



**Report 4 of  
The National Chronic Obstructive  
Pulmonary Disease Audit 2008:  
Patient Survey**

**The Royal College of Physicians of  
London,  
British Thoracic Society and  
British Lung Foundation  
December 2008**

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On behalf of the National COPD Audit 2008 Steering Group.

## **Acknowledgements**

We would like to thank all the people who have contributed to the development of the methodology and questions for the National COPD Audit 2008. We consulted widely and received extremely helpful, enthusiastic input from colleagues and patient representatives, all of which was considered by the Project Team prior to the refinement of the tools.

We are particularly indebted to members of the Steering and Implementation Groups who unreservedly gave the Project Team direction, support and the benefit of their expert opinions.

Specific thanks are due to Dr Stephanie Taylor and Dr Steve Holmes for long telephone conversations and email discussions regarding the primary care elements of the audit, and also to Dame Helena Shovelton for her support and input to the report.

Thanks also are extended to three patient support groups that supported and contributed to the development of the patient survey, namely:

- Taunton Breathe Easy Group
- The Lung Club, Whipps Cross University Hospital Chest Clinic
- Blackdown Hills Breathe Easy Group

We acknowledge and very much appreciate the time and effort given by all clinical and audit colleagues across the NHS, in order to contribute to this project.

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## Executive summary

Chronic Obstructive Pulmonary Disease (COPD) is the fifth biggest cause of death in the UK, the second most common cause of emergency admission to hospital and one of the most costly in-patient conditions treated by the National Health Service (NHS) (British Lung Foundation 2007)<sup>1</sup>. With effective services and treatment, exacerbations of COPD can be shortened, so reducing the need for hospital admission, reducing lengths of stay and improving the outcomes and quality of life for patients.

Previous national audits of COPD, in 1997 and 2003, focussed on care in Acute NHS Hospitals. Since that time, the National Institute for Clinical Excellence (NICE)<sup>2</sup> has published its guideline on the management of chronic obstructive pulmonary disease in adults in primary and secondary care (2004), followed by two Commissioning Guides to support COPD clinical service design; namely assisted-discharge service for patients with COPD, and pulmonary rehabilitation services for patients with COPD (2006)<sup>3</sup>. More recently, the Department of Health has embarked on developing a National Clinical Strategy for COPD (formerly known as the National Service Framework) for England (due to be published in 2009).

This third round of national COPD audit has been carried out to assess progress since the 2003 National COPD Audit and the 2004 NICE guidance. It builds on the two audits of acute COPD care in 1997 and 2003 and recognises the developing integration of COPD services across the primary and secondary care interface by including elements across the care pathway. Thus, assessment of the organisation and process of care within acute admitting units and Primary Care Organisations has been undertaken, as well as a clinical audit of cases. For the first time, however, we have surveyed General Practitioners admitting patients with acute exacerbation of COPD and also patients themselves.

This report only describes the patient survey element of the 2008 National COPD Audit. The four other elements of the audit (listed below) will be reported separately and will be available at the RCP web-site when published: <http://www.rcplondon.ac.uk/clinical-standards/ceeu/Current-work/Pages/copd-audit.aspx>

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<sup>1</sup> British Lung Foundation, 2007. Invisible lives: Chronic Obstructive Pulmonary Disease (COPD) finding the missing millions. Available at: <http://www.lunguk.org/NR/rdonlyres/E027CA18-B5C6-49AB-96FA-C4AF55E6F484/0/InvisibleLivesreport.pdf> (20 August 2008)

<sup>2</sup> National Institute for Clinical Excellence, 2004. National clinical guideline on management of chronic obstructive pulmonary disease in adults in primary and secondary care.

<sup>3</sup> National Institute for Clinical Excellence, 2006. Commissioning guides: supporting clinical service redesign. Available at: [http://www.nice.org.uk/usingguidance/commissioningguides/commissioning\\_guides\\_8211\\_supporting\\_clinical\\_service\\_redesign.jsp](http://www.nice.org.uk/usingguidance/commissioningguides/commissioning_guides_8211_supporting_clinical_service_redesign.jsp) (26 August 2008)

- The National COPD Audit 2008: resources and process of care in acute NHS units across the UK.
- The National COPD Audit 2008: resources and process of care in Primary Care Organisations across the UK.
- The National COPD Audit 2008: clinical audit of COPD exacerbations admitted to acute NHS units across the UK.
- The National COPD Audit 2008: General Practitioner survey.

## **Key Messages**

***[Readers are reminded that the data have been obtained from a questionnaire completed by a group of patients hospitalised, or recently discharged, with COPD exacerbation. 42% of the patient group usually attended a chest clinic in addition to being managed within primary care].***

The results suggest that the lead-in, or pro-dromal, phase of exacerbation is quite long and imply there is ample opportunity to make earlier interventions to prevent hospital admission in a selected group of patients who exacerbate frequently. There is also a need for improved patient self-management and the value of personal COPD plans should be explored in this context.

