



Public Health  
England

Protecting and improving the nation's health

# Making reasonable adjustments to cancer screening

An update of the 2012 report

## About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. It does this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. PHE is an operationally autonomous executive agency of the Department of Health.

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## Easy-read summary



The NHS runs three cancer screening programmes.

These are:

- breast screening
- cervical screening
- bowel screening



It can be difficult for people with learning disabilities to take part in cancer screening.



It is important to find out if people have cancer as early as possible.

This makes it easier to treat the cancer.



The law says public services should put 'reasonable adjustments' in place to help people with learning disabilities use the services. This means they need to change their services so they are easier to use.



This report tells you where you can find accessible information about cancer screening.



This report has lots of information about reasonable adjustments in cancer screening. Professionals and carers can use them to help people with learning disabilities take part in cancer screening.



The report also has some examples of how local services have put reasonable adjustments in place so that people with learning disabilities can take part in cancer screening.

The pictures in this report are from Photosymbols:  
[www.photosymbols.co.uk](http://www.photosymbols.co.uk)



# Introduction

Under the Equalities Act 2010,<sup>1</sup> public sector organisations have to make changes in their approach or provision to ensure that services are accessible to disabled people as well as everybody else. Improving Health and Lives (IHaL) has a database of examples of reasonable adjustments made by health services ([www.ihal.org.uk/adjustments/](http://www.ihal.org.uk/adjustments/)).

This report is the ninth in a series of reports looking at reasonable adjustments in a specific service area (see Appendix A) and is an update of a report published in 2012. The aim of these reports is to share information, ideas and good practice in relation to the provision of reasonable adjustments.

We searched for policy and guidelines that relate to people with learning disabilities and cancer screening. A summary of this information is below. We looked at websites to find resources that might be of use to people with learning disabilities who have been invited to participate in a cancer screening programme. There is a brief description of these and information about how to obtain them in the resource tables.

We asked people to send us information about what they have done to improve uptake of cancer screening services by people with learning disabilities and any resources they have developed to support this. Additionally, we asked if people had any examples of what has gone wrong for people in the past and what could have been done better. We sent this information request to individuals we know working in the field as well as circulating it via relevant networks, including:

- UK Health and Learning Disability network
- The Choice forum
- National Family Carer network
- National Valuing Families Forum
- Learning Disabilities Professionals Senate
- WeLD nurses
- cancer network
- quality assurance teams
- bowel cancer screening units
- breast cancer screening units

# People with learning disabilities and cancer screening

## Evidence and research

### Current position

People with learning disabilities have poorer health and are more likely to die at a younger age than people in the general population, in part because of poor access to health services.<sup>2,3</sup> Historically it was thought that people with learning disabilities were less likely to get cancer<sup>4</sup> but more recent data suggests they have comparable rates.<sup>5</sup> There is evidence that suggests a different pattern of malignancies, for example people with learning disabilities are at a much higher risk of gastrointestinal cancer. It is likely that the rates and pattern of cancer among people with learning disabilities is changing as they are living longer.<sup>6</sup>

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.<sup>7-9</sup> This has been further supported by data from the Joint Health and Social Care Self-Assessment Framework<sup>10,11</sup> that showed considerably lower participation by people with learning disabilities in screening programmes. This data is incomplete, as a substantial proportion of partnership boards were unable to answer the question about screening rates. However, this is currently the best source of data for participation rates in screening programmes by people with learning disabilities.

The data from Joint Health and Social Care Self-Assessment Framework in 2014 has shown significant variation in participation rates across the three cancer screening programmes. The highest rate of uptake was for the bowel screening programme, with 41.6% of people with learning disabilities having been screened (up from 28.1% in 2012/13). This is compared with 50.4% coverage for the general population. Breast cancer screening achieved the second best coverage for people with learning disabilities, with 39.0% of women with learning disabilities being screening compared to 55.9% of the general population. Cervical screening was where there was the greatest difference in uptake, as the rate for women with learning disabilities was 29% compared to 69.1% for the population as a whole.

## Barriers to uptake

Most of the research exploring the factors associated with lower screening rates for people with learning disabilities is about the breast and cervical screening programmes. There is little research about this in relation to the bowel cancer programme.

The research shows that there are many practical barriers.<sup>12</sup> These include the lack of routine use of easy-read invitations, difficulties using appointment systems, time pressures and mobility issues. Communication difficulties have been identified by healthcare professionals as one of the most significant barriers to breast cancer screening.<sup>12</sup>

The attitudes and knowledge of both professionals and carers supporting people with learning disabilities play a part in the poor uptake of screening. Ceasing someone from a screening programme means the call/recall system stops all screening programme activity for that person. Women with learning disabilities are more likely to be ceased from cervical or breast screening programmes than other women.<sup>13</sup> Many mainstream screening professionals have had little experience of supporting people with learning disabilities and may lack the appropriate knowledge and skills.<sup>14</sup> Equally, many support staff will not have had any training in relation to cancer prevention.<sup>15</sup> There is evidence that family carers do not always consider screening to be a high priority and discussions about it can be difficult because it is considered to be a sensitive topic and may involve conversations about sexual activity.<sup>16</sup>

There are also issues about the attitude and knowledge of people with learning disabilities themselves. They may not understand why screening is so important and fear, anxiety and embarrassment may stop them choosing to participate.<sup>6</sup> A large amount of accessible information exists as well as resources designed to help people with learning disabilities understand the need for screening, what it involves and how to be prepared for it (see tables 1-5). However, many staff are unaware of these resources and do not make use of them.<sup>17</sup> Accessible information can aid understanding and therefore can be used to support informed consent. Research has shown that concerns about the capacity of people with learning disabilities to consent to participate in screening programmes can also be a barrier.<sup>12</sup>

## Improving uptake

Interventions to improve uptake need to be more robustly evaluated. However, there is some research evidence about approaches that could improve participation in screening programmes. It has been suggested that education, training and support are essential for all key people, including family carers, residential staff, GPs, radiographers.<sup>12,15,18</sup> Similarly people with learning disabilities need better education, training and support.

The research suggests that careful preparation can increase the likelihood of a successful screening test.<sup>15,19</sup>

Increasing uptake for cervical screening is more difficult because of the invasive nature of the screen. However, there is evidence 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.<sup>16</sup>

## Policy and guidance

### **Breast Screening**—The NHS Breast Screening Programme

([www.cancerscreening.nhs.uk/breastscreen/index.html](http://www.cancerscreening.nhs.uk/breastscreen/index.html)) provides free breast screening every three years for all women aged 50 and over. Once women reach the upper age limit for routine invitations for breast screening, they are encouraged to make their own appointment. The age range of women eligible for breast screening is being extended, in phases, to those aged 47–73. This started in 2010 and is expected to be complete by 2016.

In 2010, the NHS Breast Screening Programme published good practice guidance on partial or incomplete screening mammography.<sup>20</sup> This acknowledges that every possible attempt should be made to obtain a diagnostic screening mammogram for a disabled woman. However, it is important that this does not cause her harm. In the past, a radiographer was not able to justify the radiation dose from a mammogram if it was not possible to get full coverage, which may be difficult to achieve for disabled women because of problems with positioning. If a woman withdraws consent during the screening mammogram this would also result in partial mammography. This guidance means it is now acceptable to do a partial mammogram on a disabled woman whilst still justifying the radiation dose. Consequently, it has enabled a larger number of disabled women to participate in the breast screening programme.

### **Cervical Screening**—The NHS Cervical Screening Programme

([www.cancerscreening.nhs.uk/cervical/index.html](http://www.cancerscreening.nhs.uk/cervical/index.html)) invites all women aged from 25 to 64 for a free cervical screening test every three to five years. Cervical screening is offered at different intervals depending on age. The NHS call and recall system invites women who are registered with a GP. It also keeps track of any follow-up investigation, and, if all is well, recalls the woman for screening in three or five years time.

In 2008, the HPV (human papillomavirus) vaccination programme began. This vaccine protects against cervical cancer and is usually given to girls in year eight at schools in England. It will be many years before the vaccination programme has an effect upon cervical cancer incidence so the screening programme is not planning any changes yet. Vaccinated women are advised to continue accepting their invitations for cervical screening as the vaccination will not prevent all types of cervical cancer.

### **Bowel Screening**—The NHS Bowel Cancer Screening Programme

([www.cancerscreening.nhs.uk/bowel/index.html](http://www.cancerscreening.nhs.uk/bowel/index.html)) offers screening every two years to all men and women aged 60 to 74. All those eligible for screening receive an invitation letter explaining the programme and an information leaflet. About a week later, 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 laboratory. The test is then processed and the results sent within two weeks.

The NHS Bowel Cancer Screening Programme is currently piloting a new screening test. Men and women in six pilot areas will be invited for 'bowel scope screening' around the time of their 55th birthday. Bowel scope screening is an examination called 'flexible sigmoidoscopy' which looks inside the lower bowel. The aim is to find any small growths called 'polyps', which may develop into bowel cancer if left untreated. Bowel scope screening is an addition to the existing NHS Bowel Cancer Screening Programme.

Several UK policy documents emphasise that people with learning disabilities should have equal access to general and preventative health services. Under the Equality Act 2010<sup>1</sup> 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 Programme has published a series of documents relating to ceasing people from the programmes.<sup>22-23</sup> These make reference to the need for accessible information for people with learning disabilities. They also stress the need for people to work in accordance with the Mental Capacity Act and to document any best interest decisions (for further information see below). This set of guidance emphasises that in general it is good practice for people with learning disabilities to continue to be invited to participate in screening programmes. The invitations can then be considered and accepted or declined on each occasion. The guidance states unequivocally that having a learning disability is not in itself an acceptable reason for being ceased from screening.

Guidance about equal access to breast and cervical screening for disabled women is clear that disabled women have the same rights of access to breast and cervical screening as other women.<sup>24</sup> This guidance provides information for health or social services staff who support disabled women, as well as for those working in the screening programmes. It covers the need for good information to enable women to make an informed choice about participating and makes recommendations on what to do if a woman is not able to consent. There is practical advice about supporting disabled women prior to, and during, screening appointments. It also addresses the next best action for those who do not have a mammogram, which for most women is breast awareness. There is information for supporters about how to encourage the women they support to be aware of changes in their breasts and what to do if they see any. There is also advice on how supporters can do a visual check for women for whom they provide personal care.

