

Best Practice Guidance for the Management of Women with a 'Lack of Capacity' within the NHS Cervical Screening Programme

FINAL

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1. Purpose of the Document

This document is intended to provide advice to professionals in the North East, Yorkshire and The Humber region when receiving requests to cease women with a lack of capacity from the NHS Cervical Screening Programme. This document is intended to support the NHS Cancer Screening Series No. 4: Consent Cancer Screening and the two documents should be read in conjunction. This document is specific only to the North East, Yorkshire and The Humber region and has been developed following Guidance from the NHS Cancer Screening Programme in light of Mental Capacity Act 2005.

The Mental Capacity Act was developed to protect people who cannot make their own decisions about some things, for example people with learning disabilities or mental health problems, and is referred to as "lacking capacity".

Primary Care Trusts should manage all requests to cease women deemed as having the lack of capacity to make such decisions in accordance to the guidance given here and in line with the Mental Capacity Act 2005.

2. Defining 'Lack of Capacity'

The Mental Capacity Act provides professionals with advice on how to assess whether an individual has a lack of capacity to make a decision. It states that it should be assumed that the woman has capacity unless it is proved otherwise. This decision will be made following an assessment detailed in the Mental Capacity Act, and the mental capacity act advises that:

- Individuals should be supported to make their own decisions – a person must be given all practicable help before anyone treats them as not being able to make their own decisions;
- Unwise decisions – just because an individual makes what might be seen as an unwise decision, they should not be treated as lacking capacity to make that decision;
- Best interests – an act done or decision made under the Act for or on behalf of a person who lacks capacity must be done in their best interests; and

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- Least restrictive option – anything done for or on behalf of a person who lacks capacity should be the least restrictive of their basic rights and freedoms.

Women who may be deemed as having a 'Lack of Capacity' to make decisions on attending NHSCSP screening or treatment may include the following:

- people with dementia
- learning disabilities
- mental health problems
- stroke or head injuries
- debilitating terminal illness which result in a lack of decision making

3. Best Interest Decisions

A best interest decision is an act done or decision made for or on behalf of a person who lacks capacity which is deemed in that person's best interests. The Mental Act recommends the following factors be considered when deciding what is in a person's best interests:

1. Encourage Participation in decision making.
2. Identify all the things that the person who lacks capacity would take into account if they were making the decision or acting for themselves.
3. Try to find out the views of the person who lacks capacity including past wishes, religious/cultural values and other factors.
4. Avoid discrimination with relation to age, appearance, condition or behaviour.
5. Consider whether the person is likely to regain capacity (e.g. after receiving medical treatment). If so, can the decision wait until then?
6. Not be motivated in any way by a desire to bring about the person's death. They should not make assumptions about the person's quality of life.
7. Consult people for their views about the person's best interests and to see if they have any information about the person's wishes and feelings, beliefs and values.
8. Avoid restricting the person's rights

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All the above should be considered when making a best interest decision both in relation to ceasing a woman from the NHS Cervical Screening Programme and when considering treatment required.

4. Who can make a Best Interest Decision

The following individuals are capable of making a Best Interest Decision on behalf of the woman:

- Lasting Power of Attorney
- Deputy appointed by the Court of Protection
- Independent Mental Capacity Advocate (IMCA)
- Responsible healthcare professional as part of a care team

Care Teams

In exceptional circumstance a care team can make the decision to cease a woman under the Mental Capacity Act: Best Interest decision. The Care team will comprise of at least the professional responsible for the woman's health care (usually her GP) and any or all formally appointed decision-makers. The care team are expected to consult the family and close friends of the woman to ensure all relevant information and opinions are taken into account. On occasions where a care team is charged with making this decision it is important that the process is well documented for future reference. This must include the decision taken, the information reviewed, how the care team came to the decision and the individuals consulted.

5. Advance Decision Making

Where a woman has previously made an advance decision in relation to the Cervical Screening Programme while they had the capacity to do so, their advance decision should be respected when they lack capacity. Even on those occasions where it is felt that the decision to refuse treatment/participation is not in their best interests this advance decision should be adhered to.

6. Managing a Request to Cease under 'Lack of Capacity'

A request to cease a woman under the Mental Capacity Act may be received in a number of ways e.g. on a Prior Notification List, via a telephone call or a letter. All requests should be managed in a uniform way in adherence with the flow-chart in appendix 3 and should be fully documented.

Once a request is received at the Call/Recall office the Screening Office Manager will inform the relevant Primary Care Trust Screening Lead and an audit log will be created. This will record the date that the request is received and the date that the PCT Screening Lead was informed.

A copy of the letter given in appendix 1 is sent from the Screening Office Manager to the individual requesting to cease along with a copy of 'Cervical Screening – The Facts' and 'Who decides when you can't?' leaflets. This requests that the individual details the reason why they feel ceasing is within the woman's best interest, their relationship to the individual and asks that they sign to take responsibility for ceasing. The Screening Office Manager records the date of this letter on the audit log. The letter and leaflets are intended to encourage women to continue to receive invites, and refers them to the local disability team.

When a response is received the Screening Office Manager records the date that the information is received and sends it to the PCT Screening Lead. They will consider the reason for ceasing and the ability of the individual to cease the woman. The decision to cease will only be agreed if it is in line with NHSCSP Ceasing guidelines. Where the individual is signing to take responsibility the PCT Screening Lead should confirm details such as current lasting powers of attorney. This information is available from the Office of Public Guardian. A record should be kept of the date the information is sent to the PCT Screening Lead and dates relating to confirmation of whether the individual is or is not able to make a best interest decision.

If no response to this letter is received the woman will automatically remain within the Screening Programme, and a note recorded in the audit log.

