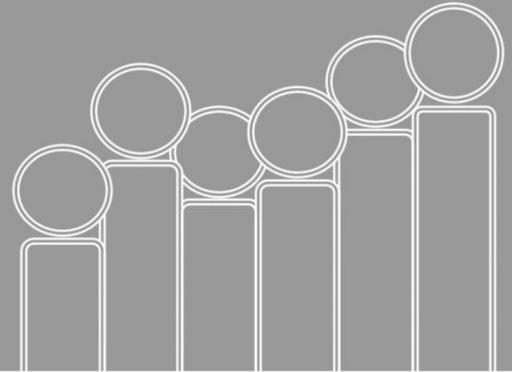




Improving Health and Lives:  
Learning Disabilities Observatory

# Making Reasonable Adjustments to Cancer Screening

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Cornwall Cancer Screening Team



*Supported by the Department of Health*



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## Introduction

The Learning Disabilities Public Health Observatory (LDPHO: [www.ihal.org.uk](http://www.ihal.org.uk)) is one of the small number of specialist public health observatories that cover England. It was established by the Department of Health in April 2010 in response a recommendation made by the *Michael's Inquiry* into access to health care for people with learning disabilities.<sup>1</sup> The LDPHO is a partnership between the North East Public Health Observatory (the contract holder), the Centre for Disability Research at Lancaster University and the National Development Team for Inclusion.

Learning disability refers to a significant general impairment in intellectual functioning (typically defined as having an IQ of less than 70) that is acquired during childhood.<sup>2</sup> In England approximately 1.2 million people have learning disabilities (300,000 children, 900,000 adults).<sup>3</sup>

People with learning disabilities have significantly higher rates of mortality and morbidity than their non-disabled peers.<sup>4-6</sup> Whilst the incidence of deaths from most cancers in the UK among people with learning disabilities is currently lower than the general population, this is likely to change in the coming years as a result of their increased their longevity.<sup>7-9</sup> People with learning disabilities have proportionally higher rates of gastrointestinal cancer,<sup>7-9</sup> and children with Down's syndrome are at particularly high risk of leukaemia.<sup>10,11</sup> Research has highlighted deficiencies in relation to breast cancer screening for women with learning disability.<sup>12</sup> People with learning disabilities with cancer are less likely to: be informed of their diagnosis and prognosis; be given pain relief; be involved in decisions about their care and are less likely to receive palliative care.<sup>13-15</sup>

The importance of actively addressing the health inequalities experienced by people with learning disabilities has been highlighted by recent reports from: the Disability Rights Commission;<sup>16</sup> Sir Jonathan Michael's independent inquiry into the healthcare of people with learning disabilities;<sup>1</sup> the Parliamentary, Health Services and Local Government Ombudsman;<sup>17</sup> the House of Lords and House of Commons Joint Committee on Human Rights;<sup>18</sup> the Department of Health;<sup>19-23</sup> Mencap.<sup>24, 25</sup>

It is a statutory requirement under the Equality Act 2010 and the NHS and Social Care Act 2008 that public sector agencies make 'reasonable adjustments' to their practice that will make them as accessible and effective as they would be for people without disabilities. Reasonable adjustments include removing physical barriers to accessing health services, but importantly also include making whatever alterations are necessary to policies, procedures, staff training and service delivery to ensure that they work equally well for people with learning disabilities.<sup>26-30</sup> A database of 'reasonable adjustments' made by health agencies is maintained by the LDPHO.<sup>31 a</sup>

This legal duty for health services is 'anticipatory'. This means that health service organisations are required to consider in advance what adjustments people with learning disabilities will require, rather than waiting until people with learning disabilities attempt to use health services to put reasonable adjustments into place.

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<sup>a</sup> <http://www.improvinghealthandlives.org.uk/adjustments/>

The recent NHS Equality Delivery System provides a framework of questions for all parts of the health service in relation to all protected groups. Its recently published 'Grades Manual' sets out four overarching goals and invites NHS organisations to identify evidence about their progress in relation to these.<sup>32</sup> The first two (better health outcomes for all, and improved patient access and experience) ask healthcare organisations to look for evidence of how members of protected groups (the term used in the Equality Act) are faring in terms of their health and their use of health services. Answering these questions comprehensively, systematically and regularly requires that health service information systems identify people in the protected groups so comparisons can be made. In addition to exploring substantive questions that should be asked, the Equality Delivery System also discusses the need to discuss the ways arrangements are made to do this for members of all the protected groups, with the people in those groups, themselves.