## Consent and capacity

The Mental Capacity Act sets out the law regarding capacity and consent and provides guidance through the correct process in cases where there are concerns that an individual may not have capacity to take an informed decision. It 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

All screening programmes require participants to give informed consent prior to testing. People with learning disabilities should be assumed to have capacity to consent to testing unless there are good reasons to think they lack capacity to make this decision at this time. Where an individual is not considered to have capacity to consent, staff involved would need to decide if it is in the individual's best interests to be screened. Where the test is non-invasive and painless, such as bowel screening, the decision to proceed would generally depend on behavioural compliance, as screening is likely to be in the patient's best interests. The decision should be specific to completing the bowel screening test kit. As completing the bowel screening test kit is not invasive, carers can make the decision, but it is important for a carer to talk to others who know the person well in order to reach the decision. A positive test will lead to further investigation. This should not affect the decision to complete the kit, but may be considered when having these discussions. If the results of the screening indicate that further investigations or treatment are required, a formal best interest decision will need to be made. This needs to encompass a wide range of professionals, carers and family members and will be arranged by the specialist screening practitioners (SSPs) at the first hospital appointment.

In the breast screening programme, women need to stand and place their breasts in an uncomfortable position. For this programme, it may be more likely to be in the best interest of those individuals who are 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 future. The cervical screening test is more invasive, and a formal best interest process is likely to be required before deciding whether to

leave an individual on the list so they can be recalled. Taking a woman off the list (ceasing her from the programme) because it was considered in her best interest should follow regional policy. Her GP would be expected to lead the process with support from specialist learning disability professionals.

It is essential that accessible information about the screening programme is provided in order to help people with learning disabilities make an informed decision about their participation. This report contains links to many such resources in a range of formats relating to all of the three national cancer screening programmes.

## Cancer screening problems experienced by people with learning disabilities

The Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) found that cancer was one of the most common underlying causes of death for people with learning disabilities. Although the frequency with which cancer was reported as an underlying cause of death (20%) was lower than that in the general population (30%), deaths from cancer occurred at a much younger age in people with learning disabilities, particularly for women.<sup>3</sup> The cases reviewed showed that access to cancer screening services for people with learning disabilities was variable and the CIPOLD report highlighted engagement in the bowel screening programme as being especially problematic:

- some people with learning disabilities received an invitation and pack but did not participate in the bowel screening. It was reported that for some this was possibly because they didn't understand the importance of screening; for others it was likely to be because they didn't have the support they required in order to complete the process
- some paid staff did not return a sample as they believed that stool samples could not be collected from incontinence pads
- some paid staff in care homes believed a resident was unable to participate in the bowel cancer screening programme due to his learning disabilities
- other staff reported they needed guidance on how to collect a sample from an individual who could not do this themselves

CIPOLD found that one of the main reasons for deaths being assessed as premature was delays or problems with diagnosis. Significantly, more people with learning disabilities experienced difficulties in the diagnosis and treatment of their illness than did the comparator group. In relation to a diagnosis of cancer there was a range of issues:

- some women with learning disabilities were denied access to cervical screening on the basis of their assumed lack of sexual activity
- failure to fast track a referral despite the criteria for this being met
- planned investigations not being undertaken because the patient apparently said they did not want them. In this case there was no formal consideration of the patient's capacity to make this decision

- a lack of the reasonable adjustments an individual might need in order to participate in screening or other investigations as illustrated in the case study below

#### **Alan's story**

Alan lived alone with daily support. He was 'fast track' referred for a colonoscopy by his GP when he had lost a significant amount of weight and was found to be anaemic. He was expected to have the investigation within two weeks. Three months later his GP was concerned that Alan had not had the procedure. On investigation by the GP it transpired that two appointments had been arranged but that Alan had sent the hospital transport away on each occasion, because he had diarrhoea and he had not understood that the special drinks he had taken in readiness for the procedure would give him diarrhoea. The lack of reasonable adjustments for him resulted in a 14-week delay between referral and diagnosis.

This example comes from page 64 of the *Confidential Inquiry into premature deaths of people with learning disabilities*.<sup>3</sup>

#### **Karen's story**

Karen died of breast cancer in April 2013 when she was 44. Karen did have a GP who took part in the annual health check DES and Karen had been for her annual health checks. A breast examination is not included as part of the annual health check. Karen's mother feels strongly that annual health checks should be widened to include cancer checks, including breast examinations.

If this had been the case when Karen was seen for her annual health checks would her outcome have been different?

## Resources and case studies

This section lists a range of resources and some case studies. Some resources may be useful in helping people with learning disabilities to decide if they want to participate in a screening programme. Others give further information about how to participate and the possible outcomes of the screening tests.

The resources are in four sections:

- Table 1 lists general resources about cancer and screening. Some are easy-read and some are aimed at those supporting people with learning disabilities
- Tables 2–5 list resources related to breast, cervical and bowel screening. These include leaflets, factsheets, webpages, videos and apps. The majority of these resources are easy-read but there are also resources for supporters, health professionals and screening services

Some resources may be available from more than one site, but we have provided only one link. We have only included resources that are free to download, although some of the websites also include resources you can buy.

### Examples of developing resources

Many of the resources have been developed with the input of people with learning disabilities.

#### **Jo's Cervical Cancer Trust**

Jo's Cervical Cancer Trust has produced two resources to help women with learning disabilities to make informed choices about their health in relation to cervical cancer. A 20-page, easy-read guide to cervical screening, *Having a smear test. What is it about?*, was produced with input from women with learning disabilities, expert peer reviewers and the easy-read specialist Inspired Services Publishing. Clip art was created to help illustrate how smear tests are conducted and the type of instruments used during the test. The guide covers some of the barriers that prevent women with learning disabilities from attending their invitation to screening.

*The Smear Test Film* is a health education film for women of cervical screening age who have mild and moderate learning disabilities. PHE and Jo's Cervical Cancer Trust made the film, which was launched in January 2015. Women who have learning disabilities appeared in the film and helped with the script and illustrations. The film aims to help women make an informed decision about whether to have cervical screening and equip carers with relevant information on cervical screening and its role in preventing cervical cancer. Links to these resources are in Table 4.

For further information, contact Claire Cohen at [claire@jostrust.org.uk](mailto:claire@jostrust.org.uk)

### **The Leicestershire, Northamptonshire and Rutland Strategic Learning Disability Working Group**

The aim was to create an innovative product to facilitate reductions in the health inequalities experienced by people with a learning disability. Information DVDs and associated literature were developed to help people with learning disabilities access screening and to increase awareness about, and uptake of, cancer screening programmes. The materials help people to make fully informed decisions and give informed consent about their healthcare.

For the DVDs to be purposeful, expertise was sought through multi-agency, collaborative working with health services, the local authority, East Midlands Strategic Cancer Network, Local Screening Services, service users, secondary care and a film maker sensitive to the ethical issues around film production and healthcare. A literature review was carried out for each of the cancer screening programmes which highlighted a national inequality in access to screening and a lower uptake by people with learning disabilities. This was followed by a local data audit that reflected the national picture. Focus groups involving local people with learning disabilities were consulted regarding current available resources.

Many of the already available resources were leaflet-based and people with learning disabilities did not always find them easy to use. The focus groups were age and gender specific, for example the women in the breast focus group had all had a mammogram and some had been treated for cancer. The focus groups shaped the design of the films to ensure they are easy to use and understand. The DVDs are broken down into chapters that can be used independently or in their entirety.

The bowel screening DVD won a local 'excellence' award and the project was a finalist for a *Nursing Times* award in 2014.

The team is currently working with a public health registrar, who is evaluating the breast screening DVD. Funding is being secured to produce a DVD to support the implementation of Bowelscope.

Links to these resources are in Tables 2 and 5.

For further information, contact Rachel Hunt at [rachel.hunt5@nhs.net](mailto:rachel.hunt5@nhs.net)

### **General**

Easy-read information and resources related to health can be found on the websites below. Relevant resources from these websites are included in the tables that follow. Be aware that these websites are constantly updating their resources and can be accessed directly at:

[www.improvinghealthandlives.org.uk/adjustments/](http://www.improvinghealthandlives.org.uk/adjustments/)

[www.easyhealth.org.uk/](http://www.easyhealth.org.uk/)

[www.apictureofhealth.southwest.nhs.uk/](http://www.apictureofhealth.southwest.nhs.uk/)

**Table 1: Resources about cancer and screening applicable to all cancer programmes**

Title	Description	Provider	Link
<b>Easy-read resources about cancer and screening</b>			
How can you help to prevent cancer?	A one-page easy-read summary about preventing cancer	From Easy Health	<a href="http://www.easyhealth.org.uk/sites/default/files/how_can_you_help_to_prevent_cancer.pdf">www.easyhealth.org.uk/sites/default/files/how_can_you_help_to_prevent_cancer.pdf</a>
Common types of cancer	A one-page easy-read summary about the different types of cancer	From Easy Health	<a href="http://www.easyhealth.org.uk/sites/default/files/common_types_of_cancer.pdf">www.easyhealth.org.uk/sites/default/files/common_types_of_cancer.pdf</a>
What is cancer?	A three-page easy-read leaflet about cancer	South Staffordshire and Shropshire Healthcare NHS foundation trust	<a href="http://www.easyhealth.org.uk/sites/default/files/what_is_cancer.pdf">www.easyhealth.org.uk/sites/default/files/what_is_cancer.pdf</a>
What is cancer? Symptoms screening and staying healthy	A 20-page easy-read booklet about what cancer is, with links to other resources and relevant organisations	CHANGE	<a href="http://www.macmillan.org.uk/Documents/Cancerinfo/EasyreadPDFs/Whatiscancer[PDF,558MB].pdf">www.macmillan.org.uk/Documents/Cancerinfo/EasyreadPDFs/Whatiscancer[PDF,558MB].pdf</a>
Screening for cancer	An 11-page easy-read booklet about cancer screening, with links to other resources and relevant organisations	CHANGE	<a href="http://www.macmillan.org.uk/Documents/Cancerinfo/EasyreadPDFs/Screeningforcancer[PDF,278MB].pdf">www.macmillan.org.uk/Documents/Cancerinfo/EasyreadPDFs/Screeningforcancer[PDF,278MB].pdf</a>
Diagnosis and treatment	An easy-read book for people with learning	Macmillan and CHANGE	Free to order, but limited amount available <a href="http://be.macmillan.org.uk/be/s-428-easy-read-titles.aspx">be.macmillan.org.uk/be/s-428-easy-read-titles.aspx</a>

