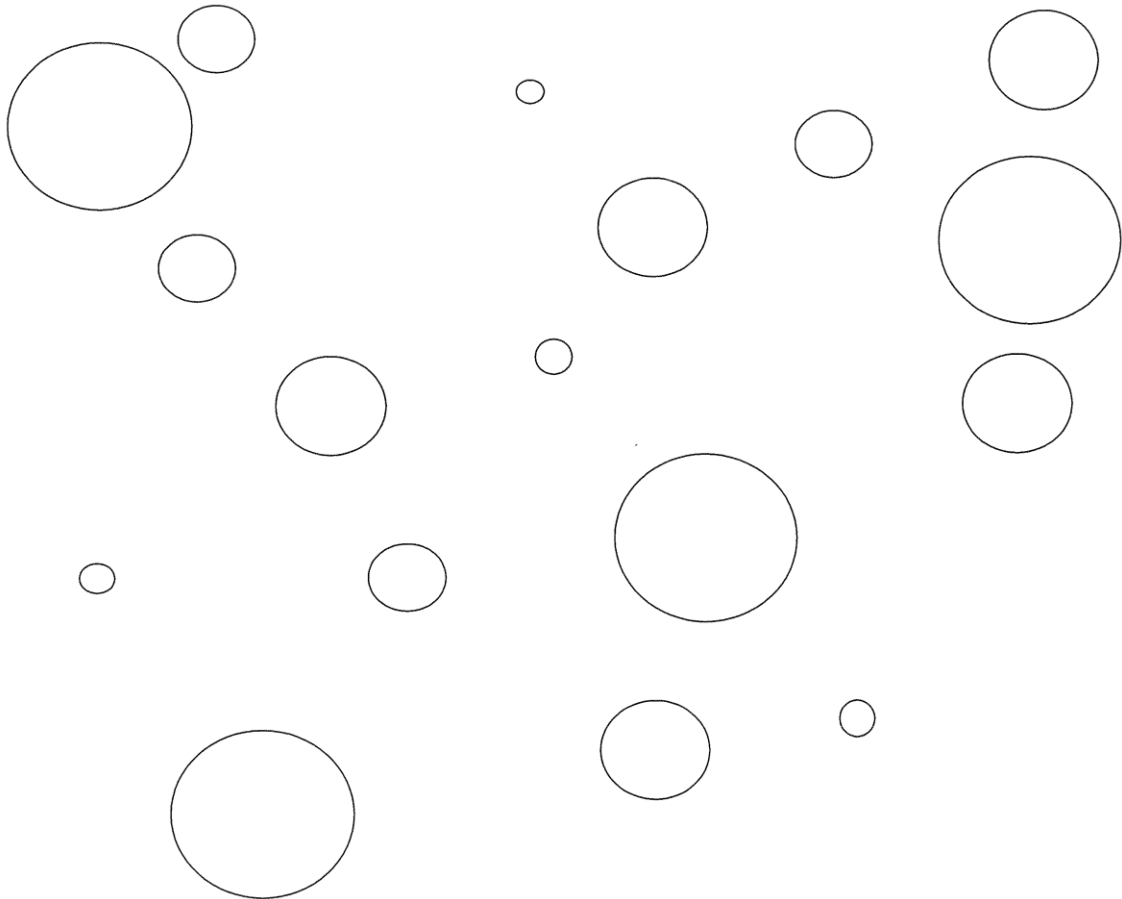
I will color the smallest sized lump circles PINK on the mammography handout. These are the size of lumps that a regular screening mammogram can find.



