

Developing the National Service
Framework - Exploring the
experience of seldom heard people
affected by Chronic Obstructive
Pulmonary Disorder

**A REPORT PREPARED FOR THE COPD NSF
DEVELOPMENT TEAM AT THE DEPARTMENT
OF HEALTH**

PETER CROSS
PICKER INSTITUTE EUROPE

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Picker Institute Europe

The Picker Institute works with patients, professionals and policy makers to promote understanding of the patient's perspective at all levels of healthcare policy and practice. We undertake a unique combination of research, development and policy activities which together work to make patients' views count. There are three key strands to our work:

- Measurement - researching and evaluating patients' experience
- Improvement - leading initiatives that make improvements happen
- Policy - building evidence to inform health policy.

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King's Mead House

Oxpens Road

Oxford OX1 1RX

Tel: 01865 208100

Fax: 01865 208101

Email: info@pickereurope.ac.uk

Website: www.pickereurope.org

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1 Executive summary

1.1 Introduction

Chronic Obstructive Pulmonary Disease (COPD) is an umbrella term covering a range of conditions including chronic bronchitis and emphysema. It is a long term condition that leads to damaged airways, causing them to become narrow, making it harder for air to get in and out of the lungs. There is no cure for COPD, but it can be managed through a series of interventions including exercise and drug therapy. With early diagnosis and the right care, the progression of the disease can be slowed down allowing people to live healthy and active lives for longer.

According to the British Lung Foundation despite its invisibility, COPD is the UK's fifth biggest killer disease, is the second most common cause of emergency admission to hospital and one of the most costly inpatient conditions treated by the NHS. It is estimated that the direct cost of providing care in the NHS for people with COPD is almost £500 million a year – more than half of which relates to hospital care.

During the late part of 2007, as part of the development of the National Service Framework (NSF) Picker Institute Europe undertook research with Chronic Obstructive Pulmonary Disease (COPD) patients (and their carers) across England on behalf of the Department of Health.

Firstly, a range of minority ethnic patients were interviewed in order to examine whether their experience and understanding of their condition was markedly different to that of the majority white population.

Secondly, some of the major themes and issues proposed in the new NSF were discussed by focus groups in order to seek the opinions of people affected by COPD about those emerging themes.

Picker Institute staff used a mixture of focus group and individual interview techniques to gather evidence from September to December 2007; what appears below is a synopsis of that data.

1.2 Overall commentary on the research

Everybody to whom we spoke had had a diagnosis of a chronic lung condition and was thus known to, and receiving services from, healthcare providers. Therefore all the data collected comes from individuals who are by definition "within the system" and engaged in self management to some extent. Many had been through pulmonary rehabilitation (PR) and were patients who were fully engaged in managing their condition and were probably at the more positive end of the spectrum of all patients affected by COPD.

In our opinion the key outcome of this research is the fact that we found so few patients with COPD from minority ethnic communities. We spoke to dozens of professionals

working in various roles with people affected by COPD across England, many working in areas with very high black and minority and ethnic (BME) populations with high smoking rates but we were consistently told that virtually their entire case load/membership was white.

There were a number of theories expressed as to why this might be so and it is our belief that this phenomenon is worthy of further research.

1.3 Results summary–seldom heard groups

It is our understanding that there are few significant differences between the experience of patients with COPD from black and minority ethnic (BME) backgrounds and those from the majority white population.

There appears to be very little understanding of COPD in any part of the population. Only one participant had ever heard of COPD before they were diagnosed.

Very few patients to whom we spoke had made any attempt to seek out information about their condition other than that which was provided by their doctors or nurses.

There were indications that some patients from South Asian backgrounds were not engaging with services such as pulmonary rehabilitation (PR) or taking an active part in self-management. Some reasons put forward were: transport, women not being used to joining in open activities, women seeing exercise as undignified and patients failing to understand the role of exercise.

People from BME communities were very appreciative of the specialist COPD teams. It is possible that more people would engage further if encouraged to do so by their health professionals.

Most patients accepted that their smoking had at least contributed to their condition.

The patients we spoke to demonstrated the likely range of experience, opinions and beliefs that would be present in any sample of any patients with this condition.

In addition:

- we suspect that there are fewer patients with COPD from minority ethnic communities known to healthcare providers than would be expected demographically. There may be cultural, sociological, practical or even physiological reasons for this. This is of itself interesting and worthy of further research.

There were some conclusions that could be drawn from our results including:

- people were extremely trusting of their doctors and nurses and grateful for their care. There may be some slight difference in the compliance of patients from Asian and West Indian backgrounds.

- Planners of healthcare services may consider cultural sensitivity when inviting patients from minority communities to group activity such as pulmonary rehab. There may be some additional cultural barriers to participation for some groups (for instance older Asian women or people with poor spoken English) that can be overcome with additional support
- Some of the very enthusiastic 'graduates' from PR could be used to encourage participation from under-represented groups. Single sex groups, or "buddying" systems could be considered.

1.4 Results summary – work with mainstream patients testing NSF themes

Three focus groups of people affected by COPD were asked for their reactions to a range of proposals that were being considered for inclusion in the proposed NSF.

How attractive is the concept of a lung health check for all people, starting at the age of seven?

This evoked a very positive response; most people could see no problems with this although there would obviously be resource implications. It would allow an early start on disease management. It might help with smoking cessation or even prevention with identifiable people if it was known that they were particularly susceptible.

What is the role of employers, in COPD prevention?

There were mixed views. Some people saw one of the roles of employers to be concerned for their employees' health however many participants were more prosaic in their understanding that commercial or public sector organisations don't exist in order to employ people but to make money or to provide services.

Some participants were very clear that their relationship with their employers was a financial transaction and that their employer had no business being concerned with any aspect of their life away from the workplace.

Would free Nicotine Replacement Therapy products act as an incentive for people to give up smoking?

