Derbyshire Healthcare
NHS Foundation Trust

INCREASING THE UPTAKE OF SCREENING FOR PEOPLE WITH LEARNING DISABILITIES ACROSS DERBYSHIRE AND NOTTINGHAMSHIRE.

Final report

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www.derbyshirehealthcareft.nhs.uk

Making a positive difference

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Nottingham West CCG – Rachael Harrold

All participating practices

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EASY READ SUMMARY

This report is about a project.

The project was for NHS England North Midlands.

It happened in Derbyshire and Nottinghamshire.

Drs sent easy read letters to adults with learning disabilities.

The letters reminded them to attend appointments they had missed.

Screening is a good idea.

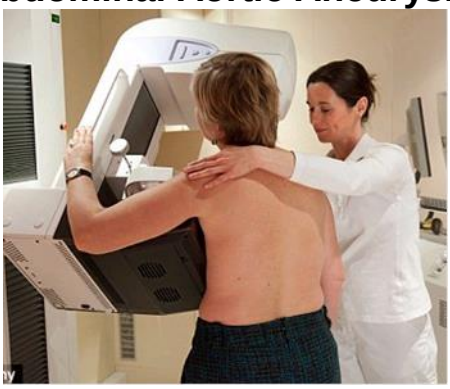
It can stop people getting ill.

It saves the NHS money.

The appointments were for 4 types of health screening:

Abdominal Aortic Aneurysm

Bowel



Breast

Cervical

More people went for screening because of the Drs letters.

We think Drs should keep sending easy read letters.

1. EXECUTIVE SUMMARY

This report represents the findings of a project undertaken within Derbyshire and Nottinghamshire with the aim of increasing screening uptake among people with a Learning Disability (LD).

In 2013, Hardwick CCG carried out a Health Needs Assessment (HNA) and Health Equity Audit (HEA) which found substantial inequalities in cancer screening coverage compared to the general population. 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 the HEA was to roll out the project to the other Derbyshire CCGs; subsequently a bid was successful to NHS England.

The project was rolled out via a Local Enhanced Service (LES) to the wider areas of Derbyshire and Nottinghamshire. The aim was to see if screening uptake would be increased if GP practices sent easy read invitation letters to patients who had not yet attended for their screening. These patients had already received their invitations from the relevant screening centre prior to being contacted by their practice.

RESULTS

Overall, there was a significant positive relationship between the number of eligible patients who received first invitation letters by a CCG and the before-after difference in the number of individuals screened across each cohort. This suggests that the easy-read letters were effective in assisting in the increased uptake of cancer screening amongst people with learning disabilities in Derbyshire and Nottinghamshire.

	Numbers of patients	Patients attending for screening increased by:
AAA	42	29%
Bowel	278	33%
Breast	275	23%
Cervical ages 25-49	340	23%
Cervical ages 50-64	158	38%

The project website which includes the process and the toolkit (including easy read letters, easy read information, and screening and best interest pathways) will continue to be available via the website: http://www.derbyshirehealthcareft.nhs.uk/services/learning-disabilities/screening-programmes/

Anecdotal evidence suggests that there was more awareness of the need for screening patients who have learning disabilities, but also awareness of screening in general within healthcare clinical and none clinical groups.

LIMITATIONS OF THE DATA

Although the data received can help analyse if screening uptake has increased among participating GPs due to sending easy read reminder letters to eligible patients, it is unable to drill deeper into the data. It would be useful if data could be analysed to ascertain whether any cancer/AAA had been detected among patients who went for screening due to the receipt of an easy read GP reminder letter. The findings are incomplete due to the lack of data provided by 12 General Practices.

RECOMMENDATIONS

- Sharing the results: at QUEST/GP educational events across Derbyshire and Nottinghamshire. The final report will also be shared with NHS England (NHSE), participating CCGs and any NHS Organisations expressing an interest in increasing screening uptake.
- Screening hubs to include easy read letters within the invitation process.
- GP Practices to continue to use the easy read letters and prompt screening.
- There is scope for the project to be expanded to other Organisations including prisons.
- Any other areas wishing to replicate the project will need to improve the reporting template.
- Use of easy read information with other social groups - One of the main points of discussion with healthcare providers related to the usefulness of sharing easy read literature to help support patients whose first language is not English. A Public Health England report (Roberts 2015) suggests that 42%-61% of working-age adults are unable to understand or make use of everyday health information.
- DHCFT to continue to maintain the screening toolkit website.
- Investment in support to accompany patients with learning disabilities to attend for their screening appointments.

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4. AIMS AND OBJECTIVES

This project aimed to increase the uptake of screening among people with LD across Derbyshire and Nottinghamshire, incorporating four screening programmes, Cancer (Bowel, Breast and Cervical) and Abdominal Aortic Aneurysm (AAA) screening. It aimed to do this by:

- Asking practices across Derbyshire and Nottinghamshire to sign up to a Local Enhanced Service agreement
- Requesting that practices identify patients via their LD QOF list and send out easy read invitation letters to patients who are eligible but who have not yet been for their screening
- Submitting baseline and final audit data for analysis. From this data will be examined to see if uptake has increased throughout the process. The data will also show if more patients declined/refused screening and if more Capacity assessments were in place after receiving easy read letters.

The anticipated project outcomes were placed into two categories: Short and medium term and long term and are identified below:

4.1 Short and medium term 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 and the AAA Screening Programs by people with learning disabilities.
- Provision of reminder systems to prompt patients/carers to take up screening offer.

4.2 Longer term outcomes:

- Increased take up of NHS Cancer and AAA 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 audit.

5. BACKGROUND AND RATIONALE

Various reports over the past few years have identified significant inequalities in provision of and access to healthcare services for people with LD.

The 'Making Reasonable Adjustments to Cancer Screening' report by Public Health England (PHE) states that people with LD not only have poorer health than the general population but are more likely to die at a younger age. One of the reasons for this is due to lack of access to health services.

This paper also details some of the barriers to the uptake of screening among the LD cohort. These include the lack of easy read invitations, difficulties using appointment systems, time pressures and mobility issues as well as communication difficulties. This research also showed that:

- Patients are more likely to be ceased from breast and cervical screening programmes
- Screening professionals have little experience of supporting patients with LD
- Screening is not always considered as a high priority among Carers
- Fear of screening can prevent patients from attending for screening
- Lack of knowledge that easy read resources are available or where to find them.

5.1 Previous Research

Research has shown that patients who receive screening reminder letters from their GP are effective in increasing uptake. The 3 project summaries that follow focus on the bowel screening programme; however, there should be no reason why this cannot be applied to the other programmes.

One of the most recent trials took place amongst GP practices in Wessex. The PEARL (Practice Endorsed Additional Reminder Letter) project (2017) was specific to the Bowel Cancer Screening programme and was rolled out to 25 GP practices

whose current screening uptake was less than 55%. The Pearl practices sent an additional reminder letter to eligible patients who had already been sent a screening invitation and reminder by the bowel cancer screening programme. Results showed that uptake in these Pearl practices had increased by 3% from 51% to 54%.

Cancer Research UK (CRUK) has also conducted research into the role of GPs in supporting patient participation in screening. This research showed a positive impact that GPs can have promoting awareness amongst their eligible practice population. This research found that a GP endorsement letter can increase participation by 6% and sending a GP letter along with a call to patients can increase participation by 8%.

The CRUK results follow on from research conducted by Hewitson,et al. They looked into whether a Primary care endorsement letter and a patient letter to improve participation in colorectal cancer screening would improve rates. The results found that there was a 10% improvement in participation after patients received a GP endorsement letter and a detailed leaflet.

The latter 2 research studies above included sending a detailed information leaflet along with a GP letter, however, the LD screening project signposts patients to call their local screening centre for further support. Screening centres are able to give extra support to people with LD.

5.2 Brief explanation of screening programmes

As mentioned previously, this project aims to increase the uptake of screening in 4 screening programmes. A brief explanation has been included to show the age groups of patients with LD who will receive an invitation.

5.2.1 Bowel screening

Bowel screening is offered to both men and women aged 60-74. Patients are invited by their local screening centre every 2 years and will receive a home testing kit in the post. It is the patient's responsibility to send a completed test back to their screening centre if they want to participate.

For the purposes of this report the results are based on the FOB test. This kit sent to patients requests that they take three samples from their stools on three separate occasions. Patients are asked to smear their sample on a specially designed card and send back to the screening centre.

The FIT test will be introduced in 2018. This is a much simpler test and requests that the patient takes a sample from one stool. The patient will then capture a small section of the stool, place in a pot and send back to the screening centre. The hope is that this new test is more effective and less complicated which may encourage more patients to complete.

5.2.2 Breast Screening

Breast screening is offered to women between the ages of 50-70 every 3 years. Women are invited via their screening centre and will be asked to attend a special clinic or a mobile unit for their Mammogram.

There is currently an ongoing trial in the UK which extends the age to 47-73 so patients may be invited earlier than expected. This is dependent on the area the patient lives in.

5.2.3 Cervical Screening

Cervical screening is offered to women between the ages of 25-64. Women between the ages of 25-49 are invited to be screened every 3 years and women 50-64 are offered screening every 5 years.

