

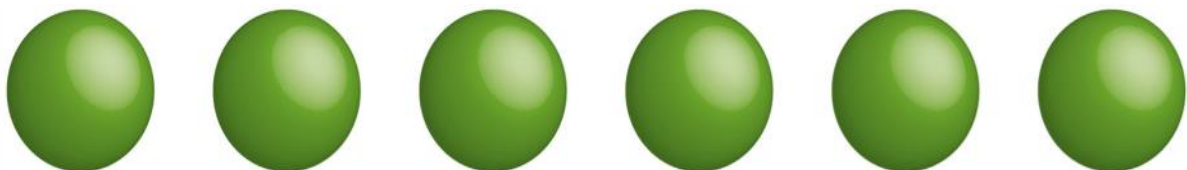


National Development Team **for inclusion**



**Improving the uptake of  
screening services by people with  
learning disabilities across the  
South West Peninsula**

**A Strategy and Toolkit**





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## 1. Introduction

People with learning disabilities have poorer health than their non-disabled peers. These differences are, to an extent, avoidable, and thus represent health inequalities. Health inequalities are in part due to poor access to health services. A number of studies have reported low uptake of health promotion or screening activities among people with learning disabilities. These include:

- Cervical smear tests;
- Breast self- examinations and mammography;
- Bowel screening.

Access to health promotion may be significantly poorer for people with more severe learning disabilities, and people with learning disabilities who do not use learning disability services<sup>1</sup>. Public services have a duty to address health inequalities by putting reasonable adjustments in place. This is a legal duty and is anticipatory, meaning that public sector organisations should plan reasonable adjustments into their services in advance, rather than wait for someone with learning disabilities to try and use them<sup>2</sup>. This applies to the national screening programmes, and there are examples of good practice in local services<sup>3</sup>. However, all the national screening programmes are organised differently, and there are variations in local implementation.

Cornwall Partners in Policymaking commissioned the development of a strategy to improve uptake of screening services. The primary objectives of the project were to:

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<sup>1</sup> Emerson et al (2012). *Health inequalities and People with Learning Disabilities in the UK:2012*. Improving Health and Lives Learning Disabilities Public Health Observatory.

<sup>2</sup> Hatton et al (2011). *Reasonable Adjustments for People with Learning Disabilities in England. A national survey of NHS Trusts*. Improving Health and Lives Learning Disabilities Public Health Observatory.

<sup>3</sup> Turner et al (2012). *Making Reasonable Adjustments to Cancer Screening*. Improving Health and Lives Learning Disabilities Public Health Observatory.

- Scope current practice in the Cornwall, Devon, Plymouth and Torbay areas (the Peninsula), with a less detailed look at practice elsewhere in the South West and relevant national evidence;
- Use this information to develop an evidence based toolkit (see Appendix 2) and strategy for improving access to screening services (bowel, cervical, breast, abdominal aortic aneurysm and diabetic retinopathy) by people with learning disabilities in the South West;
- Produce a final report and recommendations that could be used to inform the national debate on identification of people with learning disabilities in national cancer screening programmes.

A contract for the work was awarded to the National Development Team for Inclusion (NDTi) in partnership with the Norah Fry Research Centre.



## 2. Work undertaken to develop the strategy and toolkit

To inform development of the strategy and toolkit, we:

- Undertook a literature search to identify good practice;
- Sought to engage with people with learning disabilities and family carers
- Engaged with Devon Link Up and HealthWatch Devon, who talked to 86 people with learning disabilities (see Appendix 3 for details);
- Carried out a detailed scoping exercise in the Peninsula to identify current practice and resources regarding the five national screening programmes;
- Engaged with other South West health organisations and relevant individuals via the health network and by e-mail;
- Produced an interim report and discussed this with steering group;

We are most grateful to all those who made time to meet us, talk on the phone and/or correspond by email.

The project steering group has already taken action to agree a set of easy read invitation letters to complement nationally available information (see appropriate sections). These are available at the web-links below:

Cervical screening letters:

[www.improvinghealthandlives.org.uk/adjustments/?adjustment=265](http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=265)

Abdominal aortic aneurysm letters:

[www.improvinghealthandlives.org.uk/adjustments/?adjustment=266](http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=266)

Breast screening letters:

[www.improvinghealthandlives.org.uk/adjustments/?adjustment=267](http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=267)



### 3. Literature search summary

Details of the search strategy and a full review of the literature found are in Appendix 1, fully referenced. Below is a brief summary (see Appendix 1 for the references).

#### 3.1 Current position

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 (Biswas et al, 2005; Osborn et al, 2012; Reynolds et al, 2008). A recent cohort study looking at access to cancer screening by people with learning disabilities in the UK concluded that, despite recent initiatives, people with learning disabilities are still significantly less likely to receive cancer screening tests than those without learning disabilities (Osborn et al, 2012). There is a lack of significant empirical evidence about the uptake of bowel, AAA and diabetic retinopathy screening by people with learning disabilities, but there is some local data from the South West showing a lower uptake.

#### 3.2 Barriers to uptake

The vast majority of literature exploring the barriers to uptake of screening relates to cervical and breast screening programmes, as there is a paucity of research about this in relation to the bowel cancer, AAA and diabetic retinopathy screening programmes.

Factors affecting uptake of screening include:

- Practical barriers - such as lack of routine use of easy read invitations, difficulties using appointment systems and mobility issues.
- Communication barriers – identified by healthcare professionals as one of the most significant barriers to breast cancer screening (McIlfatrick et al, 2010).
- Attitude and knowledge of professionals, support services and family carers – for example, women with learning disabilities are more likely to be ‘ceased’ from cervical or breast screening programmes than women without learning

disabilities (Reynolds et al, 2008). Research suggests there is a need for improved practical support and training for both staff and family carers.

- Attitude and knowledge of people with learning disabilities – people may not understand the importance of screening and feelings of fear and anxiety can be a barrier to participation.
- Consent issues - concerns about the capacity of people with learning disabilities to consent to participate in screening programmes can also be a barrier (McIlfatrick et al, 2011).
- Accessible information and resources – this search has identified a vast amount of accessible information in relation to the cancer screening programmes, yet there seems to be lack of knowledge of such resources, as many staff have been found to be unaware of the body of accessible literature (Taggart et al, 2011).

### 3.3 Improving uptake

Although there was a lack of robust evaluation of interventions to improve uptake, the literature reviewed did identify a variety of approaches that could improve participation in screening programmes:

- Education, training and support for professionals, support staff and family carers – the evidence suggests that training is essential for all key people, including family carers, residential staff, GPs, radiographers.
- Education, training and support for people with learning disabilities – there is a need for such input to help people with learning disabilities understand the need for, and the process of, screening programmes. The literature suggests that careful preparation can increase the likelihood of a successful screening test.
- Partnership working - improved partnership working between Community Learning Disability Team nurses and primary care staff could help to increase the uptake of cervical screening by women with learning disabilities (Wood & Douglas, 2007).

### **3.4 Existing easy read resources**

The search methods undertaken retrieved a large amount of accessible resources in relation to the three cancer screening programmes. Whilst there is a paucity of peer reviewed research about access to bowel cancer, AAA and diabetic retinopathy screening, there were some easy read resources available in relation to all of these screening programmes.





## 4. Overarching issues

### 4.1 The Mental Capacity Act

The Mental Capacity Act 2005 sets out the law regarding capacity and consent and is underpinned by five key principles that must be considered when assessing capacity:

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

Those responsible for the delivery of screening programmes locally must therefore assure themselves that 'all practicable steps' have been taken to support a person with learning disabilities to make an informed choice themselves.

However, all people who support people with learning disabilities have a responsibility to make sure that individuals can access screening services in the same way as anyone else, with the appropriate reasonable adjustments. It is important to avoid discrimination, and ensure that people are not treated less favourably than others, and thus it is important not to make assumptions about someone's best interests simply on the basis of the

person's age, appearance, condition or behaviour. Withholding or preventing access to medical care or treatment could be construed as neglect.

Where an individual is not considered to have capacity to consent to a specific screening intervention, the member of staff responsible for carrying out the healthcare procedure becomes the decision maker. The decision maker needs to decide if it is in the person's best interests to be screened; in doing so they should consult with, and take into account the views of, other people who are close to the person who lacks capacity. They should also do what they can to help the person take part in the decision, even if they cannot actually make the decision. There should be a record of how the Best Interests decision is reached.

Where the test is non-invasive and painless, such as the initial test for bowel cancer or screening for abdominal aortic aneurysm (AAA), screening is likely to be in the patient's best interests. Close support can be given to maximise the chances of compliance and successful screening.

However, in the breast screening programme, women need to be able to place their breasts in an uncomfortable position in the X-ray machine and to hold this position. The options for close support are reduced by the risk from the radiation. For diabetic retinopathy, people need to be able to tolerate eye-drops, which may be uncomfortable, and an eye examination. For these programmes, it may be in the best interests of those individuals who are initially non-compliant to remain on the list so they can be invited for screening at a later date (recalled), enabling further health promotion work and support to be provided in the meantime.

The cervical screening test is more invasive. As above, health promotion and familiarisation support may enable a woman to comply with the procedure. It would be premature for a Best Interests process to conclude that she was unable to comply, or would become very distressed, before such support was given. A formal Best Interests process is then likely to be required before deciding whether to leave a woman on the list (so she can be recalled) or not. Taking a woman off the list ('ceasing' her from the programme) because it was considered in her best interests should follow a full Best Interests meeting, and the appropriate paperwork should be completed. Her GP would be expected to lead the process, with the care team and support as required from specialist learning disability staff.

## 4.2 Information governance

Services are rightly cautious about sharing information that is personal to the people who use the services. Each NHS organisation and local authority has policies and procedures in place to govern this, and these requirements will be included in contracts with any other

organisations that provide care and support. Unfortunately it sometimes happens that staff are so concerned to protect confidentiality that important information does not get passed on and a person's health is put in danger by mistake.

Arrangements for good information governance have been reviewed recently (Caldicott, 2013<sup>4</sup>). The report sets out some clear and helpful principles, including:

***7. The duty to share information can be as important as the duty to protect patient confidentiality***

*Health and social care professionals should have the confidence to share information in the best interests of their patients within the framework set out by these principles. They should be supported by the policies of their employers, regulators and professional bodies.*

It is recognised in the report that family carers and staff who are not members of regulated professions often have important roles to play in direct support and care. They may need information about a person's health in order to provide good support. Sometimes such information has been withheld because of anxiety about protecting confidentiality: the report notes that managing information sharing well can be particularly important when someone lacks capacity to make decisions for themselves about information sharing itself or about a particular health decision.

*“... a culture of anxiety permeates the health and social care sector ... Managers ... are inclined to set unduly restrictive rules ... Front-line professionals ... do not co-operate with each other as much as they would like by sharing information in the interests of patients and service users. ... This state of affairs is profoundly unsatisfactory and needs to change”*  
Caldicott, *ibid.*

For example, a woman with learning disabilities might be supported to have a mammogram. The results might indicate a need for further investigations. If her family or support staff are not told this, they might not support her to have this follow-up.

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<sup>4</sup> Caldicott, F. (Chair) (2013) *Information: To share or not to share? The Information Governance Review*. London: Department of Health

The report makes a series of recommendations relating to sharing of information:

- between registered and regulated health professionals and social workers
- between such staff and family carers and unregistered staff.

These include recommendations that health and social care organisations put in place agreed safeguards to allow appropriate sharing of information. A response from the Department of Health is expected “in the summer”.

We recommend that pathways for people with learning disabilities should include explicit consideration of information sharing to ensure that all those involved in supporting a person with learning disabilities have the information they will need to support effective participation in screening and any follow-up action.



## 5. Strategy for five screening programmes

### 5.1 Cervical screening

#### Description of programme

All women between the ages of 24 years six months and 64 are eligible for a free cervical screening test every three to five years. The NHS Cervical Screening Programme offers screening at different intervals depending on age. The screening intervals are:

- 24 years and six months old: first invitation
- 25 – 49 years old: 3 yearly
- 50 – 64 years old: 5 yearly
- 65+: only screen those who have not been screened since age 50 or who have had recent abnormal tests.

For further information about the national programme including helpful resources see: [www.cancerscreening.nhs.uk/cervical/](http://www.cancerscreening.nhs.uk/cervical/) The NHS Call and Recall System holds a list of all patients registered with a GP in the area it covers. It sends the list of women due for screening to each GP to check the records (for correct name and address and in case it is not appropriate for them to be invited), sends invitation letters and reminder letters, and sends the result letter. None of the letters are in easy read as women with learning disabilities are not identified in the NHS Call and Recall System.

Each Area Team has a nominated person responsible for its cervical screening programme and implementing the national guidelines.

#### Good practice

Devon use the Care First register to identify people with learning disabilities across all age ranges for each of the screening programmes (except eye screening). A series of reports has been created to enable the learning disability team to identify individuals due for

screening, update the register when individuals have been screened and enable the team to alert screening providers when screening is due – this can help providers be prepared to offer longer appointments where necessary. Those individuals registered on the Care First social services register have already given consent for information to be shared so there are no data protection issues. It should be noted that the register is not a comprehensive list of individuals with learning disabilities in Devon, but is a good start.

In Cornwall the Screening Liaison Nurse for Adults with a Learning Disability has a slot on the cervical smear takers' course. Further details about the screening nurse liaison role are available at Appendix 4. She gives out her contact details and shows them the easy read information available. A self-advocate is involved in the training. Plymouth worked with the practice nurse trainer to develop a learning disability e-learning pack for sample takers and are planning to update this.

In Plymouth the pathway for women with learning disabilities, along with information on capacity/consent and contact details for the primary care liaison nurses, is on the local Map of Medicine: <http://www.mapofmedicine.com/solution/whatisthemap/> GPs use this, but it is unclear whether all other practice staff know about it or can access it. There are plans to put a reminder in practice newsletters. Health checks can also be a useful way of raising awareness about sexual health and screening, but none of the people talked to by Devon Link Up and HealthWatch Devon could recall being asked about sexual activity or screening during their health checks.

The South West Region Quality Assurance Reference Centre issued best practice guidance on cervical screening for people who lack capacity and this included a protocol allowing practices and the call and recall service to cease inviting people. However, in Plymouth a variation has been agreed and the call and recall service will not accept a 'cease' request from a practice in respect of a woman with learning disabilities unless this is accompanied by properly completed Best Interests paperwork.

