

# Learning disabilities and Cancer screening.

North Yorkshire taskforce group.  
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NHS Scarborough and Ryedale CCG

# What we will cover today.

- \* National drivers.
- \* Bowel cancer screening.
- \* Breast screening.
- \* Cervical screening.
- \* What can we do to improve our screening rates?

# National Drivers.

- \* Improving and maintaining the performance of screening programmes is a Public Health England target and the government has specifically prioritised reducing inequality in uptake of national screening programmes as part of this[1];
- \* The cancer taskforce's strategy for the next five years emphasises the need for earlier diagnosis in order to improve survival rates and one of their key initiatives is to reduce variability of access to optimal diagnosis.
- \* Domain one in the NHS outcomes framework relates to preventing people dying prematurely and within this there are indicators about reducing mortality from cancer and mortality in adults with learning disabilities aged under 60 (Department of Health, 2014).

# CIPOLD – 2013.

- \* People with LD die 16 years younger than the general population.
- \* 42% of these are thought to be preventable and avoidable.
- \* Attributed to delays in diagnosis, treatment and failure to provide adequate care.
- \* Over 1000 people with LD die prematurely each year through failure to provide adequate care.

# Rates of screening – England and North Yorkshire

	%Screening in the General population - England	% Screening in the learning disabilities population - England	% Screening in general population – North Yorkshire	% Screening in learning disability population – North Yorkshire
Cervical	73.5%	29%	73%	29.6%
Breast	72.2%	39%	68%	62%
Bowel	57.9%	41.6%	59%	52%

# Scarborough screening rates

	% Population screening in general population	% Screening in LD population - SRCCG
Cervical	77.4%	32%
Breast	74.8%	45%
Bowel	61.8%	36%

Why are screening rates so low?  
Especially in those with learning  
disabilities?



# Barriers?



- \* Health care professionals
- \* Person with LD
- \* Carers
- \* Physical environment
- \* Systems



# Person.

- \* Difficulties using appointment system
- \* Lack of easy read information
- \* Mobility issues
- \* Lack of understanding about importance of having screening.
- \* Fear, anxiety, embarrassment.

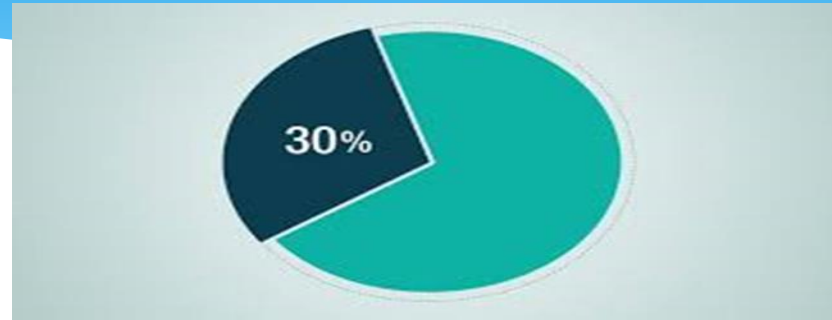
# Health care professionals.

- \* Lack of awareness of LD
  - \* Communication issues.
- \* Time pressures
- \* Attitudes
  - \* Ceasing of people from screening programmes.
  - \* Assessing capacity to consent
- \* Lack of awareness of supporting resources
  - \* Easy read leaflets
  - \* Videos on line eg Jo's trust.
  - \* LD team member

# Carers/ support staff.

- \* No training to support people with LD having screening.
  - \* No specific training on bowel screening
  - \* The belief that someone with LD does not need screening
- \* Lack of awareness of importance of screening and cancer prevention.
- \* Embarrassment in discussing issues

# Annual health check



- \* Yearly review at GP surgery for those with LD
- \* Offered to all over the age of 14.
- \* **Gain consent during this visit to share information with other health care professionals including the screening services.**
- \* **Opportunity to give information to people.**

# Mental capacity Act

- \*Understand
- \*Retain
- \*Weigh up
- \*Communicate

# Capacity

- \* A person must be assumed to have capacity unless it has been clearly established that they lack capacity regarding the specific decision under consideration at that point in time.
- \* A person is not to be treated as unable to make a decision unless all practicable steps to help him/her to do so have been taken without success.
- \* A person is not to be treated as unable to make a decision merely because he/she makes what is considered to be an unwise decision.
- \* An act done, or decision made, under the Mental Capacity Act for or on behalf of a person who lacks capacity must be done, or made, in his/her best interests.
- \* Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

# Best interest decisions

- \* Not to make assumptions about someone's best interests simply on the basis of a person's age, appearance, condition or behaviour. Withholding or preventing access to medical care or treatment could be construed as neglect.
- \* Where an individual is not considered to have capacity to consent to a specific screening intervention, the member of staff responsible for carrying out the healthcare procedure becomes the decision maker.
- \* The decision maker needs to decide if it is in the person's best interests to be screened; in doing so they should consult with, and take into account the views of, other people who are close to the person who lacks capacity.
- \* They should also do what they can to help the person take part in the decision, even if they cannot actually make the decision.
- \* There should be a record of how the Best Interests decision is reached.