This led to a fairly muted response. Some sense that it might be an issue for "other people" – lots of people were aware of price of NRT (several had had it on prescription through their GP or PCT in any case) however the general feeling was that people will give up "when they are ready" whether or not NRT is used. Most people had been shocked in to giving up around the time of diagnosis. (We need to remain aware that the participants were in the main older and from medium to higher socio-economic groups).

Exercise or pulmonary rehabilitation - which is the preference?

There was extremely positive affirmation for PR. However all of the participants were in the system – most had been through PR – and two of the focus groups took place on the final day of PR courses, so participants were by definition highly engaged and had seen the course through.

Almost everybody we spoke to had received the majority of their knowledge about COPD through the PR courses.

There was a great deal of evidence that people had undertaken the PR exercises in a group situation in a way that they would never have done on their own. Several patients had had exercise videos or DVDs and watched them but not been motivated to start exercising until they went on the PR course.

There was a call for follow-up services for PR, such as ongoing exercise classes.

Some concern was expressed that we were not able to speak to people who did not take up the invitations. There was some second hand evidence from people who were not "joiners", or who were very embarrassed about struggling in front of people or who could not see the point, but they were not heard from directly.

There was a call for PR to be "marketed better".

How important is the concept of proactive follow-up, post hospitalisation?

Only two participants had been hospitalised because of their COPD. Both experiences seemed to support the idea of intense proactive follow up to hospitalisation.

What is the reaction to the idea of self-management plans as a contract between patients and their NHS partners?

There was a very muted response to this idea – patients felt that if they were engaged they would be engaged and if not then any contract (real or implied) would not improve peoples' self-management. However there was some interest in how such a thing might work, maybe including some element of self-prescribing and a commitment on the patient's part to taking a certain amount of exercise.

At what point, and by whom, should discussions around end of life care be raised?

This was a very difficult issue to get to grips with – obviously we spent a good deal of time discussing this sensitive subject. Most of the discussion was not directly relevant to the question. In answer to the question people wanted it left as late as possible – only a handful wanted to think about it before things got much worse than they are (remember many were finishing PR and were actually more positive about the future than they had been for some time). They felt that they had a more relevant and comfortable relationship with nurses in the COPD team than with GPs (who didn't have enough time) or consultants (with whom they didn't feel they could discuss such things). Most people assumed that "the hospital will bring it up when it's time".

How acceptable is remote/innovative technology to patients?

People were very happy with the technology that they have related to oxygen and drugs and found it difficult to visualise new equipment since they "didn't know what they didn't know". A "new set of lungs" came up more than once (the perception being that there is a very strict age barrier for transplants). There was some interest in tele-monitoring especially if it could avoid hospital admissions.

Anything else?

People affected by COPD were frustrated at the low profile of COPD with the general public and health professionals. They were especially keen to raise the profile of PR.

2 Introduction

The team developing the new National Service Framework (NSF) for Chronic Obstructive Pulmonary Disease (COPD) at the Department of Health (DoH) was concerned that when taking soundings from stakeholders the voices of some patients had not been heard. They were especially keen to hear from patients from minority ethnic communities.

The Picker Institute was commissioned to undertake some research in to the experience and beliefs of people affected by COPD and this report arises from the material collected by that project.

3 Background

3.1 National Service Frameworks

National Service Frameworks (NSFs) are long term strategies for improving specific areas of care. They set measurable goals within set time frames.

NSFs:

- set national standards and identify key interventions for a defined service or care group
- put in place strategies to support implementation
- establish ways to ensure progress within an agreed timescale.

The NHS Plan re-emphasised the role of NSFs as drivers in delivering the Modernisation Agenda.

Each NSF is developed with the assistance of an External Reference Group (ERG) which brings together health professionals, service users and carers, health service managers, partner agencies, and other advocates. ERGs adopt an inclusive process to engage a full range of views. The Department of Health supports the ERG and manages the overall process.

3.2 The COPD NSF

Chronic Obstructive Pulmonary Disease (COPD) is an umbrella term covering a range of conditions including chronic bronchitis and emphysema. It is a long term condition that leads to damaged airways, causing them to become narrow, making it harder for air to

get in and out of the lungs. There is no cure for COPD, but it can be managed through a series of interventions including exercise and drug therapy. With early diagnosis and the right care, the progression of the disease can be slowed down allowing people to live healthy and active lives for longer.

Epidemiological evidence indicates that there are an estimated 3.7 million people in the UK with COPD. With only 900,000 people currently diagnosed and receiving treatment and care, the remaining estimated 2.8 million people are unaware they have a disease which, if left untreated, could severely restrict their lives and eventually kill them.

The most significant risk factor for COPD appears to be smoking, followed by other aspects of social deprivation such as diet and occupational exposure to dust, indoor pollution (such as smoke from wood and coal fires), and, in a small number of cases, inherited faulty genes. Recent research also indicates that poor airway function after birth should be recognised as a risk factor for COPD.

According to the British Lung Foundation despite its invisibility, COPD is the UK's fifth biggest killer disease, claiming more lives than breast, bowel or prostate cancer. It is the second most common cause of emergency admission to hospital and one of the most costly inpatient conditions treated by the NHS. It is estimated that the direct cost of providing care in the NHS for people with COPD is almost £500 million a year – more than half of which relates to hospital care

On the 28th June 2006, the Secretary of State announced that a National Service Framework should be developed for COPD following recommendations published in the Chief Medical Officer's Annual Report 2004.

The External Reference Group has been established and is required to produce final advice with a view to publishing the NSF for COPD towards the end of 2008.

NB This material in this section is sourced from

http://www.dh.gov.uk/en/Healthcare/NationalServiceFrameworks/DH_4138532

3.3 Picker Institute Europe

Picker Institute Europe is a registered charity with headquarters in Oxford. We work with patients, professionals and policy makers to promote understanding of the patient's perspective at all levels of healthcare policy and practice. We undertake a unique combination of research, development and policy activities which together work to make patients' views count.

