

Patient perspective

Copying clinical letters: access issues for specific patient groups

Diana Jelley

General Practitioner, Collingwood Surgery, North Shields, and Lead Researcher, North Tyneside Primary Care Trust, Newcastle upon Tyne, UK

Caron Walker

Research and Development Facilitator, North Tyneside Primary Care Trust, Newcastle upon Tyne, UK

ABSTRACT

Objectives The aim of this study was to find out the views of specific groups of patients on copying clinical letters to patients, with a focus on patients that may have difficulty accessing or understanding written English.

Design A qualitative study using semi-structured group interviews.

Setting One primary care trust (PCT) district in the urban north east of England.

Participants Eleven voluntary groups serving the needs of people with learning disabilities, visual and hearing impairments and ethnic minority communities – 29 volunteer participants from a purposive sample of these organisations based in the study PCT area.

Results Patients with the defined access needs were keen to receive copy letters. However, a series of suggestions were made to improve access, including use of a range of formats such as tapes or CDs, translation of medical terms, and provision of practice-based language translators and patient advocates.

Conclusion Copying letters is soon to become routine NHS policy. This is welcomed by patients. However, there are important issues to address if implementation is to be helpful for all patients.

Keywords: clinical letters, copying, ethnic minorities, hearing impairments, learning difficulties, patient groups, visual impairments

Introduction

The *NHS Plan* for England, published in 2000, stated that patients would receive copies of clinical correspondence written about them.¹ This policy is due to be implemented in 2004, and is set within a wider government commitment to increase shared decision making and patient choice within the NHS, and encouraging the development of health information that is accessible to all patients.² Much information about an individual's health is contained in the letters that pass between primary and secondary care but it has never been routine practice to share these letters with patients. However, some small studies and anecdotal reports suggest that patients do value receiving copies of clinical correspondence written about them.^{3–6} Findings from recent pilot studies commissioned by the Department of Health have confirmed this view.⁷ Recently completed research on

this topic, and our experience in routinely copying GP referral letters to patients, suggests that certain patient groups may have difficulty accessing written copies of clinical correspondence.⁸ These groups include people with learning disabilities, visual or hearing impairments and people whose first language is not English. The aim of this study was to explore specific issues concerning copied clinical letters with representatives of these groups and identify ways of addressing any difficulties identified.

Methods

The study was based in one primary care trust (PCT) area serving 200 000 people in the urban north east of England. A purposive sample was taken of 11 local voluntary organisations that addressed the needs of

the groups of people we had identified. Each group was approached to participate in the study and seven agreed to take part. In addition, two interviews were held with voluntary organisations supporting disabled people. All sessions were facilitated by one interviewer (CW). An interview topic guide and sample copy letters were used to focus the discussion. An integral part of the sessions involved exploring suggestions by participants to make the policy initiative work.

Patient involvement

This work on copying letters was actively supported by the PCT and prior to undertaking the work, discussions were held with a range of voluntary organisations in North Tyneside around the possible approaches to this study. The researchers acknowledged that participants could require support to participate in the sessions and this was reflected in the funding bid. All written material was provided in a range of formats – standard print (14 point), large print (26 point) or audiotape. Interpreters were available to support study participants from ethnic minority groups but none were required – however signers and lip-speakers were used in several of the focus groups. Where travel costs were required, these were also reimbursed. Prior to the publication of the final report, all participants were given copies of the summary report – which was written in simple language – in a format of their choice. They were all invited to a follow-up meeting where the overall study findings were discussed and 12 participants took part in this session. Feedback from this workshop was incorporated into the final draft of the report.

Semi-structured group interviews and some individual interviews were used in this study. The group interviews were not mixed, each group only having individuals from a single organisation. Group interviews were used as the best way to explore in greater depth the attitudes and perceptions of a small group of patients. It was also felt that group interaction – which is part of this method – might encourage a greater exchange of views and encourage participation from those who may be reluctant to be interviewed for fear of having nothing to say. Interviews and group discussions also do not discriminate against people who cannot read or write English. The length of interviews ranged between 15 and 90 minutes and all interviews were tape-recorded and fully transcribed for analysis.

The analysis of the qualitative data took a thematic content analysis approach to identify the emerging themes and issues from the data and field notes. Data

were analysed separately by the two researchers with results shared and compared.

