COPYING LETTERS TO CLIENTS IN BREAST SCREENING

NHSBSP Good Practice Guide No 8 July 2005

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ACKNOWLEDGEMENTS

This Good Practice Guide has been prepared by Sarah Cush and Margot Wheaton to assist local breast screening programmes in England to implement the Department of Health guidance *Copying Letters To Patients: Good Practice Guidelines*. It may also be useful as a reference for clients and their families.

Local protocols from Coventry and Warwick, Hull, and York NHS Trusts have been used in devising this Good Practice Guide.

INTRODUCTION

- 1. The NHS Plan (paragraph 10.3)¹ made the commitment that patients should be able as of right to receive copies of letters written about them by health professionals. This document sets out good practice for screening offices and is based on the Department of Health's good practice guidelines Copying Letters to Patients.² The aim of the change in practice is to improve communications with women and help them to understand and participate in their care.
- 2. Breast screening services should already be providing information to women on what happens at the screening unit, how to access breast screening services, and their rights and responsibilities (for example, under the Data Protection Act). Women should now also be given information about how to receive copies of letters written about them.

KEY REQUIREMENTS

- 3. A letter includes written communications between different health professionals such as those to and from GPs, hospital doctors, nurses and other health care professionals. Types of letters include:
 - referral letters or forms; for example, a letter informing a GP that a woman is being recalled for assessment or referred for treatment to another health professional
 - letters from an NHS health professional to another agency; for example, a letter to an employer, private health care provider, insurance company or social services department
 - letters from a hospital consultant to a GP; for example, following an outpatient consultation or discharge after treatment.
- 4. It is good practice for such communications to be written clearly and for technical language to be avoided as far as possible.
- 5. Raw data such as reports on mammograms or pathology reports should not be sent directly to women as the outcome will be summarised in a letter to the woman in due course. An example of a letter to a woman about the outcome of assessment is attached at Appendix 1.
- 6. Letters should not be copied to women if:
 - the woman does not want a copy if a woman expressly states that she does not want copies of letters about her then this will need to be recorded
 - the clinician feels that it may cause harm to the woman or for other reasons this will need to be recorded
 - the letter includes information on a third party who has not given consent this will need to be recorded
 - special safeguards may be needed to ensure confidentiality.

7. The process is outlined below:

The woman attends an assessment clinic following a recall from screening

The woman fills out a request form and passes it to the clinic receptionist, clinic nurse or a radiographer, or sends a letter to the screening office

An identified person in the screening office logs the request on NBSS in the notes page. The request should state whether the request is for all letters or just the ones for this appointment, and say in what format the copy is requested

This identified person puts the request form/letter in the screening packet to alert the health care professional(s) and secretary that the woman wants a copy of letters sent

The letter is typed and sent to the person to whom it is addressed. A copy is sent to the woman and a copy is put in the film packet

If a woman is referred for treatment for breast cancer, her request for copies of letters should be passed to the appropriate hospital staff

OBTAINING CONSENT TO RECEIPT OF LETTERS

- 8. In breast screening, a woman's consent to receiving copies of letters should be obtained at her first assessment visit. Local protocols should be devised, which should include the following issues:
 - explanations to women of their rights to receive copies of letters (examples of a leaflet and a poster are given in Appendices 2 and 3)
 - confirmation by the woman of where the copies of letters are to be sent
 - there must be safe haven procedures if the woman does not want the copies of letters to be sent to her home address; for example, an arrangement could be made for her to collect the letters or view them at a location in the trust
 - checking in what format the woman would like to receive the copies of the letters; reasonable steps should be taken to provide copies of letters in other formats, for example in large font, on audiotape or in a language other than English

Copying Letters to Clients in Breast Screening

- checking if the consent is for all letters or those only relating to the current episode and how this decision can be changed
- where the consent is to be recorded and by whom, and who is responsible for ensuring that the copy letters are sent out
- how a woman can complain if the information in a letter is inaccurate
- how the process should be audited by the screening service.

WOMEN WITH LEARNING DISABILITIES

9. Women with learning disabilities are equally entitled to receive letters written about them by health care professionals.³ In some cases, wording may need to be tailored to individual needs. The GP or carer may be able to advise on specific details.

LEGAL FRAMEWORK

10. The local protocols operate within a legal framework. Appendix 4, which is taken from the DH guidelines, lists the relevant legislation.

DATA PROTECTION AND CONFIDENTIALITY

11. Normal checks must be made of a woman's identity. Requests from other family members or carers for copies of letters, particularly by telephone or e-mail, should only be actioned in special circumstances and with the woman's consent. Requests should be confirmed in writing. Requests should only be recorded on NBSS and actioned after written confirmation is received.