Devon use easy read information to educate women with learning disabilities about cervical screening, along with an anatomically correct rag doll. This has been found to be very useful, and can also be used for teaching women how to insert tampons. Books Beyond Words are helpful, and the nurse also has access to some explicit photos showing what a smear test involves. (These could be scanned and made available for others to use). Talking mats have also been found helpful for women who are non-verbal.

### **Short examples of good practice**

Devon did some proactive work with twenty one women who were overdue for their smear tests. Some had capacity and chose not to have a smear; Best Interests meetings were held for those who lacked capacity. One woman had had a hysterectomy, so was not eligible. Five were supported to consent and had smears taken successfully (and one person's mother had a smear too).

J is a young woman with profound and multiple learning disabilities who lacks capacity to consent to a cervical smear. Her family, together with her health care workers and providers, used a Best Interests decision making process to agree that as a reasonable adjustment she has her smear test when her Mirena coil is changed under a general anaesthetic.

### **Recommendations for local strategy**

Good work has already been done to adopt cervical screening pathways that improve inclusion of women with learning disabilities. There are currently some variations between areas and uptake could be improved through consistent adoption of the best practice, to include assessment of capacity (and Best Interests process where appropriate). Pathways should be available on a system accessible to all GPs and other practice staff.

- A pathway is offered in the accompanying toolkit and is recommended for adoption across the Peninsula.

Because of assumptions about sexual activity/history, and ability to tolerate cervical screening, it appears that women with learning disabilities are being 'ceased' from the cervical screening programme. The call and recall service now does regular audits, and will follow up ceasing requests if there are concerns. In Plymouth, the call and recall service will not accept a 'cease' request from a practice unless it is accompanied by properly completed Best Interests paperwork. For the vast majority of women it will not be appropriate to 'cease' them from the programme.

- The Peninsula should adopt the Plymouth approach and not 'cease' anyone without properly completed Best Interests paperwork.

GPs, practice managers and other practice administrative staff need clear guidance regarding 'ceasing'. This could be included in the link practitioner scheme. GPs also need clear guidance regarding the financial impact of women who were not 'ceased' but did not take up the offer of screening. The QOF rules appear to require "informed dissent" and guidance may be required on how this is to be interpreted in relation to women who lack capacity to make this decision.

- Local cervical screening pathways should include guidance about 'ceasing', including guidance about use of Best Interests processes to avoid unreliable assumptions.

Women with learning disabilities who have had a bad experience of cervical smear taking, are much less likely to try again, as the following quote from a woman with learning disabilities illustrates:

*"I went once for a smear. It didn't work. I didn't like it. The metal bit really hurt me. I don't go any more. I'm not sure if I would go again. I would go if it didn't hurt so much."*

In contrast, another woman with learning disabilities said:

*"I've been. My Mum opened the letter and made the appointment. The nurse was very kind. She explained everything as she did it. I felt very apprehensive, nervous and jittery, but it was fine. I think it's good to go. It's good to prevent it [cancer]"*.

- Smear takers should be trained on providing reasonable adjustments to women with learning disabilities and on the Mental Capacity Act.

## **Recommendations for national programme**

Women with learning disabilities are currently not identified in the national cervical screening programme. This means it is not possible to send women with learning disabilities information in accessible formats, and data protection issues preclude identifying them in the Open Exeter System at present.



- There should be a national cervical screening pathway for women with learning disabilities, including identification and the provision of reasonable adjustments.
- QOF rules should be clarified in relation to women who lack capacity to consent or dissent.

## 5.2 Breast screening

### Description of programme

The NHS Breast Screening Programme offers screening once every three years to women aged 50-70 (gradually being extended to women aged 47-73). The programme is co-ordinated from the national office of the NHS Cancer Screening Programmes (part of Public Health England). It sets national standards, which are monitored through a national quality assurance network. For further information about the national programme and useful resources see: [www.cancerscreening.nhs.uk/breastscreen/](http://www.cancerscreening.nhs.uk/breastscreen/)

Nationally there is evidence that women with learning disabilities are not well informed about breast cancer<sup>5</sup> and that uptake of breast screening is low<sup>6</sup>.

There are four breast screening services (BSS) in the Peninsula, each inviting a defined population of eligible women through their GP practices on a rolling basis. Pathways for access to breast screening for women with learning disabilities have been developed and are available in the local Map of Medicine. The pathway is slightly different in each area.

The National Breast Screening System (NBSS) holds up-to-date lists of women compiled from GP records. Each BSS links with GP practices to select 'batches' of women to invite and to remove from the list any women who have died or are not eligible (e.g. had a double mastectomy). The BSSs ask practices to identify women with learning disabilities and can now (since mid-2012) also 'flag' on NBSS women notified to the BSS by Public Health (for Devon) or local learning disability services. Over a three year cycle each BSS should therefore be able to accumulate a more robust set of data on women with learning

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<sup>5</sup> Truesdale-Kennedy et al (2011). Breast cancer knowledge among women with intellectual disabilities and their experiences of receiving breast mammography. *Journal of Advanced Nursing* vol 67 issue 6, 1294-1304.

<sup>6</sup> Emerson et al (2012). *Health inequalities and People with Learning Disabilities in the UK:2012*. Improving Health and Lives Learning Disabilities Public Health Observatory.

disabilities who are eligible for screening, and to include learning disability as a variable in reports extracted from the NBSS. Cornwall are already doing this.

Invitations and information booklets are sent to women by the BSS. Women are invited to a specialised screening unit: this can be hospital based (Exeter, Plymouth, Torbay, Treliske), mobile, or based in another convenient location such as the Plymouth Guild Hall. The BSS can note (on NBSS) any reasonable adjustments needed. For example, they can send easy read literature to a woman with learning disabilities and can make an appointment at a suitable location for a woman who uses a wheelchair. The BSS is responsible for sending reminder letters and results. Attendance and non-attendance is recorded on the national system.

Practice varies slightly from area to area in relation to women who have attended in the past: in Cornwall the screening nurse contacts every woman known to have learning disabilities to check that she is happy to attend, whereas for other areas a woman who has attended without problems is invited again without specific support.

The BSS looks to the local learning disability service to support GPs with any Best Interests process that may be required. Women who do not have capacity to consent and are unable or unwilling to comply cannot be screened (though ultrasound can be used as a diagnostic tool if signs or symptoms justify this). Women are not 'ceased' from breast screening; even if they have never attended, efforts will continue to invite them in future years as long as they remain eligible.

As cancers can develop in the interval between screening visits, and mammography may not detect all cancers, it is important for women to be 'breast aware' even if they are participating in the programme.

## **Good practice**

*"I went to the mobile van. It wasn't very pleasant. The staff were helpful, but it wasn't very nice to have it done. It hurt. It's good for women to go. I would go again as it's important".*

(quote from woman with learning disabilities – Devon)

Plymouth People First have arranged health education sessions about screening (though these have not been well attended).

Some areas (for example, Plymouth) have done a lot of work over several years to improve the recording of learning disability in practice registers. This gives them a database against which they can check who is eligible for screening and notify the breast screening programme accordingly. Torbay are adding a 'consent to share information'

column to the QOF register (though this is laborious and only 25% coverage has been achieved so far). For Devon, Public Health are using the Care First register of people known to social care (who have given permission for data sharing), but recognise that this is a subset of the eligible population of woman with learning disabilities.

Excellent support is offered to women with learning disabilities in Cornwall by the screening nurse, who will contact the woman's GP and then directly contact the woman. She talks to them about whether they are happy to attend the screening and if there is any practical or emotional support they need in order to do so. This is seen as a key 'offer'. For a first invitation she will always visit the woman to talk about it and takes pictorial information and can offer support with a pre-visit. She will liaise with the BSS about any arrangements required. She also supports GP practices to provide good information and has provided learning disability awareness training to the Primrose Centre and Mermaid Centre staff.

Both the Mermaid Centre and the Primrose Centre have devised their own accessible information using photographs to show the process. The Mermaid Centre also developed DVDs to show a visit to the Centre and use of the mobile van; local people with learning disabilities were involved in this. (Note: it is important to keep such resources up-to-date.)

Other examples of reasonable adjustments include:

- offering a longer appointment at the end of a session
- for women who have had a pre-visit, an appointment when the same radiographer is working
- stopping if a woman is becoming distressed, and trying again another day
- availability of a last minute appointment for an anxious woman who is having a 'good' day
- 'disability days' each month when longer appointments and extra support are routinely available to any disabled woman.

Cornwall's screening nurse can support a woman with breast awareness if screening is not possible. She uses some existing resources for breast awareness work but most of these use line drawings and so she has found photo images to use alongside these. She also works with care staff in relation to breast awareness. Staff cannot undertake hands-on checks, but need to know what to look for visually if they give support with personal care.

The Primrose Centre notifies the local learning disability service if a woman does not attend, or if she is recalled. However, there is no system to notify routine uptake or to

follow through and check on action. The Centre calls on the acute liaison nurse for support if a woman is diagnosed. An acute liaison nurse map showing where acute liaison nurses are based and their contact details is now available on the IHaL website at: [www.improvinghealthandlives.org.uk/aln/](http://www.improvinghealthandlives.org.uk/aln/)

Cornwall has good data about breast screening in women with learning disabilities and this enables comparisons both over time and against the general population. For example, in St Austell the rate increased from 36% to 69% uptake, since the screening nurse has been in post. Data is being used to support completion of the Self-Assessment Framework. Cornwall are also keeping a database of reasonable adjustments offered.

### **Short examples of good practice**

One woman attended a mobile van with her parents, but became distressed. She was sent the Mermaid Centre DVD and her sister supported her to watch it in private. She was offered a longer appointment time (at the Centre) and staff were made aware that she might need extra support. She attended and was able to have the mammograms.

Another woman has attended a Centre four times (so far) and gets a little further through the process each time.

A Primary Care Liaison Nurse gave support workers information and advice about spotting signs of breast cancer. They then noticed that one woman had a breast lump. They supported her to go to her GP. The Acute Liaison Nurse was then involved in supporting the woman to undergo treatment.

### **Recommendations for local strategy**

Good work has already been done to adopt breast screening pathways that improve inclusion of women with learning disabilities. Each area has a slightly different pathway, which can cause some confusion for a BSS that serves more than one CCG. Uptake could be improved through consistent adoption of the best practice, to include assessment of capacity (and Best Interests process where appropriate) and to be available on a

system accessible to all GPs and other practice staff.

- A pathway is offered in the accompanying toolkit and is recommended for adoption across the Peninsula.
- The practice of keeping women on the system, and trying again for as long as they remain eligible, is commendable and should continue.
- As we understand it, the NBSS does now allow local BSSs to record learning disability and to analyse data using learning disability as a variable. Further, we understand that the system allows reasonable adjustments required by an individual woman to be recorded.
- These features of the system should be used to audit local performance regularly and ensure that reasonable adjustments are offered consistently.

### 5.3 Bowel screening

#### Description of programme

The NHS Bowel Cancer Screening Programme offers screening every two years to all men and women aged 60 to 69. Since April 2010, the programme is being rolled out to invite men and women up to their 75th birthday. For further information about the national programme and useful resources please see: [www.cancerscreening.nhs.uk/bowel/](http://www.cancerscreening.nhs.uk/bowel/)

Men and women eligible for screening receive an invitation letter explaining the programme, and an information leaflet entitled *Bowel Cancer Screening – The Facts*. A help line is available for people who have questions about bowel screening. About a week after the initial invitation letter, a faecal occult blood (FOB) test kit is sent out along with step-by-step instructions for completing the test at home and sending the samples to the hub. The test is then processed and the results sent within two weeks.

If the test is not returned in 4 weeks, a reminder letter is sent. If the test is still not returned, a letter goes to the GP alerting them to the patient's non-participation. GPs are not directly involved in the delivery of the NHS Bowel Cancer Screening Programme, but they are notified when invitations for bowel cancer screening are being sent out in their area. They also receive copies of the results letters sent to their patients.

If blood is detected in the sample returned, the individual will be invited for a colonoscopy. The procedure carries a slight risk of bowel perforation

There are five programme hubs:

- Midlands and North West
- Southern
- London
- North East
- Eastern.

Each hub is responsible for co-ordinating the programme in their area and works with up to 20 local screening centres. There are three centres covering the Peninsula (South Devon, Cornwall, and North & East Devon). For further information, see:

[www.cancerscreening.nhs.uk/bowel/screening-centres-hubs.html](http://www.cancerscreening.nhs.uk/bowel/screening-centres-hubs.html) .

Uptake of bowel screening nationally is 60%, which is quite low. This indicates that problems in following the screening pathway are not confined to people with learning disabilities. A simpler test is being piloted next year. Devon note they have a very low uptake of bowel screening for people with learning disabilities (estimate 2-3%) in comparison with the general population.

*"I had a letter. I don't want to do it".*

(Person with learning disabilities in Devon)

### **Good practice**

In Cornwall the screening liaison nurse has started to contact all people with learning disabilities who have been identified as eligible but have not had a screen. Sometimes screening is flagged as an issue through annual health checks. She will visit to explain the programme and process and has worked with people with learning disabilities and those who support them to demonstrate how to take part in the screening. The hub is very good at sending her kits marked as DEMO ONLY and she uses a jar of chocolate spread to demonstrate.

Devon sent a list of people with learning disabilities known to services and in the age range for bowel screening to the hub, so the hub could send them approximate invitation dates, but it would be difficult to do this across the board as it is very time-consuming and is not supported by current data systems.

If the hub are alerted, they can put a temporary address on their database for three months so that they can send the kit to a nominated person – often (in Cornwall) the screening nurse.

If people do not understand the letter, they cannot act on the advice. Cornwall have devised a one-off consent form so the results letter can go to a named supporter as well (using the temporary address facility noted above).

Reasonable adjustments can be made for a person who may be unable to cope with a colonoscopy; for example, it is possible to do a CT colonoscopy or for it to be done under general anaesthetic. Individuals should therefore not be excluded from screening based on assumptions about inability to cope with a colonoscopy.

### **Short example of good practice**

The screening liaison nurse has worked to support individuals to prepare for their colonoscopy. The information about what food you can and cannot have prior to this is quite complicated. She has worked to help someone plan their diet in advance and liaised with the cook at his day centre in order to enable this. The plan to support this particular individual also included sorting out when he needed someone else to walk his dog.