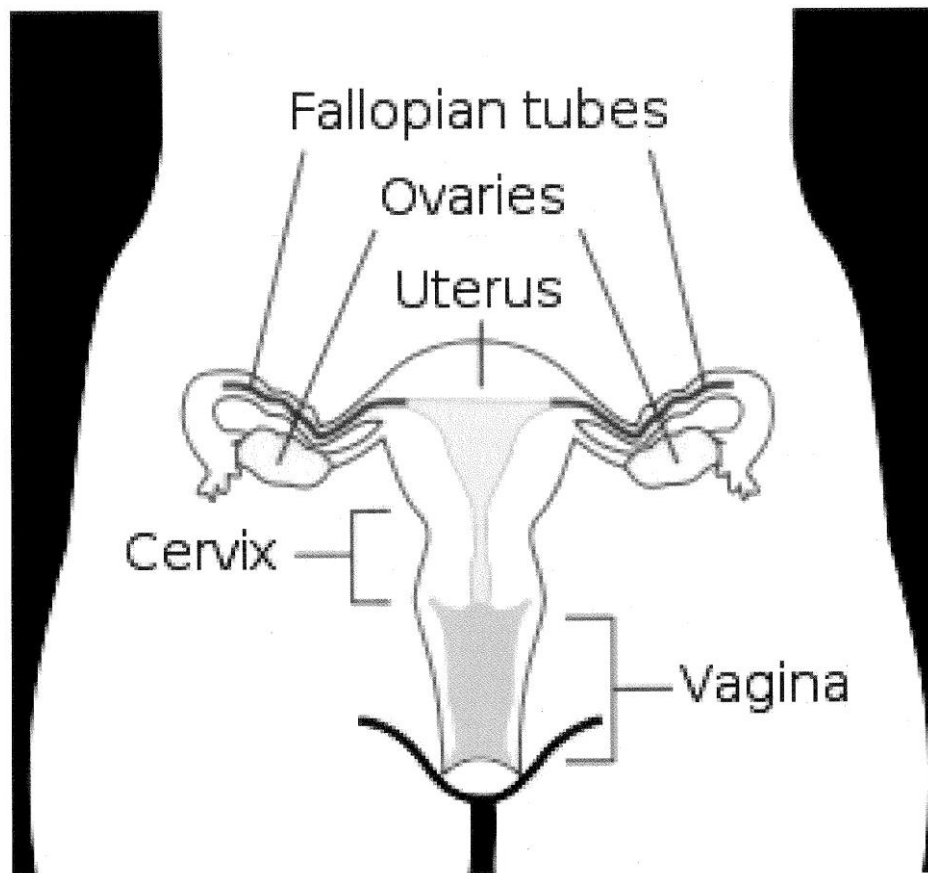
Programme Activities

Colour the size of a lump that can be found by a mammogram.

There is more than 1!



Programme Activities



Color female body parts:

- Ovaries - yellow
- Fallopian tubes - orange
- Uterus - blue
- Cervix - pink
- Vagina - green

AVI.2 EMBRACES-ID Equipment Schedule Costing

Item Description	Price (€)
Change People UK: Adapted Pictures (n=22)	400
AnatomyStuff Breast with common pathologies model	58
Books Beyond Words- breast and cervical	25
Health Books UK Budget Female Pelvic Section	60
Health Edco Breast Cancer Lump Self Exam Training Trainer Teaching Model (Used demonstration model: ebay.com)	69
<ul style="list-style-type: none"> • Health Edco Breast Cancer Awareness Necklaces • Health Edco Breastology Bag • Health Edco Cervix Models 	211
Teach a Bodies Anatomically Correct Female Doll Model (Used demonstration model: ebay.com)	56
Paints and materials	50
Total start-up cost	1009

AVI.3 EMBRACES- ID weekly lesson plans (Adapted from WBH©)

EMBRACES – ID SESSION 1 – TWO HOUR SESSION

Introduction to the programme (20 minutes)

10 minutes: Why are we here? Introductory session for the group. **(Group activity)**

- Put relevant icon on the flipchart when discussing that topic. **(Repetition of key concepts)**
- Flipchart to record ideas, key message we are healthy women here to learn about cancer and the tests to check for cancer.

10 minutes: Ground rules help the group to create a safe and comfortable place to learn enables the classes to be completed efficiently. **(Group activity)**

Suggested ground rules

- Start on time
- Allow each person time to talk
- Don't interrupt
- Keep on the topic
- Laughter is OK
- Be open minded
- Take chances
- Don't be afraid of mistakes
- Ask for help when you need it
- Give people positive feedback
- Listen
- Keep what is said private
- No comment is stupid
- Its ok to disagree respectfully
- If someone disagrees with you don't take it personally
- Each person is in charge of their own learning (take breaks, ask questions, the right to pass)

Introduction to cancer (30 minutes)

20 minutes: What is cancer?