Our activities include:

- ***Researching and evaluating patients' experience***
Measuring patients' experience using surveys and other methods to gain systematic feedback on the quality of healthcare. Original research is complemented by a suite of patient, staff, and public surveys to provide in-depth insights.
- ***Leading initiatives that make improvements happen***
Working with healthcare providers to use patient feedback to improve services.

Our educational and development work encourages and supports health professionals in implementing change.

- ***Building evidence to inform health policy***

We use our research evidence to promote innovative, intelligent approaches to meeting patients' needs. We aim to make the views of patients and citizens count throughout health policy and practice.

The Picker Institute is an approved survey contractor to the NHS and a leading provider of patient experience surveys to NHS Trusts. We have obtained feedback from more than one million patients since 2000, as well as being involved in population, patient and staff surveys in other European countries. We have expertise in all stages of survey research including design, sampling, questionnaire development, execution (including online surveys), analysis and report writing.

As well as surveys, Picker Institute researchers have expertise in all major methods of social research, including: focus groups, in-depth interviewing and qualitative analysis, evaluation research, comparative cross-national investigations and research on particular populations such as children or minority ethnic communities.

4 Research strategy

4.1 Methodology

The DoH team needed a rapid exploration of the experience of black and minority ethnic (BME) patients and what the priorities might be for service development. These criteria lent themselves to a qualitative approach.

The Picker Institute suggestion was to conduct focus groups to allow creative and constructive discussion with targeted individuals in a short timeframe.

Focus groups are small group discussions, usually involving 8 -10 participants. The discussion is led by a moderator using a topic guide (see Appendices 2 and 3) to maintain the focus on pre-determined questions. The goal is to generate information about a carefully defined research issue. Data from focus groups help to identify and clarify underlying attitudes and beliefs about the topic.

Groups work best if they are relatively homogeneous. In this case the defining factors were ethnicity in the first instance and then patient diagnosis.

Participants are generally unknown to each other. They are asked to give their informed consent and their expenses are paid, together with a small fee. Focus group discussions are best conducted in a quiet room, away from health service premises, free from distractions with refreshments available. The discussions are recorded and transcribed.

4.2 Caveat

The project team at the Picker Institute has considerable experience of researching patient experience. From the very first contact with the DoH representatives concerns were expressed over two issues.

The short timescale for the project precluded an application for ethical approval and this would limit the possible avenues for contacting patients.

Secondly, we know that people from BME communities are sometimes reluctant to take part in research, as are individuals with some long term conditions. This concern, combined with the knowledge that people in the later stages of COPD can be in very poor health and be incapacitated at short notice, led the team to suggest that the research design may need to be adapted.

5 Project design

5.1 Design

The team at the Picker Institute designed a programme of three focus groups to allow creative and constructive discussions with people from black and minority ethnic communities affected by COPD. These people would be recruited through voluntary sector COPD support organisations.

The aspiration was that these groups were to be organised in areas of the country that had not been visited by the DoH team as part of their stakeholder engagement in developing the NSF.

The participants would be led through the discussion by a facilitator equipped with a topic guide in order to maintain the discussion on predetermined questions.

A set of questions was developed by staff from the Picker Institute. These were sent to the team at DoH and referred back and forth. Thus a topic guide was iteratively developed. This appears at Appendix 2.

The discussions were to be digitally recorded, transcribed and analysed using a bespoke coding frame. The analysis was intended to be rigorous without being exhaustive. Researchers were looking for a range of common themes between participants and specifically looking for areas where the views of these patients diverged from the views of those mainstream patients already recorded in the other engagement with stakeholders.

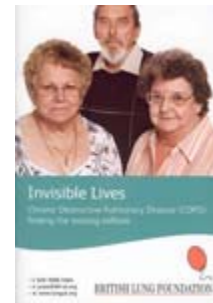
In line with the concerns expressed above the topic guide was also tailored in order to provide a guide for one-to-one guided interviews with patients, if required. This was to prove necessary as is recorded below.

6 Research process

6.1 Identifying BME patients affected by COPD

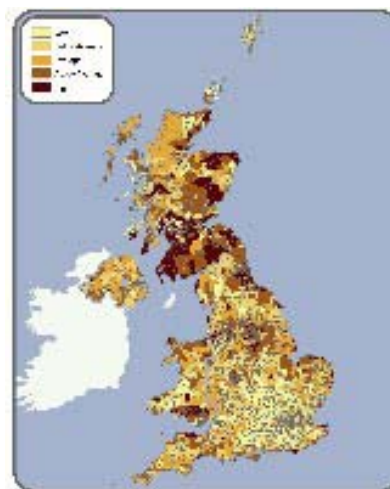
The initial strategy was to use public health data to map the incidence of smoking (as a proxy for COPD) in communities with a high proportion of people from BME communities. This proved interesting but did not highlight any geographical areas within England in which we were not instinctively interested.

Since the completion of the data collection the British Lung Foundation (BLF) has published its *"Invisible Lives"* report early in December to mark World COPD Day in 2007. This includes some relevant mapping of COPD "hot-spots" within the UK. It is unfortunate that this document was not available before the end of our data collection, however a brief review of the top eight sites in England shows that they do not actually have high concentrations of minority ethnic communities.



Invisible Lives

Source: <http://www.lunguk.org>



UK COPD Hotspots

Source: <http://www.lunguk.org/>

From the outset it was clear that researchers were going to find it very challenging to recruit participants for the planned focus groups. Several dozen healthcare professionals within and without the NHS were contacted across England, from Plymouth to Carlisle and from Kent to Newcastle. Almost universally we were told that very few patients from minority ethnic communities were represented in groups or within services.

Staff members from the BLF were particularly helpful in providing links with relevant people and organisations. However the reaction of a BLF Breathe Easy Group Chair typifies the reaction.

I have 93 members and every one of them is white!

The reaction from professionals was usually one of interest; they tended not to have noticed the lack of BME participants in their groups or on their case-loads until we brought the subject up. The usual reaction was to wonder why this was the case. There were a number of calls from, among others consultants and COPD leads, for some research into why this was the case.

