GOOD PRACTICE IN BREAST AND CERVICAL SCREENING FOR WOMEN WITH LEARNING DISABILITIES

NHSBSP Publication No 46
NHSCSP Publication No 13

October 2000

First published by:

NHSCSP Publications
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ISBN 1 871997 14 3

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Copies are free of charge to the NHS, other public sector staff and individuals and organisations supporting people with learning disabilities in the United Kingdom.

Copies of the picture leaflets *50 or over? Breast Screening is for You* and *Having a Smear Test* are also available free of charge from the NHS Cancer Screening Programmes at the above address. Requests for bulk orders (10 or more copies) should be made to the Department of Health.

By fax: 01623 724 524
By post: Department of Health, PO Box 777, London SE1 6XH
By email: doh@prolog.uk.com

Copies of the picture books *Looking After My Breasts* and *Having a Smear Test* are available from:

Book Sales
Royal College of Psychiatrists
17 Belgrave Square
London SW1X 8PG

Tel: 020 7235 2351 extension 146

The books are priced at £10.00 each including postage and packing.

Typeset by Prepress Projects Ltd, Perth (www.prepress-projects.co.uk)
Printed by Streamline Offset, Hoddesdon, Herts

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ACKNOWLEDGEMENTS

This guidance has been drafted on behalf of the NHS Cancer Screening Programmes by a working group convened by the Department of Health. The working group was organised into a core group, which considered the issues common to both the breast and the cervical screening programmes, and two subgroups, which looked at issues specific to each programme. The members of the core group and subgroups were:

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The NHS Cancer Screening Programmes are grateful to all the members of the groups for their contribution to the project. They would also like to thank all those working in the screening programmes, in primary care, in health promotion and those who work with women with a learning disability, who shared their examples of good practice with the project. In particular, they would like to thank the Surrey Oaklands NHS Trust, the Horizon NHS Trust, the Bedfordshire and Hertfordshire Breast Screening Service, the Avon Breast Screening Service and the former Phoenix NHS Trust.

1. INTRODUCTION

1.1 Purpose

The purpose of this guidance is to describe good practice to ensure that women with learning disabilities have the same rights of access as all other women to the NHS Breast Screening Programme (NHSBSP) and the NHS Cervical Screening Programme (NHSCSP).

For health or social services staff who provide support for women with learning disabilities, and for staff who work in the screening programmes, it summarises current guidance on access to health care for people with learning disabilities and explains the issues of consent for breast or cervical screening.

For staff and family members who provide support for women with learning disabilities, it explains the principles of screening, the limitations of the breast and cervical screening programmes and the possible consequences of attending for screening. It also describes how the screening programmes are organised and how women are invited for screening.

The guidance recommends good practice to ensure that, wherever possible, women with a learning disability

- have access to information to enable them to make their own decisions about whether or not to accept an invitation to attend for breast screening or cervical screening
- know what to expect when they attend for screening so that it is a positive experience
- understand the possible consequences of screening and the need to be aware of changes in their own bodies.

The guidance includes criteria for assessing the capacity of individuals to consent to screening and recommendations on what action to take if a woman is not able to consent.

This guidance has been drafted to reflect the organisational arrangements of health and social services in England. However, the principles of the guidance and recommendations for good practice are applicable to the breast and cervical screening programmes in Scotland, Wales and Northern Ireland.

1.2 Background

Guidance on clinical examination of the breast published in 1998[1] raised some concerns among staff working with women with learning disabilities that women with a profound learning disability or associated physical disability would be unable to understand or undertake breast awareness unaided. Consideration of these concerns led to the identification of a number of related issues about access to screening programmes, understanding of screening and its consequences, and valid consent. The National Screening Committee discussed these issues and agreed the following:

- each national screening programme should develop good practice frameworks in order to effect equity in access: performance management mechanisms should be used to monitor that such frameworks are in place and adhered to
- health authorities should work with other agencies to ensure that they meet the individual needs of this population
- health professionals who work with people with learning disabilities should ensure that an understanding of screening programmes is included in general education about health care for this population.

As a result, the Department of Health and the NHS Cancer Screening Programmes set up working groups to develop good practice guidance.

1.3 Supporting materials

The working groups have developed five publications that are designed to improve access to screening for women with learning disabilities. These are described below.

This good practice guidance is aimed at staff who support women with learning disabilities (members of primary care teams, community learning disability teams, social services staff and staff in the voluntary sector), at family members, and at staff who provide breast and cervical screening programmes (health authority staff, primary health care teams, breast screening unit staff).

Two leaflets in picture form (one about breast screening and one about cervical screening), are designed to tell women with a learning disability about the screening programmes and to let them know that more detailed information and support is available.

Two picture books (one about breast screening and breast awareness, and one about cervical screening) are designed to be used by women and their supporters to:

- decide whether or not to attend for screening
- prepare for the screening procedure
- understand the results of screening
- prepare for further investigations if these are necessary.

The picture books are also intended to be used by staff in breast screening units, and by smear takers to explain the screening procedure to women when they attend for screening.

Details of how to obtain copies of these publications are given at the front of this publication.

2. SCREENING PROGRAMMES

2.1 Existing guidance

Signposts for Success describes good practice in health services for people with learning disabilities.[2] This includes:

- ensuring that their rights are known and respected
- providing information
- recognising the importance of dealing with barriers to access, staff attitudes and communication skills
- ensuring that guidance on consent is available
- ensuring that people with learning disabilities and their carers receive the support, assistance and flexibility they require when using services
- showing commitment to quality improvement.

This good practice applies to the breast and cervical screening programmes as much as to other health services. However, there are significant differences between **screening**, which is offered to well women, and **diagnosis and treatment**, which are offered to women with known symptoms. These differences need to be understood by staff who support women with learning disabilities and by primary care teams who facilitate access to the breast and cervical screening programmes.

2.2 Principles of screening

Screening is a test offered to an apparently well person with the possibility of detecting a serious disease at a stage before any other symptoms are apparent. A screening programme offers a screening test to a defined population known to be at risk from the disease, at a regular interval whose frequency depends on the natural progression of the disease.[3] The aim is to offer treatment at an early stage when it is likely to be more effective and less invasive. However, no screening test is 100% effective in detecting disease in all those who are screened.

2.3 Benefits and disadvantages of screening

There are disadvantages to screening as well as benefits. These are principally psychological, in terms of increased anxiety about developing the disease, but may also be physical (for example, investigations or treatment of suspected disease that prove to be unnecessary) or social (for example, stigma associated with testing). The aim of any screening programme is to do more good than harm, but the balance for any particular individual is a personal one. Most individuals who are screened do not have the disease which is being screened for and, for some, the disadvantages of screening outweigh the benefits. There may also be adverse consequences of screening. A normal result may provide false reassurance and lead individuals to ignore symptoms of disease. An abnormal result may lead to increased anxiety until a definite diagnosis is reached, and may entail further investigations, which may be more invasive and less acceptable than the initial screening test.

2.4 Consent to screening

For the reasons discussed above, the issue of consent is central to any screening programme. As a general principle, individuals who are being screened should understand the limitations and the consequences of screening and make an informed decision whether or not to accept the invitation to participate in the screening programme. For women with learning disabilities, as with other women, the issue of valid consent is crucial. Unlike other forms of heath care, where there is an immediate and obvious benefit to the individual, there is no such tangible benefit for most individuals who have a screening test.

2.5 General principles of consent*

The law assumes that every adult has the capacity to consent unless it can be shown that the person is not able to understand and retain information material to the decision, or to use it and weigh it in the balance as part of the process of arriving at the decision.

Deciding whether a person has the capacity to consent is a matter for clinical judgement and should be made in the light of current circumstances. If a person is unable to consent to one form of medical treatment, inability to consent to different treatment should not be assumed. No one can consent to, or refuse, treatment on behalf of another adult who lacks capacity to consent. This includes the person's family and doctor.