### **Exacerbation and Accessing Care:**

- The overwhelming majority (83%) of patients reported frequent exacerbation of their COPD.
- Two thirds (68%) of patients reported a respiratory infection or flu-like symptoms in the month prior to admission, about half (57%) noticed a change in colour/volume of phlegm before admission, often 2-5 days before (46%), but with one quarter (26%) having noticed this 6 or more days before.
- Although 25% of patients admitted with COPD said this was their first admission, 60% had also been admitted to hospital with COPD in the previous 12 months.

- Just over half (57%) of patients stated they normally sought advice over the phone from their GP, respiratory nurse or hospital doctor, and most (84%) felt they could get advice either directly (26%) or the same morning or afternoon (56%).
- 41% of patients stated they would usually contact their doctor or respiratory nurse immediately when their COPD was bad, 29% would tend to wait a while before contacting their GP but 22% would go directly to hospital rather than to their doctor.
- On this particular occasion, however, 41% of the patients had called an ambulance to take them to hospital, 34% had seen the GP and then were sent to hospital and 12% went to casualty directly without calling an ambulance.
- This group of COPD Patients did not tend to use National Help Line Services.

### **Disease Management:**

- The great majority of patients stated that they understood what COPD meant (85%) and knew they already had it (79%).
- Only one quarter (24%) of this hospitalised group of patients had antibiotics and steroids to use themselves at home.
- Only one quarter (23%) had been given a written plan for what to do when their chest was getting bad.
- Only 55% of patients reported that they had regular check-ups at their doctor's surgery for their chest, although 42% were attending a hospital chest clinic.
- One-third (32%) of patients reported using oxygen at home and one-half (48%) a nebuliser.

### **Other Factors:**

- Nearly 60% of respondents were aged 70 years or older, and 21% were over 80 years old.
- Two thirds of patients (66%) felt they would still have needed to come into hospital even if they had more help at home.

- Patients provided numerous different suggestions for service improvement, which broadly fell into the following categories:
  - The need for care and help at home,
  - The need to access respiratory nurses,
  - The need to have a good home oxygen service,
  - The need for nebulisers to be available to patients.

## **Recommendations**

### **On diagnosis, and upon review, patients should:**

- Receive a personal COPD plan that is modified as the disease progresses.
- Be given clear instruction as to how the prompt treatment of exacerbation may reduce the need for hospitalisation.
- Know whom to contact, how and when, in the event of deterioration.

### **Primary and Secondary Healthcare teams should:**

- Provide more patients with access to antibiotics and steroids to help them self-manage exacerbation.
- Educate and encourage patients with COPD to seek help early on when symptoms of an exacerbation develop.
- Establish that systems and services are in place to ensure the rapid assessment and treatment of patients presenting with early symptoms of exacerbation.
- Ensure patients have sufficient domestic support and home aids to help them manage at home.

### **Commissioners should:**

- Consider commissioning quality parameters for managing this group of vulnerable and frequently exacerbating patients whose care is spread between Primary and Secondary Healthcare teams.



## Introduction

The National COPD Audit 2008 was overseen by a partnership between the Clinical Effectiveness and Evaluation unit (CEEu) of The Royal College of Physicians of London (RCP), the British Thoracic Society (BTS) and the British Lung Foundation (BLF).

The audit aimed to:

- Enable units to compare their performance against national standards.
- Identify resource and organisational factors that may account for observed variations in outcome.
- Facilitate improvement in the quality of care.
- Identify changes since the 2003 National COPD Audit (Royal College of Physicians and British Thoracic Society, 2003)<sup>4</sup>.
- Collect data about the resources and organisation of COPD services in Primary Care Organisations across the UK.

## Governance of the project

The National COPD Audit 2008 was governed by two groups (Appendix A).

- A Steering Group, comprising representatives from Respiratory Medicine and Nursing, Physiotherapy, Geriatric and Intensive Care Medicine, Public Health, Primary Care and Patients. The Group met on a quarterly basis to ensure the audit's relevance to those receiving and delivering COPD services in the UK.
- A smaller executive Implementation Group, drawn from membership of the Steering Group, met on a monthly basis to monitor progress, support and direct the project.

## Audit Methodology

The 2008 National COPD Audit was similar to previous audits of acute COPD care undertaken in 1997 and 2003, albeit with three additional elements. Thus, a cross-sectional resource and organisation of care audit was followed by a clinical audit of up to 60 cases admitted to hospital with an exacerbation of COPD during the data collection period. Cases were identified prospectively, with process of care and 90 day clinical outcomes audited retrospectively.