One manager of a COPD service in the North of England had obviously noticed this as an issue.

We have very high numbers of Asians within our catchment area and we have only ever had one Asian gentleman... we sometimes wonder where all these elderly Asian smokers are... they are not coming to us.

The search for people from minority ethnic communities affected by COPD went on for several weeks. Three focus groups were eventually planned and organised in three separate venues in Bradford, Leicester and London.

Following local advice, facilitators fluent in community languages were recruited for the groups in Bradford (Urdu) and Leicester (Gujarati).

6.2 Problems experienced with focus groups

Unfortunately because of circumstances beyond our control including a postal strike, poor weather and illness, the focus group in Bradford failed to entice any participants on the appointed day. With this experience behind us and with a very similar situation in Leicester we then cancelled the group in that town.

The London group the following week was conducted in English. Again there were a number of issues with recruitment and on the day there were problems for participants accessing the venue (a London hotel). The group took place but the evidence collected was not as comprehensive or as rich as we had anticipated.

6.3 Refocusing and extending the research

In discussions with colleagues from the Department of Health it was agreed that we would refocus the research in to individual one-to-one interviews using the same topic guide. These interviews were conducted across the country during November and December 2007.

At the same time the Picker Institute agreed to a DoH request to extend the research to meet another need expressed by the DoH team. During discussions with colleagues involved in the NSF development concerns had been raised that the patient voice had been marginalised in much of the feedback from stakeholders. A number of initiatives were being proposed for the new NSF and there was a desire to test reactions to some of these initiatives with patients.

The Picker Institute agreed to run some additional focus groups with COPD patients in order to explore these issues. A second simple topic guide was produced using directions provided by the DoH. They also provided a number of contacts, some of which proved fruitful.

After some intense work, three separate groups with patients and carers were set up in Bristol, Chertsey and Woking. These were straightforward and successfully took place in mid December so concluding the data collection.

Results

We have divided results, commentary and conclusions in to two discrete sections in order to reflect the two different phases of the research.

7 Results 1: Work with seldom heard groups

We ran a focus group and conducted a number of one-to-one interviews with a range of people from minority ethnic backgrounds affected by COPD.

7.1 Introduction and beliefs about their condition

The patients that we interviewed had few things in common other than having a lung condition and coming from non-white communities. They had come from different parts of the world, lived in different parts of the country and had been employed in a wide range of different roles. They had not even all been smokers.

Having said this, the majority of them believed that their COPD had, at least in part, been caused by their smoking behaviour.

I believe and understand that COPD is from my smoking – my brother has the same thing; he did car respraying ...mind you he smoked a lot as well! (Asian male #1)

I am understanding that COPD is because of the smoking – smoking is a very bad thing. (Asian male #3)

However there were a number of participants who had not smoked, one of whom had worked in a cloth mill, who put their conditions down to environmental factors. This was reflected in one or two other interviews.

I worked sanding and stripping furniture and all sorts for years – it can't have helped (Black Male#2)

There was one male participant who had not smoked, who had worked in an office environment but who just saw himself as desperately unlucky.

I have no reason to believe in anything that is the reason why I got this illness. (Asian male #2)

Several people had had TB when younger and blamed that.

As I far as I know my new consultant told me that as far as she knows this problem goes back to my TB problem when I was a young man – I had TB when I was young here in my chest. (Asian male #2)

Several of the participants who had lived abroad were convinced that the British weather was to blame for their condition, in one or two cases the participants were quite resentful.

I was born in Africa, educated in India then I came here... until I got my chest problem in 1991 I never had no problem with anything. (Asian male #1)

For years in Aden and in Pakistan I have no problems then I came to this country and now I have this [COPD]... it is this bloody British winter! (Asian male #4)

7.2 Diagnosis

None of the participants had ever heard of COPD before they had had it diagnosed.

I had never heard of COPD before my diagnosis, everybody had asthma - that is quite a common thing. (Asian male #3)

I did not know anything about this illness before I had it, the only time I knew it was when I was in the hospital. (Asian male #4)

A common theme was that of gradual, almost imperceptible deterioration in an ability to do things

I found that I wasn't able to fly up the stairs in quite the same way. (Black Male #2)

We are aware that several of the participants were living alone. It is possible that not having people living with them meant that they sought help earlier than those with family members who were able to do the more strenuous day-to-day tasks.

An emerging theme (that continued in the second part of the research) was that men appeared less willing to seek medical help than women; at least one suggested that they had been scared of what they might find out.

I tried to ignore it like we men do. (Black Male #2)

and several men left it until the last moment to seek medical help.

It was so frightening; cough, cough, cough until I was completely out of breath, very frightening, my wife called an ambulance, two three four times, it happened a few times and some times I called emergency doctor. Slowly, slowly I came to study my situation... (Asian male #1)

Also there was a concern among some of the Asian men we spoke to about not wanting to lose face. One carer reported:

He is not telling his son the problem – he is embarrassed, he does not want to seem weak so they ignored him. (Asian female #2)

Most interviewees had received their diagnosis from doctors at the hospital.

I wasn't told I had COPD until 2005, the hospital found out about it. (Asian male #3)

I have a lung scan and find out I have COPD... (Asian female #1)

He told me and gave me a prescription for [a] nebuliser and two, three different pumps...he explained the lungs were weak due to smoke (I started smoking in 1946) he told me about it then...the COPD - which can not be cured. (Asian male #4)

There was a general feeling that they had not had enough information about COPD when they were diagnosed:

There was no long discussion about it when I had my diagnosis you know – they told me I had this condition and that was that you know? (Asian male #2)

The only time you can ask is when you go for the appointment - when you are on the ward and the doctor comes there is it no chance, not like we are talking like this at the moment. (Asian male #1)

Doctors don't have time to explain everything. (Asian male #2)

Some strong themes emerged about the need and desire for information about their condition.

7.3 Information

Very few of the people from BME communities we spoke to had done any research or sought any information other than that provided by their healthcare professionals.

