

The National COPD Audit Programme: Assessing and improving uptake of local COPD specialist services – a pilot study

Final Report

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1. Summary

This is the report of a pilot study undertaken in North West London and Somerset to investigate health professionals' and patients' awareness of specialist COPD services. Key objectives of the pilot study were to test the validity of the questionnaires, the methodology of data collection and to derive some useful data around service knowledge. This would inform the development of a more comprehensive survey to measure baseline knowledge and change before and after a knowledge intervention.

The key methodological and practical findings following the pilot are:

- The questionnaire design and on-line data collection generally worked well amongst health professionals. On-line completion could be used in the future. However, the questionnaire could be simplified and the number of questions reduced.
- The questionnaire was completed mainly by specialists in COPD, although there will have been a selection bias related to the limited scope of the pilot. Non-specialists should also be targeted in future but may find the terminology regarding services more difficult.
- The questionnaire was too arduous for patients as evidenced by a poor response rate and comments from those that completed it. The number of questions should be reduced and the questions simplified. Patients did not understand the terminology used or the difference between 'hospital' and 'community'.
- We did not obtain a clear picture of what patients and carers wanted from a COPD service with this work, although not a primary objective.
- No patients completed the survey on-line and, while an on-line survey could be used as an adjunct, especially if data is collected from relatives and carers, paper questionnaires or interviews completed in the surgery or clinic should be used.
- The use of face-to-face interviews for a smaller, structured representative sample of patients should be considered as an adjunct to survey work. This would augment the response rate and thus the representativeness of the findings as well as the quality of the data.
- There needs to be a more robust method of getting patient and carer engagement in work of this nature.

While this was a pilot, some conclusions can be drawn from the results:

- Healthcare professionals profess a good understanding of COPD and COPD services.
- Despite this, knowledge amongst health professionals about services, particularly the services available in the community, is not as high as it could be.

- While there is some confusion about terminology, it is clear that many patients are not aware of the services available or indeed the services they use or have received.
- It is suggested that further work is undertaken across a bigger sample size of greater heterogeneity to determine service knowledge and understanding within these groups, allied to a study assessing how stakeholders feel their knowledge could be improved and the preferred receipt of information.
- Further work exploring the best way of getting information to patients, carers and healthcare professionals should be undertaken.

2. Aims and Objectives

The key objectives of the pilot study were to test the validity of the questionnaires, the methodology of data collection and to inform the development of a survey to measure baseline knowledge and then any change following interventions proposed in a larger piece of work. The deliverables of pilot phase were to:

- Establish the Project Implementation Group
- Develop a questionnaire to determine healthcare professionals' understanding of COPD services
- Develop a questionnaire to determine patients' understanding of COPD services
- Finalise questionnaires
- Distribute questionnaires to stakeholders
- Establish and run help desk
- Receive completed questionnaires
- "Clean" questionnaires
- Collate and analyse questionnaires
- Report on findings

3. Preparation

Note: blue text throughout document is hyperlinked to the relevant page or website

A Project Implementation Group was established which had weekly teleconference or meetings during the preparation phase.

As detailed in the Project Brief, the approach was to develop parallel questionnaires, one for health professionals (HPQ) working with COPD patients and one for patients with COPD (PQ).

Both questionnaires had been drafted earlier, but needed extensive revision to balance the differing views of the Working Group members with the usability of the questionnaire. The content and wording of questions as well as

the layout were revised. Both the HPQ and PQ were developed as paper and electronic copies. Electronic questionnaires were developed using Survey Monkey and available on line. <http://www.surveymonkey.com/>

It was agreed that a formal help desk was not required but a telephone number and email to contact if there were problems were given in both questionnaires.

A [Timetable and Resource Usage of Pilot Study](#) is given in the Appendix. Both of the [Questionnaires](#) are reproduced in full in the Appendix.

Issues

Two issues arose and were discussed extensively by the Project Implementation Group.

Research Ethics Committee Approval

There was a question about whether Ethics Committee approval was required. Advice was sought from the National Research Ethics Service (NRES). The following response was received from the NRES Queries Line [queries@nres.npsa.nhs.uk]:

Your query was reviewed by our Queries Line Advisers.

"Our leaflet "Defining Research", which explains how we differentiate research from other activities, is published at: <http://www.nres.npsa.nhs.uk/rec-community/guidance/#researchoraudit> Home » REC Community » Guidance

Based on the information you provided, our advice is that the project is not considered to be research according to this guidance. Therefore it does not require ethical review by a NHS Research Ethics Committee.

As this is a service evaluation, REC review would not be needed.

If you are undertaking the project within the NHS, you should check with the relevant NHS care organisation(s) what other review arrangements or sources of advice apply to projects of this type. Guidance may be available from the clinical governance office.

Although ethical review by a NHS REC is not necessary in this case, all types of study involving human participants should be conducted in accordance with basic ethical principles such as informed consent and respect for the confidentiality of participants. When processing identifiable data there are also legal requirements under the Data Protection Act 2000. When undertaking an audit or service/therapy evaluation, the investigator and his/her team are responsible for considering the ethics of their project with advice from within their organisation. University projects may require approval by the university ethics committee.

This response should not be interpreted as giving a form of ethical approval or any endorsement of the project, but it may be provided to a journal or other body as evidence that ethical approval is not required under NHS research governance arrangements.

However, if you, your sponsor/funder or any NHS organisation feel that the project should be managed as research and/or that ethical review by a NHS REC is essential, please write setting out your reasons and we will be pleased to consider further.

Where NHS organisations have clarified that a project is not to be managed as research, the Research Governance Framework states that it should not be presented as research within the NHS."

Therefore no approval was sought.

Use of postcodes

One of the aims was to investigate whether there was any relationship between deprivation and knowledge of services. The use of the full postcode was discussed but at the time of the pilot, the RCP did not endorse the collection of a full postcode and was concerned about doing so in particular regard to data protection procedures and Caldicot guidance. However, a specialist in public health advised that although the 4/5 digits would narrow it down to an electoral ward, a full postcode was required to access all health related statistics on demographics, deprivation etc.

The RCP agreed subsequently that a full postcode is acceptable with regard to data protection, and a full postcode would be requested on questionnaires in the full study.

4. Questionnaire Distribution

Health Professional Questionnaire

Requests to complete the HPQ were sent by email. Members of the Working Group sent an email accompanied by a letter with the web-link and an electronic copy of the questionnaire to colleagues. The letter is attached in the appendix. Individuals were asked to cascade the questionnaire to colleagues. This method generated a good response rate, but the respondents were in general health professionals directly working in the field of COPD and therefore quite knowledgeable and enthusiastic.

As health professionals were asked to cascade the questionnaire with no limitations, it was actually sent to health professionals far outside of the intended area.

There was an entirely unexpected difficulty in sending the email out from within the Imperial College Network which converted the hyper link from a link to the Survey Monkey questionnaire to a link to their email server.

Reminders were sent via the cascade mid-way through the time period set.

Patient Questionnaire

Because the PQ required paper printing of the questionnaires and self addressed envelopes, it was distributed two weeks after the HPQ and had a longer deadline for the return of the questionnaire. The physicians on the working group distributed questionnaires within their acute trusts. They also contacted general practices and questionnaires

were sent out to GP surgeries. A small number of questionnaires were distributed via patient organisations but it was accepted that patients involved in these organisations would tend to be more knowledgeable. Details of [Patient Questionnaire distribution](#) are in the appendix. For the pilot, no control and intervention groups were established.

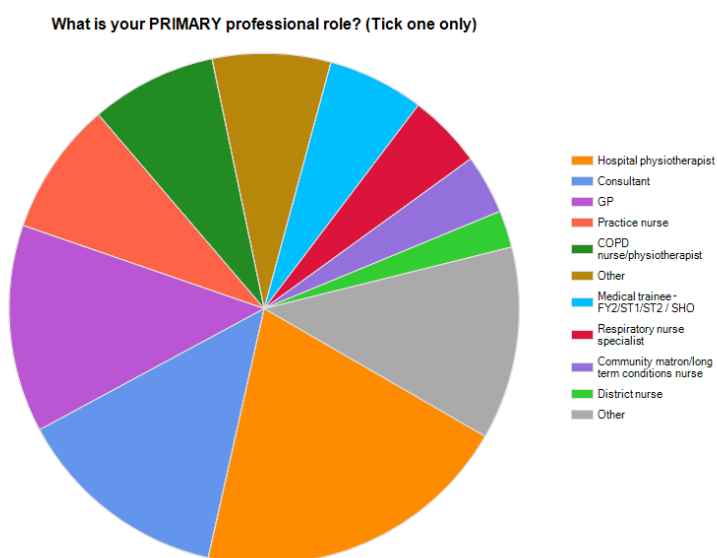
Although available and promoted, no patients completed the survey on-line.

5. Validation of questionnaires

On both questionnaires there was an open question asking respondents to comment on the questionnaire. The [Verbatim Comments made in the HPQ regarding the Questionnaire](#) and [Verbatim Comments made in the PQ regarding the Questionnaire](#) are in the appendix.

The project manager attended two clinics to interview patients about the usability of the questionnaire. She interviewed seven patients. Her key findings were:

- 1) Patients were very confused about terminology both clinical (e.g. what is non-invasive ventilation?) and structural (e.g. they didn't assume that they were at a COPD clinic as it was a mixed respiratory clinic).
- 2) Patients didn't understand the difference between community services and hospital services. They thought that everything is part of the hospital if it isn't provided by their GP.
- 3) There was no real practical difference between a 'no' answer and a 'don't know' answer.
- 4) They found the questionnaire too long and repetitive and struggled with it. Many were reluctant to remain in clinic after their appointment to complete it.



Detailed notes are in the Appendix. [Report of patient interviews](#)

6. Analysis and Results

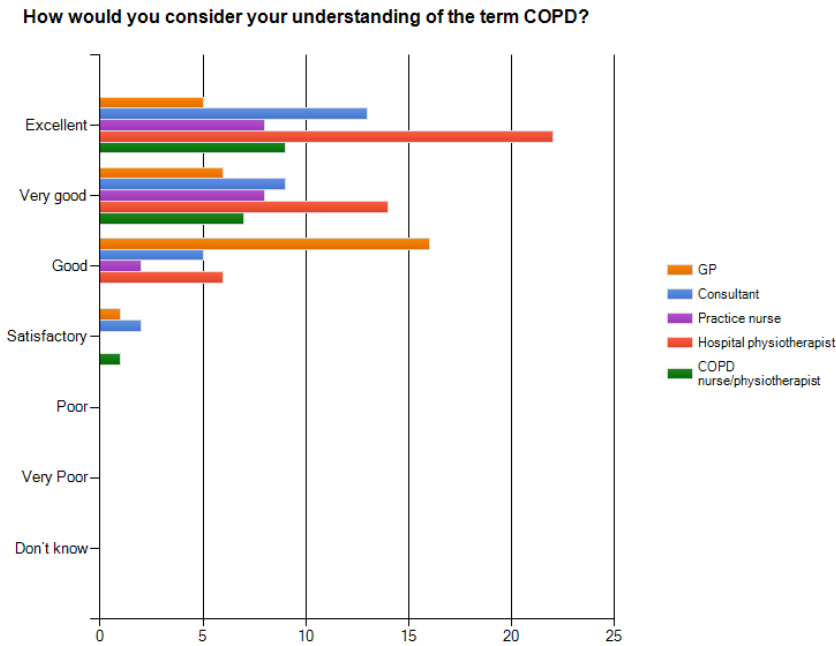
Bar charts and crosstabs were generated in Survey Monkey. Results were downloaded into Excel and further work completed.

Health professional Questionnaire

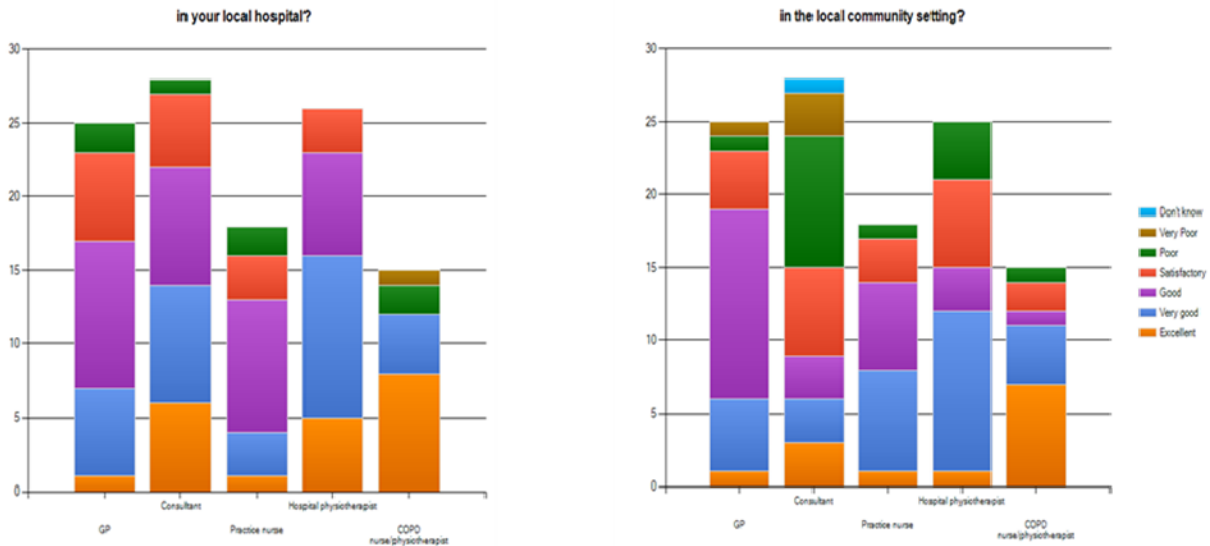
A total of 223 questionnaires were completed. Of these 16 were completed on paper or as a

Word document. The remaining were completed by the respondent on Survey Monkey. A response rate cannot be calculated as the link to the website was cascaded by email. Some of the charts were produced directly from Survey Monkey.