### **Recommendations for local strategy**

In the absence of a national pathway for people with learning disabilities, the Peninsula should agree a local approach.

- A pathway is offered in the accompanying toolkit and is recommended for adoption across the Peninsula.

There is an opportunity to identify people with learning disabilities who have not responded when the GP receives notification that an individual has not responded.

- Until a national system is in place, CCGs should put in place liaison arrangements between practices and local learning disability services to check whether non-responders may have learning disabilities and to offer additional support to enable them to participate.

- All practices should be strongly encouraged to sign up to the electronic results service.

The local bowel screening centres should have training on people with learning disabilities, and should adopt this strategy and toolkit. The centres should be notified of the contact details for local learning disability services and Acute Liaison Nurses, if they do not already have them.

### **Recommendations for national programme**

There is currently no practical way of identifying people with learning disabilities in the national bowel screening programme. This means it is not possible to send people with learning disabilities information in accessible formats, unless the hub is made aware of the need. And it is not possible to make the hub aware of the need as local learning disability nurses do not know who is being invited.

- Easy read information should be sent out as the default option. This will be of benefit to anyone who is not a confident reader.
- Easy read materials should be readily available to download or order via the national website.
- A very positive message should be conveyed that it is in everyone's interests to be screened (while not contravening informed choice).

It is possible to identify people with learning disabilities who have not responded to the invitation to screen, as a letter notifying lack of response is sent to the GP. This happens 13 weeks after the reminder, which can be problematic for people with learning disabilities who have not understood the original letter. A practice with good information about people with learning disabilities, and/or good links with the local learning disability service, may then be able to 'join the dots' and seek additional support for the person to enable participation.

A positive result triggers a fast track response. The local screening provider is informed and sends a standard appointment letter. The screening provider will not know that the person has a learning disability and the learning disability service will not know the appointment letter is coming. People with learning disabilities may not know they need to attend the appointment, and even if they do, timeframes are short (14 days in total) and it is difficult to put appropriate reasonable adjustments in place. Liaising with the screening provider can be helpful.



Failure to identify people with learning disabilities in national screening programmes and make appropriate reasonable adjustments is potentially a breach of the Equalities Act 2010. All public sector organisations have a legal duty to make reasonable adjustments for people with learning disabilities. Reasonable adjustments include changing the ways in which services are delivered and ensuring that policies, procedures and staff training all enable services to work equally well for people with learning disabilities. This duty is 'anticipatory', meaning that services should put reasonable adjustments in place in anticipation of people with learning disabilities using them.

- There should be a national bowel screening pathway for people with learning disabilities including identification and the provision of reasonable adjustments.
- The bowel screening kit should include information enabling the person returning the kit to let the screening centre know they have a learning disability, so that appropriate reasonable adjustments can be put in place should they need further investigation.
- When a sample tests positive, the fourteen day turnaround for a follow-up appointment is not sufficient to put appropriate support in place or for a Best Interests meeting. Flexibility needs to be built into the process so that reasonable adjustments can be put in place.

Local learning disability services should send hubs the link to the acute liaison nurse map on the Improving Health and Lives website (when available), for onward referral when people have had a positive screen.

## 5.4 Diabetic retinopathy screening

### Description of programme

Diabetic retinopathy screening can detect diabetic retinopathy at an early stage (prior to symptoms) for people with either type 1 or type 2 diabetes. Treatment is most effective when the disease is diagnosed early.

There are currently more than 80 local screening programmes and they use a variety of screening models, which include:

- Static sites (e.g. hospital clinic) with a fixed camera

- Mobile sites, where mobile cameras are set up for a short period of time (typically a few weeks). These are often in GP surgeries or community centres.
- High street optometry practices, where specific optometric sites offer the screening.

All people aged 12 and over with diabetes (type 1 or type 2) are invited for annual screening appointments. The only exceptions are people who already have diabetic eye disease and are seen regularly by an ophthalmology specialist. The invitation for screening is sent by the local screening programme and they get their information about who is eligible to participate from GP registers. The only route into this screening service is via GPs.

The screening process takes 30-40 minutes and requires the person to tolerate eye drops; they then need to be able to put their chin on the chin rest and sit still long enough with eyes open for four photographs of the eye to be taken. The photograph is painless, but the eye drops can cause stinging and may affect vision for a few hours after the appointment. Understanding of Best Interests processes and the support available to a person lacking capacity seemed patchy. It is not possible to do home visits, as the equipment is too large. Symbols are used for the visual acuity test if someone cannot read. Screening results are sent by letter to the GP and the patient within six weeks of the appointment.

Possible outcomes of the screening:

- Digital images are not clear enough – another appointment will need to be made or a second test using slit lamp biomicroscopy may be needed.
- If there is no evidence of retinopathy, the person will be recalled annually.
- If there is evidence of mild background retinopathy, control of risk factors should be discussed by the clinician managing the patient's diabetes and the person will be recalled annually.
- If there is evidence of referable retinopathy, the person will receive an appointment for assessment and be put on the surveillance pathway and seen every 3-6 months.

## Good practice

In theory every patient registered with a GP who has diabetes should be on the register and therefore should be invited for screening. The programme also has a system of going into GP surgeries regularly to double-check the registers; they are therefore confident that those who are eligible for screening are being invited to attend. There is no indication that, as with some other screening programmes (e.g. cervical), people with learning disability are being systematically excluded. There may be specific reasons for exclusion of a particular individual: for example, if it were thought that the person could not manage to keep their head still.

Plymouth have recently changed the forms for GPs and they do now ask if the patient has any special requirements. New software allows them to enter information about ambulatory/cognitive considerations for their patients.

Plymouth are aware of a small number of people with learning disabilities on their screening register. On an individual case basis they have tried to make adjustments for some of these people.

### **Short example of good practice**

The programme in Plymouth had a couple who both had learning disabilities, living independently in the community with support from care workers. Over a three year period the wife went from having no retinopathy to the highest level of retinopathy and needed laser treatment. The screening team were having trouble supporting this couple; the GP gave contact details for the care worker and they worked together to arrange appointments to ensure the woman received the treatment she needed.

Some people are unable to tolerate the digital image screening and manual screening can be tried for these people. This is likely to be the best approach for some patients with learning disabilities.

In Devon there was concern that, according to their existing data, they have had no-one with a learning disability who has age-related macular degeneration. This is most unlikely to be correct and was taken as an indication that they did not know the extent of the problem.

### **South Devon project**

In South Devon they established a project to improve retinal screening of people with learning disabilities. This is part of a larger project around sight that started in September 2012. It followed an audit that showed that 25% of people with learning disabilities did not turn up for diabetic retinopathy screening compared to only 11% in the general population. A Primary Care Liaison Nurse worked with the diabetic retinopathy screening team and the fail-safe co-ordinator at the local hospital to try to increase uptake. They have access to the QOF registers, so they can cross-reference diabetes and learning disability. They have used this data to identify people with learning disabilities who have not been participating in screening and the nurse has then worked to establish what the individual barriers are and tried to address these. The numbers of people are small, which makes the project more manageable.

They have created a photo booklet that shows the journey of a person undergoing screening. Feedback on this was sought from a local self-advocacy group and it is currently waiting to be ratified by the Disability Awareness and Action Group (DAAG). The DAAG has people with learning disabilities on it and meets four times a year. Once this is done it can be put on the Trust's website and they will make copies available for screeners to use.

In this area, retinal screening is usually done in GP surgeries. The diabetic retinopathy team meet quarterly with the Primary Care Liaison nurses to go through the list and review successes and failures. The Primary Care Liaison nurse will phone up home managers to find out the blocks and barriers, and trouble-shoots any issues. This is generally effective, but she has found that homes often report not receiving the letter. The Primary Care Liaison nurse is told in advance which GP practices they will be conducting screening in; this can help her support people to attend in a familiar setting, which can be helpful.

Diabetic retinopathy can require desensitisation work. The team also uses more experienced screeners for people with learning disabilities. The key objective is to do the screening in primary care, and not have to resort to secondary care; the Primary Care Liaison nurse is hopeful that some people who have traditionally been screened in hospital may be able to cope in a primary care setting following some desensitisation work.

It was reported that since they have undertaken this work the communication between the diabetic retinopathy service and the learning disability team has improved. They now have an efficient system for referring anybody with learning disabilities who has had difficulty with the screening process.

In addition to the desensitisation work, other examples of reasonable adjustments they can make are:

- Longer appointments
- First or last appointment in the day
- Pre-visits to look at the equipment.

They are planning to audit the project in the autumn, once it has been running for a year, and will then have evidence about the success of the intervention work.

### **Short examples of good practice**

A Primary Care Liaison Nurse undertook desensitisation work with a woman who had diabetes and had not been able to cope with the screening process. She visited her once a week over a three month period. They started by looking at leaflets and information about what the screening involved. Gradually they got her to feel comfortable about having a torch shone in her eyes and then she was supported to practise holding her head still. Such desensitisation work can be time consuming but effective.

In South Devon they have developed a checklist for the diabetic retinopathy screeners; this is used to identify the barriers for a specific individual. For example, were they unable to tolerate the eye drops or unable to follow instructions? The information from this can then guide the desensitisation work that is needed.

### **Recommendations for local strategy**

In the absence of a national pathway for people with learning disabilities, the Peninsula should agree a local approach.

- A pathway is offered in the accompanying toolkit and is recommended for adoption across the Peninsula.

In Plymouth there are 16,025 people on the diabetic register (90% will be Type II diabetes). 80% of people take up the digital image screening. This does not include those who are screened manually or those with diabetic eye disease who are already under the care of an ophthalmology specialist, so it is likely that the actual figure is nearer 90%. However, they have no data about the uptake rate in relation to people with learning disabilities. Plymouth have done a lot of work over several years to improve the recording of learning disability in practice registers. This gives them a database against which they can check who is eligible for screening. Whilst this has been of use for breast and AAA screening, there is no evidence that this has been linked into the diabetic retinopathy programme.

- Learning disability registers should be cross-checked with the register of those eligible for diabetic retinopathy screening to flag people who might need easy information/reasonable adjustments.
- People identified should be sent easy read invitation letters.
- This could also address the current lack of data in relation to the uptake rate of diabetic retinopathy screening for people with learning disabilities.

Appropriate access to screening could be improved by closer liaison between primary care, diabetes specialist nurses, learning disability nurses and the screening programme.

- Each needs to understand their role in the pathway and what they need to do to ensure that people with learning disabilities are identified, supported and offered reasonable adjustments.
- Annual health checks offer an opportunity to identify diabetes. Co-working between the primary care liaison nurse and the diabetes community nurses, e.g. visiting newly diagnosed people together, can embed understanding of reasonable adjustments from the start.

In some areas the programme reported a strong ethos of “normalising” their service, treating people with learning disabilities the same way they treat everybody else. They assumed that there was support for people with learning disabilities (for example, that care staff would respond to the screening invitation and facilitate the appointment). There was no recognition of “reasonable adjustments” as a concept (though individual examples could be cited), and lack of a positive approach to supported decision making or Best Interests decision making. They were unaware of easy read information in relation to

diabetic eye screening (for example, the resources produced by Seeability). They were interested to see these and said they would consider using them. They were unaware of specialists who might be able to help support people with learning disabilities to participate in screening (e.g. learning disability liaison nurse at the hospital or community based learning disability nurses).

- The co-working recommended (above) should help to raise awareness over time about Mental Capacity Act implementation, reasonable adjustments and the specialist expertise available.
- Easy read information should be made routinely available.
- There may be a short term need for a focused programme of awareness-raising in some areas.

### **Recommendations for national programme**

Failure to identify people with learning disabilities in national screening programmes and make appropriate reasonable adjustments is potentially a breach of the Equalities Act 2010. All public sector organisations have a legal duty to make reasonable adjustments for people with learning disabilities. Reasonable adjustments include changing the ways in which services are delivered and ensuring that policies, procedures and staff training all enable services to work equally well for people with learning disabilities. This duty is 'anticipatory', meaning that services should put reasonable adjustments in place in anticipation of people with learning disabilities using them.

- There should be a national diabetic retinopathy screening pathway for people with learning disabilities including identification and the provision of reasonable adjustments. This could include national easy read resources.
- The information system should be amended to include a field that would allow extra needs, e.g. in relation to learning disability, to be recorded.

The manager of the screening programme in Plymouth does not think that the issue of learning disability has been highlighted nationally. She attends the Diabetes Managers' regional forum and suggested she could raise the issue there for discussion.

## 5.5 Abdominal aortic aneurysm (AAA) screening

### Description of programme

The NHS AAA Screening Programme was announced by the Department of Health in 2008 and phased implementation began the following year, with the Peninsula programme being one of the first in place. National coverage has now been achieved and the programme is being launched formally this year. The NHS AAA Screening Programme is co-ordinated and led nationally; local screening services are delivered in line with national quality standards and protocols.

The aim of the AAA screening programme is to reduce AAA-related mortality among men aged 65-75 by up to 50%. This will be done through early detection, monitoring where indicated and active treatment where appropriate. According to the Public Health England website, the programme “aims to ensure that all individuals are treated with respect and there is equitable access to screening” (<http://aaa.screening.nhs.uk/aboutus>).

All men should be invited to attend for screening during the year they turn 65 and men aged over 65 can self-refer. Invitations are sent from the local screening centre directly. The men are identified through GP registers and are sent a letter (with a date and a time for an appointment near to them) and an information leaflet to enable them to make an informed decision about whether or not to participate in the screening programme. If they do not attend (DNA) the appointment or respond, they will be sent another letter. This will either give a second appointment or ask them to contact their local screening programme to arrange a new date. Men who DNA for a second time will be contacted to be told they will not be invited for further appointments, but that they can still contact their local screening programme and self-refer. GPs are notified of their patients who DNA.

The screening process involves an ultrasound scan of the abdomen and it is quick and painless. The result of the scan is communicated immediately to the patient verbally. A letter giving the result is also sent to the GP and, where an aneurysm has been identified, will be sent to the patient as well.

Possible outcomes of the scan:

- If the aorta cannot be visualised, a further scan appointment is made.
- If the result is normal, there is no need for any further follow-up.
- If a man is found to have a small-medium aneurysm, he will be given an information leaflet about this and a follow-up scan will be arranged, with the time interval dependent upon the size of the aneurysm.