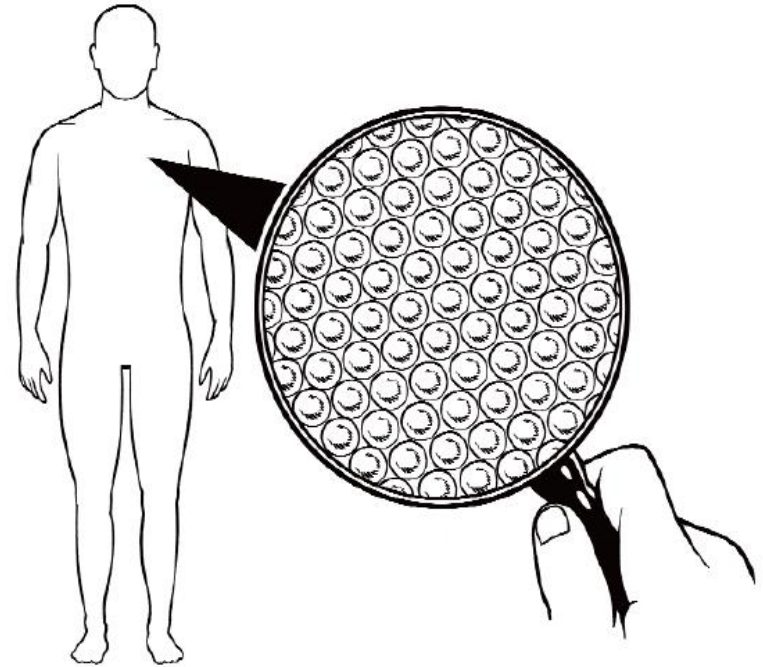
# Bowel screening

- \* What is bowel cancer?
- \* Why do we need to screen for it?
- \* Who is screened and what is the uptake of bowel screening?
- \* How do we screen for it?



# What is bowel cancer?

- \* Also known as colon or rectal cancer.
- \* Lining of the bowel is constantly renewed
- \* Sometimes the cells grow too quickly and form polyps.
- \* Adenomas
- \* Potential to change to bowel cancer if not removed.



# Incidence of bowel cancer

- \* 1 in 14 men and 1 in 19 women will be diagnosed with bowel cancer during their lifetime
- \* 4th most common cancer in the UK and 2<sup>nd</sup> leading cause of cancer death, approx 16,000 deaths per year.
- \* Over 41,000 people are diagnosed with bowel cancer every year in the UK.
- \* 8 out of 10 people who are diagnosed with bowel cancer are over 60.
- \* People with a family history of bowel cancer have an increased risk of developing the disease.

# Signs and symptoms

- \* Rectal Bleeding
- \* Change in bowel habit
- \* Severe tummy pain
- \* Lump in tummy
- \* Anaemia/ feeling tired for no reason.



# Early diagnosis is fundamental to improving survival

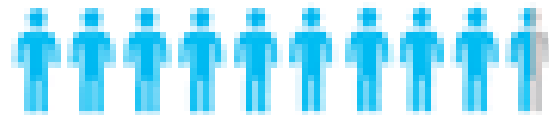
**EARLIER DIAGNOSIS**  
(STAGE 1)

**LATER DIAGNOSIS**  
(STAGE 4)

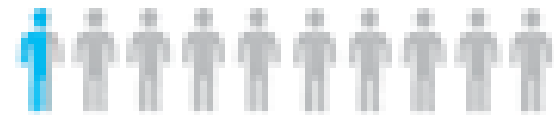


£3,400

£12,500



More than 9 in 10  
survive 5 or more years



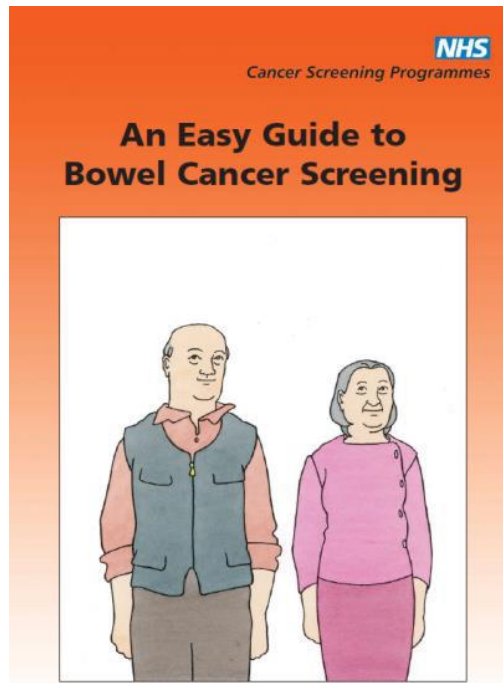
Less than 1 in 10  
survive 5 or more years