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<sup>4</sup> Royal College of Physicians and British Thoracic Society, 2003. Report of the 2003 National COPD Audit. Available at: <http://www.rcplondon.ac.uk/clinical-standards/ceeu/Current-work/Documents/NCROP%20nationalCOPDAudit2003report.pdf> (20 August 2008)

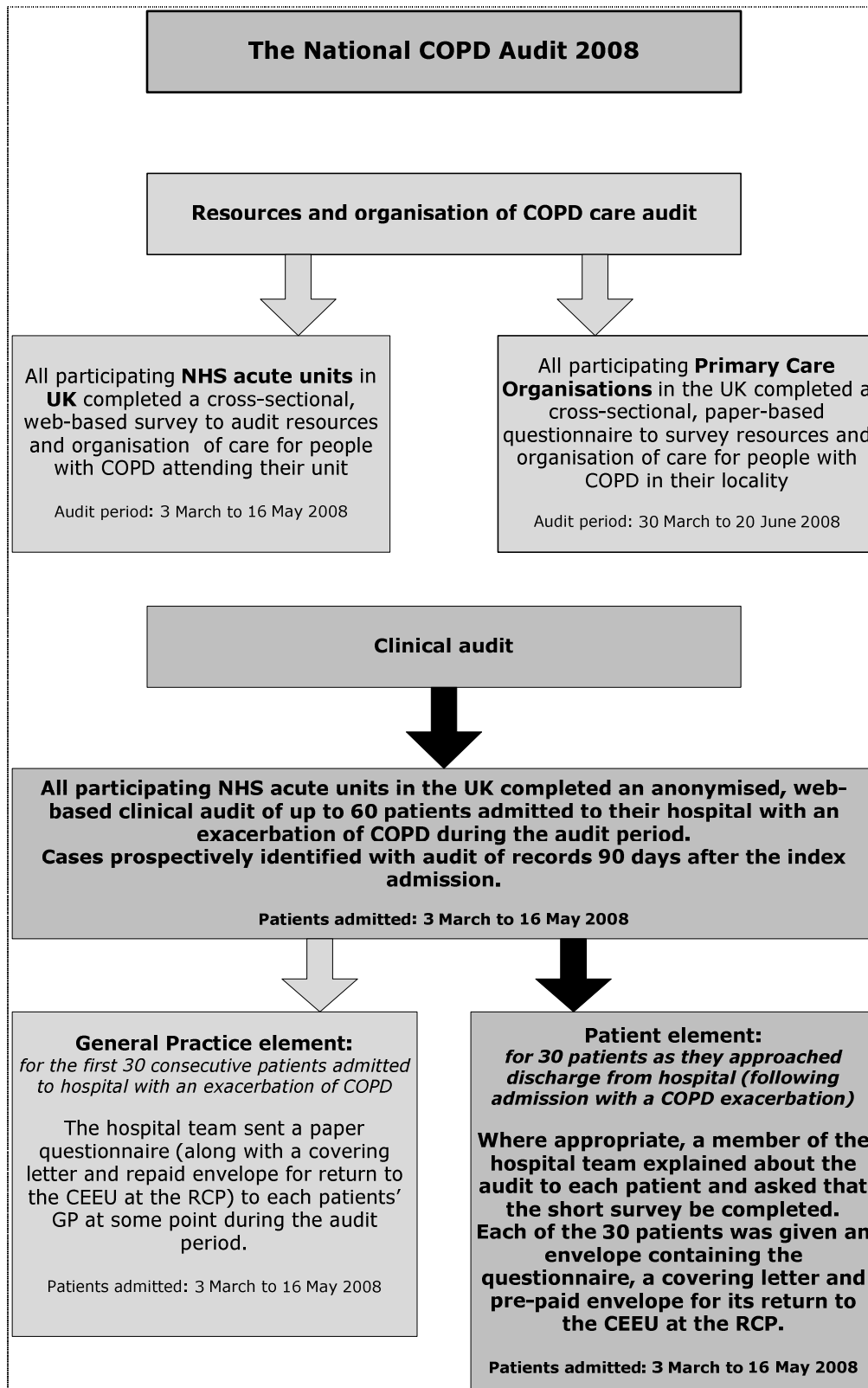
Furthermore, for the clinical case audit, hospital teams were requested to forward a survey to the General Practitioners of the first 30 audited patients admitted with a COPD exacerbation. The teams were asked also to request that 30 of their 60 audited patients complete a survey and return it anonymously to the project team at the CEEu via a pre-paid envelope.

The purpose of these surveys was to explore aspects of COPD around the acute care pathway from different perspectives.

