

Department of Health

Copying letters to Patients

Good practice guidelines

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" A relative whom I have been helping with a mental health problem recently received a copy of a psychiatrist's letter(at our specific request) following the consultation, and it made such a difference to our confidence. It showed that the doc had understood what we were saying and wasn't just fobbing us off. It also helped us understand and remember their advice. Such a boost for trust in the relationship. As an ex-NHS manager and citizen, I got such a thrill in seeing how well our Service can work. " **(A carer)**

" Sometimes for whatever reason you don't fully take on board what the doctor has told you. I found the letter useful to read over and digest properly what was written".¹ **(Dr Diana Jelley and Caron Walker).**

"Thank you for the copy of the letter. It made it seem as if I was more involved with my care. It was easier to talk to the GP about my care, without the problem of trying to remember all that was said at the hospital appointment, which would have been very difficult as I was very nervous at the time. I feel more positive knowing that I am fully informed. It has taken some of the worry of having surgery away by creating a more personal liaison between hospital Consultant and patient." **(Patient, pilot project on copying clinicians' letters to patients at Darent Valley Hospital, Dartford and Gravesham NHS Trust).**"

"I believe that the copying letters to patients programme is a key part of the NHS Plan. It goes to the heart of putting the relationship between patients and doctors on a more equal footing." **(Harry Cayton, Department of Health's Director of Patient Experience and Public Involvement)**

"I am committed to the importance of the policy of copying letters to patients as one means of improving communication with them. It enhances their ability to share in the decision-making process about their care and treatment and to make informed choices. It is encouraging that so many organisations and individuals in the NHS wish to continue or begin their efforts to make this policy a reality."² **(Barbara Meredith, Chair, Copying Patients' Letters Working Group)**

" The increase in workload of our GPs has been minimal - only the occasional query about a letter or a timely reminder that the actual letter has not been written." ³**(Dr Diana Jelley and Caron Walker)**

¹ "Shouldn't everyone know what is being written about them?" A pilot study in the North East of England 2002. (See web-site www.doh.gov.uk/patientletters/issues.htm)

² Copying Letters to Patients- A report to the Department of Health and draft good practice guidelines for consultation. (See web-site www.doh.gov.uk/patientletters/issues.htm)

³ "Shouldn't everyone know what is being written about them?" A pilot study in the North East of England 2002. (See web-site www.doh.gov.uk/patientletters/issues.htm)

Department of Health

Copying letters to Patients

Good practice guidelines for sharing letters with patients

1. Introduction

- 1.1 The NHS Plan (Paragraph 10.3) made a commitment that patients should be able to receive copies of clinicians' letters about them as of right. A working group convened by the Department of Health in 2001 set out the background to the initiative in a report in February 2002. It is available on the Department of Health's web-site, www.doh.gov.uk/patientletters/issues.htm and is in two parts: draft guidelines, and recommendations to the Department of Health.
- 1.2 This document sets out best practice guidelines for implementation, based largely on those in the working group's report and on the experience of twelve pilot projects funded by the Department of Health in 2002/03. Pilot project reports contain a wealth of detail about specific issues covered in these guidelines, and are well worth reading in full. A number of them are available on the web-site referred to in paragraph 1.1 above. Summaries of these pilot projects are also available on this web-site. Annex C lists legislation relevant to implementation of the policy, which will need to be taken into account.

Audience

- 1.3 These guidelines are intended for use in England (and for information elsewhere) in primary, community and secondary care settings by:
- healthcare professionals
 - health records and information staff, including those responsible for commissioning new systems
 - medical secretaries and administrative staff.

They are also for the information of:

- chief executives and board level appointees in NHS organisations
- training organisations, Royal Colleges and professional regulatory bodies
- PALS and Patients Forums
- local authority health Overview and Scrutiny Committees.

Patients, carers and their families, and patient and carer support organisations may also find them useful.

Primary care

- 1.4 It should be noted that at the time of publication, a new contract for GMS has been published pending a ballot across the UK. If accepted by general practitioners, the contract will put in place new arrangements for the funding and operation of general medical services.
- 1.5 The new contract's contractual and statutory requirements set out the need for practices to provide a leaflet for patients with information about services on offer, how they can be accessed, and patients' rights and responsibilities. This may provide a helpful vehicle for information on copying letters to patients.
- 1.6 Under the provisions of the contract, primary care organisations (PCTs in England) will fund the costs of practice IM&T systems that have been accredited against UK-wide standards. It

will be important that these systems incorporate the ability to integrate copying patients' letters into practice systems.