# Bowel screening

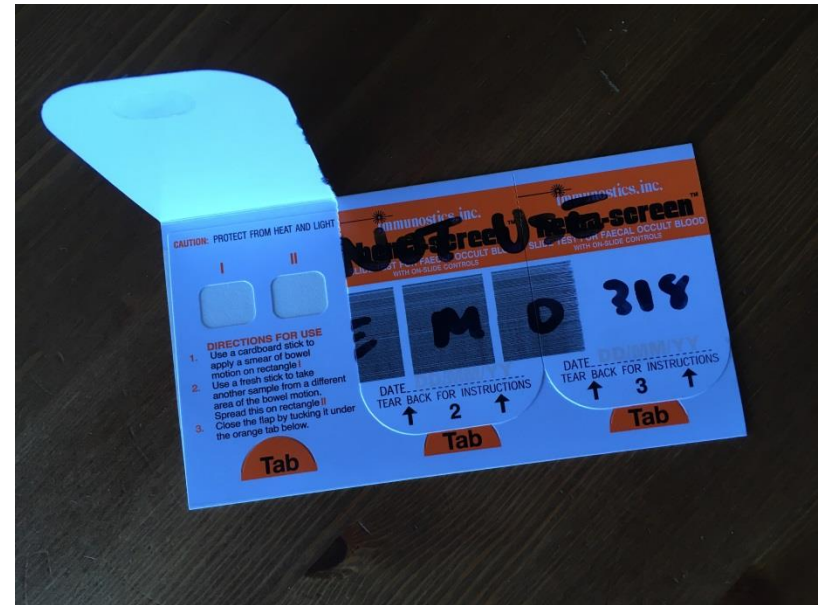


- \* Bowel screening using a test on your poo is offered every two years for men and women aged 60-75 years.
- \* A bowel scope screening programme is in the process of being rolled out to all 55 year olds in England

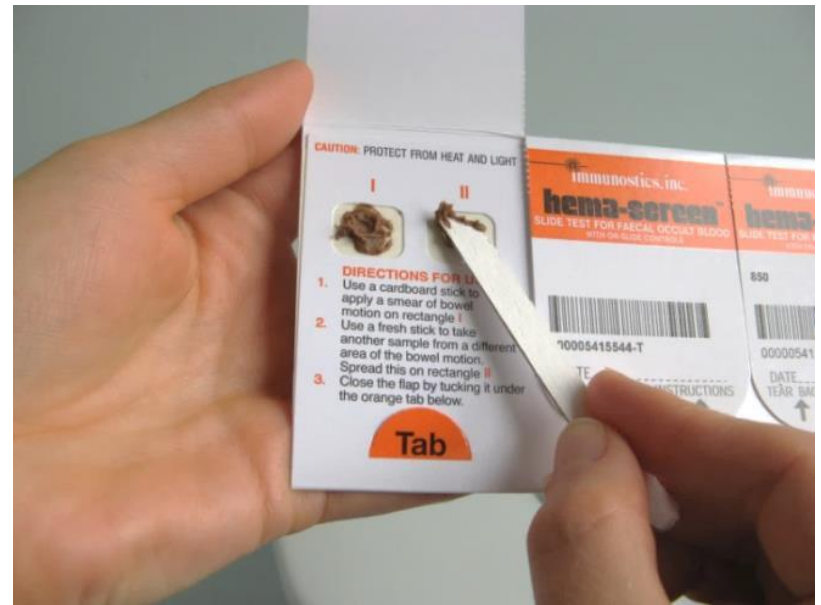
# Invitation and card sent.