However, there is at present a common law duty for clinicians to provide treatment to adults who are unable to consent to or refuse treatment, if that treatment is 'necessary' and in their 'best interests'. Necessary treatments can range from non-invasive investigations, such as eye tests, to surgery. The purpose of treatment must be either to preserve the life, health or wellbeing of that person or to ensure the improvement or to prevent the deterioration in the person's physical or mental health. A clinician must determine and act in the best interests of the person in accordance with a responsible body of medical opinion. In determining the best interests of someone who cannot consent to or refuse treatment, a clinician should take into account the views and wishes expressed by the person in the past and present, as well as the views and wishes of the people who support or know the person well, concerning the likely attitude and interests of the person.

*The material for this section is taken from *Once a Day*.[4]

Good practice in assessing capacity to consent*

When assessing the ability of the person to consent, consider the following points:

- *have you spent sufficient time talking with and listening to the person, determining their level of understanding, and have you involved someone who knows the person well and who may be better than you at communicating with that person?*
- *on what basis have you decided that the person cannot consent, and are you sure that this is not because you do not agree with the person's decision?*
- *have you fully explained, in a way the person is most likely to understand, the proposed intervention, the alternatives and the benefits and risks?*
- *if you decide that the person cannot consent, you should discuss with those who support and know the person well their understanding of the person's views and wishes*
- *although the supporter's signature on a consent form has no legal standing, you may wish to document the discussion and record their views in writing.*

2.6 Further guidance on consent

Further guidance on the legal issues surrounding consent, including the issues that need to be taken into account when assessing whether or not a person has the capacity to make treatment decisions on their own behalf, has been published jointly by the British Medical Association (BMA) and the Law Society.[5] The General Medical Council has published principles of good practice in *Seeking Patients' Consent: the Ethical Considerations*.[6] There is also discussion of the issues in the Lord Chancellor's consultation document.[7] It should be noted that the documents refer to the legal position in England and Wales; different considerations apply under Scottish law. All these documents relate to medical treatment and do not discuss directly the issues raised by the breast and cervical screening programmes. Consent to breast or cervical screening is discussed in Chapters 4 and 6 respectively.

*The material for this section is taken from *Once a Day*.[4]

3. LEARNING DISABILITIES

3.1 Definition*

A person with a learning disability has a reduced ability to understand new or complex information and difficulty in learning new skills and may be unable to cope independently. These disabilities started before adulthood and have a lasting effect on development. The term 'learning disability' was adopted by the Department of Health in 1992. It has the same meaning as its predecessor 'mental handicap' but is seen as more acceptable, particularly in reducing the confusion with mental illness. However, many service users prefer the term 'learning difficulty'.

3.2 Range of disabilities*

Learning disability may be mild, moderate, severe or profound, but these adjectives can only very generally suggest the level of disability. People with learning disabilities have many different talents, qualities, strengths and support needs. It is only a minority who have major difficulties in communicating their ideas and preferences, but most struggle with abstract concepts and need help to understand complex ideas. People with learning disabilities may live with their family, in residential care or more independently with or without support.

Some facts about people with learning disabilities

- about 2% of the population can be described as having a learning disability
- many people with mild learning disabilities receive any support they need from family and friends and do not need specialist services
- it has been estimated that about 4 in 1000 people have moderate, severe or profound learning disabilities. Of these, up to 30% have associated physical disabilities, most often due to cerebral palsy
- about 30% of people with learning disabilities have a significant impairment of sight and 40% have significant hearing problems
- some people with learning disabilities have no or little functional speech but may communicate by other means, such as signing
- people with learning disabilities may experience the indirect effects of disability such as reliance on supporters for access to services or inappropriate responses from service providers.

Some further reading about the health needs of people with learning disabilities is given on pp. 36–37.

3.3 Need for breast and cervical screening

Women with learning disabilities are living longer and fuller lives and should have access to breast and cervical screening on the same basis as other women. Many women with learning disabilities cope well in society with support from family or friends. Some, however, have other disabilities such as physical disabilities, sensory disabilities or communication problems. This means that the breast and cervical

*The material for this section is taken from *Once a Day*.[4]

screening programmes have to make sure that women have access to information about screening which is presented in a way which they can understand, and that staff in the screening programmes adopt good practice to enable women who choose to attend for screening to be screened successfully.

3.4 Leaflets for women

The NHS Cancer Screening Programmes have published leaflets about breast and cervical screening to support the good practice recommended in this publication. The leaflets are designed in picture form to tell women with learning disabilities about breast screening and cervical screening and to let them know how to get more information and support. Copies of the leaflets are available free of charge from the national office of the NHS Cancer Screening Programmes.

3.5 Picture books

Two picture books have also been developed in conjunction with St George's Hospital Medical School to support the good practice recommended in this publication. The picture books are designed to be used by women and their supporters, and by staff in the screening programmes, to explain in detail what happens in breast screening and cervical screening. They describe in sequence the events of receiving an invitation letter for screening, deciding whether to go for screening, preparing for the screening appointment, attending for screening, getting the results and being recalled for further tests. The books include suggestions for supporters on how to use them and are designed in sections so that the supporter can select the relevant sections, depending on the needs of the individual woman and the stage she has reached in the screening process. The picture books can also be used by staff in breast screening units and by smear takers to explain to a woman what will happen when she comes for a mammogram or to have a smear taken. Copies of the picture books have been distributed to all breast screening units and health authorities. Additional copies are available to purchase from the Royal College of Psychiatrists.

3.6 Using the leaflets and picture books

Family and supporters who know an individual woman well are best placed to decide how to use the leaflets and picture books. It is important to assess how much information a woman can take in at a time. It also depends on what the woman wants or needs to know. For example, younger women may want to know about breast awareness; older women who have not previously been for breast screening may want to know that they can request this. Local services may also want to supplement and sequence these materials with local health promotion, health awareness or well women work. They may also wish to personalise the material with visits to local clinics and photographs of local facilities and the addition of locally produced materials. Women with learning disabilities who wish to access the breast and cervical screening programmes have a wide range of abilities and disabilities, and these materials and others available need to be used sensitively to meet individual needs. Much of the preparation of the woman, and support for her in making her decision whether or not to attend for a screening appointment, takes place between the woman and her supporter. However, others in the screening process must be aware

of this work to ensure that the woman gets appropriate support and understanding from everyone she comes into contact with. It is good practice for the supporter to liaise with the breast screening unit, or with the practice nurse or family planning clinic, to ensure that the woman's needs are understood.

4. BREAST SCREENING

4.1 Introduction

The aim of breast screening is to offer more effective treatment and to reduce deaths from breast cancer. Breast screening is a method of detecting some breast cancers at an early stage, often before a woman has any obvious symptoms. However, breast screening does not detect all cancers in the breast. The risk of developing breast cancer increases with age. All women aged between 50 and 64 who are registered with a GP are invited for breast screening every 3 years. Women aged 65 or over are not invited routinely but are entitled to screening every 3 years at their own request. Arrangements are in progress to extend routine invitation to women up to the age of 70. Breast screening is a two stage process. The first stage is a breast x-ray (mammogram). Most women have a normal result, but between 3% and 7% of women are recalled for further investigation (assessment). This takes place at an assessment clinic and may include a further mammogram, clinical examination of the breast, ultrasound or a biopsy. About one in ten women who are recalled for assessment are diagnosed with breast cancer.

4.2 Invitation for breast screening

Women are invited for breast screening on the basis of the general practice with which they are registered. A prior notification list (PNL) is generated by the health authority of women in the eligible age range registered with the practice. This is sent to the GP to verify the women's demographic details and to identify any women who should not be invited for breast screening. The NHSBSP has issued guidance on the circumstances in which a woman may be ceased from the breast screening programme.[8] The breast screening unit then sends out invitation letters to all women on the amended PNL.

4.3 Women who are not routinely invited

Women in NHS residential care may not be registered individually with a general practice, and so are not routinely invited. It is the responsibility of the breast screening unit to make contact with the NHS unit and obtain a list of women who are eligible for breast screening. Guidance on administrative arrangements for screening women not on health authority lists has been issued by the NHSBSP.[9] Women aged 65 and over are not currently sent a routine invitation but can request a screening appointment every 3 years. Similarly, any woman over the age of 50 who has declined previous screening invitations and who now wishes to be screened may request a screening appointment.