All the information about this [COPD] I have got from the doctor and the PR. (Asian male #1)

A handful of patients were regular users of the internet and at least one obviously was used to using libraries to find answers to queries.

I had a book [carer had been a nurse] about physiology and we looked at lungs and tubes and what is bronchitis and after he learned in PR with pictures. (Asian male #3)

We detected little desire for additional information. It did not seem to be an issue for any of our interviewees.

No I haven't looked for any information. (Asian female#1)

There were one or two indications that once some interviewees realised that there was no cure they did not want to know more – in fact in some cases they actively did not want to know.

There was also a sense of deference towards doctors in many of the patients that we spoke to.

No why would I want to do that? – if there is anything I need to know my Doctor would tell me wouldn't he... (Asian male #1)

Most of our participants were older people who are often less inclined to be critical of their care. The implication was that searching out additional information would show a lack of trust in the judgement of their doctors and nurses. As we shall see below almost every healthcare professional received universal praise.

We did speak to two men from West Indian backgrounds both of whom had sought information and treatments from sources other than their doctors. One had been on a Buteyko breathing technique course and made a point about how he had not told his doctors about it.

I didn't tell my doctor, he didn't need to know, I know COPD is a different thing from asthma... I felt it worked for me. (Black Male #2)

People didn't remember taking in very much information when first diagnosed. In common with mainstream patients even the less engaged patients seem to have absorbed more information pertinent to their COPD from the PR sessions than from other sources.

7.4 Day to day care

In common with most patients our participants demonstrated a range of different levels of engagement with their conditions. In general there seemed to be an acceptance of their condition.

I am quite all right – what is the use of grumbling or becoming upset about – older people might be getting something – probably caused due to old age. (Asian male #4)

No it not curable, they told me that when I first had it... it's about managing it. (Asian male#3)

People seemed happy to leave their clinical care in the hands of professionals.

The colour of my sputum – I immediately know – I immediately contact my GP. (Asian male #2)

They seemed to have more to say about their emotional and psychological needs.

I understand I have the COPD and it is very dangerous for me sometimes I am very worried but my wife understands and gives me motivation and makes me happy. (Asian male #3)

It is getting worse – especially in this sort of weather – it doesn't make me depressed but it does make me uncomfortable. (Asian male #1)

It does make me unhappy I talk to [nurse] and get very nice mental support more than medical support. (Asian male #2)

They expressed some concerns about becoming anxious about their condition.

If I am tense or on edge – I am so fed up it gives me infections... (Asian male #2)

Sometimes it gives me anxiety..., I am in pain, I am coughing it makes me anxious, it makes it worse... (Asian male #1)

We asked whether they felt the need for emotional support or to be able to talk about their feelings, but didn't get much response.

I don't express myself too much, I keep myself you know? (Asian male #2)

I only talk to the nurse about my illness not about my feelings. (Asian male #4)

Most participants we spoke to had an adequate understanding of what they needed to do to manage their condition. We didn't detect any difference from that of the majority, white population.

I check my ankles – if they are swollen there is water in the lungs- I get my water tablets to drain them – I take my tablets one or two a day – they make me go to the toilet a lot... (Asian male #1)

I know the COPD is very dangerous but I know some exercise –lifting – walking – is very good. (Asian male #2)

7.5 End of life

In common with most patients, participants were aware of the incurable nature of COPD but did not want to dwell too much on their future.

I worry about things getting worse – sitting all the time - the loneliness... mental strength is important - if people have weak minds it is very, very dangerous.s (Asian male #2)

In common with most people the issue of becoming dependent and losing their dignity was high in people's minds.

To be frank the last time I was admitted in to hospital my breathlessness was getting worse you know? Every now and then I need to go to the toilet and you

can't breathe properly lot of frustration comes I am worried about things like that about not being able to do things for myself. (Asian male #2)

I have never been dependent you know – I have always been independent. (Asian male #1)

I'm not frightened but I don't want my mind to go down. (Asian male #2)

Increasing isolation was a concern for some of our participants.

The thing is that I can't do anything you know, you depend on some others all the time and this is putting you back you know because you can't go out... I am indoors all the time because of this oxygen - I can go out but it is a big thing you know I am stuck in all the time. (Asian male #2)

7.6 Treatment devices

A well recognised challenge with this sort of research is asking patients to imagine equipment or devices that would help manage their condition. It was not unusual to find that patients were happy with the equipment that they had access to.

Comments were generally positive.

I have everything to help me live on. (Asian male #1)

There were some “tongue in cheek” answers....

I'd be glad for you to give this COPD to somebody else. (Asian male #2)

...which probably had a kernel of truth in them.

A new set of lungs would be nice (Asian male #4)

However not one of the participants to whom we spoke mentioned the idea of a lung transplant.

We concluded that participants reflected the mainstream attitude of the general population to technological developments.

If there was something new I would want to know about it. (Asian male #1)

7.7 Medicines

In common with most patients these participants demonstrated that they were assiduous about taking their medication but that very few of them had any in depth understanding of what the individual medication was for.

All these [displays seven medications] are for my lung condition. (Asian male #1)

They are all for the breathing, I understand when to take them. (Asian female #1)

We perceived that participants from minority ethnic communities were slightly less willing than the mainstream majority to manage their own conditions in terms of altering medication without referring to a healthcare professional. Many mainstream patients were happy to have a supply of some medication - usually antibiotics - which they and their GP had agreed should be taken as necessary.

An exception was the interest that many of the participants had in steroids.

The steroids make me put on weight... (Asian male #1)

during this treatment I was given a lot of antibiotics and a lot of steroids – it took about four years to sort out the side effects from the steroids. (Asian male #2)

I was told that if you take a lot of steroids you can lose your mobility – the use of your legs - in your old age you know? (Asian male #2)

Many of them had gained much about their understanding of their medication from the PR courses, although some mentioned that their COPD nurse had outlined some information about medication.

We did ask whether they considered using pharmacists as a source of information about their drugs but none of them did.

