

## Copying clinic letters to patients: a survey of patient attitudes

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### Abstract

Guidance from the Department of Health, published in 2000, stated that, ‘as a matter of right’, communications between clinicians would be copied to patients. In further guidance, the department indicated that, from April 2004, patients would receive copies of correspondence exchanged between healthcare professionals. There has been little research on this issue, and the few existing publications have come from the hospital psychiatric clinic setting.

We examined the attitudes of 100 patients attending an ENT clinic as well as those of 100 parents of children attending a paediatric ENT clinic in a general hospital out-patient setting. At the end of consultations, patients or parents were invited to take part in the survey by completing a short questionnaire. Forty-three per cent of the adult patients and 44 per cent of the parents requested a copy of the clinic letter. These people were followed up by a telephone survey, three weeks after the copy of the clinic letter to the general practitioner was posted to the patient or parent. Eighty-one per cent of the patients and 77 per cent of the parents were successfully contacted for the follow-up telephone survey. Sixty per cent of the adults and 77 per cent of the parents reported that the copy of the clinic letter was helpful. There were no differences in responses between the adult patient and paediatric patient groups.

In this study, less than half of both groups requested a copy of the ENT clinic letter to their general practitioner. To follow Department of Health guidance and copy the letter without patient consent is arguably contradictory to best practice and also to the concept of patient choice. There are significant financial implications in adopting the departmental guidance. We propose patients should be offered a copy of their clinic letter on request.

**Key words:** Communication; Outpatients; Patient Survey; Attitudes

### Introduction

As part of a government initiative to improve communication between doctors and patients, the *NHS Plan* of 2000 stated that ‘...letters between clinicians about an individual patient’s care will be copied to the patient as a matter of right’.<sup>1</sup> Further guidance issued by the Department of Health clarified the *NHS Plan*, indicating that, from April 2004, patients should be offered copies of letters written about them by one healthcare professional to another.<sup>2</sup> The response from clinicians to these statements from the department varied considerably, from enthusiastic support to concern about the implications such a practice may have on doctor–patient relationships. There was also concern about the (unresourced) additional workload for secretarial staff and the (unfunded) costs to trusts.

Only a small number of studies have assessed from the patient’s perspective the issue of copying letters

between healthcare professionals. These few reports come mostly from psychiatric and oncology clinics, where the nature of the consultation differs considerably from that in more general out-patient clinics.<sup>3–5</sup>

A previous study from an ENT department reviewed patients’ satisfaction, after randomly allocating patients to receive or not to receive a copy of the clinic letter to their general practitioner (GP). This study did not assess patients’ attitudes to receiving a copy of the letter, and the follow up was by a postal questionnaire, with only 59 per cent of patients responding.<sup>6</sup>

Sending letters to parents following clinic appointments is a well established practice in child development centres, where information is often complex in nature, involving both the parents and many different healthcare professionals in the ongoing management of the child. There is evidence that, in this setting, the practice is seen by all to be of value and benefit.<sup>7,8</sup>

## Methods

Two hundred patients or parents of patients were included in the study. These were sequential attendees, with 100 being recruited from an adult ENT clinic and 100 from a paediatric ENT clinic. In the latter, if a child attended with a carer other than the parent or usual guardian, they were excluded from the study. Both clinics took place in a general hospital setting.

Using a standard question format, the patient or parent was asked at the end of the consultation if they wished to receive a copy of the letter written by the clinic doctor to their GP. If they agreed, oral consent was obtained to contact them by telephone within four weeks of attending to discuss the contents of the letter. The question was phrased in a neutral tone in order to avoid the patient interpreting the decision, either way, as a value judgment. Those who declined the copy letter were asked briefly if they wished to make a comment as to why they preferred not to receive the letter.

Patient or parental details were recorded for all of the 200 attendees in the study. The clinic letter was posted by second class post within a week of the appointment, and, three weeks later, those who requested a letter were contacted by telephone. If no reply was obtained, further calls were made within the week of the initial call. Those who could not be contacted within this week after three attempts were considered not contactable (Figure 1). The telephone interview consisted of a standard questionnaire, with four simple questions to confirm that the patient or parent had received their copy of the clinic letter and also to assess their attitudes to the content and helpfulness of the letter (Appendix 1).

## Results

Forty-three per cent of the adult patients and 44 per cent of the parents or guardians accepted a copy of the letter sent to their GP. There was no statistically significant difference between the rates of acceptance of the two groups ( $p = 1.0$ ). The majority (89 per cent) of those who declined a copy of the letter said they were satisfied with the information they had received during the consultation. This probably reflected the relatively focused and routine nature of the clinical problem; results may have differed in a more complex clinical setting. Another 6 per cent said that they would have accepted the letter had it been sent to them rather than to another doctor. Two patients from the adult clinic did not explain their reasons for declining the letter. Four patients declined the letter because they did not want to take part in the follow-up telephone interview. A total of 43.5 per cent of patients or parents requested a letter.