More generally, the importance of strategies to reduce health inequalities taking account of the specific situation and characteristics of high risk and marginal groups (such as people with learning disabilities) has been highlighted by Health Select Committee, NICE and The Marmot Review.<sup>33-35</sup> The UK has entered into international obligations to progressively realise the right to health of people with disabilities and to take specific measures to address the health inequalities faced by vulnerable groups such as people with learning disabilities.<sup>36 37</sup>

## 1. The national cancer screening programmes

This information has been taken from the NHS Cancer Screening Programmes website. For further information please see: <http://www.cancerscreening.nhs.uk/>

There are three national cancer screening programmes:

- Breast screening, once every three years (women 50-69 years old – but now being gradually extended to women from age 47- 73).
- Cervical screening, once every three years (women 25-49 years old), and once every five years (women 50-64 years old).
- Bowel screening every two years (men and women 60-69 years old, but in process of being extended up to the age of 75).

Informed Choice about Cancer Screening is currently leading a review of information sent to people invited for cancer screening, on behalf of NHS Cancer Screening Programmes. They are due to report in November 2012. For further information see: [www.informedchoiceaboutcancerscreening.org/](http://www.informedchoiceaboutcancerscreening.org/)

### 1.1 Breast screening

The NHS Breast Screening Programme is coordinated from the national office of the NHS Cancer Screening Programmes, based in Sheffield. It sets national standards which are monitored through a national quality assurance network. There are 80 breast screening centres across England, each inviting a defined population of eligible women (aged 50 to 69) through their GP practices. The NHS Call and Recall System holds up-to-date lists of women compiled from GP records, and records levels of attendance and non-attendance. The programme is a rolling one which invites women from GP practices in turn. Not every woman receives an invitation as soon as she is 50, but will receive an invitation before her 53rd birthday (but see above). Women are invited to a specialised screening unit, which can be hospital based, mobile, or permanently based in another convenient location such as a shopping centre.

### 1.2 Cervical screening

The national office of the NHS Cancer Screening Programmes is responsible for improving the overall performance of the cervical screening programme. It works to:

- develop systems and guidelines for cervical screening throughout the country;
- identify important policy issues and help to resolve them, and improve communications within the programme and to women.

Currently every Primary Care Trust (PCT) has a nominated person responsible for its cervical screening programme and implementing the national guidelines.

The NHS Call and Recall System holds a list of all patients registered with a GP in the area it covers. It sends the list of women due for screening to each GP to check the records (for correct name and address and in case it is not appropriate for them to be invited), sends invitation letters and reminder letters, and sends the result letter.

### **1.3 Bowel screening**

There are six programme hubs:

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

Each hub is responsible for coordinating the programme in their area and works with up to 20 local screening centres. For further information see:

<http://www.cancerscreening.nhs.uk/bowel/screening-centres-hubs.html> . The hubs send out faecal occult blood (FOB) test kits, analyse samples and send out results.

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

If blood is detected in the sample returned, the individual will be invited for a colonoscopy. Reasonable adjustments regarding colonoscopies are not covered in this report. However the procedure carries a slight risk of bowel perforation, so issues regarding informed consent/best interest decision making should be carefully considered.

### **1.4 Recommendations to national cancer screening services**

The LDPHO is putting forward recommendations to the national cancer screening programmes regarding the identification of people with learning disabilities in NHS Cancer Screening databases, enabling reasonable adjustments to be put in place systematically. The LDPHO will report progress on this separately.

### 3. Work on cancer screening pathways in Cornwall

Cornwall is working with the LDPHO as one of their local partners. For further information on local partners see: [www.ihal.org.uk/areas](http://www.ihal.org.uk/areas). In 2007/8, the PCT undertook a health equity audit to assess levels of access to local primary care services. The audit:

- Extrapolated national prevalence data back to county and practice levels.
- Extrapolated unmet healthcare need from a survey of GP practices
- Triangulated service provision sources (Department of Adult Social Care, Cornwall Partnership Trust Learning Disability Community Teams and Children, Young People and Family Services data) to show the level of service provision received and the level of partnership working achieved for a client group that can have difficulties in communicating their needs

For further information see: [www.ihal.org.uk/gsf.php5?f=7888&fv=8292](http://www.ihal.org.uk/gsf.php5?f=7888&fv=8292). The audit found that there was a low uptake of cervical and breast screening among women with a learning disability (bowel screening was not covered in the audit). The report recommended that:

- The GPs and practice staff to work with the Lead Public Health Consultant for this area and other partners to improve uptake;
- The Primary Care Liaison Nurses will work across public health, primary care and secondary care to facilitate access to screening and to establish locally what additional or different support and preparation may be needed to enable women with severe learning disabilities to access the cervical and breast screening programmes. This would include accurate registers so targeted health promotion work could be done with this group.

The PCT and Strategic Health Authority recognised screening as a local and regional priority. Following the success of the Primary Care Liaison Nursing Service in improving access to primary care services in Cornwall, it was decided to take a similar liaison approach to improving the access and uptake of screening and employed two additional Liaison Nurses who could work exclusively on screening.

## 4. Consent and capacity

All screening programmes require participants to give informed consent prior to testing. The Mental Capacity Act 2005<sup>38</sup> sets out the law regarding capacity and consent and is underpinned by five key principles which 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.