4.4 Making a decision about whether to attend for breast screening

All women who are invited must be given enough information to enable them to make an informed choice about whether to attend for breast screening. Many women with learning disabilities are able to make their own decision. The good practice described in Chapter 5, along with the leaflet and picture book, is designed to help them to do so. The aim of the screening programme is to prepare a woman and her supporter, so that when the woman receives an invitation to breast screening she knows how to get more information and support to help her to make an informed choice about whether or not to accept.

4.5 Capacity to consent to breast screening

The following points should be considered when assessing a woman's capacity to consent to breast screening:

1. Does the woman have a basic understanding of what breast screening is, what it is for, and why she has been invited?
2. Does she understand that breast screening does not always detect if something is wrong?
3. Does she understand that an abnormal mammogram means having further tests?
4. Is she able to retain the information for long enough to make an effective decision?
5. Is she able to make a free choice (ie free from pressure from carers or health professionals)?

Some women with severe learning disabilities may not have the capacity to make their own choice about breast screening, even with careful preparation.

4.6 Best interests

If the decision is made that a woman does not have the capacity to consent to breast screening, then health professionals must act in the best interests of the woman. The decision may be taken by the GP, or the responsible medical officer (consultant psychiatrist) for a woman in NHS residential care. The following points should be taken into consideration:

1. What are the woman's known wishes?
2. Involve the woman in discussions.
3. Seek the views of others who know the woman well.
4. Is there any other action which would be better for the individual?

If the woman attends for mammography, the radiographer will not proceed to take a mammogram if, in his or her professional judgement, the woman is being caused unnecessary mental or physical distress.[10] In such circumstances, the clinical director of the breast screening unit may advise the GP or responsible medical officer that the woman should be ceased from the screening programme. The NHSBSP Good Practice Guide *Consent to Breast Screening*[11] gives guidance on the administrative procedures to be followed.

4.7 Suitability for mammography

Mammography is a procedure that is technically difficult and which requires a high degree of cooperation between the radiographer and the woman. The woman has to be carefully positioned on the x-ray machine, and must be able to hold the position for several seconds. This may not be possible for women with limited mobility in their upper bodies, or who are unable to support their upper bodies unaided. In order to optimise the quality of the image and to minimise the radiation dose, the breast must be compressed. This is at best uncomfortable, and for some women may be painful. The following may be used to assess whether a woman is suitable for mammography:

1. Is the woman able to hold her head up, and does she have the flexibility to hold her arms clear of her chest and the breast support table while the mammogram is taken?

2. Is the woman able to understand the procedure when it is explained to her?
3. Is the woman able to cope in unfamiliar situations and environments, with a familiar supporter if necessary?
4. Is the woman able to comprehend and cooperate with simple requests?
5. Can the woman support herself if she is a wheelchair user?
6. Has the woman sufficient muscle control to maintain the position required?
7. Is the woman able to tolerate discomfort?
8. Is the woman able to remain still for a few minutes?

If a woman has a physical disability, or is a wheelchair user, then the breast screening unit should advise on whether breast screening is technically possible. This will depend on the design of the wheelchair, for example on whether the sides and back are removable, or whether the woman can be transferred to a chair that is suitable for mammography.

4.8 Checking understanding of breast screening

All radiographers working in the NHSBSP are expected to follow the College of Radiographers *Code of Professional Conduct*.[10] This means that a radiographer must not take a mammogram if, in his or her professional judgement, a woman who has the capacity to consent has not been given sufficient information about breast screening to give that consent. The radiographer should check:

1. Has the woman has been screened before?
2. Has she has been given a copy of the picture leaflet?
3. Can her supporter confirm that breast screening has been explained to her?

4.9 Behavioural consent to mammography

Having established that the woman has an understanding of breast screening, the radiographer should proceed on the basis of behavioural consent. This means that the woman:

1. Cooperates with the radiographer.
2. Is not unduly anxious.
3. Responds to simple requests.
4. Shows no signs of agitation or distress.

If the woman withdraws consent at any stage, then this should be seen positively as the woman’s choice on that occasion. It does not mean removal from the screening programme. Supporters and radiographers should consider whether the preparation of the woman for breast screening adversely influenced the outcome.

4.10 Establishing consent to breast screening

Establishing consent to breast screening is a complex process, and there are a number of different stages as described above. Figure 1 summarises the process. The likely sequence of events is shown from top to bottom of the page with alternatives to left and right, but the exact sequence will depend on individual circumstances and some stages may be repeated. Figure 2 summarises the points which need to be considered at the various stages.

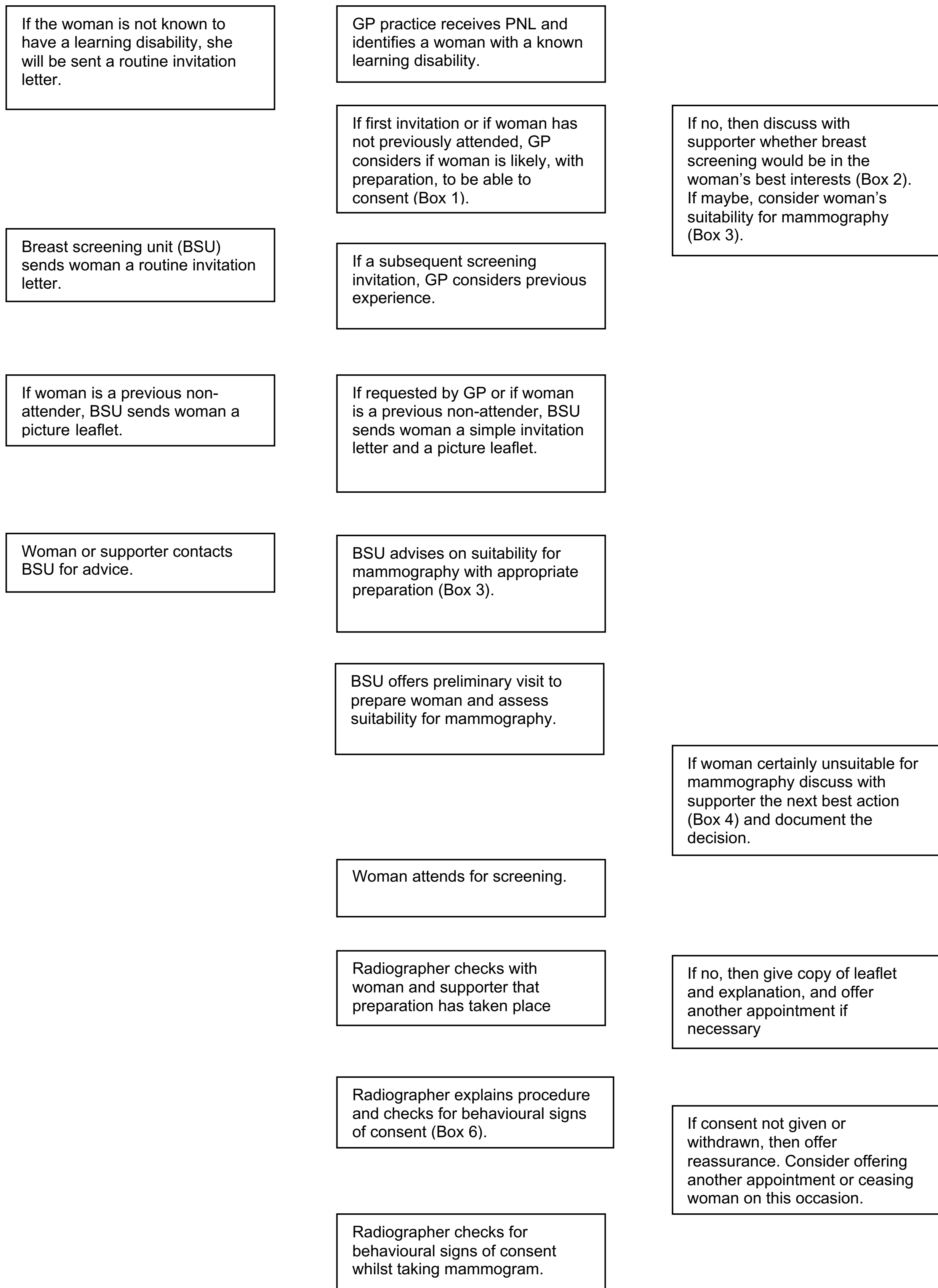

Figure 1 Establishing consent to breast screening

Box 1 Capacity to consent to breast screening

1. Does the woman have a basic understanding of what breast screening is, what it is for, and why she has been invited?
2. Does she understand that breast screening does not always find if something is wrong?
3. Does she understand that an abnormal mammogram means having further tests?
4. Is she able to retain the information for long enough to make an effective decision?
5. Is she able to make a free choice (ie free from pressure from supporters or health professionals)?

