EQUAL ACCESS TO BREAST AND CERVICAL SCREENING FOR DISABLED WOMEN

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NHS Cancer Screening Programmes
Fulwood House
Old Fulwood Road
Sheffield
S10 3TH

Tel: 0114 271 1060
Fax: 0114 271 1089
Email: info@cancerscreening.nhs.uk
Web site: www.cancerscreening.nhs.uk

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Tel: 08701 555 455
Fax: 01623 724 524
Email: doh@prolog.uk.com

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Editor TJ Day

Editorial group Sarah Cush, Pauline Gamble, Ann Mumby
With particular thanks to Ali Guest

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Vicki Allanach
Mary Button
Sue Carmichael
Jenny Caseldine
Maggie Cooper
Penny Craddock
Sylvia Denton
Jackie Downer
Peter Elton
Sue Gray
Sue Hawkett
Matthew Hoghton
Sheila Hollins
Libby Kitt
Liz Kutt
Gill Marsh
Graham Martin
Karen Morgan
Shelagh Murphy
Penny Oakley
Wendy Perez
Carole Pougher
Samia al Qadhi
Pauline Robertson
Philomena Shaugnessy
Jo Slater
Jill Toocaram

1. INTRODUCTION

1.1 Purpose

The purpose of this guidance is to describe good practice to ensure that disabled women 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 disabled women, and for staff who work in the screening programmes, it summarises current guidance on access to health care for disabled people, and explains the issues of consent for breast and cervical screening.

For staff and family members who provide support for disabled women, 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 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 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 of not having screening, and the need to be aware of changes in their own bodies.

The guidance includes a discussion of ways in which individuals may consent to screening and recommendations on what action to take if a woman is not able to consent.

This guidance has been revised to cover the requirements of the Disabilities Discrimination Act 1995 (including the new requirements effective from October 2004), and reflects 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 concerns among staff that some disabled women may be unable to understand and/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 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 The Disability Discrimination Act 1995

As of 1 October 2004, service providers now have a duty to make reasonable adjustments to ensure that disabled people do not find it impossible or unreasonably difficult to access that service. This may include changes such as:

- altering policies, procedures or practices which make it impossible or unreasonably difficult for a disabled person to access a service
- removing, altering or avoiding physical obstacles to access
- providing alternative methods of accessing the service if physical feature(s) make it unreasonably difficult for a disabled person to access it.

Example
Owing to the restricted space in mobile breast screening units, it is more appropriate to offer wheelchair users an appointment at a local static unit that is convenient to them.

1.4 Supporting materials

The original working groups developed five publications that are designed to improve access to screening for disabled women, as follows.

This guidance document is intended for staff who support disabled women (members of primary care teams, community learning disability teams, social services staff and staff in the voluntary sector), for family members, and for staff who provide breast and cervical screening programmes (primary care trust staff, primary health care teams, primary care agency staff, 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 cervical screening practitioners to explain the screening procedure to women when they attend for screening.

The leaflets are available from the Department of Health Publications Orderline, details of which are at the front of this publication. The picture books, *Looking After My Breasts* and *Keeping Healthy 'Down Below'*, are available from the Royal College of Psychiatrists. Details can be found at www.rcpsych.ac.uk.

2. SCREENING PROGRAMMES

2.1 Existing guidance

You Can Make a Difference[2,3] is a simple good practice guide produced by the Department of Health in two versions, one covering primary care services and the other hospital services. The documents outline the implications of the Disability Discrimination Act and the definition of disability (covering both mental and physical impairment). They provide guidance on the kinds of approaches and measures that may be adopted to enable improved access to services, and an enhanced patient/user experience.

Signposts for Success[4] describes good practice in health services for people with learning disabilities. This includes:

- ensuring that the rights of people with learning disabilities 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 that 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 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 a disease; screening is carried out at a regular interval that depends on the natural progression of the disease.[5] 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. The disadvantages are principally psychological in terms of increased anxiety about developing the disease, but may also be physical (eg investigations or treatment of suspected disease which prove to be unnecessary) or social (eg 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 consequences of screening or of not having screening, and should make an informed decision about whether or not to accept the invitation to participate in the screening programme. For disabled women, 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.

It may not always be possible to obtain clear verbal consent to screening from some disabled women, in which case carers and screening staff may be guided by behavioural consent. This can apply some time before screening or immediately before or during the screening appointment itself. Examples of withholding consent may include:

- refusal to accompany a carer to the screening appointment
- refusal to enter the screening unit
- refusal to comply with requests such as undressing
- becoming unduly distressed or agitated
- shying away from staff and/or equipment.

2.5 General principles of capacity to 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 their doctor.

Current Department of Health guidance is set out in the *Reference Guide to Consent for Examination or Treatment.*[6] A copy of this document can be downloaded from the Department of Health website at www.dh.gov.uk. The Mental Capacity Act 2005 has introduced certain legislative changes, and Department of Health guidance will be updated as necessary as part of the implementation programme for this Act.

Explanatory notes to the Mental Capacity Act 2005 can be found at www.opsi.gov.uk.

2.6 Further guidance on consent

Further guidance on the legal issues surrounding consent, including the issues which 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.[7] The General Medical Council has published principles of good practice in *Seeking Patients' Consent: the Ethical Considerations*.[8] There is also discussion of the issues in the Lord Chancellor's consultation document.[9] 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 specifically discuss the issues raised by the breast and cervical screening programmes. Consent to breast or cervical screening is discussed in Chapters 4 and 7, respectively, of this document.