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. However, 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 staff.

## 5. How can local services tell if they are making a difference?

An important part of every public health initiative is monitoring progress. This has two parts. Ultimately the goal would be to ask whether the programme aims, reducing deaths and improving the quality of survival by identifying and treating cancers at an early stage, are being achieved. Measuring these is the process of 'outcome monitoring'. It is important, but in programmes of this type it will take five to ten years before success in these areas can be properly evaluated. A complimentary approach is 'process monitoring'. This involves monitoring such issues as how many of those the programme is intended to target receive screening, how many of those with positive test results are followed up promptly, efficiently and appropriately and whether these process outcomes are delivered equitably across the population.

General Practice information systems, the electronic case-notes kept by GPs and other clinical staff working in general practice settings, are increasingly being used to assist monitoring. NHS commissioning organisations are able, with agreement from Practices, to submit queries to practice information systems. Once approved in the practice, these queries run on the GPs' computer systems and numerical answers are returned to the commissioning organisation through the NHSnet, a secure national computer network used for clinical information transmission. The principal use of this system is to answer statistical questions about patient demographics, clinical conditions and care delivered. The system is used to measure compliance by practices with the clinical standards for which bonuses are paid through the Quality and Outcome Framework (QOF). It also provides a potentially useful way to monitor many local health interventions. It is particularly relevant to the health and healthcare of people with learning disabilities because QOF rules require GPs to maintain a register of those with learning disabilities registered with their practice. To make the process of monitoring transparent, QOF business rules provide a list of the clinical terms which have been agreed to indicate this. This is the subject of another IHaL report which will be published later in 2012.

There are three simple statistical questions which could be asked to monitor completeness of coverage of screening programmes locally. Two are essential, one useful. In each case for proper monitoring of equality issues, it is necessary to record the situation for people with and without learning disabilities (or any other 'protected characteristic' under the 2010 Equality Act).

The two essential questions are:

1. How many people are in the target groups for screening?
2. How many people in the target groups received screening?

These are not completely simple questions. The first question is defined just in demographic terms for bowel and breast cancer screening: people aged 60 to 69 for the former, women aged 50 to 69 for the latter. For cervical cancer the broad target is women aged 25 to 64, but there is a further complication as those who have had their uterus removed are excluded. GP practice information systems can report total numbers in all these categories. Identifying numbers of individuals in specific age/sex groups is relatively simple. Because coverage of cervical cancer screening has been a target for QOF bonus payments, QOF business rules have also been developed to establish how

the exemption in terms of hysterectomy should be defined.<sup>39</sup> Note that there are two types of exemption: those in terms of physical relevance—(in this case the QOF business rules term ‘hyst\_cod’) -these should be followed in public health analyses of coverage, and those in terms of unwillingness of the patient, or failure to attend (in this case the QOF business rules term ‘cytextc\_cod’) which should not.

Definitions for asking information systems how many registered patients have had cervical screening tests are published in the QOF business rules. Coverage of breast and bowel cancer screening have not yet been the subject of QOF payments, so this definitional work has not been done by the NHS Information Centre team for these conditions. However, in both cases records of the screening tests can be identified in GP practice information systems with sufficient clarity for monitoring to be feasible. The question to be asked is regarding the number of people in the target group who, at a reference date (usually March 31st), have had a screening test within the required time interval (remembering that this changes at age 50 for cervical screening in women). This is never likely to be 100% as individuals who have only recently entered the screening window are likely to have low coverage.

The third question considered in monitoring the process of screening is the invitation. If a group of people has a low rate of coverage, it may be because they did not attend, but it may also be because they were not invited. In practice, definitions of invitations for screening are not recorded on GP systems in a sufficiently consistent way to support monitoring of this.

Whilst regular monitoring of coverage of screening (the proportion of the target population screened) is clearly feasible, to date few PCTs have established effective systems for this specifically for people with learning disabilities. Coverage of these tests has been raised as a general issue in the annual Learning Disabilities Self-Assessment Framework for a number of years: [http://www.improvinghealthandlives.org.uk/projects/self\\_assessment/](http://www.improvinghealthandlives.org.uk/projects/self_assessment/). In 2011, in at least one Strategic Health Authority area, local communities were asked how many people with learning disabilities had had cervical and breast screening tests. But target population sizes were not collected in parallel, making the numbers screened hard to interpret. In some cases the time windows were also not precisely followed. The national standard template for the local Self-Assessment for 2012 includes the questions set out in box 1. This should provide a more satisfactory view of the position where PCTs are able to provide the answers. However data gathering is only the first step. In one Strategic Health Authority area where the question was asked, 60% of PCTs were able to report a number for people with learning disability who had had cervical or breast screening, 50% a figure for bowel cancer screening. Two reported zero figures for breast screening and four zero figures for bowel cancer screening. If PCTs believe these figures to be correct they have a duty to be acting on them, illustrating why commissioners need to establish a monitoring system for access to screening.

