Service Specifications	Increasing the uptake of Cancer (Bowel, Breast and Cervical) and AAA (Abdominal Aortic Aneurysm) screening for adults with learning disabilities
Project Lead	Donna Beal, Project Manager, Derbyshire Healthcare NHS Foundation Trust
Period	
Date of review	

1. Population Needs

1.1 Context and evidence base

The Public Health England (PHE) publication *'Making Reasonable Adjustments in cancer services'* (2015) examined the research into cancer and people with learning disabilities. It demonstrated that people living with learning disabilities are amongst the most vulnerable seen by health care services. Various reports in the past 10 years have identified significant inequalities in health and access to health care for this group. A variety of health needs have been identified relating to cancer screening. For example people with a learning disability are at higher risk of developing gastrointestinal cancers and may be at higher risk of bowel cancer. There is also likely to be increased risk of other cancers as the overall life expectancy of people with learning disability increases. Additional needs, poor communication and lower health literacy may prevent people with learning disabilities from accessing services for prevention and treatment of cancers. This may lead to higher mortality from cancer once people with learning disabilities receive a diagnosis of cancer.

Historically it was thought that people with learning disabilities were less likely to develop cancer, but more recent data suggests they have comparable rates to the general population. There is evidence of a different pattern of malignancies, for example people with learning disabilities are at a much higher risk of gastrointestinal cancer. It is likely that the rates and pattern of cancer among people with learning disabilities is changing as they are living longer.

It has been well documented over a number of years that women with learning disabilities have a much lower participation rate in cervical and breast screening programmes than women in the general population. This has been further supported by data from the *Joint Health and Social Care Self-Assessment Framework* which showed considerably lower participation by people with learning disabilities in NHS Cancer Screening Programmes.

NHS Hardwick CCG carried out a Health Needs Assessment (HNA) and Health Equity Audit (HEA) in 2013, which found substantial inequalities in cancer screening coverage compared to the general population. For example, the gap between the general and learning disability populations for breast screening coverage was 26%, for cervical screening coverage the gap was 32%, and for bowel screening it was around 35%.

A series of interventions were designed to help reduce these inequalities and improve access to cancer screening for people with learning disabilities. One of the recommendations of this HEA was to roll out the project and improved pathways to the other Derbyshire CCGs.

The three cancers amenable to screening with existing programmes are bowel, breast and cervical. Routine data show that from 1999 to 2010 in the UK the number of new diagnoses (incidence) of bowel cancer increased 3%, the incidence of breast cancer increased 6% and the incidence of cervical cancer remained stable. In Derbyshire from 2008 to 2010 there were 644 new cases of breast cancer and 39 new cases of cancer of the cervix in women. This equates to age standardised rates of 126.5 new cancers per 100,000 (95% CI: 120.6 to 132.6) and 9.9 new cancers per 100,000 (95% CI: 8.1 to 12.0) respectively. There were 520 new cases of colorectal cancer in Derbyshire over the same period although the incidence rate appears to be significantly higher in men.

Abdominal Aortic Aneurysm screening was introduced in 2009 and available throughout the UK by 2013. It is a one off screening scan offered to men at 65 years of age. As the numbers of eligible men are likely to be relatively small in Derbyshire, it has been decided to include this screening programme for a potentially life-threatening condition to this project.

2. Outcomes

2.1 NHS Outcomes Framework Domains & Indicators

Domain 1	Preventing people for dying prematurely	✓
Domain 2	Enhancing quality of life for people with long-tem conditions	✓
Domain 3	Helping people to recover from episodes of ill-health or following injury	
Domain 4	Ensuring people have a positive experience of care	✓
Domain 5	Treating and caring for people in a safe environment and protecting them from avoidable harm	

2.2 Local defined outcomes

- To deliver a phased approach across Derbyshire CCGs, followed by Nottinghamshire CCGs.
- Improved patient pathways to enable practices to understand the additional needs of learning disability patients across Derbyshire then Nottinghamshire GP Practices.
- Dissemination and utilisation of the Hardwick CCG screening toolkit providing resources such as easy read literature within GP Practices.
- Increased use of existing learning disability annual health checks, mental capacity and best interest assessments to help enable discussion of screening
- Staff training and a series of communications about the need for additional time and reasonable adjustments for people with learning disabilities.
- Informing and empowering people with learning disabilities and their carers to seek additional help for screening and participate in active discussions about screening.
- Provision of audit data demonstrating uptake up of the three NHS Cancer Screening Programs by people with learning disabilities.
- Provision of reminder systems to prompt patients / carers to take up screening offer.
- Increased take up of NHS Cancer Screening Programs by people with learning disabilities
- Decreased morbidity from bowel, breast and cervical cancer for people with learning disability due to increased access to screening, early diagnosis and improve outcomes
- Decreased mortality from bowel, breast and cervical cancer for people with learning disability
- Reduction of health inequalities, evidenced by annual audit.