Good practice in assessing consent*

- *Have you spent sufficient time talking with and listening to the person and 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. Evident withholding or withdrawal of consent shown via a woman's behaviour (eg becoming unduly distressed) should be documented.*
- *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.*

*The material from this section is taken from *Once a Day*.[10]

3. DISABILITY

3.1 Definition

The Disability Discrimination Act 1995 defines a disabled person as someone with 'a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities'.

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.

3.2 Range of disabilities

A disability may be mild, moderate, severe or profound, but these adjectives can only very generally suggest the level of disability. People with 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, although many people with learning disabilities struggle with abstract concepts and need help to understand complex ideas. Physical disability arises from a physical impairment that causes substantial and long term effects on a person's ability to carry out normal day to day activities. Physical disability may cover a wide spectrum of conditions, ranging from impairment of the senses (such as sight or hearing) to impairment of physical movement or coordination. Disabled people may live with their family, in residential care or more independently with or without support.

3.3 General improvements to access

It will not always be possible to know about a woman's needs or requirements that arise from a disability before the screening appointment. It is therefore appropriate to try to ensure that simple improvements to accessibility of services and information are already in place, such as:

- invitation letters printed in 14 point font
- essential information such as 'invitation to breast/cervical screening' and contact telephone numbers printed in 18 point font
- a fax number is available
- a Mincom is available
- large print, Braille and audio information is available
- invitation letters that ask clients with specific requirements to contact the unit before the appointment.

3.4 Need for breast and cervical screening

Disabled women 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 disabilities cope well in society, either independently or with support from family or friends. Some, however, have multiple or more severe disabilities. This means that the breast and cervical 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.

Women with physical disabilities may find it difficult to access mobile breast screening units or they may have a problem with maintaining the

required position for obtaining a screening mammogram or a cervical screening sample. Screening staff need to be aware of the potential difficulties such women may face, and ensure that suitable locations and equipment for screening are available to enable women to have the best opportunity to be screened.

3.5 Screening information for women

The NHS Cancer Screening Programmes has produced information about breast and cervical screening to support the good practice recommended in this publication. There are leaflets 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. Two picture books have also been developed in conjunction with St George's Hospital Medical School. These are designed to be used by women with learning disabilities and their supporters, and by staff in the screening programmes, to explain in detail what happens in breast screening and cervical screening. Copies of the picture books have been distributed to all breast screening units and health authorities. Information about screening is also available in audio and Braille formats. Leaflets and tapes are available free of charge from the Department of Health Publications Orderline. The picture books can be purchased from the Royal College of Psychiatrists (www.rcpsych.ac.uk).

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 as a result of cerebral palsy.
- About 30% of people with learning disabilities have significant impairment of their sight, and 40% have significant hearing problems.
- Some people with learning disabilities have little or no 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.

3.6 Using the leaflets and picture books

Family and carers who know an individual woman will be best placed to decide how to use the leaflets and picture books. It is important to bear in mind how much information the woman wants or needs to know. For example, younger women may want to know about breast awareness, and older women who have not previously been screened may want to know that they can request it. At all stages of preparation for screening,

information materials need to be used sensitively to meet individual needs. Although much of the preparation may be between the woman and her supporter, others involved in the screening process must ensure that the woman gets appropriate support from everyone she comes into contact with.

3.7 Additional information – making information accessible

Local services may want to supplement these materials with local health promotion, health awareness or well women work. There is a range of organisations that provide guidance for those who wish to produce information specifically for people with physical and/or learning disabilities. A list of useful organisational contacts can be found in Appendix 1.

4. BREAST SCREENING

4.1 Introduction

Breast screening is a method of detecting some breast cancers at an early stage, often before a woman has any obvious symptoms. The aims of breast screening are to offer more effective treatment and to reduce deaths from breast cancer. 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 70 who are registered with a GP are invited for breast screening every three years. Women aged 70 or over are not invited routinely but are entitled to screening every three years at their own request. 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 1 in 10 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. All women will receive their first invitation to breast screening by their 53rd birthday.

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.[11] Women aged 70 and over are not currently sent a routine invitation but can request a screening appointment every three 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. Women with a physical disability should be able to access breast screening services if at all possible. The aim of the screening programme is to prepare a woman (and any carer or 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

Women with a physical or sensory disability should be able to access information materials on breast screening in an appropriate format in order to decide whether or not to attend for breast screening. Many women with learning disabilities are able to use these materials too, and picture books and leaflets are also available to provide key information in an easily accessible format.

Some women with learning disabilities may not have the capacity to consent to screening in the usual way. In such cases, breast screening staff should check throughout the screening process for behavioural signs that the woman has not withdrawn behavioural consent. This means considering whether:

1. the woman cooperates with the radiographer
2. she becomes agitated or upset
3. she responds to simple requests
4. she becomes unduly anxious.

Withholding or withdrawal of behavioural consent during screening should be documented in the woman's notes, and another screening appointment should be arranged at the usual three yearly interval. Withholding or withdrawal of behavioural consent may also apply before the screening appointment if a woman is clearly reluctant or refuses to attend. The NHSBSP guide *Consent to Breast Screening*[12] gives further guidance.