- If a man is found to have a large aneurysm, he will be given an information leaflet about this and will be referred to a consultant vascular surgeon to discuss treatment. This appointment should happen within two weeks of the referral; if surgery is indicated, this should happen within eight weeks of the referral.

There is some local evidence to suggest that the uptake of AAA screening may be lower for men with learning disabilities. Within the general population the uptake is about 80%; the data for Torbay indicates that about 60% of the eligible men with learning disabilities that they know about have attended. There is currently no data available for Cornwall; Plymouth are monitoring their data and planning to audit in 12 months.

### **Good practice**

Easy read versions of the Programme's public information leaflets have been developed and are available to download (<http://aaa.screening.nhs.uk/easyread>).

Firstly there is an invitation leaflet, which explains why the screening should be done, what the screening involves and what the possible outcomes are. Secondly there is a leaflet with information for men who have been found to have a small aneurysm that would require them to return for regular checks. Thirdly there is a leaflet with information for men who have been found to have a large aneurysm and therefore require a referral.

There are also short films available on the internet (<http://aaa.screening.nhs.uk/screeningresults>), which may be useful for men with limited reading ability.

The local AAA screening services are aware of the easy read information and routinely use it when a man has been identified as having a learning disability. The Plymouth database can identify men with learning disabilities eligible for AAA screening and they will then notify the AAA hub so easy read information is sent in advance. In other areas they are reliant upon the GPs identifying who has a learning disability. However, all the sonographers have access to the easy read information, which is also routinely available in the waiting room. It was reported that the sonographers are excellent at supporting people who have trouble with understanding the process.

If a man who has been identified as having learning disabilities does not respond to the first screening invitation, there is an established process throughout the Peninsula for notifying a learning disability specialist so they can make further contact to explore the reason for non-attendance and what could be done to support participation.

There are several reasonable adjustments that can be made in order to help men with learning disabilities to participate in the screening. These include longer appointment times and locations to suit the individual. If the sonographers are aware in advance that a person has learning disability, they are able to adapt how they communicate with the person during the appointment. Additionally they are then aware they may need to make an extra effort to look for the patient if they do not respond when they are called through for the appointment. It was reported that in Torbay they have photos of the staff, the rooms and the equipment to help prepare someone for the appointment. The screening liaison nurses can undertake desensitisation work prior to an appointment and can also support an individual to attend the appointment.

In the Torbay area they have developed some further resources, which are currently at the draft stage. They have drafted an easy read invitation letter to accompany the existing information leaflet. However, this is not currently used as the national AAA programme wants standardised resources. Torbay have also developed a screening pathway for men with learning disabilities. This has been shared with the Peninsula but is still to be discussed in detail. The team uses a PowerPoint presentation to explain the AAA programme; this has been used at a screening-focused meeting for local learning disability nurses and is now available for use with other groups.

### **Recommendations for local strategy**

In the absence of a national pathway for people with learning disabilities, the Peninsula should agree a local approach.

- A pathway is offered in the accompanying toolkit and is recommended for adoption across the Peninsula.

All men aged 65 and over registered with a GP should be invited to participate in this screening programme and nobody should be automatically excluded on the basis of having a learning disability. If an individual has capacity to consent to participate in the screening programme, it is their decision (though they may need support to make an informed decision). The Torbay draft pathway indicates that when an individual does not have capacity to consent to the screening, a Best Interests discussion/meeting should be initiated with the GP and supporters. Concerns have been raised that this may be unnecessarily time-consuming and delay the screen for up to a year. Under the Peninsula programme they work on the basis that it is in the best interests of the individual to participate in the screening programme, as long as they are willing to co-operate. It is a relatively non-invasive screening process and therefore a person does not need to

understand the implications of it for it to be in their best interests.

- There is a need to clarify issues relating to the Mental Capacity Act and consent for participation in the AAA screening programme, including with social care services.

Currently anyone eligible for the screening is sent two letters inviting them to an appointment. If they fail to attend either of these appointments, they will be excluded from the programme, although it is possible to self-refer at a later date. It would be useful if they could follow up with a phone call to explore the reasons for non-attendance. (It is likely some men with learning disabilities are not being flagged by their GPs and therefore will be receiving the standard invitation letter, which may be inaccessible for them.) Even if a GP identifies a man as having learning disabilities, the Exeter system does not allow for this to be recorded.

- Local information sharing and recording protocols should be agreed to enable the programme to identify men with learning disabilities; uptake could then be audited.
- Options for 'day before' reminder systems should be explored (e.g. text).
- Non-responders should be followed up.

One of the barriers identified locally has been with care homes. When non-attendance has been followed up with some care homes they have sometimes reported not having received the letter. Other reasons given for non-attendance include saying the person was unable to attend on the date given due to other plans or because the appointment was too early.

- Work to raise awareness of the programme and the importance of participating should include social care services.

The screening clinics are mobile and are held in a variety of settings and one programme manager raised concern that some people may have seen private AAA screening advertised and think that there is a fee involved. If the clinic is being held somewhere other than a GP surgery, this may reduce the likelihood that it is recognised as a free NHS

service.

- Invitation letters should make it crystal clear that this is a free NHS service.

Links between the AAA screening programme and local Primary Care Liaison Nurses are not yet well established in every area and could improve co-working.

- Regular joint review meetings could be used to build on examples of good practice and to discuss and resolve any problems relating to inclusion of men with learning disabilities in the programme.

### **Recommendations for national programme**

This scoping exercise has identified a number of issues in relation to the AAA screening programme that could be addressed at a national level:

- There should be a national AAA screening pathway for people with learning disabilities including identification and the provision of reasonable adjustments.
- The need to develop a standardised easy read invitation letter to accompany the existing easy read information leaflet.
- The need to clarify how men without capacity can be supported to participate in AAA screening with reference to the Mental Capacity Act.
- Liaison with NHS England to ensure that AAA screening is included in the specification for the Annual Health Check for people with learning disabilities

## **5.6 Recommendations relating to all screening programmes**

### **Local strategy**

There is not a robust database of people with learning disabilities in every area. Different information systems do not link up, so time is wasted comparing and cross-checking data, and maintaining and analysing separately held spreadsheets. Such systems are fragile.

- Local areas should monitor the uptake of screening by people with learning disabilities, compared to the general population<sup>7</sup>, and any health inequalities detected should be addressed with an action plan. There should be reference to screening in the Equality Delivery Plan (part of the Equality Delivery System)
- Data sharing arrangements should be agreed, in accordance with the new Caldicott principles, to ensure that systems are linked where possible (e.g. ‘flagging’ from one system to another) and that relevant information is given to family carers, support staff and other services where necessary so that they can support the person with learning disabilities. A Peninsula template for ‘closing the loop’ between the screening service and the local learning disability service and auditing uptake could be developed.

One of the barriers people with learning disabilities face regarding access to screening is confusion on behalf of support staff regarding their role, and a lack of understanding of the importance of screening. Commissioners should ensure that support to respond to screening invitations and attend health appointments is written into contracts with providers. Support staff need training on how to support people with learning disabilities to access screening services successfully.

- Support to respond to screening invitations and attend health appointments should be written into contracts with social care providers, along with the provision of training for support staff on this subject.
- Lack of support should be recorded and fed back as part of contract monitoring.

Family carers do not always understand the importance of enabling people with learning disabilities to be aware of key health issues (e.g. ‘breast aware’), to attend health

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<sup>7</sup> See guidance from Improving Health and Lives: Glover, G. et al (2012) *Using local data to monitor the health needs of people with learning disabilities*. Improving Health and Lives Learning Disabilities Public Health Observatory.

education sessions or to understand and participate in screening. Some teach people not to discuss their bodies.

- Awareness raising sessions should be run for family carers in partnership with local family carer groups.
- Health education guidance and resources should be developed: for people with learning disabilities and for family carers and support staff so they understand the importance of supporting people to participate in screening.

It does not appear that people with learning disabilities have been consulted on the screening strategies or pathways, nor always involved in the development of local accessible information.

- People with learning disabilities should be involved in agreeing new strategies, pathways and accessible information.
- Patient experience feedback systems should routinely include people with learning disabilities.

Local learning disability services vary in their capacity to support participation in screening programmes. This can cause particular difficulties in relation to arranging reasonable adjustments and supporting processes related to consent (assessment of capacity, supporting decision making, supporting Best Interests processes).

- Each CCG should include support for screening programmes in its contracts for specialist learning disability health services. The specification should include data sharing arrangements, support for health education and promotion, and liaison roles (including learning disability awareness training for screening services).
- Screening liaison nurses should be employed to facilitate access to screening programmes. One model would be that used in Cornwall, where one nurse covers all screening programmes. Her job description/person specification could be used as an exemplar (see Appendix 4).

Implementation of the Mental Capacity Act is still patchy and not all those who could support participation in screening programmes are fully confident about how the Act

should be interpreted.

- Local training and development programmes should include screening services and examples related to screening programmes, covering issues such as: not making assumptions about capacity; supporting decision making; Best Interests processes.

Concerns about confidentiality can restrict the sharing of information in ways that increase risk instead of reducing it.

- Pathways for people with learning disabilities should include explicit consideration of information sharing to ensure that all those involved in supporting a person with learning disabilities have the information they will need to support effective participation in screening and any follow-up action.

### **National recommendations**

Issues for people with learning disabilities and access to screening should be addressed within the national programmes. This should include resolution of the issue of better identification of people with learning disabilities in national databases.



## 6. Conclusions

We have presented a review of good practice across the Peninsula, across each of the five screening programmes, and made recommendations for local strategies. These recommendations are supported by the pathways set out in the accompanying toolkit and by the resource list.

We have also identified a number of actions the national screening programmes could take to help improve uptake by people with learning disabilities.





## Literature Review

### 1. Search methods

#### 1.1 Search for peer-reviewed academic literature

The search for relevant peer-reviewed academic literature was primarily conducted through online databases. Table 1 shows the search terms used. These were combined together appropriately.

**Table 1**

Search terms on learning disability	Search terms on screening
Learning difficulty	Cancer screening
Learning difficulties	Breast screening
Learning disability	Cervical screening
Learning disabilities	AAA screening
Intellectual disability	Bowel screening
Intellectual disabilities	Diabetic retinopathy screening
	Mammogram
	Smear test

The databases searched included:

- Web of knowledge
- Medline
- Cumulative Index to Nursing and Allied Health (CINAHL)
- International Bibliography of the Social Sciences (IBBS)
- Social Science Citation Index (SSCI)

- Websites such as Google, Google Scholar, NHS Cancer Screening Programme and Mencap were also searched. Hand-searching of key journals was also undertaken alongside citation searches and related records searches of key references.

## **1.2 Search for 'grey' literature and easy read resources**

The search for grey literature and easy read resources was primarily on-line. It included a search of relevant on-line forums which had discussed relevant topics. Links were followed and relevant reports obtained where possible. These forums included:

- The Choice Forum
- The UK Health and Learning Disability Network
- The PMLD Network

On-line searching through Google was used to identify further information on existing resources. Finally, key websites such as EasyHealth, A Picture of Health, NHS Library and Mencap were also searched for relevant resources and information.

## 2. Current position

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 (Biswas et al, 2005; Osborn et al, 2012; Reynolds et al, 2008). Recent data for the uptake of cervical screening by women with learning disabilities show proportions ranging from 7% (Orrell et al, 2004) to 27% (Emerson et al, 2005). In comparison, figures for the total population indicate that for a number of years the proportion of eligible women attending cervical screening has been just below the target rate of 80% (NHS Cervical Screening Programme Annual Review 2011). Similarly, in relation to participation in the breast screening programme the data vary but the consensus is that the uptake for this is lower in women with learning disabilities than for women in the general population (Elliott et al, 2003; Hogg & Tuffrey-Wijne, 2008; Taggart et al, 2011; Willis et al, 2008). This is despite some evidence that women with learning disabilities may have a greater number of risk factors for breast cancer, such as high fat diets, sedentary lifestyles and not having given birth (Taggart et al, 2011).

There are a number of UK policy documents that emphasise that people with learning disabilities should have equal access to general and preventative health services. Under the Equality Act (2010) all public bodies are required to make reasonable adjustments to ensure that people with learning disabilities can use their services. The UK NHS Cancer Screening Programmes have published good practice guidelines (NHSCSP, 2006), which are clear about the rights of women with learning disabilities to access breast and cervical screening programmes and state unequivocally that having a learning disability is not in itself an acceptable reason for being 'ceased' from screening. A recent cohort study looking at access to cancer screening by people with learning disabilities in the UK concluded that, despite recent initiatives, people with learning disabilities are still significantly less likely to receive cancer screening tests than those without learning disabilities (Osborn et al, 2012). However, the data from the decade they analysed indicated that the disparities in cervical screening rates narrowed over time.

In the general population uptake for bowel screening ranged between 55–60% across the four provincial hubs that administer the programme, but was lower in the London hub (40%) (Logan et al, 2012). There is a lack of significant empirical evidence about the uptake of bowel screening amongst people with learning disabilities, but some data indicates this is significantly lower (Osborn et al, 2012). Recent evidence from the Confidential Inquiry into the premature deaths of people with learning disabilities (CIPOLD) identified the bowel screening programme as the most problematic for people with learning disabilities to engage with (Heslop et al, 2013). Moreover, it has been argued that bowel screening should be viewed as a priority for people with learning disabilities as they have a

higher than average chance of health problems associated with bowel cancer such as obesity, poor diet and lack of exercise (Read and Latham, 2009).

Osborn et al (2012) propose that there may be specific challenges in relation to cancer screening as there is data to suggest that screening rates for other conditions such as hypertension and diabetes were fairly similar for people with and without learning disabilities. There is no clear national evidence about the number of people with learning disabilities who attend for diabetic retinopathy screening, but recent data extracted from GP information systems in England indicated lower rates of retinal screening among people with learning disabilities who have diabetes, despite their higher rates of Type 1 and Type 2 diabetes (Glover et al, 2012). There is also some local data from the South West showing a lower uptake (see section 5.4).

As the AAA screening programme has only just been rolled out nationally, it will be some time before there will be clear data about the national uptake rate in the general eligible population. However, the newsletter of the NHS AAA Screening Programme reported that data showed the overall uptake of screening was 77% for 2012-2013. Again, there is some local data from the South West suggesting this rate is lower for men with learning disabilities (see section 5.5).