Cervical screening is more invasive than the other programmes and, as such, can prevent patient attendance. There is also a myth that women who are not sexually active do not need to attend for screening. This is actually an inaccurate view and women who are not sexually active should be encouraged to attend.

Although the initial invitations are sent by the screening programme, the procedure is completed at the patient's GP surgery.

5.2.4 AAA Screening

AAA screening is offered to males during the year the patient turns 65. Patients will be invited for screening and asked to attend for an appointment at a venue in their local area. The scan involves the patient lying down and having a scan of their abdomen. Reasonable adjustments can be made if patients are unable to lie down flat but this may not be done at a local venue and patients may need to go to a hospital for their scan.

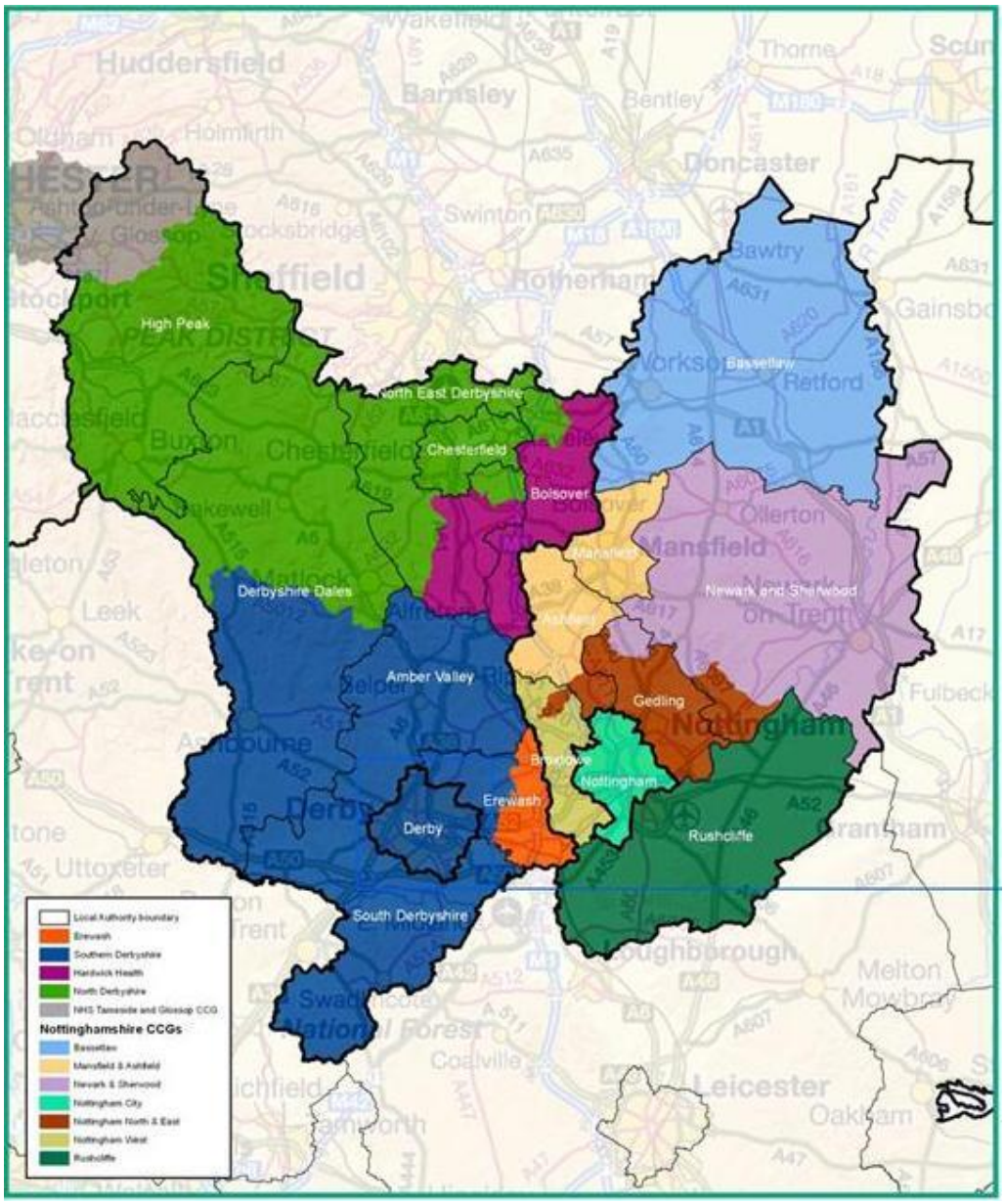
The original scope for the project was to send out easy read information letters for the 3 cancer screening programmes only (Bowel, Breast and Cervical) only. However, after further discussion within the LD screening steering group, it was decided to include AAA (Abdominal Aortic Aneurysm) screening within the project. AAA screening is offered to each male at the age of 65.

5.3 Project Setting

As mentioned previously, one recommendation of the HEA within Hardwick CCG was to roll out the project to the other Derbyshire CCGs. A bid was submitted to NHS England (NHSE) at the end of 2015 to fund a one off LD screening project to take place in Derbyshire and Nottinghamshire. The bid was written by Jackie Fleeman, Lead Learning Disability Strategic Health Facilitator (LD SHF) and Tracey Doucas Screening and Immunisation Coordinator; with oversight from the Derbyshire

Learning Disability Steering Group. The bid was submitted to the Screening and Immunisation team and the funding emanated from the previous year underspend. The amount requested included the recruitment of a Project Manager to run the project for one year and associated costs, monies to reimburse participating practices (£20 per patient invited), administration costs for CCGs to reimburse practices on behalf of the project (10% of the practice total) and funds to cover various aspects of administration.

Prior to the submission of the bid, it was decided to also include Nottinghamshire practices. Geographically, both counties are next to each other and the Screening and Immunisation team of North Midlands cover both regions. For relatively little extra work it seemed logical to increase the number of practices open to participate in a project to increase screening uptake for people with LD.



Derbyshire and Nottinghamshire CCG area Courtesy of Hardwick CCG website

At the time of bid submission there were 120 practices in Derbyshire and 140 in Nottinghamshire.

5.3.1 Derbyshire

According to PHE, approximately 785,800 people lived in Derbyshire in 2016. The QOF prevalence of LD amongst people of all ages in Derby is 0.78 and 0.59 in Derbyshire (2015 data).

There are four CCGs covering the whole of Derbyshire: Erewash, Hardwick, Southern Derbyshire and North Derbyshire. All four CCGs supported the project with local intelligence throughout the project (see 3.3 for further details). NHS Tameside and Glossop CCG was not included for the purposes of this project as, the CCG is only partly in Derbyshire and the area is covered by a different NHSE locality team.

A total of 79 practices signed up to the LES including 12 practices that had no eligible patients at the time of their baseline audit.

5.3.2 Nottinghamshire

According to PHE, 2015 data shows that approximately 806,000 people live in Nottinghamshire and this is predicted to rise to 830,000 by 2020. The QOF prevalence of LD amongst people of all ages in Nottingham is 0.49 and 0.56 in Nottinghamshire.

There are 6 CCGs within Nottinghamshire: Mansfield and Ashfield, Newark and Sherwood, Nottingham City, Nottingham North & East, Nottingham West and Rushcliffe. Bassetlaw CCG was not included within this project as, although part of Nottinghamshire, the area is covered by a different NHSE locality team and therefore funding for the project did not include this area.

48 practices signed up to the LES. However, due to a conflicting scheme running at the time of the project, Nottingham City CCG declined to take part in the project. The remaining 5 CCGs gave a great deal of support to the project (see 3.3 for further details).

5.3.3 Sustainability and Transformation Partnerships (STP)

The way Derbyshire and Nottinghamshire deliver their services is changing due to the development of STPs. However, at the time of writing this report, NHS Organisations across Derbyshire and Nottinghamshire are in the process of developing their Sustainability and Transformation plans within their region. These plans are designed to meet the needs of the regions as a whole and not just the needs of individual organisations. This means a move to Place based care and during the lifespan of this project, those areas had not yet been finalised.

6. METHOD

Once the bid was successful and a project manager appointed, work began on rolling out the project to Derbyshire and Nottinghamshire. Paying close attention to the bid document, the project was to be rolled out to Derbyshire practices initially followed by Nottinghamshire practices.

6.1 Project Process

The process below and subsequent flow chart was shared with Derbyshire and Nottinghamshire practices. The narrative below was included within the Local Enhanced Service (LES) sign up agreement and the basic flowchart was included in the leaflet and in any presentations given to practice managers and GP events:

Upon sign up to a Local Enhanced Service administered by *CCG Primary Care Development Manager* GPs will be asked to complete the following audit and process:

1. Each GP Practice to identify all registered patients aged eighteen or over with a diagnosis of Learning Disability. Maintaining a list of patients with Learning Disabilities is part of the Quality and Outcomes Framework (QOF), and hence should be readily available. Should there be any doubt as to the accuracy of this list the Learning Disability Strategic Health Facilitators can offer assistance.