4.6 Suitability for mammography

Mammography is a procedure which 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 up her head 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 cope in unfamiliar situations and environments, with a familiar supporter if necessary?
3. Is the woman able to comprehend and cooperate with simple requests?
4. Can the woman support herself if she is a wheelchair user?
5. Has the woman sufficient muscle control to maintain the position required?
6. Is the woman able to tolerate discomfort?
7. 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, eg on whether the sides and back are removable, or whether the woman can be transferred to a chair which is suitable for mammography. If a mammogram is not technically possible at a screening appointment, the woman should still remain in the call and recall programme, as any increased mobility at a future date may subsequently facilitate screening.

8. All radiographers working in the NHSBSP are expected to follow the Society of Radiographers' *Statements for Professional Conduct*.[13] This means that a radiographer must not take a mammogram if, in her professional judgement, a woman is physically unsuitable for the procedure or withdraws consent (either verbally or behaviourally) during the screening appointment.

4.7 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.

4.8 Ceasing a woman from the screening programme

A woman should be ceased from breast screening only if she:

- has had a bilateral mastectomy
- is terminally ill, and a screening invitation would be distressing
- has made her own informed choice that she no longer wishes to be invited for breast screening
- is physically unable to be screened, both now and in the future.

In all other instances, a woman should receive an invitation for screening every three years between the ages of 50 and 70. This includes women who have been deemed to withdraw behavioural consent at a previous screening appointment.

4.9 Next best action

If a woman withdraws consent during breast screening for that episode, or a mammogram is not possible, then she (and any 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:

1. encourage the woman to be aware of any changes in her own body
2. encourage the woman to tell someone if she notices any changes
3. know what changes to the normal appearance of breasts to look for while providing personal care.

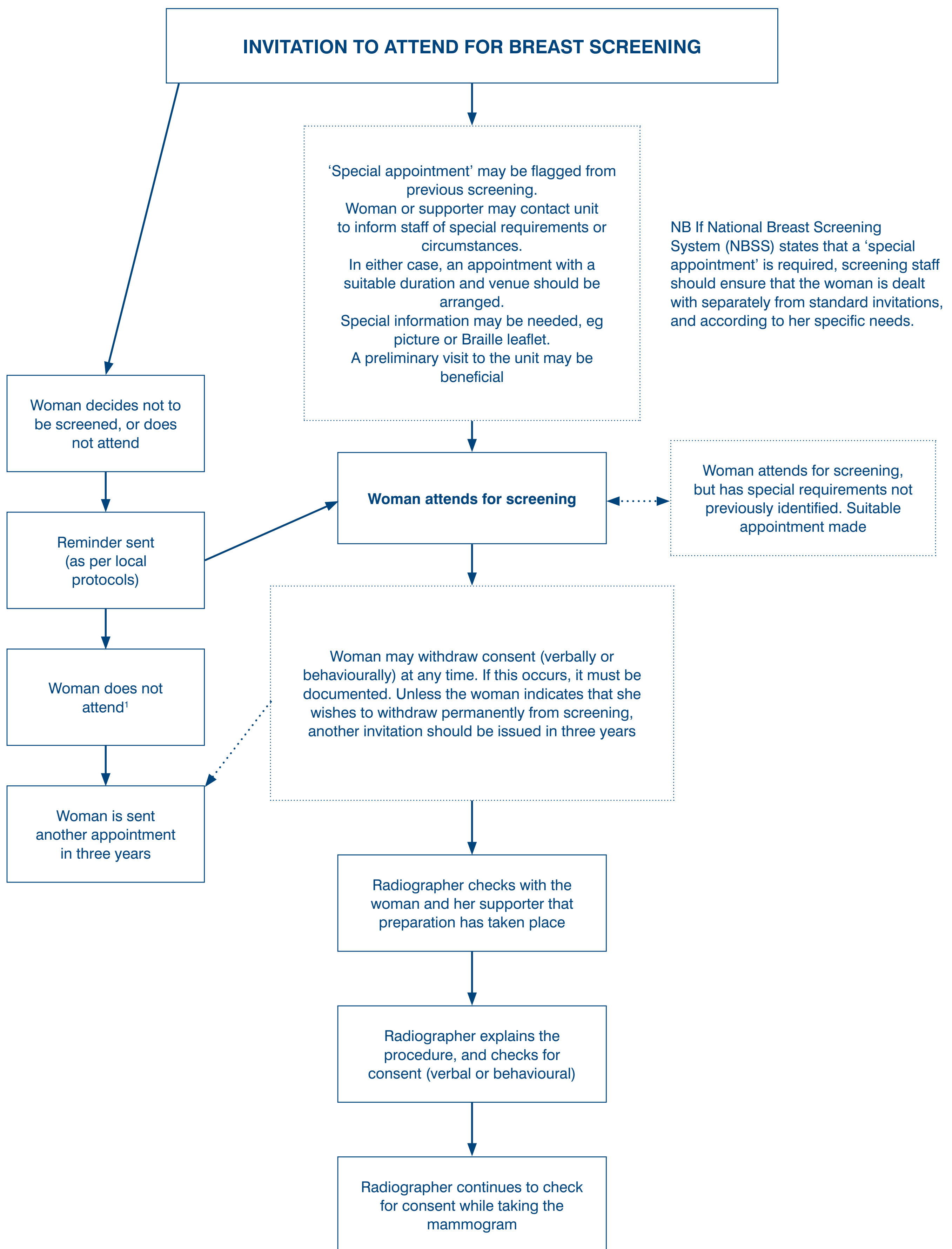

Figure 1 Establishing consent to breast screening.