No 'new' activities

- 1.7 There are no completely new activities associated with the policy on copying letters. These guidelines show that the issues to be tackled are mainly those already required throughout the health service and in good professional practice. They include good communication, obtaining consent, record keeping and handling (including IT support systems), and provisions to meet legal requirements to prevent discrimination on the grounds of disability or race. In particular, issues involve provisions around confidentiality and data protection.
- 1.8 Implementation of the 'copying patients' letters' policy may, however, reveal problems which need attention in such processes and arrangements. The pilot projects have shown that introducing systems for sharing letters have yielded overall improvements in many areas. These include contributing to the general improvement in communication between patients and healthcare professionals that this policy aims to achieve. Annex A gives some examples of the benefits of copying letters from the point of view of healthcare professionals and patients.

2. What is 'copying patients' letters' about?

- 2.1 As a general rule and where patients agree, letters written by one health professional to another about a patient should be copied to the patient or – where appropriate, parent or legal guardian. The general principle is that all letters that help to improve a patient's understanding of their health and the care they are receiving should be copied to them as of right. Where the patient is not legally responsible for their own care (for instance a young child, or a child in care), letters should be copied to the person with legal responsibility, for instance a parent or guardian.

What constitutes a 'letter'?

A 'letter' includes communications between different health professionals, for instance those from and to GPs, hospital doctors, nurses, therapists and other healthcare professionals. Different types of letters include (among others):

- Letters or forms of referral (including hand-written two-week wait referral forms) from primary care health professionals to other NHS services
- Letters from NHS health professionals to other agencies (such as social services or housing, employers or insurance companies)
- Letters to primary care from hospital consultants or other healthcare professionals following discharge or following an outpatient consultation or episode of treatment

Writing directly to patients

- 2.2 In many cases, healthcare professionals (or services, such as screening services) write directly to patients or parents of patients, copying the letter to the general practitioner or others as necessary. There is no implication in the 'copying letters' policy that such practices should be stopped and, indeed, some healthcare professionals may choose to increase such practices. One of the pilot projects⁴ documents the practice of a healthcare professional who writes directly to parents of patients and, with their permission, copies letters to other

⁴ Gulson Hospital-Children and Carers of Children-Presentation of over seven years experience of writing clinic letters to patients. (See web-site www.doh.gov.uk/patientletters/issues.htm)

healthcare professionals. A copy of the report of this project is on the web-site referred to in the footnote at the bottom of this page.

'Raw data'

- 2.3 'Raw' data, such as single test results, should not normally be sent directly to patients. Such data could include, for instance, an x-ray and its accompanying report, or the results of blood tests taken as part of a wider investigation of symptoms. In due course, the outcome of such tests should be included in a letter that is copied to the patient. Where no such letter is needed (for instance where a general practitioner has commissioned a range of tests), some other means of communicating the results to patients will be necessary.

Frequency of copies

- 2.4 Where there is frequent communication, the person responsible for writing the letter should consider if it would be useful for the patient to have a copy every time. The decision should be based on a discussion with the patient about whether receiving a copy will improve communication with them and assist them to understand their own healthcare or treatment.

No surprises

- 2.5 Where the letter contains abnormal results or significant information that has not been discussed with the patient, it will be important for arrangements to be made to give the patient a copy of the letter after its contents have been discussed in a consultation with the receiving professional. As a general rule the contents of copied letters should reflect the discussion in the consultation with the sending healthcare professional, and there should be no new information in the letter that might surprise or distress the patient.

3. When letters should not be copied

- 3.1 There may be reasons why the general policy of copying letters to patients should not be followed. These include:
- where the patient does not want a copy
 - where the clinician feels that it may cause harm to the patient or for other reasons
 - where the letter includes information about a third party who has not given consent
 - where special safeguards for confidentiality may be needed.

Patients who do not want a copy

- 3.2 Examples of why people may not want a letter could include:
- they feel they already have the information (for instance, a care plan as part of the Care Programme Approach)
 - there are problems of privacy at home (for example for young people)
 - there is domestic violence or information not known to a partner or other members of the household
 - they do not feel able to accept a diagnosis
 - they feel they are criticising the doctor by wanting to see a copy letter. (In such cases, the support of the clinician could be important in helping the patient obtain better information about their care and treatment.)

Harm to the patient

- 3.3 Giving of "bad news" is not in itself enough to justify not copying a letter. The pilot studies showed that it is sometimes the case that health professionals are anxious to protect patients,

who themselves often wish to have as much information as possible, even if it may be 'bad news' or uncertainty.