The research retrieved through the literature search has identified a number of reasons for the lower uptake of screening services by people with learning disabilities. Evidence has also been retrieved of interventions aimed at increasing the uptake and this data is described below.

### 3. Barriers to uptake/factors affecting uptake of screening in general

A number of factors have been proposed as having an impact on participation rates in screening programmes by people with learning disabilities. The vast majority of the relevant literature relates to cervical and breast screening programmes as there is a paucity of research specifically exploring screening uptake in the bowel cancer, AAA and diabetic retinopathy screening programmes.

#### 3.1 Practical barriers

There are a number of practical issues that affect the uptake of screening services by people with learning disabilities. First, some people with learning disabilities may not be registered with a GP and therefore would not receive screening invitations. Moreover, Perry (2001) found that some people were not successfully invited as their GPs did not have correct contact details. People with learning disabilities are unlikely to self-refer for screening and therefore it is crucial that they receive formal invitations for appointments.

Even when people with learning disabilities are on a GP register with up-to-date details, many GP practices lack robust mechanisms to identify which of their patients has a learning disability (Wood & Douglas, 2007). This means there is no opportunity for easy read letters or information to be sent (see section 3.3.5) and no referral for support from a specialist team can be initiated. There is a wide range in the percentage of people who are identified as having a learning disability on GP registers across the country. As part of the Quality and Outcomes Framework (QOF), GPs are now asked to keep registers of adults on their list whom they know to have learning disabilities. There is a general pattern of increasing recognition, but this has slowed more recently (Emerson et al, 2012). The first recommendation from CIPOLD was the need for clear identification of people with learning disabilities on the NHS central registration system (Heslop et al, 2013). Without this initial flag there is no opportunity to put reasonable adjustments in place.

Other practical factors include difficulties using appointment systems and waiting rooms (Stein & Allen, 1999), access to transport and appropriate timing of appointments (McIlfratrick et al, 2011). A research study exploring health professionals' perspectives on supporting women with learning disabilities to undergo breast screening revealed that some professionals view mobility difficulties and poor physical health as potential problems (McIlfratrick et al, 2011).

### **3.2 Communication barriers**

In Wood and Douglas' (2007) study, primary care professionals noted that communication difficulties were the principal challenge in relation to care provision for their patients with learning disabilities. Screening is a complex issue and discussions often need to address sensitive topics, such as sexual history. Another study with healthcare professionals supported this and argued that communication is one of the most significant barriers to women with learning disabilities accessing breast cancer screening (McIlfatrick et al, 2010). The authors stated that there is a great need for appropriate, accessible resources for people with learning disabilities and their carers.

The issue of communication in relation to bowel screening is discussed in Read and Latham (2009) as they argued that consideration of an individual's communication needs is crucial in order to provide appropriate assessment and timely diagnosis.

### **3.3 Attitude and knowledge of professionals, support services and family carers**

There is evidence that women with learning disabilities are more likely to be 'ceased' from cervical or breast screening programmes than women without learning disabilities (Reynolds et al, 2008). Other healthcare professionals have expressed some concern about GPs acting as gatekeepers (McIlfatrick et al, 2011). Watts (2008) reviewed evidence that some GPs remove women eligible for cervical screening from the invitation list, on the basis of their having learning disabilities, despite the fact that guidance explicitly states this is not an acceptable reason in itself (NHSCSP, 2006). GPs may also make the assumption that a woman with learning disabilities is not sexually active and therefore does not need cervical screening. The assumption of sexual inactivity can often be wrong and some women may have been sexually active as a consequence of sexual abuse (Watts, 2008). Furthermore, even if a woman is sexually inactive this does not completely negate her risk of cervical cancer (Reynolds et al, 2008).

Some women may be correctly 'ceased' on the basis that they have physical disabilities preventing them getting into the correct position for a screen (Reynolds et al, 2008). It is crucial for these women that awareness of signs and symptoms should still be encouraged (Willis et al, 2008). Gillings and Taylor (2004) discussed the issue of breast examination for women who are unable to do this themselves. They argued that not providing breast examination for such women is a failure in duty of care and that if necessary they should be seen regularly by a breast specialist nurse.

Misinformed assumptions about people with learning disabilities may be partially due to the poor training about learning disabilities that GPs receive (Taggart et al, 2011; Willis et

al, 2008). Similarly, other specialists such as radiographers do not necessarily have much knowledge about how to support people with learning disabilities (McIlfratrick et al, 2011).

A general lack of health promotion, training and good information for support workers and family members has been identified as another barrier (Gribben & Bell, 2010). Research with learning disability support staff showed that the majority of them had not received any training in relation to cancer prevention and concluded there is a need for training for care staff about the early signs of cancer (Hanna et al, 2011). They also found evidence that staff were reluctant to discuss sensitive health promotion topics, such as breast screening and bowel issues. GPs may not be the only gatekeepers in relation to access to screening services. Research suggests that sometimes family carers do not see screening as a high priority for their relative. It can be a difficult issue as it may be a taboo subject (Taggart et al, 2011) and involve discussions about sexual activity; staff and family carers may be concerned about invasive investigations causing distress and participation is not always seen as a priority (McIlfratrick et al, 2011). CIPOLD found one care home appeared to have a 'blanket' policy of not sending women for cervical screening.

In relation to bowel screening, CIPOLD found evidence of some confusion on the part of staff and family carers as to what the process should be. For example, some did not return a sample as they believed that stool samples could not be collected from incontinence pads. Others reported that there was a lack of advice about how to get a sample from a person who could not collect their own and/or who found changes to their routine, or interference with privacy, distressing (Heslop et al, 2013). This suggests a need for improved practical support and training for both staff and family carers.

There is also evidence that a lack of partnership working may be another barrier; specialist learning disability teams can support primary care, but there is a dearth of formalised joint working arrangements (Broughton & Thomson, 2000; Gribben & Bell, 2010). A survey of primary care professionals revealed there was seldom any consideration of proactive work with people with learning disabilities to help them to tolerate screening or investigations. GP surgeries rarely even kept a record of named Community Learning Disability Team nurses working with their patients (Wood & Douglas, 2007).

### ***3.4 Attitude and knowledge of people with learning disabilities***

Truesdale-Kennedy et al (2011) ran a series of focus groups with women with learning disabilities to explore their understanding of breast cancer and their experiences of breast screening. They found a limited understanding as to what breast cancer is, as well the signs and symptoms of it. The women's lack of understanding as to what the process of mammography involved was associated with feelings of fear and anxiety about the

screening. The majority of women who had undergone breast screening did describe it as painful or uncomfortable. Research with community nurses and residential staff has shown that they think that fear and anxiety about the process as well as embarrassment are also factors that stop women with learning disabilities attending breast screening (Taggart et al, 2011). These same issues have been identified in research into the barriers to cervical screening for women with learning disabilities (Broughton & Thomson, 2000; Watts, 2008). The potential for embarrassment may be increased if a woman is unaware of her right to be examined by a female clinician (Watts, 2008).

The reluctance to attend a potentially uncomfortable and embarrassing examination is particularly understandable if the benefits of the screening programme are not known. There is a role for good, appropriate health promotion aimed at people with learning disabilities in relation to the need for screening. However existing media campaigns are often abstract and hard for them to understand (Davies & Duff, 2001).

CIPOLD showed that the greatest difficulties for people with learning disabilities appeared to be with access to bowel cancer screening. Many did not respond to the invitation to participate, possibly because they did not understand the importance or implications of the screening, and possibly because they found the process difficult to follow. There was little evidence found of support for people with learning disabilities to enable them to engage with the bowel screening programme; there was no evidence that people had received accessible information about the screening programme, and it appeared that no reasonable adjustments had been made to support their participation (Heslop et al, 2013).

### **3.5 Consent issues**

It is evident from the literature reviewed that concerns about the capacity of people with learning disabilities to consent to participate in screening programmes can also be a barrier (McIlfatrick et al, 2011). Wood and Douglas' (2007) survey of primary care professionals showed that some GP practices would not even consider the possibility of supporting a woman to have a cervical screen if she could not consent to it. Broughton and Thomson (2000) suggested that women with learning disabilities are less likely to have a smear test as it may be assumed they are unable to consent to the process. However, they also note the need for accessible information to aid understanding and to increase the likelihood that an individual will be able to make an informed decision. It is understandable that clinicians are reluctant to perform an invasive procedure, such as a cervical smear test, if they are unsure whether the woman is able to give her informed consent. Nevertheless there is also a need to consider a woman's right to access cervical screening, irrespective of having a learning disability (NHSCSP, 2006).



In relation to bowel screening, Read and Latham (2009) discussed the need to make a decision in someone's Best Interests if they lacked the capacity to consent. If an individual lacks the mental capacity to consent to screening, they should only be 'ceased' from the programme if a decision has been made appropriately that it is in his or her Best Interests to be removed from the screening list (NHSCSP, 2009).

(See section 4.1 for further discussion about the MCA in relation to participation in screening programmes).

### **3.6 Accessible information and resources**

In the articles retrieved in this literature search there has been a lot of discussion about the need for good easy-read resources (Taggart et al, 2011; Watts, 2008; Willis et al, 2008). However, the search for such resources has identified a vast amount of accessible information in a variety of formats in relation to the three cancer screening programmes (see section 3.5 for further details). The problem seems to be lack of knowledge of such resources, as many staff have been found to be unaware of the body of accessible literature (Taggart et al, 2011). Another limitation noted of some of the breast cancer resources was the lack of actual photos of breasts. Descriptions and line drawings of what signs to look for were not always thought to be adequate (Barnes et al, 2008).

## 4. Improving uptake

### 4.1 Education, training and support for professionals, support staff and family carers

Primary care based research has concluded that there is a need for improved guidance and support for primary care professionals to enable them to offer screening appropriately to people with learning disabilities (Gribben & Bell, 2010; Wood & Douglas, 2007). In relation to cervical and breast screening it has been acknowledged that there is a need for staff and family carers to have more information about the importance of participation of the women they are supporting (Broughton & Thomson, 2000; McIlfatrick et al, 2010). Focus groups with community nurses and residential staff (Taggart et al, 2011) concluded that all participants highlighted that training is essential for all key people, including family carers, residential staff, GPs, radiographers, etc. More specifically, the need for education for health professionals around the issue of obtaining consent for screening from people with learning disabilities is paramount (McIlfatrick et al, 2010).

The majority of these suggestions for improving uptake to screening services through education and training have stemmed from research exploring attitudes of professionals in various settings. However, there is a paucity of evaluations of the effectiveness of such training and education for professionals and care staff. One such study in the UK evaluated how a teaching pack for residential staff working with women with learning disabilities was received. This consisted of a teaching pack, checklist and resource pack and was about breast awareness and preparing women for breast screening. It was demonstrated that the scheme was well received by care staff, but there was no data about outcomes in relation to screening uptake (Symonds & Howsam, 2004). A similar study about awareness training for care staff was also inconclusive as to whether knowledge increased following the intervention (Isaacs, 2006). There is a need for robust evaluation of such education schemes.

### 4.2 Education, training and support for people with learning disabilities

In addition to education and training for professionals, care staff and family carers, there is also a role for such input for people with learning disabilities themselves, to help them understand the need for, and the process of, screening programmes (Watts, 2008). McIlfactrick et al (2010) argue that such education programmes and health promotion activities must be done in a structured and targeted manner, rather than on an opportunistic basis. Focus groups with women with learning disabilities showed that those

who had been given more information about breast mammography reported less stress and anxiety (Truesdale-Kennedy et al, 2011).

The initial contact from the breast screening unit should be accompanied by easy-read information, as it is important that people are prepared for what the screening entails (Taggart et al, 2011). This is particularly crucial in relation to the more invasive screening procedures. There is a legal obligation for reasonable adjustments to be made in order to ensure equal access to healthcare services for people with learning disabilities. The literature suggests that careful preparation can increase the likelihood of a successful screening test. A significant aspect of this is the use of accessible resources to help explain what processes are involved. Advance visits to the environment where the screen will take place and a chance to look at the equipment and meet staff can be useful. Basic relaxation techniques may also be effective, such as relaxation tapes or listening to music of the person's choice. It is likely that it will be beneficial for the person to be accompanied to the actual appointment by someone whom they trust and are comfortable with (Broughton & Thomson, 2000; Watts, 2008). In addition to such preparatory work, there are reasonable adjustments that can be made by the services, such as longer appointments (Wicks, 2007).

In one of the few studies to explore the views of women with learning disabilities themselves, the women were able to identify that it was emotional and informational support that was key (Truesdale-Kennedy et al, 2011).

Again, there is a lack of evidence based evaluations of such interventions. One study explored whether one to one counselling improved the uptake of cervical and breast screening in women with moderate to severe learning disabilities (Biswas et al, 2005). However, this found that within the study area the uptake of breast screening was already 77%, which is close to the national average. Some women were able to undergo cervical screening following the counselling, but the numbers remained low and the authors acknowledged that the impact of this intervention was modest. However, it does demonstrate that such one to one education can be beneficial and it may be a more effective model for women with mild learning disabilities.

The first stage of the bowel screening programme is relatively unobtrusive; however, if this test is positive then the second part to the bowel screening programme is much more intrusive and has risks attached. There is little literature exploring how to improve uptake at this stage, but there are reasonable adjustments that can be made if the individual cannot tolerate a colonoscopy. These include alternative investigations such as X-ray imaging or computerised tomography colonography (Read & Latham, 2009).

### 4.3 Partnership working

It has been suggested that improved partnership working between Community Learning Disability Team nurses and primary care staff could help to increase the uptake of cervical screening by women with learning disabilities (Wood & Douglas, 2007). This was supported by Reynolds et al (2008), who also concluded that women with learning disabilities in need of cervical screening would be better supported if there were improved communication between learning disability teams and GPs. On a local scale it has been demonstrated that referrals from GPs and practice nurses to a learning disability nurse provided the opportunity for the learning disability nurse to teach women with learning disabilities about their bodies and the cervical screening process. Following this work some women were able to tolerate smear tests at their local GP surgery and another had a smear test at home (Wilkins, 2004). If an appropriate referral is made from primary care, specialist learning disability nurses could play a key role in providing the support needed to help women cope with a cervical smear test (Broughton & Thomson, 2000).