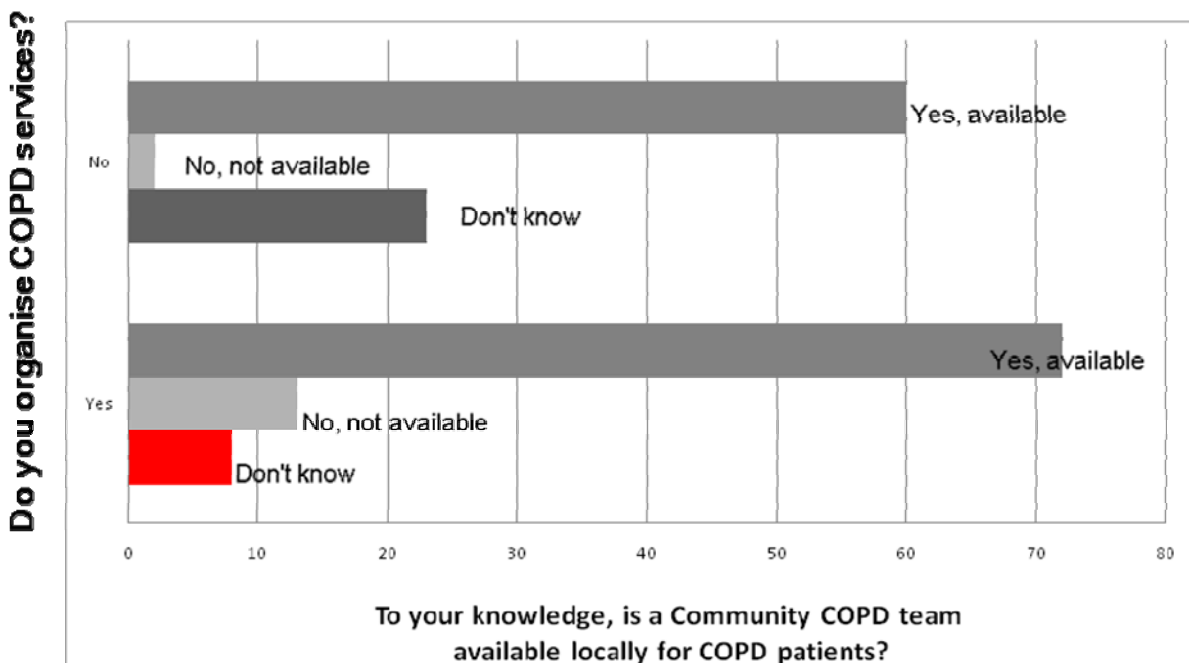
Data were also downloaded into Excel and coded with location (1= North West London, 2=Somerset, 3= Other) the sector (1= hospital, 2= community). The medical statistician at the Royal College of Physicians (RCP) also produced frequencies. A sample of the results produced on Survey Monkey is illustrated here.



How would you rate your UNDERSTANDING of what services are available for patients with COPD..



Do those who organise services know what is available?



Of people organising services. 9% didn't know if there is a Community COPD team!

(Last two charts created one week before end of survey)

Information about knowledge and use of services is given below.

| Are the following, to your knowledge, available locally for COPD patients: | | | | |
|--|-----------------------|--------------------------|-------------------|-----------------------|
| Answer Options | Yes, available | No, not available | Don't know | Response Count |
| a) Pulmonary rehabilitation in hospital | 136 | 28 | 33 | 197 |
| b) Pulmonary rehabilitation in the community | 154 | 11 | 32 | 197 |
| c) COPD early/supported discharge team based at the hospital | 122 | 37 | 37 | 196 |
| d) COPD early / supported discharge team hospital at home scheme based in the community | 80 | 50 | 64 | 194 |
| e) Community COPD team | 143 | 18 | 32 | 193 |
| f) Telephone support service or other rapid access service that provides advice for COPD patients based in hospital | 74 | 46 | 75 | 195 |
| g) Telephone support service or other rapid access service that provides advice for COPD patients based in the community | 111 | 16 | 65 | 192 |
| h) Oxygen assessment service in hospital | 167 | 9 | 20 | 196 |
| i) Oxygen assessment service in the community | 119 | 39 | 35 | 193 |
| j) Nebuliser assessment service in hospital | 147 | 12 | 36 | 195 |
| k) Nebuliser assessment service in the community | 100 | 30 | 63 | 193 |
| l) Non-Invasive Ventilation in hospital | 170 | 2 | 23 | 195 |
| m) Non-Invasive Ventilation in the community | 71 | 50 | 73 | 194 |
| n) Breathlessness service in hospital | 86 | 45 | 61 | 192 |
| o) Breathlessness service in the community | 63 | 49 | 81 | 193 |
| p) Dietetic advice for COPD patients | 127 | 12 | 55 | 194 |
| q) Patient support group(s) | 125 | 12 | 57 | 194 |
| r) Community COPD clinics | 124 | 18 | 53 | 195 |
| s) Hospital COPD clinics | 167 | 11 | 16 | 194 |
| t) Hospital based smoking cessation services | 113 | 35 | 47 | 195 |
| u) Community based smoking cessation services | 163 | 6 | 27 | 196 |
| v) Community Pharmacy support services | 80 | 15 | 94 | 189 |
| Please put any comments you wish to make here | | | | 26 |
| answered question | | | | 198 |
| skipped question | | | | 25 |

Please tell us how you refer to these services– please tick all that apply:

| Answer Options | Letter | Fax | E-mail | Direct phone contact | Don't know | Walk-in service | Open access | I can't refer to this service | Response Count |
|--|--------|-----|--------|----------------------|------------|-----------------|-------------|-------------------------------|----------------|
| a) Pulmonary rehabilitation in hospital | 76 | 44 | 14 | 36 | 26 | 1 | 3 | 39 | 169 |
| b) Pulmonary rehabilitation in the community | 90 | 72 | 20 | 27 | 33 | 2 | 5 | 22 | 177 |
| c) COPD early/supported discharge team based at the hospital | 17 | 22 | 8 | 74 | 38 | 0 | 4 | 40 | 165 |
| d) COPD early / supported discharge team hospital at home scheme based in the community | 24 | 26 | 5 | 42 | 48 | 0 | 3 | 52 | 158 |
| e) Community COPD team | 84 | 66 | 23 | 50 | 35 | 2 | 5 | 21 | 173 |
| f) Telephone support service or other rapid access service that provides advice for COPD patients based in hospital | 19 | 15 | 9 | 58 | 47 | 0 | 8 | 40 | 160 |
| g) Telephone support service or other rapid access service that provides advice for COPD patients based in the community | 33 | 35 | 11 | 51 | 49 | 2 | 12 | 32 | 161 |
| h) Oxygen assessment service in hospital | 92 | 38 | 23 | 56 | 19 | 0 | 5 | 25 | 173 |
| i) Oxygen assessment service in the community | 72 | 52 | 11 | 27 | 40 | 3 | 2 | 33 | 168 |
| j) Nebuliser assessment service in hospital | 78 | 34 | 19 | 52 | 31 | 1 | 4 | 24 | 172 |
| k) Nebuliser assessment service in the community | 57 | 41 | 11 | 29 | 48 | 3 | 5 | 32 | 160 |
| answered question | | | | | | | | | 185 |
| skipped question | | | | | | | | | 38 |

Three free text questions regarding the services were asked and are reproduced in the appendix. These were answered by most of the respondents. The questions were (hyperlinked to appendix):

- [In your opinion what is the best thing about COPD services in your area?](#)
- [In your opinion what is the worst thing about COPD services in your area?](#)
- [Please use the space below to tell us more about COPD services in your area or how access to local COPD services could be improved.](#)

The [Abstract Submitted to the British Thoracic Society](#) is in the appendix and the raw results are available as an Excel spreadsheet.

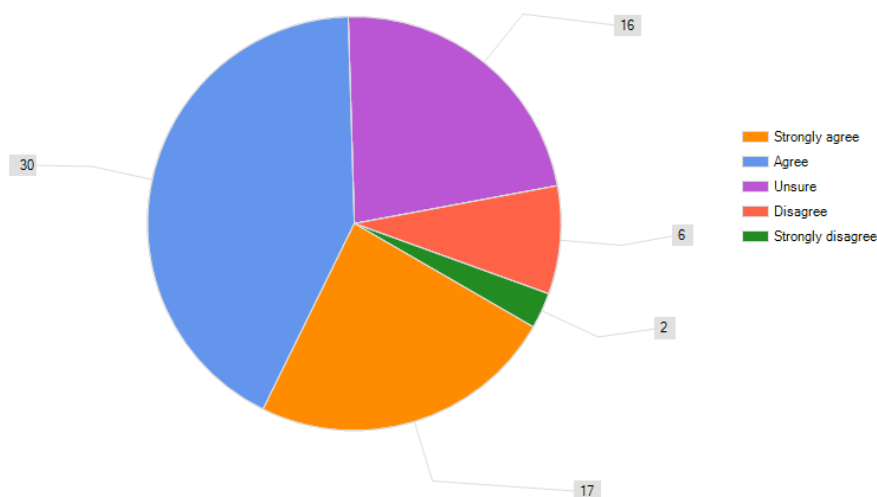
Patient Questionnaire

A total of 528 questionnaires were distributed and 74 questionnaires were completed. None were completed directly on line. This is a response rate of 14%.

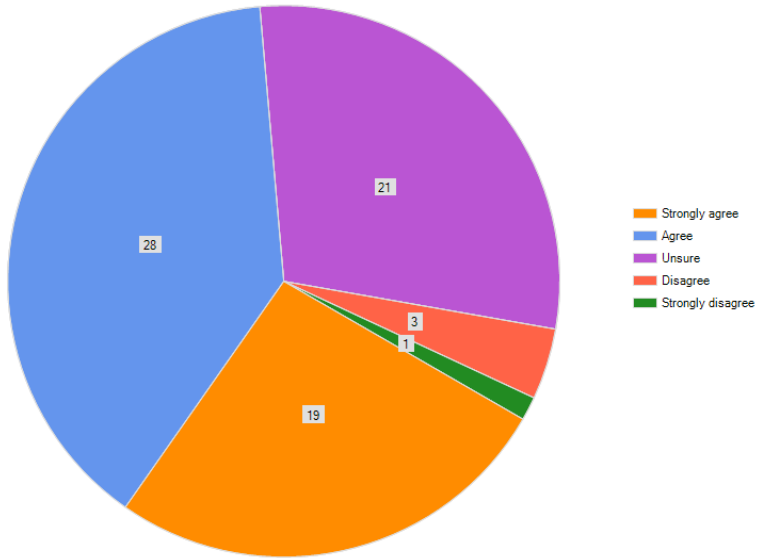
33 of responders were men and 33 were women with 8 non-responders to this question (Q1). A large majority (57) were White British (Q3). Only 3 said that no health professional had explained COPD to them (Q8)

The following pie charts demonstrate responses with regard to understanding local services.

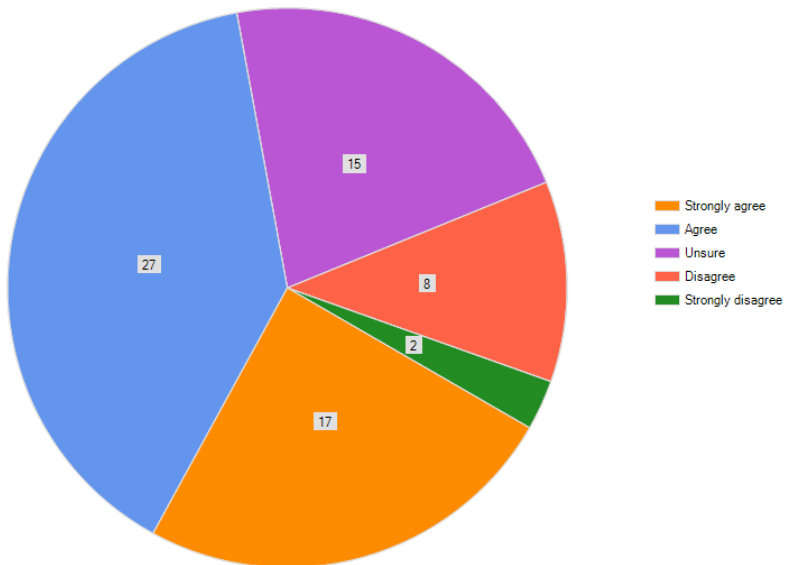
I know about the services AVAILABLE for people with COPD at my local hospital.



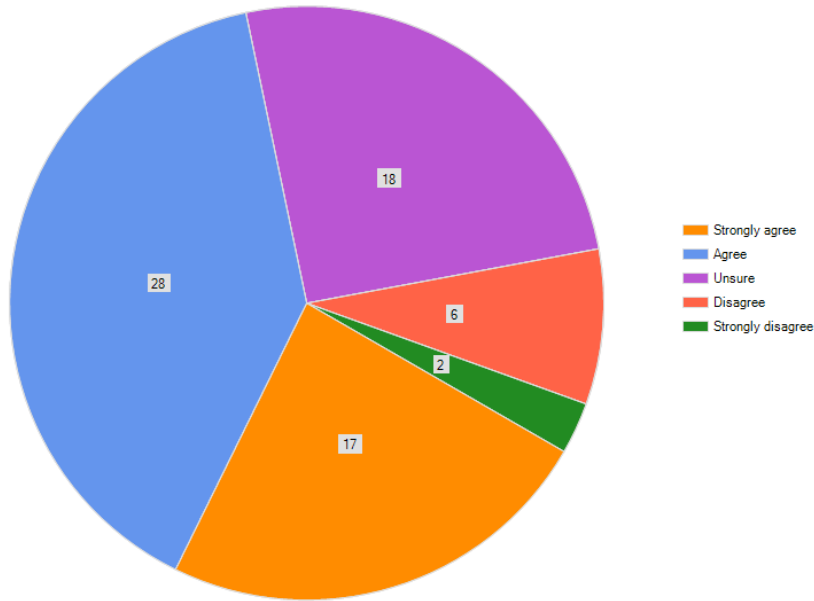
I know HOW TO USE my local hospital COPD services.



I know about the services AVAILABLE for people with COPD with COPD in the local community setting.



I know HOW TO USE my local community COPD services.



The tables below show knowledge and usage of local services.

| COPD care – patient questionnaire | | | | |
|---|-----------------------|--------------------------|-------------------|-----------------------|
| Are the following, to your knowledge, available locally to COPD patients? | | | | |
| Answer Options | Yes, available | No, not available | Don't know | Response Count |
| a. Pulmonary rehabilitation in HOSPITAL | 45 | 3 | 20 | 68 |
| b. Pulmonary rehabilitation in the COMMUNITY | 35 | 1 | 34 | 70 |
| c. COPD early/supported discharge team based at the HOSPITAL(A team to help you go home from hospital sooner. These can be called 'hospital at home' or 'assisted discharge' schemes) | 23 | 1 | 43 | 67 |
| d. COPD early/supported discharge team (see explanation above) based in the COMMUNITY. | 20 | 2 | 42 | 64 |
| e. A COMMUNITY COPD team | 41 | 1 | 24 | 66 |
| f. A team that you can call instead of going to Accident & Emergency | 39 | 4 | 27 | 70 |

| | | | | |
|--|----|---|----|-----------|
| g. A telephone support service or other rapid access service that provides advice for COPD patients based in HOSPITAL | 25 | 1 | 41 | 67 |
| h. Telephone support service or other rapid access service that provides advice for COPD patients based in the COMMUNITY | 29 | 1 | 38 | 68 |
| i. An oxygen assessment service in HOSPITAL | 39 | 0 | 28 | 67 |
| j. An oxygen assessment service in the COMMUNITY | 24 | 2 | 41 | 67 |
| k. Nebuliser assessment service in HOSPITAL | 43 | 0 | 24 | 67 |
| l. Nebuliser assessment service in the COMMUNITY | 28 | 3 | 37 | 68 |
| m. Non-Invasive Ventilation in HOSPITAL | 19 | 1 | 42 | 62 |
| n. Non-Invasive Ventilation in the COMMUNITY | 10 | 1 | 51 | 62 |
| o. A breathlessness service in HOSPITAL | 27 | 1 | 36 | 64 |
| p. A breathlessness service in the COMMUNITY | 22 | 2 | 42 | 66 |
| q. Dietetic advice for COPD patients | 29 | 1 | 36 | 66 |
| r. Patient support group(s) e.g. a Breathe Easy Group | 39 | 3 | 27 | 69 |
| s. COPD clinics in HOSPITAL | 52 | 1 | 12 | 65 |
| t. COPD clinics in the COMMUNITY | 29 | 2 | 33 | 64 |
| u. Smoking cessation service in HOSPITAL | 28 | 1 | 34 | 63 |
| v. Smoking cessation service in the COMMUNITY | 28 | 0 | 37 | 65 |
| w. COMMUNITY Pharmacy support services | 27 | 1 | 36 | 64 |
| Please add your comments here | | | | 2 |
| answered question | | | | 72 |
| skipped question | | | | 2 |