Facilitator: In the next few weeks we are going to learn about health and certain kinds of cancer that women get called breast and cervical cancer (use the anatomically correct doll when discussing the body parts)

If these terms are unfamiliar don't worry, we will explain these terms in our classes

Raise your hand if you have heard of cancer.

Group activity: What types of cancer have you heard of? Some of you might even have known somebody who has cancer (Use flipchart board to record the answers)

Facilitator: EMBRACES PROGRAMME BOOKLET Pages 4-11 – providing accessible information about what cancer is.

10 minutes Cell growth activity (**Group activity**)

Facilitator Let's place a piece of yarn on the floor in a circle, the size of a small hula hoop.

Let's pretend each of us is a cell in the breast. One person pretends to be a cell in the breast and stands inside the yarn circle. Have the next person stand in the yarn circle (breast). Then the next person gets in the circle. Eventually there will be too many people that can fit into the circle (make the circle small enough so that all students cannot fit).

This is how cancer works. It grows and grows and sometimes it won't stop unless a doctor can help with medicine or other treatments.

Have women sit down once everyone has tried to fit in the circle.

Does anyone have any questions about cancer?

Spotting cancer early (15 minutes)

15 minutes EMBRACES Booklet pgs 12-14. Put spotting cancer early icon on the board.

Facilitator: Cancer is when parts of the body have lumps that won't stop growing.

Breast and cervical cancer can be serious but can be treated if found early by a doctor

You can't tell by looking at someone that they have cancer- only a doctor can tell with tests

It is important for women to get mammograms and smear tests to look for breast and cervical cancer. This is called breast and cervical cancer screening.

Staying healthy (25 minutes)

10 mins Brain storm (group activity)

We are here today to begin learning what it means to be a healthy woman. What does it mean to be a healthy woman- record answers on the flipchart, ensure each item is discussed with the group.

- Feeling good
- Not being sick
- Everything is working alright
- Wear a seatbelt when in the car
- Wear sunscreen
- Wear a helmet when riding a bike
- Brush your teeth twice a day
- Go to the doctor when you are sick
- Go to the doctor for regular check ups
- Take medication regularly when the doctor told you
- Get regular screening such as breast and cervical screening.
- Don't smoke
- Don't drink alcohol
- Eat healthy foods- name some
- Eat foods low in salt sugar and fat
- Don't eat too much fried food
- Healthy snacks
- Three meals a day
- Eat slowly
- Be physically active- name some activities

15 mins EMBRACES booklet 15-22.

Facilitator discusses the changes you can make in your life to stay healthy, repetition of the key ideas given by the women.

Building advocacy skills – (10 minutes) (SCT-Self-efficacy) (Group activity)

Keeping healthy

The facilitator will read out each scenario. The facilitator then asks ‘What would you do?’

- You want to do something healthy but don’t know what to choose.
- You want to lose some weight but don’t know where to start.
- Someone offered you a beer to drink but you wanted to say NO.
- Someone offered you a cigarette to smoke but you wanted to say NO.
- You think it’s time for a smear test.
- You think it’s time for a mammogram.

Think about what you would do if you had one of these problems and then say what you would do to ask for help. It’s okay if you don’t know how to do this or feel shy because we will help you along the way. The class members then share their ideas.

Relaxation technique (10 minutes) (Suggested music Bach Air on a G string)

Facilitator Breathing: Your breathing is relaxed when it is slow and regular (**SCT-Modelling**). It is not relaxed if it is rapid or if there are interruptions such as coughing, yawning, sneezing, sniffing or talking. Place one hand on your stomach, and one hand on your chest, sit back in your seat with your legs on the ground, close your eyes and breathe in through the nose and out through the mouth like you are smelling a flower. If in a wheel chair practice the same breathing technique.

Please show me how you can do relaxed breathing. Do the best you can.

Feedback for each person

Positive: Notice the relaxed feelings in your chest as you breathe in in a relaxed way.