There is also evidence from healthcare professionals that such joint working could be used to support access to breast cancer screening. McIlfatrick et al (2010) argued “it is vital to promote an interdisciplinary approach to the care of these women, recognising strengths and weaknesses of all professional groups” (p. 419).

This search has not identified any relevant research about partnership working in relation to the other screening programmes, but it is likely that good partnership working between primary care and learning disability specialists could improve uptake in these areas as well.

## 5. Existing easy read resources

The search methods undertaken retrieved a large amount of accessible resources in relation to the three cancer screening programmes. Whilst there is a paucity of peer reviewed research about access to bowel cancer, AAA and diabetic retinopathy screening, there were some easy read resources available in relation to all of these screening programmes. The majority of the resources found were easy read booklets. These used simple words and pictures to explain various processes. Some of these would still be difficult for people with learning disabilities to use independently, but they are useful resources for supporters to use as a basis for discussions about screening and what it will involve. There were also a number of video clips or DVDs available, as well as some audio recordings.

A lot of the journal articles reviewed in this section identified the benefits of, and a greater need for, accessible resources to be used with people with learning disabilities who have been invited to attend for screening (Taggart et al, 2011). Such resources can help to ensure that individuals are able to make an informed choice as to whether or not they wish to participate (McIlpatrick et al, 2010). If they do opt to attend the screening appointment, accessible information can help prepare them for what to expect, which will increase the chance that they will be able to participate. Photos that are specific to the people and places they will encounter are particularly useful.

As this search identified that a lot of accessible resources are available, yet recent academic journals are calling for the development of more, this raises the question as to whether there is really a need for more, or rather a need for greater awareness of what resources are available. Forums such as the UK Health and Learning Disability Network can be useful for finding such resources, as well as websites such as Easyhealth.

There are links to a range of resources that could be useful for professionals, support staff, family carers and people with learning disabilities in each of the five pathways (see Appendix 2). There is also a list of some of the general websites that have relevant, useful resources and information (see Appendix 3).



## Toolkit

### Cervical screening for women with learning disabilities – why is it important?

A number of studies have reported low uptake of cervical screening by women with learning disabilities (IHaL health inequalities report). The Confidential Inquiry that presumptions were made about women’s sexual history and activity, reducing access to screening. Some women were excluded from the screening even though nothing was known about their past history, and one care home appeared to have a ‘blanket’ policy of not sending women for screening.

**Pathway for a woman with learning disabilities – cervical screening** (note: the Plymouth pathway is on the local Map of Medicine, which cannot be accessed unless you have an Athens account)

Step	For whom	What needs to be in place	Who needs to do it	Useful links/examples
Being aware of the normal menstrual cycle and things to look out for	Women with learning disabilities	Easy read/audio/video information about menstruation and any abnormal signs and symptoms which may need further investigation	Health promotion (and general practice – particularly if the person has not undergone cervical screening), supported by learning disability health professionals and involving women with learning disabilities	<a href="http://www.easyhealth.org.uk/sites/default/files/what_is_that_in_my_pants.pdf">http://www.easyhealth.org.uk/sites/default/files/what_is_that_in_my_pants.pdf</a> <a href="http://be.macmillan.org.uk/be/s-428-accessible-information.aspx">http://be.macmillan.org.uk/be/s-428-accessible-information.aspx</a>
	Family carers/support workers	Information about menstrual health for women with learning disabilities:	As above	<a href="http://be.macmillan.org.uk/be/s-428-accessible-information.aspx">http://be.macmillan.org.uk/be/s-428-accessible-information.aspx</a>

		<ul style="list-style-type: none"> <li>• Why it is important to help women understand</li> <li>• What you can do</li> </ul>		
Information about cervical screening	Women with learning disabilities approaching or in the target age group	<p>Easy read/audio/video information about cervical screening and awareness raising training.</p> <p>Discussion about cervical screening as part of Annual Health Check</p>	<p>Cervical screening service supported by learning disability health professionals and women with learning disabilities.</p> <p>Primary care, supported by learning disability health professionals</p>	<p><a href="http://www.easyhealth.org.uk/search/node/cervical">http://www.easyhealth.org.uk/search/node/cervical</a></p> <p><a href="http://www.easyhealth.org.uk/listing/smear-test-(leaflets)">http://www.easyhealth.org.uk/listing/smear-test-(leaflets)</a></p> <p><a href="http://www.cancerscreening.nhs.uk/cervical/publications/its-your-choice.html">http://www.cancerscreening.nhs.uk/cervical/publications/its-your-choice.html</a></p> <p><a href="http://www.cancerscreening.nhs.uk/cervical/publications/easy-guide-cervical-screening.pdf">http://www.cancerscreening.nhs.uk/cervical/publications/easy-guide-cervical-screening.pdf</a></p> <p><a href="http://www.betterlives.org.uk/Libraries/Local/782/Docs/cervical%20cancer%20leaflet%20FINAL%20compressed.pdf">http://www.betterlives.org.uk/Libraries/Local/782/Docs/cervical%20cancer%20leaflet%20FINAL%20compressed.pdf</a></p>
	Family carers/support workers	<p>Information about cervical screening for women with learning disabilities:</p> <ul style="list-style-type: none"> <li>• why it's important to help women participate</li> <li>• what you can do</li> </ul> <p>Training for support staff and clear guidance about their role.</p> <p>Awareness raising sessions for</p>	Cervical screening service supported by learning disability health professionals	<p><a href="http://www.screeningservices.org.uk/csw/pr of/train/learn_dis/learn_dis_pub.asp">http://www.screeningservices.org.uk/csw/pr of/train/learn_dis/learn_dis_pub.asp</a></p> <p><a href="http://www.screeningservices.org.uk/csw/pr of/train/learn_dis/learn_dis_prof.asp">http://www.screeningservices.org.uk/csw/pr of/train/learn_dis/learn_dis_prof.asp</a></p> <p><a href="http://be.macmillan.org.uk/be/s-428-accessible-information.aspx">http://be.macmillan.org.uk/be/s-428-accessible-information.aspx</a></p> <p><a href="http://www.betterlives.org.uk/Libraries/Local/782/Docs/cervical%20cancer%20leaflet%20FINAL%20compressed.pdf">http://www.betterlives.org.uk/Libraries/Local/782/Docs/cervical%20cancer%20leaflet%20FINAL%20compressed.pdf</a></p>

		family carers.		
Identification	GP practice level (local variations)	A system for sharing information between the GP practice and the learning disability health professionals	General practice supported by learning disability health professionals	
Invitation	Cervical screening service	System for sending out invitation and information appropriate to the recipient  Send letter to family carers where appropriate	Cervical screening service (although this is not possible at present), so – would need to be via the learning disability health professionals	<a href="http://www.easyhealth.org.uk/search/node/cervical">http://www.easyhealth.org.uk/search/node/cervical</a> (has an example of an invitation letter)  <a href="http://cancerawaresstoolkit.com/resources/download/cervical-screening-invite-letter-learning-disability">http://cancerawaresstoolkit.com/resources/download/cervical-screening-invite-letter-learning-disability</a>
Deciding about participation	Women who have received an invitation. Best interests process for women assessed as not having the capacity to decide*	Easy read/audio/video information about cervical screening. Other reasonable adjustments as appropriate.	Family carers, support services, learning disability professionals, cervical screening service.	<a href="http://www.easyhealth.org.uk/search/node/cervical">http://www.easyhealth.org.uk/search/node/cervical</a> <a href="http://www.easyhealth.org.uk/listing/smear-test-(leaflets)">http://www.easyhealth.org.uk/listing/smear-test-(leaflets)</a> <a href="http://www.screeningservices.org.uk/csw/prof/train/learn_dis/learn_dis_pub.asp">http://www.screeningservices.org.uk/csw/prof/train/learn_dis/learn_dis_pub.asp</a> <a href="http://www.screeningservices.org.uk/csw/prof/train/learn_dis/learn_dis_prof.asp">http://www.screeningservices.org.uk/csw/prof/train/learn_dis/learn_dis_prof.asp</a> <a href="http://www.2gether.nhs.uk/files/cervicalscreening.pdf">http://www.2gether.nhs.uk/files/cervicalscreening.pdf</a> <a href="http://www.cancerscreening.nhs.uk/cervical/publications/easy-guide-cervical-screening.pdf">http://www.cancerscreening.nhs.uk/cervical/publications/easy-guide-cervical-screening.pdf</a> <a href="http://be.macmillan.org.uk/be/s-428-accessible-information.aspx">http://be.macmillan.org.uk/be/s-428-accessible-information.aspx</a>



				<a href="http://www.hft.org.uk/supporting-people/family-carers/resources/mca-guide/">http://www.hft.org.uk/supporting-people/family-carers/resources/mca-guide/</a> <a href="http://bma.org.uk/practical-support-at-work/ethics/mental-capacity">http://bma.org.uk/practical-support-at-work/ethics/mental-capacity</a>
Making arrangements	Women who have received invitation with support as required	Suggestions from cervical screening service about reasonable adjustments that can be offered. Support to make these arrangements.	Family carers, support services, learning disability health professionals.	<a href="http://www.ndti.org.uk/uploads/files/IHaL_RA_-2012_-01.pdf">http://www.ndti.org.uk/uploads/files/IHaL_RA_-2012_-01.pdf</a>
Attending	Women who have received invitation with support as required.	Support to accompany as appropriate.	Family carers, support services, learning disability health professionals	<p>Cervical smear takers course in Cornwall includes input from the cancer screening nurse and a self-advocate.</p> <p>Plymouth supported development of an e-learning pack for those carrying out cervical smears (used by the training organisation)</p>
Getting results	Women who have been screened	Easy read/audio/video information about cervical screening results. Offer of support to go through this.	Family carers, support services, learning disability professionals.	
What happens next	Women who need further investigation	Easy read/audio/video information about further investigations. Offer of support to go through this	Cervical screening service, family carers, support services, learning disability health professionals.	<a href="http://www.hft.org.uk/supporting-people/family-carers/resources/mca-guide/">http://www.hft.org.uk/supporting-people/family-carers/resources/mca-guide/</a> <a href="http://bma.org.uk/practical-support-at-work/ethics/mental-capacity">http://bma.org.uk/practical-support-at-work/ethics/mental-capacity</a>

\*It should not be assumed that women cannot tolerate cervical screening. Appropriate reasonable adjustments should be considered first.



## Breast screening for women with learning disabilities – why is it important?

Nationally there is evidence that women with learning disabilities are not well informed about breast cancer<sup>8</sup> and that uptake of breast screening is low<sup>9</sup>.

### Pathway for a woman with learning disabilities – breast screening

Step	For whom	What needs to be in place	Who needs to do it	Useful links and examples
Breast awareness	Women with learning disabilities	Easy read/audio/video information about breast health: <ul style="list-style-type: none"> <li>• your breasts start to grow when you're a teenager</li> <li>• why it's important to check your breasts</li> <li>• things to look out for</li> <li>• what to do if you have any</li> </ul>	Health promotion (and general practice), supported by learning disability health professionals and involving women with learning disabilities  NB new LA public health duties re sexual health	<a href="http://www.healthscotland.com/uploads/documents/12056-AGuideToExaminingYourBreasts.pdf">http://www.healthscotland.com/uploads/documents/12056-AGuideToExaminingYourBreasts.pdf</a> <a href="http://www.easyhealth.org.uk/listing/breast-s-(leaflets)">http://www.easyhealth.org.uk/listing/breast-s-(leaflets)</a> <a href="http://be.macmillan.org.uk/be/s-428-accessible-information.aspx">http://be.macmillan.org.uk/be/s-428-accessible-information.aspx</a>

<sup>8</sup> Truesdale-Kennedy et al (2011). Breast cancer knowledge among women with intellectual disabilities and their experiences of receiving breast mammography. *Journal of Advanced Nursing* vol 67 issue 6, 1294-1304.

<sup>9</sup> Emerson et al (2012). *Health inequalities and People with Learning Disabilities in the UK:2012*. Improving Health and Lives Learning Disabilities Public Health Observatory.

		worries		
	Family carers, support services	Information about breast health for women with learning disabilities: <ul style="list-style-type: none"> <li>• why it's important to help women understand</li> <li>• what you can do</li> </ul>	Health promotion, supported by learning disability health professionals	<a href="http://www.easyhealth.org.uk/listing/breast-s-(leaflets)">http://www.easyhealth.org.uk/listing/breast-s-(leaflets)</a> <a href="http://be.macmillan.org.uk/be/s-428-accessible-information.aspx">http://be.macmillan.org.uk/be/s-428-accessible-information.aspx</a>
Information about breast screening	Women with learning disabilities approaching or in the target age group	Easy read/audio/video information about breast screening plus accessible versions of invitation	Breast screening service and general practice, supported by learning disability health professionals and involving women with learning disabilities	<a href="http://www.easyhealth.org.uk/listing/breast-s-(leaflets)">http://www.easyhealth.org.uk/listing/breast-s-(leaflets)</a> <a href="http://www.cancerscreening.nhs.uk/breastscreen/">http://www.cancerscreening.nhs.uk/breastscreen/</a> <a href="http://be.macmillan.org.uk/be/s-428-accessible-information.aspx">http://be.macmillan.org.uk/be/s-428-accessible-information.aspx</a> <a href="http://www.screeningservices.org.uk/btw/train/learn_dis.asp">http://www.screeningservices.org.uk/btw/train/learn_dis.asp</a>
	Family carers, support services	Information about breast screening for women with learning disabilities: <ul style="list-style-type: none"> <li>• why it's important to help women participate</li> <li>• what you can do</li> </ul>	Breast screening service, supported by learning disability health professionals	<a href="http://www.screeningservices.org.uk/btw/train/learn_dis.asp">http://www.screeningservices.org.uk/btw/train/learn_dis.asp</a>
Identification	Breast screening service	System for sharing information between breast screening service, general practice and learning disability health team to identify eligible women to invite and to flag for any reasonable adjustments required	Breast screening service and general practice, supported by learning disability health professionals	<a href="http://cancerawarenesstoolkit.com/resources/download/breast-screening-invite-letter-learning-disabilities">http://cancerawarenesstoolkit.com/resources/download/breast-screening-invite-letter-learning-disabilities</a>