- 3.4 In some cases involving particularly sensitive areas, however, such as child protection or mental health problems, it may not be appropriate to copy a letter to the patient, although the patient has the right to request access under the Data Protection Act 1998. Unless the health professional's judgement is that there might be a serious possibility of harm to the patient, it is up to the patient to decide whether they wish to receive a copy of a letter. (See paragraphs 4 to 4.16 for a more detailed discussion on issues around consent to receipt of letters.)

Third party information

- 3.5 It will not be appropriate to copy a letter which contains information about a third party, who has not given permission for this use of the information, unless the information was originally provided by the patient. (See paragraphs 4.7 to 4.9 for further information on this aspect of data protection.)

Safe haven procedures

- 3.6 There are some services (for instance STD clinics) where there are special arrangements for protecting confidentiality. For instance, information may not routinely be recorded in patients' GP records. The implications of someone else seeing a copy letter about treatment by such a service may be serious for the patient, and should be discussed if the patient wants a copy sent by post. There is provision under Caldicott⁵ arrangements for 'safe-haven' procedures. Local consideration is needed as to how particularly sensitive information (and related copy letters) can be channelled to patients through the 'safe-haven' point or other secure means in an NHS or Primary Care Trust, or general practice.

4. Consent to receipt of letters; identifying appropriate recipients

- The person responsible for generating a letter should be responsible for ensuring provision is made for obtaining the patient's consent to receipt of a copy, and for making and sending copies. This does not mean that this person is necessarily the person who carries out these activities.
- Each NHS trust should ensure individual departments and central records systems include arrangements for recording and acting on patients' wishes about receiving copy letters. Primary Care Trusts should work with general practices along similar lines, as part of ensuring good quality in 'patient experience', provision of information to patients and IM&T systems. In setting up such systems, reference should be made to existing legislation and guidance on access to medical records, data protection, confidentiality arrangements and related issues.
- Reference should also be made to guidance on obtaining consent to treatment. Although 'consent' to receipt of letters is materially different to 'consent to treatment', the general approach should be the same. As a general rule, practitioners should work within the guidelines on consent produced by professional bodies and the Department of Health. The Department of Health's Good Practice in Consent Implementation Guide gives advice on obtaining consent in different settings and from patients with different needs and competencies.

- 4.1 In line with the overall NHS policy of informed consent, these guidelines recommend that it is for each patient to decide whether they wish to receive copies of letters written about them by health professionals. The copying letters policy is underpinned by a presumption of the patient's informed consent to the receipt of any letter. This should not be a difficult issue. The

⁵ Protecting and Using Patient Information. A Manual for Caldicott Guardians

aim is that within a consultation, the possibility of receipt of the letter should be raised as part of the wider discussion about 'what will happen next.' In other words, patients should routinely be asked during a consultation whether they want a copy of any letter written as a result of that consultation and any related tests or interventions, and there should be a clear process for recording their views, similar to that for recording their consent to treatment.

Records handling

- 4.2 The circumstances of letters about an individual patient will vary. It might be sufficient to seek consent once rather than each time a letter is written. This is as long as it is explained at the start of an episode that copies of letters will be sent routinely to the patient or responsible person unless the patient decides to opt out of receiving copies of letters, which can be done at any time. Good practice suggests, however, that the patient be reminded each time a letter is to be copied.
- 4.3 One way of recording such consent (or not) is to include it in the letter itself as described in the model letter at Annex B. The letter can make clear what arrangements have been agreed with the patient. Sometimes this will be a statement that the copy letter has been sent directly to the patient. At other times the letter may indicate that a copy is attached for giving to the patient after a consultation with the receiving healthcare professional.
- 4.4 Otherwise, there should be provision for recording the consent in the patient's record with a clear procedure for putting that into practice when the letter is generated. This process should become automated once electronic records are in place. (It should be noted that systems for obtaining and recording the consent might vary. In some systems, the person responsible for obtaining and recording the consent may not be the person who writes the letter. The point is that responsibility for this should be clear.)
- 4.5 Where a letter is to be written at the request of an outside agency, other factors apply in addition to the question of whether the letter should be copied to the patient. Organisations and practices must be sure that relevant legislation on data protection (and writing letters to insurance companies) is complied with. The legislation includes the Data Protection Act 1998 and the Health and Social Care Act 2001. The Access to Medical Reports Act 1988 now only relates to records of deceased people.
- 4.6 Improving the quality of information is part of ongoing work in the NHS and is fundamental in ensuring the right information reaches the right person, maintains patient confidentiality and ensures there is compliance with the Data Protection Act 1998. The Information for Health Strategy for the NHS⁶ reported that 'the use of Data Accreditation process will be mandatory', Acute Trusts were expected to have completed Stage 2 of Data Accreditation by 31st March 2002. For further information visit the NHS Information Authority website at <http://www.nhsia.nhs.uk/dataquality/pages/accredit.asp>
- One approach in working toward Data Accreditation is to seek accreditation through a quality accreditation scheme, which addresses such issues as data quality, as well as more general areas. Such schemes as CASPE (www.caspe.co.uk) or The Health Quality Service (www.hqs.org.uk) will provide further information.

