CLINICAL PROTOCOL FOR COPYING LETTERS TO PATIENTS

RATIONALE

The Copying Letters to Patients initiative is a government objective which originated in the NHS Plan: "letters between clinicians about individual patient's care will be copied to the patient as of right".

The NHS has an obligation to involve patients in decisions about their health care and communicate with them. Copying letters is an effective way of keeping patients up-to-date with their diagnosis and treatment and demonstrates a commitment to good communications and valuing patients.

Engaging and informing patients is at the heart of good clinical practice. Involving patients also pays dividends in terms of outcomes. We know that almost half of patients with chronic conditions do not take their medication as recommended, resulting in huge personal and financial cost in avoidable continuing illness and premature death, as well as increased health expenditure. The traditional method of "compliance" (follow doctor's orders and take your medicine) does not work very well. By contrast, there is clear evidence that shared decision making - concordance - in which patients understand and negotiate with clinicians the best course for themselves, can lead to higher follow through with the agreed course of treatment and better outcomes and satisfaction. Copying letters to patients is an important strand of involving patients in understanding and agreeing their treatment.

TARGET GROUP

The procedure applies to all staff and students working within the Trust.

TRAINING

All staff in the Trust are required to comply with mandatory training as specified in the Trusts Mandatory Training Matrix. Clinical Staff are also required to comply with service specific mandatory training as specified within their service training matrix.

RELATED POLICIES

Please refer to relevant Trust policies and procedures
WHAT DOES COPYING LETTERS TO PATIENT ENTAIL?
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 under the care of local authority), letters should be copied to the person with legal responsibility, for instance a parent/ guardian and/or social worker.

WHAT CONSTITUTES A ‘LETTER’?
A ‘letter’ includes communications (also electronic 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 health care 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
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’ protocol that such practices should be stopped and, indeed, some healthcare professionals may choose to increase such practices.

RAW DATA
‘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
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
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.

WHEN LETTERS SHOULD NOT BE COPIED
There may be reasons when the Protocol 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
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
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.

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.

THIRD PARTY INFORMATION
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.

SAFE HAVEN PROCEDURES
There are some services (for example sexual health services) 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 Caldicott 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 a Trust environment, or general practice.
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.
- The Trust should ensure individual departments and General Practices include arrangements for recording and acting on patients’ wishes about receiving copy letters 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 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, healthcare practitioners should work within the guidelines on consent produced by professional bodies and the Department of Health. The Trust’s Patient Information and Consent Policy provides advice on obtaining consent in different settings and from patients with different needs and competencies.

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 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
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.

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 in each service /practice area.)

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 Health Records Act 1990...
now only relates to records of deceased people. Also refer to the Trust’s Health Records Policy.

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.

THIRD PARTY CONSENT TO USE OF INFORMATION
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 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. See the Trust’s Health Records Policy for further information on how patients access their health records.

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.

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.

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.

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. However, the Mental Capacity Act 2005 implemented 2007, issues a new safeguard, the Independent Mental Capacity Advocate (IMCA), to represent patients who lack capacity to make important decisions when there is no one else to be consulted.

The Act allows patients to make a Lasting Power of Attorney (LPA) enabling them to appoint someone to make decisions about their finances, property or health care and welfare, should they ever lack the capacity to make decisions themselves. However the Code of Practice published in April 2007 does not specifically mention copying letters to patients. The health professional should ascertain whether the patient’s representative has Lasting Power of Attorney.
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, or LPA. An assessment of capacity may require the sharing of information amongst health and social care workers. If a person lacks capacity to consent to disclosure then you must work out whether it is in their best interests to disclose the information. Only as much information as necessary should be divulged.

**CARERS**
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 a carer without Lasting Power of Attorney, 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.

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 provided to the Trust 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.

**CHILDREN AND YOUNG PEOPLE**
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 and agreement to the destination of the sharing of this information. It is up to healthcare professionals to assess the competence of younger children to understand and make a decision (referred to as Fraser Competence). 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. Please refer to Department of Health guidance for further information.