COPD care – patient questionnaire

Which of these services, if any, have you used in the last 6 months?

| Answer Options | Yes, I have used | No, I haven't used | Don't know | Response Count |
|---|------------------|--------------------|------------|----------------|
| a. Pulmonary rehabilitation in HOSPITAL | 21 | 37 | 9 | 67 |
| b. Pulmonary rehabilitation in the COMMUNITY | 14 | 37 | 13 | 64 |
| c. COPD early/supported discharge team based at the HOSPITAL(A team to help you go home from hospital sooner. These can be called 'hospital at home' or 'assisted discharge' schemes) | 18 | 32 | 16 | 66 |
| d. COPD early/supported discharge team (see explanation above) based in the COMMUNITY. | 15 | 34 | 16 | 65 |
| e. A COMMUNITY COPD team | 27 | 22 | 17 | 66 |
| f. A team that you can call instead of going to Accident & Emergency | 21 | 34 | 14 | 69 |
| g. A telephone support service or other rapid access service that provides advice for COPD patients based in HOSPITAL | 14 | 33 | 21 | 68 |
| h. Telephone support service or other rapid access service that provides advice for COPD patients based in the COMMUNITY | 22 | 28 | 19 | 69 |
| i. An oxygen assessment service in HOSPITAL | 26 | 28 | 12 | 66 |
| j. An oxygen assessment service in the COMMUNITY | 13 | 35 | 18 | 66 |
| k. Nebuliser assessment service in HOSPITAL | 32 | 23 | 11 | 66 |
| l. Nebuliser assessment service in the COMMUNITY | 18 | 46 | 6 | 70 |
| m. Non-Invasive Ventilation in HOSPITAL | 8 | 34 | 22 | 64 |
| n. Non-Invasive Ventilation in the COMMUNITY | 5 | 36 | 25 | 66 |
| o. A breathlessness service in HOSPITAL | 16 | 40 | 11 | 67 |
| p. A breathlessness service in the COMMUNITY | 14 | 36 | 17 | 67 |
| q. Dietetic advice for COPD patients | 12 | 48 | 8 | 68 |
| r. Patient support group(s) e.g. a Breathe Easy Group | 22 | 36 | 10 | 68 |
| s. COPD clinics in HOSPITAL | 38 | 22 | 6 | 66 |
| t. COPD clinics in the COMMUNITY | 20 | 37 | 9 | 66 |
| u. Smoking cessation service in HOSPITAL | 5 | 47 | 13 | 65 |
| v. Smoking cessation service in the COMMUNITY | 9 | 47 | 11 | 67 |
| w. COMMUNITY Pharmacy support services | 10 | 41 | 13 | 64 |
| Please add your comments here | | | | 1 |
| answered question | | | | 72 |
| skipped question | | | | 2 |

Three free text questions regarding the services were asked and are reproduced in the appendix. These were answered by several of the respondents. The questions were (hyperlinked to appendix):

- [In your opinion what is the best thing about COPD services in your area?](#)
- [In your opinion what is the worst thing about COPD services in your area?](#)

- [Please use the space below to tell us more about COPD services in your area or how access to local COPD services could be improved.](#)

7. Focus Group volunteers

Both healthcare professionals and patients were asked to volunteer to be part of focus groups. The record of the names of those who volunteered is logged with the RCP.

8. Recommendations for future surveys

Questionnaire Distribution

- If the aim is to have one target geographic area this should be clear in the covering letter to health professionals.
- The link to the Survey Monkey website should not simply be copied and pasted into the letter or the questionnaire but hyperlinked within Word and tested before sending by each distributor.
- GP practices need to be contacted very early and there needs to be someone to facilitate the distribution of questionnaires.
- The majority of respondents were from specialist COPD teams. Surveying a more diverse group with less understanding of COPD services may prove more challenging. If a broader sample of health professionals, beyond the 'COPD cogniscente', is required, a method of targeting respondents other than cascading to colleagues is required and use of service specific terminology considered.
- Distributing questionnaires to carers or relatives should be considered as they may have more knowledge of services and usage than the patient, particularly in the case of frail or elderly people.
- The use of face-to-face interviews for a smaller, structured representative sample of patients should be considered. This would improve the response rate and representativeness of the findings as well as the quality of the data.

Questionnaire Design

Health Professional Questionnaire

On the whole the HPQ appeared to work well. Most of the comments about the questionnaire were favourable. The following changes are recommended:

- Using a partial postcode was very confusing. Virtually no one understood. As this information is required to determine level of deprivation, respondents should be asked for their full postcode.
- Either 'Don't know' or 'No' options should be deleted to simplify question 13 and make it quicker to answer. There appeared to be no distinction between whether people answered 'don't know' and 'no' so no valid additional information was gathered. Questions 13 & 14 could be re-written as:
Tick the services which, to your knowledge, are available locally for COPD patients and the method by which you refer to these services. (Followed by a list of services and the referral method).

Patient Questionnaire

Refer to section above with regard to the problems the questionnaire presented to patients. In addition, when inputting the questionnaire, it was apparent that many respondents had difficulty completing it. There were a high number of missed questions and inappropriate answers.

- As above for item 1
- As with item 2 above, more so than in the HPQ, the 'Don't know' and 'No' options should be considered. Few patients could say for certain that a service was NOT available and ticked don't know. By having these options patients were required to answer every question even if the service wasn't available. As questions 15 and 16 were too complex to combine these two questions alone took up 5 pages. A simpler question and format would be along the lines of :

| | <i>Tick the services which to your knowledge are available locally to COPD patients</i> | <i>Tick the service you have used in the last year</i> |
|--|---|--|
| <i>Pulmonary rehabilitation in hospital</i> | <input type="checkbox"/> | <input type="checkbox"/> |
| <i>Pulmonary rehabilitation in the community</i> | <input type="checkbox"/> | <input type="checkbox"/> |

- Simplify the questionnaire!
 - Consider cutting down on professions - patients didn't know what a community matron was nor could they differentiate between a respiratory specialist and hospital doctor.
 - Consider reducing the services asked about in questions 15 and 16 from the current 23.
- Define words or use lay terms
- Try to tease out what information is really needed about hospital and community and be clear about it.

5. Additional questions about what services patients would like to see and how they would like to obtain information should be considered.

6. Delete the comments boxes following the closed questions as these appeared to confuse patients, but leave those at the end of the questionnaire.

Data Collection

1. The use of Survey Monkey and on-line responses was successful for health professional and is a convenient and economical method of data collection. This method was not successful with patients and should not be relied upon for this group. However, as there is little effort in setting it up, it could be used as an adjunct to a paper questionnaire for the convenience of the computer literate patient or carer.

2. As the patient population contains a high proportion of older people, extending the questionnaire to carers and relatives who may know more about services should be considered.

3. The open ended questions at the end of both surveys yielded very interesting information. Given the population, in depth interviews with both structured and unstructured questions may yield higher quality more representative data. This may need to be in the home to avoid the bias of sampling only those that attend clinics.

4. Once HPQ was complete, it was made clear that the analysis by area and sector i.e. was Somerset vs. North West London and community vs. secondary care respectively was required. As this was not part of the questionnaire, it involved hand coding where this information was clear. Ideally this should be included in the questionnaire in some form.

Barriers to the project

- Just as the HP questionnaire was due to be distributed, the early discharge COPD service in Taunton was threatened and this delayed the distribution of the questionnaire.
- It was difficult to reach the correct person in the GP surgery. There is a need for dedicated time in the project budget to meet with practice managers.
- Difficulties among the patient population in completing questionnaire

9. Conclusions

On the whole the questionnaire and methodology worked well with health professionals. While the wording of questions could be improved, the approach was generally sound. The results indicate the even amongst staff specialising in COPD care, knowledge about available services, particularly those in the community, is variable. On the other hand, the questionnaire proved to be too complex for patients and the method of distributing questionnaires with an self addressed envelope yielded a poor response rate. The precise response rate is unknown but, nevertheless, it appeared that patients did not have a good grasp of locally available COPD services. The patient survey questions need to be clearer, simpler and data collected in a more personalised way.

10. Appendices

Timetable and Resource Usage of Pilot Study

| | Activity | Resources |
|-------------------------------------|--|--|
| 20 th May - 15th June | Development <ul style="list-style-type: none"> • Development of both health professional and patient questionnaires in web and Word formats. • Development and collation of supporting material including <ul style="list-style-type: none"> – Covering letters – Email lists – Instructions – Covering email – Self addressed envelopes | <ul style="list-style-type: none"> • Time of project manager (40 hours) • Clinical leadership • Three teleconferences, organising papers and writing up minutes • Survey Monkey subscription |
| 15th June -- 15th July | HP Questionnaire completion <ul style="list-style-type: none"> • 15 June -HP Questionnaire distributed by email in London (delayed by 1 week in Somerset) • 21 June- Email reminder for HPQ sent(one week later in Somerset) • 13th July - Final Deadline for HP questionnaire (delayed by two weeks) Patient Questionnaire Distribution to collection points <ul style="list-style-type: none"> • Printing • 30th June -Distribution of questionnaires and SAE's (refer to table in appendix) | <ul style="list-style-type: none"> • Time of project manager (21 hours) • Clinical leadership • Questionnaire printing • Self addressed envelopes • Three teleconferences, organising papers and writing up minutes |
| 30th June - 1st August | <ul style="list-style-type: none"> • Patient Questionnaire Completion • Interview of Patients • Analysis of HP Questionnaire | <ul style="list-style-type: none"> • Time of project manager (16 hours) • Clinical leadership |
| 1st -15th September | <ul style="list-style-type: none"> • Data Entry of Patient Questionnaires • Analysis of patient questionnaires • Writing of Report | <ul style="list-style-type: none"> • Time of project manager (15 hours) • Clinical leadership • Data entry of patient questionnaires (7.5 hours) • One teleconference, organising papers and writing up minutes |

Chronic Obstructive Pulmonary Disease (COPD) care in your area

Questionnaire for healthcare professionals and managers

About this questionnaire

This questionnaire is for:

- Healthcare professionals who care for people with COPD
- Managers and commissioners who are responsible for COPD services

The questionnaire is about specialist services for people with COPD in your area. Recent work suggests the NHS needs to improve access to COPD services for both patients and healthcare professionals. Part of the problem seems to be that the pathways for referral, and information about what is available, are often unclear to those caring for and with the disease. We are trying to develop a strategy to improve things, and would be grateful for your help in completing this short questionnaire. The findings of this questionnaire will be used to improve knowledge and uptake of those services.

This questionnaire is anonymous and confidential. No information about you will be stored and nothing will be presented which would identify you.

Completing the questionnaire

You can complete this questionnaire in 3 ways.

1. You can complete it online. This is the quickest way. Please go to <http://www.surveymonkey.com/s/789FLHW> and follow the instructions.
2. You can complete as an electronic documents by typing your answers into this questionnaire. To select your answer replace the with an X. Type your comments in the boxes. When finished, email the completed and saved Word document to copd.audit@rcplondon.ac.uk.
3. You can print out the document, complete the questionnaire. Please tick inside the relevant response box / boxes using a black or blue pen. There are some questions where space is provided for you to add additional information in your own words. If you make a mistake, cross it out and put a tick in the correct box. When you have completed the questionnaire, please send it to the address given on the last page.

Please complete the questionnaire as soon as possible after receiving it and return it to us by

28th June 2010

If you need help completing the questionnaire, please call the helpline on 0203 0751551 or send an email to copd.audit@rcplondon.ac.uk

Thank you for completing the questionnaire.

About You



1. Please tell us the first part of your work post code

2. What is your professional role?

- GP
- Consultant
- Medical trainee – FY1
- Medical trainee – FY2/ST1/ST2 / SHO
- Medical trainee – ST3 and above
- Specialist registrar
- Hospital pharmacist
- Community pharmacist
- Practice nurse
- District nurse
- Hospital physiotherapist
- Community physiotherapist
- Other – *if so please state your role:*
Other please indicate [_____]
- Community matron/long term conditions nurse
- COPD nurse/physiotherapist
- Respiratory nurse specialist
- Respiratory physiologist
- Hospital manager
- Community manager
- Commissioner
- A&E doctor / nurse
- Out of hours service doctor/nurse
- Paramedic
- NHS Direct advisor

3. Which acute Trust / Primary Care Trust employs you?

Please state: [_____]

4. How would you consider your understanding of the term COPD?

- Excellent Very good Good Satisfactory Poor Very Poor Don't know

5. Do you refer patients to local COPD services? Yes No

6. Do you provide COPD services? Yes No

7. Do you organise COPD services? Yes No

8. How do you generally access information about COPD – please tick all that apply:

- Electronic (e.g. Websites) Verbally (Seminars, Conferences and Colleagues)
 Written (e.g. Journals, Books, Leaflets) Other, please specify _____

If you use the internet, what website(s) do you commonly use to information for your own use? _____

If you use the internet, what website(s) if any, do you recommend to patients? _____

You and the COPD Service

9. How would you rate your UNDERSTANDING of what services are available for patients with COPD in your local hospital?

- Excellent Very good Good Satisfactory Poor Very Poor Don't know

Please explain your selection in a few words _____

10. How would you rate the QUALITY of these hospital services?

- Excellent Very good Good Satisfactory Poor Very Poor Don't know

Please explain your selection in a few words _____

11. How would you rate your UNDERSTANDING of what services are available for COPD patients in the local community setting?