We were able to complete the telephone questionnaire with 77 per cent of the parents and 81 per cent of the adult patients. Eight patients did not receive a copy of their letter due to incorrect address details being held on the trust patient record system. Four from the adult patient group were unwilling to take part in the telephone questionnaire as they 'had not realized that they were part of a study'. After excluding the above patients, we were able to complete the

follow-up questionnaire with 79 per cent of the initial group of 200. We further divided the subjects in the study into new patient and follow-up patient groups. Comparing the two groups, we found no statistically significant difference in the proportion wishing to receive a copy of the letter. This was true for both the parent and adult subgroups ( $p = 1.0$  and  $p = 1.05$ , respectively).

Sixty per cent of the adult patients and 77 per cent of parents found the letter very useful and felt that sending letters to patients should be routine practice. We compared the views of the two groups using the chi-square test and found that the difference in positive responses between adults and parents was statistically significant ( $p < 0.05$ ). This may reflect the fact that parents are more anxious about consultations when their children are directly involved and therefore want a written 'proof' of what has been discussed in clinic. All respondents agreed that although the letters did not contain new information, it was useful to have a summary of the consultation in writing, because 'it is difficult sometimes to absorb all that the doctor says in the clinic'. Interestingly, amongst patients finding the letter useful, there was no statistically significant difference between those from new or follow-up appointments ( $p = 0.2$ ). Three patients expressed concern that 'the doctors might disclose less information than they normally would if they knew I was going to receive a copy of the letter'. Two patients complained about not understanding some of the medical terminology. The parents of one child wrote back to complain about the content of the letter; they felt that the letter did not accurately describe what they thought was the cause of their child's symptoms.

Thirty-eight per cent of the adult patients and 20 per cent of the parents thought that letters should only be sent when the nature of the clinical

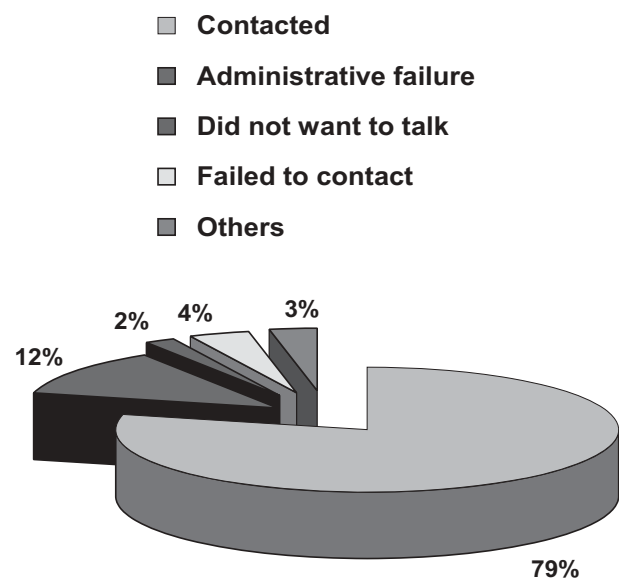


FIG. 1  
Results of telephone follow up.

problem was complex and would need long-term management and follow up.

None of the patients described feeling more worried or anxious about their ENT problems as a result of receiving or reading their copy of the clinic letter.

### Discussion

Giving patients a copy of letters from one healthcare professional to another is intended to empower patients by ensuring that they have the opportunity to become aware of personal medical information written about them.<sup>9</sup> The fact that some patients may not wish to take part in this communication has not been previously explored. If central government imposes such communication on patients in the assumption that it will benefit them, this could be seen as contradictory to the prevailing theme of 'patient choice'. This situation illustrates the current political paradox of consumerism versus the 'nanny state'.

In our study, set in general adult and paediatric ENT clinics, we found that less than 45 per cent of the patients or parents wished to have a copy of the letter written to their GP when this was offered to them.

Following receipt of these letters by those who requested them, 60 per cent of adult patients and 77 per cent of parents of paediatric patients responded positively to the content of the letter and to the proposal that clinic letters to GPs should routinely be copied to patients following an out-patient clinic consultation.

Previously published studies report a generally more enthusiastic response from individuals with mental illnesses and from parents of children with developmental disorders. Marzanski *et al.*<sup>3</sup> reported that 76 per cent of patients attending a psychiatric clinic wished to receive a copy of the letter written by the psychiatrist to their GP, if available. Nixon and Courtney,<sup>10</sup> when posing the same question to patients attending a rheumatology clinic, found that 91 per cent answered 'yes' and 9 per cent answered 'don't mind'. Both these studies involved written questionnaires given to the patients at the time of their clinic appointment. Nixon and Courtney's response rate was 61 per cent. In a primary care study, Morrow<sup>11</sup> concluded that only 20 per cent of patients wanted a copy of the clinician correspondence.