	disabilities		
Symptoms, screening and staying healthy	An easy-read book for people with learning disabilities	Macmillan and CHANGE	Free to order, but limited amount available <a href="http://be.macmillan.org.uk/be/s-428-easy-read-titles.aspx">be.macmillan.org.uk/be/s-428-easy-read-titles.aspx</a>
Cancer warning signs	A two-page easy-read leaflet to raise awareness of the early warning signs of cancer	NHS Highland	<a href="http://www.easyreadhealthwales.org.uk/media/47599/cancer-warning-signs.pdf">www.easyreadhealthwales.org.uk/media/47599/cancer-warning-signs.pdf</a>
<b>For carers and paid supporters</b>			
Cancer awareness toolkit	A resource to support front line staff to promote awareness of cancer and the importance of early detection	National Cancer Action Team, NHS	<a href="http://cancerawarenesstoolkit.com/">cancerawarenesstoolkit.com/</a>
Diagnosis and treatment	A book for carers of people with learning disabilities	Macmillan and CHANGE	Free to order, but limited amount available <a href="http://be.macmillan.org.uk/be/s-428-easy-read-titles.aspx">be.macmillan.org.uk/be/s-428-easy-read-titles.aspx</a>
Symptoms, screening and staying healthy	A book for carers of people with learning disabilities	Macmillan and CHANGE	Free to order, but limited amount available <a href="http://be.macmillan.org.uk/be/s-428-accessible-information.aspx">be.macmillan.org.uk/be/s-428-accessible-information.aspx</a>
Making decisions: A guide for family, friends and other unpaid carers	This booklet gives guidance on what should happen when someone lacks capacity to make decisions	Mental Capacity Implementation Programme	<a href="http://www.cancerscreening.nhs.uk/publications/making-decisions-opg602-1207.pdf">www.cancerscreening.nhs.uk/publications/making-decisions-opg602-1207.pdf</a>
Office of the Public Guardian website	A series of booklets and links to information to assist decision making	Office of the Public Guardian	<a href="http://www.gov.uk/government/organisations/office-of-the-public-guardian">www.gov.uk/government/organisations/office-of-the-public-guardian</a>
Mental Capacity	A toolkit to help good decision-	British Medical	<a href="http://bma.org.uk/practical-support-at-work/ethics/mental-capacity">bma.org.uk/practical-support-at-work/ethics/mental-capacity</a>

Toolkit	making for people who lack, or who may lack, the mental capacity to make decisions on their own behalf	Association	
Using the Mental Capacity Act	This resource has been developed specifically for family and friends of people with learning disabilities, so they understand how the Act affects them and those they care about. It is a written guide supported by eight videos	Home Farm Trust	<a href="http://www.hft.org.uk/Supporting-people/Family-carers/Resources/Using-the-Mental-Capacity-Act/">www.hft.org.uk/Supporting-people/Family-carers/Resources/Using-the-Mental-Capacity-Act/</a>

**Examples of reasonable adjustments and case studies in cancer screening applicable to all cancer screening programmes**

**The screening liaison nurse role, Peninsula Community Health, Cornwall**

In 2011, Peninsula Community Health employed two screening liaison nurses with the aim of improving the uptake of the cancer screening programmes by people with learning disabilities.

The screening liaison nurses work with the screening programmes and GPs to identify people with learning disabilities eligible for screening and ensure they have the appropriate information and support to participate. A vital aspect of their role is working with the main screening programmes to put reasonable adjustments in place. This includes the development of easy-to-understand letters and information, and training for mainstream screening staff regarding the needs of people with learning disabilities. Many of the resources they have developed are available for general use and are listed in the resource tables. Alongside a self-advocate, one of the screening liaison nurses provides input on the cervical smear takers' course. This provides an opportunity to direct nurses to available easy-read information, explain the screening liaison nurse role and share contact details.

The screening liaison nurses have worked with the mainstream screening programmes to develop ways to identify the people who need support. For example, for the bowel

screening programme the nurse contacts people with learning disabilities who have been identified as eligible but have not had a screen. These people are identified through cross-checking of GP registers. Sometimes, this is flagged as an issue through annual health checks. The screening liaison nurses regularly attend mainstream screening meetings, to ensure that they are up-to-date with any programme changes and to maintain their high profile.

The liaison nurses also do direct work with people with learning disabilities to support them to participate in the screening programmes. Examples of their individualised support are provided below.

The screening liaison nurses collect data to monitor changes in screening rates. Data from one of the breast screening services showed that there was an increase from 36% of eligible women with learning disabilities being screened in 2011 to 70% in 2013.

For further information, contact Deborah Rees at [deborah.rees@nhs.net](mailto:deborah.rees@nhs.net) or Sharon Ashby at [sharonashby@nhs.net](mailto:sharonashby@nhs.net)

#### **Check 4 Change**

Check 4 Change is the name of educational workshops that have been developed by the Macmillan Learning Disability Project in Wales. The three-year project is led by Tracey Lloyd, a Registered Nurse for Learning Disabilities and is hosted by Hywel Dda University Health Board. Tracey began the project by working with Carmarthenshire People First (CPF), a self-advocacy organisation. They agreed to create and co-train a package of educational workshops for people who have learning disabilities.

Check 4 Change seeks to empower people with learning disabilities to manage and enhance their own health, obtain advice where needed and detect early signs of illness. It was designed, with full user involvement, by experts at CPF and uses accessible forms of information, ensuring a place where new information can be learned in a safe and supported environment.

It is a proactive process that discusses cancer, health, bodies and screening whilst assisting people to learn about learning disability health checks. The completion of a health passport is encouraged and supported, and attempts are made to engage family and/or carers of the students.

The course has evolved greatly over the past year and is reviewed following each completed group of learners. It currently uses props such as a DVD, prosthetic breasts and testes, plus interactive group work. CPF volunteers have a 'script' to enable them to deliver training and full support from Tracey is available to all, including following the sessions. Feedback from people with learning disabilities and carers has been positive with people reporting increased knowledge.

Contact Tracey for advice or support or to access Check 4 Change via:

Facebook–LDNurse Macmillan, Twitter–LDMacnews, phone–01554 783726 or email–[tracey.lloyd@wales.nhs.uk](mailto:tracey.lloyd@wales.nhs.uk)

### **Coventry and Warwickshire Partnership Trust**

Coventry and Warwickshire Partnership Trust secured funding from Warwickshire North CCG and Public Health Warwickshire to run a screening event for people with learning disabilities and their family carers and paid supporters. The aim was to promote cancer screening and, hopefully, to increase the uptake of these screens by people with learning disabilities in the area.

The event ran from 10am–3pm and was attended by more than 80 people with learning disabilities and their carers/paid supporters. The day started with an interactive cancer screening quiz to get people thinking. Presentations were made by a breast care nurse and a woman with learning disabilities who has had breast cancer. She was supported to tell her story to encourage others to attend their screening. This also highlighted how learning disability teams can support people through this journey and work together with primary care for positive outcomes.

Workshops were held on cervical, bowel, breast and testicular and prostate screening and accessible information packs with easy-read information were provided. Mini health checks were offered throughout the day and one-to-one sessions with a breast care nurse for those with more personal questions or for people who struggle to learn in a group. One highlight was a huge, interactive, inflatable colon that people could walk through and learn about the stages of colorectal cancer.

Referrals were taken for follow-up support or work with regard to accessing cancer screening. Feedback from attendees was very positive, with some saying that they now felt more comfortable and confident to attend screening.

Other benefits from planning the event included improved links with screening teams. The organisers have now developed a close relationship with the breast screening team in the area and are planning further initiatives:

- they intend to run accessible education sessions at the local breast screening centres for woman with learning disabilities which will also include visits to the screening centres at each hospital and a demonstration of a mammogram
- they are exploring the possibility of 'breast screening champions'. The suggestion is that these champions would support the education sessions and act as peer support to other women with learning disabilities
- they hope to develop accessible information individualised to each screening unit
- the learning disability teams provide learning disability awareness training for the breast screening teams and vice versa

These planned activities have given a further sense of collaborative working towards increasing the uptake of cancer screening by people with learning disabilities.

For further information, contact Claire Geary at [Claire.geary@covwarkpt.nhs.uk](mailto:Claire.geary@covwarkpt.nhs.uk)

### **Middlesbrough**

More than 50 people with learning disabilities, and family carers and support staff attended an event to raise awareness and promote take up of cancer screening among women with learning disabilities. The day was organised by a partnership of health,

social care and Middlesbrough 1st to underline the importance of taking part in cervical and breast cancer screening. Funding from Middlesbrough Public Health was made available to promote good health and living healthy lifestyles for people with learning disabilities.

Three screening champions facilitated the event. A GP practice nurse and the South Tees CCG Lead for Learning Disabilities were present to answer questions.

Representatives from Tees Public Health Shared Service attended with easy-read information about things such as smoking, healthy eating, healthy heart and alcohol awareness.

The first part of the session focused on cervical cancer and a DVD by Jo's Trust was shown. The GP practice nurse gave further information about cervical screening and showed the women some of the equipment used in cervical to dispel myths and fears. In small groups, the women discussed why it important to attend cervical screening appointments. They also talked about what prevents women from taking part in cervical screening and what would help make the appointments better. These groups also provided an opportunity for women to share their personal experiences of cervical screening.

A presentation about the breast screening programme followed, with information about the equipment used. A discussion about how to check your breasts was also held, which included the message that every woman should have an idea of what their body looks like, what is normal and what is not. Women were encouraged to see their GP if they noticed any changes. Breast teaching aids were available so that members of the audience were able to feel different types of lumps.

Feedback from the day was positive, with some women who had never been for screening saying that they would now go. Further information can be found at

[www.ihal.org.uk/adjustments/?adjustment=360](http://www.ihal.org.uk/adjustments/?adjustment=360) or contact Linda Lord at [Linda\\_Lord@middlesbrough.gov.uk](mailto:Linda_Lord@middlesbrough.gov.uk)

### **North East and Cumbria Learning Disability Network**

The North East and Cumbria Learning Disability Network obtained funding from Health Education North East to run a one-day training programme looking at improving access to cancer screening for people with learning disabilities. Training is being offered to all practice nurses and health professional engagement facilitators (CRUK) in the North East and Cumbria Network area.