- Excellent Very good Good Satisfactory Poor Very Poor Don't know

Please explain your selection in a few words _____

12. How would you rate the QUALITY of these community COPD services?

- Excellent Very good Good Satisfactory Poor Very Poor Don't know

Please explain your selection in a few words _____

COPD Services available in your area

| | | 13. To your knowledge is this service available locally for COPD patients? | 14. If yes, please tell us how you refer to this service– please tick all that apply: |
|----|--|--|--|
| a. | Pulmonary rehabilitation in hospital | <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know | <input type="checkbox"/> Letter <input type="checkbox"/> Fax <input type="checkbox"/> E-mail <input type="checkbox"/> Direct phone contact <input type="checkbox"/> Don't know <input type="checkbox"/> Walk-in service <input type="checkbox"/> Open access <input type="checkbox"/> I can't refer to this service |
| b. | Pulmonary rehabilitation in the community | <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know | <input type="checkbox"/> Letter <input type="checkbox"/> Fax <input type="checkbox"/> E-mail <input type="checkbox"/> Direct phone contact <input type="checkbox"/> Don't know <input type="checkbox"/> Walk-in service <input type="checkbox"/> Open access <input type="checkbox"/> I can't refer to this service |
| c. | COPD early/supported discharge team based at the hospital | <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know | <input type="checkbox"/> Letter <input type="checkbox"/> Fax <input type="checkbox"/> E-mail <input type="checkbox"/> Direct phone contact <input type="checkbox"/> Don't know <input type="checkbox"/> Walk-in service <input type="checkbox"/> Open access <input type="checkbox"/> I can't refer to this service |

| | | 13. To you knowledge is this service available locally for COPD patients? | 14. If yes, please tell us how you refer to this service– please tick all that apply: |
|----|---|--|--|
| d. | COPD early / supported discharge team hospital at home scheme based in the community | <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know | <input type="checkbox"/> Letter <input type="checkbox"/> Fax <input type="checkbox"/> E-mail <input type="checkbox"/> Direct phone contact <input type="checkbox"/> Don't know <input type="checkbox"/> Walk-in service <input type="checkbox"/> Open access <input type="checkbox"/> I can't refer to this service |
| e. | Community COPD team | <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know | <input type="checkbox"/> Letter <input type="checkbox"/> Fax <input type="checkbox"/> E-mail <input type="checkbox"/> Direct phone contact <input type="checkbox"/> Don't know <input type="checkbox"/> Walk-in service <input type="checkbox"/> Open access <input type="checkbox"/> I can't refer to this service |
| f. | Telephone support service or other rapid access service that provides advice for COPD patients based in hospital | <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know | <input type="checkbox"/> Letter <input type="checkbox"/> Fax <input type="checkbox"/> E-mail <input type="checkbox"/> Direct phone contact <input type="checkbox"/> Don't know <input type="checkbox"/> Walk-in service <input type="checkbox"/> Open access <input type="checkbox"/> I can't refer to this service |
| g. | Telephone support service or other rapid access service that provides advice for COPD patients based in the community | <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know | <input type="checkbox"/> Letter <input type="checkbox"/> Fax <input type="checkbox"/> E-mail <input type="checkbox"/> Direct phone contact <input type="checkbox"/> Don't know <input type="checkbox"/> Walk-in service <input type="checkbox"/> Open access <input type="checkbox"/> I can't refer to this service |

| | | 13. To your knowledge is this service available locally for COPD patients? | 14. If yes, please tell us how you refer to this service– please tick all that apply: |
|-----------|--|--|--|
| h. | Oxygen assessment service in hospital | <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know | <input type="checkbox"/> Letter <input type="checkbox"/> Fax <input type="checkbox"/> E-mail <input type="checkbox"/> Direct phone contact <input type="checkbox"/> Don't know <input type="checkbox"/> Walk-in service <input type="checkbox"/> Open access <input type="checkbox"/> I can't refer to this service |
| i. | Oxygen assessment service in the community | <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know | <input type="checkbox"/> Letter <input type="checkbox"/> Fax <input type="checkbox"/> E-mail <input type="checkbox"/> Direct phone contact <input type="checkbox"/> Don't know <input type="checkbox"/> Walk-in service <input type="checkbox"/> Open access <input type="checkbox"/> I can't refer to this service |
| j. | Nebuliser assessment service in hospital | <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know | <input type="checkbox"/> Letter <input type="checkbox"/> Fax <input type="checkbox"/> E-mail <input type="checkbox"/> Direct phone contact <input type="checkbox"/> Don't know <input type="checkbox"/> Walk-in service <input type="checkbox"/> Open access <input type="checkbox"/> I can't refer to this service |
| k. | Nebuliser assessment service in the community | <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know | <input type="checkbox"/> Letter <input type="checkbox"/> Fax <input type="checkbox"/> E-mail <input type="checkbox"/> Direct phone contact <input type="checkbox"/> Don't know <input type="checkbox"/> Walk-in service <input type="checkbox"/> Open access <input type="checkbox"/> I can't refer to this service |

| | | 13. To your knowledge is this service available locally for COPD patients? | 14. If yes, please tell us how you refer to this service– please tick all that apply: |
|-----------|--|--|--|
| i. | Non-Invasive Ventilation in hospital | <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know | <input type="checkbox"/> Letter <input type="checkbox"/> Fax <input type="checkbox"/> E-mail <input type="checkbox"/> Direct phone contact <input type="checkbox"/> Don't know <input type="checkbox"/> Walk-in service <input type="checkbox"/> Open access <input type="checkbox"/> I can't refer to this service |
| m. | Non-Invasive Ventilation in the community | <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know | <input type="checkbox"/> Letter <input type="checkbox"/> Fax <input type="checkbox"/> E-mail <input type="checkbox"/> Direct phone contact <input type="checkbox"/> Don't know <input type="checkbox"/> Walk-in service <input type="checkbox"/> Open access <input type="checkbox"/> I can't refer to this service |
| n. | Breathlessness service in hospital | <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know | <input type="checkbox"/> Letter <input type="checkbox"/> Fax <input type="checkbox"/> E-mail <input type="checkbox"/> Direct phone contact <input type="checkbox"/> Don't know <input type="checkbox"/> Walk-in service <input type="checkbox"/> Open access <input type="checkbox"/> I can't refer to this service |
| o. | Breathlessness service in the community | <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know | <input type="checkbox"/> Letter <input type="checkbox"/> Fax <input type="checkbox"/> E-mail <input type="checkbox"/> Direct phone contact <input type="checkbox"/> Don't know <input type="checkbox"/> Walk-in service <input type="checkbox"/> Open access <input type="checkbox"/> I can't refer to this service |

| | | 13. To your knowledge is this service available locally for COPD patients? | 14. If yes, please tell us how you refer to this service– please tick all that apply: |
|-----------|--|--|--|
| p. | Dietetic advice for COPD patients | <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know | <input type="checkbox"/> Letter <input type="checkbox"/> Fax <input type="checkbox"/> E-mail <input type="checkbox"/> Direct phone contact <input type="checkbox"/> Don't know <input type="checkbox"/> Walk-in service <input type="checkbox"/> Open access <input type="checkbox"/> I can't refer to this service |
| q. | Patient support group(s) | <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know | <input type="checkbox"/> Letter <input type="checkbox"/> Fax <input type="checkbox"/> E-mail <input type="checkbox"/> Direct phone contact <input type="checkbox"/> Don't know <input type="checkbox"/> Walk-in service <input type="checkbox"/> Open access <input type="checkbox"/> I can't refer to this service |
| r. | Community COPD clinics | <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know | <input type="checkbox"/> Letter <input type="checkbox"/> Fax <input type="checkbox"/> E-mail <input type="checkbox"/> Direct phone contact <input type="checkbox"/> Don't know <input type="checkbox"/> Walk-in service <input type="checkbox"/> Open access <input type="checkbox"/> I can't refer to this service |
| s. | Hospital COPD clinics | <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know | <input type="checkbox"/> Letter <input type="checkbox"/> Fax <input type="checkbox"/> E-mail <input type="checkbox"/> Direct phone contact <input type="checkbox"/> Don't know <input type="checkbox"/> Walk-in service <input type="checkbox"/> Open access <input type="checkbox"/> I can't refer to this service |

| | | 13. To you knowledge is this service available locally for COPD patients? | 14. If yes, please tell us how you refer to this service– please tick all that apply: |
|----|---|--|--|
| t. | Hospital based smoking cessation services | <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know | <input type="checkbox"/> Letter <input type="checkbox"/> Fax <input type="checkbox"/> E-mail <input type="checkbox"/> Direct phone contact <input type="checkbox"/> Don't know <input type="checkbox"/> Walk-in service <input type="checkbox"/> Open access <input type="checkbox"/> I can't refer to this service |
| u. | Community based smoking cessation services | <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know | <input type="checkbox"/> Letter <input type="checkbox"/> Fax <input type="checkbox"/> E-mail <input type="checkbox"/> Direct phone contact <input type="checkbox"/> Don't know <input type="checkbox"/> Walk-in service <input type="checkbox"/> Open access <input type="checkbox"/> I can't refer to this service |
| v. | Community Pharmacy support services | <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know | <input type="checkbox"/> Letter <input type="checkbox"/> Fax <input type="checkbox"/> E-mail <input type="checkbox"/> Direct phone contact <input type="checkbox"/> Don't know <input type="checkbox"/> Walk-in service <input type="checkbox"/> Open access <input type="checkbox"/> I can't refer to this service |

Improving the Service

15. In your opinion what is the best thing about COPD services in your area?

16. In your opinion what is the worst thing about COPD services in your area?

17. Please use the space below to tell us more about COPD services in your area or how access to local COPD services could be improved

18. Please use the space below to tell us how to improve this questionnaire. For example, tell us what questions, in your opinion, were unclear or unhelpful.

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

Please return it by **28th June**.

Email to copd.audit@rcplondon.ac.uk

Or mail to: COPD Programme, Clinical Effectiveness and Evaluation unit, Royal College of Physicians, 11 St Andrews' Place, Regent's Park, London NW1 4LE.

If you would be willing to take part in a focus group to help improve services, please email your name and address to copd.audit@rcplondon.ac.uk. Put the words 'FOCUS GROUP' in the title of the email.

Chronic Obstructive Pulmonary Disease (COPD) Care in your Area

Patient questionnaire

About this survey

This questionnaire is for people with COPD. COPD stands for Chronic Obstructive Pulmonary Disease. It's what we used to call chronic bronchitis and emphysema. The condition is caused mainly by smoking, although some people who don't smoke can still get COPD. Inflammation in the breathing pipes (bronchi) and lungs leads to shortage of breath, cough and phlegm. The word 'chronic' means that the problem is long-term.

The purpose of the questionnaire is to out how much you know about the COPD services that are available locally and which ones you use. Recent work suggests the NHS needs to improve access to COPD services for both patients and healthcare professionals. Part of the problem seems to be that information about what is available is unclear to those caring for and with the disease. We will use the information you provide to help improve services. The questionnaire is being carried out by the Royal College of Physicians and the Collaboration for Leadership in Applied Health Research and Care (CLAHRC) for North West London. The survey is being carried out in Somerset and Northwest London.

This questionnaire is anonymous and confidential. No one who is responsible for your care will see your questionnaire. No information about you will be stored and nothing will be presented which would identify you.

Completing the questionnaire

For each question, please tick in the box in front of your answer using a black or blue pen. There are some questions where you can also write in your response or comments. If you make a mistake, simply cross it out and put a tick in the correct box. You do not need to write your name or address anywhere on the questionnaire.

When you have completed the questionnaire, please send it to the address given on the last page using the freepost envelope provided. If you would prefer to complete the questionnaire online instead of this paper version, please go to <http://www.surveymonkey.com/s/JLMP9FJ> and follow the instructions. Please complete the questionnaire as soon as possible after receiving it and post it to us no later than **1st August 2010**. If you need help completing the questionnaire, please call the helpline on 0203 0751551 or send an email to copd.audit@rcplondon.ac.uk

About You

Please put the date you are filling in this questionnaire D/MM/YYYY[_____]

1. What is your gender?

- Male
- Female

2. Please tell us the first part of your home post code

-

3. How would you describe your ethnic group?

Collecting information on ethnicity will help us to understand whether specialist COPD services in your area can be accessed fairly by all ethnic groups.

White

- White British
- White Irish
- White (other)

Black

- Black British
- Black Caribbean
- Black African
- Black (other)

Chinese

- Chinese

Other

Other not listed above – if so please specify: [_____]

Asian

- Asian British
- Asian Indian
- Asian Pakistani
- Asian Bangladeshi
- Asian (other)

Mixed

- White / Black Caribbean
- White / Black African
- White / Asian
- Other

4. How would you rate the severity of your COPD?

- Mild
- Moderate
- Severe
- Don't know

5. How would you consider your understanding of the term COPD?

- Excellent
- Very good
- Good
- Satisfactory
- Poor
- Very Poor
- Don't know

6. Where would you generally go for information about COPD? – Please tick all that apply.

- My doctor or nurse
- Patient information leaflet from the hospital or GP practice
- BLF Breathe Easy group
- Other patient group
- Electronic (e.g. Internet websites)

If you use the internet, which websites do you helpful?

[_____] Other, Please specify _____

You and the COPD Service

7. Has any health professional explained what COPD is to you?

- Yes
- No

8. Which of the following list of health care professionals have you had contact with about your COPD in the past 6 months? Please tick all that apply:

- | | |
|--|---|
| <input type="checkbox"/> GP | <input type="checkbox"/> Community matron / long term conditions nurse |
| <input type="checkbox"/> Practice nurse | <input type="checkbox"/> Respiratory nurse specialist |
| <input type="checkbox"/> Consultant/COPD specialist doctor | <input type="checkbox"/> Social Worker |
| <input type="checkbox"/> Hospital doctor | <input type="checkbox"/> A&E doctor / nurse |
| <input type="checkbox"/> Hospital pharmacist | <input type="checkbox"/> Out of hours service doctor/nurse |
| <input type="checkbox"/> Community pharmacist | <input type="checkbox"/> Paramedic |
| <input type="checkbox"/> District nurse | <input type="checkbox"/> NHS Direct advisor |
| <input type="checkbox"/> Hospital physiotherapist | <input type="checkbox"/> Psychology/Counselling service |
| <input type="checkbox"/> Community physiotherapist | <input type="checkbox"/> Other – if so please state the role of the person you saw: |
| <input type="checkbox"/> Occupational therapist | [_____] |
| <input type="checkbox"/> COPD nurse/physiotherapist | |

Your local hospital COPD Service

Please indicate whether you agree or disagree with the following statements

9. I know about the services AVAILABLE for people with COPD at my local hospital.

Strongly agree Agree Unsure Disagree Strongly Disagree

10. I know HOW TO USE my local hospital COPD services.

Strongly agree Agree Unsure Disagree Strongly Disagree

11. The QUALITY of these hospital services are.....

Excellent Good Satisfactory Poor Very Poor Don't know

Please explain your answers in this section in a few words _____

Your local community COPD Service

These are the services you receive outside of hospital for example from the community COPD or Pulmonary Rehab teams or in your GP surgery.