NB For a woman to be permanently ceased from the screening programme, one or more of the following must apply:
a. she is physically unable to be screened (both now and in the future)
b. she requests that she is removed from the screening register
c. she has had a bilateral mastectomy
d. she is terminally ill, and a screening invitation would be distressing.
In all other cases (including when consent has been withdrawn either before or during previous screening appointments), invitation letters should continue to be sent.

[1]A woman may change her mind and ask for a new screening appointment in the time leading up to the next screening round.

Messages about breast screening

- Breast screening is a routine mammogram offered to well women over the age of 50.
- Women will receive their first invitation for breast screening by their 53rd birthday.
- Disabled women have the same rights of access to breast screening as other women.
- Disabled women are entitled to information in an appropriate format to help them decide whether or not to attend for breast screening.
- Disabled women (and/or their carers) may need to contact the screening unit before their appointment to facilitate effective access to services.
- The aim of breast screening is to reduce mortality by detecting breast cancer at an early stage so it can be treated more effectively.
- Breast screening does not prevent breast cancer.
- Breast screening does not detect all breast cancers.
- Mammography requires a high degree of cooperation between the woman and the radiographer.
- Having a mammogram can cause discomfort, and may be painful for some women.
- For some women, breast screening may cause anxiety or distress.
- For some disabled women, it may not be possible to take a mammogram, but this should be discussed with the radiographer at the screening appointment.
- Most women who attend for breast screening will not be diagnosed with 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 during the intervals between screening, or if screening is not appropriate.

5. GOOD PRACTICE IN BREAST SCREENING

5.1 Preparation for residential care teams and community learning disability teams

Staff and carers need to be aware of:

- what breast screening is, its purpose and which women are eligible to be invited
- the benefits and limitations of breast screening
- what information is available to women and their supporters, in various formats
- the possible consequences of attending or not attending for breast screening
- the issues of consent, both verbal and behavioural
- the possible results from screening, and how to prepare a woman if she is referred for assessment
- the next best action if a woman is not suitable for mammography, ie the concept of breast awareness.

They can make contact with staff at the local breast screening unit, who may be able to provide information and arrange visits to the unit.

5.2 Preparation in breast screening units

Breast screening units should investigate opportunities for training staff about disabilities and equality of access. 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 disabled women. There should be open dialogue between unit staff and disabled women to discuss their needs

5.3 Raising awareness of breast screening

Information about breast screening should be part of health promotion activities for all women. Primary care teams, disability groups and carers should identify to screening units those women with a known disability who are in the age range eligible for breast screening. This gives them the opportunity to provide appropriate advice and information to these women and their supporters.

5.4 Inviting women for breast screening

The breast screening unit sends invitation letters to all women identified as eligible for screening by the primary care trust (PCT). Routine letters include a sentence encouraging women to contact the breast screening unit for advice if they have any concerns or requirements which may make breast screening more difficult for them. Help offered may include:

- an appointment at a static unit where there is more space
- a longer appointment time
- picture leaflets explaining the screening process.

BEFORE THE APPOINTMENT

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, the community disability team and the supporter, depending on the woman's personal circumstances. They must make sure that the woman has a copy of the screening information in an appropriate format. Information is available from breast screening units. The picture book can be used to explain the breast screening process in more detail to women with a learning disability. 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 of 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 information materials.*
- *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 to 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. 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. Disabled women should be offered a longer appointment time, at a static unit. 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 a 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.*

DURING THE APPOINTMENT

5.7 Taking the mammogram

Radiographers need to understand the issues of consent and to know their responsibilities under their *Statements for Professional Conduct.*[13] 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 to decline screening on that occasion. They need to consider whether the preparation adversely influenced the outcome and understand that non-compliance does not mean removal (ceasing) from the screening programme.

Good practice

- *Explain again to the woman what will happen.*
- *Allow time for the woman to express herself.*
- *If verbal communication is limited, 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.*

AFTER THE APPOINTMENT

5.8 Recall for assessment

Breast screening is a two stage process, and around 5% 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 in providing support to women on an individual basis.

Good practice

- *Use appropriate information materials 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.*

6. BREAST AWARENESS

6.1 Breast awareness

Breast awareness is the process of getting to know what is normal as part of a 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 70 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 70 and over should continue to be breast aware.

A leaflet on breast awareness, *Be Breast Aware*,[14] is available from the NHSBSP.

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.

6.2 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.

6.3 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 normally covered by clothes. Bathing and drying is a good time to do this. Feeling and looking in a mirror are a good way 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**.

7. CERVICAL SCREENING

7.1 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 NHSCSP is to reduce the number of women who develop invasive cervical cancer (incidence) and the number of women who die from it (mortality).

7.2 The cervical screening test and results

The cervical screening test is used to examine a sample of cells from the cervix. The standard method for screening was the smear test, in which 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.

This method is being replaced with liquid based cytology (LBC). LBC uses a brush or broom type instrument to collect the cells, and either the brush head or entire instrument is then deposited into a vial for transportation to the laboratory.