Box 1. Monitoring questions for cancer screening included in 2012 national Self-Assessment Framework template.

- a. How many women are there with learning disability in the age range 25 to 64 inclusive and who have not had a hysterectomy (ie are eligible for cervical cancer screening)?
- b. How many of the women in 10a have had a cervical smear test in the last three years if aged under 50 or else in the last 5 years?
- c. How many women are there with learning disability in the age range 50 to 69 inclusive (i.e., are eligible for breast cancer screening)?
- d. How many of the women in 10c have had mammographic screening in the last three years?
- e. How many people are there with learning disability in the age range 60 to 69 inclusive (i.e., are eligible for bowel cancer screening)?
- f. How many of the people in 10e have satisfactorily completed bowel cancer screening in the last two years?

## 6. Resources

The following four sub-sections include cancer screening pathways which may be adapted to local circumstances, some examples from practice, and links to easy read resources which can be found on the national cancer screening website: [www.cancerscreening.nhs.uk](http://www.cancerscreening.nhs.uk) the easyhealth site: [www.easyhealth.org.uk](http://www.easyhealth.org.uk) the picture of health site: [www.apictureofhealth.southwest.nhs.uk](http://www.apictureofhealth.southwest.nhs.uk) and the LDPHO reasonable adjustments database [www.ihal.org.uk/adjustments/](http://www.ihal.org.uk/adjustments/)

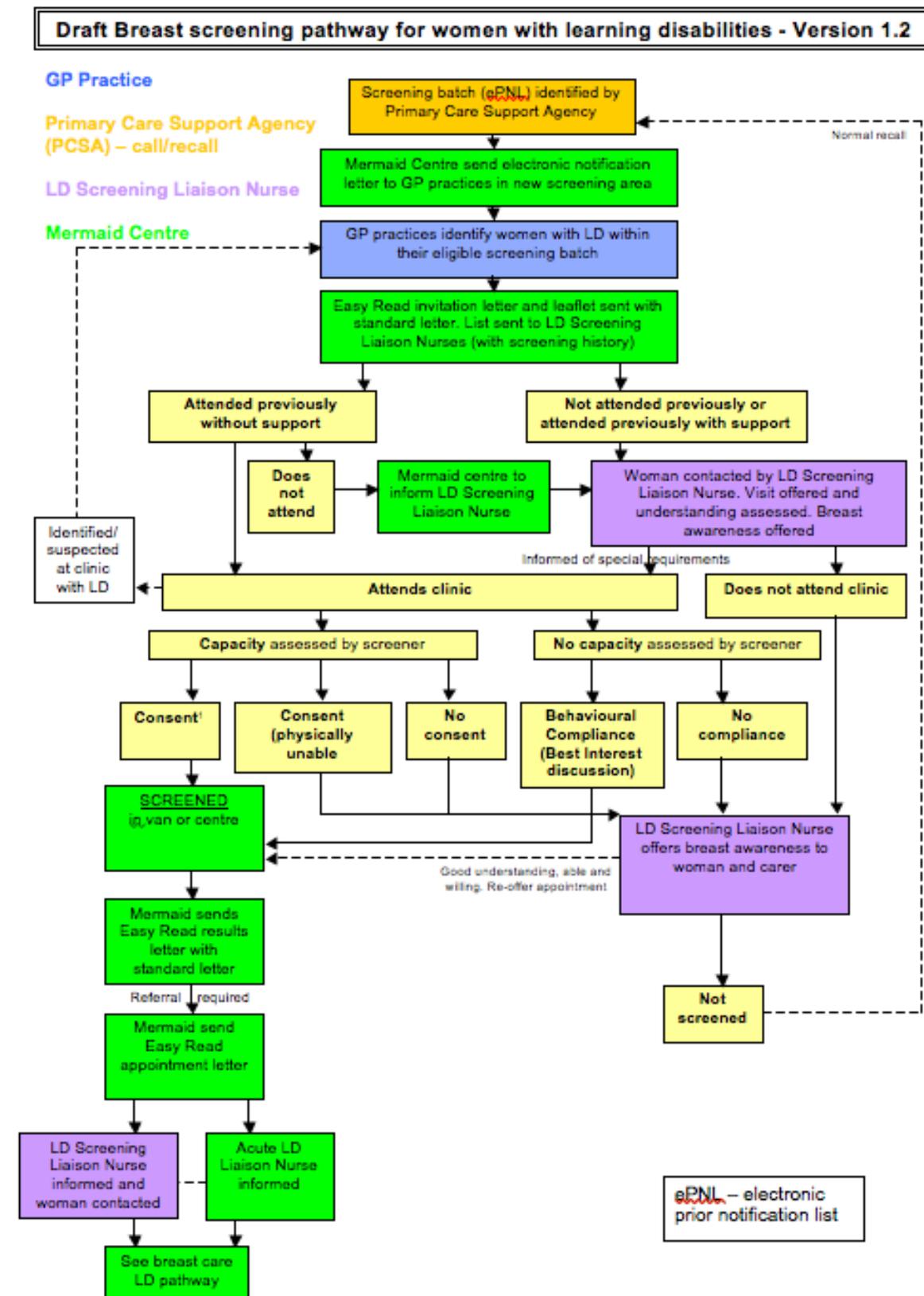
Please note, some resources may be available from more than one site, but we have only included one link per resource, and we have only included resources that are free to download, although the Easyhealth site includes resources you can buy.