The aim of the day is to enable attendees to understand the challenges facing people with learning disabilities accessing the three cancer screening programmes. They will also learn how to support people to participate in screening through the provision of reasonable adjustments. Elements of the training will focus on capacity and consent, the screening pathways, impact of reasonable adjustments and personal stories. The training will be supplemented by an area-specific information pack to support the understanding of issues for specific areas. This resource pack will include local cancer screening, learning disability and population update data, easy-read resources and

local contact sheets. For further information, contact Judith Thompson at [judith.thompson1@nhs.net](mailto:judith.thompson1@nhs.net) or Julie Tucker at [Julie.tucker11@nhs.net](mailto:Julie.tucker11@nhs.net)

### **NHS Hardwick Clinical Commissioning Group**

Following work carried out by a local cancer screening focus group in 2011, NHS Hardwick CCG undertook a baseline audit of current learning disability screening services and found substantial inequalities in screening coverage compared to the general population. The gap between the general and learning disability populations for breast screening coverage was 26%, for cervical screening coverage it was 32%, and for bowel screening it was estimated to be around 35%.

Quality Innovation Productivity and Prevention Plans (QUIPP) was a programme of priority improvements across the CCG, one of which was to improve experience and uptake of patients with learning disabilities in regard to cancer screening. The target was for each GP practice to audit the uptake of cancer screening for patients with learning disabilities, and introduce improved pathways. A series of interventions were designed to help reduce these inequalities and improve access to screening of patients with learning disabilities. These included:

- improved patient pathways to enable practices to understand the additional needs of patients with learning disabilities
- development and introduction of a screening toolkit providing resources such as easy-read literature
- efforts to increase use of existing annual health checks and capacity and best interest assessments to help enable discussion of screening
- staff training and a series of communications about the need for additional time and reasonable adjustments for learning disability patients. The reasonable adjustments suggested included arranging for the patient to visit the practice or breast screening units prior to screening in order to familiarise themselves
- informing and empowering patients and carers to seek additional help for screening and participate in active discussions about screening
- improved use of mental capacity and best interest assessments
- guidance and documentation supporting best interest assessments
- guidance and documentation supporting best capacity assessments
- documentation for ceasing patients and withdrawing from screening

Best interest pathways/decision-making pathways were added as the Mental Capacity Act was not always followed. A follow-up audit in 2014 showed statistically significant increases in the use and recording of mental capacity and best interest assessments across all three screening programmes in a range of GP practices. This suggests that practices did engage with this work. There was no significant change in screening coverage in people with learning disabilities, although this may in part reflect that full change will not be apparent until a full call and recall cycle is completed for all patients. NHS Hardwick CCG is continuing to work with practices to ensure that actions are taken to reduce inequalities in screening for people with learning disabilities.

The full report about this work can be found at

[www.ihal.org.uk/adjustments/index.php?adjustment=316](http://www.ihal.org.uk/adjustments/index.php?adjustment=316)

For further information, contact Jackie Fleeman at [Jackie.fleeman@derbyshcft.nhs.uk](mailto:Jackie.fleeman@derbyshcft.nhs.uk)

### **Lancashire Learning Disability and Screening Working Group**

The Lancashire screening and immunisation team (SIT), embedded within NHS England Lancashire and Greater Manchester, recognised there were no specific pathways to encourage uptake of screening by people with learning disabilities in Lancashire. It was known, from work undertaken for the learning disability self-assessment framework, that people with a learning disability are less likely to attend for screening than the general population.

Members of the SIT held a meeting with representatives from local learning disability teams where they told them about the set-up of the various screening programmes and explored ways to make improvements.

Following this meeting, the SIT held a workshop and invited screening providers and learning disability professionals from across Lancashire as well as some self-advocates. As part of this day they were able to explore the sort of reasonable adjustments that can make a difference to individuals. It was useful to have self-advocates there as they were able to talk about their personal experiences and this was particularly valuable for the screening professionals.

As a result of this workshop, a working group has been established that aims to increase the participation rates in the three cancer screening programmes, as well as in AAA and diabetic retinopathy screening. A number of themes emerged from discussions and from these a number of general actions were identified. These included:

- all programmes to source easy-read resources to use during clinical appointments
- training required for carers and self-advocates on screening programmes who could support people prior to invitation and during the screening process
- walk through of screening programmes by service user to identify reasonable adjustments
- contact EMIS to understand capabilities to support data collection and sharing
- contact lists to be circulated so screening providers know who they can ask for advice about supporting someone with learning disabilities

There were also specific actions for each of the screening programmes. For example, exploring the possibility of including a core module about learning disabilities in the cervical sample taker training (including the update training) and planning to pilot a new bowel screening pathway in one area to assess improvement in uptake.

For further information, contact Kathryn Jones at [kathryn.jones23@nhs.net](mailto:kathryn.jones23@nhs.net)

## The ACE Programme

The ACE programme is an NHS England-led early diagnosis of cancer initiative, supported by Macmillan and Cancer Research UK. The programme began in June 2014 and is scheduled to run until March 2016. The ACE programme:

- accelerates progress
- co-ordinates implementation
- consistently evaluates best practice and innovative approaches to early diagnosis of cancer

The ACE programme aims to collect evidence on different approaches to early diagnosis of cancer in order to inform future commissioning. It incorporates 60 projects and has been organised into eight thematic clusters with each project being placed in at least one cluster. The clusters are run as learning sets to maximise peer support and learning. Each cluster is facilitated by an ACE programme team member. One of the clusters is 'screening uptake for vulnerable groups' and there are seven funded projects within this cluster. The scope and definition of each of the projects are similar in that all are exploring opportunities to improve screening uptake rates in population groups that are often described as 'hard to reach'. These projects use a mixture of GP outreach activity and community outreach in collaboration with voluntary sector organisations. Underpinning the associated activities, all projects objectively want to reduce screening inequalities, enabling screening access to be more supportive, streamlined and engaging. Two of the projects in this cluster specifically focus on people with learning disabilities:

### **NHS Cancer Screening: Improving access for people with learning disabilities in the North East and Cumbria (part of the ACE programme)**

This project aims to increase the uptake of the three national cancer screening programmes by people with learning disabilities in the North East and Cumbria. A project manager was brought into post in July 2015 for 12 months.

The planned outcomes and benefits of the programme are:

1. A CQUIN to incentivise breast screening centres to improve the offer to, and access to, eligible women with learning disabilities
2. Develop and embed a flagging system to enable screening centres to identify those people with learning disabilities in order that a reasonably adjusted screening offer can be made
3. Research regional and national best practice examples of reasonably adjusted communication materials for people with learning disabilities that include the screening pathways, invitation letter and the results letter
4. Develop standardised communication screening materials (pathways, invite and results letters) for use across the North East and Cumbria aimed at people with learning disabilities
5. Identify opportunities for workforce development to improve awareness, knowledge and skill. Targeted groups for workforce development include:

- screening provider workforce
  - primary care workforce
  - community learning disability team workforce
  - social care workforce
6. Establish a regional current data set in relation to cancer screening uptake
  7. Ensure best use of Mental Capacity Act in relation to capacity to consent and best interest decision-making in relation to cancer screening programmes
  8. Provide clarification and guidance for 'capacity to consent' in relation to implied versus informed consent for screening
  9. Identify and deliver marketing opportunities to promote cancer screening programmes among people with learning disabilities and family carers, ensuring they have accurate information and dispelling any myths
  10. Analyse the effectiveness and value of embedding 'system leadership' versus designated cancer screening posts (similar to the Cornwall model)
  11. Identify opportunities to strengthen annual health checks for people with learning disabilities in relation to cancer screening
- For further information, contact Judith Thompson at [judith.thompson1@nhs.net](mailto:judith.thompson1@nhs.net) or Julie Tucker at [Julie.tucker11@nhs.net](mailto:Julie.tucker11@nhs.net)

### **Blackburn with Darwen and East Lancashire CCGs: Improving cancer screening uptake in patients with learning disabilities (part of the ACE programme)**

The project aims to improve cancer screening uptake in patients with learning disabilities. The objectives are to:

- reduce barriers to cancer screening
- ensure patients with learning disabilities are not inadvertently or erroneously excluded from cancer screening programmes
- share good practice and advice on supporting patients with learning disabilities to undertake cancer screening
- train and educate primary healthcare staff

GP practices have been asked to perform an audit focusing on their learning disabilities population. This task involves reviewing the uptake for patients with learning disabilities who meet the criteria for the three cancer screening programmes. These figures have been shared with other colleagues at a locality group meeting (involving several other practices). The surgeries were asked to share good practices and make recommendations for improvement. At this meeting they were provided with additional information and resources to help improve uptake.

Each locality and practice is now expected to produce an action plan to improve uptake of cancer screening for patients with learning disabilities. The audit cycle will be repeated later in the year and any improvement documented. At a later stage, the results will be collated and priority factors that helped to make a difference will be summarised and recommendations made on the basis of this.