Box 2 Best interests

1. What are the woman's known wishes?
2. Involve the woman in discussions.
3. Seek the views of others who know the woman well.
4. Is there any other action which would be better for the individual?

Box 3 Suitability for mammography

1. Is the woman able to hold her head up, and have the flexibility to hold her arms clear of her chest and the breast support table while the mammogram is taken?
2. Is the woman able to understand the procedure when it is explained to her?
3. Is the woman able to cope in unfamiliar situations and environments with a familiar supporter if necessary?
4. Is the woman able to comprehend and cooperate with simple requests?
5. Can the woman support herself if she is a wheelchair user?
6. Has the woman sufficient muscle control to maintain the position required?
7. Is the woman able to tolerate discomfort?
8. Is the woman able to remain still for a few minutes?

Box 4 Next best action

1. Encourage woman to be aware of changes in her own body.
2. Encourage woman to tell someone if she notices any changes.
3. Ensure that supporters know what changes to normal appearance of breasts to look for whilst providing personal care.

Box 5 Checking understanding of breast screening

1. Has the woman been screened before?
2. Has she been given a copy of the picture leaflet?
3. Can her supporter confirm that breast screening has been explained to her?

Box 6 Behavioural consent to mammography

1. Cooperates with the radiographer
2. Is not unduly anxious
3. Responds to simple requests
4. Shows no signs of agitation or distress

Figure 2 Issues for consideration in establishing consent to breast screening

4.11 Ceasing a woman from the screening programme

If efforts to prepare the woman for breast screening have not been successful, or the woman has been found to be unsuitable for mammography on previous occasions, then her GP may indicate on subsequent PNLs that she should not be invited (this is called 'ceasing' a woman from the programme). An NHSBSP Guide to Good Office Practice gives further guidance on administrative procedures.[8] It should be emphasised that a learning disability is not in itself sufficient reason to cease a woman. For women in NHS residential care who are not registered with a GP, the decision that a woman should be ceased from the programme should be taken by the consultant in charge. The decision should be documented, and the Good Practice Guide *Consent to Breast Screening* gives guidance on suitable wording.[11]

4.12 Next best action

If a woman is not suitable for mammography and is ceased from the programme then she and her carers should consider the next best action. For most women, this is breast awareness. For women with learning disabilities, this should be part of encouraging a more general awareness of their own bodies and the need to seek advice if there are changes from what is normal for them. Supporters should know what visual changes to look out for:

1. Encourage woman to be aware of changes in her own body.
2. Encourage woman to tell someone if she notices any changes.
3. Ensure that supporters know what changes to normal appearance of breasts to look for whilst providing personal care.

Further details about breast awareness are given in Chapter 8.

Messages about breast screening

- breast screening is a routine mammogram offered to well women over the age of 50
- breast screening does not prevent breast cancer
- the aim of breast screening is to reduce mortality by detecting breast cancer at an early stage so that it can be treated more effectively
- breast screening does not detect all breast cancers
- mammography requires a high degree of cooperation between the woman and the radiographer
- having a mammogram causes discomfort, and may be painful for some women
- for some women, the anxiety and distress caused by breast screening may outweigh the benefits.
- for some women with physical disabilities, it may not be possible to take a mammogram but this should be discussed with the radiographer
- most women who attend for breast screening do not have breast cancer
- women should be aware of the importance of consulting a doctor if any changes to the normal appearance of the breast are noticed in the intervals between screening, or if screening is not appropriate.

Messages for primary care teams, and community learning disability teams

- women with learning disabilities have the same rights of access to breast screening as other women
- women with learning disabilities are entitled to information in an appropriate format (leaflets and picture books) to help them to decide whether or not to attend for breast screening
- the breast screening unit needs know about women with learning disabilities who are to be invited for breast screening so that they can be offered a longer appointment time and an appointment at a static breast screening unit – the GP may alert the breast screening unit at PNL stage or the woman or her supporter may contact the breast screening unit at invitation stage
- primary care staff need to understand the issues of consent
- many supporters have no personal experience of breast screening and may not know what is involved in having a mammogram
- cooperation with breast screening units and supporters is needed to prepare women for mammography and identify those who are not suitable for mammography.

5. GOOD PRACTICE IN BREAST SCREENING

5.1 Preparation for residential care teams and community learning disability teams

Staff in residential care teams and community learning disability teams need training about the breast screening programme so that they understand:

- what breast screening is, its purpose and which women are eligible to be invited
- the benefits and limitations of breast screening
- the possible consequences of going for breast screening
- the next best action if a woman is not suitable for mammography.

They should make contact with the local breast screening unit, which may be able to arrange a training session and a visit to the screening unit for staff.

Staff need to know what information is available to women and their supporters to help them to respond to an invitation for breast screening and to prepare a woman for a breast screening appointment so that it is a positive experience for the woman and results in a mammogram that is adequate for breast screening. Staff also need to know about the possible results of breast screening and how to prepare a woman if she is referred for assessment.

Staff need to understand the issues of consent and how to proceed if a woman is not able to give valid consent to breast screening or is unable to cooperate with the breast screening procedure.

Staff who provide personal care also need to understand the concept of breast awareness and the need to look for visual signs of changes in a woman's breasts either in the interval between breast screening or if the woman is not suitable for mammography (see Chapter 8).

Good practice

- *develop links with the local breast screening unit and establish local protocols for assessing the suitability of women for mammography*
- *have copies of picture leaflets to give to women who are in the age range for breast screening*
- *have copies of the picture book available to use with women who have received an invitation letter*
- *develop local information materials in cooperation with the local breast screening unit.*

5.2 Preparation for staff in breast screening units

Breast screening units should arrange training for receptionists and radiographers about learning disabilities. This can often be arranged in cooperation with community learning disability teams. Preliminary

visits to the breast screening unit by women and their supporters can also provide the opportunity for staff to learn about the needs of women with a learning disability.

Good practice

- *ask learning disabled women who have been for breast screening to talk to radiographers about their needs*
- *encourage one or two radiographers in a breast screening unit to specialise in working with women with learning disabilities*
- *ensure that radiographers who work with learning disabled women are fully trained and experienced in mammography.*

5.3 Raising awareness of breast screening

Information about breast screening should be part of health promotion activities for older women, including those with learning disabilities. Primary care teams and community learning disability teams should identify those women with a known learning disability who are in the age range eligible for breast screening. This gives them the opportunity to provide advice and information to these women and their supporters. The picture leaflets are designed to tell women about breast screening. More information is available in the picture book when they are invited for breast screening. The receipt of the PNL should be a prompt to the GP to prepare a woman and her supporter for the invitation to breast screening either through personal contact or by giving them a copy of the picture leaflet.

Good practice

- *identify women with a known learning disability who are eligible for breast screening*
- *involve supporters and make sure they know what having a mammogram involves*
- *offer informal sessions on what to expect when breast screening is due.*

5.4 Inviting women for breast screening

The breast screening unit sends invitation letters to all women on the amended PNL. Women with a learning disability are not identified as such on the PNL, and most women will therefore receive a routine letter. Routine letters include a sentence encouraging women to contact the breast screening unit for advice if they have any special needs which may make breast screening more difficult for them. They can then be offered an alternative breast screening appointment at a static unit where there is more space, more time can be allowed and physical access is easier than on a mobile screening van. However, if the screening unit knows that a woman to be invited has a learning disability, either because she has been for screening on a previous occasion or because they have been informed of this by the woman's GP or supporter, it may be possible to send her a simply worded invitation

letter. An example is included at Appendix 1. It is designed to encourage women with learning disabilities to contact the breast screening unit for information and advice to help decide whether or not they wish to come for breast screening.