Third party consent to use of information

- 4.7 Even where a patient (or legal guardian) consents to the receipt of a letter, there may be good reasons not to provide it. For instance, where a letter includes information given by or about a third party (such as a neighbour or family member), it is a breach of confidentiality to pass this information to the patient without the consent of the third party, unless the information was originally provided by the patient. In such cases, the provisions of the Data Protection Act 1998 must be followed, for instance by deleting the part of the letter that refers to the third

⁶ Information for health-An Information Strategy for the Modern NHS 1998-2005 A National strategy for local Implementation

party information or to include this information as an attachment letter not copied to the patient. If it is not possible to do this, the letter should be withheld and the reasons for this explained to the patient. Patients have the right to make a 'subject access request' under the provisions of the Data Protection Act. In such cases, it might be helpful to have a standard template letter to explain the situation.

- 4.8 Some third party information may refer to another healthcare professional. Under the Data Protection Act, such information can be passed on without the person's consent. However, if access to their own information is denied on such grounds, patients can make a formal access request and information about healthcare professionals must be disclosed unless there is the likelihood of serious harm to that health professional from disclosure.
- 4.9 There may be occasions when one healthcare professional wishes to comment on the clinical care provided by another and offer advice on the care of future patients with a particular condition or symptoms. It may not be appropriate for such information to be copied to the patient, but it is important for continuing professional development and clinical governance that such an opportunity for professional development not be lost. The professional concerned should write a separate letter that is not copied to the patient. (There could, however, be arguments for copying such information to the patient on the grounds of openness and including the patient in a more open discussion about problems in providing appropriate care.)

Mental capacity

It is important not to make 'blanket' assumptions about mental capacity. Whereas it may be judged that a person lacks mental capacity for one purpose, they may have sufficient capacity for another.

- 4.10 Some people may not have the appropriate mental capacity to make a decision about whether they would like a copy of a letter, for instance because they have certain types of learning difficulties or dementia.
- 4.11 The current legal framework for decision-making for adults who lack mental capacity makes no provision for decisions about a patient's care or treatment, or, for instance, about whether to receive a copied letter. In such circumstances, it can be difficult for healthcare professionals to obtain appropriate consent – both for treatment and to receipt of copied letters.
- 4.12 It should already be recorded on a patient's record if they have someone to act on their behalf or to represent their views – a carer, advocate or key worker. Advocates can offer independent support where someone, for instance with learning disabilities, needs support in decision-making and wants an alternative to a carer or family member. There is, however, no formal legal provision underpinning such arrangements, and health professionals must fall back on the advice from their professional bodies and the Good Practice in consent Implementation Guide to ensure that arrangements are in the best interests of patients.

Carers

- 4.13 As noted in the case study above, some adults have carers, family members or others who are actively involved in their care. As carers, they need information and support from professionals involved in the treatment of the person they care for, and they have a right to an assessment of their own needs through the Carers and Disabled Children Act 2000. Frequently patients want information shared with their carers. With the patient's consent, a copy of letters can be sent to the carer. Copies of letters to carers may be particularly important where medication is changed following discharge from hospital. Again, in the absence of a clear legal framework for deciding what to do, health professionals will often have to exercise judgement in deciding where it is in the patient's best interests to share information with a carer.

- 4.14 Occasionally, however, the patient may not want a letter copied or shown to the carer. Both the patient and the carer have the right to expect that information either provides to the health service will not be shared with other people without their consent. In such circumstances, unless there is an over-riding reason to breach confidentiality, the wishes of the patient must be respected. It is the Department of Health's policy that carers of people with mental illness should be provided with as much information as possible to enable them to carry out their caring role as effectively as possible without breaking the patient's confidentiality.

One of the pilot projects⁷ looked particularly at issues for carers of people with dementia. The small sample of carers was drawn from the Asian community. All expressed a need for more information about both the disease and the different forms of care and treatment on offer. The study notes the importance of sensible solutions appropriate to individual circumstances, respecting privacy and confidentiality and yet supporting the carer's role. It should be noted that possession by a carer of Power of Attorney over financial matters is not the same as a legal right to jurisdiction over care matters about the patient.

