

Reviewing your cervical screening history

Information for patients diagnosed with cervical cancer

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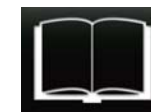
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A patient's guide



.... caring for you 

Reviewing your cervical screening history

We realise this is a difficult time for you and we would like to offer you as much support as possible. This leaflet provides information about what happens when we review your screening history and why it is important. You will be required to fill out the form on the back page of the leaflet to tell us if you would like to discuss the results of your review.

Cervical screening reduces the risk of developing cervical cancer. The cervical screening test (smear test) is part of the cervical screening programme and aims to identify and treat early changes to the cervix and prevent cervical cancer.

As you have been diagnosed with cervical cancer, your screening history will automatically be reviewed.

The cervical screening process involves many different steps, including the smear test. It may be that despite all steps being followed efficiently, a cervical cancer has still developed. Or it could be that something may not have worked as well as it should. For each individual case the review aims to find out whether anything should have been done differently.

Reviews are essential for every high-quality screening programme and are a routine part of the cervical screening process. The information we gather from individual cases helps us to improve the programme.

When we review your cervical screening history, we will check all records of previous medical investigations and tests related to cervical screening.

Further information regarding the Caldicott Principles is available from the following web site:

<http://www.doh.gov.uk/confiden/cgmintro.htm>

Section 251 of the NHS Act 2006 replaces Section 60 of the Health and Social Care Act 2001. It provides relief from the common law duty of confidentiality which requires that patient identifiable data is only used with consent.

References

Cancer screening Series No 3, April 2006. Disclosure of Audit Results in Cancer Screening.

West Midlands Cervical Screening Quality Assurance Reference Centre Publication No C07/09. Guidance for the Disclosure of Audit Results in Cancer Screening.

After reading this leaflet we would like you to decide whether or not you would like to know the result of the review. You can either hand the signed leaflet to a member of the treating team or return it to the address shown on the form.

If you want to know the results we will contact you to arrange a convenient time for you to discuss the results with your doctor or a specialist nurse. Normally the review is completed within six months of your diagnosis. You may also discuss the matter with your GP, who has been informed of your results.

What does the review involve?

We review all your records from cervical screening tests and any previous medical investigations related to cervical screening. We also look again at all your smear tests from the last 10 years as well as any related samples, such as biopsies or previous treatments.

Who carries out the review?

This is done by a group of professionals from the local cervical screening team. They will also examine whether your screening history meets national guidelines. The review of your previous tests may involve them being sent for assessment by a team not connected with our hospital. This will be dealt with in a totally confidential manner so that your personal details cannot be identified in any way.

What will the review show?

In most cases, the review will show that the correct procedures have been followed and that you received appropriate care. Occasionally, the review may show that one or more steps in the process have not worked as well as they should and may highlight where improvements could be made for everyone.

What happens if I want to know the results of the review?

If you want to know the results of the review, fill in the form on page seven and hand it to the specialist nurse or return it to the address on the form. Your doctor will let you know when the outcome is available and will arrange to discuss the results with you at a convenient time.

What if I don't want to know the results of the review now but change by mind later?

We understand this is a difficult time and you may not want to receive the results of the review now. If you decide you do want to know the results in the future, please contact your hospital doctor. They will then arrange a date to discuss the review with you.

What if I don't want to know the results of the review?

If you prefer not to know the results of the review please indicate this on the form and you will not be told. This will not make any difference to your care.

Can my family ask for the results if I don't want to know?

No, unless you give permission, we cannot give your relatives access to any details of your medical records, including the results of this review.

Could my cancer have been found earlier?

In most cases the cancer will have been detected at the earliest possible stage. Cervical screening prevents about 75 per cent of cervical cancers but it cannot prevent all of them. The review process aims to highlight any possible areas of weakness so we can try to answer this question for you.

Further information

If you have any more questions about your referral or treatment, phone our clinic on 020 7272 3070 extn. 4677 and ask to speak to one of our specialist nurses or our office on 020 7288 5542.

If you need information or advice about NHS services, please contact

Patient Advice and Liaison Services (PALS)

Tel: 020 7288 5551

Fax: 020 7288 5822

Email: pals@whittington.nhs.uk

Large print, braille and translations

To receive this leaflet in large print, Braille or to have it translated please call the Interpreting Service Department on 020 7288 5114/3974/5191.

Data Protection Act 1998

Further information regarding the Data Protection Act (1998) is available from the following web sites:

<http://www.dataprotection.gov.uk/principi.htm>

<http://www.hmsa.gov.uk/acts/acts1998/19980029.htm>

I do/do not (delete as appropriate) wish to know the results of my cervical screening history review. If I choose not to know the review at present, I understand that I can change my mind at any time.

Signature

Name in Block Capitals

Date

Please return the signed form to a member of your treating team or post it to:

Dr S Ramachandra,
Hospital Based Programme Coordinator for Cervical Screening,
Department of Histopathology,
The Whittington Health NHS Trust,
Magdala Avenue
London
N19 5NF.

Why do some women who are screened still develop cervical cancer?

It is important to understand that a smear test is a predictive rather than a definitive diagnostic test. The NHS Cervical Screening Programme can identify and treat most women either before cervical cancer has developed or when it is at its earliest stages. Even the best services, however, will not be able to achieve this for all women.

This is because:

- Some women whose cervical screening tests are normal can go on to develop cancer during the interval before their next test
- Some women previously treated for changes to the cells of their cervix will still go on to develop cancer
- Abnormal cells may be present but not be detected in the smear test (see below)
- Abnormal areas may not be seen on colposcopy – visual examination of the cervix (see page five)

Why are abnormal cells not always detected on the smear test?

Screening cannot always identify abnormal cells in a smear test slide because:

- Sometimes the cells do not look very different from normal cells
- There may be very few abnormal cells on the slide

The person reading the slide may simply miss the abnormality (this is rare but does happen occasionally, no matter how experienced the reader is)

Why are abnormal areas on the cervix not always detected on colposcopy?

Colposcopy cannot always identify abnormal areas of the cervix because:

- The abnormal area might not be clearly visible during the examination and therefore not be taken as a sample in a biopsy
- The abnormal area might be hidden higher up inside the cervix
- Some types of abnormality are simply not easy to identify during a colposcopy.

What happens to the information collected for my review?

We collect screening information as part of an ongoing process. Your information (without your name) helps to improve the systems of the programme and helps us to find out more about how cancers develop and how they are diagnosed and treated. This is done whether or not you want to know the results of the review.

The review process aims to highlight any areas of weakness so that we can make improvements for everyone. Section 251 of the NHS Act 2006 replaces Section 60 of the Health and Social Care Act 2001. It provides relief from the common law duty of confidentiality which requires that patient identifiable data is only used with consent.

Why should women have cervical screening if abnormalities can be missed?

Cervical screening reduces the risk of developing cervical cancer. It is estimated that the cervical screening programme saves 4500 lives a year nationally. Regular screening is the best way to detect early changes to the cervix and stop cervical cancer from developing.

Your notes or questions

(Please write down any questions you have and bring them with you to your next appointment).