Results

Seven organisations serving the needs of people with learning disabilities, hearing or visual impairments or ethnic minority communities within the study agreed to participate in the study, and each organisation identified members who would be willing to take part in a group discussion. Organisations chose participants in a variety of ways – some sent out material to members while others asked the researcher to come along to their sessions over an extended period to explain the study and recruit individuals. This resulted in a total of 29 people taking part. The results arising from this qualitative approach are presented in terms of the themes that emerged from analysis of the interview transcripts.

Common themes: general points and issues raised by specific groups

Content of the letter and terminology

People in all groups identified the need for clarity within the letter, both in terms of its style and the medical terminology contained in the letter. Some also felt that there needed to be appropriate support mechanisms for people unable to understand the content of the letter, ‘if you’re upset about anything, you don’t really take it all in at once, do you – maybe seeing it written down might help’. Although many were prepared to share the information with partners or parents, some people suggested that someone with a clinical background at their local practice should be designated to explain the content. Some participants also suggested that, although explaining the content of the proposed referral letter might make that consultation longer, time might be saved in the longer term, as patients would have less need to keep asking for explanations and clarification:

‘If the English is of an advanced level, I go to CAB [Citizens’ Advice Bureau] and there’s somebody there who can sign, [who] explains to me what it means, they translate it because English is my second language.’

Some appreciated that the nature of the letter – i.e. a means of communication between medical professionals – meant that medical terminology had to be used. ‘If they use medical terms, I wouldn’t be able to understand anything in a letter, even if it was read to me.’

Nevertheless there was a strong feeling that there needed to be some kind of explanation of the terms.

Suggestions included putting the medical term in brackets after a lay person's explanation (or vice versa), or a glossary or dictionary at the end of the letter.

Anxiety and reassurance

Some of the studies on this topic have suggested that receiving copy letters might make patients more anxious.⁸ In the discussion groups, the question of anxiety was seen as being very much linked to the level of communication between patient and health-care professional. Many participants took the view that they wanted to know everything and that knowing the full situation made it easier to cope with, 'a patient who thinks he might have a brain tumour, would say to the doctor, do you think I've got a brain tumour, so seeing that written down, wouldn't have any more effect'. Whether this was shared within the consultation or in a letter was not the main issue – their main emphasis was on openness and sharing of information between patient and healthcare staff. Several others took the view that if openness within the consultation could be achieved then a copy letter would not contain any surprises and so not raise anxieties. 'I would be pleased that he was asking to have everything investigated. I would be, personally, reassured. But then it's a personal thing.'

Amongst those participants whose first language was not English, they placed emphasis on the need for the general practitioner (GP) or other health professional to fully explain the terms used in any diagnosis. There was some feeling that although they did not need the assistance of a translator because they spoke English, there was no recognition that they were not familiar with even common medical terms. Similar comments were made which related to procedures – both medical and relating to access to services – as well issues around the expected time-scales, such as length of waiting lists. Often all these aspects were new to them so they had no experience against which to measure these aspects. Patients in the groups who had had experience of receiving a copy letter or viewing their medical records, made the point that seeing the content of the letter provided reassurance rather than increased anxiety. Their reason for this was that they often feared the worst when presenting with symptoms and felt that excluding those possibilities provided reassurance. Other people suggested that the inclusion of possible serious diagnoses would make them feel reassured that every avenue was being explored.

Sensitive and harmful information

Many participants took quite a straightforward view about whether or not sensitive or potentially harmful information should be included in the copied letter.

A recurrent view was that as long as the information was accurate – for example about previous alcohol or drug misuse – then they saw no problem including it. Most felt that it was legitimate for such aspects to be included but felt less comfortable with other background information which might be included – such as personal judgements or irrelevant aspects of their life:

'The thing is if the doctor thinks it's relevant, I mean, the patient ought to be made aware of it. There's no harm in turning round and saying, well, you're drinking too much. If the doctor thinks that's his problem.'

Consent and confidentiality

The issue of consent was important for people not only in terms of when it is sought but also who should provide the consent. Consent itself was seen by some as something which would be indicated at the start of an episode while others took the view that once a person had opted to receive copies of letters, this would continue until they decided to opt out. The responsibility of obtaining consent was seen to lie with the GP or other health professional, rather than with administrative staff. The feedback session also raised an issue about who would decide about the competency of an individual patient to be able to provide consent for a third party to receive information on their behalf, 'you have a right to know, but some people don't want to know, would rather not, and therefore it's a choice really'.