Children and young people

- 4.15 Young people aged 16 and 17 are able to make health care decisions for themselves, and should, therefore, be asked for their agreement to receive copies of letters about them. It is up to healthcare professionals to assess the competence of younger children to understand and make a decision (referred to as Gillick competence). The Department of Health's guidelines on consent to treatment⁸ are helpful here. It is good practice to offer adolescents consultations alone so that they have the opportunity to speak freely and give information that they may be unwilling to talk about in front of their parents. In such cases, young people may prefer to collect in person copies of letters giving personal information rather than having them sent to their home.
- 4.16 The issue may arise as to whether a letter should be copied to the young person or their parents. Some initiatives in copying letters have been developed in children's services, and the general experience is that there are few difficulties, as long as the issue is discussed with the family. Often adolescents appreciate the letter being sent to them. Where parents are separated, it is important to discuss who should receive the copy of letters.

A pilot project⁹ in a children's hospital showed that provisions for copying letters about children often need to take account of complex issues. These include who is responsible for the children; lack of continuity of carer accompanying children to hospital; information and records handling; potential child abuse; and judgements about which information to share with whom. These issues are not all about the consultation and the subsequent letter, but overall they are about the quality of communication with patients, families and guardians, and about good processes for records handling.

5. How is it to be done?

Generating and sending the copy

The person who writes the letter should be responsible for arranging that a copy is made and provided to the patient, after it is confirmed:

- that the patient wishes to receive a copy;
- how the patient wishes to receive it; and

⁷ Wolverhampton City PCT-Dementia Patients and their Carers from Ethnic Minorities(See web-site www.doh.gov.uk/patientletters/issues.htm)

⁸ Good practice in consent implementation guide: consent to examination or treatment.(See web-site: www.doh.gov.uk/consent/guidance)

⁹ Great Ormond Street Hospital-Children and Carers of Children. Copies of letters about children. Areas of Consensus and potential Conflict between Professionals, Parents and Children. (See web-site www.doh.gov.uk/patientletters/issues.htm)

- the preferred format.

5.1 Arrangements for copying patients' letters will need to take into account different 'pathways of care', perhaps involving communications with people or organisations outside the NHS, or internal communications which may not take the form of a formal letter. Examples include:

- letters written by a clinician to social services or a private residential or nursing home. They should only be written with a patient's agreement and should indicate whether the patient has been sent a copy and ask that a copy of the reply be sent to the patient (if they agree), in line with practice in the NHS.
- letters from non-NHS agencies to health professionals, not copied to patients. The healthcare professional may consider it important to show the letter or give a copy to the patient. However, it is not the responsibility of the healthcare professional who receives the letter to send a copy to the patient.

5.2 Commissioners of NHS services from NHS Foundation Trusts or other non-NHS organisations should bear in mind the need for service level agreements to include a reference to copying letters.

Writing style and standard letters

5.3 Letters between healthcare professionals are technically 'personal data' which forms part of the patient's record. As such, it is important they are adequate for their purpose, and accurate. As a matter of good practice, letters between healthcare professionals that are copied to patients should be written clearly. It is advisable to avoid unnecessarily complex language, and subjective statements about the patient.

5.4 A balance is required between simplification for the patient's understanding, and what is needed for the primary purpose of a letter between healthcare professionals discussing symptoms, test results and possible diagnoses or treatment. Clinical accuracy and ensuring the professional receiving the letter has all the information he/ she needs is the main purpose of the letter and it is important not to compromise this in order to make the letter easier to understand.

5.5 Templates and standard letters can make it easier for healthcare professionals and patients to achieve this balance of technical excellence and correctness, and ease of understanding. Some suggested models already in use are attached at Annex B. Others are included in reports of pilot projects which can be seen at the web-site given at the bottom of this page.

5.6 Issues to be considered in drafting letters include:

- use of plain English to improve readability
- avoiding giving offence unintentionally or generating misunderstandings
- avoiding unnecessarily technical terminology and acronyms, including using alternative terms without losing meaning or clarity, such as 'kidney' for 'renal' or 'heart attack' for 'myocardial infarction', or explaining a technical term in a short additional sentence or phrase
- using standard terms consistent with clinical coding (such as Read codes or Snomed). As electronic records become more widely available there will be more standardisation of terminology, giving more consistency and making computer searches simpler
- setting out the facts and avoiding unnecessary speculation
- reinforcing and confirming the information given in discussion with the patient in the consultation.

- 5.7 Some healthcare professionals prefer to write letters directly to patients, with a copy to the general practitioner or other healthcare professionals. Evidence shows that patients appreciate such practices, which give the clinician the option of adding additional information and advice about life style and management of the illness or condition.
- 5.8 From time to time, it will be helpful to check with patients how they feel about copied letters, perhaps as part of patient surveys.