RECORDING CONSENT ON NBSS

12. Details of the woman's request for copies of letters written about her should be held on NBSS in the notes page. If a woman states that she does not wish to receive copies of letters written about her, this must also be recorded on the notes page. For audit purposes, the standard recording format shown in Figure 1 must be used for each record.

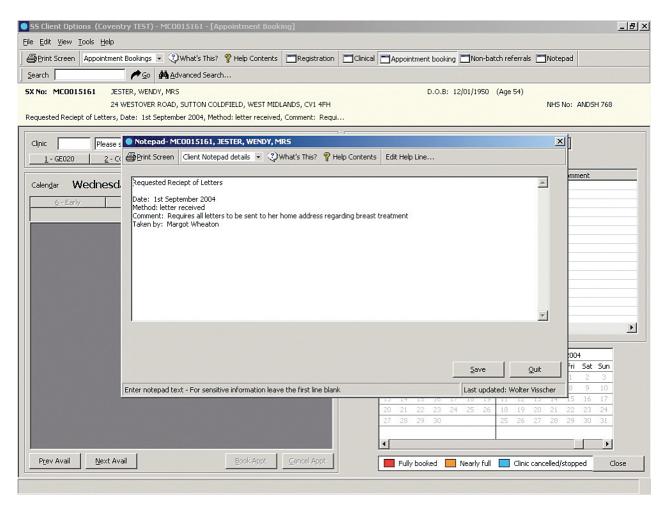


Figure 1 Example of an NBSS record.

AUDIT OF REQUESTS FOR COPIES OF LETTERS

13. It is good practice to audit requests for copies of letters and compliance with women's wishes. A log of requests should be set up for ease of monitoring and should be audited by the screening service on an annual basis.

STAFF TRAINING

14. All staff should receive training on the introduction of this new policy and the implications for women attending the service. Training should also be included in induction for new staff.

REFERENCES

- 1. The NHS Plan. Department of Health, 2003.
- 2. Copying Letters to Patients: Good Practice Guidelines. Department of Health, 2003.
- 3. Good Practice in Breast and Cervical Screening for Women with Learning Disabilities. NHS Cancer Screening Programmes, 2000 (NHSBSP Publication No 46).

Example of standard letter – normal assessment

Dear

Thank you for coming for your recent assessment appointment. I am pleased to tell you that following further assessment of your breasts the results were normal in that no signs of breast cancer were seen. This means that your next routine screening appointment will be due in three years' time.

In the meantime, please remember that screening will not find all breast cancers and breast cancer can occur in the interval between screens. You should continue to be breast aware as described in the enclosed leaflet.

If you notice any changes from what is normal for you, you should report them to your doctor without delay, even if you have been recently screened.

If your name or address changes at any time please tell your GP so that your next invitation will be sent to your new address. If you will be over 70 in three years' time you will no longer be automatically invited for screening. Should you wish to continue to receive breast screening, you can ask for an invitation by phoning or writing to your local breast screening unit.

If you have any questions about your result or would like to have copies of the correspondence regarding your assessment please contact the breast screening unit on telephone no. XXXXX.

Yours sincerely

Example leaflet

HOW TO OBTAIN A COPY OF LETTERS WRITTEN BY HEALTH CARE PROFESSIONALS ABOUT YOU

Introduction

The NHS Plan said that patients should be able to receive copies of the letters written about them by one health care professional (eg doctor, nurse, radiographer, surgeon) to another (eg their general practitioner – family doctor). If you do wish to receive a copy of letters that are about you, please let us know by writing to the address at the end of this leaflet.

Why should I want to see copies of letters?

Letters written by one health care professional to another will often contain details of future tests and care, the results of tests or advice on managing your condition.

This has probably been explained to you but having the information repeated in a letter may be helpful. In addition, it allows you to share the information with your family if you wish.

Please discuss the pros and cons of receiving copy letters with the health care professional at the time you see them.

Will I receive copies of all letters written about me?

Yes, you will usually receive all the letters written about you. However, it may be that they are sent to you at different times, eg at the end of your treatment or after each consultation. You will not receive letters written about you that contain confidential details about other people without their express permission or, rarely, if it is felt someone could be caused harm.

How do I make the request?

Please make your request to the address at the end of the leaflet, in writing. This service is free. You need to state if the request is just for this visit(s) to our unit or for all visits now or in the future. The Data Protection Act 1998 allows you to request a copy of your medical records if you wish; however, there will be a charge for this.