In 2008, for the first time, an organisational survey of United Kingdom NHS Primary Care Organisations (PCOs) was undertaken, with participating PCOs completing a cross-sectional paper-based questionnaire about the resources and organisation of care for people with COPD in their locality. The methodology for the entire National COPD Audit 2008 is illustrated in Figure 1 below.

This report describes the results from the patient survey element only (illustrated dark grey in figure 1 below). Reports of the other audit elements can be obtained from <http://www.rcplondon.ac.uk/clinical-standards/ceeu/Current-work/Pages/copd-audit.aspx>

**Figure 1:** The National COPD Audit 2008: methodology



## **The National COPD Audit 2008 Patient Questionnaire**

Cases for the clinical audit were admitted from 3rd March to 16th May 2008. Hospital teams were asked to request that 30 of their 60 audited patients complete a survey (Appendix B) and return it anonymously to the project team at the CEEu via a pre-paid envelope. 2864 questionnaires were returned of which 1 was a nil blank return and 2 were said not to be applicable, leaving 2861 for analysis.

The clinical audit overall comprised 9716 cases from 232 hospital teams. The response rate for the patient survey is estimated as being 45% (2864/6354) where the denominator 6354 is the sum of 30 cases for each hospital submitting 30 or more cases to the clinical audit and the sum of all other cases for hospital submitting fewer than 30 cases overall. Patient survey returns were received from 221 hospital teams, median 13, Inter-Quartile range 8-17 per site.

See Appendix C for a statement about data collation.

## Results

### Date you are filling the questionnaire

This was stated for 2649 responses and of these 38% (1001) completed the survey in March 2008, 48% (1265) in April 2008 and 12% (323) in May 2008.

### Age and gender

Gender was not stated by 6% (198) patients. When known, 49% (1314) were female and 51% (1349) were male.

Age was asked within category ranges. Estimates of mean age were obtained by multiplying mid-category ages by the number of patients, summing these totals and then dividing by the total number of patients. Thus the overall mean age was estimated as 72 years, males 71 years, females 72 years and gender not stated 71 years.

| Age-group (years) | All patients (2861) |      | Female patients (1314) |     | Male patients (1349) |     | Gender not stated (198) |     |
|-------------------|---------------------|------|------------------------|-----|----------------------|-----|-------------------------|-----|
| 20 to 29          | -                   | 1    | 0.1%                   | 1   | -                    | 0   | -                       | 0   |
| 30 to 39          | 0.3%                | 8    | 0.4%                   | 5   | 0.2%                 | 3   | -                       | 0   |
| 40 to 49          | 2%                  | 56   | 2%                     | 23  | 2%                   | 29  | 2%                      | 4   |
| 50 to 59          | 11%                 | 308  | 12%                    | 163 | 10%                  | 132 | 7%                      | 13  |
| 60 to 69          | 27%                 | 785  | 29%                    | 375 | 27%                  | 358 | 26%                     | 52  |
| 70 to 79          | 38%                 | 1081 | 36%                    | 475 | 37%                  | 500 | 54%                     | 106 |
| 80 to 89          | 20%                 | 571  | 19%                    | 254 | 23%                  | 305 | 6%                      | 12  |
| 90 to 99          | 1%                  | 30   | 1%                     | 15  | 1%                   | 15  | -                       | 0   |
| 100 or older      | 0.1%                | 2    | 0.1%                   | 1   | 0.1%                 | 1   | -                       | 0   |
| Not stated        | 0.6%                | 19   | 0.2%                   | 2   | 0.4%                 | 6   | 6%                      | 11  |

### Do you understand what COPD stands for?

|            |     |      |
|------------|-----|------|
| Yes        | 85% | 2432 |
| No         | 12% | 340  |
| Not stated | 3%  | 89   |

**Did you know you had COPD before your recent hospital admission?**

|            |      |      |
|------------|------|------|
| Yes        | 79%  | 2253 |
| No         | 21%  | 590  |
| Not stated | 0.6% | 18   |

**Was this the first time you have been admitted to hospital with COPD [bad chest]?**

|            |     |      |
|------------|-----|------|
| Yes        | 25% | 709  |
| No         | 74% | 2124 |
| Not stated | 1%  | 28   |

**If 'no', when your chest [COPD] is bad do you usually:**

|  |     |          |
|--|-----|----------|
| • Contact your doctor [GP] immediately   | 32% | 685/2124 |
| • Contact a respiratory nurse  | 9%  | 191/2124 |
| • Wait a bit and then contact your doctor [GP]   | 29% | 608/2124 |
| • Go to a hospital rather than your doctor [GP]  | 22% | 465/2124 |
| • Phone a NHS Helpline for advice [ <i>NHS Direct, NHS 24 – Scotland, NHS Direct Wales</i> ] | 5%  | 98/2124  |
| • I have antibiotics and / or steroids that I can take when my chest is bad                  | 24% | 503/2124 |
| • Something else *   | 2%  | 53/2124  |
| • Not stated (none of the above listed options were selected)                                | 6%  | 132/2124 |

\* includes 15 making contact with a community matron and 22 waiting upon the effect of using nebuliser and/or inhaler medication.