A report of a pilot study¹⁰ in the North East of England suggests a number of actions which are helpful for patients in the context of copying letters. These include:

- *tell people how they can see their medical records*
- *reduce problems about medical terms and worries through good face to face talking between clinicians and patients*
- *use simple words and bold and sub-headings*
- *use lay terms, with explanations of medical terms or medical terms in brackets after explanations*
- *explore issues of consent and confidentiality around the involvement of third parties*
- *ask patients to opt-in rather than opt out of deciding to get copied letters*
- *ensure a doctor or nurse at the surgery is available to give help and advice about words in letters*
- *work with the PCT, voluntary organisations and other NHS organisations to develop models of good practice.*

How copies are provided

Patients should be able to say where they would like to receive a copied letter and in what format. Where general practices or NHS organisations are considering new information handling systems, different ways of generating copy letters should be one area of consideration. People with special communication or language needs should be able to specify how they would like to receive information. This should be recorded in an appropriate way.

- 5.9 Options for providing copies of letters include:
- a printed copy of the letter
 - copies in large print, or in some other format, such as on audio-tape
 - viewing letters on screen in the hospital or practice
 - sending by post or collection from an appropriate place, where there are concerns about privacy at home
 - copies of letters dictated in the presence of the patient.
- 5.10 As improved information systems evolve, it should become easier to generate an extra copy of a letter for a patient. When patients are able to access their records through safe Internet sites, paper copies of letters may not automatically be required.

People with special communication or language needs

- 5.11 Patients who choose to do so should be able to receive copies of communications in a form they can understand and use. Those responsible for copying letters to patients will need to ensure that they comply with equal opportunities legislation, including the provisions of the Disability Discrimination Act 1995, the Race Relations (Amendment) Act 2000 and the Human Rights Act 1998. NHS and primary care trusts should already have arrangements to meet the requirements of these Acts. Once again, it is important to remember that complying with these Acts is not just about copying letters to patients.

¹⁰ "Shouldn't everyone know what is being written about them?" A pilot study in the North East of England 2002. (See web-site www.doh.gov.uk/patientletters/issues.htm)

- 5.12 The Race Relations (Amendment) Act 2000 places a general statutory duty on NHS bodies to have due regard to the need to eliminate unlawful discrimination, promote equality of opportunity and promote good relations between people of different racial groups. Each NHS Hospital Trust and Primary Care Trust is required under the legislation to set out in a Race Equality Scheme how they will deliver non-discriminatory services to local people, including where relevant, access to language support services.
- 5.13 Some people cannot read well enough to understand a copied letter. Such people are often reluctant to admit the problem, and it may fall to them to seek someone to help them read the letter.
- 5.14 Consideration should be given to the needs of people with learning disabilities or deaf people, who may not easily read written English. People with visual impairment can often read large print. They can also access their information on computer in the GP practice or hospital, using voice recognition or other specialist software.

Further information for patients

- 5.15 Some patients may want further information about the contents of the letter or an explanation of terms. The letter should indicate who can be contacted for further information, and the patient can also refer to the local Patient Advice and Liaison Service (PALS), or NHS Direct on-line.

Correcting inaccurate records

- 5.16 Healthcare professionals who routinely share records with patients report that patients and carers often identify inaccuracies and mistakes. There should be arrangements to annotate their records to ensure they are correct.
- 5.17 While this may initially be time-consuming, the result should be improved and more accurate records that comply with the provisions of the Data Protection Act 1998 and benefit the overall quality of the service. Procedures for making such changes should be included in protocols for electronic records.

Protecting confidentiality

All NHS organisations and general practices should have arrangements in place for protecting security and confidentiality, and ensuring the fair and lawful handling of data. These arrangements should be reviewed to take account of the policy of copying letters to patients.

- 5.18 In reviewing their security and confidentiality procedures, NHS organisations and general practices should assess and take steps to minimise the following risks:
- breaches of confidentiality of information of third parties (such as carers or other professionals)
 - breaches of confidentiality of the patient's own information where communications are misdirected or read by someone other than the patient or his or her authorised agent.
- 5.19 Procedures should minimise the likelihood of information being accessed by unauthorised people and ensure patients who choose to have information posted or e-mailed are aware of the risks such procedures might entail. Envelopes should be marked 'confidential' and patients' addresses routinely checked. Patients' full names, rather than initials, should be used as a matter of good practice. It should also be a matter of good practice to check whether two people with the same name live at one address.