Expected outcomes include:

- improved uptake of cancer screening in patients with learning disabilities

- enhanced primary care staff awareness of challenges faced by patients with learning disabilities
- development of attitude and skill to support patients with learning disabilities
- peer review and support with enhance networking and communication between practices.
- sharing ideas and good practice
- creation of a resource pack
- building a data set on screening uptake
- the potential to spread recommendations to the wider cancer care and learning disabilities community

For further information, contact Dr Neil Smith at [neil.smith2@nhs.net](mailto:neil.smith2@nhs.net) or Angela Dunne at [angela.dunne@eastlancscg.nhs.uk](mailto:angela.dunne@eastlancscg.nhs.uk)

Some of the other ACE projects looking at vulnerable patients may also have useful findings for improving screening uptake by people with learning disabilities:

- in the North East, text messages from GPs are being used to see if they improve understanding and awareness of screening in vulnerable groups such as hearing impaired people and those with learning disabilities
- in Northumberland a project is looking at whether personal contact from GP practices, to those patients who have failed to attend their third cervical smear invite, will improve uptake

Further information about all the projects in the ACE programme can be found at <http://www.cancerresearchuk.org/health-professional/early-diagnosis-activities/ace-programme>

## Breast screening

**Table 2: Resources about breast cancer and screening**

Title	Description	Provider	Link
<b>Easy-read resources about breast cancer and screening</b>			
Breast cancer and how to spot it	A 12-page easy-read leaflet about how to spot signs of breast cancer and what to do	Public Health England	<a href="http://www.nhs.uk/be-clear-on-cancer/assets/b70-easyread-leaflet.pdf">www.nhs.uk/be-clear-on-cancer/assets/b70-easyread-leaflet.pdf</a>
Breast care for women	A 24-page booklet about checking your	CHANGE	<a href="http://www.macmillan.org.uk/Documents/Cancerinfo/EasyreadPDFs/Breastcareforwomen[P">www.macmillan.org.uk/Documents/Cancerinfo/EasyreadPDFs/Breastcareforwomen[P</a>

	breasts and breast screening		DF,517MB].pdf
My boobs and me	A 20-page booklet designed to promote breast health in women with learning disabilities	University of Ulster and Compass Advocacy Network Ltd.	<a href="http://www.easyhealth.org.uk/sites/default/files/My%20boobs%20and%20me.pdf">www.easyhealth.org.uk/sites/default/files/My%20boobs%20and%20me.pdf</a>
Breast cancer and breast screening	A 28-page easy read booklet about checking your breasts, risk factors and screening for breast cancer	Liverpool Community Health NHS Trust and Mersey Care NHS Trust	<a href="http://www.easyhealth.org.uk/sites/default/files/null/Breast%20Cancer%20%26%20Breast%20Screening.pdf">www.easyhealth.org.uk/sites/default/files/null/Breast%20Cancer%20%26%20Breast%20Screening.pdf</a>
Keep yourself healthy: A guide to examining your breasts	A 12-page easy-read guide to breast examination	NHS Health Scotland and FAIR	<a href="http://www.healthscotland.com/uploads/documents/12056-AGuideToExaminingYourBreasts.pdf">www.healthscotland.com/uploads/documents/12056-AGuideToExaminingYourBreasts.pdf</a>
Breast awareness	A three-page easy-read guide to breast awareness		<a href="http://www.easyhealth.org.uk/sites/default/files/breast_awareness.pdf">www.easyhealth.org.uk/sites/default/files/breast_awareness.pdf</a>
Taking care of your breasts	A 24-page easy-read guide to taking care of your breasts and breast screening	Breast Cancer Care	<a href="http://www.easyhealth.org.uk/sites/default/files/null/taking%20care%20of%20your%20breasts.pdf">www.easyhealth.org.uk/sites/default/files/null/taking%20care%20of%20your%20breasts.pdf</a>
Be breast aware	A 12-page easy-read leaflet about being breast aware	Cornwall and Isles of Scilly NHS Primary Care Trust	<a href="http://www.easyhealth.org.uk/sites/default/files/Be_Breast_Aware.pdf">www.easyhealth.org.uk/sites/default/files/Be_Breast_Aware.pdf</a>
Looking after your breasts	A short leaflet about looking after your	The Cheshire and Wirral Partnership NHS	<a href="http://www.easyhealth.org.uk/sites/default/files/Looking%20after%20your%20breasts.pdf">www.easyhealth.org.uk/sites/default/files/Looking%20after%20your%20breasts.pdf</a>

	breasts	Foundation Trust	
Six short films about breast screening	Series of short films about breast screening and checking your breasts	Leicestershire Partnership NHS Trust	<p>What is breast screening?  <a href="http://www.youtube.com/watch?v=HphkoUbfNQ&amp;feature=youtu.be">www.youtube.com/watch?v=HphkoUbfNQ&amp;feature=youtu.be</a></p> <p>Breast Screening: Getting Ready for Your Appointment  <a href="http://www.youtube.com/watch?v=H9hqXHH0Qok">www.youtube.com/watch?v=H9hqXHH0Qok</a></p> <p>What happens at your HOSPITAL breast screening appointment?  <a href="http://www.youtube.com/watch?v=7OVR_KP1QoA">www.youtube.com/watch?v=7OVR_KP1QoA</a></p> <p>What happens at your MOBILE UNIT breast screening appointment?  <a href="http://www.youtube.com/watch?v=vw34i0ZzUxg">www.youtube.com/watch?v=vw34i0ZzUxg</a></p> <p>Other Things You Need to Know About Breast Screening  <a href="http://www.youtube.com/watch?v=NArUArthMPM">www.youtube.com/watch?v=NArUArthMPM</a></p> <p>How to check your breasts  <a href="http://www.youtube.com/watch?v=SDw3sMSxVYE">www.youtube.com/watch?v=SDw3sMSxVYE</a></p>
NHS Breast Screening Programme: Audio and video resources	A series of audio and video resources explaining about the breast screening programme. These are not specifically aimed at people with learning disabilities	NHS Breast Screening Programme	<a href="http://www.cancerscreening.nhs.uk/breastscreen/publications/audio-video-resources.html">www.cancerscreening.nhs.uk/breastscreen/publications/audio-video-resources.html</a>
An Easy Guide to Breast Screening	An eight-page easy-read leaflet about breast screening	NHS Breast Screening Programme	<a href="http://www.cancerscreening.nhs.uk/breastscreen/publications/easy-guide-breast-screening.html">www.cancerscreening.nhs.uk/breastscreen/publications/easy-guide-breast-screening.html</a>
Breast screening	An 11-page easy read booklet about breast screening	The Foundation for People with Learning Difficulties,	<a href="http://www.easyhealth.org.uk/sites/default/files/null/Breast%20screening%20completed%20updated%20Dec%202011.pdf">www.easyhealth.org.uk/sites/default/files/null/Breast%20screening%20completed%20updated%20Dec%202011.pdf</a>

		Prodigy and Easyhealth	
Having a mammogram	A nine-page easy-read leaflet about having a mammogram	Health Awareness Group, Devon	<a href="http://www.easyhealth.org.uk/sites/default/files/Having-a-mammogram.pdf">www.easyhealth.org.uk/sites/default/files/Having-a-mammogram.pdf</a>
Breast screening presentation	A presentation on breast cancer screening	Liverpool Learning Disability Making It Happen Partnership and Liverpool PCT	<a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=206">www.improvinghealthandlives.org.uk/adjustments/?adjustment=206</a>
Breast Screening: Photo journey for women with learning disabilities	A photo journey about breast screening for women with learning disabilities	Rotherham, Doncaster and South Humber Mental Health NHS Foundation Trust	<a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=239">www.improvinghealthandlives.org.uk/adjustments/?adjustment=239</a>
<b>For carers and paid supporters</b>			
Supporting people with learning disabilities to take care of their breasts	A 20-page booklet aimed at supporters to help them assist women with learning disabilities to be breast aware	Breast Cancer Care	<a href="http://www.easyhealth.org.uk/sites/default/files/null/supporting%20people%20with%20learning%20disabilities%20to%20take%20care%20of%20their%20breasts.pdf">www.easyhealth.org.uk/sites/default/files/null/supporting%20people%20with%20learning%20disabilities%20to%20take%20care%20of%20their%20breasts.pdf</a>
<b>For screening services and learning disability health professionals</b>			
	An easy-read invitation letter for breast screening	Royal Cornwall Hospitals NHS Trust	<a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=209">www.improvinghealthandlives.org.uk/adjustments/?adjustment=209</a>
	An easy-read initiation letter targeting women in the extended age range	Royal Cornwall Hospitals NHS Trust	<a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=235">www.improvinghealthandlives.org.uk/adjustments/?adjustment=235</a>
	Did not attend	Royal Cornwall	<a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=235">www.improvinghealthandlives.org.uk/adjustments/?adjustment=235</a>

	follow up invitation letter	Hospitals NHS Trust	<a href="#">ments/?adjustment=208</a>
	Breast screening result letter. No problems detected	Royal Cornwall Hospitals NHS Trust	<a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=194">www.improvinghealthandlives.org.uk/adjustments/?adjustment=194</a>
	Breast screening recall letter. Pictures not clear	Royal Cornwall Hospitals NHS Trust	<a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=233">www.improvinghealthandlives.org.uk/adjustments/?adjustment=233</a>
	Breast screening recall letter	Royal Cornwall Hospitals NHS Trust	<a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=234">www.improvinghealthandlives.org.uk/adjustments/?adjustment=234</a>
Ceasing women from the NHS breast screening programme	System for deciding, with the woman and her GP, using Best Interests process where appropriate	NHS Cancer Screening Programmes	<a href="http://www.cancerscreening.nhs.uk/breastscreen/publications/nhsbsp-gpg7.pdf">www.cancerscreening.nhs.uk/breastscreen/publications/nhsbsp-gpg7.pdf</a>

**Table 3: Apps about breast cancer and screening**

Title	Description	Link
Keep a Breast	This app is to help women to remember to do a monthly breast exam. It teaches women how to perform a step-by-step examination and it sends an automatic reminder.	Available in Apple i-store. <a href="https://itunes.apple.com/us/app/keep-a-breast/id366745482?mt=8">https://itunes.apple.com/us/app/keep-a-breast/id366745482?mt=8</a>  Android <a href="https://play.google.com/store/apps/details?id=org.keep_a_breast.keepabreast">https://play.google.com/store/apps/details?id=org.keep_a_breast.keepabreast</a>
Breast Aware	This app aims to educate women about being breast aware and the importance of screening. There are videos that offer advice on screening and checking your breasts. There is also a reminder facility.	<a href="https://itunes.apple.com/us/app/breast-cancer-ireland-breast/id554670556?mt=8">https://itunes.apple.com/us/app/breast-cancer-ireland-breast/id554670556?mt=8</a>

## Examples of reasonable adjustments and case studies in breast cancer screening

### **Cornwall and Devon**

The liaison nurse visited a patient who had been unsuccessful at completing a breast screen in the past. The patient is very unsteady on her feet and lives with her family, including a niece. The liaison nurse was able to give the patient information on breast screening in a format she could understand. The liaison nurse also talked to the patient's family and found that the patient had a really close relationship with her niece, who was able to talk to her about the screening information. She also found out that the patient loved going for cream teas, and liked looking at pictures. The liaison nurse shared this information with the radiographer, and more time was set aside for the patient and her family. When the patient arrived she was greeted by someone with a cup of tea. The niece was able to go into the room with the patient, and the patient was reassured that her mum was just outside. She was able to sit on a chair for the screening, and there were plenty of pictures for her to look at. The screening was successful and the patient had a cream tea as promised on the way home.