2. The following criteria for patient record searches should be set:

   - Females aged 50 to 70 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 74 who have had bowel cancer screening performed in the previous three years, or who have a documented AND VALID exclusion reason.

   - Males aged 65 and over 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.

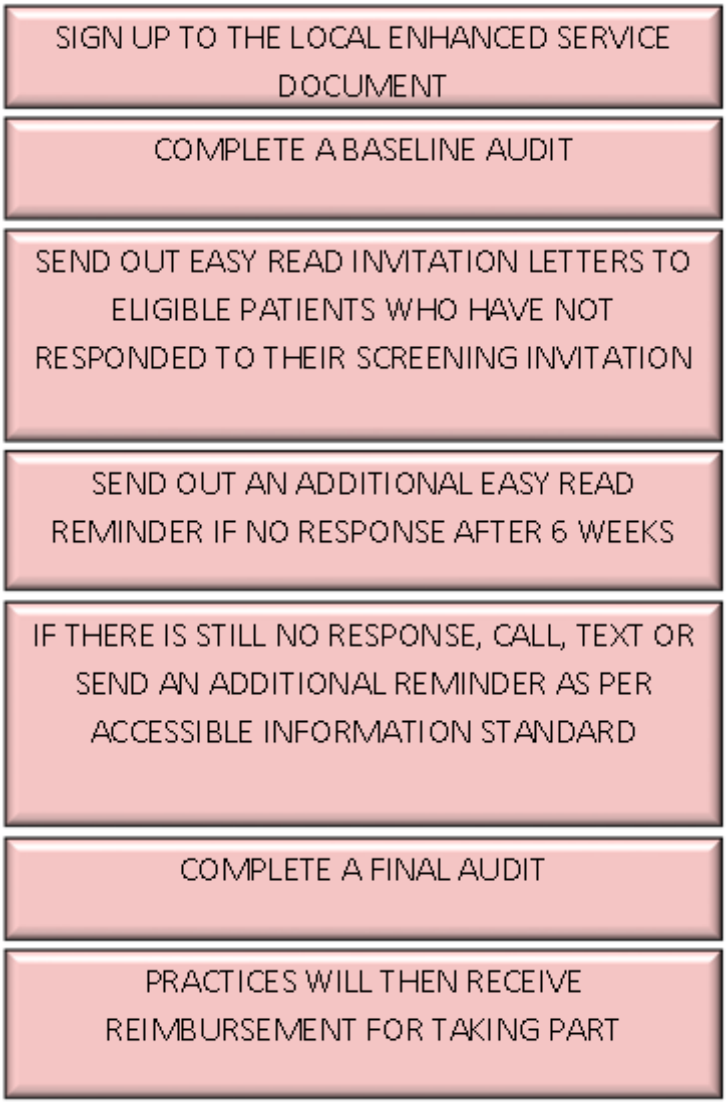
5. A further six weeks later a third contact and invitation should be made to non-responders.

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.

Project process flowchart



6.2 Development of a LES

As the project requested support from practices in addition to their standard contract, a Local Enhanced Service (LES) document was developed. Each CCG was sent a copy prior to contacting practices and invited to give their input. Once agreed, practices were sent a copy of the LES via email and invited to sign up. If interested in taking part, practices were asked to complete and return by a given date.

6.3 Support from CCGs

Contact was made with each CCG and meetings arranged to introduce the project, its importance and discuss any CCG and practice requirements. Input from CCGs was required, not only to help push the project to its practices, but also to provide local intelligence including dates, locations and contacts for practice manager meetings; optimum times to contact practices; periods to avoid project start up; advice about tailoring the LES to obtain maximum sign-up; communication methods

available to the CCG (i.e. website, newsletters, screensaver, QUEST sessions and any other effective methods used).

6.4 Payment Mechanisms

Agreements were made with each CCG to put payment mechanisms in place to reimburse their practices. These agreements were put in place prior to the LES being shared across their region. As each CCG has up to date practice information including codes and account information, reimbursement to each participating practice was made much easier. CCGs were offered an administration fee for completing the process in a one-off payment run.

Regular meetings also took place with the DHCFT finance department to keep abreast of the funding and to offer advice on information required before monies could be paid to CCGs.

6.5 Local Authority support with analysis

Support has also been received from the Public Health Department within the Local Authority to analyse the data received from practices at the end of the process. This support will help to conclude if the uptake of screening has been increased.

7. MARKETING AND COMMUNICATIONS

The next phase of the rollout was to spread awareness of the project. The aim was to try and disseminate information across the regions to capture as many practices as possible. The various tools used are as follows:

7.1 Website

A website has been developed with the support of Derbyshire Healthcare's Communications team. There is a link to the project website from the Annual Health Check pages which was developed as a resource for Derbyshire practices. The project website contained the entire toolkit for practices including easy read invitation letters, sources of easy read information, information for carers, pathways within Derbyshire, capacity assessment pathways and forms for GPs to complete, etc. The aim of this page is to act as a comprehensive resource for practices and to be available for all after the project end.

The address for the project website:

www.derbyshirehealthcareft.nhs.uk/services/learning-disabilities/screening-programmes/

7.2 Project Leaflet

A copy of the project leaflet for practices was disseminated throughout Derbyshire and Nottinghamshire prior to the LES being sent to practices. It was also given out during practice manager meetings, GP training given by Strategic Health Facilitators and QUEST (GP training) events. The leaflet contained the project process and

contact details and, when it was first sent to practices, generated a large amount of interest and enquiries. Please see Appendix 2 for further details.

7.3 Screensaver

A screensaver was produced to be added to CCG systems where available in order to help raise awareness of the project. In Southern Derbyshire, the screenshot shown in Appendix 3 could be seen on practice PCs. When a computer has not been used for a period of time, the screen shows a number of messages and the screenshot was included on this. This proved to be very effective as staff at some practices were already aware of the project.

7.4 Practice Manager Meetings

CCGs throughout Derbyshire and Nottinghamshire supplied contact details of relevant practice manager meetings across their region. Where possible, each meeting was attended and the project introduced to practice managers. In the main this was a quick overview of the project and what is required of practices, followed by a short question and answer session. The original plan was to hold a number of 'launches' across Derbyshire; however Practice Managers dismissed this idea and instead suggested smaller meetings. The project lead therefore visited practices, meetings and attended education sessions.

7.5 Quest Sessions within Derbyshire

Regular GP training sessions are held throughout the year. These events are organised by CCGs and are held when convenient for most practices (either on Wednesdays or in the evening) and, as such, are well attended. Due to the popularity, the sessions' agendas have a tendency to fill up quickly. A number of Quest sessions were attended throughout Derbyshire to introduce the project and to answer any questions or concerns from GPs.

7.6 Support from Cancer Research UK

Cancer Research UK Facilitators have been working across Derbyshire and Nottinghamshire to help increase the uptake of bowel screening among the general population. One of the roles of the Facilitators is to visit practices whose bowel screening rates are low and discuss methods of improvement. When visiting these practices, this project was discussed as a useful tool to help increase bowel screening among patients with LD and this proved extremely useful and generated enquiries.

7.7 Support from Learning Disability Strategic Health Facilitation (LD SHF) and Primary Care Liaison teams

The role of the LD SHF and Primary Care Liaison teams in Derbyshire and Nottinghamshire is to promote good health for people with LD within primary care, train health care professionals, conduct quality checks on Annual Health Checks

(AHC) and generally raise awareness of health issues of people with LD across their regions.

The SHF team in Derbyshire supported the project by discussing the importance of screening during Enhanced Service (ES) training days, Cervical cytology training and mentioned the project during various presentations. They also responded to practice enquiries during AHC visits to practices and fed back any comments.

Support was also obtained by Nottinghamshire's Primary Care Liaison Team who attended initial meetings with CCGs and ensured that the project was included on various agendas including screening events and Partnership Boards.

7.8 Information for people with learning disabilities and their carers.

In Derbyshire the Project Lead presented at the Learning Disability Good Health Group to explain the project. The information was shared with Learning Disability Partnership Boards and various Advocacy Groups. In Nottinghamshire the Lead presented at the Learning Disability Partnership Board.

8. STREAMLINING THE PROCESS

The aim of this project is to increase the uptake of screening and, in order to encourage the sign up from as many practices as possible, it was important to make the project cycle as simple and as less work intensive as possible for practices to complete. There were a few areas where there was the opportunity to streamline the process:

8.1 Template development

TPP SystmOne and EMIS are the two practice computer software systems used throughout Derbyshire and Nottinghamshire. SystmOne is the most popular system in the regions and is the sole provider within 3 of the participating CCGs.

Due to an action from the first LD steering group specific to this project, Gem and Arden (a CCG Commissioning Support Unit within Derbyshire) were contacted to help develop a reporting tool within both systems. The aim of this tool was to make the process of identifying eligible patients much smoother and quicker for practices and, as such, would hopefully encourage more practices to sign up to the LES. Working with the LD QOF database, the tool searches for eligible patients within each screening program using READ codes. As participating practices have access to this tool after the end of the project, it has the added benefit of being available for practices to continue following up their patients. The tool was developed with the support of Limes Medical Centre who helped advise upon design and tested the template with the Informatics lead.