A leaflet by and for men and women with learning disabilities



# Step two!



## Test Card Results

For every **1000** people that send a Test Card to us

**20 people** have blood in their poo sample



**16 people** need to see a nurse at their local hospital





# Colonscopy.



# Colonoscopy Result

For every **16** people that have a camera test



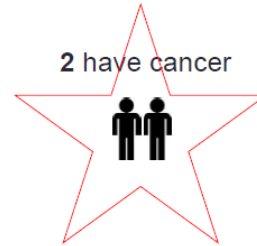
8 have no cancer



6 have small polyps  
that could turn into  
cancer



2 have cancer

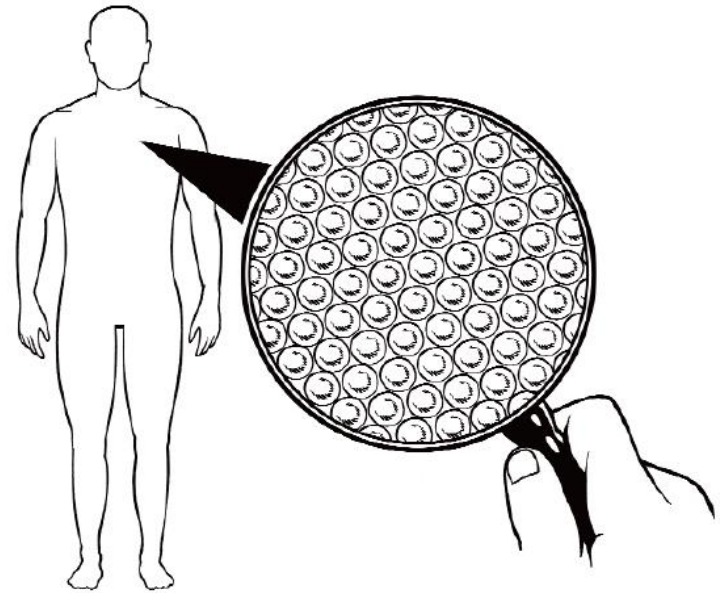


# Breast cancer.

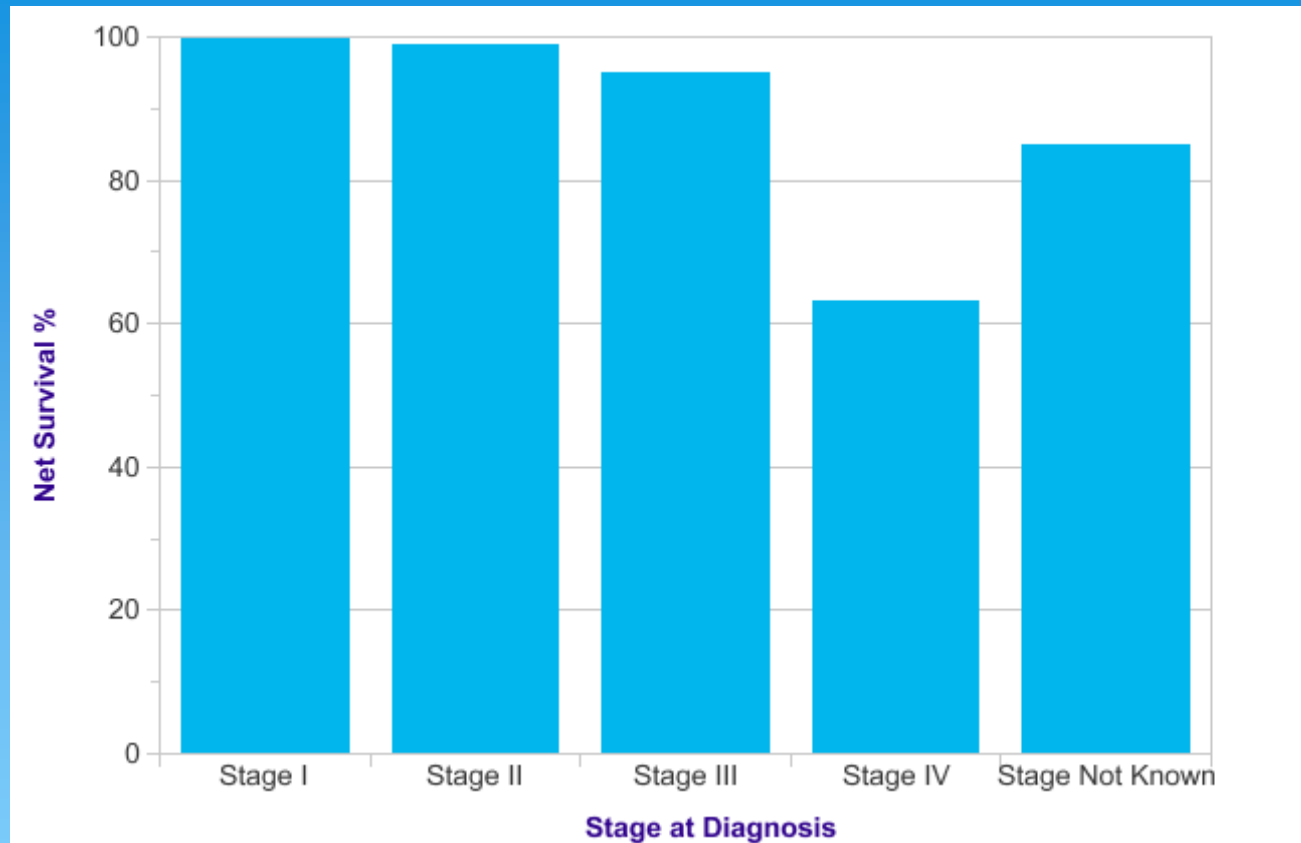
- \* What is breast cancer?
- \* Why do we need to screen for it?
- \* Who is screened?
- \* How do we screen for it?