Some caution is required when interpreting the table above as some patients ticked more than one of these options; from their mix of ad-hoc comments, a few qualified their answer by statements such as it depended on how severe the chest was, or whether it happened in or out of normal working hours. A few ticked the option that had occurred on the previous occasion, whilst others gave a summary of whatever they had done previously.

**On this occasion, by what route were you admitted to hospital for your chest?  
[Please choose all / any that apply] n=2861**

|   |     |      |
|---|-----|------|
| • I saw my GP and [s]he sent me to hospital                         | 34% | 962  |
| • I went to casualty [A&E] under my own steam – not in an ambulance | 12% | 333  |
| • I did not see my GP but called an ambulance                       | 41% | 1176 |
| • Other *   | 16% | 461  |
| • Not stated  | 1%  | 35   |

\* Other included situations such as “spouse called ambulance”, “family member called ambulance”, “matron/nurse called ambulance”, “warden called ambulance”, “doctor advised patient to call ambulance but didn’t see patient”, “helpline advised patient to call ambulance”, “careline advised patient to call ambulance”, “out of hours service sent to hospital”, “paramedics sent to hospital”, “admitted via clinic”, “saw GP and treated but needed admission at later stage”.

**Did you have a cold, ‘flu-like illness or chest infection during the month before your recent admission to hospital for your chest?**

|                |     |      |
|----------------|-----|------|
| Yes            | 68% | 1934 |
| No             | 26% | 744  |
| Can’t remember | 5%  | 141  |
| Not stated     | 1%  | 42   |

**Did you notice a change in the colour or amount of phlegm you coughed up before your recent admission to hospital?**

|                |     |      |
|----------------|-----|------|
| Yes            | 57% | 1638 |
| No             | 35% | 998  |
| Can’t remember | 6%  | 160  |
| Not stated     | 2%  | 65   |

**If 'yes', for how long before the admission did you notice this change?**

|                        |      |          |
|------------------------|------|----------|
| ▪ Less than 48 hours   | 21%  | 348/1638 |
| ▪ Between 2 and 5 days | 46%  | 747/1638 |
| ▪ More than 6 days     | 26%  | 426/1638 |
| ▪ Can't remember       | 6%   | 106/1638 |
| ▪ Not stated           | 0.7% | 11/1638  |

**Has anyone explained the medicines you should be taking for your chest condition [COPD]?  
[This could be your GP, the Practice Nurse, a Pharmacist, Hospital Consultant or Respiratory Nurse]**

|            |     |      |
|------------|-----|------|
| Yes        | 83% | 2368 |
| No         | 13% | 372  |
| Not stated | 4%  | 121  |

**Do you understand what your chest medicines are for and how they will affect you?**

|            |     |      |
|------------|-----|------|
| Yes        | 81% | 2311 |
| No         | 15% | 418  |
| Not stated | 5%  | 132  |

**Do you live on your own?  
[i.e. with no other relative or friend in the same property?]**

|            |     |      |
|------------|-----|------|
| Yes        | 36% | 1043 |
| No         | 60% | 1708 |
| Not stated | 4%  | 110  |



**In your opinion, if you had more help at home, would you still have needed to come into hospital recently?**

|            |     |      |
|------------|-----|------|
| Yes        | 66% | 1877 |
| No         | 16% | 458  |
| Don't know | 14% | 391  |
| Not stated | 5%  | 135  |

**If 'no', what help do you think the Health Service could have provided to have helped you stay at home rather than be admitted to hospital recently?**

This was an opened-ended question and the options in the table below have been derived from what was said. Thirteen patients indicated help in more than one category.

|  |     |         |
|--|-----|---------|
| • Nebuliser/oxygen/inhaler/steroids/antibiotics/better medication        | 17% | 77/458  |
| • More visits or phone calls by health professionals / home help visits  | 18% | 82/458  |
| • Better/quicker contact with/access to health professionals/specialists | 5%  | 24/458  |
| • Other *  | 3%  | 14/458  |
| • None/Nothing else/Don't know stated                                    | 14% | 63/458  |
| • No response – left blank   | 46% | 211/458 |

\* Other included aids in the house, ability to self-medicate, improved knowledge about disease.