In the only other published study of patients in a general ENT clinic, researchers assessed the perceived added satisfaction of adults receiving a copy of the clinic letter.<sup>6</sup> In this study, patients were randomized to receive or not to receive a copy of the correspondence, without being asked if they wished to have the copy letter or not. The study used a written postal questionnaire, resulting in a response rate of only 59 per cent. The randomization process resulted in two groups of considerably different size; 125 patients were sent a copy of the letter to their GP, while 75 were randomized to receive no letter. The overall patient satisfaction score regarding the consultation was 9.0 for those who received the letter, compared with 7.75 for those who did not. The authors concluded that receiving a copy of

their GP letter was a variable independently associated with overall patient satisfaction.

Our study used a telephone interview, and we attributed our high response rate (79 per cent) to this. Our study differed from some of the previously published reports in that the latter surveyed patients attending clinics in which copying letters to patients was routine; some patients would have previously received correspondence and therefore become accustomed to this practice.

One limitation of our study was that those who requested the copy letter might have developed an expectation bias and therefore may have felt more positive about receiving the letter and also about its contents. Doctors may potentially have been biased by knowing which patients had requested letters, giving doctors the opportunity to tailor their letter content. Before study commencement, we had decided to allow doctors to be aware of those patients receiving letters, rather than blinding them, to facilitate letter writing with a minimum of medical terminology and jargon, thus allowing patients to understand the contents. This seems to have been effective; only two patients (1.2 per cent) reported difficulty in understanding their letter. Patients like letters that they can understand and that contain minimal medical terminology.<sup>12</sup>

It has been proposed that letters should be written to the patient and copied to their health professionals, if the objective of providing information to patients about their treatment is to be fulfilled.<sup>13</sup> This view is supported by 11 per cent of our patients, who would have welcomed a letter following the consultation if it had been addressed to them, personalized and copied to their GP.

- **Guidance from the Department of Health in England, published in 2000, stated that, 'as a matter of right', communications between clinicians should be copied to patients**
- **This survey examines the attitudes of 100 patients attending an ENT clinic and 100 parents of children attending a paediatric ENT clinic in a general hospital out-patient setting**
- **Less than half of both groups requested a copy of the clinic letter to their general practitioner**
- **Adopting the departmental guidance has significant financial implications. The authors propose that patients be offered a copy of their clinic letter on request**

The previous guidance given by the Department of Health failed to recognize or address the potential resource issues arising from introducing routine copying of correspondence to patients. In our own department there are 12 clinics weekly, with approximately 350 patient attendances. Each additional letter takes approximately 90 seconds to print off and place in an envelope. This produces an additional secretarial workload of 8.75 hours per week, for a nominal 40 weeks of the year. Supply

costs include stationery, consumables (e.g. printer ink) and postage.

A published economic evaluation of the letter copying policy estimated an additional cost of 115p per letter sent.<sup>14</sup> This compares well with the cost of £1.00 per letter estimated in a primary care pilot study.<sup>15</sup>

The additional cost to the UK primary care system alone has been estimated at £15 million per annum.<sup>14</sup> If these additional costs are not to be funded centrally, there will be an inevitable demand on the budget at hospital directorate or practice level, which can only be met by reducing direct patient care expenditure.

Doctors in both primary and secondary care may expect an increased workload resulting from copied clinic letters, as they deal with patient enquiries prompted by such communication.<sup>16</sup>

In addition, healthcare professionals may need to revise the style of their letters, and they would inevitably need to judge how much and what type of information to include. This may result in less than adequate information passing between clinicians. Doctor training in letter-writing skills may be required to avoid letters causing patient disappointment and apprehension.<sup>2,12,13</sup>

### Conclusion

Our study indicates that approximately 40 per cent of patients or parents of patients attending an ENT clinic in a general hospital wanted to receive a copy of their clinic letter to their GP when this was offered. Of those requesting a letter, 30 per cent felt (after receiving the letter) that copied correspondence should be reserved for consultations of a complex nature or for those patients who requested such a copy.

We believe that patients or their parents should be given the choice to receive a copy of their clinic letter. Central government guidance to the effect that receiving such a copy is a 'matter of right' conveniently ignores the right of the patient to positively decline a copy letter. From the doctors' point of view, copying to the patient a letter summarizing the clinic discussion may confer a medico-legal advantage in these days of defensive practice. However, offering 'patient choice' must respect the wishes of patients who do not want to be part of the professional communication, and this may avoid unnecessary patient anxiety. The professional, administrative and financial burden to the National Health Service were not considered prior to the Department of Health's publication of this guidance.

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### Appendix 1. The questionnaire

LABEL:

DATE:

CONTACT NUMBER:

NEW PATIENT:

FOLLOW UP:

Letter requested: yes/no

Follow-up call date:

QUESTIONS (patient/parent):

Did you receive the covering letter? yes/no

Was it helpful? yes/no

Did it contain any new information? yes/no

Do you think every parent should receive a covering letter? yes/no

Other comments:

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Mr P J Robb takes responsibility for the integrity of the content of the paper.

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