### 6.1 Information about cancer (general)

Preventing cancer	How can you prevent cancer: <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>
What is cancer	What is cancer: <a href="http://www.easyhealth.org.uk/sites/default/files/what_is_cancer.pdf">http://www.easyhealth.org.uk/sites/default/files/what_is_cancer.pdf</a>  Cancer awareness toolkit: <a href="http://cancerawarenesstoolkit.com/">http://cancerawarenesstoolkit.com/</a>

## 6.2 Breast screening

The breast screening pathway developed by Cornwall below can be adapted to suit other areas.



## 6.2.1 Breast screening resources

<p>General awareness raising information</p>	<p>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></p> <p>Be breast aware: <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></p> <p>Looking after your breasts: <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></p> <p>My boobs and me: <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></p>
<p>Easy read invite letters</p>	<p>An easy read invite letter can be found at: <a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=209">www.improvinghealthandlives.org.uk/adjustments/?adjustment=209</a></p> <p>An easy read invite letter targeting women in the extended age range can be found at: <a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=235">www.improvinghealthandlives.org.uk/adjustments/?adjustment=235</a></p> <p>Did not attend follow up invite letter: <a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=208">www.improvinghealthandlives.org.uk/adjustments/?adjustment=208</a></p>
<p>Breast cancer screening</p>	<p>Information about breast cancer screening can be accessed from the NHS cancer screening website at: <a href="http://www.cancerscreening.nhs.uk/breastscreen/index.html">www.cancerscreening.nhs.uk/breastscreen/index.html</a></p> <p>There is an easy read leaflet about breast screening: <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></p> <p>Having a mammogram: <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></p> <p>Breast screening: <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></p> <p>Breast screening booklet: <a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=51">www.improvinghealthandlives.org.uk/adjustments/?adjustment=51</a></p> <p>Breast screening presentation: <a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=206">www.improvinghealthandlives.org.uk/adjustments/?adjustment=206</a></p>
<p>Follow up letters</p>	<p>Breast screening result letter. No problems detected: <a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=194">www.improvinghealthandlives.org.uk/adjustments/?adjustment=194</a></p> <p>Breast screening recall letter. Pictures not clear: <a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=233">www.improvinghealthandlives.org.uk/adjustments/?adjustment=233</a></p> <p>Breast screening recall letter: <a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=193">www.improvinghealthandlives.org.uk/adjustments/?adjustment=193</a></p>

## 6.2.2 Breast screening good practice examples

### Example of Breast awareness sessions – Knowsley

In Knowsley, the Learning Disability Nurse Health Facilitator worked in partnership with Breast Cancer Care UK and Knowsley Being Involved Advocacy Group to develop and deliver accessible/easy to understand breast awareness sessions for women with disabilities and their carers.

The sessions include a woman with learning disabilities sharing her experiences of screening and peer group discussion. A variety of resources are used as part of the session including photographs, a power point presentation, easy read/picture leaflets and parts of a video 'Your guide to breast screening.' The video is in a format suitable for people with disabilities and was developed by Merseyside and Cheshire Cancer Network funded by Knowsley PCT Public Health Team and neighbouring PCT's. The video is available from: <http://www.mccn.nhs.uk/index.php/videos>

Feedback from sessions to date:

After attending a session a woman disclosed to her support worker that she had some symptoms that she had seen in the session (discharge from her nipple). The support worker went with the woman to see her GP, who referred her to the breast clinic. She had a mammogram and was diagnosed with a benign tumour which she is going to have removed.

A GP reported that a patient told him that she had recently attended a breast cancer awareness session and she is now 'breast aware'. She explained to him what she needs to do and her mum confirmed she has observed her examining her breasts in front of the mirror in her bedroom.

A parent reported that her daughter who is not of age yet for breast screening informed her she attended the session and is now 'breast aware' examining her breasts, and asked to attend her mum's breast screening appointment. She did this and at the session asked the radiographer lots of questions. She enjoyed the experience of seeing what the mobile unit looked like.