Invitation	Breast screening service	System for sending out invitation and information appropriate to the recipient (e.g. to include easy read, offer of reasonable adjustments) Notify learning disability health team if possible	Breast screening service, with advice from learning disability health professionals	<a href="http://cancerawarenesstoolkit.com/resources/download/breast-screening-invite-letter-learning-disabilities">http://cancerawarenesstoolkit.com/resources/download/breast-screening-invite-letter-learning-disabilities</a>
Deciding about participation	Women who have received invitation.  Best Interests process for women assessed as not having capacity to decide	Easy read/audio/video information about breast screening; offer of support to go through this	Family carers, support service, learning disability health professionals  GP practice	<a href="http://www.hft.org.uk/supporting-people/family-carers/resources/mca-guide/">http://www.hft.org.uk/supporting-people/family-carers/resources/mca-guide/</a> <a href="http://bma.org.uk/practical-support-at-work/ethics/mental-capacity">http://bma.org.uk/practical-support-at-work/ethics/mental-capacity</a>
Deciding about ceasing	Breast screening service	System for deciding, with the woman and her GP, using Best Interests process where appropriate	Breast screening service, GP	<a href="http://www.cancerscreening.nhs.uk/breastscreen/publications/nhsbsp-gpg7.pdf">http://www.cancerscreening.nhs.uk/breastscreen/publications/nhsbsp-gpg7.pdf</a>
Making arrangements	Women who have received invitation, with support as required	Suggestions from breast screening service about reasonable adjustments that can be offered; offer of support to make these arrangements	Family carers, support service, learning disability health professionals	<a href="http://www.ndti.org.uk/uploads/files/IHaL_RA_-2012_-01.pdf">http://www.ndti.org.uk/uploads/files/IHaL_RA_-2012_-01.pdf</a>

Attending	Women who have received invitation, with support as required	Offer of support to accompany	Family carers, support service, learning disability health professionals	
Getting results	Women who have been screened	Easy read information about breast screening results; offer of support to go through this	Breast screening service Family carers, support service, learning disability health professionals	
What happens next	Women who need further investigation	Easy read/audio/video information about further investigations; offer of support to go through this	Breast screening service Family carers, support service, learning disability health professionals	<a href="http://www.hft.org.uk/supporting-people/family-carers/resources/mca-guide/">http://www.hft.org.uk/supporting-people/family-carers/resources/mca-guide/</a> <a href="http://bma.org.uk/practical-support-at-work/ethics/mental-capacity">http://bma.org.uk/practical-support-at-work/ethics/mental-capacity</a>



## Bowel screening for people with learning disabilities – why is it important?

Risk factors for bowel cancer include being overweight, having a poor diet, and not taking enough exercise. People with learning disabilities are more likely to be overweight than the general population, and research has shown that many people with learning disabilities eat a poor diet, and take little exercise (IHaL health inequalities paper), therefore putting them at higher risk of bowel cancer. People with profound and multiple learning disabilities are the most likely group to have bowel problems. However, the Confidential Inquiry into the deaths of people with learning disabilities (CIPOLD) found that people with learning disabilities had more difficulty accessing to bowel cancer screening than the other cancer screening programmes. Many people with learning disabilities did not respond to the invitation to participate in bowel screening, possibly because they did not understand the reason for screening, and possibly because they found the process difficult to follow. CIPOLD found no evidence that people had received accessible information about the screening programme, and no evidence of reasonable adjustments to enable their participation. There was also some evidence confusion on the part of carers as to what the process should be. Some carers did not send in samples for testing as they believed they could not be collected from incontinence pads. Others said there was a lack of advice about how to get a sample from a person who could not collect their own and/or who found changes to their routine, or interference with privacy, distressing.

### Pathway for people with learning disabilities – bowel screening

Step	For whom	What needs to be in place	Who needs to do it	Useful links and examples
Information about bowel screening	People with learning disabilities in the age band for screening	Easy read/audio/video information about bowel screening. Awareness raising sessions.	Bowel cancer screening programme and hubs. Learning disability health professionals and involving people with learning disabilities.	Picture leaflet: <a href="http://www.cancerscreening.nhs.uk/bowel/publications/nhsbcsp-learning-disabilities-leaflet.html">www.cancerscreening.nhs.uk/bowel/publications/nhsbcsp-learning-disabilities-leaflet.html</a> <a href="http://www.cancerscreening.nhs.uk/bowel/publications/audio-video-resources.html">http://www.cancerscreening.nhs.uk/bowel/publications/audio-video-resources.html</a>

				<a href="http://be.macmillan.org.uk/be/s-428-accessible-information.aspx">http://be.macmillan.org.uk/be/s-428-accessible-information.aspx</a> <a href="http://www.ldcarerscommunity.org.uk/ bowel-screening-for-people-with-learning-disabilities/">http://www.ldcarerscommunity.org.uk/ bowel-screening-for-people-with-learning-disabilities/</a> <a href="http://www.bowelcanceruk.org.uk/resources/bowel-health-and-screening/">http://www.bowelcanceruk.org.uk/resources/bowel-health-and-screening/</a> <a href="http://www.easyhealth.org.uk/search/node/bowel">http://www.easyhealth.org.uk/search/node/bowel</a> <a href="http://www.easyhealth.org.uk/listing/bowel-and-bladder-(videos)">http://www.easyhealth.org.uk/listing/bowel-and-bladder-(videos)</a>
	Family carers, support services	<p>Information about bowel screening for people with learning disabilities:</p> <ul style="list-style-type: none"> <li>• Why it is important</li> <li>• What you can do</li> </ul> <p>Training for support staff and clear guidance about their role.</p> <p>Awareness raising sessions for family carers.</p>	Bowel cancer screening programme and hubs. Learning disability health professionals.	<p>Free national helpline available 0807076060</p> <a href="http://be.macmillan.org.uk/be/s-428-accessible-information.aspx">http://be.macmillan.org.uk/be/s-428-accessible-information.aspx</a> <a href="http://www.ldcarerscommunity.org.uk/ bowel-screening-for-people-with-learning-disabilities/">http://www.ldcarerscommunity.org.uk/ bowel-screening-for-people-with-learning-disabilities/</a> <a href="http://www.bowelcanceruk.org.uk/resources/bowel-health-and-screening/">http://www.bowelcanceruk.org.uk/resources/bowel-health-and-screening/</a> <a href="http://www.wales.nhs.uk/sites3/page.cfm?orgid=747&amp;pid=41731">http://www.wales.nhs.uk/sites3/page.cfm?orgid=747&amp;pid=41731</a> <a href="http://www.easyhealth.org.uk/search/node/bowel">http://www.easyhealth.org.uk/search/node/bowel</a> <a href="http://www.nhsinform.co.uk/screening/~/media/Files/Documents/Microsites/Screening/PDFs/Bowel/Bowel%20Health%20and%20">http://www.nhsinform.co.uk/screening/~/media/Files/Documents/Microsites/Screening/PDFs/Bowel/Bowel%20Health%20and%20</a>

				<a href="#">Screening%20leaflet%20for%20carers%20of%20people%20with%20learning%20disabilities.ashx</a>
	Support services	Contracts that clearly state the duty support services have regarding enabling people with learning disabilities to use screening services	Commissioners	
Identification	Currently not possible in national programme	System for sharing information between bowel screening service and learning disability health professionals?	Bowel cancer screening programme and hubs. Learning disability health professionals	Identification of people with learning disabilities can happen if they do not respond to the invitation and reminder; at this point, 13 weeks after the initial invitation, a letter goes to the GP.
Invitation	Bowel screening service	Plain English leaflet sent. Need for easy read invitation to be sent out.	Bowel cancer screening programme/hubs. Learning disability health professionals	
Sending out the test kit	Bowel screening service	Support to use test kit	Family carers, support services, learning disability health professionals	Hubs will sometimes provide 'wasted kits' which can be used by learning disability health professionals to demonstrate use (using chocolate spread can be helpful!)
Getting results	People who have been screened	Support to understand results	Family carers, support services, learning disability health professionals	In Cornwall, the screening liaison nurse is suggesting all GPs sign up to the electronic results service. The service is free and just requires a form to be filled in. The results come in as per normal pathology results. The info can be cross referenced with the QOF, so that people



				<p>with learning disabilities can be identified and support given.</p> <p>Cornwall have put together a one off consent form so the results letter can go to the carer as well. The hub puts a temporary address on their database to enable this to happen.</p> <p><a href="http://www.wales.nhs.uk/sites3/page.cfm?orgid=747&amp;pid=41731">http://www.wales.nhs.uk/sites3/page.cfm?orgid=747&amp;pid=41731</a></p>
What happens next	People who need further investigation	<p>Easy read/audio/video information for people regarding implications of a positive screen and what it means to have a colonoscopy.</p> <p>Process for obtaining consent for colonoscopy or best interests meeting to determine the appropriate course of action including any reasonable adjustments that need to be put in place *.</p> <p>Reasonable adjustments regarding the fast track appointment including extra time if necessary.</p> <p>Easy read/audio/video information regarding preparation for a colonoscopy including what people can and can't eat, the</p>	<p>Person with learning disabilities, family carers, support services, learning disability health professionals, GP, screening service, acute liaison nurse.</p>	<p><a href="http://be.macmillan.org.uk/be/s-428-accessible-information.aspx">http://be.macmillan.org.uk/be/s-428-accessible-information.aspx</a></p> <p><a href="http://www.ldcarerscommunity.org.uk/bowel-screening-for-people-with-learning-disabilities/">http://www.ldcarerscommunity.org.uk/bowel-screening-for-people-with-learning-disabilities/</a></p> <p><a href="http://www.wales.nhs.uk/sites3/page.cfm?orgid=747&amp;pid=41731">http://www.wales.nhs.uk/sites3/page.cfm?orgid=747&amp;pid=41731</a></p> <p><a href="http://www.easyhealth.org.uk/search/node/bowel">http://www.easyhealth.org.uk/search/node/bowel</a></p> <p><a href="http://www.easyhealth.org.uk/listing/bowel-and-bladder-(videos)">http://www.easyhealth.org.uk/listing/bowel-and-bladder-(videos)</a></p> <p><a href="http://www.cancerscreening.nhs.uk/bowel/publications/nhsbcsp-colonoscopy-learning-disabilities-leaflet.pdf">http://www.cancerscreening.nhs.uk/bowel/publications/nhsbcsp-colonoscopy-learning-disabilities-leaflet.pdf</a></p> <p><a href="http://www.ndti.org.uk/uploads/files/IHaL_RA_-2012_-01.pdf">http://www.ndti.org.uk/uploads/files/IHaL_RA_-2012_-01.pdf</a></p>

		need to drink a lot of fluid, and what to expect (would need to be adapted as centres use different preparations). Referral system to acute liaison nurse or similar		<a href="http://www.hft.org.uk/supporting-people/family-carers/resources/mca-guide/">http://www.hft.org.uk/supporting-people/family-carers/resources/mca-guide/</a> <a href="http://bma.org.uk/practical-support-at-work/ethics/mental-capacity">http://bma.org.uk/practical-support-at-work/ethics/mental-capacity</a>  Having a plan in place for the person going for a colonoscopy including diet, transport, and any other issues
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\*Note – People with learning disabilities should generally be screened for bowel cancer unless there are very good reasons not to do it. Assumptions about a person’s ability to cope with a colonoscopy is not a good reason not to screen. People with learning disabilities should also be given information, where possible, about what will happen if there is a positive screen.



## Diabetic retinopathy screening for people with learning disabilities – why is it important?

Diabetic retinopathy (DR) is the most common cause of sight loss in people of working age in England and Wales and it is estimated that annually in England there are over a thousand new cases of blindness caused by diabetes (<http://diabeticseye.screening.nhs.uk/diabetic-retinopathy>). There are currently 2.9 million people in the UK with diabetes and these numbers are rapidly growing (especially in relation to type 2 diabetes) and are estimated to rise to 5 million by 2025 (Diabetes UK, 2012). Between 2006 and 2010, diabetic retinopathy increased by 118%. It is often asymptomatic during the early stages but it can be diagnosed through DR screening and this will increase the chances of minimal and effective treatment.

### Pathway for people with learning disabilities and diabetes – diabetic retinopathy screening

Step	For whom	What needs to be in place	Who needs to do it	Useful links and examples
DR awareness	People with learning disabilities and diabetes.	Easy read/audio/video information about good diabetes management.	Primary care and learning disability health professionals.	<a href="http://www.easyhealth.org.uk/search/node/diabetes">http://www.easyhealth.org.uk/search/node/diabetes</a> <a href="http://www.easyhealth.org.uk/search/node/diabetes">http://www.easyhealth.org.uk/search/node/diabetes</a> <a href="http://www.apictureofhealth.southwest.nhs.uk/wp-content/uploads/2010/06/Diabetes.pdf">http://www.apictureofhealth.southwest.nhs.uk/wp-content/uploads/2010/06/Diabetes.pdf</a> <a href="http://www.apictureofhealth.southwest.nhs.uk/wp-content/uploads/2010/06/Diabetes.doc">http://www.apictureofhealth.southwest.nhs.uk/wp-content/uploads/2010/06/Diabetes.doc</a>

				<a href="http://www.seeability.org/myeyecare/default.aspx">http://www.seeability.org/myeyecare/default.aspx</a> <a href="https://www.som.uq.edu.au/research/research-centres/queensland-centre-for-intellectual-and-developmental-disability/resources/diabetes-to-the-point/people-with-diabetes.aspx">https://www.som.uq.edu.au/research/research-centres/queensland-centre-for-intellectual-and-developmental-disability/resources/diabetes-to-the-point/people-with-diabetes.aspx</a>
DR awareness	Family carers and support services.			<a href="http://www.seeability.org/eyecare_hub/carersandsupportersinfo/eye_problems/diabetes.aspx">http://www.seeability.org/eyecare_hub/carersandsupportersinfo/eye_problems/diabetes.aspx</a> <a href="http://www.diabetes.org.uk/upload/How%20we%20help/catalogue/EatingWell_T2.pdf">http://www.diabetes.org.uk/upload/How%20we%20help/catalogue/EatingWell_T2.pdf</a> <a href="http://bedfordshirediabetes.org.uk/">http://bedfordshirediabetes.org.uk/</a> <a href="https://www.som.uq.edu.au/research/research-centres/queensland-centre-for-intellectual-and-developmental-disability/resources/diabetes-to-the-point/carers.aspx">https://www.som.uq.edu.au/research/research-centres/queensland-centre-for-intellectual-and-developmental-disability/resources/diabetes-to-the-point/carers.aspx</a>
Information about DR screening.	People with learning disabilities and diabetes aged 12 and over.	Easy read/audio/video information about DR screening. Awareness raising sessions.	Health promotion and general practice, supported by learning disability health professionals.	<a href="http://www.easyhealth.org.uk/search/node/diabetes">http://www.easyhealth.org.uk/search/node/diabetes</a> <a href="http://www.easyhealth.org.uk/search/node/diabetes">http://www.easyhealth.org.uk/search/node/diabetes</a> <a href="http://www.seeability.org/myeyecare/default.aspx">http://www.seeability.org/myeyecare/default.aspx</a>