5.20 There should be clarity about who is responsible for checking and recording:

- the patient's address and full name for addressing a letter
- the wishes of the patient and preferred method of communication and format.

Sources of advice

5.21 Copying letters is part of wider initiatives to strengthen patient and public involvement in health. Patient Advice and Liaison Services (PALS) will be a good source of advice to trusts on patient issues in implementing the policy and will provide support to patients who want further information (especially by signposting them to sources of expertise). Patient and Public Involvement Forums may want to monitor how the policy works in practice.

Training

5.22 As with other aspects of cultural change in the NHS, training has an important role to play. Topics to be covered could include:

- challenging negative attitudes and stereotyped thinking, and building on the expertise of patients as described in the Expert Patients programme¹¹
- improving IT skills
- drafting letters
- procedures for obtaining and recording consent
- raising or reinforcing awareness around confidentiality issues.

The pilot project 'Letter sharing has it all!' illustrates the power of the copying patients' letters policy to provide the impetus for tackling wider issues around communication (including about risk), information and records handling, and reflecting on how to adapt professional practice to cope with change in relationships with patients. This work is ongoing through the 4Ps programme – Preparing Professionals for Partnership with the Public – and can be seen on www.4Ps.com

New technologies

The development of new IT systems in the NHS should take account of the technological requirements for implementing the 'copying patients' letters' policy.

5.23 The introduction of new IT systems in NHS organisations and general practices should minimise the need for extra staff time in generating automatically copies of letters for patients. It will allow for the use of templates and standard forms of words in writing letters. In future it is intended that communications between healthcare professionals will be in electronic format and be safe, understandable and able to be processed without duplication of labour. Patients' records will be kept electronically and they will be able to read their personal records.

5.24 The Department of Health has made links with parallel programmes and new initiatives - such as electronic appointments booking - to ensure that they take account of the initiative to copy letters to patients. It is important that this initiative is not seen in isolation from other drivers for changed cultures and information management in the National Health Service. Parallel initiatives include the development of Electronic Patient Records as part of the Integrated Care Records Services (ICRS), work on electronic booking systems, and programmes on confidentiality and consent.

¹¹ See www.doh.gov.uk/healthinequalities/ep report

A number of the pilot projects explore practical issues in information systems and records handling. They include provisions for patients to view their records electronically in the surgery (Bury Knowle)¹²; templates for obtaining consent and copying letters to families and children (Great Ormond Street)¹³; terminology (Leeds)¹⁴; and making links with system changes in IT (George Eliot Hospital NHS Trust)¹⁵, among others. The reports identify issues and make practical recommendations for change.

END

¹² Bury Knowle Health Centre and the Department of Public Health-Letters On-Line

¹³ Great Ormond Street Hospital-Children and Carers of Children. Copies of letters about children. Areas of Consensus and potential Conflict between Professionals, Parents and Children.

¹⁴ Street Lane Practice, Leeds. Copying letters to patients: An Assessment of whether modifying letters by explaining medical terminology improves patients understanding & an economic evaluation of one system in general practice.

¹⁵ George Elliott Hospital NHS Trust-Cancer patients. Cancer Communications-Making the Links-Report on Copying Letters to Patients.

Annex A

Views of healthcare professionals who have routinely copied letters

"I think it has benefits for the doctor in that you have to clarify your own thoughts about really why you are referring someone and what message you are giving not only to the doctor, but to the patient. So I think it's a useful process and makes patients more involved in something which is critically their own affair."

"...we may not be right and if we're not right it's better that the patient knows about it because they can tell us....but not just for medical legal reasons...also in terms of sharing information, the patients can see that we misunderstood it and can put us right which is fine."

" Copying letters profoundly de-mystifies the process of the doctor-patient consultation. Seeing clearly the thought processes of the doctors and other professionals allows a real unexpurgated insight into the certainties and uncertainties of the medical process. "

"There is a great need for patients to have some record of their reason for their referral. It would make the initial consultation easier and improve the take up of advice."

Views of patients

"I knew they'd covered everything (in the letter) because when you go to the hospital you tend to forget what you were going to ask, so it's useful for reference. It makes you less anxious..."

"Lets the hospital know what you know. There should be no secrets, no constraints – generally I thought it was brilliant – in the past you never got to know anything. You walked in the hospital grounds not knowing what to expect." Mother of 10-year-old referred boy.

" I thought the letter was a good idea because I knew exactly what had been written about me. I knew there was a chance that I had cancer in my breast before the appointment so I wasn't shocked when the consultant began talking about radiotherapy and chemotherapy. I think it's a good idea because it really put my mind at rest." 72-year-old woman with suspected breast cancer.