Good practice

- *send a simple invitation letter and picture leaflet to women who are known to have a learning disability*

5.5 Helping a woman to respond to an invitation for breast screening

This may be done by a combination of the primary care team, community learning disability team, or the supporter, depending on the woman's personal circumstances. They must make sure that the woman has a copy of the picture leaflet (copies of this and a simple invitation letter are available from breast screening units). They may also use the picture book to explain the breast screening process in more detail. Each breast screening unit has a copy of the book and community learning disability teams may also have a copy. The supporter should seek advice from the breast screening unit if physical disabilities may prevent successful breast screening. If necessary, it may be possible to arrange a preliminary visit to the breast screening unit to prepare the woman for her screening appointment. The aim is to help the woman to make her own decision whether or not to accept the invitation for breast screening.

Good practice

- *use one-to-one sessions with a person (such as the community learning disability nurse or the key worker) whom the woman knows and trusts*
- *use appropriate language*
- *use appropriate materials (picture leaflet and picture book)*
- *answer questions honestly to avoid the unexpected*
- *emphasise that the staff at the screening unit are all female*
- *provide lots of reassurance*
- *arrange a preliminary visit to the breast screening unit at a time when screening is not taking place to allow the woman to become familiar with the surroundings and meet the radiographer.*

5.6 Arranging an appropriate screening appointment

If screening office staff know that a woman with a learning disability has been invited for screening, they should send her the picture leaflet and the simple invitation letter. They should offer the woman a longer appointment time, at the static unit. They should consider arranging sessions when the unit is less busy for women who may have difficulty complying with the social expectations of a waiting room. Physical aspects should also be considered, such as wheelchair access, space for supporters, changing facilities and privacy. The advice of the radiographer should be sought on the technical feasibility of screening women who are in specialised wheelchairs, such as the Matrix wheelchair, which do not have removable arms.

Good practice

- *book a longer appointment (at the static unit)*
- *if a supporter, friend or relative is due for breast screening at about the same time, it may be helpful to book the screening appointment in the same session*
- *if possible, provide dedicated time and space for those women who find it difficult to comply with the social expectations of a waiting room*
- *check that the supporter who will accompany the woman understands the screening process and if necessary arrange for a preliminary visit*
- *discuss issues of consent with the supporter*
- *consider suitability for mammography and seek advice from the radiographer on what is technically possible for women with a physical disability*
- *ask the GP or care home to arrange suitable transport for the woman if required.*

5.7 Taking the mammogram

Radiographers need to understand the issues of consent and to know their responsibilities under their *Code of Professional Conduct.*[10] They need to check a woman's understanding of breast screening and establish behavioural consent to mammography. They need to be comfortable with dealing with women with learning disabilities and to know about the technical possibilities of mammography for women with physical or mobility difficulties. They also need to ensure that a woman is not caused unnecessary distress and that, where a woman has the capacity to consent, a refusal to cooperate is seen positively as the woman's choice on that occasion. They need to consider whether the preparation adversely influenced the outcome and understand that non-compliance does not mean removal from the screening programme.

Good practice

- *explain again to the woman what will happen, using the picture book*
- *allow time for the woman to express herself*
- *check with the supporter how the woman would communicate if she did not wish the procedure to continue*
- *use plenty of eye contact and check understanding with the woman and the supporter at each stage*
- *invite the supporter to help and participate if that is what the woman wishes*
- *some women with physical problems may need two people to ensure adequate positioning*
- *pulling out of compression is a common reaction; a gentle reassuring hand on the back may help the woman to keep still*
- *some women may become anxious when the radiographer moves away to take the exposure; the supporter may stay close to the woman*
- *ensure that all supporters or assistants are protected against radiation and that the slight risks of exposure are explained to them*
- *some women with breathing difficulties or who hyperventilate when anxious may find it difficult to keep still during the exposure*
- *the supporter can be very influential in calming a woman who is anxious*
- *remind the woman that the exposure will make a noise so that she is not startled by it*
- *distress must be taken as withdrawal of consent on that occasion.*

5.8 Recall for assessment

Breast screening is a two stage process, and between 3% and 7% of women are recalled to an assessment clinic for further investigation. This may include further mammograms, ultrasound, clinical examination and a biopsy. Being recalled for assessment is an anxious time for all women, and most breast assessment clinics have a breast care nurse who is experienced in explaining the assessment process and providing support to women on an individual basis. Some questions and suggested answers about assessment are given in Appendix 2.

Good practice

- *use picture book to prepare the woman*
- *allow plenty of time for preparation*
- *answer questions honestly*
- *provide support and reassurance*
- *seek advice and information from the breast care nurse.*

5.9 Training for radiographers

Training for the Certificate of Competence in Mammography should include sessions on screening women with learning disabilities, as well as screening women with other special needs such as hearing impairment, sight impairment or communication difficulties. Training course should also include training about the technical possibilities of mammography for women with physical disabilities.

Good practice

- *include sessions by the local community learning disability team*
- *include sessions with learning disabled women who have been for breast screening*
- *include sessions on non verbal communication*
- *include sessions on the use of the leaflet and picture books and other locally developed materials.*

6. CERVICAL SCREENING

6.1 Introduction

Cervical screening is a method of preventing cancer by detecting and treating abnormal cells in the cervix which, if left untreated, may turn into invasive cervical cancer. It is not a test for cancer. The aim of the NHS Cervical Screening Programme is to reduce the number of women who develop invasive cervical cancer (incidence) and the number of women who die from it (mortality).

6.2 Smear test and results

The smear test is used to examine a sample of cells from the cervix. A doctor or nurse inserts an instrument (speculum) to open the woman's vagina and uses an extended tip spatula to sweep around the cervix and take a sample of cells. The sample of cells is then 'smeared' onto a slide, which is sent to a laboratory for examination under a microscope. The results of the smear test are notified to the woman and to the smear taker (and the GP where this is not the smear taker). If the result is normal, the woman is recalled for another smear test at the routine screening interval (between three and five years).If the smear is inadequate (for example, because it contains insufficient cells or is obscured by blood or mucus), the woman is asked to come back for a repeat smear. If the smear is found to contain mild abnormalities, the woman is asked to come back for further smears at a six or twelve month interval. If the smear contains moderate or severe abnormalities, the woman is referred for further investigation (colposcopy) and possible treatment.

6.3 Women registered with a general practitioner

Women between the ages of 20 and 64 who are registered with a GP are invited to have a cervical smear test every three to five years. A prior notification list (PNL) of women due to be invited is sent by the health authority for the GP to check that the demographic details are correct. This gives the GP the opportunity to identify any women with a known learning disability and to consider whether they should be invited for a smear test. Women on the amended PNL are sent a standard letter informing them that a smear test is due and asking them to make an appointment with their GP or with a community clinic. If the woman does not respond, she is sent a reminder letter and the GP is sent a non-responder card. This provides the GP with another opportunity to contact the woman to discuss cervical screening and to send her the picture leaflet about cervical screening. The GP may also send the woman a simple invitation letter and an example is include at Appendix 3.

6.4 Women in residential care

Women in an NHS residential unit may not be registered individually with a general practice. It is the responsibility of the staff to consider which of their residents are eligible for cervical screening and to make appropriate arrangements for them to be included on the health authority call and recall system.

6.5 Risk factors for cervical cancer

The exact cause of cervical cancer is not known, but certain types of human papillomavirus (HPV) are associated with around 95% of all cases. Women who are sexually active and who have many sexual

partners, or whose partners have had many partners, are more at risk. Using a condom gives some protection. Women who smoke are about twice as likely to develop the disease as non-smokers. However, women who have not had a recent smear test make up a disproportionately high number of those who develop cervical cancer. For women who are sexually active, the biggest risk factor is non-attendance for a smear test.[12] There is still some incidence of cervical cancer among women have never been sexually active, although the risk is very low.

6.6 Assumptions about sexual activity

It is common for women with a learning disability not to be offered a routine smear test, on the assumption that they have never had sexual intercourse.[13] However, it may not be possible to be sure that someone has never been sexually active. Women with learning disabilities may experience sexual abuse that goes unrecognised, and are therefore at risk of developing cervical cancer.[14]

6.7 Capacity to consent to cervical screening

The following points should be considered when assessing a woman's capacity to consent to cervical screening:

1. Does the woman have a basic understanding of what cervical screening is, what it is for, and why she has been invited?
2. Does she understand that the smear test does not always find if something is wrong?
3. Does she understand that an abnormal smear result means having more tests?
4. Is she able to retain the information for long enough to make an effective decision?
5. Is she able to make a free choice (i.e. free from pressure from supporters or health professionals)?