The results of the test are notified to the woman and to the screening practitioner (and the GP where this is not the screening practitioner). If the result is normal, the woman is recalled for another test at the routine screening interval (every three years for women aged 25–49, and every five years for women aged 50–64). If the test sample is inadequate (eg because it contains insufficient cells or is obscured by blood or mucus), the woman is asked to come back for a repeat test. If the sample is found to contain mild abnormalities, the woman will either be asked to return for early repeat tests or referred for further investigation (colposcopy). If the sample contains moderate or severe abnormalities, the woman is referred for colposcopy and possible treatment.

7.3 Women registered with a general practitioner

Women between the ages of 25 and 64 who are registered with a GP are invited to have a cervical screening test every three to five years. Women identified as eligible for cervical screening by their PCT are sent a standard letter informing them that a cervical screening test is due and asking them to make an appointment with their GP or alternatively 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.

7.4 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.

7.5 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. Women who smoke are about twice as likely to develop the disease as non-smokers.

However, women who have not had a recent cervical screening 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 cervical screening test.[15] There is still some incidence of cervical cancer among women who have never been sexually active, although the risk is very low.

7.6 Assumptions about sexual activity

It is common for women with a learning disability not to be offered a routine cervical screening test, on the assumption that they have never had sexual intercourse.[16] However, it may not be possible to be certain 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.[17] Similarly, women with a physical disability should have equal access to cervical screening and assumptions should not be made about sexual history.

7.7 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, its purpose and why she has been invited?
2. Does she understand that the test does not always find that something is wrong?
3. Does she understand that a positive test result will mean 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 supporters or health professionals)?

Some women with severe learning disabilities may not have the capacity to give informed consent to cervical screening, even after careful preparation. In such cases, screening may proceed on the basis of behavioural consent. This means that the woman:

1. cooperates with the screening process
2. is not unduly anxious
3. responds to simple requests, such as getting undressed
4. is willing to be positioned
5. does not show undue agitation or distress.

If a woman appears to be withdrawing behavioural consent for screening at any point during the process then the test should be ceased and the reasons documented in the woman's notes. She should be given another routine screening appointment in three to five years' time, as normal. Withholding or withdrawal of behavioural consent prior to the screening appointment may also apply if a woman is clearly reluctant or refuses to attend.

7.8 Suitability for cervical screening

There are some instances in which a woman's disability may make the cervical screening test either difficult or impossible to carry out. This

may include women with limited mobility who are unable to position themselves. Some difficulties may be overcome by:

- offering a screening venue with equipment such as a hoist
- offering a longer screening appointment (there are some medical conditions whereby a woman will be able to comply with screening requirements, given sufficient time).

If a cervical screening test is not technically possible at a screening appointment, the woman should still remain in the call and recall programme, as any increased mobility at a future date may subsequently facilitate screening.

7.9 Checking understanding of cervical screening for learning disabled women

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

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

The screening practitioner may decide not to proceed to carry out the screening test if she thinks that preparation has not been adequate. The attendance on this occasion should be seen as part of the preparation process, and the woman should be given the opportunity for further explanation and consideration before making another appointment to have the screening test.

7.10 Establishing consent

Establishing consent to cervical screening can be a complex process and there are a number of different stages, as described above. Figure 2 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.

7.11 Ceasing a woman from the screening programme

Women should be ceased from the cervical screening programme **only**:

- after the first test following their 60th birthday, if their last three consecutive tests were all negative
- if they are persistent non-responders, in which case they should be ceased for recall on their 65th birthday
- if they have undergone radiotherapy for cervical cancer
- if they have no cervix, ie women with a total hysterectomy, male