For further information, please contact: [Johanna.Lee@5bp.nhs.uk](mailto:Johanna.Lee@5bp.nhs.uk)

### Improving uptake of breast screening in the Pennine area

In the Pennine area, the Breast Screening Department worked with the Strategic Health Facilitator from Bradford District Care Trust, to discuss access to the breast screening programme for women with learning disabilities and assess current uptake. Information on women with learning disabilities aged 50 – 70 in the Bradford and Airedale area was obtained from the Learning Disability Register. Using the woman's NHS number, the information was cross checked with records on National Breast Screening Service to assess attendance. 201 women aged 50 to 70 were on the Learning Disability Register. The information gathered showed a high percentage of women recorded as DNAs and cancelled/opted out. Although some reasonable adjustments were already in place, a review of current practice identified the need for better communication with women with learning disabilities including an easy read invitation letter, and the need to increase the knowledge and confidence of carers to support women to attend breast screening / take care of their breasts.

In response to the needs identified, an easy read screening invitation letter was developed in partnership with Bradford People First, and a training package was developed for carers and supporters of women with learning disabilities. The course aimed to increase awareness of breast screening and breast health awareness and explore ways of supporting women with learning disabilities. The course has run twice and has evaluated positively.

For further information please contact Lynn Clark on [lynn.clark@bthft.nhs.uk](mailto:lynn.clark@bthft.nhs.uk)



### 6.3.1 Cervical screening resources

Information about preventing cervical screening	There is information about the cervical cancer vaccination: <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>
Easy read invite letters	An easy read invite letter (HPV 1) can be found at: <a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=192">www.improvinghealthandlives.org.uk/adjustments/?adjustment=192</a>  A reminder easy read invite letter (HPV A2) can be found at: <a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=196">www.improvinghealthandlives.org.uk/adjustments/?adjustment=196</a>  An early repeat invite letter (HPV B1) can be found at: <a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=195">www.improvinghealthandlives.org.uk/adjustments/?adjustment=195</a>  A reminder early repeat invite letter (HPV b2) can be found at: <a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=218">www.improvinghealthandlives.org.uk/adjustments/?adjustment=218</a>
Having a cervical screen	Information about cervical screening can be accessed from the NHS cancer screening website at: <a href="http://www.cancerscreening.nhs.uk/cervical/index.html">http://www.cancerscreening.nhs.uk/cervical/index.html</a>  There is an easy read leaflet about cervical screening: <a href="http://www.cancerscreening.nhs.uk/cervical/publications/easy-guide-cervical-screening.html">www.cancerscreening.nhs.uk/cervical/publications/easy-guide-cervical-screening.html</a>  Having a cervical smear easy read leaflet: <a href="http://www.apictureofhealth.southwest.nhs.uk/wp-content/uploads/2010/06/Having_A_Cervical_Smear_Test.pdf">www.apictureofhealth.southwest.nhs.uk/wp-content/uploads/2010/06/Having_A_Cervical_Smear_Test.pdf</a>  What is (cervical) cancer screening: <a href="http://www.apictureofhealth.southwest.nhs.uk/wp-content/uploads/2010/06/What_Is_Cancer_Screening.pdf">www.apictureofhealth.southwest.nhs.uk/wp-content/uploads/2010/06/What_Is_Cancer_Screening.pdf</a>  Cervical screening: <a href="http://www.easyhealth.org.uk/sites/default/files/cervical_screening.pdf">www.easyhealth.org.uk/sites/default/files/cervical_screening.pdf</a>  Cervical screening presentation: <a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=205">www.improvinghealthandlives.org.uk/adjustments/?adjustment=205</a>
What happens after the cervical screen	What happens after cervical screening: <a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=189">www.improvinghealthandlives.org.uk/adjustments/?adjustment=189</a>
Letter following a cervical screen	Result letter – no problems detected (HPV C3): <a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=201">www.improvinghealthandlives.org.uk/adjustments/?adjustment=201</a>  Results letter – no problems detected (HPV G1 G2): <a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=230">www.improvinghealthandlives.org.uk/adjustments/?adjustment=230</a>  Results letter – no problems detected but another test would be helpful