8.2 Payment Mechanisms

Due to the volume of practices taking part across both regions, a simple method of payment was required to ensure that practices were reimbursed as quickly as possible. As CCGs have up-to-date information regarding their practices, each one was approached to reimburse participating practices on behalf of the project. Each CCG agreed to make a one-off payment to their practices.

9. BARRIERS/DIFFICULTIES

As with many projects, delays were experienced throughout the process. In the main, these delays were IT based, however, there were also delays in the receipt of audits from practices. This is unavoidable in the current health climate as practices have an increasing number of targets and priorities.

9.1 Information Technology Issues

During the first steering group it was decided to develop a reporting template to be used within TPP SystmOne and EMIS, the two electronic and patient record databases used within Derbyshire and Nottinghamshire. The increasing GP practice workload meant that the something simple had to be developed which made the completion of the process of identifying eligible patients and sending out easy read invitations as easy and quick as possible.

This new method had to be developed from scratch by Arden & Gem and took much longer than anticipated. This delayed the rollout to Erewash, North Derbyshire and South Derbyshire CCGs and also resulted in the reporting template not being tested thoroughly prior to sharing with practices. Background work on getting practice sign-ups was completed whilst the reporting template was under development and this did save time. However, the momentum from sign-up to completing the process may have been lost to some practices that were eager to commence the process. When the template was complete, it was tested by staff at Limes Medical Centre in Alfreton, Derbyshire before being rolled out to participating practices.

9.2 Cyber Attack

On the 12th May, many NHS Organisations fell victim to a global cyber-attack. Whilst Derbyshire Healthcare was not directly affected by the ransomware attack, emails were taken offline for a week in order to upgrade systems and ensure that staff laptops had the latest security installed. CCGs across both Derbyshire and Nottinghamshire were also affected and they had to focus on other priorities during the attack and for quite a while afterwards. Whilst this did not affect the project in Derbyshire, it did delay Nottinghamshire rollout with meetings and practice sign up being directly affected.

9.3 Staff Changes within practices

A number of practices have been difficult to contact due to changes in staff. These changes have made communication difficult and have slowed down the process somewhat in affected practices. While some practices have attempted to pick up where previous colleagues have started, others have not had the capacity to support.

9.4 Anomalies within IT template

A number of practices and screening centres have reported that patients who were not eligible for screenings have been sent invitation letters.

For example, in Nottinghamshire, the AAA screening centre reported 5 patients contacting the screening centre to arrange screening. These patients were over 65 and were not eligible for screening and therefore had to be turned away. These patients were sent an easy read apology letter by affected practices. Practices were also asked not to send further information to these patients for the remainder of the project and practices from the wider area were contacted and asked to only send AAA letters to patients who are 65 years of age.

9.5 LD QOF searches

Each practice maintains a list of patients with Learning Disabilities as part of the Quality and Outcomes Framework (QOF) and as such, searches were based on the LD QOF list. However, the LD QOF list also contains details of patients with Learning Difficulties including dyslexia and autism. This is a relatively small number of patients, however, it must be recognised that this group of patients may have also received easy read invitation letters from practices.

9.6 Pilot breast screening age ranges

The original search criteria asked practices to search for Females aged 47 to 73 who have had breast screening performed within the previous three years, or have a documented AND VALID exclusion reason. However, it became clear that patients are only routinely invited for breast screening between the ages of 50-70.

There was some initial confusion as to what age ranges to include for the Breast screening as both regions had taken part in the national Breast screening pilot to extend the age ranges to 47-73. This pilot began in 2009 an was set up in six breast screening units to try and work out the feasibility of extending the age ranges for inviting women to screening. Following on from the pilot, the study was rolled out as a randomised controlled trial to 67 out of 80 screening units. Results of this study are not expected until 2020.

As soon as feedback was received saying that patients under 50 years of age had contacted the screening centre to be told that they were too young to be invited for screening, the reporting template was changed to search for female aged 50-70 within Derbyshire.

9.7 Difficulties completing the baseline and final audit template document

Some practices reported having difficulties in completing the audit documentation and as such a number of data queries were raised. Some submissions had to be clarified with the practices by the project lead as there were less people identified in the final submission than in the baseline. This was explained by practices as their second submission only included patients that had not had screening. The data therefore needed to be checked and cleansed.

The point of the document was to ascertain the following information:

Baseline audit

- Number of patients were eligible for screening at baseline
- Number of eligible patients had already been for screening
- Number of eligible patients had declined or refused to go for screening
- Number of these eligible patients had a capacity assessment in place

Final audit

- Number of patients have been for screening after completing the process
- Number of patients have declined or refused to go for screening after completing the process
- Number of patients have a capacity assessment in place after completing the process

The baseline and final audit document can be found in Appendix 4.

9.8 Understanding of Mental Capacity Assessments

The inclusion of mental capacity assessment data is in the baseline and final audit document. It has been included so that there is a measure of the use of assessments by practices.

Having a learning disability does not automatically mean that the patient lacks the capacity to make a specific decision. The patient should be helped to make their own decision and the information provided to practices in easy read can help to inform patients. If someone lacks the capacity to make a decision and the decision needs to be made for them, then the Mental Capacity Act states the decision must be made in their best interests. A mental capacity assessment / best interest decision is made by GPs/ Nurses in consultation with close friends/ family/ carers. This would be completed if they believe that their patient does not have enough understanding (specifically regarding cervical screening) to make their own decision.

A number of enquiries were received from practices concerning capacity assessments and their meaning. It has to be said that these enquiries were not from GPs themselves but from members of staff contacting patients.

Data received has shown that there have been many capacity assessments in place across all screening programmes.

A GP from one practice has acknowledged that they should 'do a better job documenting capacity assessment/best interest decisions. A best interest pathway and practice form can be found on the project website.

9.9 Map of Medicine

The Map of Medicine was mentioned within the successful project bid as an area of sustainability to be utilised by most CCGs within Derbyshire and Nottinghamshire. The Map of Medicine is an electronic tool which gives health professionals instant access to patient pathways.

At the time of rolling out the project within Derbyshire it was clear that Map of Medicine was not as widely used as anticipated. However, the up to date pathways for the screening programmes as well as the project process are included on the project website and can be accessed by clinicians. If required, these pathways can be shared with interested organisations for inclusion in the Clinical guidelines section of their website.

9.10 Florence Telehealth (Flo)

The use of the Flo system was detailed within the original bid:

'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.'

The Flo system is used within CCGs across the country to contact patients and send them appointment reminder texts as well as tailored health tips if required. It had previously been used within certain clinical groups of North Derbyshire CCG, but it became clear that some CCGs did not use the system at all and others had no plans to join. Practices do however have the tools to text reminders to their patients within their practice systems and, therefore, if required can text patients and remind them that they had not been for screening.

9.11 Accessible Information Standard (AIS)

Introduced on the 1st August 2016, the AIS sets out a 'specific consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents with a disability, impairment or sensory loss' (NHSE).

When introducing the project, it was requested that participating practices send out 2 easy read invitation letters followed by contacting a patient via their preferred method

of communication as stated in the AIS. AIS had only just been introduced when approaching practices to take part. The Care Quality Commission have since announced that they will be checking adherence to the AIS in future inspections.

10. GOOD NEWS STORIES

The results of the project will be presented later in this report. However, the receipt of regular updates has revealed some good news stories reported by participating practices. Listed below are just a few of the positive outcomes of the project:

10.1 Continuing support for LD patients

After discussing the project with participating practices, it became clear that some already had procedures in place to support patients and ensure that every effort is made to encourage patients to go for screening visits.

A good example is Gresleydale Healthcare Centre in Derbyshire regularly follows up all of their LD patients. They check that they have attended for screening and follow up if they have not to discuss any reasons for non-attendance. They also send easy read information to their patients to help answer initial questions and explain what will happen at a screening appointment. This of course, is not limited to screening invitations.

A number of practices have confirmed that they already send easy read invitation letters to patients. This is specifically to remind them to attend their AHC but the importance of screening is discussed during their appointment.

Obviously, whilst this is a very good example of good practice, it must be said that many practices may not have the resources to support patients in this manner.

10.2 Responses from ineligible patients

Although largely a negative and unforeseen outcome of the project, there were a number of ineligible patients invited to go for screening (see section 6). These patients made contact with their local screening centre or GP practice for further support. Screening centres and GP practices fed this issue back immediately and were informed not to send out any further information to these patients. However, although this was an unforeseen event, it is another example of patients responding to letters from their GPs.

10.3 Practices unable to continue participation

Due to some of the reasons identified in section 6 of this report, a number of practices who signed up to the LES were unable to complete the process. Although this was a disappointment, the majority of these practices confirmed that they either already contact patients to remind them of screening or have since put measures in place to send reminders to their LD patients.

10.4 Increased awareness in LD screening among Health Professionals

After meeting with the LD steering group and discussing project progress it became apparent that there have been benefits amongst healthcare professionals, both clinical and non-clinical. Many of these staff have been made aware of the importance of screening for people with LD through their practices participation in the project and the training given by the SHF/PCL teams through ES training and through Cervical screening (Cytology) training.

