

# Cervical Screening for Women with Learning Disabilities

## Information for Primary Health Care Teams in Gloucestershire

(Report compiled by Esia Dean and Kevin Elliott – March 2006)

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This paper is based on the NHS Cancer Screening Programme - 'Good Practice in Breast and Cervical Screening for Women with Learning Disabilities' document, (NHSBSP Publications 2000).

The purpose of this guidance is to describe best practice to ensure that women with learning disabilities have the same rights to access the NHS Cervical Screening Programme. It is aimed at health professionals from Primary Health Care and Learning Disability Services.

Cervical cancer is the commonest cancer in women aged less than 35 years.

In 1988 the NHS Cervical Screening Programme (CSP) was set up with the aim of reducing the incidence and mortality of invasive cervical cancer by the detection and treatment of pre-invasive disease.

The incidence of cervical cancer has since fallen by 26% over the last 5 years.

A number of studies however have identified a low uptake of cervical screening in women with learning disabilities, ranging between 13% and 25%. A study carried out by MENCAP in 2000 revealed that out of 560 women aged 20 - 70 years, only 25% had ever had a cervical smear. The majority of the remaining 75% had been 'ceased' by their General Practitioner.

The term 'ceased recall' is used by the NHS CSP to identify women whose name has been permanently removed from the recall system.

A women can choose to be ceased from recall for clinical reasons. A high number of women with learning disabilities are ceased from the cervical screening programme.

A study in Shropshire highlighted that the main 'clinical reasons' why women with a learning disability were ceased from CSP were:

- low or no sexual activity
- unable to understand the procedure or give consent

- unable to undertake the procedure
- due to their 'medical condition'.

Having a learning disability alone is not a valid reason for ceasing women from the programme. Nor can a parent or carer make this decision on behalf of an adult woman. It must be assumed that every adult has the capacity to consent until proven otherwise.

The woman should be assisted in making an informed choice about whether or not to participate in the programme. Accessible, easy read materials are available to maximise capacity and assist understanding;

[www.cancerscreening.nhs.uk](http://www.cancerscreening.nhs.uk)

[www.intothemainstream.cswebsites.org](http://www.intothemainstream.cswebsites.org)

[http://www.nhslothian.scot.nhs.uk/health\\_promotion/resources/library/library\\_leaflet.pdf](http://www.nhslothian.scot.nhs.uk/health_promotion/resources/library/library_leaflet.pdf)

### Consent and Best Interest

( see **appendix 3** for 10 key points on Consent and People with Learning Disabilities.

If a woman with a learning disability does not demonstrate the capacity to understand the procedure ( whether complacent or actively dissenting ), it is the health professionals responsibility to determine a course of action that is in the patients best interest, using a multidisciplinary approach and following the new Mental Capacity Act (2005) checklist:

1. Will capacity be regained in the future?
2. Has the person been involved to their maximum extent?
3. Has regard been paid to the past and present wishes and beliefs and values?
4. Have the views of significant others been taken into account?
5. Can the procedure be carried out in a less restrictive way?
6. Has the person been appropriately informed of the proposed treatment in a manner understandable to them?
7. Have all practical steps been taken to enable the person to communicate their choice?
8. Have all decisions regarding consent and capacity been documented in patient notes?

The issue of consent is central to any screening programme and the aim of any screening programme is to do more good than harm, but the balance for each particular individual is a personal one and should be assessed on an individual basis. 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.

Unlike other forms of health 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.

### Barriers to cervical screening for women with learning disabilities

- The assumption that women with learning disabilities are not sexually active.
- Some women with learning disabilities may be unaware of their own sexual health needs.
- They may be ill prepared for the examination - (anxiety + confusion).
- There may be communication problems (50% of people with learning disabilities have difficulty communicating their needs).
- Lack of assertiveness and confidence.
- Reliance on written information.
- Time pressures - women with a learning disability may need a longer appointment time and the procedure should not be rushed.