If you require the letters in any special format, eg large font, Braille, foreign language, please give details in the letter

What do I do if I don't understand what is written about me?

Medical terms will be used as little as possible. If you require more information about the meaning of some terms, you should speak to the author of the letter at your next visit or telephone the number at the end of this leaflet.

Who can receive copies of my letters?

Only you can receive copies of letters written about you unless you give us written permission to send them to someone else who has agreed to receive them on your behalf.

What if I change my mind?

If you reconsider your decision to receive letters, you can write to us at the address at the end of the leaflet and tell us.

How do I complain if the information is incorrect?

If you think some of the information you receive in the letters is wrong, please write to the address at the end of this leaflet, stating your concerns. If you wish to discuss your concerns with a health care professional, telephone the number at the end of this leaflet.

Useful contacts

NHS Direct

PALS

Breast Screening Unit

Information about you

As part of your care, when you come to the breast screening unit, information about you is shared between members of the team, some of whom you may not meet. It may be used to help train staff involved in your care. Information we collect may also be used after you have been screened to help us to maintain and improve the quality of our care, to plan services or to carry out research into new developments.

We may pass on information to other health organisations to help improve the quality of care provided in the NHS generally.

All information is treated as strictly confidential and is not given to anyone who does not need it. If you have any concerns, please ask your doctor or the person caring for you.

Under the Data Protection Act 1998, XXXXX Trust is responsible for maintaining the confidentiality of any information we hold about you.

Example poster

XXXXX NHS Trust

How do I obtain copies of letters about me?

If you wish to find out more about how to obtain copies of letters, please take one of the leaflets for further information or phone:

XXXXXXXXXXX

Extract from DH guidelines *Copying Letters to Patients* **Annex C:** Legal framework

Access to Medical Reports Act 1988

This Act originally established a right of access by individuals to reports relating to themselves provided by medical practitioners for employment or insurance purposes (subject to exceptions, broadly as those for the Data Protection Act, described below). It now only relates to records of deceased people.

Data Protection Act 1998

The Data Protection Act 1998 is based on principles that are legally enforceable.

These include:

- that people should have access to data about them
- that data should be processed fairly and lawfully
- that data should be accurate
- that data should be protected by appropriate security.

Access can be denied only:

- when the information may cause serious harm to the physical or mental health, or condition of the patient or any other person, or
- when giving access would disclose information relating to or provided by a third person who had not consented to the disclosure.

The patient, anyone authorised by the patient, parents of children under 16 years or a 'Gillick competent' child (eg a girl under 16 who asks for contraception and the health care professional decides she is competent) are entitled to access their medical records.

Disability Discrimination Act 1995

The Act makes it unlawful for service providers to discriminate against disabled people in certain circumstances. Since 1 October 2000, service providers have been required to make 'reasonable adjustments' for disabled people, such as providing extra help or making changes to the way they provide services. From 2004, service providers will also have to make 'reasonable adjustments' to the physical features of their premises to overcome physical barriers to access.

Health and Social Care Act 2001

Section 60 makes provision for requiring communications of any nature that contain patient information to be disclosed in prescribed circumstances to the person to whom it principally relates.

Human Rights Act 1998

The Human Rights Act 1998 came into effect on 2 October 2000. It gives UK citizens recourse to the UK courts if they consider their rights under the European Convention on Human Rights are breached. Article 8 states:

You have the right to respect for your private and family life, your home and your correspondence. This right can only be restricted in specified circumstances.

Article 14 in Schedule 1 of the Articles in Part 1 of the Convention to this Act refers to the prohibition of discrimination. It states that:

The enjoyment of the rights and freedoms set forth in this convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.

Race Relations (Amendment) Act 2000

The 1976 Race Relations Act (RRA) remains the basic law in Great Britain that defines and outlaws racial discrimination, and gives individuals the right to seek legal redress for acts of racial discrimination. The 2000 Act extends the scope of the 1976 Act and makes it unlawful for public authorities to discriminate on racial grounds in carrying out any of their functions. It places a general statutory duty on a wide range of public authorities to actively promote racial equality and prevent racial discrimination. It gives the Home Secretary the power to make Orders imposing specific duties on all or some public authorities bound by the general duty. These specific duties are enforceable by the Commission for Racial Equality (CRE), serving compliance notices, backed up by court orders, if necessary. The RRA has been drawn up in such a way as to cover external contractors (including the private and voluntary sector when they are discharging public functions). External contractors are not directly covered by the duty to promote, but are covered by the provisions that outlaw discrimination in all public functions; the EU Race Directive will remove the current exemption of partnerships of less than six people from the race legislation.

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