# What is breast cancer?

“**Breast cancer** is a kind of **cancer** that develops from **breast cells**. **Breast cancer** usually starts off in the inner lining of milk ducts or the lobules that supply them with milk. A malignant **tumour** can spread to other parts of the body.”



## Breast Cancer (C50): 2014 One-Year Net Survival (%) by Stage, Women Aged 15-99, England



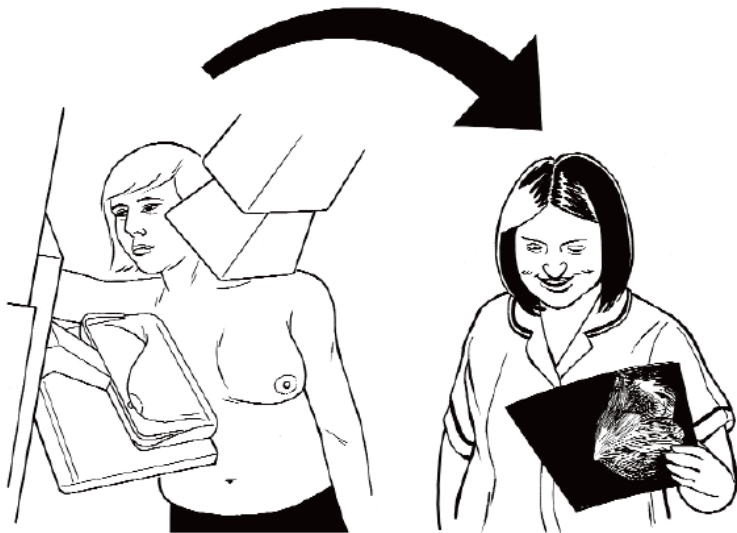
Source: [cruk.org/cancerstats](http://cruk.org/cancerstats)

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# Symptoms and signs.

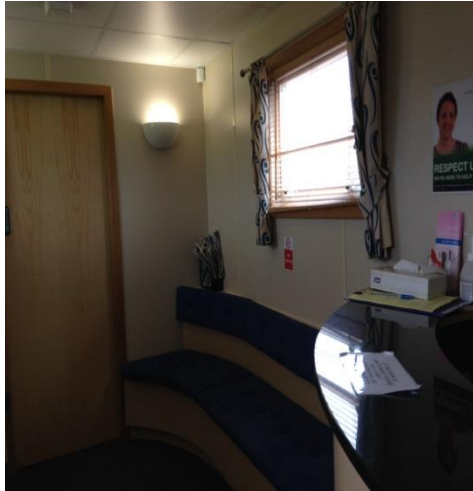


# Breast screening



- \* Breast screening is offered once every three years to women aged 50-70 years old. The programme is in the process of being extended as a trial to invite women aged 47-73.

# Mammogram – takes place either in hospital or in mobile van.





**The learning disability liaison nurse  
will be able to help you.**

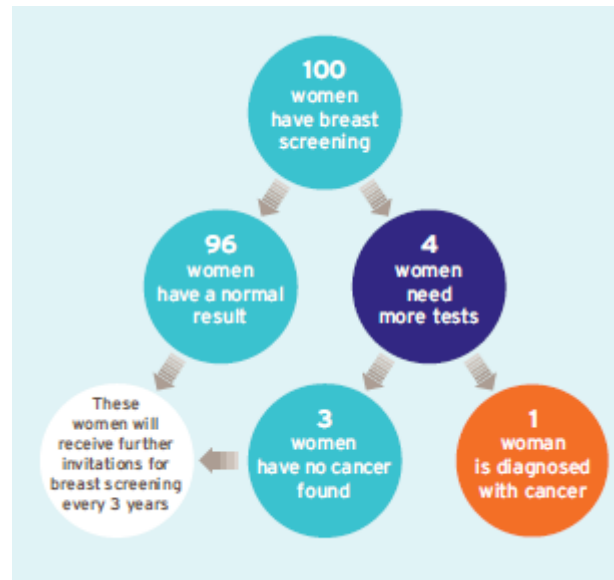


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# Risks of screening.