### Benefits & disadvantages of screening

There are disadvantages to screening as well as benefits. These include:

- Psychological - in terms of increased anxiety about developing the disease,
- Physical - for example, investigations or treatment of suspected disease that prove to be unnecessary
- Social - for example, stigma associated with testing.

### Sexual Activity in Women with learning disabilities

"All women have the right to mature sexually, become sexually active and develop relationships with a person of their choice".

- Healthcare professionals often assume that people with learning disabilities are not sexually active.
- Carers and parents may not wish to accept that their child or client is sexually active.
- Women with learning disabilities often have their rights denied.
- The culture within care situations may drive sexual activity underground.
- Some women will not have access to appropriate information about sexual health issues.
- Women with learning disabilities are vulnerable to sexual abuse (8% - 58%) and are therefore at risk of developing cervical cancer.

## Recommendations:

- Smear takers need to be aware of the needs of women with learning disabilities by introducing specific training as part of the local screening education programmes, (which would include consent issues and ceased recall).
- All general practices and providers who undertake smears should follow the guidance, "Good Practice in Breast and Cervical Screening for women with learning disabilities". (NHS Cancer Screening Programmes October 2000).  
[www.cancerscreening.nhs.uk](http://www.cancerscreening.nhs.uk)
- The NHSCSP Good Practice guidelines should be readily available in all practices and provider work places offering cervical screening.
- Easy read information packages should be made available to women with learning disabilities to help them to fully understand the procedure.  
(Information available from the Gloucestershire Learning Disability Health Facilitation Team - 07876 548827).
- Invitations to the practice for cervical smear tests need to be simple and clear and easy to read with pictures illustrating the message.
- Effective preparation before the procedure will minimise individual's anxieties and fears.
- Eligibility for the cervical screening programme must be a carefully made, multidisciplinary decision.
- Extra time for preparation and explanation of the procedure should be considered.
- For women with a severe learning disability, who do not demonstrate a capacity to consent to the procedure, the 'best interest' option must apply. (see [appendices](#)).

### 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.

Appendix 1 Issues for consideration in 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 (i.e. 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 the risks of developing cervical cancer?
2. Encourage woman to tell someone if she notices any changes.

### Box 5 Check understanding of cervical screening

2. Does the woman have a basic understanding of why smears are taken?
3. Has she had a smear before?
4. Has she been invited for a routine smear, or follow-up smear after a previous smear.
5. Has she seen a copy of the picture leaflet?
6. 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?

**[NHS organisation name]  
consent form 4**

**Form for adults who are unable to  
consent to investigation or treatment**

**Patient details (or pre-printed label)**

Patient's surname/family name.....

Patient's first names .....

Date of birth .....

Responsible health professional.....

Job title .....

NHS number (or other identifier).....

☐ Male

☐ Female

Special requirements .....  
(eg other language/other communication method)

To be retained in patient's notes

**Patient identifier/label**

**All sections to be completed by health professional proposing the procedure**

**A Details of procedure or course of treatment proposed**

(NB see guidance to health professionals overleaf for details of situations where court approval must first be sought)

**B Assessment of patient's capacity**

**I confirm that the patient lacks capacity to give or withhold consent to this procedure or course of treatment because:**

- ☐ the patient is unable to comprehend and retain information material to the decision; and/or
- ☐ the patient is unable to use and weigh this information in the decision-making process; or
- ☐ the patient is unconscious

Further details (excluding where patient unconscious): for example how above judgements reached; which colleagues consulted; what attempts made to assist the patient make his or her own decision and why these were not successful.



## **C Assessment of patient's best interests**

**To the best of my knowledge, the patient has not refused this procedure in a valid advance directive. Where possible and appropriate, I have consulted with colleagues and those close to the patient, and I believe the procedure to be in the patient's best interests because:**

(Where incapacity is likely to be temporary, for example if patient unconscious, or where patient has fluctuating capacity)

**The treatment cannot wait until the patient recovers capacity because:**

## **D Involvement of the patient's family and others close to the patient**

The final responsibility for determining whether a procedure is in an incapacitated patient's best interests lies with the health professional performing the procedure. However, it is good practice to consult with

those close to the patient (eg spouse/partner, family and friends, carer, supporter or advocate) unless you have good reason to believe that the patient would not have wished particular individuals to be consulted, or unless the urgency of their situation prevents this. "Best interests" go far wider than "best medical interests", and include factors such as the patient's wishes and beliefs when competent, their current wishes, their general well-being and their spiritual and religious welfare.