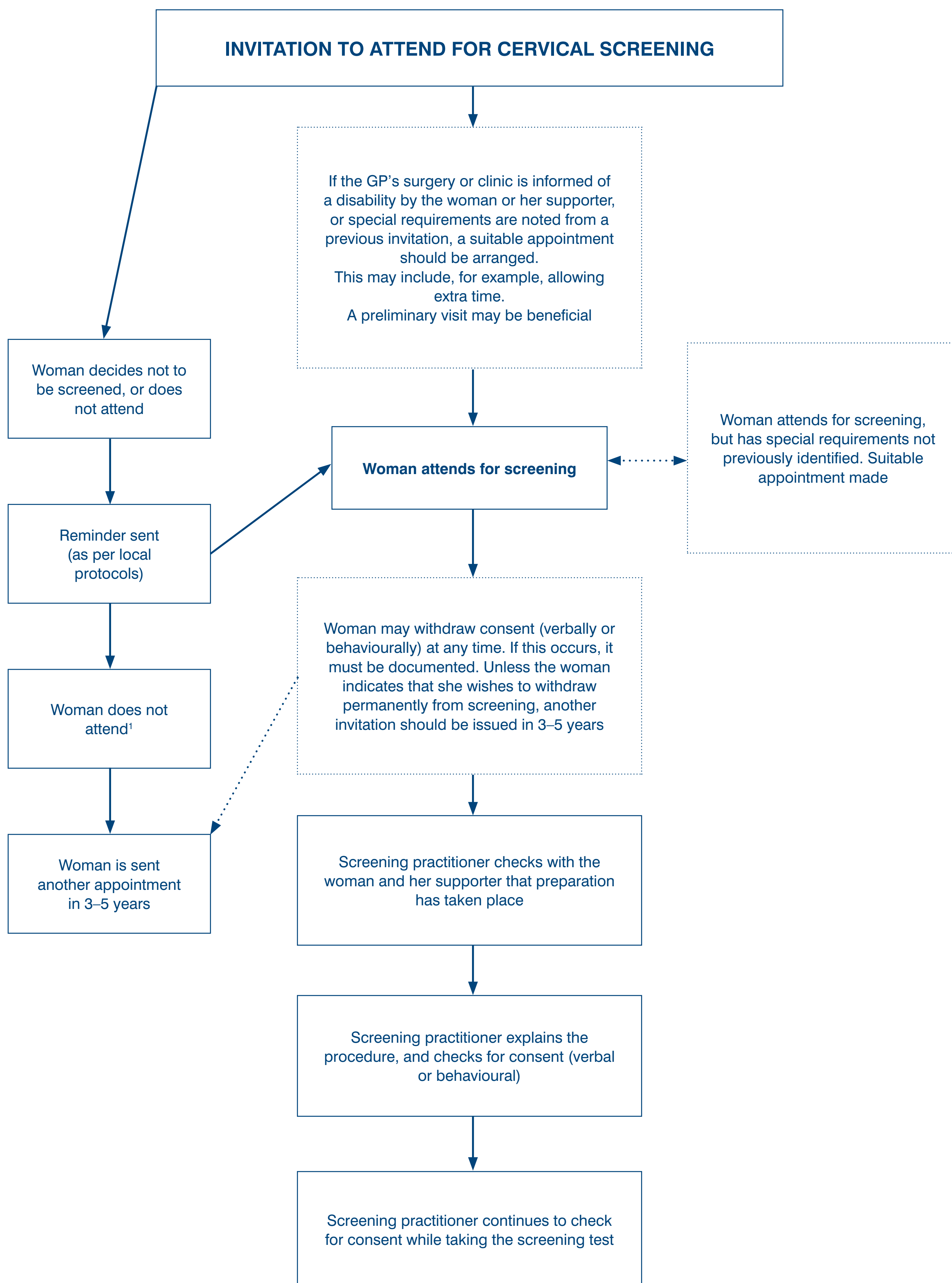

Figure 2 Establishing consent to cervical screening.

NB For a woman to be permanently ceased from the screening programme, one or more of the following must apply:
a. she is physically unable or unsuitable to be screened (both now and in the future)
b. she requests that she is removed from the screening register
c. she is terminally ill, and a screening invitation would be distressing.
In all other cases (including when consent has been withdrawn before or during previous screening appointments), invitation letters should continue to be sent.

[1]A woman may change her mind and ask for a new screening appointment in the time leading up to the next screening round.

to female transsexuals or women with a congenital absence of the cervix.

In all other instances, women should receive an invitation for screening every three years between the ages of 25 and 49, and every five years between the ages of 50 and 64. This includes women who have been deemed to withhold or withdraw behavioural consent at a previous screening appointment.

If a woman decides that she does not want to be invited for any future cervical screening tests, she can be ceased from the programme. It should be emphasised that a 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 a carer/supporter about the woman's history of sexual activity. The NHSCSP guide *Consent to Cervical Screening*[18] gives further guidance.

7.12 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 previously chosen to be ceased can be reinstated at any time at her request. It is suggested that PCTs should undertake a regular audit of women who are ceased from the screening programme to identify those who may have been ceased inappropriately.

7.13 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 cervical screening test 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.

Messages about cervical screening

- Disabled women have the same right of access to cervical screening as other women.
- Disabled women should not be assumed to be sexually inactive.
- Disabled women are entitled to information in an appropriate format in order to make their own decision about whether to attend for 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 intercourse, and having more sexual partners, both increase the risk of developing cervical cancer.
- Smoking increases the risk of developing cervical cancer.
- Having a smear may be embarrassing, uncomfortable or even painful for the woman.

8. GOOD PRACTICE IN CERVICAL SCREENING

8.1 Deciding if cervical screening is important

A woman may need help in deciding whether cervical screening is important for her. A learning disabled 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 screening is introduced. Talking about having a cervical screening test may raise other issues about sexual activity (or sexual abuse) which need to be addressed.

If there is a family carer involved, the carer may have her own personal circumstances and lack of knowledge about cervical screening. Separate discussions with the family carer may be needed to address these issues and to help the carer feel better able to support the woman in making her own choice about going for a 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

- *There should be open dialogue between screening practitioners and disabled women (and carers) to discuss any specific needs.*
- *Offer appropriate information (leaflets and booklets), advice and support to disabled women and their supporters.*
- *Develop client specific action plans in collaboration with the screening practitioner, eg ensuring a suitable screening venue can be made available if special equipment is required.*
- *Include discussion of cervical screening and risk factors for cervical cancer in discussions about healthy living.*

BEFORE THE CERVICAL SCREENING TEST

8.2 Preparing women to have the test

This may be done by a primary care team, a community learning disability team, a 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 information about cervical screening in an appropriate format, eg a picture leaflet for learning disabled women or a large print/Braille version for visually impaired women. The supporter should seek advice from the screening practitioner if there is a concern that a physical disability may prevent a screening test being taken successfully and should 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 test, but staff, carers or paid supporters must understand the issue of valid consent and be clear about how to

proceed if the woman is not able to consent verbally (see section 7.7 on behavioural consent).