Corrective: You need to breathe slowly like this (**SCT- Modelling and reinforcement**)

Please take a deep breath slowly when I say ‘in’ and breathe out slowly when I say ‘out’

Good job

Setting Jobs for Health (10 minutes)

Every week we will have a job to do before the next group meeting. It is to help everybody to practice some of the things we learned in class at home. Weekly record chart in EMBRACES booklet.

This week our job for health is practicing the relaxation technique.

Close the session by thanking everyone for attending. Ask if there are any questions. Remind everybody to do their jobs for health and the next class date, time and location.

EMBRACES- ID SESSION 2 – TWO HOUR SESSION

Welcome everybody to EMBRACES again

Time: 5 minutes

Briefly highlight the ground rules posted on the board where everybody can see

Ask if anybody has any questions, additions or changes.

Review

Time: 5 minutes

Review agenda and key messages from last class. Place laminated icons on the board for this week's topics

- Breast cancer
- Breast care self-checking
- Changes to look out for

Things that make women special (group activity)

Time: 10 minutes:

Materials: Anatomically correct doll

Steps: We are all in this class for one reason. We want to keep ourselves healthy. Let's talk about what makes women's bodies special

Show the doll, undress the doll. Ask the group what they think makes the woman's body different from a man. Use the doll throughout to alleviate embarrassment, some women may like to hold the doll.

- Women have periods
- Women can have babies
- Women can breastfeed babies
- Women have a vagina rather than a penis
- Women have smooth faces rather than beards or moustaches
- Some women have curvy bodies

Invite the class to give as many answers as they can think of but make sure the above are included. Record answers on the flipchart.

Breasts

Time: 10 minutes

Materials

- Breast chart/poster
- Breast anatomy handouts
- Crayola twistables
- Anatomically correct female doll

Procedure

- Let's talk about our breasts now.
- Let's look at the poster and see if we can name some of the parts.
- As we look at the poster and see if we can name some of the parts
- There are crayons on the table

Breast parts

Facilitator: The areola is the big round circle in the centre of the breast. It might be pink or brown

The nipple is the raised part in the centre of the areola.

The milk glands make milk when a woman has a baby. The baby can be breast fed from the mother's breast

Fat is all around the breast and makes it feel soft.

What colour should we make these parts on our handout?

Have the group agree on colours for the four main parts of the breast.

How do you take care of your breasts?

- Wash underneath them and dry carefully afterwards
- Wear the right size bra

There are some problems we can take care of ourselves, like a bra that does not fit. Like if there is something that is not normal for our bodies like a lump, we need to go and tell the doctor.

Breast Cancer and risks of breast cancer (EMBRACES booklet pg 25-29)

Time: 10 minutes

Class discussion about breast cancer and the risk factors for breast cancer

Breast care self checking- know what is normal for you (EMBRACES booklet pg 30-33)

Time: 10 mins

Materials booklet, DVD from Embarrassing bodies (3 mins 42 secs)

Facilitator: It is your job to take care of your health. It is okay for you to look at your breasts in the mirror and to press them with your fingers when you are in a private place like your bedroom or in the shower, to learn what they normally feel and look like. Everybody's breasts are different. It is important to know what is normal for your breasts and what is the same about them every time you touch or look at your breasts. **If you notice something different, you should see your doctor straight away.**

Play DVD for the group, open up short group discussion about knowing what is normal for you, how your breasts should look and feel. Encourage all participants to take part in the discussion

How to check your breasts (EMBRACES booklet pg 34-35)

Time 10 mins

Materials

- Breastology® bag
- Health Edco® Breast Self Examination model

Facilitator demonstrates how to check the breast models for the group. Have each of the women feel the breast models and feel the lumps (**SCT- Modelling and direct experience**)

Changes to look out for (EMBRACES booklet page 36-41)

Time 10 minutes

Facilitator: Using the booklet introduce the Cancer Research UK 11 signs of breast cancer to the group.