Another time, the screening liaison nurse was able to support two women to have breast screening by organising for the two friends to attend together. Both had attended for screening previously but not managed it. One was particularly nervous as she had heard some negative things about the process by someone she trusted and so her friend went first. Once she had successfully had the screen she told her friend it was fine. Despite her anxiety this woman was then able to cope with the screen. The screening liaison nurses have found this approach can work very well as the women give each other courage.

From Marriott et al (2015)<sup>25</sup> Tizard Learning Disability Review

### **Newcastle upon Tyne**

In Newcastle, a collaborative team (Newcastle Hospitals NHS Foundation Trust, Newcastle Gateshead Alliance and Northumberland Tyne and Wear NHS Foundation Trust) ran a pilot project to explore how women with learning disabilities can be supported to access breast screening services.

The Breast Screening Unit, based at the Royal Victoria Infirmary, identified three GP practices willing to engage with the project whose female patients were to be called for routine breast screening during the months of July to December 2014. Access to patient records was essential to ensure that it was possible to put reasonable adjustments in place to support access to breast screening. Two of the practices agreed to allow the team to contact the individuals and the other practice contacted their own patients.

There was no additional resource to carry out this pilot.

Easy-read letters explaining the role of the learning disability nurses in the pilot, and information about the breast screening invitation were sent to the women prior to formal contact being made. The questions asked by the learning disability nurses followed a pathway to elicit further information. All the women within the pilot were assumed to have capacity to consent to participating in the breast screening programme unless

proven otherwise. The provision of accessible information was used to facilitate informed decision-making regarding participation. The majority of the women that responded to the invitation chose to have a home visit from the learning disability nurse. Some women who had previously attended breast screening chose to be interviewed over the telephone.

In total, 17 women were identified across the GP practices; 13 of these women attended breast screening (76.5%) and 11 received successful imaging (64.7%). The women highlighted the importance of having full explanations about the procedure and they reported that pictures helped them. Two women from one practice went on to attend a regional event to discuss their experiences. Carers appreciated the easy-read information they had obtained to assist in supporting the women to understand the procedure. The GP practices were very positive. They were keen to be involved and believed the time and expense was minimal in relation to helping the women access breast screening.

In terms of paid professionals, the largest impact was on the learning disability nursing team. Each woman received approximately two hours and 45 minutes allocated time from a learning disability nurse. The GP practices contributed time and money on postage but this was deemed negligible in comparison to the benefits to the patients. For the women contacted there was no evidence of any negative impact.

On reflection, the nurses believed this pilot was very valuable and worthwhile. In addition to the nurses being able to meet with the women and discuss their concerns and issues regarding breast screening, they were able to facilitate liaison with the breast screening services to provide reasonable adjustments.

The data from this pilot suggests that direct personal contact with the women by the learning disability nurses was more successful in engaging them. The pilot engaged with fewer women when a practice retained exclusive contact and, as a result, the women with learning disabilities or their carers were expected to contact the nurses. The GP practices contributed and also gained in terms of shared learning about making NHS cancer screening more accessible to people with learning disabilities. The collaborative approach enabled a positive outcome for all stakeholders but essentially held firmly the importance of equitable person centred healthcare.

The full report of this pilot project can be downloaded at

[www.ihal.org.uk/adjustments/index.php?adjustment=349](http://www.ihal.org.uk/adjustments/index.php?adjustment=349)

For further information, contact Suzanne Taylor at [suzanne.taylor@ntw.nhs.uk](mailto:suzanne.taylor@ntw.nhs.uk) or Dr Clare Scarlett at [clare.scarlett@nhs.net](mailto:clare.scarlett@nhs.net)

### **Poole Hospital NHS Foundation Trust**

In Poole, staff at the breast screening clinic have begun to contact GP surgeries to see if they can identify women who have learning disabilities so they can target them more appropriately. They identified breast cancer care booklets which have proved to be a useful resource for women with learning disabilities. They also ran a focus group with women with learning disabilities and found that none of the women wanted to attend a

hospital for their screening. This suggests that it may be better for them to attend van clinics, but there is a problem with offering extended visits to the vans. Radiographers have found that, sometimes, it is not helpful if carers strongly try to encourage a woman to have screening when she is very apprehensive.

## Cervical screening

**Table 4: Resources about cervical cancer and screening**

Title	Description	Provider	Link
<b>Easy-read resources about cervical cancer and screening</b>			
About the cervical cancer vaccination	An eight-page easy-read guide about the cervical cancer vaccination	Mencap	<a href="http://www.easyhealth.org.uk/sites/default/files/About%20the%20Cervical%20Cancer%20Vaccination.pdf">www.easyhealth.org.uk/sites/default/files/About%20the%20Cervical%20Cancer%20Vaccination.pdf</a>
An easy guide to cervical screening	An eight-page easy-read guide to cervical screening	NHS Cervical Screening Programme	<a href="http://www.cancerscreening.nhs.uk/cervical/publications/easy-guide-cervical-screening.pdf">www.cancerscreening.nhs.uk/cervical/publications/easy-guide-cervical-screening.pdf</a>
NHS Cervical Screening Programme: Audio and video resources	A series of audio and video resources explaining about the cervical screening programme. These are not specifically aimed at people with learning disabilities	NHS Cervical Screening Programme	<a href="http://www.cancerscreening.nhs.uk/cervical/publications/audio-video-resources.html">www.cancerscreening.nhs.uk/cervical/publications/audio-video-resources.html</a>
The smear test film	A film resource (16 minutes) developed to give women and their carers information about smear tests and their role in preventing cervical cancer	Jo's Cervical Cancer Trust	<a href="http://www.jostrust.org.uk/videos/smear-test-film">www.jostrust.org.uk/videos/smear-test-film</a>
Cervical screening	A 22-page easy-read guide	CHANGE	<a href="http://www.macmillan.org.uk/Documents/Cancerinfo/EasyreadPDFs/Cervicalscreening">www.macmillan.org.uk/Documents/Cancerinfo/EasyreadPDFs/Cervicalscreening</a>

	about cervical screening		<a href="#">PDF,477MB].pdf</a>
Having a cervical smear test	An easy-read presentation about having a cervical smear test	Westminster PCT	<a href="http://www.improvinghealthandlives.org.uk/adjustments/index.php?adjustment=205">www.improvinghealthandlives.org.uk/adjustments/index.php?adjustment=205</a>
Cervical screening	A photo journey about cervical screening for women with learning disabilities	Rotherham, Doncaster and South Humber Mental Health NHS Foundation Trust	<a href="http://www.improvinghealthandlives.org.uk/adjustments/index.php?adjustment=240">www.improvinghealthandlives.org.uk/adjustments/index.php?adjustment=240</a>
Cervical cancer and cervical screening	A 24-page easy-read booklet about the risks and screening for cervical cancer	Liverpool Community Health NHS Trust and Mersey Care NHS Trust	<a href="http://www.easyhealth.org.uk/sites/default/files/null/Cervical%20Cancer%20%26%20Cervical%20Screening.pdf">www.easyhealth.org.uk/sites/default/files/null/Cervical%20Cancer%20%26%20Cervical%20Screening.pdf</a>
Cervical screening	A four-page easy-read leaflet about cervical screening	Easy Health	<a href="http://www.easyhealth.org.uk/sites/default/files/cervical_screening.pdf">www.easyhealth.org.uk/sites/default/files/cervical_screening.pdf</a>
Having a smear test: what is it about?	A 20-page easy-read booklet	Jo's Cervical Cancer Trust	<a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=345">www.improvinghealthandlives.org.uk/adjustments/?adjustment=345</a>
What Happens After Cervical Screening?	A one-page easy-read leaflet explaining the possible outcomes of cervical screening	Brighton and Hove City Council and Brighton and Hove City PCT	<a href="http://www.improvinghealthandlives.org.uk/adjustments/index.php?adjustment=189">www.improvinghealthandlives.org.uk/adjustments/index.php?adjustment=189</a>
Keep yourself healthy: Do I need a smear test?	A 15-page easy-read guide designed to help women with learning disabilities to choose if they need a smear test	NHS Health Scotland and FAIR	<a href="http://www.easyhealth.org.uk/sites/default/files/null/Keep%20Yourself%20Healthy%20-%20Do%20i%20Need%20a%20Smear%20Test_0.pdf">www.easyhealth.org.uk/sites/default/files/null/Keep%20Yourself%20Healthy%20-%20Do%20i%20Need%20a%20Smear%20Test_0.pdf</a>
Keep yourself healthy: A guide to	A 16-page easy-read guide to having a smear	NHS Health Scotland and FAIR	<a href="http://www.easyhealth.org.uk/sites/default/files/null/Keep%20Yourself%20Healthy%20-%20A%20Guide%20to%20Having%20a%20Smear%20Test.pdf">www.easyhealth.org.uk/sites/default/files/null/Keep%20Yourself%20Healthy%20-%20A%20Guide%20to%20Having%20a%20Smear%20Test.pdf</a>

having a smear test	test		
The Cervical Screening Test: Information for women after treatment	A five-page easy-read guide	NHS Health Scotland and FAIR	<a href="http://www.healthscotland.com/uploads/documents/20365-Cervical%20screening%20CIN%20Easy%20read.pdf">www.healthscotland.com/uploads/documents/20365-Cervical%20screening%20CIN%20Easy%20read.pdf</a>
Cervical screening test	A short film (12 minutes) about cervical screening		<a href="http://www.easyhealth.org.uk/content/cancer-screening-test">www.easyhealth.org.uk/content/cancer-screening-test</a>
About cervical cancer	An easy-read three-page guide about the warning signs of cervical cancer	Cornwall People First	<a href="http://www.improvinghealthandlives.org.uk/adjustments/index.php?adjustment=350">www.improvinghealthandlives.org.uk/adjustments/index.php?adjustment=350</a>
<b>For screening services and learning disability health professionals</b>			
	Tool to create an easy-read invitation to cervical screening letter	NHS Lanarkshire	<a href="http://www.healthlanarkshire.co.uk/letter-templates/easy-read-cervical-screening-appointment-letter-tool">www.healthlanarkshire.co.uk/letter-templates/easy-read-cervical-screening-appointment-letter-tool</a>
	A series of 21 easy-read invitation letters for cervical screening and all possible results. The letters can be adapted for your local area.	Peninsular Community Health	<a href="http://www.improvinghealthandlives.org.uk/adjustments/index.php?adjustment=265">www.improvinghealthandlives.org.uk/adjustments/index.php?adjustment=265</a>
Guidance about best interests decisions and capacity in relation to cervical screening	The first document offers guidance on how to increase a woman's understanding of cervical screening. The second provides advice for when a woman has not understood	Peninsular Community Health	<a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=358">www.improvinghealthandlives.org.uk/adjustments/?adjustment=358</a>

	enough to make her own decision on cervical screening and needs a best interest decision made for her.		
Letter about continuing in cervical screening programme	A draft of a letter to carer/paid supporter to explain why a woman with learning disabilities will continue to receive invitations for a smear test.	Peninsular Community Health	<a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=359">www.improvinghealthandlives.org.uk/adjustments/?adjustment=359</a>
Cervical cytology screening for women with learning disabilities	A report detailing the actions that were taken to increase the uptake and understanding of cervical smears amongst women with a learning disability following two health equity audits in the area. It contains many ideas that could be helpful to other areas.	NHS Sefton	<a href="http://www.improvinghealthandlives.org.uk/adjustments/index.php?adjustment=204">www.improvinghealthandlives.org.uk/adjustments/index.php?adjustment=204</a>
Cervical Screening for Women with Learning Disabilities	Information aimed at primary healthcare teams	2gether NHS Trust	<a href="http://www.2gether.nhs.uk/files/cervicalscreening.pdf">www.2gether.nhs.uk/files/cervicalscreening.pdf</a>