3. Scope

3.1 Scope of service

Upon sign up to a Local Enhanced Service, Practices are asked to complete the following audit and process:

1. Identify all registered patients aged 18 or over with a diagnosis of LD. Maintaining this list is part of the Quality and Outcomes Framework (QOF), and should be readily available. Strategic Health Facilitators can offer assistance in the event of any doubt as to the accuracy of this list. http://www.derbyshirehealthcareft.nhs.uk/services/learning-disabilities/annual-health-check/who/
2. The following criteria for patient record searches should be set:

    - *Females aged 47 to 73 who have had breast screening performed within the previous three years, or have a documented AND VALID exclusion reason.*
    - *Females aged 25 to 49 who have had cervical cancer screening performed in the previous three years, or have a documented AND VALID exclusion reason.*
    - *Females aged 50 to 64 who have had cervical screening performed in the previous five years, or who have a documented AND VALID exclusion reason.*
    - *Male and females aged 60 to 75 who have had bowel cancer screening performed in the previous three years, or who have a documented AND VALID exclusion reason.*
    - *Males aged 65 who have had Aortic Aneurysm screening performed, or who have a documented AND VALID exclusion reason.*

3. All patients identified as eligible for screening, but not shown as having taken part, and without a valid and current exemption should be contacted using the approved letter and invited to attend screening by the GP surgery or local screening unit.
4. Six weeks later a further check of non-responders to the first invitation letter should be performed and a second contact and invitation made. Consideration should also be given to reasonable adjustments such as contacting the patient by phone and involving Learning Disability Strategic

Health Facilitators for support.

5. A further six weeks later a third contact and invitation should be made to non-responders.
6. If there has been no response to the third invitation after a final six week period then the medical records should have an entry of exception to the identified screening on the grounds of no patient consent and the patient should be deferred to recall for screening.
7. If at any point in the above procedure the patient or their carer indicate that they do not wish to participate in a particular screening programme then a defer or cease recall / exclude from screening action plan should be used. NOTE: THAT A FULL ASSESSMENT OF COMPETANCY FOLLOWING THE MENTAL CAPACITY ACT GUIDELINES SHOULD BE PERFORMED.
8. Ideally the whole cycle should be completed six months after the first action to complete the audit cycle and assess uptake of NHS cancer screening across this group. On repeating the audit, contact with Learning Disability Strategic Health Facilitators for further investigation as to the reasons for non-response.
9. Data collection will be repeated after 12 months to assess screening uptake across all practices.
10. Cancer screening will be prompted during the annual Learning disability health check for those that attend.
11. Practices will request participation from patients with learning disabilities and/ or their carers in the CCG Telehealth scheme (if available in the locality), and follow local procedures in order to commence text reminders for future screening.

3.2 Timescales

Date of first audit	
1st Invitation letter	
2nd Invitation letter	6 weeks after 1st invitation
3rd Invitation as per Accessible Information Standard	6 weeks after 2nd invitation
Date of second audit	
Repeat data collection	

3.3 Population covered

Any adult with a learning disability who is eligible for screening within South Derbyshire, North Derbyshire and Erewash CCG area.

Applicable Service Standards

The Public Health England (PHE) publication *'Making Reasonable Adjustments in cancer services'* (2015)

Quality and Performance Indicators

Upon receipt of the 2nd audit, practices will be reimbursed to cover costs of participation. Practices will be reimbursed by £20 per patient (TBC) to cover the costs of:

- Admin time for the following: to consider details and sign up to Local Enhanced service; to complete a baseline audit and complete 4 searches of the electronic patient record; for printing and posting letters potentially 2 letters to each patient (dependant upon response to first letter); costs of printing off easy read resources and including with letters; cost of potentially one telephone call (dependant upon response to letters); to process Telehealth support (if applicable to your practice).
- Time for Clinician to assess capacity for potential withdrawal from the programmes
- Time for Clinician to make referral for additional support by the Clinician into the LD Service.
- Costs of attendance at any launches and/or information events

Practices will need to return a completed template *to TBC* by *TBC*. Payment will be received after a full validation of this template.

Variation/Termination Notice Period
6.1 Service Variation Some variation to the criteria detailed within 3.1 may occur. However, any changes will be minor. **6.2 Service Termination** The service will terminate once the relevant audits and searches have been completed, a report produced and reimbursement made to participating GP practices. However, we hope that the good practice followed within the project will continue after its completion.

Practice Sign-up sheet	
Practice Name:	
Practice Code:	
CCG:	
Signature:	
Job Title:	
Date:	