Facilitator: Encourage them to feel their breasts in a private place like the bedroom or bathroom or in the shower. Look in the mirror at their breasts. Look for any changes (**SCT - Reinforcement**). Always contact a doctor if you feel or see something different (early medical help seeking)

Adapted talking mat activity- breast cancer signs and symptoms (Group activity)

Time:10 minutes

Materials required

Yes (green tick) , no (red x) and don't know (grey question mark) laminated pictures;

Flipboard;

Magnets;

Possible signs and symptoms of breast cancer, laminated A4 sheets from EMBRACES booklet pg 35-38.

Facilitator: Has anybody ever played this game

Yes- you should go to your doctor as soon as possible

No- Hold up the no sign if you should stay at home

Instructor reads the statements, each woman has an opportunity to agree, disagree, or say she doesn't know in this activity. Where a don't know symbol is shown by any of the group, the sign or symptom is once again discussed to enhance the woman's understanding of the symptom and that it may be a sign or symptom of breast cancer which needs to be checked out by a doctor.

Possible signs and symptoms of breast cancer (EMBRACES booklet pg 36-41)

Unlikely signs and symptoms of breast cancer

- A cold breast that doesn't get warm
- Smooth skin on the breast
- Small breasts
- A darker circle around the nipple
- Sagging breasts
- Breasts that don't fit in your bra

- Having milk in your breasts after you have a baby.

Papier Mache Activity to make breast models (Group activity)

20 minutes

Materials required

Small balloons slightly inflated to around B/ C cup size

Newspaper

PVA Glue/ water

Bowls

Paintbrushes with easy grip handles

Plastic cups to hold the model

Each participant layers the newspaper onto the balloon, if she wishes, to make a model of the breast. This group work activity is designed to encourage discussion about the breasts, to normalise the discussion and to remove embarrassment when discussing the breasts. This may impact on early medical help seeking on the discovery of a sign or symptom of breast cancer.

Building advocacy skills – (SCT- Self-efficacy)

Time: 10 minutes

Talking to the doctor about what's wrong with your breast.

During this course we will try to solve some problems that may come up with your health. We will practice how to talk to the doctor about a health problem. How to advocate for yourself. It's okay if you don't know how to do this or feel shy because we will help you along the way. Okay let's try some

The instructor will read each scenario. The instructor then asks- What would you do?

- While in the shower you felt a lump in your breast?

- While looking in the mirror at your breasts, you notice a dent in the side of your breast;
- Your breast is sore in one place;
- You felt liquid on your breast coming out of your nipple.

Relaxation technique (5 minutes) (Suggested music Bach Air on a G string)

Facilitator Breathing: Your breathing is relaxed when it is slow and regular (**SCT-Modelling**). It is not relaxed if it is rapid or if there are interruptions such as coughing, yawning, sneezing, sniffing or talking

Please show me how you can do relaxed breathing. Do the best you can.

Feedback for each person

Positive: Notice the relaxed feelings in your chest as you breathe in in a relaxed way.

Corrective: You need to breathe slowly like this (**SCT-Modelling**) Please take a deep breath slowly when I say ‘in’ and breathe out slowly when I say ‘out’ Good job (**SCT- Positive reinforcement**)

Setting Jobs for Health (5 minutes)

Every week we will have a job to do before the next group meeting. It is to help everybody to practice some of the things we learned in class at home.

This week our job for health is practicing the relaxation technique – weekly record chart in EMBRACES booklet.

Close the session by thanking everyone for attending. Ask if there are any questions. Remind everybody to do their jobs for health and the next class date, time and location.

EMBRACES- ID SESSION 3 – TWO HOUR SESSION

Welcome everybody to EMBRACES again

Review

Time: 10 minutes

Briefly highlight the ground rules posted on the board where everybody can see

Ask if anybody has any questions or concerns from the last class.

Let us take a look at what we did in the last class

How can you know what is normal for your breasts?

Does anybody have any questions?

Tell me about your Job for Health? What challenges did you face?

Thanks for sharing

Breast Screening including video clip (30 minutes)

Time: 20 mins EMBRACES- ID booklet pgs 42-50.