(to be signed by a person or persons close to the patient, if they wish)

**I/We have been involved in a discussion with the relevant health professionals over the treatment of.....(patient's name). I/We understand that he/she is unable to give his/her own consent, based on the criteria set out in this form. I/We also understand that treatment can lawfully be provided if it is in his/her best interests to receive it.**

Any other comments (including any concerns about decision)

Name ..... Relationship to patient.....

Address (if not the same as patient).....  
.....  
.....

Signature ..... Date.....

If a person close to the patient was not available in person, has this matter been discussed in any other way (eg over the telephone?)

☐ Yes ☐ No

**Details:**

## **Signature of health professional proposing treatment**

The above procedure is, in my clinical judgement, in the best interests of the patient, who lacks capacity to consent for himself or herself. Where possible and appropriate I have discussed the patient's condition with those close to him or her, and taken their knowledge of the patient's views and beliefs into account in determining his or her best interests.

I have/have not sought a second opinion.

Signature:..... Date .. .....  
Name (PRINT) ..... Job title .....

## **Where second opinion sought, s/he should sign below to confirm agreement:**

Signature:..... Date .. .....  
Name (PRINT) ..... Job title .....

## **Guidance to health professionals** (to be read in conjunction with consent policy)

This form should only be used where it would be usual to seek written consent but an adult patient (18 or over) lacks capacity to give or withhold consent to treatment. If an adult **has** capacity to accept or refuse treatment, you should use the standard consent form and respect any refusal. Where treatment is very urgent (for example if the patient is critically ill), it may not be feasible to fill in a form at the time, but you should document your clinical decisions appropriately afterwards. If treatment is being provided under the authority of Part IV of the *Mental Health Act 1983*, different legal provisions apply and you are required to fill in more specialised forms (although in some circumstances you may find it helpful to use this form as well). If the adult now lacks capacity, but has clearly refused particular

treatment in advance of their loss of capacity (for example in an advance directive or ‘living will’), then you must abide by that refusal if it was validly made and is applicable to the circumstances. For further information on the law on consent, see the Department of Health’s *Reference guide to consent for examination or treatment* ([www.doh.gov.uk/consent](http://www.doh.gov.uk/consent)).

### **When treatment can be given to a patient who is unable to consent**

For treatment to be given to a patient who is unable to consent, the following **must** apply:

- the patient must lack the capacity (‘competence’) to give or withhold consent to this procedure AND
- the procedure must be in the patient’s best interests.

### **Capacity**

A patient will lack capacity to consent to a particular intervention if he or she is:

- unable to comprehend and retain information material to the decision, especially as to the consequences of having, or not having, the intervention in question; and/or
- unable to use and weigh this information in the decision-making process.

Before making a judgement that a patient lacks capacity you must take all steps reasonable in the circumstances to assist the patient in taking their own decisions (this will clearly not apply if the patient is unconscious). This may involve explaining what is involved in very simple language, using pictures and communication and decision-aids as appropriate. People close to the patient (spouse/partner, family, friends and carers) may often be able to help, as may specialist colleagues such as speech and language therapists or learning disability teams, and independent advocates or supporters.

Capacity is ‘decision-specific’: a patient may lack capacity to take a particular complex decision, but be quite able to take other more straight-forward decisions or parts of decisions.

### *Best interests*

A patient’s best interests are not limited to their best medical interests. Other factors which form part of the best interests decision include:

- the wishes and beliefs of the patient when competent
- their current wishes
- their general well-being
- their spiritual and religious welfare

Two incapacitated patients, whose *physical* condition is identical, may therefore have different best interests.