## Examples of reasonable adjustments and case studies in cervical cancer screening

### **Cervical screening and best interests decision-making**

Jane is a young woman with profound and multiple learning disabilities who lacks capacity to consent to a cervical smear. Her family, together with her healthcare 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. This has now happened twice. Jane has not been upset by this and her family consider it to be very good practice for women with profound and multiple learning disabilities.

### **Developing good practice guidance to improve access to cervical screening for GPs in Sussex**

In Sussex, work to develop best practice guidance was completed in summer 2012. The work involved a range of professionals and services including public health professionals; primary care professionals – GPs and practice nurses; screening support services; hospital cytology and colposcopy services; learning disability health facilitation and community teams; and the regional Local Medical Councils.

The aim of the guidance is to offer a step-by-step process outlining reasonable adjustments that can be made, and offering information to support a consistent approach to offering and delivering cervical screening, including assessing capacity, and making best interest decisions.

The guidance includes signposting to useful resources, and also incorporates a locally developed easy-read resource about what happens after screening takes place. The guidance has been agreed by the three Local Medical Councils and was first distributed across Sussex in summer 2012. At that time, the guidance was also adapted for use in Surrey and Kent, with core content remaining the same but appropriate local service information included for each county.

In summer 2014, the Sussex version of the guidance was updated with new information and resources and re-circulated to GP practices and learning disability services. It was shared with key contacts in Surrey for them to adapt further as required.

For further information, contact Natalie Winterton at [natalie.winterton@brighton-hove.gcsx.gov.uk](mailto:natalie.winterton@brighton-hove.gcsx.gov.uk) or Corinne Nikolova at [corinne.nikolova@nhs.net](mailto:corinne.nikolova@nhs.net)

### **Devon and Cornwall**

In Devon and Cornwall, the screening liaison nurses are developing a 'no permanent ceasing policy' for women who do not have the capacity to make their own decision around cervical screening. Alternatives to ceasing are to close or suspend a current screening episode. The nurses have created an electronic pack about cervical screening for women with learning disabilities, which they share with GPs. This includes:

- capacity guidance and best interest guidance (available at [www.ihal.org.uk/adjustments/?adjustment=358](http://www.ihal.org.uk/adjustments/?adjustment=358))
- easy-read leaflet about cervical cancer
- two easy-read guides to having a smear test
- a draft of a letter to carer/paid supporter to explain why the woman will continue to receive invitations for a smear test (available at [www.ihal.org.uk/adjustments/?adjustment=359](http://www.ihal.org.uk/adjustments/?adjustment=359))

The aim is to keep the subject on everyone's agenda and to ensure that women who cannot manage screening are kept as safe as possible. From the nurses' experience, it is helpful to keep talking about screening because this can help to desensitise women. Services should not be taking decisions that affect women for the rest of their lives. It is good practice to revisit a best interest decision about screening as the situation may have changed over a three- to five-year period.

Even if it is still decided that it is not in the best interests of the woman to have a smear test, the appointment provides an opportunity for information on signs and symptoms of cervical cancer to be given to carers/supporters, allows up to date information to be shared and ensures that any new supporters are updated. This is important because supporters can change frequently. If women are permanently ceased, then they may not benefit from any future medical advances as they will be off everyone's radar with regards to cervical screening.

For further information, contact Deborah Rees at [deborah.rees@nhs.net](mailto:deborah.rees@nhs.net) or Sharon Ashby at [sharonashby@nhs.net](mailto:sharonashby@nhs.net)

### **Case studies from Cornwall**

The liaison nurse was contacted by the practice nurse about a patient who had been attending for cervical screening for many years, but had never managed to complete a screen, despite the practice nurse trying all the usual ways of explaining and attempting the smear test. The liaison nurse visited the patient in their own home a few times to get to know her. The patient explained that she really wanted to have the screening, but became anxious and unable to relax so the test could not be completed. The liaison nurse suggested the possibility of some medication to help her relax. With the agreement of her GP, the liaison nurse was able to put together a plan with the patient, the practice nurse, and the carer from the day centre, and the patient had a successful screen.

The liaison nurse received a letter from a doctor at the family planning clinic as she had a patient who wanted to know about cervical screening. The liaison nurse phoned the patient, and found that the staff had questioned whether she needed a screen. The mother was not happy about this. The liaison nurse made an appointment to visit the patient and her mother. During the visit the nurse showed the patient an easy-read guide to cervical screening and talked about why it was an important test to do, if she could manage it. She showed her the equipment used, and talked about the importance of being relaxed and lying in the right position. She suggested practising this in the privacy of her own room so that she got used to how it felt. The patient said she would

give it a go and an appointment for her screen was made with the liaison nurse to support her. The patient managed her screening without problems.  
From Marriott et al (2015)<sup>25</sup> Tizard Learning Disability Review.

### **Mid-Devon: Reasonable adjustments regarding cervical screening**

The primary care liaison nurse in Mid-Devon worked with a sample group of 21 women who were known to social services, and who had not attended a cervical screening appointment for five years or more. She visited all the women to talk to them about why they had not attended. Ten were clear that they did not want a smear, one had had a total hysterectomy, and some did not have the capacity to consent and so required a best interest decision. However, five women decided to have a smear test, and were supported to have one by the nurse. The project demonstrated that a letter alone is not enough. The women would have continued to ignore the letters without support, encouragement and guidance.

The nurse used a range of aids to help the women understand about cervical screening including the 'keeping healthy down below' guide, and the equipment used when taking a smear. She has realised it is important to find out what terminology the women use about their own body parts so she can then use vocabulary they understand.

Checking what sort of sanitary protection women use can be helpful, as women generally find it easier to have a smear test if they use tampons rather than towels. Teaching a woman to use tampons not only helps them to be exactly aware where the speculum is to be inserted but also really helps them to go ahead with the smear test. The nurse uses a rag doll that has the correct body parts so that she can see them safely insert tampons first. It is helpful to operate the speculum so that women get used to the noise it makes, and to get women to assume the position they will be in when they have the smear taken, as this can make women feel vulnerable, and it is better to rehearse this prior to the appointment. Visiting the GP surgery and meeting the nurse that will do the smear test before the appointment can also be helpful. It may sometimes be necessary to have a few visits to build up trust and it can be helpful for the woman to lie on the examination couch which in itself can be daunting. This will help prepare her for the day of the appointment.

For further information, contact Julie Moules at [julie.moules@nhs.net](mailto:julie.moules@nhs.net)

### **SEQOL team, Swindon**

In Swindon, all cervical smear training for GPs and practice nurses includes a session about people with learning disabilities. This session is delivered by the Community Learning Disability Team (SEQOL). It explains what reasonable adjustments are and the need for them and provides an opportunity for the attendees to look at accessible resources that they could use. There is also the chance to discuss any issues or concerns that people have. For further information, contact Elaine Scott at [elaine.scott6@nhs.net](mailto:elaine.scott6@nhs.net)

## Bowel screening

**Table 5: Resources about bowel cancer and screening**

<b>Title</b>	<b>Description</b>	<b>Provider</b>	<b>Link</b>
<b>Easy-read resources about bowel cancer and screening</b>			
An Easy Guide to Bowel Cancer Screening	A 16-page easy-read guide about bowel cancer screening	NHS Bowel Screening Programme	<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>
Bowel cancer and bowel screening	A 24-page easy-read booklet about the risks and screening for bowel cancer	Liverpool Community Health NHS Trust and Mersey Care NHS Trust	<a href="http://www.easyhealth.org.uk/sites/default/files/null/Bowel%20Cancer%20%26%20Bowel%20Screening.pdf">www.easyhealth.org.uk/sites/default/files/null/Bowel%20Cancer%20%26%20Bowel%20Screening.pdf</a>
Bowel cancer	A short easy-read leaflet about bowel cancer	South Staffordshire Healthcare NHS Foundation Trust	<a href="http://www.easyhealth.org.uk/sites/default/files/null/bowel%20cancer.pdf">www.easyhealth.org.uk/sites/default/files/null/bowel%20cancer.pdf</a>
Bowel screening	A 16-page easy-read booklet about bowel cancer screening	Cheshire and Merseyside Bowel Cancer Screening Programme	<a href="http://www.easyhealth.org.uk/sites/default/files/null/bowel%20screening.pdf">www.easyhealth.org.uk/sites/default/files/null/bowel%20screening.pdf</a>
Bowel health and screening: A resource for people with learning disabilities	A 24-page easy-read report	Bowel Cancer UK - Scotland	<a href="http://www.bowelcanceruk.org.uk/media/171227/923_bcuk_scottish_b5.pdf">www.bowelcanceruk.org.uk/media/171227/923_bcuk_scottish_b5.pdf</a>
Bowel cancer screening audio and video resources	A series of audio and video resources explaining about the bowel screening programme. These are not specifically aimed at people with learning disabilities.	NHS Bowel Screening Programme	<a href="http://www.cancerscreening.nhs.uk/bowel/publications/audio-video-resources.html">www.cancerscreening.nhs.uk/bowel/publications/audio-video-resources.html</a>
DVD Animation Bowel	This is a short (three minute) animated	NHS Bowel Screening Programme	You can contact your local hub for a copy on the free phone number 0800 707 60 60