Facilitator put icons for this week on the flipchart. This week's topics are

Breast screening- explaining the purpose of breast screening (10 minutes)

Mammogram – what happens? Explanation of what happens during a breast screening appointment (5 minutes)

What happens next? Dealing with results and repeat testing (5 minutes)

DVD Breast screening procedure

Time:10 minutes

Short video clip about a woman having a breast screening (Breast check mammography

DVD)

Getting Screened 10 minutes (group work)

Time:10 minutes

Materials required

Laminated pictures in kit;

Flipchart;

Yes (green tick), no (red x) and don't know (grey question mark) laminated pictures.

Facilitator reads the statements, each woman has an opportunity to agree, disagree, or say she doesn't know in this activity. Where a don't know symbol is shown by any of the group, the statement is once again discussed with the group to enhance the woman's understanding of the purposes of breast screening and the screening appointment.

Statements to be read out in conjunction with the laminated picture from the kit.

- Any woman can get breast cancer, even women with disabilities.
- A mammogram can save your life
- A mammogram is an xray of your breast. It checks if your breasts are healthy.
- It's important to get a mammogram when you turn 50 it can save your life.
- You can bring someone along to support you when you get your mammogram.
- After you have made the appointment, plan on how you will get there. Ask staff, a friend or family.
- Wear a top, as you will be asked to undress form the waist up.
- Don't wear deodorant when you get your mammogram, it can block the x-ray. You can wear deodorant after the mammogram.

Breast cancer awareness Beaded Necklace

Time: 20 minutes

Materials

Beaded necklace©

Breast models

Breast model with common pathologies

Procedure

1. Show the women the breast model and allow each woman to feel a lump inside the breast. Facilitator: Mammograms caber find the smallest lumps, ones that are so small your fingers can't even feel. A mammogram can save your life by finding cancer very early (key learning point- repetition to encourage early help seeking either on the discovery of a sign or symptom of breast cancer or by a screening procedure).

2. Next show the breast cancer awareness beaded necklace. Look at the different sizes of the lumps, focusing on the smallest lumps that can be found by a mammogram
(Repetition of key concept) (SCT modelling).
3. Groupwork- allow the women to touch the beads to help to identify which size lumps can be found by a mammogram, by self exam, a doctor etc.

The smaller the lump found, the easier it is for the doctor to make the lump go away **(SCT-Reinforcement of the purpose of screening).**

Colouring activity (group activity)

Time:10 minutes

Materials: Individual activity sheet

Pink twistables

A1 size poster of the activity sheet to act as a guide for the activity

Facilitator: Colour the size of the lump that can be found by regular mammogram. There is more than one, using the cancer awareness beaded necklaces to reinforce the concept **(SCT-Reinforcement).**

Building advocacy skills – (SCT- Self-efficacy)

Time: 10 minutes

During this course we will try to solve some problems that may come up with your health. We will practice how to talk to the doctor about a health problem, how to advocate for yourself. It's okay if you don't know how to do this or feel shy because we will help you along the way. Okay let's try some

The facilitator will read each scenario. The facilitator then asks 'What would you do?'

- Your breasts hurt when the radiographer touches them
- When the radiographer asks you to hold your breath, you don't know how long to hold your breath.
- At your yearly doctor's appointment, the doctor says women with disabilities don't need to get a mammogram. You know this is not right?
- You feel embarrassed taking off your top to get a mammogram.

Papier Mache Activity to make breast models (Group activity)

Time: 20 minutes

Materials required

Small balloons slightly inflated to around B/ C cup size covered with papier maché in Week 2

Bowls

Water

Paintbrushes with easy grip handles

Poster paints

Plastic cups to hold the model

Small pom poms

PVA glue

Each participant paints the papier mache breast model, if she wishes, skin tone on the breast with the areola painted darker, small pom poms can be glued on to represent the nipple. This group work activity is designed to encourage discussion about the breasts, to normalise the discussion and to remove embarrassment when discussing the breasts. This may impact on early medical help seeking on the discovery of a sign or symptom of breast cancer.

Relaxation technique (5 minutes) (Suggested music Bach Air on a G string)

Facilitator Breathing: Your breathing is relaxed when it is slow and regular (**SCT-Modelling**). It is not relaxed if it is rapid or if there are interruptions such as coughing, yawning, sneezing, sniffing or talking

Please show me how you can do relaxed breathing. Do the best you can.