Some women with severe learning disabilities may not have the capacity to make their own choice about cervical screening, even after careful preparation.

6.8 Best interests

If a woman does not have the capacity to consent, then health professionals must act in the best interests of the woman. The following points should be taken into consideration:

1. What are the woman's known wishes?
2. Involve the woman in discussions.
3. Seek the views of others who know the woman well.
4. Is there any other action that would be better for the individual?

The decision may be taken by the GP, or the responsible medical officer (consultant psychiatrist) for a woman in NHS residential care who is not registered with a GP, to cease her from the cervical screening programme (see section 6.13). The decision must be documented. An NHSCSP Good Practice Guide *Consent to Cervical Screening* gives guidance on suitable documentation.[15]

6.9 Deciding if cervical screening is important

The assumption is often made that women with learning disabilities are not sexually active and they are therefore ceased from the screening programme and never receive a routine invitation letter. The issue of sexual activity is often a difficult one for supporters, particularly those who are also the woman's parents. Women with learning disabilities have the right to privacy about their personal relationships. The involvement of a family supporter in the decision about having a smear test may be embarrassing for the woman. The picture leaflet and picture book about having a smear test have been designed to address this and to help women to make their own decision about whether or not to have a smear test. The following points should be considered in deciding if cervical screening is important for an individual woman:

1. Does the woman understand what is meant by sexual intercourse?
2. Has she had (unprotected) sexual intercourse?
3. Does she smoke?
4. Are there concerns about sexual abuse now or in the past?

6.10 Checking understanding of cervical screening

The community learning disability team have an important role in preparing a woman for having a smear and should work closely with the smear taker to ensure that women who attend for a smear have an understanding of cervical screening and how a smear is taken. The following may be used by the smear taker to assess a woman's understanding:

1. Does the woman have a basic understanding of why smears are taken?
2. Has she had a smear before?
3. Has she been invited for a routine smear, or for a follow-up smear after a previous smear?
4. Has she seen a copy of the picture leaflet?
5. Can her supporter confirm that cervical screening has been explained to her?

The smear taker may decide not to proceed to take the smear if he or she thinks that preparation has not been adequate. The attendance should be seen as part of the preparation and the woman given the opportunity for further explanation and consideration before making another appointment to have the smear taken.

6.11 Behavioural consent to smear taking

The smear taker must check throughout for behavioural signs that the woman has not withdrawn consent that she has previously given. This means considering :

1. Is the woman relaxed and cooperative?
2. Is she able to keep still?
3. Is she willing to get undressed?
4. Is she willing to be positioned?
5. Is she willing to accept having the speculum passed?
6. Does she maintain awareness throughout?

6.12 Establishing consent

Establishing consent to cervical screening can be a complex process, and there are a number of different stages, as described above. Figure 3 summarises the process. The likely sequence of events is shown from top to bottom of the page with alternatives to left and right, but the exact sequence will depend on individual circumstances and some stages may be repeated. Figure 4 summarises the points which need to be considered at the various stages.

6.13 Ceasing a woman from the screening programme

If a woman decides that she does not want to be invited for a smear, or screening is not important for her, she can be ceased from the programme. It should be emphasised that a learning disability is not in itself sufficient reason to cease a woman, nor should a decision to cease her be based on assumptions by the GP or the supporter about the woman's history of sexual activity. The NHSCSP Good Practice Guide *Consent to Cervical Screening* gives guidance on the administrative steps to be taken if a woman is unable to consent to cervical screening, if screening would not be in her best interests, or if she makes the choice that she does not want to be invited for screening.[15]

6.14 Next best action

If a woman has been ceased from the programme, then she and her carer should consider the next best action. A woman who has been ceased can be reinstated at any time at her request, if she changes her mind or if her circumstances change. It is suggested that health authorities should undertake a regular audit of women who are ceased from the screening programme to identify those who may have been ceased inappropriately.

6.15 Exceptional circumstances

In exceptional circumstances, where a woman is not able to consent to cervical screening but is thought to be at very high risk, for instance where there is concern about multiple sexual partners or sexual abuse, a clinician may consider taking a smear under general anaesthetic. This is a clinical judgement and is not part of the cervical screening programme. Colposcopic assessment of the cervix by a gynaecologist should also be considered if the degree of risk is thought to be sufficiently high to justify a general anaesthetic.

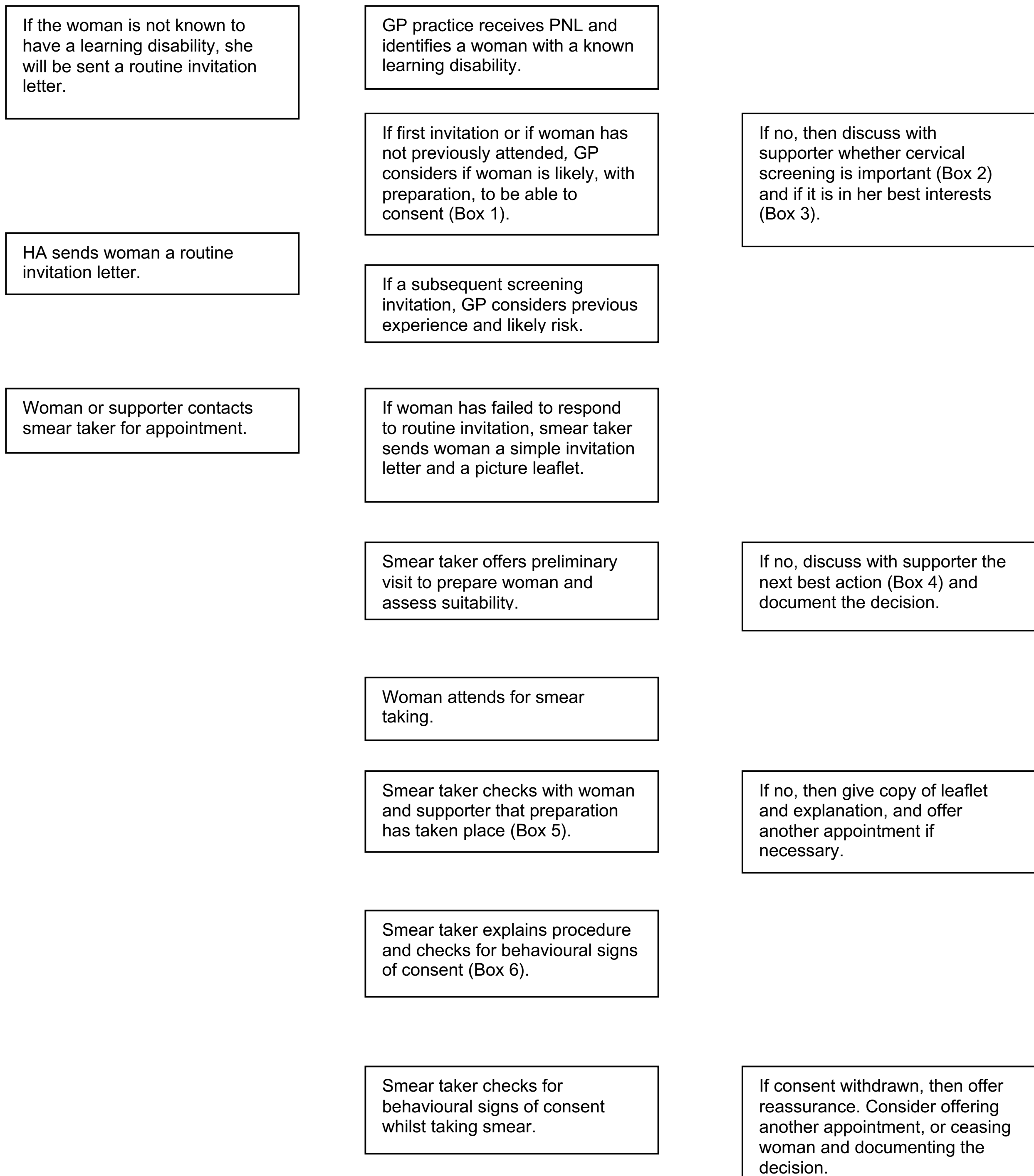

Figure 3 Establishing consent to cervical screening

Box 1 Capacity to consent to cervical screening

1. Does the woman have a basic understanding of what cervical screening is, what it is for, and why she has been invited?
2. Does she understand that the smear test does not always find if something is wrong?
3. Does she understand that an abnormal smear test means having more tests?
4. Is she able to retain the information for long enough to make an effective decision?
5. Is she able to make a free choice (ie free from pressure from carers or health professionals)?

