

# Does the use of a glossary aid patient understanding of the letters sent to their general practitioner?

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**ABSTRACT** – The NHS Plan suggests that all patients should be offered copies of letters regarding their treatment which are currently sent from a specialist clinic to their general practitioner (GP). Previous work has suggested that this enhances patient satisfaction, but medical letters can be difficult to understand. This report concerns the production and evaluation of a lung disease glossary to enhance patient understanding of terms used within the letter sent to their GP. Non-clinical staff reviewed 219 letters sent to GPs and words not likely to be understood by patients were listed and used to produce a glossary of 133 terms. One hundred and thirty-one participants from nine respiratory outpatient clinics in a London teaching hospital were sent the glossary and a questionnaire with their copy of the letter also sent to their GP. Of the 131 participants, 93 patients (71%) returned the questionnaire. Eighty-three (89%) found the glossary useful and the number of words checked ranged from 0 to 14 with a median of three words. Those who did not find the glossary useful explained that their understanding was already optimal or that the words they did not understand were not contained within the glossary. This was usually because the words related to non-respiratory comorbidities. This study confirms that the inclusion of a specialty specific glossary with the patients' copy of the letter being sent to their GP is appreciated by patients and appears to aid their understanding.

**KEY WORDS:** general practitioner's letters, glossary, letters to patients, patient understanding

## Introduction

For many years some hospital specialists have made it their practice to copy letters which they are sending to the referring primary care physician to the patient. Evaluations of this practice have demonstrated its value in a wide range of specialties.<sup>1-4</sup> More recently, the NHS Plan suggested that all patients should have the opportunity to receive copies of letters sent to

their general practitioner (GP) following outpatient consultations.<sup>5</sup> A subsequent justification for that policy has been published.<sup>6</sup> The former secretary of state for health extended this proposal, suggesting that patients should have a specific letter addressed to themselves after a hospital consultation.<sup>7</sup> An Irish study suggested that such a letter would also be acceptable to the GP<sup>8</sup> but an English study<sup>9</sup> showed that such a letter would not be acceptable and that patients also wished to see the separate letter being sent to their GP.

The English study highlighted the fact that the content of the letters was sometimes inaccurate and that patients' comprehension of the content of the GP letters was sub-optimal. Others have already demonstrated how dictation of the letter in front of the patient can, among other benefits, reduce factual errors<sup>10</sup> but the problem of comprehension may be harder to solve. One possibility is for specialists to write more 'patient-friendly' letters to GPs. An alternative might be to issue patients with a glossary to aid their understanding of their copy of the letter. A lung disease glossary has therefore been developed and its usefulness to patients has been assessed.

## Methods

Three non-clinical members of staff independently read 219 copies of letters sent to primary care physicians from nine different respiratory clinics:

- two general clinics
- tuberculosis clinics
- difficult asthma clinics
- clinics for those with chronic obstructive pulmonary disease (COPD)
- lung cancer clinics
- diffuse parenchymal lung disease clinics
- the West London Sleep Centre.

The three staff members highlighted words which either they did not understand or which they thought patients might not understand. Those words were placed in alphabetical order and a brief definition for each, written by a respiratory specialist (MRP) was supplied. This draft glossary was circulated to all of the consultant respiratory physicians working in the

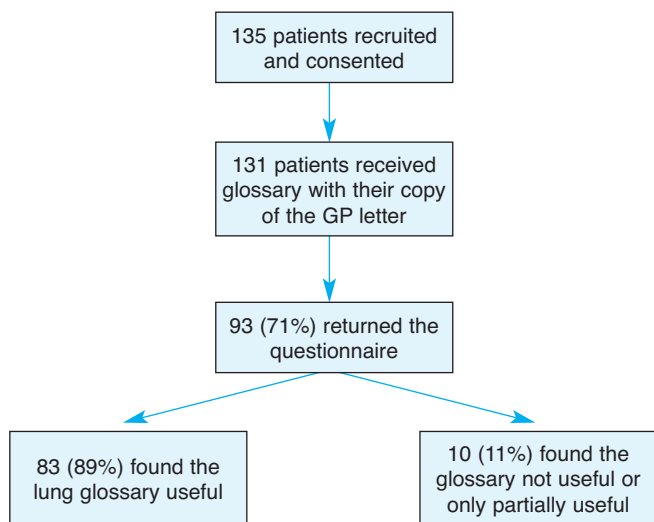
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**Fig 1. A summary of the questionnaire process and patients views regarding the glossary.** Four consenting patients did not receive a letter because one was not sent to their GP on that occasion (3) or because of a secretarial delay (1).

Charing Cross Hospital clinics and input and feedback were encouraged. The subsequent revised glossary was produced as a small 20-page booklet containing an introduction, the glossary, and a list of useful websites related to respiratory conditions.

One hundred and thirty-five consecutive patients attending the respiratory clinics were invited to receive a glossary with their copy of the GP letter. They consented to complete a short questionnaire and return it to us after they had received their copy of the letter being sent to their GP.