**Do you use oxygen at home?**

|            |     |      |
|------------|-----|------|
| Yes        | 32% | 905  |
| No         | 65% | 1868 |
| Not stated | 3%  | 88   |

**If 'yes', did you use it to try to avoid coming into hospital?**

|            |     |         |
|------------|-----|---------|
| Yes        | 74% | 672/905 |
| No         | 17% | 154/905 |
| Not stated | 9%  | 79/905  |

### Do you use a nebuliser at home?

|            |     |      |
|------------|-----|------|
| Yes        | 48% | 1386 |
| No         | 48% | 1369 |
| Not stated | 4%  | 106  |

### If 'yes', did you use it to try to avoid coming into hospital?

|            |     |           |
|------------|-----|-----------|
| Yes        | 75% | 1045/1386 |
| No         | 14% | 199/1386  |
| Not stated | 10% | 142/1386  |

### Have you been admitted to hospital for your chest [COPD] within the last year?

|            |     |      |
|------------|-----|------|
| Yes        | 60% | 1724 |
| No         | 36% | 1023 |
| Not stated | 4%  | 114  |

### Do you have regular check-ups at your doctor's surgery for your chest? [This could be with your GP or the Practice Nurse at the surgery]

|            |     |      |
|------------|-----|------|
| Yes        | 55% | 1571 |
| No         | 41% | 1168 |
| Not stated | 4   | 122  |

### Do you attend a hospital clinic for your chest?

|            |    |      |
|------------|----|------|
| Yes        | 42 | 1190 |
| No         | 54 | 1540 |
| Not stated | 5  | 131  |

**How often do you get flare-ups of you chest condition?  
[Worsening spells of coughs, phlegm, wheezing or  
breathlessness that need treatment]**

|                            |     |      |
|----------------------------|-----|------|
| ▪ A number of times a year | 83% | 2369 |
| ▪ I don't get flare-ups    | 11% | 324  |
| ▪ Not stated               | 6%  | 168  |

**Have you been given a written plan for what to do when your chest is getting bad?**

|            |     |      |
|------------|-----|------|
| Yes        | 23% | 658  |
| No         | 70% | 2005 |
| Don't know | 4%  | 117  |
| Not stated | 3%  | 81   |

**When your chest is getting bad do you seek advice over the phone from your GP, Respiratory Nurse or Hospital Doctor?**

|                                     |     |      |
|-------------------------------------|-----|------|
| Yes                                 | 57% | 1640 |
| No                                  | 30% | 846  |
| My chest has only recently been bad | 10% | 285  |
| Not stated                          | 3%  | 90   |

**If 'yes', how quickly can you speak to someone and get advice when your chest is worsening?**

|   | %   | N        |
|---|-----|----------|
| • I have a number that puts me directly through to someone who advises me | 26% | 428/1640 |
| • The same morning or afternoon   | 58% | 950/1640 |
| • The next day  | 6%  | 94/1640  |
| • Within 48 hours   | 7%  | 114/1640 |
| • Not sure  | 5%  | 78/1640  |
| • Not stated  | 3%  | 51/1640  |

71 patients responded to more than one option:

- 59 had a direct number but also said 'the same morning or afternoon'.

- 2 had a direct number but also said 'the next day'.
- 2 had a direct number but also said 'the same morning or afternoon' and 'the next day'.
- 1 had a direct number but also said 'within 48 hours'.
- 1 had a direct number but also said 'not sure'.
- 5 had no direct number but said 'the same morning or afternoon' and 'the next day'.
- 1 had no direct number but said 'the same morning or afternoon' and 'within 48 hours'.
- 1 had no direct number but said 'the same morning or afternoon' and 'not sure'.

**Now that you are home – or about to go home – is there any kind of additional home support [health service or otherwise] that could help you but is not available to you?**

|            |     |      |
|------------|-----|------|
| Yes        | 17% | 499  |
| No         | 40% | 1139 |
| Not sure   | 34% | 968  |
| Not stated | 9%  | 255  |

**If 'yes', (n=499), what is missing?**

The freetext comment has been categorised into 'themes' as summarised below.

For some patients their comment falls into several categories.

|   |     |
|---|-----|
| • Would like extra domestic help and / or home aids                                 | 147 |
| • Would like, or feels they need, oxygen / nebuliser at home                        | 132 |
| • Would like increased clinical care and supervision from a healthcare professional | 92  |
| • Would like a personal carer   | 31  |
| • Would like help with personal care  | 21  |
| • Would like written advice / plan about what to do when bad                        | 13  |
| • Would like a contact number to ring when in difficulty                            | 11  |
| • Would like someone to talk to or some company                                     | 8   |
| • Would like to be offered rehabilitation or exercise                               | 6   |
| • Would like to see own doctor  | 4   |
| • Would like help with transport to clinic, or parking                              | 3   |
| • Would prefer to be in residential care  | 2   |
| • Would like to be able to self-medicate  | 2   |
| • Left blank / don't know   | 44  |

Key messages from patient comment above:

- The commonest requirement is for domestic support (particularly cleaning and stairlifts).
- Many patients feel they would benefit from oxygen or a nebuliser, for reasons which are unclear.
- There seems to be a requirement for enhanced clinical supervision after discharge.
- Not many patients remark on the need to see their own doctor.
- There is little comment about any need for exercise or rehabilitation.
- Patients don't seem to perceive a need to self-medicate.
- There is little appetite for wishing to be in residential care.