## Screening finds breast cancers that would never have caused a woman harm

Some women will be diagnosed and treated for breast cancer that would never otherwise have been found and would not have become life-threatening. This is the main risk of screening.

- \* **Non-invasive breast cancer**

- \* About 1 in 5 women diagnosed with breast cancer through screening will have non-invasive cancer.

- \* **Invasive breast cancer**

- \* About 4 in 5 women diagnosed with breast cancer through screening will have invasive cancer.

**NHS**

*Cancer Screening Programmes*

# **An Easy Guide to Breast Screening**

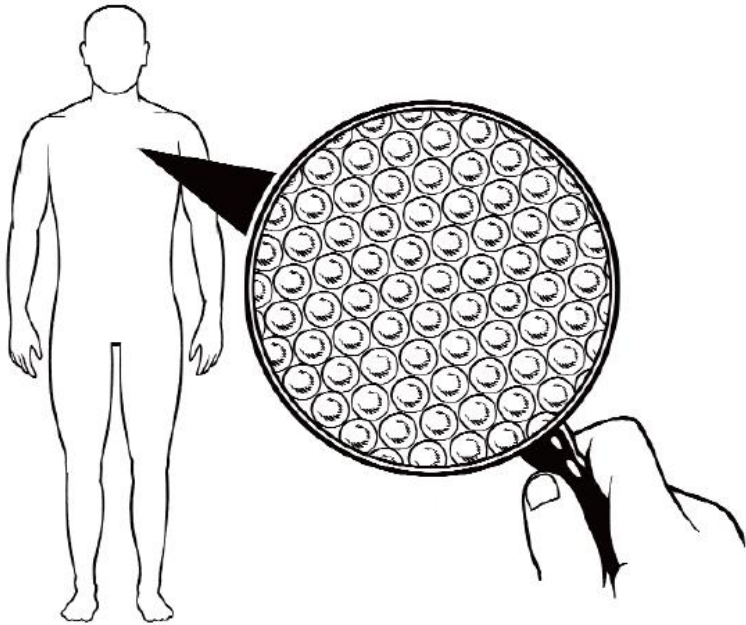


*A leaflet by and for women with learning disabilities*

# Cervical screening

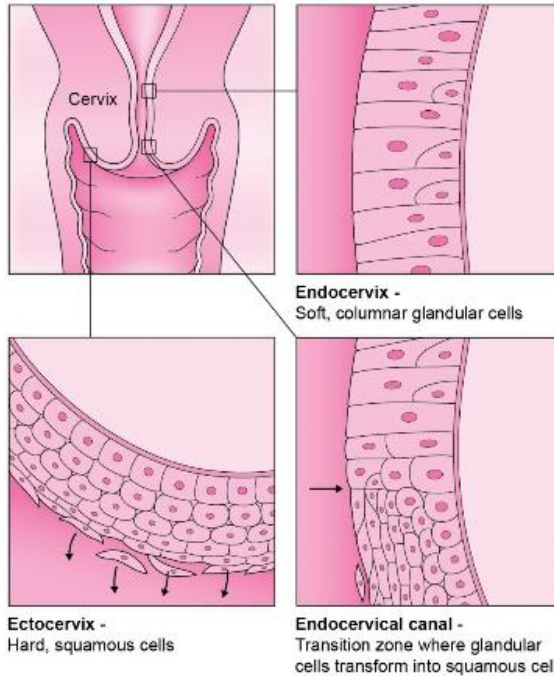
- \* What is cervical cancer?
- \* What are the symptoms of cervical cancer?
- \* Who is screened?
- \* Why do we need to screen for it?
- \* How do we screen for it?
- \* What can we do?