Comments received from participating practices that have sent letters and who have subsequently made appointments for patients to go for their cervical screening have been positive. The following quote was received from a Nottinghamshire practice, Oakwood Surgery:

"It's so satisfying to see when patients have responded positively or have an appointment in the pipeline."

11. COSTS

The project did not include the ability to complete a cost benefit analysis, however a study by Laudicella (2016) highlighted that earlier diagnosis and treatment can save thousands of pounds per patient, compared to late diagnosis. Tuffney (2009) found that people with learning disabilities are likely to have late diagnosis of cancer which can be due to their reliance upon others to spot symptoms, and lack of healthcare. CIPOLD (2013) reiterated the barriers and problems with early diagnosis.

The majority of the budget for the project was spent upon engaging a Project Lead who could dedicate all their working hours to the project. Setting up costs included recruitment which involved a family carer.

A rough calculation of cost per patient is based upon the first letters sent to 1092 patients. This works out at a cost of £118.26 per patient.

12. RESULTS

The results were collated by the practices and submitted to the project Leads using the audit template (Appendix 4). Not all practices returned their results. Therefore the results are missing information from 12 Nottinghamshire practices.

A key aspect of the intervention was the inclusion of easy-read letters for eligible patients. This was comprised of the following stages:

1. First audit – all registered patients aged 18 or over with a learning disability diagnosis were identified.

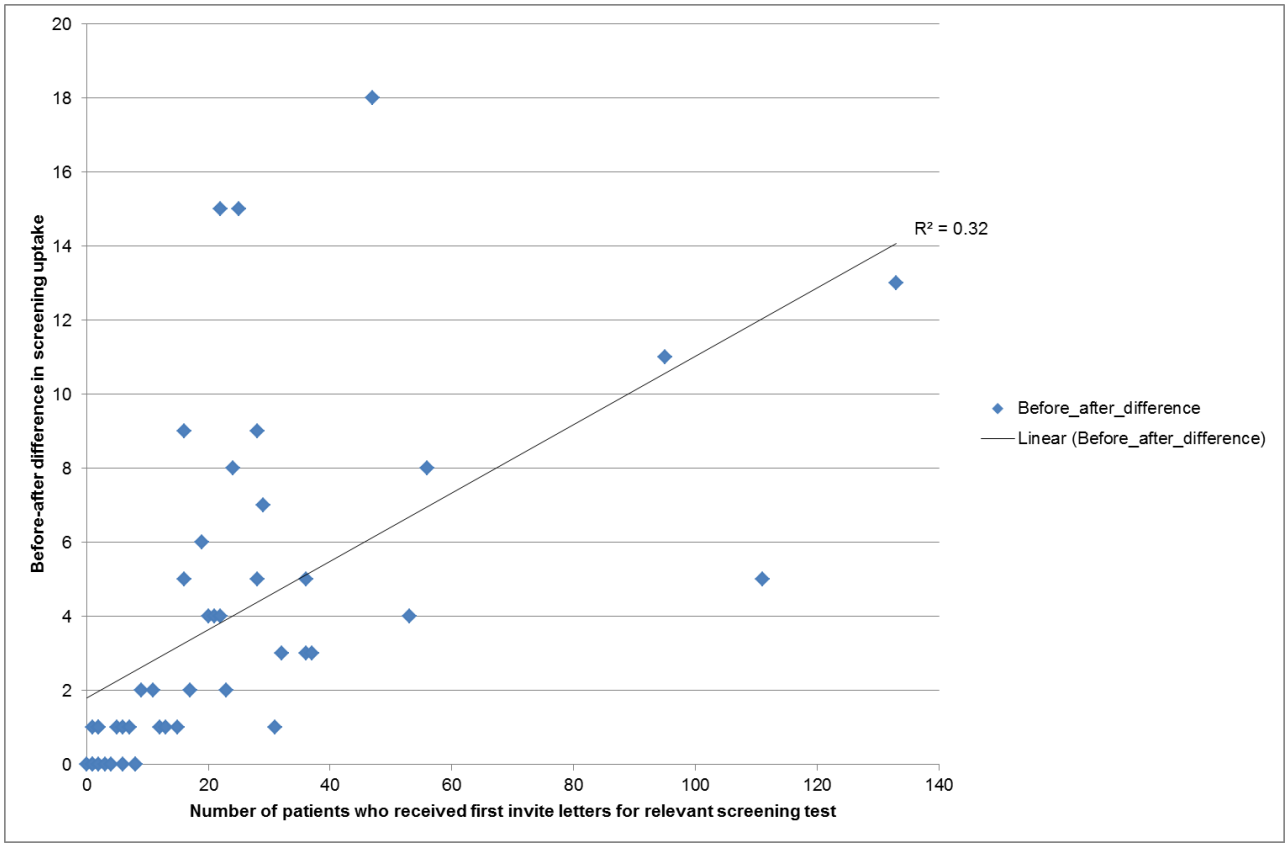
2. First invitation letter sent out – all patients identified as eligible for screening, but not shown as having taken part, and without a valid and current exemption were contacted using the approved letter and invited to attend screening by the GP surgery or local screening unit.
3. Second invitation letter distributed to non-responders six weeks later, with consideration of reasonable adjustments such as contacting the patient by phone and involving Learning Disability Strategic Health Facilitators for support.
4. Third invitation letter and contact made with non-responders a further six weeks later.
5. Second audit conducted 12 weeks after the third invitation.

A Public health Support Officer has completed a detailed analysis of the data and provided the following high level summary.

12.1 High-level summary

Correlational analyses were conducted to examine the relationship between the number of eligible patients who received first invitation letters by a CCG and the before-after difference in the number of individuals screened across each cohort. There was a strong, positive relationship between the two variables, which was statistically significant ($r(43) = 0.79$, $p = 0.000$). The SPSS output can be found in appendix 5. Figure 1 presents the relationship between the number of patients who received first invitation letters for a relevant screening test and the before-after difference in screening uptake across the clinical commissioning groups. It suggests that the number of patients who received first invite letters accounted for 32% of the variability in the before-after difference in screening uptake. The tables for individual GP practices have been retained for dissemination of the full report but are available via a briefing paper prepared by Sereena Raju.

Figure 1: The relationship between the number of letters sent and the before-after difference in screening uptake grouped by test and clinical commissioning group



Linear regression is a common form of predictive analysis that examines the extent to which an independent (predictor) variable predicts an outcome variable. The following assumptions were tested in order to determine whether it was appropriate to conduct a linear regression:

1. There is a linear relationship between the two variables.
2. The data shows homoscedasticity, where the variances along the line of best fit remain similar as you move along the line.
3. The residuals (i.e. the difference between the observed value of the dependent variable and the predicted value) of the regression line are approximately normally distributed. Two common methods to check this assumption include using either a histogram (with a superimposed normal curve) or a Normal P-P Plot.

The results of the tests of these assumptions can be found in appendix 6. Whilst there was a linear relationship between the two variables, the residuals were not normally distributed. Although it is possible to “transform” data to normality, this

resulted in an extensive number of missing values due to the initial volume of zeros. As such, a linear regression analysis was not conducted.

The remainder of the report provides a summary of the differences in screening uptake amongst eligible patients across each cohort.

The number of first invite letters sent is sometimes higher than the number screened in the first audit. In addition to sending letters practices were also asked to prompt screening during the LD Annual Health check and any other consultations. The baseline is taken at one point in time and the second audit some weeks later. There may have been some movement of patients between practices which may account for some small differences. Patients may also have responded to the usual invite.

12.2. Abdominal aortic aneurysm screening

Table 1 provides a breakdown of the data by clinical commissioning group. No patients were identified as eligible within Newark and Sherwood CCG. Primary suppression was applied to numbers less than 5. Take up increased Table 1 provides a breakdown of the data by clinical commissioning group.

Table 1: CCG-level breakdown of abdominal aortic aneurysm screening amongst patients with a learning disability

CCG	Eligible AAA patients	Number of first invite letters sent	Number screened - first audit	Number screened - second audit	Percentage uptake (as a proportion of eligible patients)
Southern Derbyshire	19	7	9	10	52.6%
Hardwick	17	17	5	7	41.2%
North Derbyshire	5	<5	<5	<5	*
Erewash	<5	<5	<5	<5	100.0%
Nottingham North & East	5	<5	<5	<5	*
Nottingham West	5	8	<5	<5	*
Mansfield & Ashfield	<5	<5	<5	<5	*
Rushcliffe	<5	<5	<5	<5	*
Grand Total	**59**	*****	**21**	*****	**45.8%**

* *Secondary suppression has been implemented in order to protect the confidentiality of cells that pose an unacceptable risk of disclosure.*

12.3. Bowel cancer screening

Overall, there was a 33% increase in the number of patients screened between the first and second audit (145 to 193). Table 2 provides a summary of the data grouped by clinical commissioning group.