The side effects are given on the leaflets and I read them. Why would I ask the chemist? (Asian male #1)

However the majority of our interviews were with people who did not collect their own medication and did not have any form of a relationship with their pharmacists.

7.8 Hospital treatment

Most of our participants had had some recent experience of being in hospital as an inpatient although their admissions were not necessarily connected to their COPD. In general people were extremely positive about their experience. Certainly they are as positive, perhaps more so, than mainstream white patients.

Staff in the hospital are very, very nice, it was very, very good. (Asian female #1)

Although, in common with most patients, they saw hospital admission as something to be avoided if at all possible.

From 1992 until 1997 every year an admission in to hospital sometimes for two weeks sometimes for three - after 1998 I did not go, I was managed by the GP. (Asian male #2)

Similarly, in common with most patients, they seemed in awe of the hospital-based clinicians and nurses and wished that they had more time to engage with patients. This

contrasted with the extremely high levels of praise that our participants had for the specialist community nurses.

My respiratory nurse [name] is very, very useful. (Asian male #2)

She comes and talks about what is going on – she asks about my problems I ask her things – you can talk to her everything. (Asian female #1)

It was the nurse that explained it all to me ... some doctors can be quite blunt, not rude just... you know? (Black Male #2)

7.9 Pulmonary rehabilitation

Pulmonary rehabilitation provided some good material for our discussions. Many of the participants had been on the courses and were, in line with most patients, extremely positive about the courses.

I had to wait a year to get on the course... I had to go. (Asian male #1)

it improved me a lot – they taught me to breathe out, breathe in, suck it, in puff it out, you see? - I learned things. (Asian male #1)

I learned a lot of things there you know? I didn't do treadmill but a lot of cycling... (Asian male #3)

They found it enjoyable and as with most patients who complete the course, they bemoaned the temporary nature of the courses.

I went this year, early part of the year it was ok actually, I enjoyed that but the thing is they are very busy you know? They can't give you more than 14 weeks, I keep it going... I do every morning. (Asian male #1)

But they seemed quite passive about seeking out further opportunities.

If there was another opportunity, something organised, I would go... there is nothing else I could think of that is like this. Exercise for older people? (Asian male #1)

Although some of the younger participants who came from Caribbean backgrounds had made determined efforts, including joining gyms.

I grasped the opportunity to get back in to exercise you know? (Black Male #2)

Many of our original contacts with patients had been engineered through pulmonary rehabilitation courses. We had been told by healthcare professionals that there were a significant number of people from minority ethnic communities who either did not take up invitations to pulmonary rehabilitation courses or dropped out of them before completion. By definition our participants did not fall in to these categories but we spent

quite some time asking about whether people knew of, or could imagine reasons why, people would not want to come.

Our first interview was with an Asian woman and she was very sure of her reasons.

I just don't enjoy things like that... in front of other people you know? (Asian female #1)

There were some illustrative comments from people who had been to PR.

There were no black faces when I went in to the room... shyness is a very dangerous thing, like a disease.... if you are afraid to put yourself forward you could hold yourself back. (Black Male #2)

There was only one lady when I went – there were four ... five Indian men – no problem, it was very friendly... they look after you, you know (Asian male #1)

Although we heard from people from many ethnic groups that shyness and embarrassment was an issue when they first accessed PR.

There were some concerns about whether some older people from minority communities might struggle with the English language.

My view is that sometimes that that lady or that gentleman don't go because the communication is not good, nobody can explain to them, sometimes they can't understand what is the importance of that thing (Asian male #3)

Why they are backwards [unwilling to come to PR] probably the language, maybe they don't feel comfortable something like that? Depends on what age she is – maybe she thinks too late for me now? (Asian male #1)

In the main the response was that the people from minority ethnic communities had exactly the same reasons for not attending PR as anybody else.

Why don't people turn up? It is just about their health, my type of people [disabled] aren't mobile, can't drive themselves there, it takes us so long to get ready. (Asian male #2)

There were many practical, transport related reasons.

Sometimes the ambulance goes round many, many people, takes hours, sometimes I go by taxis. (Asian male #1)

Trouble is I have no transport for myself – I don't want to go miles some days. Some days I want to but most days I read, I write, I am not motivated to go out. (Asian male #1)

7.10 Healthy living

Many people had comments about lifestyle changes that they had made that they believed had helped their COPD from the prosaic...

I am getting my five fruit and veg. a day! (Black Male #2)

I take a cup of Bovril every day at half past eleven! (Asian male #1)

...to some more thoughtful thinking about diet:

I have worked out for myself some foods I am eating make my breathing worse... (Asian male #3)

I don't eat my Indian food, nobody told me this, I have worked it out I don't have chillies or salt or anything - I would change myself according to the problems I was getting. (Asian male 1)

I have come to an understanding of my situation - I know what to eat and drink and what not to eat and drink... certain things I avoid cold drinks I never touch, fresh oranges, fresh tomatoes, citrus things... (Asian male #2)

Some ginger is always helping my breathing. (Asian female #1)

and most people were trying to get some rudimentary exercise whether or not they had been on PR...

Now I try to go five minutes every day even when the weather is like this. (Asian male #1)

Every morning I do elementary exercises to get more oxygen in. (Asian male #2)

...although there were several people who led an extremely sedentary lifestyle.

I just don't want to be bothered with that... [exercise] (Asian male #4)

Mainly my family look after me. (Asian male #2)

I am quite self contained I have my TV with my sports I do not want for much. (Asian male #2)

7.11 Awareness raising

As stated earlier, none of our participants had heard of COPD until they themselves had been diagnosed with it and they were supportive of the idea that the profile of COPD should be raised.

I tell people - but before I was smoking a lot and people need to know what is happening... (Asian male #3)

Lot of people ask me about it and I tell them – cold and coughs is nothing to be ignored it can get worse ... I realise that it is an illness I tell them get yourself checked out. (Asian male #1)

There was a sense that they were annoyed about the lack of available information about prevention.