# Cervical Cancer



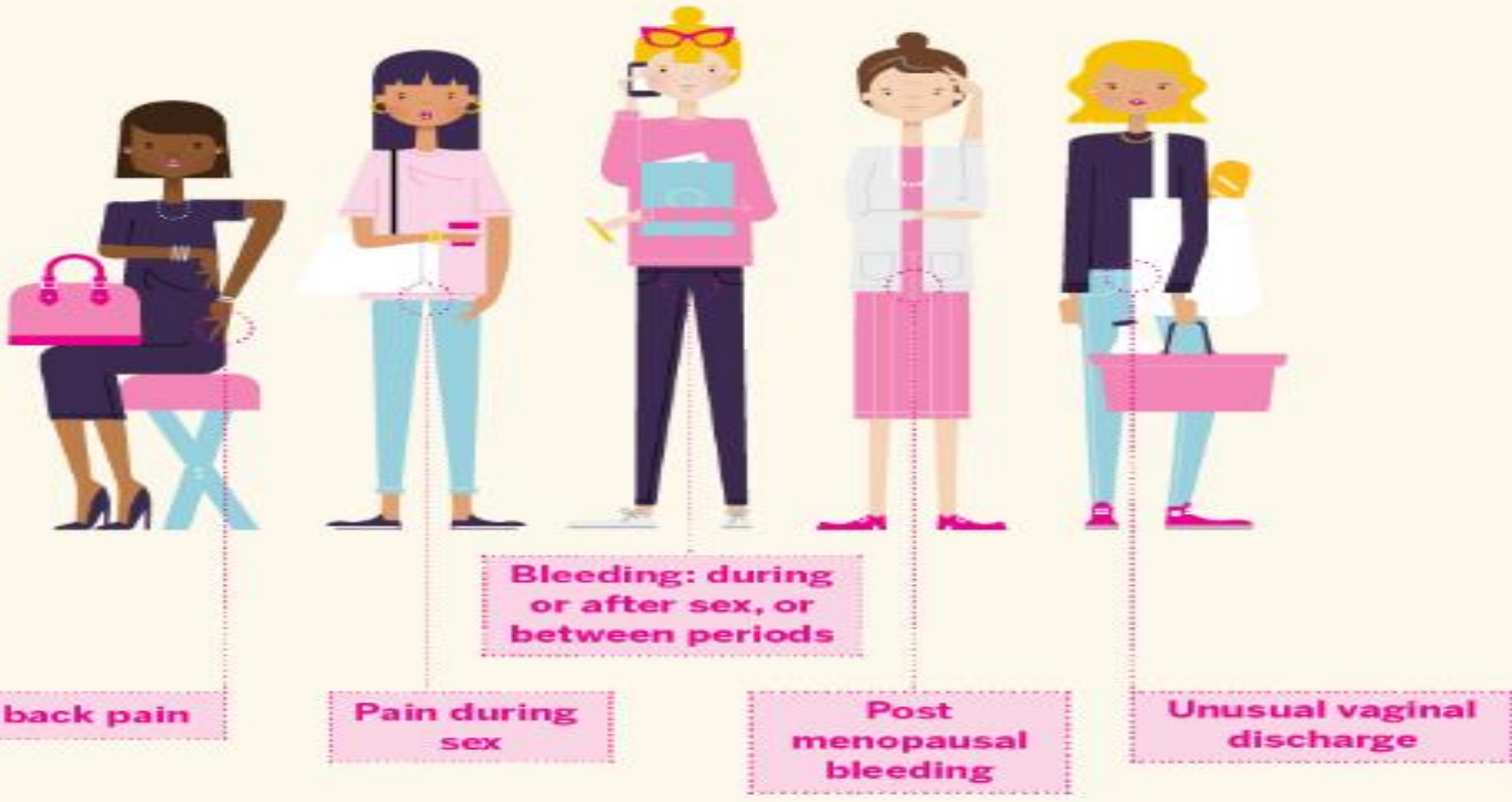
99.7% of cervical cancers are caused by persistent high-risk [HPV](#) infections, which cause changes to the cervical cells. These abnormal cells, found through cervical screening (smear test), are not cancerous, but given time (often years) they may go on to [develop into cancer](#).

# What is does a smear look for?



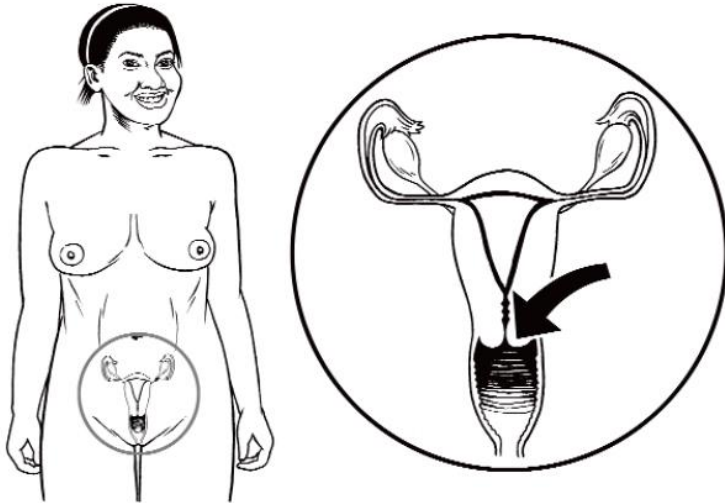
# Cervical cancer – symptoms.

There are some recognised symptoms associated with cervical cancer that you should be aware of.