Table 2: CCG-level breakdown of bowel cancer screening amongst patients with a learning disability

CCG	Eligible bowel patients	Number of first invite letters sent	Number screened - first audit	Number screened - second audit	Percentage uptake (as a proportion of eligible patients)
Southern Derbyshire	137	111	32	37	27.0%
North Derbyshire	65	37	22	25	38.5%
Erewash	42	21	24	28	66.7%
Hardwick	28	28	10	19	67.9%
Mansfield & Ashfield	57	25	34	49	86.0%
Nottingham North & East	35	23	7	9	25.7%
Nottingham West	32	16	15	24	75.0%
Rushcliffe	21	15	<5	<5	*
Newark & Sherwood	<5	<5	<5	<5	*
Grand Total	*****	*****	**145**	**193**	**46.0%**

12.4. Breast cancer screening

The number of individuals screened increased between the first and second audit. Table 3 provides a breakdown of the data by clinical commissioning group.

Table 3: CCG-level breakdown of breast cancer screening amongst patients with a learning disability

CCG	Eligible breast cancer patients	Number of first invite letters sent	Number screened - first audit	Number screened - second audit	Percentage uptake (as a proportion of eligible patients)
Southern Derbyshire	151	95	57	68	45.0%
North Derbyshire	84	56	27	35	41.7%
Erewash	36	11	22	24	66.7%
Hardwick	50	36	18	21	42.0%
Mansfield & Ashfield	56	29	24	31	55.4%
Nottingham North & East	48	20	22	26	54.2%
Nottingham West	28	19	8	14	50.0%
Rushcliffe	7	6	<5	<5	*
Newark & Sherwood	5	<5	<5	<5	*
Grand Total	**465**	*****	*****	**222**	**47.7%**

12.5. Cervical screening (25-49 years)

Overall, 671 patients with a learning disability aged 25-49 were identified as eligible for cervical screening. In total, 340 first invitation letters were distributed. There was a 23% increase in the number of patients screened between the first and second audit (229 to 281). Table 4 provides a breakdown of the data grouped by clinical commissioning group.

Table 4: CCG-level breakdown of cervical screening amongst patients with a learning disability aged 25-49

CCG	Eligible cervical screening patients (25-49 years)	Number of first invite letters sent	Number screened - first audit	Number screened - second audit	Percentage uptake (as a proportion of eligible patients)
Southern Derbyshire	253	133	95	108	42.7%
Erewash	75	32	21	24	32.0%
North Derbyshire	68	31	34	35	51.5%
Hardwick	53	36	19	24	45.3%
Mansfield & Ashfield	85	47	26	44	51.8%
Nottingham North & East	64	28	22	27	42.2%
Nottingham West	41	16	6	11	26.8%
Rushcliffe	23	12	<5	<5	*
Newark & Sherwood	9	5	<5	<5	*
Grand Total	**671**	**340**	**229**	**281**	**41.9%**

12.6. Cervical screening (50-64 years)

There was a 38% increase in the number of patients screened between the first and second audit (90 to 124). Table 5 provides a summary of the data grouped by clinical commissioning group.

Table 5: CCG-level breakdown of cervical screening amongst patients with a Learning disability aged 50-64

CCG	Eligible cervical screening patients (50-64 years)	Number of first invite letters sent	Number screened - first audit	Number screened - second audit	Percentage uptake (as a proportion of eligible patients)
Southern Derbyshire	101	53	29	33	32.7%
Hardwick	42	22	16	31	73.8%
Erewash	31	8	9	9	29.0%
North Derbyshire	29	22	13	17	58.6%
Mansfield & Ashfield	45	24	12	20	44.4%
Nottingham North & East	29	13	5	6	20.7%
Nottingham West	16	9	<5	5	31.3%
Rushcliffe	12	6	<5	<5	*
Newark & Sherwood	<5	<5	<5	<5	*
Grand Total	*****	*****	**90**	**124**	*****

12.7 Conclusions and limitations of results

The first audit acted as a baseline stage and was conducted before the first invitation letters were sent out. This will explain why the number of first invite letters sent is sometimes higher than the number screened in the first audit. In addition to sending letters practices were also asked to prompt screening during the LD Annual Health check and any other consultations, so this could also increase take up without the letters being involved. The baseline is taken at one point in time and the second audit some weeks later. Practices taking part may have improved their coding of patients with learning disabilities and screening. It is also possible that there were some movement of patients between practices which may account for some small differences. Data was only provided in relation to first invite letters so we cannot report on 2nd or 3rd invitations.

It is important to note that the findings are incomplete due to the lack of data provided by 12 General Practices in Nottinghamshire. Additionally, the reported uptake in screening was calculated as a proportion of those identified as eligible for screening. Since this cohort may have included individuals who had already been screened, the actual levels of uptake could be higher. It should also be noted that some data cleansing was required for the Nottinghamshire data. Specifically, some figures in the second audit were lower than those provided in the first audit. From discussions with GP Practices, the project Team anticipated that the figures within the second audit only included individuals who hadn't been screened at baseline.

There were variations in how the uptake of screening compared with the national average for those with learning disabilities across each test. For example, the overall uptake of cervical screening was significantly higher amongst those aged 25-49 (41.9%; 95% CI: 38.2 to 45.6) and 50-64 years (40.4%; 95% CI: 35.1 to 46.0) than the national level of uptake amongst those with learning disabilities (30%). For breast cancer screening, the reported uptake amongst learning disability patients (47%; 95% CI: 43.2 to 52.3) was comparable with the national average for this cohort (51%). Re bowel cancer screening, the overall uptake was significantly lower (46.0%; 95% CI: 41.2 to 50.7) than the national level of uptake for eligible people with learning disabilities (75%). Across all tests, however, there were considerable variations in uptake at a CCG level.

Overall, there was a significant positive relationship between the number of eligible patients who received first invitation letters by a CCG and the before-after difference in the number of individuals screened across each cohort. This suggests that the easy-read letters were effective in assisting in the increased uptake of cancer screening amongst people with learning disabilities in Derbyshire and Nottinghamshire.

13. LESSONS LEARNED FOR FUTURE PROJECTS

As detailed previously in this report, there are areas of the project that have not run smoothly. The project was rolled out in phases via region and then via CCG to make it easy to rectify any issues and makes improvements in communication if necessary. However, on reflection there are some areas that can be improved upon should other Organisations wish to develop their own project:

13.1 Investment in a more detailed reporting template

As shown in section 9, there have been occasions where ineligible patients have been invited for screening and have contacted screening centres to arrange an appointment. This is obviously an unwanted outcome as it is not intended to adversely upset or inconvenience a patient or their carer. These issues may be due to the reporting template and/or slightly different coding used by practices.

Arden and Gem were extremely supportive with the development of the reporting tool, however, the time constraints of the project and the workload of the CSU at the time of development may have resulted in a few issues with the searches. The expectation for the template initially was that the Informatics team would extract the data and provide the report to the Project Lead. The template was created but there was no capacity for the Informatics team to extract the report. This would save time for practices who had to run the search and provide the report, and limit the need for data cleansing, it would also streamline the process and ensure that all data was submitted and in a timely manner.

An improved template may be able to collect data from 2nd and 3rd letters and therefore identify which were most effective in screening take up.

Therefore, it is a recommendation that a further time is invested in the reporting tool prior to rolling out to other areas.

13.2 Explanation of mental capacity assessment

The baseline and final audit document developed over time. Its aim was to capture screening information as accurately as possible and it was important to keep the document simple and easy to follow. In hindsight however, the document resulted in a few queries from practices. In the future it would be a good idea to develop a user guide or detailed explanation of what information is required to pre-empt any queries and help prevent any confusion.

14. SUSTAINABILITY / LEGACY

Throughout the project, it has been documented that patients with LD have certainly reacted to the easy read reminder invitation letters sent to them. Whilst sometimes not being under the best circumstances, for example, patients being invited who are not of the correct age, however, although this is not an ideal outcome it acts as evidence that patients have been reacting to the letter received from their GP practice.

Now that the project cycle has been completed, it is important to establish if the good work will continue beyond this report. Many tools put in place to facilitate practices will continue beyond the life of the project and can be utilised by practices from both Derbyshire and Nottinghamshire wanting to continue reminding their LD patients about screening or by practices outside the regions who have heard about the LD screening project.

The toolkit was aimed at people who have learning disabilities but is also available from the website for people who have English as a second language and those who need support with Health Literacy. Roberts (2015) explains health literacy as *'having the appropriate skills, knowledge, understanding and confidence to access, understand, evaluate, use and navigate health and social care information and services……People with limited health literacy are less likely to use preventive services and more likely to use emergency services, are less likely to successfully manage long-term health conditions and as a result incur higher healthcare costs.*' Roberts suggests that 42-61% of the adult population in England have problems with health literacy.

14.1 Website

The website which was specifically developed for the project is permanently available for practices who wish to continue the good work. The website contains easy read invitation letters, sources of easy read information, pathways, supporting information for carers, etc. and is available to be used by all healthcare providers and GPs.

