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?
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).
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

<table>
<thead>
<tr>
<th></th>
<th>%Screening in the General population - England</th>
<th>% Screening in the learning disabilities population - England</th>
<th>% Screening in general population – North Yorkshire</th>
<th>% Screening in learning disability population – North Yorkshire</th>
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</thead>
<tbody>
<tr>
<td>Cervical</td>
<td>73.5%</td>
<td>29%</td>
<td>73%</td>
<td>29.6%</td>
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<tr>
<td>Breast</td>
<td>72.2%</td>
<td>39%</td>
<td>68%</td>
<td>62%</td>
</tr>
<tr>
<td>Bowel</td>
<td>57.9%</td>
<td>41.6%</td>
<td>59%</td>
<td>52%</td>
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<td></td>
<td>% Population screening in general population</td>
<td>% Screening in LD population - SRCCG</td>
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<tr>
<td>Cervical</td>
<td>77.4%</td>
<td>32%</td>
<td></td>
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<tr>
<td>Breast</td>
<td>74.8%</td>
<td>45%</td>
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</tr>
<tr>
<td>Bowel</td>
<td>61.8%</td>
<td>36%</td>
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</table>
Why are screening rates so low? Especially in those with learning disabilities?
Barriers?

- Health care professionals
- Person with LD
- Carers
- Physical environment
- Systems
- 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
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.
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.
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 2nd 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.
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.
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

NHS Bowel Cancer Screening Programme - North East Programme Hub
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

NHS Bowel Cancer Screening Programme - North East Programme Hub
Breast cancer.

- What is breast cancer?
- Why do we need to screen for it?
- Who is screened?
- How do we screen for it?
“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: cru.org/cancerstats

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Symptoms and signs.
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.

07795126473

jo.blades@york.nhs.uk
Risks of screening.

- 100 women have breast screening
- 96 women have a normal result
- 4 women need more tests
- 3 women have no cancer found
- 1 woman is diagnosed with cancer

These women will receive further invitations for breast screening every 3 years.
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.

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.
An Easy Guide to Breast Screening

A leaflet by and for women with learning disabilities
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?
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 a smear look for?

- **Cervix**
- **Ectocervix** - Hard, squamous cells
- **Endocervix** - Soft, columnar glandular cells
- **Endocervical canal** - Transition zone where glandular cells transform into squamous cells

© Jo’s Cervical Cancer Trust
Cervical cancer – symptoms.

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

- Lower back pain
- Pain during sex
- Unusual vaginal discharge
- Bleeding: during or after sex, or between periods
- Post menopausal bleeding

Post menopausal bleeding
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.
Having a smear test
What is it about?

Jo’s cervical cancer trust
jostrust.org.uk
• 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.

- Make sure physically accessible
- Be clear that people understand.
- What the outcome of being screened might be?

Don’t be afraid to talk about it.

- Why it is important?
  - Awareness of worrying symptoms and signs.
  - Train (someone) to talk things through first.
  - Understanding whose responsibility it is.

- What happens during screening?
  - It was uncomfortable and I did not understand.
  - Understanding whose responsibility it is.

It was uncomfortable and I did not understand.
Main aim!

RAISE AWARENESS
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.