" I felt the consultant dealt with me very briefly at Outpatients Department, but when I read the notes I realised that a comprehensive assessment was indeed made. The consultant had information already and worked very quickly."

Benefits of Copying letters to patients¹⁶

Potential benefits of copying letters between professionals to patients

More trust between patients and professionals: Increased openness leads to greater trust and openness between professionals and patients.

Better informed patients: Patients and carers have a better understanding of their condition and how they can help themselves.

Better decisions: Patients are more informed and better able to make decisions about treatment options.

Better compliance: Patients who understand the reasons for taking medication or treatment are more likely to follow advice.¹

More accurate records: Errors can be spotted and corrected by the patient.

Better consultations: Professionals confirm that patients understand what is said during the consultation. Patients are better prepared and less anxious.

Health promotion: The letters can be used to reinforce advice on self-care and life styles.

Clearer letters between professionals: Letters written between professionals are clear and understandable to both professional and lay people.

¹⁶ Copying Letters to Patients- A report to the Department of Health and draft good practice guidelines for consultation.

Annex B: Examples of model letters for communication between primary and secondary care

There are well-documented problems with ordinary free-text communication between GPs and consultants. The GP's letter often misses out important data, such as investigation results and previous history.¹⁷ The consultant's letter to the GP can provide inadequate or irrelevant information.¹⁸ A collection of templates, particularly those integrated with the word-processing facilities for correspondence associated with primary and secondary care, would encourage better communication.

Electronic Booked Admissions and referral procedures are becoming routine. These procedures depend on templates for efficient performance.

The Working Group on Copying Letters to Patients has identified a number of benefits of template letters. These include:

- letters with a common format should be easier for patients to read and understand
- healthcare professionals would be prompted to carry out essential procedures such as:
 - checking the patient's address
 - obtaining consent
 - checking format
 - checking language
- clinicians would be reminded to write in language that was accessible, but without sacrificing accuracy.

As part of a separate audit project funded by the Department of Health, Dr Brian Fisher has developed such templates. The fields are based on advice from consultants and GPs about what would be most useful in such letters.¹⁹

¹⁷ RM Jenkins. The quality of GP referrals to out-patient departments: assessment by specialists and a GP. BJGP 1993; vol 43:111-3

¹⁸ Roland, Porter et al. Improving care: a study of orthopaedic referrals. BMJ 1991 May 11;302(6785):1124-8

¹⁹ Fisher BH, Rennie D et al The process of defining a measure of the appropriateness of elective referrals from primary to secondary care. Submitted for publication.

DRAFT TEMPLATE FOR OUTPATIENT CONSULTANT LETTERS TO GPs

(Dept and hospital details)

GP:	Date:
Address:	

Patient's full name (Mr, Miss, Mrs, Mr, Ms):		
Address:	DoB:	Consultant: Contact nos: Email/fax
Hospital number:	NHS number:	

Patient's decision about copy of letter:
--

Dear

Your patient was seen by me on .

Diagnosis/problem:

Investigations undertaken/findings results:

Recommended management/response to specific query from GP:

Medication advised/prescribed/for how long:

Information (written/verbal) given to patient:

Follow up (appointment made or length of waiting list for procedure):

Yours sincerely,

Signed:
Consultant/SR/Registrar/SHO

Print name:
Contact no/bleep:

Guidelines for GP Referral to a Hospital Outpatients Department

Note: guidelines for good practice will assist in the prompt processing and prioritising of your referrals. Please ensure that the following information is provided to enable appropriate assessment.

I Practice Details

GP Code:	Practice Code:
Practice Address:	
Telephone:	
Fax:	

II Patient Details

Title: (Mrs/Miss/Ms/Mr/(other))	First Name:
Surname:	
Sex:	DOB:
Hospital Number:	NHS Number:
Home Address:	
Telephone:	

III Referral Details

Note: please specify if referral to a non-consultant is acceptable as this may enable the patient to be offered an earlier appointment.

Department:	Consultant:
GP Assessment of Urgency:	

A Reason for Referral (are there any specific questions you would like answering?)

B Recent Medical History (and relevant previous history if appropriate)

C Current Treatment/Medication

D Allergies

E Special/Social Circumstances (relevant to appointment arrangements and consultation e.g. interpreter (specify language), transport, childminder, carer, etc.)

F Investigations/Results to Date

G Patient's decision about copy of letter

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 only be denied where:

- the information may cause serious harm to the physical or mental health, or condition of the patient or any other person or
- where 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 or a 'Gillick competent' child (e.g., 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 which 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 6 people from the race legislation.