Particularly from people with learning disabilities, the view was expressed strongly that it should be the patient who should decide which third parties – whether relatives or carers – should have access to copied letters. They favoured the idea of a nominated person who could receive information on their behalf, on the understanding that they could still decide whether or not an individual letter would be copied.

Issues of confidentiality and the use of advocates and interpreters require further consideration – a number of comments were made. Independent advocates took the view that they could assist the people they worked with but there could be issues around confidentiality with carers who acted as advocates. A suggestion was made by others that there should be a separate agency that could provide this service – such as an advocacy service – which could either be part of the health service or a voluntary organisation. However, at the feedback session concerns were raised that confidentiality could be compromised if an agency outside the health service was responsible for providing this type of service and, similarly, if an outside organisation was used to transcribe letters:

'Unless you make a stand that you want to see, you want to know about results, they're not going to tell you,

they're going to tell the people you're with, care staff or the nurses. They're not, you know, it's like it's none of your business. And yet it's you, yes, it's about you.'

For people from minority ethnic communities, the issue of confidentiality was viewed in terms of their relationships with translators or others sharing information about them. There was a view that translators and interpreters had codes of conduct that included confidentiality clauses but there was some feeling that healthcare professionals may have reservations about this. People also raised concerns about others being able to access the contents of the letter. For some, they would prefer to collect a copied letter from their surgery rather than having it sent in the post. This could involve a collection slip that could also be used by a person, such as a carer, who was acting on behalf of another.

Other ways of providing copy letters

An integral part of the sessions involved exploring how the policy could be made to work for patients. Importantly, several people made the point that voluntary organisations had already done work in the area of making material accessible and that there were existing models of good practice available which could be shared.

People gave a range of suggestions around how letters could be more accessible for them (see Box 1). Some related to alternative formats – such as tape,

Box 1 Recommendations and suggestions

- Letter format
 - consider the use of tape recordings, CDs or the use of large print, or videos with signing
- Letter content
 - use pictures or diagrams to help explain the text, or linked prompts to explanatory sites if email letter copies are sent
 - use simplified English with headings and sub headings to make the main points clear
 - include a glossary of medical terminology
- Letter interpretation and understanding
 - have a practice-based advocate/advice worker who could help explain the content of letters
 - have a practice-based interpreter for other languages and sign language
 - provide a confidential phone number to ring to get an explanation of the content of the letter

CD, video, pictures and drawings – but some suggestions emphasised the support mechanisms required to make the contents of letters understandable. Designated staff in practices, telephone advice lines and support from external agencies were all suggested. Some felt that a written letter may not be accessible but they still felt a written letter would be useful for partners and relatives. For people who were able to read, suggestions around the importance of plain or simplified English and the need for explanations were felt to be important.

Conclusions

This study involved small numbers of individuals from a non-random sample of voluntary groups. It does not claim to be representative of the views of all people with specific access issues for copying letters, particularly of ethnic minority groups which are under-represented in the north east in terms of national profiles. Nevertheless, it does highlight some important factors that need to be addressed if implementation of this new policy is to be useful and effective for all health service users. Most study participants felt that having copies of clinical correspondence was a positive initiative in that it recognised a greater openness and sharing between them and their doctor. Potential advantages of copying clinical letters discussed in the groups echoed findings from other studies – namely feeling better informed, less anxious and more in control.^{3–5} Effective 'patient partnership' requires a significant shift in the thinking of clinicians, patients do not only want information they want also want involvement in decisions affecting their health and healthcare.^{9,10} For the groups of people who took part in this study, simply providing information in a standard format is not enough. If copied letters are to be helpful and meaningful, they must be provided in a way that is accessible for those who cannot see, hear or understand the written word. The issues of readability, the use of plain English and translation when necessary, the avoidance of jargon and the provision of explanations must all be considered before this policy is implemented. An organisation called 'Preparing Professionals for Partnership' has already produced some web-based guidance in this area.¹¹ This new NHS policy is a critically important component of the broader thrust of greater public involvement in healthcare delivery. Its successful implementation will depend on making letters accessible to everyone. It is hoped that consideration of the recommendations suggested by the study participants will contribute to its effective delivery.

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ADDRESS FOR CORRESPONDENCE

Dr Diana Jelley, Collingwood Surgery, Hawkeys Lane, North Shields NE29 0SF, UK. Tel: +44 (0)191 257 1779; fax: +44 (0)191 226 9909; email: di.jelley@gp-A87004.nhs.uk

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