Please indicate whether you agree or disagree with the following statements

12. I know about the services AVAILABLE for people with COPD in the local community setting.

Strongly agree Agree Unsure Disagree Strongly Disagree

13. I know HOW TO USE my local community COPD services.

Strongly agree Agree Unsure Disagree Strongly Disagree

14. The QUALITY of these community services are.....

Excellent Good Satisfactory Poor Very Poor Don't know

Please explain your answers in this section in a few words _____

COPD Services available in your area

15. Are the following, to your knowledge, available locally to COPD patients?

| | | |
|----|--|---|
| a. | Pulmonary rehabilitation in hospital | <input type="checkbox"/> Yes, available <input type="checkbox"/> No, not available <input type="checkbox"/> I don't know |
| b. | Pulmonary rehabilitation in the community | <input type="checkbox"/> Yes, available <input type="checkbox"/> No, not available <input type="checkbox"/> I don't know |
| c. | COPD early/supported discharge team based at the hospital (A team to help you go home from hospital sooner) These can be called 'hospital at home' or 'assisted discharge' schemes) | <input type="checkbox"/> Yes, available <input type="checkbox"/> No, not available <input type="checkbox"/> I don't know |
| d. | COPD early/supported discharge team (see explanation above) based in the community. | <input type="checkbox"/> Yes, available <input type="checkbox"/> No, not available <input type="checkbox"/> I don't know |
| e. | A community COPD team | <input type="checkbox"/> Yes, available <input type="checkbox"/> No, not available <input type="checkbox"/> I don't know |
| f. | A team that you can call instead of going to Accident & Emergency | <input type="checkbox"/> Yes, available <input type="checkbox"/> No, not available <input type="checkbox"/> I don't know |
| g. | A telephone support service or other rapid access service that provides advice for COPD patients based in hospital | <input type="checkbox"/> Yes, available <input type="checkbox"/> No, not available <input type="checkbox"/> I don't know |
| h. | Telephone support service or other rapid access service that provides advice for COPD patients based in the community | <input type="checkbox"/> Yes, available <input type="checkbox"/> No, not available <input type="checkbox"/> I don't know |

| | | |
|----|--|---|
| i. | An oxygen assessment service in hospital | <input type="checkbox"/> Yes, available <input type="checkbox"/> No, not available <input type="checkbox"/> I don't know |
| j. | An oxygen assessment service in the community | <input type="checkbox"/> Yes, available <input type="checkbox"/> No, not available <input type="checkbox"/> I don't know |

Continued next page.....

| | | |
|----|---|---|
| k. | Nebuliser assessment service in hospital | <input type="checkbox"/> Yes, available <input type="checkbox"/> No, not available <input type="checkbox"/> I don't know |
| l. | Nebuliser assessment service in the community | <input type="checkbox"/> Yes, available <input type="checkbox"/> No, not available <input type="checkbox"/> I don't know |
| m. | Non-Invasive Ventilation in hospital | <input type="checkbox"/> Yes, available <input type="checkbox"/> No, not available <input type="checkbox"/> I don't know |
| n. | Non-Invasive Ventilation in the community | <input type="checkbox"/> Yes, available <input type="checkbox"/> No, not available <input type="checkbox"/> I don't know |
| o. | A breathlessness service in hospital | <input type="checkbox"/> Yes, available <input type="checkbox"/> No, not available <input type="checkbox"/> I don't know |
| p. | A breathlessness service in the community | <input type="checkbox"/> Yes, available <input type="checkbox"/> No, not available <input type="checkbox"/> I don't know |
| q. | Dietetic advice for COPD patients | <input type="checkbox"/> Yes, available <input type="checkbox"/> No, not available <input type="checkbox"/> I don't know |
| r. | Patient support group(s) e.g. a Breathe Easy Group | <input type="checkbox"/> Yes, available <input type="checkbox"/> No, not available <input type="checkbox"/> I don't know |
| s. | COPD clinics in hospital | <input type="checkbox"/> Yes, available <input type="checkbox"/> No, not available <input type="checkbox"/> I don't know |
| t. | COPD clinics in the community | <input type="checkbox"/> Yes, available <input type="checkbox"/> No, not available <input type="checkbox"/> I don't know |

| | | |
|----|---|---|
| u. | Smoking cessation service in hospital | <input type="checkbox"/> Yes, available <input type="checkbox"/> No, not available <input type="checkbox"/> I don't know |
| v. | Smoking cessation service in the community | <input type="checkbox"/> Yes, available <input type="checkbox"/> No, not available <input type="checkbox"/> I don't know |
| w. | Community Pharmacy support services | <input type="checkbox"/> Yes, available <input type="checkbox"/> No, not available <input type="checkbox"/> I don't know |

16. Have you used this service within the past 6 months?

| | | |
|----|---|--|
| a. | Pulmonary rehabilitation in hospital | <input type="checkbox"/> Yes, I've used <input type="checkbox"/> No, I haven't used <input type="checkbox"/> I don't know |
| b. | Pulmonary rehabilitation in the community | <input type="checkbox"/> Yes, I've used <input type="checkbox"/> No, I haven't used <input type="checkbox"/> I don't know |
| c. | COPD early/supported discharge team based at the hospital (A team to help you go home from hospital sooner) These can be called 'hospital at home' or 'assisted discharge' schemes) | <input type="checkbox"/> Yes, I've used <input type="checkbox"/> No, I haven't used <input type="checkbox"/> I don't know |
| d. | COPD early/supported discharge team (see explanation above) based in the community . | <input type="checkbox"/> Yes, I've used <input type="checkbox"/> No, I haven't used <input type="checkbox"/> I don't know |
| e. | A community COPD team | <input type="checkbox"/> Yes, I've used <input type="checkbox"/> No, I haven't used <input type="checkbox"/> I don't know |
| f. | A team that you can call instead of going to Accident & Emergency | <input type="checkbox"/> Yes, I've used <input type="checkbox"/> No, I haven't used <input type="checkbox"/> I don't know |
| g. | A telephone support service or other rapid access service that provides advice for COPD patients based in hospital | <input type="checkbox"/> Yes, I've used <input type="checkbox"/> No, I haven't used <input type="checkbox"/> I don't know |
| h. | Telephone support service or other rapid access service that provides advice for COPD patients based in the community | <input type="checkbox"/> Yes, I've used <input type="checkbox"/> No, I haven't used <input type="checkbox"/> I don't know |
| i. | An oxygen assessment service in hospital | <input type="checkbox"/> Yes, I've used <input type="checkbox"/> No, I haven't used <input type="checkbox"/> I don't know |

16. Have you used this service within the past 6 months?

| | | |
|----|--|--|
| j. | An oxygen assessment service in the community | <input type="checkbox"/> Yes, I've used <input type="checkbox"/> No, I haven't used <input type="checkbox"/> I don't know |
| k. | Nebuliser assessment service in hospital | <input type="checkbox"/> Yes, I've used <input type="checkbox"/> No, I haven't used <input type="checkbox"/> I don't know |

Continued next page.....

| | | |
|----|--|--|
| l. | Nebuliser assessment service in the community | <input type="checkbox"/> Yes, I've used <input type="checkbox"/> No, I haven't used <input type="checkbox"/> I don't know |
| m. | Non-Invasive Ventilation in hospital | <input type="checkbox"/> Yes, I've used <input type="checkbox"/> No, I haven't used <input type="checkbox"/> I don't know |
| n. | Non-Invasive Ventilation in the community | <input type="checkbox"/> Yes, I've used <input type="checkbox"/> No, I haven't used <input type="checkbox"/> I don't know |
| o. | A breathlessness service run in hospital | <input type="checkbox"/> Yes, I've used <input type="checkbox"/> No, I haven't used <input type="checkbox"/> I don't know |
| p. | A breathlessness service in the community | <input type="checkbox"/> Yes, I've used <input type="checkbox"/> No, I haven't used <input type="checkbox"/> I don't know |
| q. | Dietetic advice for COPD patients | <input type="checkbox"/> Yes, I've used <input type="checkbox"/> No, I haven't used <input type="checkbox"/> I don't know |
| r. | Patient support group(s) | <input type="checkbox"/> Yes, I've used <input type="checkbox"/> No, I haven't used <input type="checkbox"/> I don't know |
| s. | COPD clinics in hospital | <input type="checkbox"/> Yes, I've used <input type="checkbox"/> No, I haven't used <input type="checkbox"/> I don't know |
| t. | COPD clinics in the community | <input type="checkbox"/> Yes, I've used <input type="checkbox"/> No, I haven't used <input type="checkbox"/> I don't know |

16. Have you used this service within the past 6 months?

| | |
|--|--|
| u. Smoking cessation service in hospital | <input type="checkbox"/> Yes, I've used <input type="checkbox"/> No, I haven't used <input type="checkbox"/> I don't know |
| v. Smoking cessation service in the community | <input type="checkbox"/> Yes, I've used <input type="checkbox"/> No, I haven't used <input type="checkbox"/> I don't know |
| w. Community Pharmacy support services | <input type="checkbox"/> Yes, I've used <input type="checkbox"/> No, I haven't used <input type="checkbox"/> I don't know |

Improving the Service

17. In your opinion what is the best thing about COPD services in your area?

18. In your opinion what is the worst thing about COPD services in your area?

19. Please use the space below to tell us more about COPD services in your area or how access to local COPD services could be improved

20. Please use the space below to tell us how to improve this questionnaire. For example, tell us what questions, in your opinion, were unclear or unhelpful.

~ Thank you very much for taking the time to complete this survey ~

Please return it by **1st August 2010**

You may email it to copd.audit@rcplondon.ac.uk

or post to: COPD Programme, Clinical Effectiveness and Evaluation Unit, Royal College of Physicians, 11 St Andrews' Place, Regent's Park, London NW1 4LE.

A freepost addressed envelope is provided

If you would be willing to take part in a focus group to help improve services, please email your name and address to copd.audit@rcplondon.ac.uk. Put the words 'FOCUS GROUP' in the title of the email. If you prefer, you can put your name and address on the next page this will be torn off before the questionnaire is processed.

I would be interested in taking part in a Focus Group

Name _____

Address _____

City _____ County _____

Postcode _____

Email _____

Patient Questionnaire distribution

| Questionnaire numbers | Person distributing | Comments | Questionnaires & SAEs sent? |
|------------------------------|----------------------------|--|--|
| 1 -100 | Sarah Elkin | 100 | Yes |
| 101 - 125 | Jackie Valentine | These are for Sandy Wilson, Project Manager COPD to distribute to C&W team Consultants, CNS nurses and local Breathe Easy Group (25) | Yes |
| 126 - 149 | Nancy P | Victoria Davidson Respiratory Service St.Charles Centre for Health and Wellbeing Community Clinics- Orange Department Exmoor Street W10 6DZ (25) | Yes |
| 150 - 165 | Nancy P | Rafiqun Khanom Practice manager Exmoor surgery First Floor St Charles Health Centre Exmoor Street London W10 6DZ (16) | Yes |
| 166 - 181 | Nancy P | Krystina Ewin Deputy Manager Latimer Surgery First Floor St Charles Health Centre Exmoor Street London W10 6DZ (16) | Yes |

| | | | |
|-----------|------------------------|--|-------------|
| 182 - 199 | Nancy P | Elizabeth Mcdonic Practice Nurse Barlby Surgery First Floor St Charles Health Centre Exmoor Street London W10 6DZ (17) | Yes |
| 200 - 224 | Nancy P | Ricky Banarsee Brent PCT (25) | Yes |
| 225 - 239 | Nancy P | Essam at West Middlesex Hospital (15) | Yes |
| 240- 250 | Nancy P | COPD CNS Nurse at Northwick Park Hospital (10) | Yes |
| 251 - 500 | Nancy P – Rob Stone | Sent to Dr Robert Stone for distribution in Taunton (250) | Yes |
| 501- 525 | Nancy T | Nancy Turnbull printed off additional 25 to take to a COPD clinic at St Mary's Hospital | Only 3 used |
| 526 – 550 | Nancy P | Send to Victoria Davidson Victoria reports that 22 were not distributed to patients | Yes |

Verbatim comments made in the HPQ regarding the questionnaire

Please use the space below to tell us how to improve this questionnaire. For example, tell us what questions, in your opinion, were unclear or unhelpful.

- Responses relate to most local PCT (K&C) not provision across NW London which of course varies.
- Good questionnaire
- Too many services
- Good questionnaire. Easy to use.
- could have had an option for electronic referral and a n/A option for that section
- Difficult to answer some questions as respondents presumably hospital based or community based
- If you are the person providing the service there was no option for how do document this in the multiple choice answers
- I think the categories for physiotherapy choices were not ideal - hospital or community, as some work in both, equally. Difficult to interpret the quality difference between the service you supply, and the services to COPD within a PCT population overall. They may be quite different.
- There needs to be a "not applicable" option.
- clear questionnaire - no suggestions
- Pretty self explanatory. Difficulties with link as no user name/password for Imperial - community based
- Less free text boxes would make this easier to fill in and may potentially improve response
- it was fine
- no options on referral criteria e.g specialist referral criteria
- You could ask specific questions about services available in each area to increase health professionals. awareness of them.
- need to be concise
 - I DON'T PROVIDE A SERVICE AS OPPOSED TO CAN'T WOULD MAKE LIFE MUCH CLEARER. 2) A SERVICE PROVIDOR HAS AN HOLISTIC MANAGEMENT POLICY WHERE THE PATIENT IS PLUGGED INTO AREAS WHICH ARE OF PARTICULAR IMPOROTANCE TO THE INDIVIDUAL. IS THIS WHAT IS MEANT BY OPEN ACCESS? OR MANAGED.

- I am specialist GI consultant who sees patients with COPD occasionally on acute wards. I then refer to the COPD team and they take over so well I don't need to do or know any more! Hence the questions you ask are beyond my ken.
- I'm sure our responses will be very different from the patient ones, otherwise well thought thru' seems to address all the main issues and only took 8 Mins to do .
- some of the referral questions irrelevant
- very clear questionnaire
- Practice nurses are employed by the Surgery, not the PCT or Trust
- nil of note
- I thought it was a good questionnaire.
- Unsure what was meant by hospital clinics and community clinics - did you mean outpatients?
- Question 11 was probably worded quite vaguely
- I had already stated that some services were not available locally, and yet the next questions asked how we can refer in to them. I ticked the 'not able to refer' box, but this is because there services do not exist.
- This questionnaire has been answered from the point of view of a user, but they seemed to be directed more to Primary care.
- Very clear.
- terminology to describe the services is not entirely clear e.g. breathlessness services
- I think some of the options on some of the questions were limited. When asking about whether certain services were available for patients there was no way of saying yes some patients have access to these services but some do not depending on where their GP is located. I could only indicate yes or no.
- More tick box answers
- You need a N/A option Rather than how do 'you' refer to..., better to ask how are referrals made to...so that if we run the service makes more sense
- Q16 and Q17 needed the option of proactive pickup. Eg all NIV patients are automatically seen by the NIV consultant. Also does the response "Direct phone include by bleep?
- I feel there is a hidden agenda here. What is it??I wonder. It would be good to know all COPD services pulled together and were not wasting effort on demarcation disputes, as in the past!! You are all excellent and the patients appreciate all involved as do I. Many many thanks.

Verbatim comments made in the PQ regarding the questionnaire

Please use the space below to tell us more about COPD services in your area or how access to local COPD services could be improved

1. All clear
2. Didn't understand some questions
3. Possible question repeat too many time could include "Not Sure"
4. None
5. N/A
6. OK
7. Unsure about 15 Rehabilitation
8. I have only just been sent to St Charles Hospital to be assessed, which took three hours and said they would be in touch with me.
9. Layout very good
10. More publicity
(Sorry for writing I am 89 years old)
11. Questions 17 to 20. As I said on Page 4 I only found out today so I have not had a chance to out things.
12. I've filled out what I thought was best.
13. Question about Hospital and community was rather unclear as all my treatment except for my GP is given in another town.
14. To include all lung infections
15. There are other support groups which should be acknowledged
The Somerset Assessment Clinic could also be acknowledged Mon, Aug 9, 2010 11:11 AM ...
16. No Comment
17. Page 6 No M & N
18. All I know that I want to get well as I have chronical Bronchitis. I have Bronchal infections very often. I want to get well.
19. As indicated
20. None
21. Some of the hospital questions were unclear. I have attended services at St. Mary's W2 as an outpatient - was not sure what to put.
22. Found questions OK to answer. 23. N/A
24. Unsure about the question about services in hospital or community

- 25. Questionnaire is quite clear and easy to understand.
- 26. I have only moved in the last 9 months so I am still learning.
- 27. Shorter!
- 28. They are clear however too many

Report of patient interviews

General Comments on problems:

- 1) Patients very confused about terminology
 - a) Non-invasive ventilation
 - b) Pulmonary
 - c) Telephone support what is this service?
 - d) All of the 'long winded' explanations of services – e.g. rapid access service
 - e) Consultant is a hospital doctor
 - f) Didn't know if the current clinic was a COPD clinic
- 2) Don't understand what are community services and what are hospital services
 - a) Think 'in hospital' is inpatient
 - b) Think that everything is from the hospital if it isn't GP
- 3) Too long and complicated
 - a) There is really no practical difference between 'don't know' and no.
 - b) Repetitive

Patient 1

Very long questionnaire – very slow – had difficulty

Do we want to encourage relatives to do it (question about patient or relative)

Q 4 – didn't know how to identify how severe

Q5 Confusion on knowledge – didn't know they had COPD term not used

Q6 – think of doctor as GP not hospital doctor – may need to say hospitals or GP

Q 7- as above

Q 8 Confusion about hospital doctor and consultant

Didn't understand word pulmonary

Very laborious – could we just have one option of 'yes available' and 'yes used' and accept we won't know the difference between don't know's, no's and non response.