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The PCT Screening Lead will make the decision as to whether the woman can be ceased from the Programme. They will then send email instruction to the Screening Office Manager stating whether the woman is to remain on recall or be ceased from the programme. This information should be recorded in the audit log.

A letter should be sent from the PCT Screening Lead to the individual requesting the ceasing (with a copy to the GP), indicating if the woman has been ceased, and where she has remained on recall detailing the reason why they have not been ceased. Dates of these letters should be recorded in the audit log.

It is recommended that PCTs consider sending a letter to the woman being ceased (appendix 2) informing her that she has ceased from the programme following a request under a Best Interest decision. This will also include the name of the person who requested that she be ceased. If this woman responds to the letter to request that they remain within the

Once the agreement to cease under a Best Interest decision, the Screening Office Manager will cease the woman from the programme using the MCA ceasing code.

7. Documentation

The Screening Office Manager should retain copies of all documentation on behalf of the Primary Care Trusts as part of the management of the Call/Recall programme. It is recommended that a log be used to record all information and that a file be compiled for each request. These should be kept in a lockable cabinet.

8. References

1. *Consent to Cancer Screening*: NHSCSP Cancer Screening Series No. 4; January 2008
2. *Mental Capacity Act 2005: Code of Practice*: Issued by the Lord Chancellor on 23 April 2007 in accordance with sections 42 and 43 of the Act
3. *Making decisions about your health, welfare and finances... Who decides when you can't?* Information Leaflet 2007

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4. *Mental Capacity Act: Easy Read Summary*: Information Leaflet 2007

Appendix 1: Letter to Individual to Cease under Best Interest

NHS Cervical Screening Programme
[Call & Recall Office]
[Address 1]
[Address 2]
[Town], [Postcode]

Dear

Re: *PATIENT DETAILS*

We have received a request (*INSERT FORM OF REQUEST*) to cease the above patient from the NHS Cervical Screening Programme. It has been indicated that this woman is classed as having a lack of capacity and that you have made this request in your capacity as *LASTING POWER OF ATTORNEY/A DEPUTY APPOINTED BY THE COURT OF PROTECTION/AN INDEPENDENT MENTAL CAPACITY ADVOCATE (IMCA)/THE RESPONSIBLE HEALTHCARE PROFESSIONAL AS PART OF A CARE TEAM*.

Women aged 25 to 49 are invited for cervical screening every three years, and women aged 50 to 64 are invited every five years. The risk of contracting cervical cancer can be significantly reduced by having regular screening.

I understand that you do not wish the NHS Cervical Screening programme to invite the above patient for future screening tests. I enclose the leaflet *Cervical Screening: The Facts* which explains the benefits and disadvantages of cervical screening, and the importance of screening in reducing deaths from cervical cancer. If you need further information please do not hesitate to contact your General Practitioner (GP).

It should be remembered that the individual responsible for the decision to proceed with (or withhold) screening in someone's best interest must be able to justify the decision should it be challenged. To this end, any decision to screen or withhold screening due to best interests decisions should be clearly documented, including detailed information on why the decision was considered to be in the individual's best interest. Enclosed is a copy of the leaflet *Who decides when you can't?* which provides additional information.

Support in making this decision can be gained from the *TITLE* Learning Disability Team. Your local contact is *NAME* who is available on *TELEPHONE NUMBER*.

We need your written instruction to remove the above woman from the list of women invited for cervical screening. I would be grateful, therefore, if you could **sign and return** the lower part of this letter to confirm **along with the evidence for the reason for ceasing** that you have the legal responsibility to make a best interest decision on behalf of *PATIENT NAME* and that you do not want her to receive any future invitations to be screened for cervical cancer or any further information about the NHS Cervical Screening Programme.

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We will send you and *PATIENT NAME*'s General Practitioner written confirmation when she has been removed from the screening list.

If you wish to restore the above woman to the screening list at any time, please contact the woman's GP who will be able to support you in this matter.

You may wish to keep the top part of this letter for future reference.

Yours sincerely,

Screening Programme Manager

Call & Recall Office

To: [Screening Programme Manager], [Call & Recall Office]

Please do not send *PATIENT NAME* any further invitations to participate in the NHS Cervical Screening Programme. I _____ assume full responsibility for this decision in a Best Interest Capacity and confirm that I have understood the leaflet *Cervical Screening: The Facts* which explains the benefits and disadvantages of cervical screening and the importance of screening in preventing cervical cancer and reducing deaths from it. **I have enclosed the relevant documentation to support this request.**

I understand that *PATIENT NAME* can be restored to the screening list at any time at my request to her GP.

Patient Name:
Patient NHS No.:
Patient Date of birth:
Patient Address:
.....

Name
Capacity under which Best Interest Decision is undertaken (delete as appropriate):
Lasting Power of Attorney / deputy appointed by the Court of Protection / Independent Mental Capacity Advocate (IMCA) / the responsible healthcare professional as part of a care team

I certify that it is in the best interest of the above woman that they are ceased from the NHS Cervical Screening Programme due to:

.....

Address:
.....
.....

Signed:
Dated:

Appendix 2: Letter to confirm ceasing to woman

NHS Cervical Screening Programme
[Call & Recall Office]
[Address 1]
[Address 2]
[Town], [Postcode]

Dear *PATIENT DETAILS*

Re: Ceasing from the NHS Cervical Screening Programme

At the request of *INSERT NAME OF PERSON REQUESTING THAT THE WOMAN IS CEASED* I have removed your name from the database and you will not receive any further invitations for cervical screening. This person has requested that you are ceased as a Best Interest request, I have enclosed a leaflet explaining this.

If you do not agree with this decision, or want to receive cervical screening invitations again at any point in the future, please contact the office at the details above.

Yours sincerely,

Screening Programme Manager

Call & Recall Office

Appendix 3: Flow chart