~

## **Appendix A      Membership of the National COPD Audit 2008 Steering and Implementation Groups**

### **Members of both Steering and Implementation Groups are indicated in *italics***

- *Professor Mike Roberts, Associate Director of the National COPD Audit 2008: Consultant Respiratory Physician, Whipps Cross University Hospital NHS Trust, Barts and The London School of Medicine and Dentistry, Queen Mary University of London.*
- *Dr Robert Stone, Associate Director of the National COPD Audit 2008 and Consultant Respiratory Physician, Musgrove Park Hospital, Taunton.*
- Dr Ian Basnett, Public Health Consultant, Tower Hamlets Primary Care Trust, London.
- *Rhona Buckingham, National COPD Audit 2008 Project Manager, Clinical Effectiveness and Evaluation unit, Royal College of Physicians.*
- Maria Buxton, Consultant Physiotherapist, Central Middlesex Hospital and Brent Primary Care Trust.
- Dr John Coakley, Medical Director, Homerton University Hospital NHS Foundation Trust.
- Denise Daly, Consultant Physiotherapist, Royal Surrey County Hospital, Guildford.
- *Sheila Edwards, Chief Executive, British Thoracic Society.*
- *Professor Brian Harrison, British Thoracic Society.*
- Dr Steve Holmes, General Practitioner, General Practice Airways Group (GPIAG).
- Kevin Holton, Head of the COPD National Service Framework (NSF) Team, Department of Health.
- *Dr Harold Hosker, Consultant Respiratory Physician, Airedale General Hospital, Keighley.*
- *Jane Ingham, Director of Clinical Standards, Royal College of Physicians.*
- Dr Lawrence McAlpine, Consultant Physician, Monklands Hospital, Airdrie.
- Dr Phyo Myint, Honorary Consultant Physician, Norfolk and Norwich University Hospitals.
- Fiona Phillips, Public Health Consultant, COPD National Service Framework (NSF) Team, Department of Health.
- *Dr Jonathan Potter, Clinical Director, Clinical Effectiveness and Evaluation unit, Royal College of Physicians.*
- *Samantha Prigmore, Respiratory Nurse Consultant, St George's Hospital, London.*
- *Nancy Pursey, National COPD Audit 2008 Project Co-ordinator, Clinical Effectiveness and Evaluation unit, Royal College of Physicians.*
- *Carol Rivas, Research Fellow, Queen Mary's School of Medicine & Dentistry, University of London.*
- *Anil Seiger, Manager, Clinical Effectiveness and Evaluation unit, Royal College of Physicians.*
- *Dame Helena Shovelton, Chief Executive, British Lung Foundation.*
- Teresa Smith, Chest Clinic Manager, King Edward VII Hospital, Windsor.
- *Dr Stephanie Taylor, Reader in Applied Research, Barts and The London School of Medicine & Dentistry, Queen Mary, University of London / Honorary Consultant in Public Health Tower Hamlets Primary Care Trust.*

**Appendix B The National COPD Audit 2008: patient survey**

|   |   |   |
|---|---|---|
| <br>Royal College of Physicians<br><small>Leading in professional excellence</small> | <b>The National COPD Audit 2008</b><br><b>Patient questionnaire</b> |  |
|---|---|---|

Unique ID       *For office use only*

**Your completed form will be scanned to enable a quick and accurate analysis of results. To aid this process please keep the following in mind:**

a. Print firmly and neatly

b. Use only pens with dark blue or black ink

c. Please print in capital letters or numbers (where applicable) and avoid contact with the edges of the boxes - for example:

|   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| A | B | C | D | E | F | G | H | I | J | K | L | M | N | O | P | 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|

d. Shade selection boxes like this:

...and mark any errors like this:

Date you are filling in the questionnaire  /  /

1. Do you understand what COPD stands for?  Yes  No

*COPD stands for Chronic Obstructive Pulmonary Disease. This is a term used for a number of conditions; including chronic bronchitis and emphysema. COPD leads to damaged airways in the lungs, causing them to become narrower and making it harder for air to get in and out of the lungs. The word 'chronic' means that the problem is long-term.*

2. Did you know you had COPD before your recent hospital admission?  Yes  No


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*The following questions relate to your recent admission to hospital with COPD (bad chest)*