The project process is also available on the website and, as such, can be repeated by other regions if required. The web address below will be shared as part of this report and can be utilised by other CCGs and practices nationwide.

http://www.derbyshirehealthcareft.nhs.uk/services/learning-disabilities/screening-programmes/

The website will hopefully be updated with DHCFT support, with any new or amended documentation. Any further helpful documentation can currently be submitted for inclusion onto the website.

In Derbyshire the letters and easy read information from the website are being provided as hard copies, within the learning disability packs given, to GP Practices as part of the LD Annual Health checks support.

14.2 Increased knowledge amongst Healthcare professionals

The LD SHF team has reported an increase in awareness of the project and of the importance of screening for people with LD across the region. During training sessions, they have been approached to discuss the project further. It is generally felt during steering group meetings that awareness of the issues has increased beyond expectations across the regions for people with and without LD.

14.3 Return to screening

Once patients have attended for screening for the first time, the more likely it is that they will return in the future. Obviously this is dependent on whether the patient had a good experience on their first visit and if reasonable adjustments were made to accommodate their needs.

The results show there has been an increase in uptake for screening across Derbyshire and Nottinghamshire. The hope for the future is for other practices across the country to start to send out easy read invitation letters or contact patients to remind them that they have not been for screening.

15. RECOMMENDATIONS

After running a cycle of the project and receiving data from participating practices, the following recommendations are made to disseminate the findings and to carry the good work forward further:

15.1 Sharing the results:

Results should be shared at QUEST/GP educational events across Derbyshire and Nottinghamshire. The final report will also be shared with NHS England (NHSE), participating CCGs and any NHS Organisations expressing an interest in increasing screening uptake.

15.2 GP Practices to continue using the easy read letters.

The results have shown that easy read letters sent from the GP Practice does have an impact upon the take up of screening.

- Making contact with patients who have learning disabilities via their preferred method of communication was mentioned within the scope of this project. However the Accessible Information Standard (AIS) had just been introduced when initially approaching practices to participate. It is now 2 years since the Standard came into play and practices are now better informed and should

have updated their systems accordingly. Use of the letters can support GP practices adherence to the Accessible Information standard, which will be part of the CQC checking process from October 2017.

- We have not checked if the style of the letters was useful (symbols) or if photograph images would have more impact.
- Prompting for screening continues to be part of the learning disability Annual Health check; it would be helpful to add sending out the easy read prompts to the Enhanced Service specification.
- We suggest that the Screening hubs' invitation process should include the sending of easy read letters as standard. This could be an easy read version printed on the back of the usual letter.

15.3 Expand to other organisations.

There is scope for the project to be expanded to other Organisations including prisons. Initially a local prison was interested in participating in the project, however, the care provider for this prison was not a GP practice.

Any other areas wishing to replicate the project will need to improve the reporting template.

15.4 Use of easy read information with other social groups

One of the main points of discussion with healthcare providers related to the usefulness of sharing easy read literature to help support patients whose first language is not English. In addition a Public Health England report (Roberts 2015) suggests that 42%-61% of working-age adults are unable to understand or make use of everyday health information. The information and letters can be used to support understanding of the screening processes.

15.5 Maintaining the website.

The project website was created by the project lead and Communications Departments at DHCFT. The project website which includes the process and the toolkit (including easy read letters, easy read information, screening and best interest pathways) will need to be updated with new information as and when required and the information contained within can be used by any interested organisations. The toolkit should continue to be freely available via the internet.

15.6 Include Bowel scope screening

Bowel Scope - screening for patients aged 55 is now being phased in across the UK. There is already easy read material available for patients with LD. This has been

added to the website and easy read invitation letters should be devised to support patients with LD.

15.7 Investment in support to accompany patients with learning disabilities to attend for their screening appointments.

Anecdotal evidence is suggesting that some people with learning disabilities are not receiving enough support to enable them to attend appointments aimed at preventing ill health including screening. Over the last few years local Social Service provision and criteria for access has been cut. During the commissioning process for packages of care we hope that the schedule of expected health appointments is used. However, stories are coming to Healthwatch Derbyshire and the Learning Disability Groups to suggest that the amount of social care support calculated is not considering what are generally referred to as 'health appointments.' The schedule of expected health appointments was circulated in Derbyshire as part of the Learning Disability Self-Assessment Action Plan in 2014 and includes screening appointments.

Tyson et al (2017) found that people with learning disabilities who lived with families were even less likely to attend their LD Annual Health check than those with Social care support.

Therefore one of our recommendations is a project to support patients in attending for their screening appointments.

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APPENDIX 1 – LOCAL ENHANCED SERVICE SIGN UP DOCUMENT

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	**April 2017 onwards**
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. The toolkit is available on the LD screening project website:

  http://www.derbyshirehealthcareft.nhs.uk/services/learning-disabilities/screening-programmes/

- 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 this 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 weeks 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	12 weeks after 3rd invitation
Send report back to donna.beal@derbyshcft.nhs.uk	

3.3 Population covered

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

4. Applicable Service Standards

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

5. 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 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 text 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 Donna Beal (donna.beal@derbyshcft.nhs.uk) as soon as possible after completing the second audit. Payment will be received after a full validation of this template.

6. Variation/ 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:	

APPENDIX 2 – PROJECT LEAFLET

Contact us

You can contact our team in any of the following ways:

Project Manager, c/o Strategic Health Facilitators
Learning disability Services
St. Andrews House (2nd floor)
201 London Road
Derby, DE1 2SX

07789 924422

Donna.beal@derbyshcft.nhs.uk

Or visit our project website:

http://www.derbyshirehealthcareft.nhs.uk/services/learning-disabilities/screening-programmes/

If you would like this information in a different language or format please contact communications@derbyshcft.nhs.uk

communications@derbyshcft.nhs.uk اذا كنت تريد هذه المعلومات بلغة أو تنسيق مختلف يرجى الاتصال بنا.

如果您想要将本信息用其他语言或格式显示，请联系 communications@derbyshcft.nhs.uk

Si vous souhaitez recevoir ces informations dans une autre langue ou un autre format, veuillez contacter communications@derbyshcft.nhs.uk

अगर आप यह जानकारी अलग भाषा या स्वरूप में चाहते हैं तो कृपया संपर्क करें communications@derbyshcft.nhs.uk

Jeżeli chcieliby Państwo otrzymać kopię niniejszych informacji w innej wersji językowej lub w alternatywnym formacie, prosimy o kontakt z communications@derbyshcft.nhs.uk

ਜੇ ਤੁਸੀ ਇਸ ਜਾਣਕਾਰੀ ਨੂੰ ਹੋਰ ਭਾਸ਼ਾ ਜਾਂ ਫਾਰਮੈਟ ਵਚਿ ਚਾਹੁੰਦੇ ਹੋ ਤਾਂ ਕਰਿਪਾ ਕਰਕੇ ਸੰਪਰਕ ਕਰੋ communications@derbyshcft.nhs.uk

communications@derbyshcft.nhs.uk اگر آپ یہ معلومات کسی مختلف زبان یا فارمیٹ میں وصول کرنا چاہیں تو براہ مہربانی رابطہ کریں

Derbyshire Healthcare NHS
NHS Foundation Trust

Increasing the uptake of Cancer & AAA Screening for people with Learning Disabilities

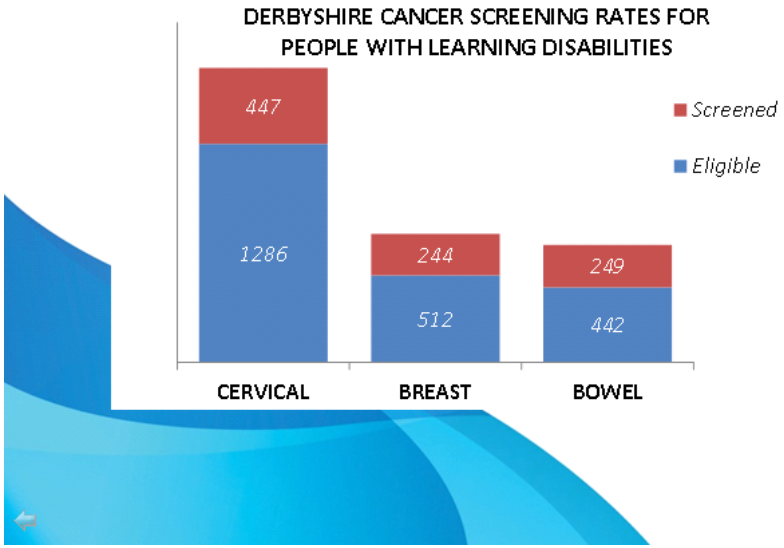
Better together

AIMS OF THE PROJECT …..

This project aims to increase take up of the four NHS Cancer Screening Programmes (bowel, breast and cervical cancer & AAA screening) in people who have learning disabilities across Derbyshire.

…..WHY?