**Results**

Of the 135 participants recruited, 131 were sent a copy of their GP letter, the glossary and the questionnaire by the hospital consultant. Ninety-three (71%) returned the questionnaire. A summary of the results is shown in Fig 1.

Out of the 93 patients, 83 (89%) found the glossary useful (Table 1). Nine (10%) did not find the glossary useful and one person found it only partially useful. Those who did not find the glossary useful were asked to state their reasons and this reflected either that the words in which they were interested were not included in the glossary, or that the patients had found

**Table 1. Reasons and additional comments from the 83 respondents who found the glossary useful.** Respondents could offer more than one comment.

	Frequency (n)
Very useful/aids understanding	40
Excellent idea	7
Letter easy to understand/knew all the words	7
Benefits service to patients	5
Explanation given by consultants difficult to remember/glossary is a useful reminder of consultations	4
Copies of correspondence to GP reassuring	2
Feel more empowered	2
Letters to all patients should be accompanied with a glossary	2
All hospital departments should have a glossary	1
Would like this process (receiving copies of GP letters) to continue	1
Aids discussion with family	1
Useful on diagnosis	1
Further elaboration needed on some words	3
Suggestions about cross referencing	2
Would like a glossary more specific to disease (eg emphysema)	1
Glossary covers too much	1
There were no pictures	1
Would like a more accessible version of glossary with less medical language	1
Did not understand parts of letter	1
Words looked up not included	1
Understands words, but the way the doctors use them is confusing	1
Still worried about condition	1
Sarcoidosis website out of date	1

GP = general practitioner; n = number.

their consultation straight-forward and the letter easy to understand (Table 2). Seventy-eight of the 93 patients (84%) did find the words they needed in the glossary. The number of words looked up ranged from zero to 14 with a median of three words per patient. To evaluate the potential usefulness of the included list of websites relating to respiratory conditions, we asked the respondents whether they had easy access to the internet and 55 of the patients (59%) said yes.

The patients were additionally asked to record words/terms which they looked up in the glossary but still could not understand. These included FEV/FEC, RCP, BMI and atrovent. Patients were also asked to record words/terms which they looked for but could not find. These numbered 144 words/terms. As a result of this some terms, such as 'alpha 1 antitrypsin deficiency' and 'bronchopulmonary aspergillosis' were added to the glossary. The majority of the other words which were not in the glossary related to those which referred to non-respiratory comorbidities, for example, 'troponin'. Spontaneous comments on the questionnaire adjacent to this section made it clear that some of the patients who did not benefit from the glossary despite having seen the definition still did not know whether their result was normal. For example, one patient recorded looking up 'oxygen saturation' and reported, 'I do not know if a saturation of 93% is good or not?'

## Discussion

Patient satisfaction with secondary care health provision is generally high.<sup>11</sup> Optimal communication enhances satisfaction and subsequent compliance<sup>12</sup> but much that is said during a consultation is forgotten by the patient soon after it finishes. Dictating clinic letters in front of the patient has been shown to

increase patient understanding of their condition<sup>4,10,13</sup> but the letter clearly has to be comprehensible to the patients. We have previously demonstrated how the Flesch Reading Ease score was significantly higher (ie the information was easier to understand) when letters are specifically written to the patient rather than to the GP<sup>9</sup> but such letters may<sup>8</sup> or may not be<sup>9</sup> acceptable to the GPs as a substitute for the letter to them and writing two letters is probably only practical in a minority of circumstances. We have therefore demonstrated that the glossary may enhance a patient's understanding of the letter to the GP and the positive, spontaneous comments would certainly suggest that it enhances patient satisfaction with the whole consultation process.

The burden of disease in respiratory medicine has moved over the last two decades from a burden which was predominantly one of communicable diseases to a burden of long-term conditions, such as asthma, COPD, diffuse parenchymal lung disease and ventilatory abnormalities during sleep. For these conditions, patients need to be in control of the condition themselves. To do this they need to fully understand their condition and the information which they have been given about its management.

We should not assume, however, that a glossary will solve all problems, for up to 15% of our patients may be functionally illiterate.<sup>14,15</sup> For these patients other methods of reinforcing the information given within a consultation and contained within a letter to the GP may be needed, such as pictorial representations, telephone follow up or provision of tape recordings of the consultation.<sup>16</sup>

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**Table 2. Reasons and additional comments from those who did not find the glossary useful (n=9).**

	Frequency (n)
Letter easy to understand/knows all the words	3
Found glossary interesting, but not necessary	1
Useful on a rack in clinic for first-time patients to pick up	1
Did not contain words sought	7
Found the letter confusing	3
Would like a more accessible version of glossary with less medical language	2
Not able to use glossary	2
Further explanation on certain words needed	2
Has other non-respiratory problems	1
Letter best left for health professionals to read	1
Glossary might become too big	1
Larger font	1
'A little knowledge is a dangerous thing'	1

GP = general practitioner; n = number.

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