Good practice

- *Use appropriate information materials (leaflets, information booklets and client specific story books).*
- *Answer questions honestly to avoid the unexpected.*
- *Emphasise that the woman can choose to have a female screening practitioner.*
- *Arrange a preliminary visit to the surgery or clinic at a quiet time to assess any physical needs and to allow women to become familiar with the surroundings.*
- *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 verbally.*
- *Help women to decide whether or not to go for cervical screening.*

8.3 Preparation for the screening practitioner

Test takers need to be aware of the needs of disabled women and the possible barriers to taking a screening test successfully. They need to understand the issue of consent and be clear about how to proceed if the woman is not able to give clear verbal consent. Local community learning disability teams may be able to arrange training about the needs of learning disabled women for practice nurses who take cervical screening tests.

Good practice

- *Ask disabled women who have been for cervical screening to talk to screening practitioners about their needs.*
- *Encourage one or two practice nurses in a primary care team or group to specialise in working with women with disabilities.*
- *Ensure that screening practitioners who work with disabled women are confident and experienced in cervical screening.*

8.4 Making an appointment to have a cervical screening test

It may be possible to carry out the screening test at the first appointment, but for some disabled women the first appointment will be a preparatory visit before the visit at which the cervical sample is taken. The woman should be given a copy of the leaflet about having a cervical screening test for her to keep.

Good practice

- *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 expectations of a waiting room.*
- *Check that any carer who will accompany the woman understands the screening process.*
- *Discuss issues of consent with the carer.*
- *Consider any physical limitations for women with a physical disability.*
- *Show the screening instruments 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 carry out the screening test if suitable facilities (lighting, couch, etc) are available.*

DURING THE APPOINTMENT

8.5 Carrying out the cervical screening test

Screening practitioners need to understand the issue of consent and to be involved in the preparation of a woman for having her screening test. They need to be comfortable in dealing with disabled women. Screening practitioners should be familiar with best practice in carrying out cervical screening, which is set out in the NHSCSP publication *Taking Samples for Cervical Screening – A Resource Pack for Trainers*.[19]

Good practice

- *Make sure the room is comfortable and private.*
- *Ask the woman if she wants a supporter with her during the screening process.*
- *Allow sufficient time to explain to the woman how the sample is taken using the appropriate information booklet if required.*
- *Respect the woman's privacy and dignity.*
- *Offer the woman a choice of position if physically possible (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 sample 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 sample if the woman needs more reassurance.*
- *Ensure that refusal at any stage before or during cervical screening is seen positively as the woman's choice to refuse the test on this occasion.*
- *Understand that non-compliance does not mean that the woman should be ceased from the screening programme.*

AFTER CERVICAL SCREENING

8.6 Inadequate samples and abnormal test results

If a woman has an inadequate test result (for example when the sample contains insufficient cells or is obscured by blood or mucus), then she is asked to have a repeat test as soon as possible. If the test result shows a mild abnormality, then the woman is asked to have two repeat tests in six and twelve months' time. If the test 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 test 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.

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APPENDIX 1: LIST OF CONTACTS

Action for Blind People
14–16 Verney Road
London SE16 3DZ
Tel: 0207 635 4800
Fax: 0207 635 4900
www.afbp.org

Adult Dyslexia Organisation
336 Brixton Road
London SW9 7AA
Tel: Admin: 0207 737 7646
Help: 0207 924 9559
Fax: 0207 207 7796
www.futurenet.co.uk/charity/ado/adomenu/adomenu.htm

Alzheimer's Disease Society
Gordon House
10 Greencoat Place
London SW1P 1PH
Tel: 0207 306 0606
Fax: 0207 306 0808
www.alzheimers.org.uk

Arthritis Care
18 Stephenson Way
London NW1 2HD
Tel: 0207 380 6500
Fax: 0207 380 6505
www.arthritiscare.org.uk

British Council of Organisations of Disabled People (BCODP)
Litchurch Plaza
Litchurch Lane
Derby DE24 8AA
Tel: 01332 2955551
www.bcodp.org.uk

British Deaf Association (BDA)
1–3 Worship Street
London EC2A 2AB
Tel: 0207 588 3520
Fax: 0207 588 3527
www.bda.org.uk

Carers UK
Ruth Pitter House
20–25 Glasshouse Yard
London EC1A 4JS
Tel: 0808 808 7777
www.carersuk.org

Central England People First
Instrumental House
207–215 Kings Cross Road
London WC1X 9DB
Tel: 01604 721 666
Fax: 01604 721 1011
www.peoplefirst.org.uk

Central Office of Information
Informability Unit
Hercules Road
London SE1 7DU
Tel: 0207 928 2345
www.coi.gov.uk

Centre for Accessible Environments
Nutmeg House
60 Gainsford Street
London SE1 2NY
Tel: 0207 357 8182
www.cae.org.uk

CHANGE
(represents people with learning disabilities and sensory impairment)
Unit Business Centre
Units 19 and 20
26 Roundhay Road
Leeds LS7 1AB
Tel: 0113 242 0202
Fax: 0113 243 0220
Minicom: 0113 245 2225
www.changepeople.co.uk

Council for the Advancement of Communication with Deaf People (CACDP)
Pelaw House
School of Education
University of Durham
Durham DH1 1TA
Tel: 0191 383 1155
Text: 0191 383 7914
Fax: 0191 383 7915
www.cacdp.org.uk