Feedback for each person

Positive: Notice the relaxed feelings in your chest as you breathe in in a relaxed way.

Corrective: You need to breathe slowly like this (**SCT-Modelling**). Please take a deep breath slowly when I say ‘in’ and breathe out slowly when I say ‘out’ Good job (**SCT- Positive reinforcement**)

Setting Jobs for Health (5 minutes)

Every week we will have a job to do before the next group meeting. It is to help everybody to practice some of the things we learned in class at home.

This week our job for health is practicing the relaxation technique – weekly record chart in EMBRACES booklet.

Close the session by thanking everyone for attending. Ask if there are any questions. Remind everybody to do their jobs for health and the next class date, time and location.

EMBRACES- ID SESSION 4 – TWO HOUR SESSION

Welcome everybody to EMBRACES again

Review

Time: 5 minutes

Put up icons for today's class on the flipchart

Briefly highlight the ground rules posted on the board where everybody can see

Ask if anybody has any questions or concerns from the last class.

Let us take a look at what we did in the last class

Does anybody have any questions?

Tell me about your Job for Health? What challenges did you face?

Thanks for sharing

What is cervical cancer (20 minutes)

Time: 5mins

Topic: What is cervical cancer? EMBRACES-ID booklet pg 52- short explanation of what cervical cancer is, and an introduction to the anatomy of the body re the cervix.

Time: 5 minutes

Using the pelvic section to for repetition of the anatomy of the woman's body ie the location of the cervix (**SCT - Direct experience and reinforcement**)

Time 10 minutes – Female reproductive system colouring activity (**Group activity**)

Materials

Individual activity sheets

Twistables

A1 poster of the activity sheet to guide the activity

What affects my risk of getting cervical cancer?

Time: 5 minutes

EMBRACES – ID booklet pg 54; key risk factors for cervical cancer as per Irish Cancer Society Guidance

Cervical Screening

Time: 15 minutes

EMBRACES- ID booklet pg 55- 58

Health Edco Cervical feel it yourself model (**SCT- Modelling and direct experience**)- shows different stages of cervical cancer progression which can be seen via the screening procedure. Each of the women gets the opportunity to look at the cervix close up from normal to invasive cancer. This is to reinforce the importance of regular smear tests to prevent the risk of cervical cancer developing.

Smear test what happens/ and what happens next

Time: 15 minutes

EMBRACES-ID booklet pg 59-62.

Speculum, brush and bottle (**SCT- Direct experience**). Each of the women get the opportunity to look at and feel the equipment used for the cervical screen. The pelvic model is use to repeat the procedure for the cervical smear. If preferred, the procedure can be replicated on the A1 poster of the female anatomy.

Short discussion about getting the results of a smear test, and the possibility that you may be called back for a repeat test because of an abnormal result.

Changes to look out for (10 minutes)

Time: 10 minutes

Possible signs and symptoms of cervical cancer (EMBRACES booklet pg 66-68)

Adapted talking mat activity-cervical cancer signs and symptoms (Group activity)

Time:10 minutes

Materials required

Yes (green tick), no (red x) and don't know (grey question mark) laminated pictures;

Flipboard;

Magnets.

Possible signs and symptoms of cervical cancer laminated A4 images from EMBRACES booklet pg 66-68

Facilitator: Has anybody ever played this game

Yes- you should go to your doctor as soon as possible

Instructor reads the statements, each woman has an opportunity to agree, disagree, or say she doesn't know in this activity. Where a don't know symbol is shown by any of the group, the sign or symptom is once again discussed to enhance the woman's understanding of the symptom and that it may be a sign or symptom of cervical cancer which needs to be checked out by a doctor.