	<p>(HPV C5):  <a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=219">www.improvinghealthandlives.org.uk/adjustments/?adjustment=219</a></p> <p>Results letter – can't get a result. Need for a re-test in three months (HPV C1): <a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=236">www.improvinghealthandlives.org.uk/adjustments/?adjustment=236</a></p> <p>Results letter – still can't get a result. Need for another type of test:  <a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=237">www.improvinghealthandlives.org.uk/adjustments/?adjustment=237</a></p> <p>Results letter – no changes detected but HPV present. Need for treatment (HPV J2):  <a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=231">www.improvinghealthandlives.org.uk/adjustments/?adjustment=231</a></p> <p>Results letter (HPV J7). Need for a re-test in three months:  <a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=232">www.improvinghealthandlives.org.uk/adjustments/?adjustment=232</a></p> <p>Results letter (HPV D1 E1) – Need for a repeat test:  <a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=198">www.improvinghealthandlives.org.uk/adjustments/?adjustment=198</a></p> <p>Results letter (HPV D2) – changes seen but no HPV infection:  <a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=220">www.improvinghealthandlives.org.uk/adjustments/?adjustment=220</a></p> <p>Results letter (HPV D3 E2 E3) – Changes found but no HPV infection:  <a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=221">www.improvinghealthandlives.org.uk/adjustments/?adjustment=221</a></p> <p>Results letter (HPV D5 E5) – changes found and HPV infection present:  <a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=200">www.improvinghealthandlives.org.uk/adjustments/?adjustment=200</a></p> <p>Results letter (HPV D6 E6 F2 F3) – Some changes seen. Need for further investigation:  <a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=222">www.improvinghealthandlives.org.uk/adjustments/?adjustment=222</a></p> <p>Results letter – changes seen and not able to tell if HPV is present (HPV D 7). Need for another test:  <a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=223">http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=223</a></p> <p>Results letter (HPV E1) Some changes seen. Need for another test):  <a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=225">www.improvinghealthandlives.org.uk/adjustments/?adjustment=225</a></p> <p>Results letter – (HPV E7) – changes detected. Another test needed:  <a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=226">www.improvinghealthandlives.org.uk/adjustments/?adjustment=226</a></p> <p>Result letter – (HPV E8) – changes detected. Another test needed:  <a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=227">www.improvinghealthandlives.org.uk/adjustments/?adjustment=227</a></p> <p>Result letter – (HPV F1) – changes detected. Treatment needed:  <a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=228">www.improvinghealthandlives.org.uk/adjustments/?adjustment=228</a></p> <p>Results letter – (HPV F4) – changes detected. Treatment needed:  <a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=229">www.improvinghealthandlives.org.uk/adjustments/?adjustment=229</a></p>
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### 6.3.2 Cervical Screening Good Practice Examples

#### **Example of reasonable adjustments regarding cervical screening from Devon**

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. 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. It is helpful to operate the speculum so that women get used to the noise it makes, and 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 before the appointment itself can also be helpful.

For further information please contact Julie Wilkins on [juliea.wilkins@nhs.net](mailto:juliea.wilkins@nhs.net)

### **A pilot to increase uptake of cervical screening in Wakefield**

The results of a health equity profile done in Wakefield showed that over the last 5 years 14% of women without a learning disability were ceased from Cervical Screening Register compared to 47% of women with learning disabilities. Women with a learning disability aged 25-40 were almost 5 times more likely to be ceased from the programme or be placed in an exceptions category.

In response to these findings, the local strategic health facilitator and public health commissioning manager developed a pilot programme to look into this matter further. They decided to use the Open Exeter system to examine the cervical screening histories of women with learning disabilities. This system was used to identify women who are up to date with cervical screening, identify women who have been ceased from the recall system and identify women where cervical screening has been successful in the past but is now overdue.

The pilot plans to look at approximately 60 women who have a learning disability and are between 24-64 years of age. These women have had a cervical screen in the past but are now overdue.

The proposal to undertake this work has been reviewed by a clinical governance lead and the Cancer Screening Co-ordinator for Wakefield to ensure that it adheres to the Caldicott principles surrounding the sharing of patient identifiable information

The purpose of this pilot is to identify and reduce physical and organisational barriers and improve access to cervical screening for women with learning disabilities in Wakefield. It is also intended to provide guidance for support workers, general practice and decision makers in order to increase screening uptake.

10 women whom we support have consented to be involved in this pilot and are being supported through their journey of screening via the flow chart below.

For further information please contact Karen Gillott on: [Karen.gillott@choicesupport.org.uk](mailto:Karen.gillott@choicesupport.org.uk)