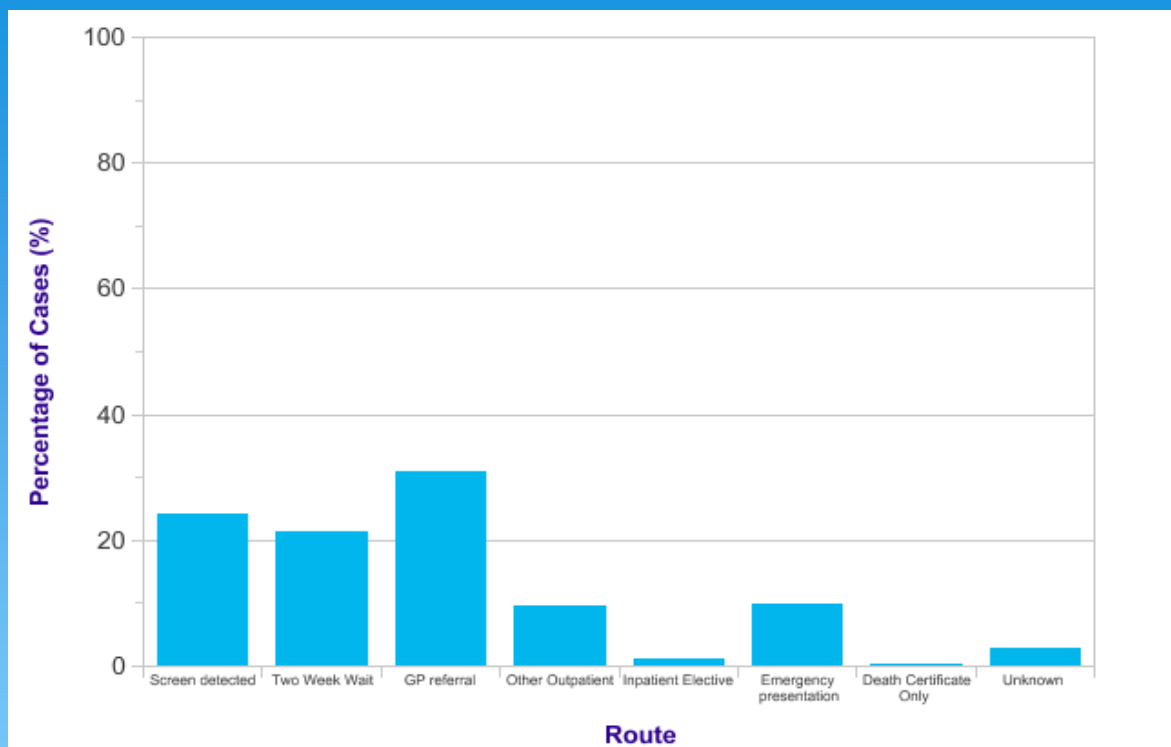
# Cervical screening.



- \* Cervical screening is offered once every three years to women aged 25-49 years and once every five years to women aged 50-64 years.

## Cervical cancer (C53): 2012-2013

### Percentage of Cases by Route to Diagnosis, Women Aged 15-99, England



Source: [cruk.org/cancerstats](http://cruk.org/cancerstats)

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CANCER  
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UK

# Having a smear test

What is it about?



# Tips for cervical screening.

- \* Ask what sanitary protection they use. If someone is using tampons they may find it easier as they will understand where the speculum goes.
- \* Show them physical position that the patients will need to adopt - they can then practice this at home until it feels less awkward.
- \* Show the speculum and use it so that they are familiar with what it looks like – and the noise it makes!

So what can we do?



# What did people say?

\* Easy Read leaflets are really helpful.

It was uncomfortable and I did not understand.

Don't be afraid to talk about it.

Why it is important?

Awareness of worrying symptoms and signs.

What the outcome of being screened might be?

Train (someone) to talk things through first.

Make sure physically accessible

What happens during screening?

Be clear that people understand.

Understanding whose responsibility it is.

# Main aim!





Awareness

Willingness  
to be  
included

Participation  
in screening.



# Key people

- \* Service users
- \* Carers
  - \* Family and friends
  - \* Professional carers
- \* Health care professionals
  - \* GPs
  - \* Practice nurses
  - \* Screening providers

# What we are doing.

- \* Data gathering.
- \* Educational events for carers and providers.
- \* Information for practice nurses and GPs.
  - \* Newsletters
    - \* CCG newsletter
    - \* Screening and imms. team newsletters
  - \* Liaison nurses in trusts ( breast screening, bowel scoping)
  - \* Community LD teams
- \* Desensitization work ( via LD teams)
- \* Building relationships with screening services.



THANK YOU