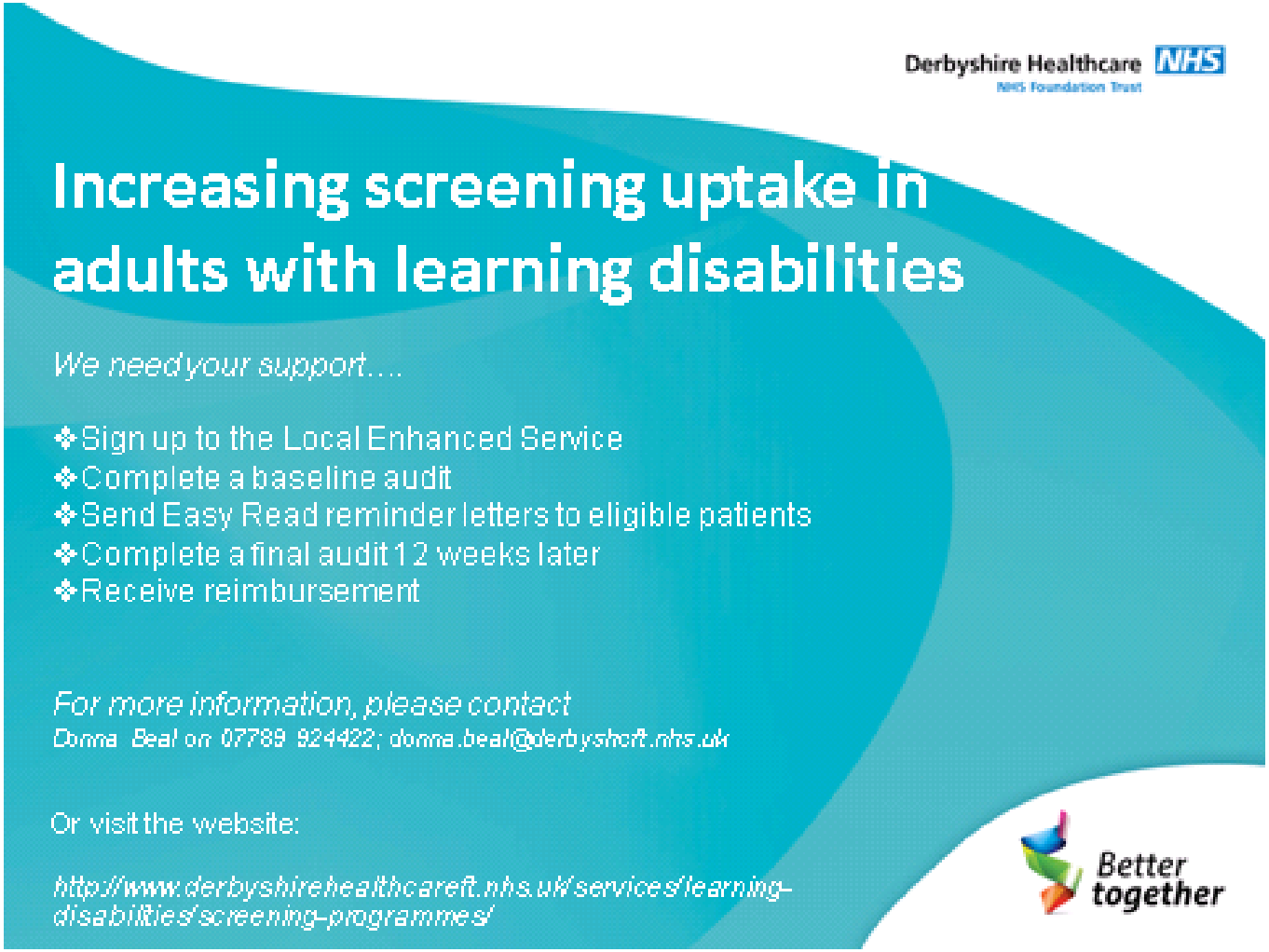
It is recognised that adults with learning disabilities have low screening uptake and this project aims to engage GP practices in promoting this and embed processes in order to influence future GP Practice activity.



HOW PRACTICES CAN GET INVOLVED

- SIGN UP TO THE LOCAL ENHANCED SERVICE DOCUMENT
- COMPLETE A BASELINE AUDIT
- SEND OUT EASY READ INVITATION LETTERS TO ELIGIBLE PATIENTS WHO HAVE NOT RESPONDED TO THEIR SCREENING INVITATION
- SEND OUT AN ADDITIONAL EASY READ REMINDER IF NO RESPONSE AFTER 6 WEEKS
- IF THERE IS STILL NO RESPONSE, CALL, TEXT OR SEND AN ADDITIONAL REMINDER AS PER ACCESSIBLE INFORMATION STANDARD
- COMPLETE A FINAL AUDIT
- PRACTICES WILL THEN RECEIVE REIMBURSEMENT FOR TAKING PART

APPENDIX 3 – PROJECT SCREENSAVER



APPENDIX 4 – BASELINE AND FINAL AUDIT DOCUMENT

Learning Disability Screening Audit

DATA COLLECTION SHEET

Please contact Donna Beal with any questions about data collection: donna.beal@derbyshcft.nhs.uk, 07789 924422.

Practice name (Please print)	

Date of data collection	
Data collected by (Please printname)	

Number of patients registered at practice					
Number of patients on QOF LD register					
Number of patients sent an Easy read letter	AAA	Bowel	Breast	Cervical (25-49)	Cervical (50-64)

BASELINE AUDIT

Screening programme	Eligibility criteria	Number eligible	Number screened within standard screening period[1]	Number declined/refused/ceased/not applicable*	Number with documented capacity assessment
Breast Cancer	On QOF LD register Female Aged 50-70				
Bowel Cancer	On QOF LD register Any sex Aged 60-75				
Cervical Cancer	On QOF LD register Female Aged 25 – 49				
Cervical Cancer	On QOF LD register Female Aged 50 – 64				
AAA	On QOF LD register Male Aged 65				

FINAL AUDIT

Screening programme	Eligibility criteria	Number eligible	Number screened within standard screening period[1]	Number declined/refused/ceased/not applicable*	Number with documented capacity assessment
Breast Cancer	On QOF LD register Female Aged 50-70				
Bowel Cancer	On QOF LD register Any sex Aged 60-75				
Cervical Cancer	On QOF LD register Female Aged 25 – 49				
Cervical Cancer	On QOF LD register Female Aged 50 – 64				
AAA	On QOF LD register Male Aged 65				

1. Breast: All patients screened every 3 years
   Bowel: All patients screened every year
   Cervical: Patients aged 24- 49 every 3 years, aged 50-64 every 5 years
   AAA: Male patients screened once only at age 65.
2. For example; patient declined screening, did not attend appointment, cervical screening may be stopped if patient has had hysterectomy

*Not applicable– patients eligible but on palliative care, etc

Thank you for collecting this data. Please scan and return to donna.beal@derbyshcft.nhs.uk.

Please retain a copy of the completed data collection sheet in your practice.

APPENDIX 5: SPSS output for correlational analysis

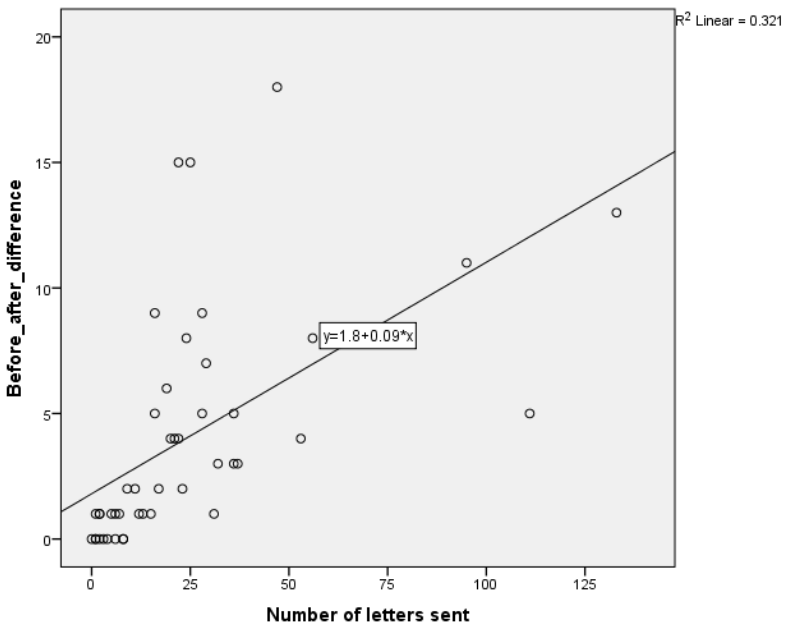
Correlations

			Number of letters sent	Before_after_difference
Spearman's rho	Number of letters sent	Correlation Coefficient	1.000	.792**
		Sig. (2-tailed)	.	.000
		N	45	45
	Before_after_difference	Correlation Coefficient	.792**	1.000
		Sig. (2-tailed)	.000	.
		N	45	45

**. Correlation is significant at the 0.01 level (2-tailed).

APPENDIX 6: Results of the tests of the assumptions of linear regression

The scatter plot below suggests a linear relationship between the number of letters sent by a CCG and the before-after difference in the number of individuals screened across each cohort. There is generally some homoscedasticity in the data.



Within the normal P-P plot below, the residuals deviate from the regression line. This suggests a lack of normality in the residuals.