Deafblind UK
100 Bridge Street
Peterborough PE1 1DY
Tel: 01733 358100 (voice)
01773 358858 (text)
Fax: 01733 353356
www.deafblind.org.uk

Department for Education and Skills
Sanctuary Buildings
Great Smith Street
London SW1P 3BT
Tel: 0207 925 5555
Fax: 0207 925 6971
www.dfes.gov.uk

Department of Health
Richmond House
79 Whitehall
London SW1A 2NS
Tel: 0207 210 4850
Fax: 0207 925 6971
www.doh.gov.uk

Diabetes UK
10 Parkway
London NW1 7AA
Tel: 020 7424 1000
Fax: 020 7424 1001
www.diabetes.org.uk

Dial UK
Park Lodge
St Catherine's Hospital
Tickhill Road
Balby
Doncaster DN4 8QN
Tel: 01332 310123
www.dialuk.info

Disability Alliance
1st Floor East
Universal House
88/94 Wentworth Street
London W1 7SA
Tel: 0207 247 8776
Fax: 0207 247 8765
www.disabilityalliance.org

Disabled Living Foundation
370–4 Harrow Road
London W9 2HU
Tel: 0207 289 6111
www.dlf.org.uk

Down's Syndrome Association
The Longdon Down Centre
2a Langdon Park
Teddington
Middlesex TW11 9PS
Tel: 0845 230 0373
Fax: 0845 230 0372
www.downs-syndrome.org.uk

Dyslexia Institute
152 Buckingham Palace Road
London SW1W 9TR
Tel: 01784 222300
Fax: 01704 222333
www.dyslexia-inst.org.uk

Epilepsy Action
New Anstey House
Gateway Drive
Yeadon
Leeds LS19 7XY
Tel: 0113 210 8800
Free phone helpline: 0808 800 5050
www.epilepsy.org.uk

Guide Dogs for the Blind Association (GDBA)
Hillfields
Burghfield
Reading RG7 3YG
Tel: 0118 983 5555
Fax: 0118 983 5433
www.guidedogs.org.uk

Hearing Concern
275–281 King Street
London W6 9LZ
Tel: 0208 233 2929
www.hearingconcern.com

Joint Mobility Unit
105 Judd Street
London WC1H 9NE
Tel: 0207 391 2002
Fax: 0207 387 7109
www.jmuaccess.org.uk

Mencap National Centre
123 Golden Lane
London EC1Y 0RT
Tel: 0207 454 0454
Fax: 0207 696 5540
www.mencap.org.uk

Mind (National Association for Mental Health)
Manor Gardens
London N7 6LA
Tel: 0207 272 6797
www.mind.org.uk

The Multiple Sclerosis Society of Great Britain and Northern Ireland
MS National Centre
372 Edgware Road
London NW2 6ND
Tel: 0208 438 0700
Fax: 0208 438 0701
www.mssociety.org.uk

National Autistic Society
393 City Road
London EC1V 1NE
Tel: 0207 833 2299
Fax: 0207 833 9666
www.nas.org.uk

National Centre for Deafblindness
John and Lucille van Geest Place
Cygnet Road
Hampton
Peterborough
Cambridgeshire PE7 8FD
Tel: 01733 358100
Fax: 01733 358356
www.deafblind.org.uk

National Deaf Children's Society (NDCS)
15 Dufferin Street
London EC1Y 8PD
Tel: 0207 490 8656
Fax: 0207 7251 5020
Minicom: 0207 490 8656
www.ndcs.org.uk

National Development Team
St Peter's Court
8 Trumpet Street
Manchester M1 5LW
Tel: 0161 228 7055
Fax: 0161 228 7059
www.ndt.org.uk

National Information Forum
BT Burne House
Post Point 10/10 Bell Street
London NW1 5BZ
Tel: 0207 402 6681
Fax: 0207 402 1259
www.nif.org.uk

Partially Sighted Society (PSS)
PO Box 322
Queens Road
Doncaster DN1 2NX
Tel: 01302 323132/01302 368998
Fax: 01302 365998

Rethink Severe Mental Illness
30 Tabernacle Street
London EC2A 4DD
Tel: 0207 330 9100
Fax: 0207 330 9102
www.rethink.org

Royal Association for Deaf People (RAD)
27 Old Oak Road
London W3 7HN
Tel: 01206 509 509
Text: 01206 577 090
Fax: 01206 769 755
www.royaldeaf.org.uk

Royal Association for Disability and Rehabilitation (RADAR)
12 City Forum
250 City Road
London EC1V 8AF
Tel: 0207 250 3222
Fax: 0207 250 0212
www.radar.org.uk

Royal Institute for the Blind (RNIB)
Royal National Institute of the Blind
105 Judd Street
London WC1H 9NE
Tel: 020 7388 1266
Fax: 020 7388 2034
www.rnib.org.uk

SCOPE
(for people with cerebral palsy)
6 Market Road
London N7 9PW
Tel: Helpline: 0808 800 3333
Media Enq.: 0207 617 7200
www.scope.org.uk

Sense
11–13 Clifton Terrace
Finsbury Park
London
Tel: 0207 272 9648 (text/phone)
Fax: 0207 272 6012
www.sense.org.uk

Spinal Injuries Association
3rd Floor, Acorn House
387–391 Midsummer Boulevard
Milton Keynes MK9 3HP
Tel: 0845 678 6633
www.spinal.co.uk