				<a href="http://diabeticeye.screening.nhs.uk/cms.php?folder=2768">http://diabeticeye.screening.nhs.uk/cms.php?folder=2768</a> <a href="http://diabeticeye.screening.nhs.uk/getdata.php?id=11508">http://diabeticeye.screening.nhs.uk/getdata.php?id=11508</a> <a href="http://www.nhslanarkshire.org.uk/Services/Diabetes/patient-info/Documents/6257-DiabeticRetinopathy-EasyRead-Mar13.pdf">http://www.nhslanarkshire.org.uk/Services/Diabetes/patient-info/Documents/6257-DiabeticRetinopathy-EasyRead-Mar13.pdf</a>
	<p>Family carers, support services.</p>	<p>Information about DR screening for people with learning disabilities.</p> <p>Awareness raising sessions for support staff and family carers.</p>	<p>Health promotion and general practice, supported by learning disability health professionals.</p>	<a href="http://www.easyhealth.org.uk/search/node/diabetes">http://www.easyhealth.org.uk/search/node/diabetes</a> <a href="http://www.easyhealth.org.uk/search/node/diabetes">http://www.easyhealth.org.uk/search/node/diabetes</a> <a href="http://www.seeability.org/myeyecare/default.aspx">http://www.seeability.org/myeyecare/default.aspx</a> <a href="http://www.seeability.org/eyecare_hub/carersupportersinfo/eye_problems/diabetes.aspx">http://www.seeability.org/eyecare_hub/carersupportersinfo/eye_problems/diabetes.aspx</a> <a href="http://diabeticeye.screening.nhs.uk/cms.php?folder=2768">http://diabeticeye.screening.nhs.uk/cms.php?folder=2768</a> <a href="http://diabeticeye.screening.nhs.uk/getdata.php?id=11508">http://diabeticeye.screening.nhs.uk/getdata.php?id=11508</a>

Identification	Local screening centres use GP diabetes registers to identify eligible people.	A system for flagging people who have learning disabilities and any reasonable adjustments they may need.	GP practices could cross reference with their learning disability register.  Alternatively people with learning disabilities need to be flagged on the Exeter system so this information can be extracted by local screening centres.	
Invitation	Local screening centres	Plain English leaflet and easy read invitation letter should be sent.	Local screening centres.	<a href="http://www.seeability.org/myeyecare/default.aspx">http://www.seeability.org/myeyecare/default.aspx</a>
Deciding about participation	People who have received invitation.  Best Interests process for people assessed as not having capacity to decide.	Easy read/audio/video information about DR screening; offer of support to go through this.	Family carers, support service, learning disability health professionals.  GP practice.	<a href="http://www.seeability.org/myeyecare/default.aspx">http://www.seeability.org/myeyecare/default.aspx</a>  <a href="http://diabeticeye.screening.nhs.uk/cms.php?folder=2768">http://diabeticeye.screening.nhs.uk/cms.php?folder=2768</a>  <a href="http://www.hft.org.uk/supporting-people/family-carers/resources/mca-guide/">http://www.hft.org.uk/supporting-people/family-carers/resources/mca-guide/</a>  <a href="http://bma.org.uk/practical-support-at-work/ethics/mental-capacity">http://bma.org.uk/practical-support-at-work/ethics/mental-capacity</a>

Making arrangements	People who have received invitation, with support as required.	Suggestions from DR service about reasonable adjustments that can be offered; offer of support to make these arrangements.	Family carers, support service, learning disability health professionals.	<a href="http://www.improvinghealthandlives.org.uk/publications/1176/Making_Reasonable_Adjustments_to_Diabetes_Services_for_People_with_Learning_Disabilities">http://www.improvinghealthandlives.org.uk/publications/1176/Making_Reasonable_Adjustments_to_Diabetes_Services_for_People_with_Learning_Disabilities</a>
Attending	People who have received invitation, with support as required.	Offer of support to accompany.	Family carers, support service, learning disability health professionals.	
Getting results	People who have been screened.	Easy read information about DR screening results. Offer of support to go through this.	Family carers, support service, learning disability health professionals.	
What happens next	People who need further investigation or assessment.	Offer of support for follow up appointment. Process for obtaining consent or best interests decision about laser treatment if needed. Reasonable adjustments put in place if treatment is needed.	Primary care (re optimal diabetes management). Ophthalmology specialists when further assessment is needed. Family carers, support service, learning disability health professionals.	<a href="http://www.hft.org.uk/supporting-people/family-carers/resources/mca-guide/">http://www.hft.org.uk/supporting-people/family-carers/resources/mca-guide/</a> <a href="http://www.seeability.org/myeyecare/eye_operations/">http://www.seeability.org/myeyecare/eye_operations/</a> <a href="http://bma.org.uk/practical-support-at-work/ethics/mental-capacity">http://bma.org.uk/practical-support-at-work/ethics/mental-capacity</a>



## Abdominal aortic aneurysm (AAA) screening for men with learning disabilities – why is it important?

The Abdominal Aortic Aneurysm screening programme is a relatively new screening programme. An abdominal aortic aneurysm (AAA) is a dilation of part of the aorta that is within the abdomen. Ruptured AAA deaths account for 2.1% of all deaths in men aged 65 and until recently accounted for approximately 10,000 deaths annually in the UK (Vascular Society Report, 2012). There is evidence that screening can reduce deaths from AAA by up to 50% (Thompson et al, 2010). AAAs are found in 5-10% of men aged 65-79 years. They are often asymptomatic but the major complication is a rupture which is a surgical emergency and often fatal (Cosford & Leng, 2007). The mortality rate following rupture is over 80% but following planned surgery the post-operative mortality rate in high quality vascular services is as low as 2.4% (Vascular Society Report, 2012). This data demonstrates the potential benefits of this screening programme.

### Pathway for a man with learning disabilities – AAA screening

Step	For whom	What needs to be in place	Who needs to do it	Useful links and examples
Information about AAA screening.	Men with learning disabilities aged 65 and over.	Easy read/audio/video information about AAA screening.  Awareness raising sessions – in relation to the need to self-refer if aged over 65.	The National AAA screening programme.  Public Health England.	



	Family carers, support services.	Information about AAA screening for people with learning disabilities.  Awareness raising sessions for support staff and family carers - – in relation to the need to support someone to self-refer if aged over 65.	The National AAA screening programme.  Public Health England.  Should this be flagged up in annual health checks for men aged over 65?	
Identification	Local screening centres use the Exeter register to identify eligible men.	A system for flagging those men who have learning disabilities and any reasonable adjustments they may need.	The local screening centres and GP practices, supported by learning disability health professionals.  Alternatively people with learning disabilities need to be flagged on the Exeter system so this information can be extracted by local screening centres.	
Invitation	Local screening centres	Plain English leaflet and easy read invitation letter should be sent.	Local screening centres.	<a href="http://aaa.screening.nhs.uk/easyread">http://aaa.screening.nhs.uk/easyread</a>

Deciding about participation	Men who have received invitation.  Best Interests process for men assessed as not having capacity to decide.	Easy read/audio/video information about AAA screening; offer of support to go through this.	Family carers, support service, learning disability health professionals.  GP practice.	<a href="http://aaa.screening.nhs.uk/easyread">http://aaa.screening.nhs.uk/easyread</a>
Making arrangements	Men who have received invitation, with support as required.	Suggestions from AAA service about reasonable adjustments that can be offered; offer of support to make these arrangements.	Family carers, support service, learning disability health professionals.	
Attending	Men who have received invitation, with support as required.	Offer of support to accompany.	Family carers, support service, learning disability health professionals.	
Getting results	Screening technicians, as verbal results are given at the appointment.	There is existing easy read information about the possible outcomes of screening.  Training for technicians on how to communicate information simply.	Screening technicians.  Family carers, support service, learning disability health professionals.	<a href="http://aaa.screening.nhs.uk/easyread">http://aaa.screening.nhs.uk/easyread</a>

<p>What happens next</p>	<p>Men who need further investigation or assessment.</p>	<p>There is existing easy read information about the possible outcomes of screening. Offer of support to go through this. Offer of support for follow up appointment.</p> <p>Process for obtaining consent or best interests decision about surgery if needed.</p> <p>Reasonable adjustments put in place if surgery needed.</p>	<p>GPs.</p> <p>Family carers, support service, learning disability health professionals.</p> <p>Consultants.</p> <p>LD liaison nurses.</p>	<p><a href="http://aaa.screening.nhs.uk/easyread">http://aaa.screening.nhs.uk/easyread</a></p> <p><a href="http://www.hft.org.uk/supporting-people/family-carers/resources/mca-guide/">http://www.hft.org.uk/supporting-people/family-carers/resources/mca-guide/</a></p> <p><a href="http://bma.org.uk/practical-support-at-work/ethics/mental-capacity">http://bma.org.uk/practical-support-at-work/ethics/mental-capacity</a></p>
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### **Health screening for adults with Learning Disabilities.**

Devon Link Up, in conjunction with Healthwatch Devon was asked to seek information from people with learning disabilities about their experiences of health screening.

The nature of Health Screening can be a personal and difficult subject to discuss, particularly in mixed group settings so it was decided to start with conversations about annual health checks and from the outcome of this to then focus on those individuals who had been for screening and their experience. 86 people attended the various groups from across the Devon County Council area.

The majority of group members have regular contact with their GP surgery and attended an annual health check. The majority did not regularly see the same Doctor but nobody expressed any concerns about this or had any complaints about the way they were treated.

The annual health check form was used as an aid to prompt discussion and it was evident that very few people were asked about their smoking or drinking habits and nobody said that they had been asked about any sexual relationships. It is not possible to state that this is applicable to everyone as some people were unable to recall what they were asked, however, it would be an area for further investigation, particularly as it can be very relevant to further discussion and explanation about the need for screening.

The majority of people had not been to any screening and did not know if they had ever been sent a request to attend. Only seven people gave information about screening and their comments are outlined overleaf.

The following information was gathered from those who said they had been for screening.

### Female 26-50

#### Breast screening

*"I went to the mobile van. It wasn't very pleasant. The staff were helpful, but it wasn't very nice to have it done. It hurt.*

*It's good for women to go.*

*I would go again as it's important".*

#### Smear test

*"I don't like it. I've been, but I don't like it. I don't like it twisting to open. I've got a letter at home, but I'm not going.*

*If there was an easier way (to have the test done), I would go".*

### Female 51-65

#### Breast screening

*"It was alright. I think everyone should go.*

*It's a good thing to be checked"*

### Female aged 26-50

#### Smear test

*"I went once for a smear. It didn't work. I didn't like it. The metal bit really hurt me. I don't go any more.*

*I'm not sure if I would go again.*

*I would go if it didn't hurt so much."*

### Female aged 26-50

#### Smear Test

*"I've been. My Mum opened the letter and made the appointment.*

*The nurse was very kind. She explained everything as she did it.*

*I felt very apprehensive, nervous and jittery, but it was fine. I think it's good to go. It's good to prevent it (cancer)".*

### Female - aged 51-65

#### Breast screening

*"I've been, but I wouldn't go again. I went to the mobile van."*

#### Bowel screening -

*"I had a letter. I don't want to do it".*

Only two gentlemen talked about their experiences and both said that it was ok. Both had attended appointments with support staff. They gave no further information.

Due to a variety of factors it was not possible to give this consultation as much time as would be preferable considering the nature of the conversations involved. It is clear that although general health checks are undertaken there are relevant questions that are being overlooked and these clearly link to the importance of the screening programme.

Although group members do not appear to be being offered the opportunity to attend screening there may also be influences in relation to information gatekeeping which could be examined as well as the role of GP's in identifying those who may be at greater risk due to lifestyle choices.

Devon Link Up is a delivery partner of Healthwatch Devon and works to give people with Learning Disabilities in Devon a real Voice and Choice about things that are important in their lives.

Jo Morgan  
Chief Officer  
Devon Link Up  
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### Screening liaison nurse role

Make contacts with the main screening programmes and clinical commissioning groups, build links, and try to get reasonable adjustments put into place.

Provide training for mainstream screening staff around the needs of people with learning disabilities and the importance of reasonable adjustments.

Work with staff to help them to understand the mental capacity act and the importance of following the correct procedure for best interest decisions where they are needed.

Make contacts and try to get LD leads within mainstream services.

Attend the working party meetings of the main screening programmes- this ensures everyone knows us, as well as keeping us up to date with changes.

It also means that we are able to keep the needs of people with learning disabilities included in the agenda of the main screening programmes.

Develop pathways to identify our patient group so that they can get extra support.

Development of easy to understand letters and information.

Health promotion to carer's e.g. breast awareness.

Individual work with patients to help them to understand the importance of screening, also ensure they have information in a format that they can understand.

Support patients to attend or complete screening, e.g. Support at appointments, phone calls, ensuring the provision of suitable appointments, home visits, provision of easy read information.



### Useful Links

Links to useful resources and further information that relate specifically to each of the five screening programmes can be found in the pathways. Listed below are some of the general websites that may be useful:

#### **Easy read information:**

<http://www.easyhealth.org.uk/>

<http://www.apictureofhealth.southwest.nhs.uk/>

#### **Cancer screening information:**

<http://www.cancerscreening.nhs.uk/>

#### **Mental capacity issues:**

<http://www.hft.org.uk/supporting-people/family-carers/resources/mca-guide/>

<http://bma.org.uk/practical-support-at-work/ethics/mental-capacity>

#### **Reasonable adjustments:**

<http://www.improvinghealthandlives.org.uk/publications>