Unless the patient has clearly indicated that particular individuals should not be involved in their care, or unless the urgency of their situation prevents it, you should attempt to involve people close to the patient (spouse/partner, family and friends, carer, supporter or advocate) in the decision-making process. Those close to the patient cannot require you to provide particular treatment which you do not believe to be clinically appropriate. However they will know the patient much better than you do, and therefore are likely to be able to provide valuable information about the patient’s wishes and values.

### *Second opinions and court involvement*

Where treatment is complex and/or people close to the patient express doubts about the proposed treatment, a second opinion should be sought, unless the urgency of the patient’s condition prevents this. Donation of regenerative tissue such as bone marrow, sterilisation for contraceptive purposes and withdrawal of artificial nutrition or hydration from a patient in PVS must never be undertaken without prior High Court approval. High Court approval can also be sought where there are doubts about the patient’s capacity or best interests.

## 10 key Points on Consent and People with Learning Disabilities

### WHO CAN GIVE CONSENT?

1. No-one can give consent on behalf of another adult with learning disabilities. Parents/relatives or carers should not be asked to sign consent forms
2. It must be assumed that every adult has the capacity to consent. The presence of a learning disability or a communication difficulty does not in itself imply incapacity. Many people with learning disabilities can make decisions and express their choices through non-verbal methods of communication.

Consent can be given non-verbally, verbally or in writing.

### VALID CONSENT

3. A signature on a consent form does not itself prove that consent is valid. To give valid consent a person must be able to demonstrate the following 4 stages:
  - a) Understand and retain the information.
  - b) Communicate their choice.
  - c) Understand the risks, benefits, alternatives and consequences.
  - d) Weigh up the information to make a decision.
4. For consent to be valid it must be demonstrated that information has been shared with the patient, about the proposed intervention, in a format that is understandable to the patient. For example, if the person cannot read then photographs or symbols or pictures may be appropriate.

5. To enable patients with a learning disability to make valid decisions about their health, capacity can be maximised by using the following techniques:
  - Using simple language, (key words).
  - Using illustrations, photographs or practical demonstrations (role play).
  - Present information in small chunks.
  - Allow plenty of time and encourage question asking.
  - Check level of understanding using the preferred method of communication.

### WHO DECIDES?

6. The health professional carrying out the procedure or intervention is ultimately responsible for ensuring that the patient is genuinely consenting. However, this should not be a decision made solely, and opinions of significant others including family, carers and other health professionals should be taken into consideration.

### BEST INTEREST

7. The lack of capacity in a person unable to make a decision to a given procedure or intervention, does not imply consent. It places a duty on health professionals to determine a course of action that is in the person's best interest by asking the following questions:
  1. Will capacity be regained in the future?
  2. Has the person been involved to their maximum extent?
  3. Has regard been paid to the past and present wishes and beliefs and values?
  4. Have the views of significant others been taken into account?
  5. Can the procedure be carried out in a less restrictive way?
  6. Has the person been appropriately informed of the proposed treatment in a manner understandable to them?
  7. Have all practical steps been taken to enable the person to communicate their choice.
  8. Have all decisions regarding consent and capacity been documented in patient notes?

8. **DOH CONSENT FORM 4** - for adults who are unable to consent to investigation or treatment. This form must be completed for every significant intervention/procedure carried out on a patient who does not demonstrate the capacity to give or withhold their consent

### ADVANCE DIRECTIVES

9. Where an adult patient lacks the mental capacity to give or withhold consent, treatment may be given in their best interest as long as it has not been refused in advance in a valid advance directive. If competent when making the Advance Directive, it is legally binding and treatments can be refused. If adult incapacitated when making advance directives, these are not legally binding but should influence any 'best interest' decisions.

### MENTAL CAPACITY ACT - 2005

10. The new Mental Capacity Act will become Law in 2007. The act places a duty of care on professionals to assess each intervention on a 'decision - specific' basis and provides a best interest checklist. The Act defines the law around restraint, restriction of liberty and restriction of movement and introduces a five year prison sentence for the ill treatment of a person who lacks capacity.