In the gym [PR] people came and gave us lectures about it but I've already got it then. (Black Male #2)

I will tell anybody about this... I tell them not to smoke; the doctor won't tell them until it is too late. (Asian male #2)

8 Conclusions (Exploring the experience of BME patients)

Our overall impression was that the patients we spoke to demonstrate the range of experience, opinions and beliefs that would be present in any sample of any patients with this condition.

However this project was not designed as a representative survey and thus it would be inappropriate to draw too many conclusions about "all patients" from minority ethnic communities. Nonetheless there are a number of themes to which we would draw attention:

- we suspect that there are fewer patients with COPD from minority ethnic communities known to healthcare providers than would be expected demographically. There may be cultural, sociological, practical or even physiological reasons. This is of itself interesting and worthy of further research
- many of the participants had no immediate family and this may be significant. People with chest problems who are unknown to healthcare professionals, and who could benefit from medical and lifestyle interventions, may be currently being cared for solely by their families and without professional advice.
- we had little sense that patients from minority ethnic communities have a very different experience of COPD than patients from the mainstream white population.

Some of the conclusions that can be drawn for our findings are:

- people were extremely trusting of their doctors and nurses and grateful for their care. There may possibly be some slight difference in the compliance of patients from Asian and West Indian backgrounds.

- there may be a case for some cultural sensitivity when inviting patients from minority communities to group activity such as pulmonary rehab. There may be some additional cultural barriers to participation for some groups (for instance older Asian women or people with poor spoken English) that can be overcome with additional support.
- some of the very enthusiastic 'graduates' from PR could be used to encourage participation from under-represented groups. Single sex groups, or "buddying" systems could be considered.

9 Results 2: Work with mainstream patients testing NSF themes

People affected by COPD were invited to three focus groups and offered the opportunity to consider a number of ideas that were being proposed for the new NSF.

9.1 Introductions

In order to break the ice at each event participants were asked to introduce themselves, describe their conditions and outline their beliefs about what had caused their conditions. Whilst not directly relevant to the research questions it generated some interesting material about patients' perceptions of their condition which is worth recording.

As might be expected, some patients were much more engaged with their condition than others

I'm not sure about my diagnosis it now I think about it. (white male #3)

The vast majority of participants had been medium to heavy smokers and very few people looked further than their smoking behaviour.

I have COPD - I believe it started with 50 years of smoking which I now regret. (white male #9)

I've got COPD because I smoked – no two ways about it else I wouldn't be sitting here. (white male #9)

Several people blamed their having had damage caused when they were younger.

Mine is through childbirth when the damage was done – they tried to drain my lungs but it was too late, all my life I've had breathing problems since.... (white male #7)

Several people felt that TB had been a factor.

I had TB in 1972 – that's why I have COPD now. (white female #1)

Some felt that the causes were in part environmental.

In that twelve hours we fired over a thousand shells at the incoming planes – I think that is where quite a bit of damage was done to my lungs. (white male #5)

I blame the atmosphere, I used to walk every day from Waterloo to Gray's Inn across Waterloo Bridge – the stench used to take my breath away – the pollution in the air is at least 50% of it [the COPD]. (white female #1)

I believe that the pollution at the roadside exceeds the permitted maximum on lots of streets in London but what does the government do about it? Even the simple things like moving the exhausts on the buses away from the pavement aren't being done. (white male #5)

I have found that when I lived on sandy soil with pine trees and things like that - my chest was much better. (white male #5)

Several patients understood that their lung conditions had been inherited. These patients tended to be more engaged with their own care and were aware that they in turn were handing their vulnerability along to their children.

I have COPD but it is hereditary ... (white female #4)

My children have got problems with their lungs. (white male #7)

My other daughter hasn't had the tests; she has no plans to have children and doesn't want to know at this stage. (white female #4)

We were impressed by how engaged many of these patients were with managing their own condition and there seems to be an opportunity to use these “expert patients” as a resource that could be used by healthcare planners in trying to raise the profile of COPD.

9.2 The concept of a lung health check for all people, starting at the age of seven

The idea of a lung health check met a very positive response; most people could see no problems with this.

When are they going to start the test? – for years I thought I had asthma (white female #5)

They felt that younger people could be encouraged to modify their health behaviour (at a time when it could make the most difference). Virtually **everybody** wished that they had been diagnosed earlier (their diagnosis was often the trigger to stop smoking).

he said if you don't stop smoking you will be dead inside 10 years. (white male #4)

They also wished they could have begun to manage their condition at an earlier stage.

If I'd been picked up earlier the treatment I've been given since would have helped me to manage it (white male #9)

Prevention is much better than cure, much better to start combating it as early as possible (white male #9)

Good idea definitely... I just used to get breathless – I had one particularly bad experience carrying parcels to the post office... then I had the tests. (white male #8)

In the midst of the very positive reception to screening there were one or two concerns; firstly about the cost effectiveness.

Sounds an excellent idea – might be expensive. (white male #8)

Secondly there were some considered responses from people with inherited forms of the disease – although they were largely positive...

Screening can only be a good thing especially for people with bronchitis in the family. (white female #4)

My daughter is a carrier if her husband is also a carrier I'd like them to be tested so they can have some intervention. (white female #4)

There were concerns expressed by a patient with a son who already has a diagnosis of COPD about the stigma of labelling people as 'ill' from a young age.

9.3 The role of employers in prevention

There were mixed views on the role of employers in helping to prevent COPD. Some people saw one of the roles of employers to be concerned for their employees' health.

I think they do, you are there for half your waking hours – they should encourage people to be screened – if they catch people earlier it's better (white female #1)

But many participants were more prosaic in their understanding that businesses or public sector employers don't exist primarily to employ people but rather to make money or provide services.

I don't think employers can do an awful lot they are in business to produce a product. (white male #5)

The responsibility is on the individual. (white female #1)

Some were more cynical in their views.