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

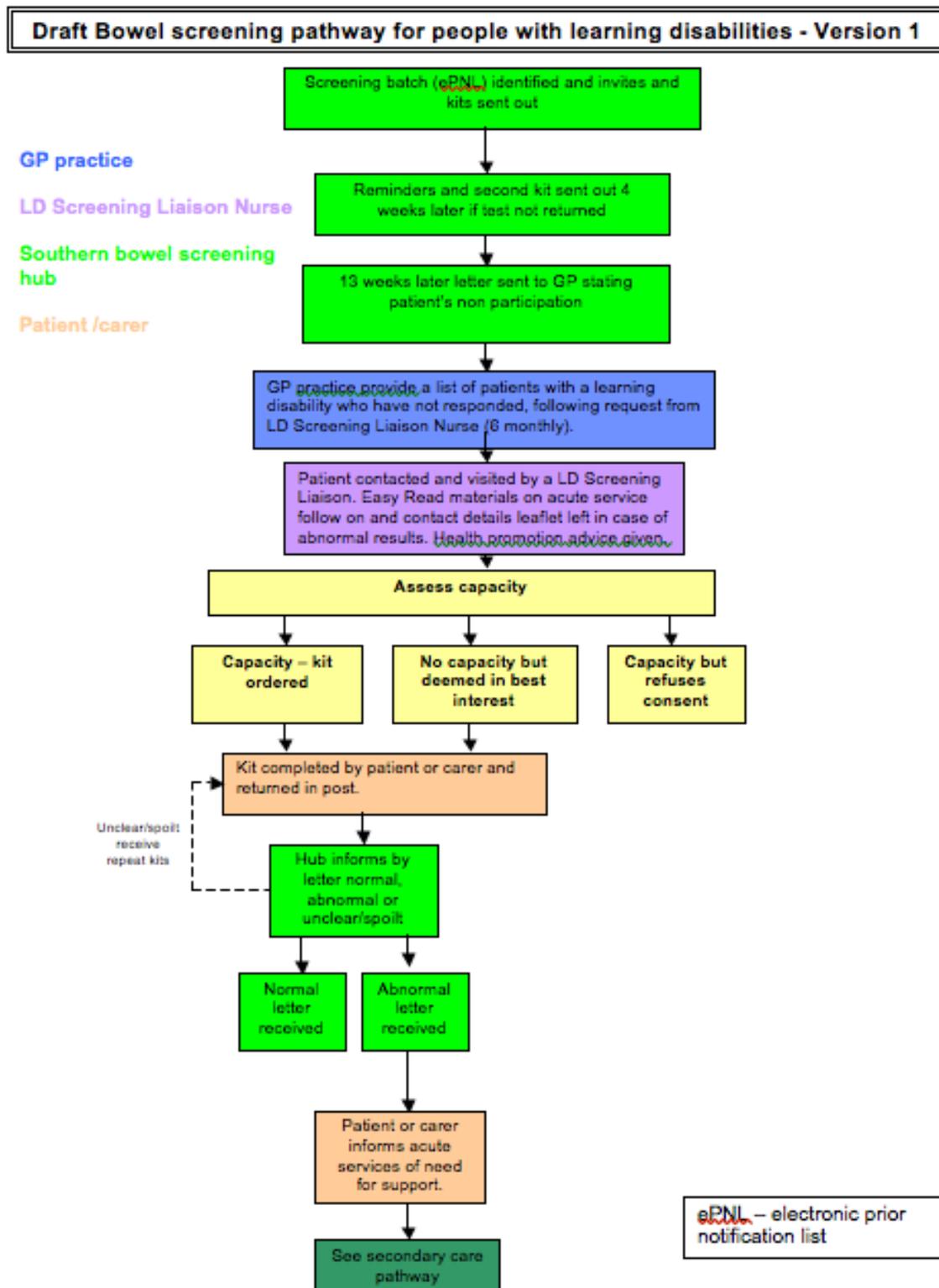
In Sussex, work to develop best practice guidance has been going on for 18 months. The work has involved a range of professionals and services including public health professionals; primary care professionals – GPs and Practice Nurses; screening support services; hospital cytology & colposcopy services; learning disability health facilitation & 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 in offering & 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 LMC's and has been distributed across Sussex, with an aim of achieving agreement for it to be piloted in a number of practices.

For further information please contact: [Natalie.Winterton@brighton-hove.gcsx.gov.uk](mailto:Natalie.Winterton@brighton-hove.gcsx.gov.uk) or [corinne.nikolova@nhs.net](mailto:corinne.nikolova@nhs.net)

## 6.4 Bowel screening

The bowel screening pathway developed by Cornwall below can be adapted to suit other areas.



### 6.4.1 Bowel screening resources

General awareness raising information	There is information about bowel and bladder awareness: <a href="http://www.easyhealth.org.uk/sites/default/files/bowel_and_bladder_awareness_2.pdf">www.easyhealth.org.uk/sites/default/files/bowel_and_bladder_awareness_2.pdf</a>
Bowel screening kit and information	<p>Information about bowel screening can be accessed from the NHS cancer screening website at: <a href="http://www.cancerscreening.nhs.uk/bowel/index.html">www.cancerscreening.nhs.uk/bowel/index.html</a></p> <p>There is an animated film on using the bowel cancer screening kit. DVDs of the cartoon are available from the five regional NHS BCSP hubs, or from the national office of the NHS Cancer Screening Programmes: Email <a href="mailto:info@cancerscreening.nhs.uk">info@cancerscreening.nhs.uk</a> Tel: 0114 271 1060</p> <p>There is a picture leaflet about bowel cancer screening by and for people with learning disabilities: <a href="http://www.cancerscreening.nhs.uk/bowel/publications/nhsbcsp-learning-disabilities-leaflet.pdf">www.cancerscreening.nhs.uk/bowel/publications/nhsbcsp-learning-disabilities-leaflet.pdf</a></p> <p>There is a picture leaflet about bowel screening from Derbyshire Hospitals NHS Foundation Trust: <a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=188">http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=188</a></p> <p>Bowel screening presentation: <a href="http://www.improvinghealthandlives.org.uk/adjustments/?adjustment=207">www.improvinghealthandlives.org.uk/adjustments/?adjustment=207</a></p>
Information about colonoscopy	There is picture leaflet about colonoscopy by and for people with learning disabilities: <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>

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