Cancer Screening	cartoon showing how to complete the kit.		
Bowel cancer screening test instructions	An easy-read leaflet describing how to use the bowel cancer screening test	Derby Hospitals NHS Foundation Trust	<a href="http://www.improvinghealthandlives.org.uk/adjustments/index.php?adjustment=188">www.improvinghealthandlives.org.uk/adjustments/index.php?adjustment=188</a>
Bowel cancer presentation	An easy-read presentation about the signs and symptoms of bowel cancer and how to take part in screening	Liverpool learning disability making it happen partnership	<a href="http://www.improvinghealthandlives.org.uk/adjustments/index.php?adjustment=207">www.improvinghealthandlives.org.uk/adjustments/index.php?adjustment=207</a>
Five short films about bowel screening	Series of short films about bowel screening	Leicestershire, Northamptonshire & Rutland Learning Disability Cancer Screening Strategic Working Group	<p>Why do I need to have bowel screening?  <a href="http://www.easyhealth.org.uk/content/part-1-why-do-i-need-have-bowel-screening">www.easyhealth.org.uk/content/part-1-why-do-i-need-have-bowel-screening</a></p> <p>Doing your test kit at home  <a href="http://www.easyhealth.org.uk/content/part-2-doing-your-test-kit-home">www.easyhealth.org.uk/content/part-2-doing-your-test-kit-home</a></p> <p>The appointment with the nurse at the Screening Centre  <a href="http://www.easyhealth.org.uk/content/part-3-appointment-nurse-screening-centre">www.easyhealth.org.uk/content/part-3-appointment-nurse-screening-centre</a></p> <p>Getting ready for the colonoscopy  <a href="http://www.easyhealth.org.uk/content/part-4-getting-ready-colonoscopy">www.easyhealth.org.uk/content/part-4-getting-ready-colonoscopy</a></p> <p>The colonoscopy  <a href="http://www.easyhealth.org.uk/content/part-5-colonoscopy">www.easyhealth.org.uk/content/part-5-colonoscopy</a></p>
Having a colonoscopy	A 24-page easy-read guide to having a colonoscopy	CHANGE	<a href="http://www.macmillan.org.uk/Documents/Cancerinfo/EasyreadPDFs/Havingacolonoscopy[PDF,512MB].pdf">www.macmillan.org.uk/Documents/Cancerinfo/EasyreadPDFs/Havingacolonoscopy[PDF,512MB].pdf</a>
An easy guide to having a colonoscopy	A 15-page easy-read guide to having a colonoscopy	NHS Bowel Screening Programme	<a href="http://www.cancerscreening.nhs.uk/bowel/publications/nhsbcsp-colonoscopy-learning-disabilities-leaflet.pdf">www.cancerscreening.nhs.uk/bowel/publications/nhsbcsp-colonoscopy-learning-disabilities-leaflet.pdf</a>

<b>For carers and paid supporters</b>			
Bowel health and screening: Resource for carers of people with learning disabilities	A 12-page guide aimed at supporters to help them assist people with learning disabilities to have good bowel health	Bowel Cancer UK - Scotland	<a href="http://www.bowelcanceruk.org.uk/media/171230/923_bcuk_scottish_carerguide.pdf">www.bowelcanceruk.org.uk/media/171230/923_bcuk_scottish_carerguide.pdf</a>
<b>For screening services and learning disability health professionals</b>			
Bowel Screening Wales Learning Disability Pack	This pack is designed to be used by the health professional to assist people with learning disabilities to make an informed choice about screening. There is a pack for professionals to work through as well as a series of presentations to use with people with learning disabilities.	Bowel Screening Wales	<a href="http://www.bowelscreening.wales.nhs.uk/learning-disability-packs">www.bowelscreening.wales.nhs.uk/learning-disability-packs</a>

### Examples of reasonable adjustments and case studies in bowel cancer screening

#### **Cornwall and Devon**

The screening liaison nurse visited a patient who had not participated in bowel screening – the carer had reported that he was not keen to do so. The liaison nurse used an easy-read booklet to explain what the test looked like and why it was important. She showed the patient how to complete the kit, using the easy read guide, some chocolate spread and a test kit.

The patient agreed to take part, and so did another person living in the home. The carer also asked if the liaison nurse could leave the information for another person she supported and asked if she could order a kit for her too. They all wanted to participate once they had understood what the test was looking for and also that it was not difficult to do.

In another case, the liaison nurse was contacted by the GP surgery to say that they had a patient who had not ever completed his bowel cancer screening kit. The surgery knew very little about the patient and the contact details they had for him were out of date. The liaison nurse investigated this and visited the patient at home to discuss the bowel screening process. The patient lives alone and has some support from a brother who

lives locally. The liaison nurse explained why people are invited for bowel screening and how the kit is completed. He was able to use the trial kit while the nurse was there and he was able to manage this by himself. He decided he would like to take part in the screening. The only aspect he had difficulty with was writing the date on the kit and getting it posted. The liaison nurse spoke to his brother whilst she was still at the patient's home and he said she could fill the dates in and post the kit. With this small amount of support the patient was able to successfully complete his bowel screening. From Marriott et al (2015)<sup>25</sup> Tizard Learning Disability Review

### **Wolverhampton**

In Wolverhampton, there is a shared pathway for bowel scope screening. In conjunction with the bowel scope nurses at Royal Wolverhampton Hospitals Trust, reasonable adjustments have been introduced to help patients with learning disabilities.

Generally, the bowel scope screening programme entails self-administration of an enema at home prior to attending bowel scope. However, people with learning disabilities can now have their enema at the hospital prior to the procedure. If there are any concerns about the person's capacity to consent to the screening, the learning disability nurses visit the patient at home to talk through specifically developed easy-read information/pictures to support the process of establishing capacity. They will then notify the hospital team accordingly. The learning disability nurses are able to take more time explaining the procedure to the patient so that capacity and consent can be more accurately determined. The same process is applied to screening for abdominal aortic aneurysms.

For further information, contact Diane Webb at [diane.webb@bcpft.nhs.uk](mailto:diane.webb@bcpft.nhs.uk)

### **Bowel Health Awareness and Screening Project, Bridgewater Community Healthcare NHS Foundation Trust/Wigan Adult Learning Disability Service**

This project has been running since November 2014 and aims to increase the uptake of the NHS Bowel Screening Programme among patients with a learning disability, aged 60 to 74. General practices are encouraged to refer patients that have a learning disability that have not completed bowel screening kits to the Adult Learning Disability Service. The patients are then supported to make an informed choice about accessing bowel screening.

The Wigan Adult Learning Disability Team, which is part of Bridgewater Community Healthcare NHS Foundation Trust, worked with the Greater Manchester Bowel Movement and the charity Bowel Cancer UK to produce an easy-read resource called *Good Bowel Health Awareness*. This is a pictorial, easy-read booklet that can be used as a presentation or in one-to-one sessions. It focuses on basic anatomy of the bowel, healthy eating and lifestyle changes and has information about signs and symptoms of bowel problems and bowel screening. The team has also developed a bowel health

awareness toolkit that contains training materials, booklets, flyers, evaluations and GP invitation letters.

These resources can be used during individual sessions with patients with a learning disability and also in group bowel health awareness sessions. They have developed a session aimed at carers, which provides more in depth information. Patients are offered bowel health awareness sessions and the learning disability team facilitate access to the screening programme for those patients who decide they want to have bowel screening.

One patient they have supported is Betty Charlesworth, a 68-year-old woman with a learning and physical disability who had not returned any of the three screening kits she had been sent during the past six years. Betty lives independently in her own flat with some home care support. Once Betty was registered with the team's Bowel Screening Project she was offered one-to-one sessions and the easy-read resources, which enabled her to make her mind up to go ahead with screening. The NHS bowel screening hub was contacted to request that a kit be sent to Betty and she was then supported to complete the bowel screening kit as directed and send it back to the hub. It was also identified that the home care team that support Betty with her food shopping would benefit from advice and guidance about healthy eating. Carers were given a meal planner that includes guidance to ensure that Betty has healthy options at meal times and improves her bowel health.

For further information, contact Claire Wilmot, Clinical Manager, Adult Learning Disability Service at [claire.wilmot@bridgewater.nhs.uk](mailto:claire.wilmot@bridgewater.nhs.uk)

### **South Tyneside NHS Foundation Trust community Learning Disability Service**

Data from South Tyneside and Gateshead showed that of the people with learning disabilities they could identify as eligible for bowel screening only 47% had participated in a bowel screening test. In addition, only 23% of people had had the issue discussed with a member of the Community Learning Disability Team.

The Community Learning Disability service therefore decided to undertake an intensive project to implement ways to improve the uptake of bowel screening. A project co-ordinator was appointed to lead the project and to collect and collate the data. The aim was to increase screening uptake by at least 10% in the first 12 weeks.

Learning disability user groups were contacted along with cancer screening leads, the Community Learning Disability multidisciplinary team, carers and families to explore their views and consider any reasons why people with a learning disability may not take the bowel screening test. Five barriers were identified:

- screening letters were not user friendly
- people felt embarrassed often failing to understand what was required to undertake the test
- issues with mental capacity were identified
- no clear links between cancer screening hubs, general practices or Community Learning Disability services to identify those who had a learning disability

- no clear pathway between GPs and Community Learning Disability services when those with a learning disability were 'non responders' to the NHS bowel screening letters

Work to address these issues included the development of easy-read letters and a training pack for the Community Learning Disabilities Team to help members provide appropriate support. A pathway for non-responders was developed between the Community Learning Disabilities Team and GP practices to provide about processes and communications. At the end of the 12-week project, the vast majority of people with learning disabilities eligible for bowel screening had had the issue discussed with them and 61% undertook bowel screening. This exceeded the target of a 10% increase and also exceeded the uptake rate by the general population. Of those who participated in screening, 15% required follow-up colonoscopy due to the presence of occult blood. These individuals had support from the Community Learning Disabilities Nursing Team to understand this process.

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