Patient 2

Difficulty w Q 4

Lists too long – don't read all

Does in hospital mean as an inpatient (? Should say at the hospital)

What is 'non-invasive' ventilation

Sometimes doesn't know where the service is based

Is this current clinic a COPD clinic? Both weren't sure

Liberal interpretation of 6 months

Knowing staff are well informed and take time.

? Why you haven't used service – stopped because didn't get on with person.

Patient 3

Combine questions 16| 17

Don't understand can tick more than one.

Don't know terms

Explain your answer – might need to change wording to add anything extra here.

Unsure and disagree.

Patient 4

Consultants are hospital doctors don't distinguish between the two

Confusion over what are community services

Q 16. Going on 11 week course – is that community?

A team you can call instead of does that mean out of hours? Does it mean a dedicated team – she would phone hospital clinic or GP.

Query over non-invasive ventilation – what does that mean? ? come to hospital to get an inhaler.

Community pharmacy – is this your local chemist?

Q 17 – Misunderstood the question – put don't know – repeating from above. Put don't know for the ones no available.

Patient 5

Agree/disagree questions difficult to grasp what she was supposed to do - could make yes/no

Confusion over community services. Don't know about community

Don't know about what the telephone support service is

Patient 6

Hospital meant inpatient

Patient 7

Doesn't understand long term conditions nurse

In hospital = inpatient

Rapid access service – not understood

Had trouble with layout of questionnaire

Abstract Submitted to the British Thoracic Society Winter Meeting 2010

What do health professionals understand about their local COPD services?

RA Stone, S Elkin, J Valentine, N Turnbull, D Lowe, NA Pursey, JM Potter

The 2008 National COPD Audit showed evidence of self-reported innovative practice but low levels of referral into specialist services such as pulmonary rehabilitation. We believe this may be due in part to a lack of understanding about local COPD services among health professionals (HP's). To explore this, as part of the preamble to a larger piece of work, we undertook a preliminary on-line survey of HP's in North West London and Somerset. The survey was marketed via initial e-mails sent from three of us (SE, JV, RS) to our network groups. The survey asked HP's to rate their understanding of hospital and community COPD services, and whether they knew of specific aspects. There were 223 valid responses (hospital physiotherapists 19%, consultants 13%, GP's 13 %, practice nurses 8%, COPD nurses / physiotherapists 8%, medical trainees 8%, respiratory nurse specialists 5%, community matrons 4%, others 23%). 78% both referred into and provided COPD services. Understanding of hospital and community COPD service *availability* was rated respectively as excellent (22%, 17%), very good (27%, 25%), good (26%, 22%), satisfactory (14%, 14%), poor (9%, 15%), very poor (1%, 4%) and don't know (1%, 3%). Understanding of hospital and community service *quality* was rated respectively as excellent (14%, 10%), very good (40%, 26%), good (24%, 26%), satisfactory (10%, 12%), poor (2%, 5%), very poor (1%, 1%), don't know (9%, 20%). Hospital consultants in particular stated poor understanding or knowledge of community COPD service availability and quality. Respondents were then asked to state whether specific aspects of COPD service were available (Table):

| Service available? | Yes, available | No, not available | Don't know |
|---|-----------------------|--------------------------|-------------------|
| Pulmonary Rehabilitation in hospital | 69% | 14% | 17% |
| Pulmonary Rehabilitation in the community | 78% | 6% | 16% |
| COPD early/supported discharge service based at the hospital | 62% | 19% | 19% |
| COPD early/supported discharge service based in the community | 41% | 26% | 33% |
| Community COPD team | 74% | 9% | 17% |
| Telephone support service or other rapid access service that provides advice for patients, based in hospital | 28% | 24% | 38% |
| Telephone support service or other rapid access service that provides advice for patients, based in community | 58% | 8% | 34% |
| Oxygen assessment service in hospital | 85% | 5% | 10% |
| Oxygen service based in the community | 62% | 20% | 18% |
| Nebuliser service based in the hospital | 75% | 6% | 19% |
| Nebuliser service based in the community | 52% | 15% | 33% |
| NIV in the hospital | 87% | 1% | 12% |
| NIV in the community | 36% | 26% | 38% |
| Breathlessness service in hospital | 45% | 23% | 32% |

| | | | |
|--|------------|------------|------------|
| Breathlessness service in the community | 33% | 25% | 42% |
| Dietetic advice for COPD patients | 66% | 6% | 28% |
| Patient support groups | 65% | 6% | 29% |
| Community COPD clinics | 64% | 9% | 27% |
| Hospital COPD clinics | 86% | 6% | 8% |
| Hospital based smoking cessation services | 58% | 18% | 24% |
| Community based smoking cessation services | 83% | 3% | 14% |
| Community pharmacy support services | 42% | 8% | 50% |

These data show that appreciable percentages of an, albeit hospital-biased, group of HP's do not know whether specific aspects of COPD service are available despite the majority being responsible for providing and referring. These preliminary results suggest it is necessary to undertake a comprehensive assessment of service knowledge amongst health professionals to determine educational needs within specific groups across the health spectrum and to develop strategies for knowledge transfer. There would seem to be merit in developing common sources of information that professionals and patients alike can use.

Free text comments in Health Professional Questionnaire

In your opinion what is the best thing about COPD services in your area?

Response Count 144

Integration of pulmonary rehabilitation between RBH and C&W. Advanced COPD service providing comprehensive assessment and triage to appropriate specialist interventions.

It's easily accessible, and the staff are all competent in their fields.

We have an excellent Oxygen service and Pulmonary Rehab facilities

The team are visible and straddle acute and primary care - there are open access spirometry clinics and also dedicated COPD one stop clinics. Good support with respect to oxygen assessments.

Resp team/nurse specialist v. helpful and accessible

?

Easy to contact COPD nurse in working hours

Don't know

N/A

Easy access and available promptly if needed

I don't know much about them as I don't deal with COPD patients day to day

Very active and enthusiastic hospital services, always looking to expand local services

The variety of service

Multi disciplinary with sound communication. Support of respiratory physician the span of service from in patient through to community setting and flow of refs to various COPD services - no gaps psychology access specific to COPD

pulmonary rehabilitation

Early medical discharge available Community respiratory service available with rapid response element
Support of respiratory team for early discharges Close working with chronic disease practitioners Direct
phone contact and joint assessment as appropriate Ongoing training

Now that we have standardised form things are easier and all are aware of whats been done

An advanced COPD clinic, easy provision and support of NIV patients

Good supportive team that work well together and cover all aspects of COPD

the relationship and close working between the services

Pulmonary Rehabilitation across the community and hospitals

Routine home visit , comprehensive care package which include end-of life-care and ambulance service
involvement in the plan of care.

Comprehensive service for severe, high user COPd patients as they are case managed by specialist teams, who
are based in hospital and so have close daily contact / liaison with secondary care physicians, but who provide
the care to patients at home. They have access to a rapid response service from this team, and get a visit
within 2 hours.

easily accessible in aptient COPD team who receive patients and support early discharge they have good links
to community services to a lot of referrals can be made via them and reduces the need for paperwork
integrated COPD Consultant

Very follow up of patients after discharge from hospital

Community COPD and early discharge service.

Available Pulmonary rehabilitation for patients Good home support Nurse lead clinics Good networking
amongst care workers (except GPs)

They include a 1-stop clinic in the hospital, smoking cessation clinics and pulmonary rehab. Patients admitted
to hospital are, on the whole, followed up on discharge in the community.

There is a large group of hosp and community physicians working together to move services out of hosp and
into the community allowing or specialist hosp to remain a true specialist centre

High quality hospital and community services

The Community Respiratory Specialist Nurses (CRNS) play a key role improving the quality of care for patients
by reducing unplanned hospital admissions, facilitating early discharge, nurse led clinics in the community and
improving patient self-management skills. To ensure patients receive the most appropriate care the Nurses
are working closely with health professionals and social care across primary and secondary interface sharing
skills, knowledge and expertise. We also have specialist nurses on our helpline who are able to provide advice
to healthcare professionals and the public.

great team of community nurses well supported by nurse consultant at st georges

Respiratory nurses supported by community respiratory consultant. Local sleep clinic available at Charing Cross
where i refer all my patients with suspected obstructive sleep apnoea.

The flexibility of the team, close liaison/communication about patients. Always happy to answer queries and

do joint visits.

A good team and patients can receive high quality care

Availability of specialist nursing input

Excellent

The accessibility of The Community COPD Nurse Specialist.

-pt state they feel supported and happy with service

The excellent community COPD team, providing support and expert advice to patients and staff.

OPA for COPD patients in secondary care by chest physician. COPD community service available for advice.

Rapid response team for patient advice after hours.

All patients have the choice of various hospitals and GPs to choose from. They have excellent community services

Pulmonary Rehabilitation Community Respiratory Service Good link with hospital and community COPD services (St. Marys and Community COPD)

community COPD service

level of support patients receive, more structured management relevant to patients condition, happy with service and feel more confident in self management.

Good working relationship with some local hospitals allows good community care

Supports one or two severely ill pt at home

Could be "more out there" helping us to find cases and assessing those at risk of admission, although for those under their care this is good

its local, it spans and delivers a range of quality services

Respiratory team's prompt response when needed.

good multi-disciplinary working by specialist professionals

Early discharge services

THERE ARE SERVICES BOTH IN THE COMMUNITY AS ADMISSION PREVENTION AND AT THE HOSPITAL FOR ACUTE EVENTS PROVIDING AN EARLY ASSISTED DISCHARGE SCHEME WHICH SUPPORTS EDUCATION AND SELF MANAGEMENT

prompt advice available

Highly qualified motivated staff, striving for a joint up service with the community, we have over the years established a robust pulmonary rehabilitation service, nebuliser, home ventilation early discharge service. This could have been extended into the community

The support system in place provides essential contact for patients who are very frightened.

That they rapidly assess patients and usually keep them out of hospital.

there appears to be good follow up for patients in the community, after discharge from hospital good consultant service

To enable early discharge

That it exists! patients are getting the support to manage their condition, prevent hospital admissions.

good in hospital service

Hospital services are excellent

The best thing about the COPD services in my area is the close links in between community teams and secondary care. Excellent consultant support and virtual weekly ward rounds.

Good hospital service

I am specialist GI consultant who sees patients with COPD occasionally on acute wards. I then refer to the COPD team and they take over so well I don't need to do or know any more! Hence the questions you ask are beyond my ken.

The COPD early discharge scheme in hospital is a quality service that saves hospital bed days and enables patients to recover within a familiar environment. The patients develop a trusting relationship with their nurses and know they always have someone they can call when they need advice. The pulmonary rehab program is also provided by the early discharge scheme and can be offered to patients with moderate/severe disease and they can exercise safely in a controlled environment.

Don't know.

not alot it was the hospital team but we are going backwrads fast with the decision to disinvest in hospital services in favour of a suspect community service for political reasons.

24hour service including breakdown of equipment

Accessibility for patients. Quality and expertise in this area for assessment & treatment

Good team skills, good communication, patients have confidence in our service and the support that they receive from us.

A dedicated team now in situ who just deal with COPD, & access to nebulisers is now easier.

personal service from the hospital

LOCAL AVAILIBILITY FOR PATIENTS

there are many people who are passionate and care about the services for patients with COPD.

The community copd service has improved services considerably through out the area, but more communication needs to occur bewteen the service and general practice

Well motivated teams. Accessible services

Quick service, excellent treatment & good rapport

range of services available, excellant respiratory consultants, with good team

Excellent consultant opinions and support

comprehensive provision

Hospital based pulmonary rehab

hospial service has got dedicated team, THREADS and nurse specialists in lung lab particularly helpful.

Home visit and information packs for patients.

Getting additional support for pulmonary rehab and oxygen.

Accessibility and quality

there are support services out there, County Community service sounds very good, awaiting feedback from the

first pt I have referred!

gives access to pulmonary rehab!

I think there is very good support for pts who have been d/c from hosp . and I know the pts do find this v helpful . The telephone support they also get is very good for when they have a exacebation of their COPD

Easy access

Local hospital consultants and nurses.

THREADS team very supportive post discharge Clinovia team well recieved by patients. Good telephone advice available from Resp nurse specialists MPH

The community service is excellent but there is little co-operation between the hospital and community service. I have no evidence of any referrals from the hospital service to community service.

General practice support where 94% of the work takes place.

Countywide community support for patients with COPD by specialist team

The GP surgery and the hospital services are good

They are well organised and available to all people across the county

available across area

We have an active and experienced group of Nurses within secondary care who provide an Excellent service.

We also have excellent Leadership of such services.

Support and advice given by the hospital in conjunction with follow ups by COPD service

The outreach team offer fantastic services in line with the COPD strategy. Work very closely with respiratory physician (hospital based) and community services

We offer a 24/7 support service to our patients. We review the patient hoistically providing educational support and encourage self-management

The PCT that provides MDT PR and Specialist respiratory intermediate care services as it has aided patients to improve their functional independence, mastery of their condition, imprved their knowledge of their conditon and reduced their levels of disability. In addtion admissions to hospital have reduced and pateint love the PR cleasses. They feel that it helps to redcue their isolation and anxiety associated with the condtion.

Community and hopital based pulmonary rehab

Well coordinated with enthusiastic dedicated staff

Developing NIV service and the fact we can offer some pulmonary rehabilitation service. Hospital discharge team

We have a team called Respire who provide COPD services for county patients. They provide admission avoidance, pumlmnary rehad and early supported discharge. They are an excellent service who seem to be very proactive.

The pulmonary rehabilitation program. We also have Respiratory support and sleep centre which provides NIV service to COPD patients.

the one trust has an excellent COPD service in the area and the other is very poor, creating a postcode lottery which is extremely unfair

Highly Specialist Physio skills provided

Multi-disciplinary approach with good communication between professionals to optimise management of patients.

Proactive consultants and physiotherapy service within the hospital. PR services across sites. NIV services lead by physiotherapist, both acute and domiciliary. Community respiratory nurses supporting patient within their own environment.

Excellent MDT working. Close working between physio/resp nurse/cons provide successful ESD scheme A dedicated physiotherapist to treat COPD pts very supportive smoking cessation service Patient help record / oxygen alert card

COPD nurses

Service Leads in nursing and Physio are both colleagues working towards the same aims with a very supportive and proactive consultant at the acute trust. We are hopefully about to get commissioning for a county wide PR service to ensure equity and quality across the county.

Very good pulmonary rehabilitation service and patients receive very good support from Early Supported Discharge nurses.