Some things that make it hard for women to get cervical screening (group activity)

Time: 15 mins

Brainstorm and record answers on the flipchart

Sample responses include

- Feeling embarrassed
- Feeling scared
- Worried about wasting the doctors time
- The doctor would be difficult to talk to
- It would be difficult to get an appointment with the doctor
- Too busy to make an appointment
- Hard to get an appointment
- Too many other things to be worried about
- Difficult to get transport to the doctors surgery
- Would feel confident talking about the symptom with the doctor
- Dislike being examined by male doctors
- Believe they won't get cancer
- Do not have any symptoms
- Worried about what the doctor will find

Women's attitude about going for screening - Jo's Cervical cancer Trust

Time: 5 mins

Short video clip from Jo's cervical cancer trust to reinforce for the women with intellectual disabilities that many women are apprehensive and do not want to participate in the screening

programme. However, many women do have the procedure. (**SCT -Modelling and building experience of the procedure**)

Building advocacy skills – (SCT- Self –efficacy) (Group activity) (10 minutes)

Time: 10 minutes

During this course we will try to solve some problems that may come up with your health. We will practice how to talk to the doctor about a health problem, how to advocate for yourself. It's okay if you don't know how to do this or feel shy because we will help you along the way. Okay let's try some

The facilitator will read each scenario. The facilitator then asks 'What would you do?'

- You don't want to go to a male doctor
- You don't know where to go to get your screening
- You don't know who could go with you to your appointment

Think about what you could do if you had one of these problems and then say what you would do to ask for help. The class members then share their ideas.

Relaxation technique (5 minutes) (Suggested music Bach Air on a G string)

Facilitator: Your breathing is relaxed when it is slow and regular (Model). It is not relaxed if it is rapid or if there are interruptions such as coughing, yawning, sneezing, sniffing or talking

Please show me how you can do relaxed breathing. Do the best you can.

Feedback for each person

Positive: Notice the relaxed feelings in your chest as you breathe in in a relaxed way.

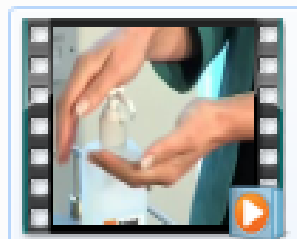
Corrective: You need to breathe slowly like this (**SCT-Modelling**). Please take a deep breath slowly when I say 'in' and breathe out slowly when I say 'out' Good job (**SCT-positive reinforcement**).

Certificate presentation (10 minutes)

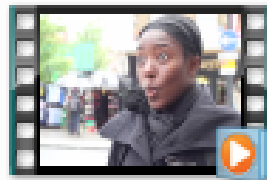
Presentation of Certificates of Attendance at the EMBRACES-ID programme to promote the women's self-efficacy in attending the programme to learn about their health and advocacy skills to become more active participants in their own health care decisions.

AVI.4 EMBRACES-ID video clips and anatomy posters

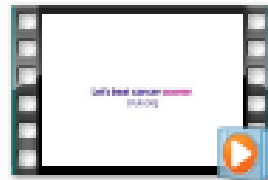
Video clips from Channel 4, Jo's Cervical Cancer Trust and NHS



Embarrassing Bodies - How to Check Your Breasts

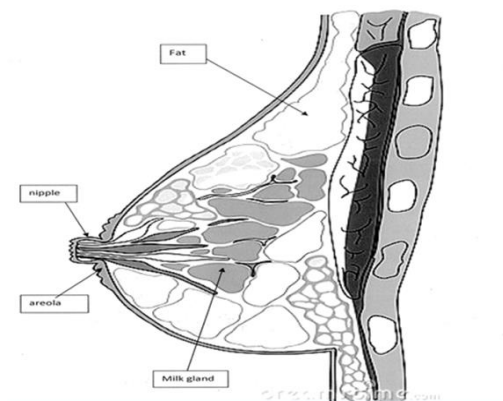


What do you think of cervical screening (smear test)

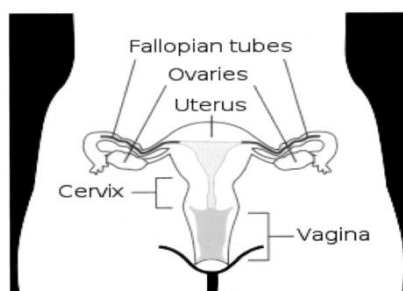


What It's Like to Have a Mammogram Cancer Researc...

Breast poster (Size A0)



Cervical poster (Size A0)



AVI.5 EMBRACES-ID Participation Certificate