3. Was this the first time you have been admitted to hospital with COPD (bad chest)?  Yes  No

*Please check that you have answered each question*

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- if 'no', when your chest (COPD) is bad do you usually:

- Contact your doctor (GP) immediately
- Contact a respiratory nurse
- Wait a bit and then contact your doctor (GP)
- Go to a hospital rather than your doctor (GP)
- Phone a NHS Helpline for advice *(NHS Direct, NHS 24 - Scotland, NHS Direct Wales)*
- I have antibiotics and/or steroids that I can take when my chest is bad
- Something else (please tell us more below)

4. On this occasion, by what route were you admitted to hospital for your chest? *(Please choose all/any that apply)*

- I saw my GP and (s)he sent me to hospital
- I went to casualty (A&E) under my own steam - not in an ambulance
- I did not see my GP but called an ambulance
- Other (please tell us more below)

5. Did you have a cold, 'flu-like illness or chest infection during the month before your recent admission to hospital for your chest?

- Yes
- No
- Can't remember

6. Did you notice a change in the colour or amount of phlegm you coughed up before your admission to hospital?

- Yes
- No
- Can't remember

- if 'yes', for how long before the admission did you notice this change?

- Less than 48 hours
- Between 2 and 5 days
- More than 6 days
- Can't remember

*Please check that you have answered each question*





7. Has anyone explained the medicines you should be taking for your chest condition(COPD)? (This could be your GP, the Practice Nurse, a Pharmacist, Hospital Consultant or Respiratory Nurse)  Yes  No

8. Do you understand what your chest medicines are for and how they will affect you?  Yes  No

9. Do you live on your own? (i.e. with no other relative or friend in the same property)  Yes  No

10. In your opinion, if you had more help at home, would you still have needed to come into hospital recently?

Yes  No  Don't know

- if 'no' what help do you think the Health Service could have provided to have helped you stay at home rather than be admitted to hospital recently?

11. Do you use oxygen at home?  Yes  No

- if 'yes' did you use it to try to avoid coming into hospital?  Yes  No

12. Do you use a nebuliser at home?  Yes  No

- if 'yes' did you use it to try to avoid coming into hospital?  Yes  No

13. Have you been admitted to hospital for your chest (COPD) within the last year?  Yes  No

14. Do you have regular check-ups at your doctor's surgery for your chest? (This could be with your GP or the Practice Nurse at the surgery)  Yes  No

15. Do you attend a hospital clinic for your chest?  Yes  No

16. How often do you get flare-ups of your chest condition? (Worsening spells of coughs, phlegm, wheezing or breathlessness that need treatment)

A number of times per year  I don't get flare-ups

Please check that you have answered each question



17. Have you been given a written plan for what to do when your chest is getting bad?

- Yes       No       Don't know

18. When your chest is getting bad do you seek advice over the phone from your GP, Respiratory Nurse or Hospital Doctor?

- Yes       No       My chest has only recently been bad

- if 'yes', how quickly can you speak to someone and get advice when your chest is worsening?

- I have a number that puts me directly through to someone who advises me  
 The same morning or afternoon  
 The next day  
 Within 48 hours  
 Not sure

19. Now that you are home - or about to go home - is there any kind of additional home support? (health service or otherwise) that could help you but is not available to you?       Yes       No       Not sure

- if 'yes', what is missing?

20. What is your age-group (in years)?

- 20 to 29       30 to 39       40 to 49  
 50 to 59       60 to 69       70 to 79  
 80 to 89       90 to 99       100 or older

21. What is your gender?

- Male       Female

\_\_\_\_\_

*Please return the completed questionnaire using the pre-paid envelope before 16th May 2008 to:*

*The National COPD Audit, Clinical Effectiveness & Evaluation Unit, The Royal College of Physicians, 11 St Andrews Place, Regents Park, London, NW1 4LE*

\_\_\_\_\_

Thank you very much for taking the time to complete this questionnaire

*Please check that you have answered each question*



## **Appendix C     The National COPD Audit 2008: data collation**

The questionnaires were scanned automatically one-by-one with a manual check of every field, amending free-text and deciphering handwriting as necessary. The final database contained data from 2864 patient questionnaires. A systematic sampling method was used to generate a checking sample of 100 cases. A log was kept of inconsistencies found and corrections to the database were made. A total of 34 columns of data were checked per case by a person not involved in overseeing the initial scanning process. There were thus  $100 \times 34 = 3400$  cells of data that were cross-checked between paper form and data on an excel dataset. A total of 29 discrepancies were found in 17 cases involving 10 data columns. Over half of these were discrepancies in text from open-ended questions. With 29 discrepancies from 3400 relevant cells the discrepancy rate was 8.5 per thousand, or 0.85%.

With this checking exercise completed, the database was deemed fit for analysis.