Good teamworking Excellent, knowledgeable staff

That there is physiotherapy involvement in the service

access to pulmonary rehab and early supported discharge from hospital

Multidisciplinary service, joint in service training and excellent team dynamics

The pulmonary rehab groups are very effective and well organised,

There are staff here with lots of skills and experience, and who are eager to help the patients, adopting a flexible approach to patient needs. Keen to embrace all relevant research and evidence.

We all work very closely together

Inpatient and outpatient pulmonary rehab

Service is well coordinated across acute trust and community with collaborative working. New services in process of being set up include nebuliser service and assessment for NIV in hospital.

Admission avoidance and supported discharge schemes 24 hour COPD Action Line Hospital based pulmonary rehabilitation In-patient optimisation

COPD out reach Acute NIV service

The innovative and joined up working with our colleagues at KCH i.e. we have extended our COPD passport and 24 hour telephone service to them and together we have written patient management plans.

COPD strategy project funded by Guy's and St. Thomas' Charity - provides joined up care. This 3 year project has established community COPD STAR clinics, a 24/7 support and advice line to patients and an excellent PR service, providing services at hosp and community sites. The admission avoidance and early supported and supported discharge scheme.

The PR service is A1 The community team services and the hospital NIV service are both good. The fact that we want to work together (comm and acute) and are trying, despite barriers in place due to separation of

trusts and managers who want to be protectionist about their own services and discourage sharing

I provide a good service to those on my caseload

A well established service.

The Community Respiratory Team- early supported d/c, home pul rehab ,COPD education, management of exacerbations,prevention of hospital admissions, Telehealth monitoring

MDT working

Large community and hospital PR service. COPD Outreach service within the hospital with home visit service.

Specialist COPD clinics in community (but temporary funding) 24/7 helpline for COPD patients (temporary funding)

Integration with other resp services, primary and acute care

Breathingspace provides excellent specialist care to all patients across their whole disease trajectory

Specialist centre for COPD providing diagnostics, pulm rehab, O2 service, in patient care, end of life care

The Trust provides an excellent service in managing COPD patients. The ward refers to the Nurse specialists who visit & assess the patients quickly and efficiently. Due to the Trust having such specialists, they will arrange any follow up needed in the community. It is because of their input I have such limited understanding of the service provided in the Community

the gps generally manage COPD well with support from specialist nurses the hospital service has won national awards

There is a lot of expertise available to us from a lot of primary , secondary and community team members

Somerset community copd service - refer all willing patients with an fev1 50% or less - excellent pulmonary rehab and breathlessness service. All nebuliser trials and oxygen therapy assessments carried out - overall an excellent service.

THE COMMUNITY COPD SERVICE IS VERY GOOD FOR REFERRING PATIENTS WHO DO NOT QUITE FIT THE CRITERIA FOR A HOSPITAL REFERRAL, THE COPD SERVICE REFERS PATIENTS ON FOR PULMONARY REHAB AND NEBULISER TRIALS AND THEY ARE GOOD WITH THEIR COMMUNICATION BACK TO US

In your opinion what is the worst thing about COPD services in your area?

Response count 134

Lack of early supported discharge Underprovision of PR by PCT

Perhaps just the lack of people in the teams - in cases of sickness or A/L, it is sometimes difficult to cover all areas.

There is no supported discharge or intermediate care system

No knowledge of community services

?

Don't know

N/A

Difficult to access and not really promoted

Don't know

Lack of similar enthusiasm by local PCT/not involving hospital specialists in service redesign.

Not knowing who is doing what

Variable from pct to pct as trust serves several therefore one patient within the trust may not receive the same as another due to their post code

lack of a community respiratory team to support patients after discharge lack of doctors/ physio at the weekend meaning that discharge is delayed or reduced over the weekend

Early medical discharge uptake could be better Lack of knowledge by non-respiratory teams for management on discharge Lack of knowledge by ward staff of management of COPD for discharge

Pul rehab. Palliative care

Short staffed therefore have trouble covering all areas as effectively as they would like.

the different systems - however a new project will try and reduce some of these

Hospital at home/early supported discharge not available

They are still under-resourced and cannot engage with commissioning to review this. We have no official oxygen service and Pulmonary Rehab is in need of expanding, but restricted by limited personnel. Also there is no ongoing education, support for practice nurses or GP's with regards to respiratory care.

variable access to services depending on postcode

No weekend cover. This would require more resources .

Unequal post code dependent services Lack of hospital run and based early supported discharge scheme Poor community management Poor integration of PCT/secondary care(despite trying)

Still lots of duplication in the area and variations in practice.

There have been difficulties encouraging all Gp's to identify patients and also patients have occasionally been reluctant to leave high quality specialist services

Currently some difficulty with community pulmonary rehab provision due to staffing

We are in the process of developing the End of Life Care for COPD patients.

I can honestly say I find no faults - except we could do with more of them! I was horrified to hear that the service may be closed!

The service is currently being redesigned so there is a very long waiting list for Pulmonary Rehab, which will take time to reduce

communication between secondary care and district nursing services following change of treatment

It could do with more staff so that they can provide a bigger service

Not widely advertised

Not knowing enough about the services available - this questionnaire has highlighted that!

-time it take for the community team to pick up a new referral -they don't 'Highlight' their service

The links between hospital and community services are still limited.

Lack of communication and coordination between primary and secondary care services in COPD. Although there is a COPD team available in the community they are not accepting referrals to manage COPD patients and follow them up.

GPs not referring into the correct services and not using Pulmonary rehab more

Nil

Non availability of hospital at home service.

lack of funding and investment from commissioning bodies, no oxygen/ nebuliser service despite several business cases being presented, by to the lack of capacity the team have, local GP education and support is neglected. High level of palliative patients with little input from local palliative care teams due capacity.

GP referrals and involvement is not consistent and very variable

Variability in enthusiasm and level of service

As above

we need a full respiratory services

No concerted action for sufferers to stop smoking.

duplication of services can appear confusing for staff in primary care

Needs more slots in pulmonary rehab

IT IS FRAGMENTED. THERE APPEAR TO BE GAPS BETWEEN THE ACUTE AND NON ACUTE COMMUNITY SERVICES. A LINK BETWEEN THE 3 AREAS NEEDS TO BE MADE RESULTING IN A CONTINUAL SUPPORT SERVICE FOR ALL COPD PATIENTS NOT JUST A SELECT FEW. I SEE THESE AS BEING THE SURGERY, THE COMMUNITY SERVICE AND HOSPITAL SERVICE.

poor community support through primary care

The fragmentation of the service by the changes in the provision of the care, The loss of control to a service which is not as good as the service which it is to replace. The loss of continuity

Not knowing about the service

That they are threatened.

my ignorance of what is available!

A limited area is covered

Primary and secondary care don't work well together

limited scope of early discharge from hospital depending upon limited postcodes thus many patients fall outside this

Access to supported discharge over greater geographical area

I don't think is the worst but it would be nice if there were more of us in the community and in hospital

Dont know

That its not a 24hr, 7 days a week service. But due to cost and lack of staff, it is not feasible.

Poor collaborative work with ambulance service possibly leading to increase in unnecessary admissions.

the above politics

Lack of "End of life care" service for patients with severe COPD.

Delay in assessment of patients discharged from hospital and long waits for those who need to be seen at home

Confusion about the community and hospital provision & who is providing what

Community based service is not adequate and the staffing is poor. Pulmonary Rehabilitation is provided but patient feedback is not complementary to them.

The wait time to see them and the repeat visits needed to deal with different things , such as splitting O2,nebs, and general assessment into 3 trips, for patients who tend not to have great mobility in the first place.

lack of integration and a weak community service

NOT ENOUGH PULMONARY REHAB SERVICES LOACALLY

very disjointed service with lack of communication between services. many P/N deal solely with COPD patients but are unable to refer to consultants. thankfully we have a community based service for pulmonary rehab

The variability across the area from practice to practice as to the level of care patients receive.

COPDcommunity service-slow feed back; Needs closer liaison with surgery,prior to making treatment changes and to avoid overlap of services provided.

Nothing regarding the MPH service

not really sure about extra service that has been commissioned, and how it fits with the rest, a combined service would have been better, as lots of duplication that doesn't make sense

not being able to use threads service to stop people being admitted

still some unhappiness between community and hospital services

Community COPD service virtually duplicates what we do in house, will only see acute patients who are already under their care, and expect to take over patients' care which is not what we or the patients want. Hardly ever refer to them.

can't really think of anything really bad. I suppose more direct contact for the patient might be helpful. A direct advice/helpline. further increase of lung rehab/exercise programmes to reduce waiting lists and encourage ongoing exercises.

Lack of home based services. Travel costs and disruption to patients.

I feel all the services are fragmented, with poor communication between secondary, intermediate and primary care

confusing criteria about referral eg who to refer to when

its the only way to get pulmonary rehab!!

There are 2 different services, and the community one is not run from the DGH here .

Poor communication following referral

Oxygen services. Communication regarding local community services with individual practices rather than via commissioning organisations.

Long waits for pulmonary rehab. Poor information supplied on clinovia feedback letters/ FEV1 /VC not recalculated correctly if >200ml to FVC Still remains cinderella service

lack of a seamless service

Communication - we are as bad as specialist services.

Lack of equity of pulmonary rehab and lack of a community oxygen service

Not widespread enough. Very ad-hoc

Poor communication between different Teams involved in managing COPD. Lack of understanding of Service, what is available and how to refer.

The GP surgery does not refer patient with COPD and their carers to our support group.

Some confusion remains about the role of the Community COPD service

patients wait a long time to access appointments

Not 'joined up' Silo working as the 4th Sector almost sit's out on a limb and GP and Practice Nurses find the service no better than their own care! There is duplication of work and the community setting is not acute care driven hence it does not affect admission rates (primary outcome of service). The community service will not see anyone who has not been assessed by them previously, severely limiting the impact of the service. Subsequently the skill set of the nurse is poor at best.

The inability to refer all patients because geographically they are not entitled to all the services

Poor communication between hospital. Patients reviewed in clinic who would benefit from self management plans, 24/7 numbers but not referred. These patients then end up being admitted - their admission perhaps

could be avoided.

Not being able to refer patients reviewed in community clinic to chest clinic if outcome of consultation is outwith the scope of community COPD clinics

The fact that one PCT has an excellent service and patients in another PCT has no specialist service available particularly PR. We have noticed that this group has a higher level of admissions and are more dependant on health services to manage their condition and their functional ability is reduced - including MRC and St George's. Questionnaire.

Lack of maintenance pulmonary rehab

wider knowledge about COPD management across the hospital and general awareness of services/what they offer/how to contact - I find I am constantly telling the doctors and nurses about the COPD management, the COPD service and what it offers as they rotate so frequently

Lack of funding. No specialist clinics and massive waiting list for pulmonary rehabilitation

End of life care as patients don't always get referred to palliative care in a timely fashion

The pulmonary rehabilitation in the poorly funded trust

Not enough RSU beds.

Variable service across counties means you have to think about postcode before referring to certain services.

Lack of early discharge support following an exacerbation, lack of early rehab following admission. Minimal dietitian and social support. Benefits and pensions services limited to none.

lack of community services poor understanding within the hospital of COPD lack of resources to treat COPD (within physio for example no access to PEP/flutter/acapella devices)

Community support

Inequality of care depending where you are admitted (hospital) and the ward you are admitted onto. Transport is not available for access to Pulm Rehab services. Services are currently led by one service lead in acute care and one in community both fighting for the same pot of cash!

Difficult to give sufficient support in the community to reduce hospital re-admissions. No physiotherapist involved in the Early Supported Discharge team.

Not enough interest from Commissioners

Access, long waiting list for community team and pulm rehab. Poor service within the acute trust

Post code lottery for pulmonary rehab and early supported discharge from hospital

Staffing levels and PCT funding (can cause prolonged time just agreeing funding application)

I think the awareness of what they can provide in the hospital and community to health care professionals. lack of guidance at the appropriate ways of referring patients.

Lack of physiotherapy and occupational therapy input , which can make a huge difference to the patient managing their own condition and keeping active and functional for the greatest time. Lack of specialist

community physiotherapy making acute and subacute care take place in the acute trust as there is no option

Lack of access over a large geographical area - poorly funded

I am new in the post, have not met many COPD patients (working on ITU and SHDU) and I am not familiar yet with all the services available in the hospital and the community

Underfunded in the community with a long waiting list for pulmonary rehab

Lack of psychological support for patients Access to GP and availability of home visits

Poor access to services if patient severely impaired physically

Money for some of these services is temporary

Palliative and end of life care provision is lacking. There is a dearth of experience, expertise and interest in the community teams with respect to COPD care provision. The detection, diagnosis and management of those with COPD is inconsistent at best.

separation of trusts making integrated care very difficult to provide managers who want to be protectionist about their own services and discourage sharing and don't see the advantage of integrated care. The lack of coordination therefore between us and acute as a result The lack of a good Oxygen and NIV home service Physicians who 'demand' or prescribe inappropriate oxygen and/or nebulisers for patients GP who 'demand' or prescribe inappropriate oxygen for patients

there is only myself as a single community based COPD practitioner. No GPWSI or consultant access

Not able to expand. Staffing issues.

No transport for unwell community patients who need urgent assessment at hospital rapid access respiratory clinic

Acute hospital has in-patients and clinic patients from more than one PCT but the community services are only available to one PCT so many patients are not able to access community services

No community based rapid response service for COPD patients in exacerbation Temporary funding for community based COPD clinics Lack of psychological services for COPD patients

poor management of the services

The need for staff to have a better understanding of the services available to COPD patients in the Community

th PCT commissioning a underpowered service in the community without close collaboration between primary and secondary care

There are no magic wands for the worst of lungs but the hospice offer palliative care .

POSSIBLY NEED MORE COPD NURSES AND COMMUNITY MATRONS WHO ARE QUALIFIED TO MANAGE COPD PATIENTS. SECONDARY CARE AND PRIMARY CARE SERVICES DO NOT ALWAYS APPEAR TO BE SUPPORTIVE OF EACH OTHER

Please use the space below to tell us more about COPD services in your area or how access to local COPD services could be improved.

Response Count 95

Sevices are being developed through an integrated service improvement program

The current referral system uses different forms for rapid response nursing and for COPD community team, whether there is a possibility to unify the referral form or use a generic form for both it may cut time spent filling out paperwork. Improving awareness of existing services would be good, maybe a poster campaign, or just drop in sessions for hospital staff as well, not just for patients, then COPD patient referrals may change.

?

Don't know

More information

More information

I don't access them

4 community matrons supporting early hospital discharge scheme

see above

Community team based in hospital so can liasie directly Gp need to be more aware of service and therefore increase referral to this Rehabilitation services need to be better communicated to hospital staff

More of those listed in 19)

Infromation on how to access all the local COPD services would be benificail, however this is usually covererd by the COPD inpatient team.

not all the local PCT offer the same level and provision of services, so different patients get different levels of care.

Frequent meetings between acute and community services Improved funding

ability to refer to them from the Emergency Department

Services are easily accessible to local GPs, Carers, other multi-disciplinary team in the hopsital and the community. Annual road show of COPD service will increase the awareness in the wider community

Very important to get commissioning onside, so that service specifications are matched to local need. If these are limited, then access must also be limited, as unable to manage capacity otherwise. It seems very unfair, that there is such a difference between PCT's, so that it seems a post code lottery.

more access for those from Brent to rehab and nursing sercices in teh community

Services could be improved with more expert input and better integration with hospitals. There is a risk with care moving to the community (which I support if correctly managed) that care will become dumbed down and patients will suffer. There must be joined up working with no distancing from experts. GPs must be brought into process and support COPD patients. education re: diagnosing must be improved. More work with

palliative care Less post code care

Reps from each group need to get together to standardise practice and support each other to provide a high quality, efficient service across the whole area.