Box 2 Is cervical screening important?

1. Does the woman understand what is meant by sexual intercourse?
2. Has she had (unprotected?) sexual intercourse?
3. Does she smoke?
4. Are there concerns about sexual abuse now or in the past?

Box 3 Best interests

1. What are the woman's known wishes?
2. Involve the woman in discussions.
3. Seek the views of others who know the woman well.
4. Is there any other action which would be better for the individual?

Box 4 Next best action

1. Encourage woman to reduce risks of developing cervical cancer.
2. Encourage woman to tell someone if she notices any changes.

Box 5 Checking understanding of cervical screening

1. Does the woman have a basic understanding of why smears are taken?
2. Has she had a smear before?
3. Has she been invited for a routine smear, or a follow-up smear after a previous smear?
4. Has she seen a copy of the picture leaflet?
5. Can her supporter confirm that cervical screening has been explained to her?

Box 6 Behavioural consent to smear taking

1. Is the woman relaxed and cooperative?
2. Is she able to keep still?
3. Is she willing to get undressed?
4. Is she willing to be positioned?
5. Is she willing to accept having the speculum passed?
6. Does she maintain awareness throughout?

Figure 4 Issues for consideration in establishing consent to cervical screening

Messages about cervical screening

- the aim of cervical screening is to prevent cervical cancer by identifying changes which may develop into cancer
- cervical screening does not always identify changes
- sexual activity increases the risk of developing cervical cancer
- having multiple partners increases the risk of developing cervical cancer
- smoking increases the risk of developing cervical cancer
- having one smear test before the age of 35 reduces the lifetime risk of developing cervical cancer by about 60%
- having a smear may be embarrassing, uncomfortable or even painful for the woman.

Messages for primary care teams

- women with learning disabilities have the same right of access to cervical screening as other women
- women with learning disabilities cannot be assumed to be sexually inactive
- women with learning disabilities are entitled to information to make their own decision about cervical screening
- the PNL and non-responder notification can be used as a prompt to give women the picture leaflet about cervical screening.

7. GOOD PRACTICE IN CERVICAL SCREENING

7.1 Deciding if cervical screening is important

A woman may need help in deciding if a smear test is important for her. This may be done by the community learning disability team, or by the care team if the woman is in residential care. A woman may need help with issues such as understanding the human body, self-awareness, confidence and assertiveness, relationships, and sexuality before the topic of cervical smears is introduced. Talking about having a cervical smear may raise other issues about sexual activity (or sexual abuse) which need to be addressed. A woman may have overheard remarks or complaints from others (about cervical screening, or visits to doctors or hospitals in general) which may create or add to anxieties about having a smear. If there is a family carer involved, the carer's personal circumstances and lack of knowledge about cervical screening may need to be addressed and the issue of the woman's sexual activity may also be a source of concern. Separate discussions with the family carer may be needed to address these issues and help her feel better able to support the woman in making her own choice about going for a smear test or not. Paid carers also need training to ensure that they understand the benefits and limitations of cervical screening, the risk factors for cervical cancer and the issues of valid consent.

Good practice

- *arrange training about the cervical screening programme for paid supporters*
- *identify women who are eligible for cervical screening including those who may be at increased risk of developing cervical cancer*
- *offer information (leaflets and booklets), advice and support to these women and their supporters.*
- *develop client specific story books*
- *develop client specific action plans in collaboration with the smear taker*
- *include discussion of cervical screening and risk factors for cervical cancer in discussions about healthy living.*

7.2 Preparing women to have a smear test

This may be done by the primary care team, the community learning disability team, the care team for a woman in residential care or the family supporter, depending on the woman's personal circumstances. They must make sure that the woman has a copy of the leaflet designed for women with a learning disability. They may also use the picture book to explain the cervical screening process in more detail. The supporter should seek advice from the smear taker if physical disabilities may prevent a smear being taken successfully, and arrange a preliminary visit to the surgery or clinic if this is appropriate. The aim is to help the woman to decide whether or not to accept the invitation for a smear test, but staff and paid supporters must understand the issue

of valid consent and be clear about how to proceed if the woman is not able to consent.

Good practice

- *use one-to-one sessions with a person (such as the community learning disability nurse or the key worker) whom the woman knows and trusts*
- *use appropriate language*
- *use appropriate materials (picture leaflets, picture books and client specific story books)*
- *answer questions honestly to avoid the unexpected.*
- *emphasise that the woman can choose to have a female smear taker*
- *provide lots of reassurance*
- *ask women who have had a successful cervical smear to talk to other women close to them*
- *arrange a preliminary visit to the surgery or clinic at a quiet time to allow the woman to become familiar with the surroundings and meet the smear taker*
- *be aware that the presence of a family supporter may be inhibiting*
- *understand issues of consent and be clear about how to proceed when someone is not able to consent*
- *help women to decide whether or not to go for cervical screening.*

7.3 Preparation for the smear taker

Smear takers need to be aware of the needs of women with learning disabilities and possible barriers to taking a smear successfully such as previous bad experience, or possible sexual abuse. Smear takers need to be aware of the possible beliefs and anxieties of family or other carers and to work with women and their supporters to ensure that women understand what is involved in taking a smear. Smear takers need to understand the issue of consent and be clear about how to proceed if the woman is not able to give valid consent. Local community learning disability teams may be able to arrange training about the needs of learning disabled women for practice nurses and others who take smears.

Good practice

- *ask learning disabled women who have been for cervical screening to talk to smear takers about their needs*
- *encourage one or two practice nurses in a primary care team or group to specialise in working with women with learning disabilities*
- *ensure that smear takers who work with learning disabled women are confident and experienced in taking smears.*

7.4 Making an appointment to have a smear test

The preparation for a smear test should be done jointly by the supporter and the smear taker before the visit at which the smear will be taken. It may be possible to take the smear at the first appointment, but for some women the first appointment will be a preparatory visit before the visit at which the smear is taken. The woman should be given a copy of the leaflet about having a smear test for her to keep.

Good practice

- *encourage preliminary visits by a woman and her supporter to become familiar with the person who will take the smear and the surroundings in which the smear will be taken*
- *book an appointment at a time when the surgery or clinic is not busy*
- *if possible, provide dedicated time and space for those women who find it difficult to comply with the social expectation of a waiting room*
- *check that the supporter who will accompany the woman understands the screening process*
- *discuss issues of consent with the supporter*
- *if a supporter, friend or relative is due for cervical screening at about the same time, and is willing, it may be helpful to book the screening appointment in the same session*
- *consider any physical limitations for women with a physical disability*
- *show the speculum and spatula to the woman and allow her to handle them if she wishes*
- *for women in residential care, it may be possible to offer a domiciliary visit to take the smear if suitable facilities (lighting, couch, etc) are available.*

7.5 Taking the smear

Smear takers need to understand the issue of consent and to be involved in the preparation of a woman for having a smear taken. They need to be comfortable in dealing with women with learning disabilities. Smear takers should be familiar with best practice in taking smears which is set out in the NHSCSP *Resource Pack for Training Smear Takers*.[16]