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.

**HOW IS IT TO BE DONE?**
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
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- The preferred format

Arrangements for copying patients’ letters will need to take into account different ‘pathways of care’, for instance 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. (In relevant circumstances follow the Trust’s child protection and vulnerable adults policies)

- Letters from non-NHS agencies to health professionals are 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.

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

WRITING STYLE AND STANDARD LETTERS
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.

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.

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. Please refer to the Trust’s Discharge Policy for further guidance on information to be used within letters copied to patients.

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). As electronic records become more widely available there will be more standardisation of terminology, giving more consistency and making computer searches simpler
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- setting out the facts and avoiding unnecessary speculation
- Reinforcing and confirming the information given in discussion with the patient in the consultation.

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 lifestyle and management of the illness or condition.

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.

Options for providing copies of letters include:

- A printed copy of the letter
- Copies in large print, or in some other format, such as an 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

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

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.

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. The Trust has a Race Equality Scheme stating how they will deliver non-discriminatory services to local people, including where relevant, access to language support services.

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.

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.
DISCHARGE PROCESS
Safe, efficient discharge requires input from an experienced practitioner who has an understanding of the discharge planning process, working closely with the multidisciplinary team and other agencies.

Discharge is when an episode of care has been completed. There are Service specific systems and processes within the Trust for recording that a patient has been discharged including any relevant information to self manage, please refer to the Trust’s Discharge Policy.

On discharge from the Trust a discharge letter must be given to the receiving health care professional and a copy of this document must be placed within the patient’s health care records.

A copy of the discharge letter is offered to patients and provided upon request accordingly.

FURTHER INFORMATION FOR PATIENTS
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
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.

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 Protocol of Copying Letters to Patients.

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.

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.

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**
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 Trust staff on patient issues to support the implementation of the policy and will provide support to patients who want further information (especially by signposting them to sources of expertise).

**NEW TECHNOLOGIES**
The development of new IT systems in the NHS should take account of the technological requirements for implementing the Clinical Protocol for Copying Letters to Patients.

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. It is acknowledged that IT provision differs across the services provided within the Trust.

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.

**WERE TO GET ADVICE FROM**
When Trust staff need advice relating to the process of copying letters to patients they should contact their Line Manager for guidance and support.

**INCIDENT REPORTING**
Clinical incidents or near misses must be reported via the Trust’s incident reporting system.

**SAFEGUARDING**
In any situation where staff may consider the patient to be a vulnerable adult, they need to follow the Trust Safeguarding Adult Policy and discuss with their line manager and document outcomes.

**EQUALITY ASSESSMENT**
During the development of this protocol the Trust has considered the clinical needs of
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each protected characteristic (age, disability, gender, gender reassignment, pregnancy and maternity, race, religion or belief, sexual orientation). There is no evidence of exclusion of these named groups.

If staff become aware of any clinical exclusions that impact on the delivery of care a Trust Incident form would need to be completed using the Trust’s incident reporting system and an appropriate action plan put in place.

REFERENCES

Access to Health Records Act (1990)

Carers and Disabled Children Act (2000)

Data Protection Act (1998)

Equality Act (2010)

Health and Social Care Act (2001)

Mental Capacity Act (2005)
CONTROL RECORD

Title  Protocol for Copying Letters to Patients
Purpose  To form staff of the fundamental principles and guidelines when copying letters to patients
Author  Quality and Governance Service (QGS)
Equality Assessment  Integrated into procedure
Yes  No
Subject Experts  Caroline Hewitt

Document Librarian  QGS
Groups consulted with :-  Clinical Policies and Procedures Group
Infection Control Approved  N/A
Date formally approved by Risk and Governance Group  October 2012
Method of distribution  Email  Intranet
Archived  Date 16th October 2012
Location:- S Drive QGS
Access  Via QGS

VERSION CONTROL RECORD

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Status – New / Revised / Trust Change