Already very good

already have single point of contact and Saturday service

Better information on hospital website. Emailing practice managers with a list of all the available services and numbers/referral forms would I think be the best way to improve local GP Practices knowledge of services and how to access them.

COPD team covering Westminster is excellent both in terms of care they provide directly to patients at home and in clinics, but also in upskilling community nurses in their management, understanding and knowledge of COPD.

We are beginning to have more involvement with local hospital teams to provide a link between hospital and community

There is a hospital based chest clinic, community COPD service including nurse specialist, rapid response nursing service covering 24hrs offering patient support, community matrons and level 2 case managers supporting people with COPD The coordination and communication between these services could be improved

Access is excellent, the community team have links with all teams and they have nurses, physios and a psychologist in their service. They have excellent links with the Hospital which greatly helps

The services available are currently easily accessible, through a telephone call to the COPD team, advice can be given on how to access each service and/or make referrals.

Direct link for community matrons to access chest physicians for advice in the management of patients. Regular meetings with COPD services (every 2-3 months?) in local hospitals (in my case more than one). Better discharge coordination by secondary care and liaison with community matrons to follow the patient up after discharge.

GP referral need to increase

more staff to implement respiratory specific palliative care role. Again more staff to run services such as oxygen/nebuliser/ pulmonary rehab.

Closer working with commissioners for other services would help involve other services like rapid response teams etc with the specialist COPD service delivery

.

Increase awareness of services available in the community

hoping to have single point of access by the end of the year and a single COPD service that spans hospital and community provision - bring all services available under 1 team.

Pulmonary rehab ,support groups & dietitian advise

PATIENTS SEEING THEIR COPD NURSE AT THE SURGERY FOR THEIR ANNUAL REVIEW COULD BE PROVIDED WITH WRITTEN INFORMATION ABOUT THE SUPPORT THAT IS PROVIDED IN THEIR AREA. LIKEWISE PATIENTS IN THE HOSPITAL COULD BE PROVIDED WITH A WHOLE PACKAGE OF INFORMATION. PATIENT CHOICE IS PARAMOUNT BUT DUPLICATION OF SERVICE PROVISION IS NOT APPROPRIATE.

This needs to be led by the specialist center, lead chest physician and not just a GP with an interest, there needs to be a service audit by the specialist centre and have a hub and spoke approach with complex in the hub

THREADS are based within hospital, I would probably gain access by telephoning the respiratory ward. We have had a number of patients with confirmed COPD and they find contact a life line, as well as their families.

it would be useful to have a list of contact numbers, to refer to community services, to give to patients

Greater understanding of available services and how to refer

The close links and excellent communication with the community teams help a lot to referred appropriate patients between secondary and primary care. I think the lack of SpR difficult the r/v of these patients. When the patients are referred by the community and I can find an SpR or they are too busy to r/v the patient. Makes the whole system fail. As is unpredictable case load low priority is given by SpR's to the service

The early discharge scheme won an award for innovation in 2005 and in November 2009 was recognised by the Top High Impact Actions for nursing and midwifery. It was a new initiative commissioned by organisations including the Department of Health, The Royal College of Nurses, the NMC and the Institute for Innovation and Improvement. In June 2010 it was decided that this service was to be axed by the hospital trust because of money saving plans. The scheme is due to finish over the next few months.

Greater collaborative work with ambulance services.

it is not joined up at all

The services vary depending on where patient's GP is. This is unfair and denies fundamental care ie rehab. In hospital patients are seen by a respiratory CNS who communicates effectively with community team. Early discharge service needs to be funded

More interaction with the community and sharing ideas and services.

We need to plan a cross county team for early discharge, probably run by the same team as the COPD service, hence cutting down admin and support staff as all in same team. Also either outreach or inreach would aid smooth early discharges.

proper specialist in charge of the community service

MORE COPD NURSES, LOCAL CLINICS/SUPPORT GROUPS

patients have benefited since the introduction of community based referral and local pulmonary rehab. community matrons are a link between primary and secondary care

Improvement in communication between all areas of care for COPD service to ensure we are all working together

Well supported in Somerset for COPD services. More space to write comprehensive referral on COPD referral

form with room for specific requests. Quicker feed back and full copy of COPD assessment.

I don't really need to know as I am very happy with the service I have

streamlined approach, combining what is there

The community COPD service has provided useful extra capacity, pity not more joined up with the local hospital teams

access not a problem

nil of note

To have a one-stop shop to answer all queries and refer from to all other available services.

Improve communication as to all available services and access to them

Clear guidelines on referral to each service and when it would be appropriate to refer to specific services eg community COPD service or breathlessness service by hospice

referral form could be less prescriptive be more explicit about what follow up / access pts have once initially assessed

Change the whole service to a community service with inreach to DGHs

There is in development a countywide clinical strategy to ensure that all providers of care to COPD patients are offering the most appropriate advice and support as well as providing an equitable service, so things are about to start changing for the better. This will lead to a community oxygen service and equal access to PR as mentioned in the last question.

We offer Breathlessness Management at Hospice and individually in Community. Available to all Palliative Care Patients.

Our support group would like to be more closely linked to the local GP practice.

shorter waiting times

Commission a virtual COPD Team ie primary and secondary care labels removed and have a truly combined intermediate service caring for the chronic and acute needs for all the COPD population.

Extending the services to include all the patients in the community.

As discussed above - improved communication to prevent admissions to hospital. Improved MDT communication to reduce length of stay with improved use of community services. A lot of patients could be managed at home but not as awaiting social services or refusing to be d/c despite being at baseline. I have just finished an audit that has looked at this.

Increase utilisation of community pharmacists in both the referral to community services and basic management of disease e.g. inhaler technique, management of exacerbations

I think commissioners and GP's (commissioners) should be more aware of the skills of the wider MDT in aiding patients to manage their condition and / or skills sharing should occur. For example a patient following an acute exacerbation of COPD asked a GP to refer him to a physio for exercises and the GP asked if they meant for their back or knees rather than PR, secretion management exercises or breathlessness management exercises.

(GP) Commissioners should also be encouraged to appreciate GOLD, BTS Guidelines and the COPD NS more when commissioning services for this patient group.

Joint specialist and community working and clinics works very well and should be increased. Consultants are available to give advice to community matrons.

more preventative possibly greater input from dietetics, psychology and continence specialists

It would be great if the community services all merged and we just had to make a referral to one service instead of several. Referral systems can often be too complex and this puts people off referring patients when they are unsure

As stated earlier the differences in funding and investment into COPD services the 2 trusts is massive.

more dedicated staff to pulmonary rehab/resp outputs to reduce wait times

Quicker referrals within community setting

Amalgamate acute and community COPD teams into a single countywide service providing care across a patient journey/pathway that all services are interlinked into. Needs a coordinator to ensure equity of a quality service across the county. Needs more AHP involvement at an acute level and community level with specialist professional leads ensuring quality of staff within these roles. Networking forums for these services would allow services to learn from other services about implementing certain phases and develop clinical requirements in a more streamlined manner.

Improved transport options for those patients with reduced exercise tolerance. Better access to patient support groups such as breathe easy. Easy to find information on the British Lung Foundation website with regards local support groups.

Greater use of venues and space. Increase number of specialist staff

The PCT are slow to provide a Dorset wide service despite many meetings with them and so is not equitable and until this is addressed things will not improve. Transport is also a big problem for a rural community to access services as buses run infrequently and many can not afford taxis

In Berkshire East · No oxygen assessment service in place in Berkshire east. We put a bid in but not accepted · Pulmonary rehab is in place but not specifically funded and not in enough areas around the county. No Maintenance classes in place due to resources and funding · No domiciliary respiratory physiotherapy available for patients without COPD and limited for those with, currently dispensed by neuro community physios. ·

A move towards community based services. Extension of role of COPD practitioner to include prescribing

Better Integrated care between acute and community Properly funded and run Oxygen assessment and review service and an NIV home service

need a respiratory team. needs to be MDT. Need access to respiratory consultant / GPWSI

Communication lines excellent.

Access to services for all patients

need further joined up thinking and service development between the two large acute trusts in this area as

patients tend to go to both hospitals, so the services should be equitable (which they are not are present)

couldn't be much better than they already are better management of services and improved communications with GP's and community teams more multidisciplinary leadership instead of just "nurse led"

As above

allow the primary and secondary care users to discuss an integrated service directly

I do not think changes are needed tho a newsletter from community COPD service may be helpful to inform us of service developments as we do not need to use them often given our in house expertise.

access to somerset COPD services excellent.

WE NEED MORE PULMONARY REHAB PLACES.

Free text comments in Patient Questionnaire

In your opinion what is the best thing about COPD services in your area?

Response Count 56

I can only quote the hospital as I use no services in the community. St Mary's Hospital is absolutley excellent in treating COPD.

MUA smoking cessation

Nurse visits at home. Big help

I have nothing but praise for the support I receive.

THEY STAFF AT THE HOSPITAL AND IN THE COPD TEAMS ARE VERY GOOD.,

Excellent Time Limit on Appointment after GP Referral & speedy treatment after appointment.

It does help maybe when people hear about the subject which perhaps will be explained to them.

Prevents hospital admission. No contact with sick people with infections. Named nurses whom you can talk to.

Informed nurses. No bullies so you can go at your own speed in recovery.

When you have a problem you can talk to someone

Good

Always helpful

People with breathing problem needs Advantage for the treatment locally.

The specialists and rehab team at Musgrove Park Hospital and my local respiratory nurse at GPs

I can call them at any time.

Apart from going to my GP, I do not know what services there are.

The service from the COPD team is excellent

It is very good.

Don't know about it

The nurses are good

Varies sources

I am waiting for an appointment with the Somerset Community COPD Service.

I have had excellent support & help from Westminster COPD team. Home visits when I couldn't get out & v. rapid reponse + fast tracking.`

A & E. Help and Support at Home.

I have the COPD Nurse's Phone Number so that I can call if I'm not sure about something.

Went to Stowe Cente aboute 12 months ago.

I have had wonderful help in every way.

BEING BLESSED WITH THE C & W & ROYAL BROMPTON HOSPITALS

Suffering only mild symptoms - not used fully any of the services.

The entire service is excellent

I don't know

Hospital lung department very good

Having support from Threads Team.

Coming to Home or over phone.

All staff visited have been very kind & helpful

Meeting other people who are like myself

The Somerset COPD Assessment Clinics

Community COPD Service

Help & support available

St Charles Hospital

Seen quickly and then regularly checked. Confidence in the Consultant & the whole team including the Physios.

The Rehab Programme is very helpful.

I don't think I have any services in my area, but going to the next town I have been given help and support by a great team.

Don't know of any

Don't know any services in my area apart from going to the hospital.

Their ability to enable us to help ourselves as much as possible

Physioat Gabrielo twice a week Tue & Thursday

Threads Respiratory Nurses. They are only a phone call away but it only Mon to Fri. 8.30am - 5.00 pm

THREADS 8 week courses at Musgrove P H

Never used

24 Hr Service

Very attentive and available.

Well run by physio team. Informative & very person orientated. Easy to get to.

They listen and help

Satisfactory.

Knowing they are there gives you peace of mind.

From this point of view the hospital access is excellent

Threads

Don't use

In your opinion what is the worst thing about COPD services in your area?

Response Count 43

Response Text

I have no knowledge of services in my area

Good

THE DOCTORS SHOULD TALK TO ME MORE NOT TALK IN FRONT OF ME TO OTHERS AND NOT INCLUDE ME ,
DONT KNOW

MORE INFO ON IT SHOULD BE TO TO THE PERSON WITH COPD

I haven't seen any so I cannot speak about the subject.

Telephone service could be improved

Nothing bad

N/A
I don't know
No ongoing rehab or exercise classes. Tried Gyms but most are expensive and wont take COPD clients.
There isn't
Not knowing about the services.
All good.
Cannot answer
I have no complaints
N/A
Have not had any dealings with them yet.
Nothing
No weekend cover in hospital except A & E or at home.
When I went they was helpfull
Can't fault at all
N/P
Travel to hospital.
N/A
I don't know
Return phone calls (2-3 days later)
N/A As always used Threads Team MPH
Cannot fault this service at all. Doing a Great Job.
They do not exercise like we at Breathability
LTOT Services (i.e. O2 Supplies and the fulfillment pf approved HOOF's)
Rehab only for 6 weeks. No advice given thereafter.
Oxygen cylinders desperately need upgrading
I don't think I have any in my town?
Not known
Waiting time to get to consultant for diagnosis
Not enough information everywhere
Paying Car Park Charges at Hospital
Don't know
They have been re-situated on the 2nd floor from the ground floor. When the lifts break down (often) I have to struggle up four flights of stairs!
Can't think of anything negative.
N/A
None
I think the GP surgery could send you to the lung assessment clinic at the hospital sooner.
Could do with a rapid response team.

Please use the space below to tell us more about COPD services in your area or how access to local COPD services could be improved.

Response Count 34

I'm not sure of where services are.
Central Mddx are good to me
I DONT KNOW ANYMORE
I ca't tell more about the subject as I haven't been around talking to other people cocerning the subject. To me it does help me alot.
Better telephone service
Don't know about it

Everything Good

I don't really know

I have not needed to find services in my area at present, but if I get worse I may need to.

The COPD service is excellent. I have had a lot of help with the COPD Nurse, Physio.

I don't think COPD can be improved any more.

N/A

Do not know anything about them at the moment. Hope to learn more in the future

See above

The only way I can get treated when my COPD gets bad is A & E. Lucky if I get to be resus. If not too bad spend 6-8 Hrs in A & E. No cover on wards after 4.30 Friday to 10am Monday.

Those who I have dealt with are very competent in every way

I THINK THAT MOST OF COPD SERVICES ARE BEING COVERED IN THE AREA BUT THERE'S ALWAYS ROOM FOR IMPROVEMENT

Each time I've visited - Service excellent & speedy

I have no idea as I have not used any of the Services

Helpful 24 hr service

I have been involved with Threads Team assisting me from hospital to home.

Attending Rehab. Giving advice on benefits with the right people talking to us. Supporting with form filling in.

No Comment

I am assessed for LTOT as:-

2L/minute 24hr/day - sedentary

3L/minute up to 12hrs/day - ambulatory

Nevertheless The O2 provider states it can be supplied.

COPD sessions at our local Hospice

COPD exercise classes

I only know what my G.P. and Hospital Dr. tells me, therefore I cannot comment on the questionnaire.

I go to the hospital every 3 mths for my check ups I have phone number if I'm worse at any time.

Apart from good service from Lung Centre there is the advantage of "BUPA Homecare"

More information at GPs

See above

Usually referral by GP or Asthma Nurse. COPD units do give out cards with telephone number to contact direct to me which is useful. Do not know if this practice is widespread.

Not sure.

Service is good and reliable. Do not see any room for improvement.

I think the GP surgery could be improved but difficult with resources. Hospital COPD are excellent in all areas.

Unsure