Good practice

- *make sure the room is comfortable and private*
- *ask the woman if she wants a supporter with her during the smear taking*
- *allow sufficient time to explain to the woman how the smear is taken using the picture book*
- *show her the speculum and give the opportunity to handle it and insert it if she chooses*
- *use appropriate language for the individual woman, for example, talk about 'down below' rather than 'cervix'*
- *respect the woman's privacy and dignity*
- *offer the woman a choice of position (the left lateral position is often the one associated with sexual abuse)*
- *be prepared for the possibility that the woman may become distressed*
- *be patient and gentle when taking the smear and have due regard for the woman's reactions*
- *if at any time the woman is resistant or uncooperative, or pushes the speculum away, stop and only proceed with her cooperation*
- *be prepared to arrange another appointment to take a smear if the woman needs more reassurance*
- *ensure that refusal at any stage prior to or during the smear taking is seen positively as the woman's choice on this occasion*
- *understand that non-compliance does not mean removal from the cervical screening programme*
- *reflect on the outcome and if the preparation affected the outcome.*

7.6 Inadequate smears and abnormal smear results

If a woman has an inadequate smear result (for example where the smear contains insufficient cells or is obscured by blood or mucus), then she is asked to have a repeat smear as soon as possible. If the smear result shows a mild abnormality, then the woman is asked to have repeat smear in 6 or 12 months' time. If the smear result shows a moderate or severe abnormality, then the woman is asked to attend a colposcopy clinic for further investigation and possible treatment. Being recalled for a repeat smear or referred for colposcopy can be an anxious time for all women. Most colposcopy clinics have a colposcopy nurse who is experienced in explaining the process and providing support to women on an individual basis. Some questions and suggested answers about repeat smears and colposcopy are given in Appendix 4.

8. BREAST AWARENESS

8.1 Breast awareness

Breast awareness is the process of getting to know what is normal as part of general body awareness. The aim of breast awareness is to encourage women to become familiar with their normal breast tissue at different times of the month. All women, especially those over the age of 40, should be breast aware because

- early detection is the single most important factor in improving survival from breast cancer
- the majority of palpable breast cancers are found by women themselves or by their partners
- it is better to start breast awareness early, to establish what is normal
- women between the ages of 50 and 64 years who attend for routine breast screening should continue to be breast aware as cancers can develop in the interval between screening mammograms
- the risk of developing breast cancer continues to rise with age so women who are 65 and over should continue to be breast aware.

A training pack for primary care teams on breast awareness is available.[17]

The breast awareness five point code

1. Know what is normal for you.
2. Look and feel.
3. Know what changes to look and feel for.
4. Report any changes without delay.
5. Attend for routine screening if aged 50 and over.

8.2 Clinical examination

The breast awareness policy was recommended by the Advisory Committee on Breast Cancer Screening in 1991. In 1998, advice issued by the Chief Medical Officer and the Chief Nursing Officer reiterated that breast self-examination (monthly palpation performed by a woman at the same time each month to a set method) should not be promoted as a screening method. Moreover, palpation of the breast by either medical or nursing staff should not be included as part of routine health screening for women.[1] This applies equally to women with learning disabilities.

8.3 Breast awareness for women with learning disabilities

All learning disabled women should be encouraged to get to know their own bodies so that they can notice changes. This should involve being aware of all parts of the body, especially those parts normally covered by clothes. Bathing and drying is a good time to do this. Feeling and looking in a mirror are good ways of noticing changes. If a woman is not able to do this for herself, then a supporter who provides personal care should do a **visual** check for changes. Some women with learning disabilities may not act on signs which are very obvious, and carers

need to be aware of an unusual smell or a weeping and sticky sore on the breast.

Look for:

- changes in shape, size, symmetry
- puckering, dimpling or 'orange peel' appearance of the skin
- veins which stand out more than normal
- rashes
- discharge from the nipple
- change in position of the nipple(pulled in or pointing in a different direction)

Look for anything that is **new for the woman**.

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APPENDIX 1: SIMPLE INVITATION LETTER FOR BREAST SCREENING

Dear ______ ______

I am writing to ask if you would like to come to have your breast check because all women over 50 can have their breasts checked every 3 years.

This check will be an X-ray called a mammogram.

The check helps to find some breast cancers when they are very small.

We would like you to come on ______ ______ to have your breast check.

You can bring someone along to support you. It can be a supporter, a family member or a friend that you trust.

The person doing the check will talk to you before they do it and when they are doing it.

We look forward to seeing you. If you or your supporter have any questions, you can ring us at ___________.

APPENDIX 2: QUESTIONS WHICH MIGHT BE ASKED BY WOMEN WHO ARE RECALLED FOR BREAST SCREENING ASSESSMENT

Why do I have to go back to the screening unit again?

Because the doctors are unsure about a small area in your breast shown on your mammogram (breast x-ray). This does not usually mean you have cancer, but it does mean you have to have more tests to find out what the area is. You can take someone with you when you go back to the screening unit.

Do I have to have more x-rays?

Sometimes by taking extra pictures, the area can be sorted out. You may not need any more tests.

What else might happen this time?

The doctor (who may be a man) will talk to you and then he or she may examine your breasts. The doctor may do other tests which he or she will explain to you. You will be able to ask as many questions as you like. You can take someone with you.

APPENDIX 3: SIMPLE INVITATION LETTER FOR CERVICAL SCREENING

Dear ______ ______

I am writing to ask if you would like to come to have your cervical screening test (to have a check down below). All women between 20 and 64 can have this check every 3 or 5 years.

The check is called a smear test.

The smear test helps to find some changes which may become cancer if they are not treated.

We would like you to come on ______ ______ to have your check.

You can bring someone along to support you. It can be a supporter, a family member or a friend that you trust.

The nurse or person doing the check will talk to you before they do it and when they are doing it.

We look forward to seeing you. If you or your supporter have any questions, you can ring us at ___________.

APPENDIX 4: QUESTION WHICH MIGHT BE ASKED BY WOMEN ABOUT THE RESULTS OF A SMEAR TEST

Normal result

Do I have to go back?

Yes, but not yet, not next year or the year after that. Not until you are … years old.

Do I have to look out for anything after the smear?

You must tell someone if you get soreness, smelliness, or bleeding which is not a period, in case you have an infection. You need to have another smear in a few years.

Is there anything that my boyfriend/partner needs to know?

Your smear is normal. It is OK. However, the cervix is very delicate and it can pick up infections like anywhere else in your body. Some infections can lead to changes in the cells. When you have sex, always ask your boyfriend/ partner to use a condom (even if you are on the pill). This will protect you inside and help you not to pick up infections.

Is it a good idea to have a smear next year to be sure?

No. Every 3 years is enough. The laboratory has looked at your smear and you are healthy. You don't have to worry.

Inadequate smear

What does this mean?

There might not have been enough of the special cells which the doctors are looking for to show that the smear was taken from the right place inside you. Another reason could be that the cells on the smear were covered by blood or discharge and couldn't be seen clearly. It is really important that the laboratory has a good smear to look at so that it can be checked carefully.

Why do I need to go back?

You need to have another smear taken because the laboratory needs a good smear to look at so that they don't miss any changes in the cells. Even with the best smear test, every single small change in the cells may not be found, so it is very important that we start with a really clear sample.

Have I got cancer?

It is very unlikely. You haven't had a proper smear yet so we can't tell if it is normal.

Will the next smear be alright?

I expect so. The person taking your smear will do her best to get a good smear next time. If it still isn't good enough, we will try again, but it is usually OK the second time.

What will they do?

Just the same as last time. I will come with you. It may be a different doctor or nurse but it will probably be the same person. Would you like to look at the pictures again to help you to remember?

Will it hurt again?

It may be easier this time, because you have done it before and you feel happier to go. It is usually easier the second time.

Didn't the nurse do it right?

Maybe the nurse didn't get enough on the smear or maybe the smear was covered in mucus. It should be alright this time. She is very good at taking smears and does a lot of them.

I don't want to go back – do I have to go?

I can understand that – many women do not like having smears taken. But if you think about why you are having the test it might help you to feel better about it. Most smear tests are normal but if there is a problem it is better to find it before it cause you to be unwell.

Abnormal result

What does this mean?

The smear shows changes in some of the special cells. These changes may get better – they often do. But they might get worse and do real harm. They are not cancer, but may become cancer if the right treatment is not given.

Do I need to go back?

You may need to have another smear, or to go to a special clinic for another test called colposcopy. Colposcopy takes longer, so we wouldn't do it on every woman. We do it to see if you need any treatment.