There is a role but all you are is a number to them. (white male #7)

If employers can't see anything – they don't believe it. (white female #2)

My boss was one of these – "if you can't work you're no good to me" people. (white female #1)

One participant was very anxious that employers should understand COPD more (he knew of patients who were in hospital for two weeks every three months).

If they know about your illness then you might be out the door. (white male #7)

Some participants were very clear that they viewed their relationship with their employers as a financial transaction and that their employer had no business being concerned with any aspect of their life away from the workplace.

I don't want my boss telling me how to run my life - it is a bit "I'm here between nine and six it is none of your business what I do when I'm not here so don't tell me that I've got to stop smoking." (white male #7)

Work is a place that pays me - I don't want people following me up the road after telling me what to do. (white male #2)

Much of the discussion was around smoking in the workplace which, of course, is no longer an issue given recent legislation.

I did give up once but my colleague smoked like a chimney. (white female #1)

Nobody works now in smoky environments. (white male #5)

However, we found that the idea of employers playing a major role in raising awareness of COPD was not a high priority (other than perhaps providing venues for screening 'road shows'). Participants felt that dealing with environmental pollution would be a better way of talking COPD.

If they could concentrate as much on diesel and petrol fumes it would make more difference. (white female #2)

A more cynical view was that,

Governments of all parties have been very half hearted in their attempts to stop people smoking because of the income that get from the tax (white female #1)

9.4 Would free Nicotine Replacement Therapy act as an incentive for people to give up smoking?

A fairly muted response was received to the idea of NRT acting as an incentive for giving up smoking. There was some support for the idea.....

People think if you can afford to smoke you can afford the patches but it doesn't work that way psychologically (white male #3)

.....but only as an idea for 'other people'.

I don't think it would have much effect. (white female #1)

I've used them it didn't work on me. (white male #6)

Are people actually put off by the price? (white male #8)

If people don't have any obvious wrong with them – if they were just wanting to give up it might help I suppose (white male #1)

Lots of people were aware of the high price of NRT.

It might make more people give it a go... it was quite a lot of money. (white male #4)

Several had had it on prescription through their GP.

My doctor was only too happy to give me them [NRT patches] because he could see that I needed to give up. (white female #1)

However, the general feeling was that people will give up “when they are ready” whether or not NRT is used.

I do believe that people won't succeed in smoking unless they want to stop. (white male #8)

You can talk about patches and all that but I think it is all in the head. (white female #7)

I think once you want to stop smoking whatever it takes... (white male #3)

Many people had been shocked in to giving up smoking.

The majority of people stop smoking because of the illness it causes – I definitely did – I was so chesty. (white female #7)

My nurse said if you don't stop smoking you won't see 80.... (white male #4)

The advert with the woman on oxygen that's what got to me... (white female#6)

I was given them – I was given a range of things but they were all useless ... what made me give up was my sister in law... she was 40... healthy girl, smoked, was diagnosed at the Christmas with cancer and she was dead nine weeks later. What made me give up was sitting at her bedside for eighteen straight days just watching her die. I haven't smoked a cigarette since. (white male #6)

Most participants feelings might be summed us thus.....

Free NRT won't make a big difference to people – it might for some I suppose. (white female #1)

However, we were aware that all three focus groups took place in areas with low levels of deprivation. It is possible that the cost of NRT may be more of an issue for people from disadvantaged socio-economic groups.

9.5 Exercise or pulmonary rehab (PR) - which is the preference?

There was very positive affirmation for pulmonary rehab courses throughout this research.

It's brilliant innit? (white male #8)

However, we are aware that all of the participants had completed a PR course recently – one of the focus groups actually took place on the final afternoon of a course. Therefore our participants were by definition, diagnosed, engaged in managing their COPD and had completed their PR course.

Almost everybody to whom we spoke had really enjoyed the social aspect of PR group.

We had a hilarious time - we became the best of pals. (white female #1)

Moreover, there were some very positive feelings about the benefits of being with people in similar conditions.

Some people feel isolated with any kind of disease – when you go in to a group you feel better about what and how you are. (white female #4)

I went back the second week and said that I feel like a normal person again. (white female #7)

If you have a group around you with the same condition you can have a laugh and had a joke you feel a lot freer – if the information came one to one it might go in one ear and out the other sort of thing. (white male #1)

So many people are afraid of illness, afraid of hospital afraid of what might turn up – they won't admit that there is something wrong. This is where this group (PR) is such a good thing, you turn up, you see that there are people who have a similar problem, who are handling it – if you can see somebody else handling their condition. (white female #5)

Almost everybody we spoke to had received almost all of their knowledge about COPD through the PR courses.

They've taught me a lot more than my own doctor/nurse did. (white male #2)

Can't fault it, definitely, I've learned more in the last ten weeks than I ever knew before. (white male #1)

They had learned more and made more changes because of the group environment.

If it hadn't been for the group I wouldn't have done it, I was bothered by it [COPD] but wasn't able to do it. (white female #7)

There was a great deal of evidence that people had undertaken the PR exercises in a group situation in a way that they would never have done on their own. One or two patients had had exercise videos/DVDs and watched them but not been motivated to start exercising until they went to the PR.

My practice nurse gave me a DVD of exercises I took it home watched it carefully, saw that I could do them but I never actually got out of my chair any more than I was doing until I went to the group. (white male #8)

I had one of those whatchacallit DVDs and I must admit that coming to the rehab group is far better than doing it on your own with the machine (white male #9)

The idea of follow up services for PR, such as ongoing exercise classes and so on, proved popular.

I wish I could come back next term and go for my a-levels. (white male #8)

It is a great tragedy that at the end of the end of the 10 week course people are left in limbo. (white male #5)

Those of us who got together afterwards found that it was much harder to carry on, on their own than when you had somebody there to compete against – there isn't much incentive to walk round the close on your own. (white female #1)

We asked about whether people had stories about friends or colleagues who had dropped out or never taken up the PR opportunities. This provoked some dismissive comments.

Some people who have smoked all their life and set in their ways don't want to exercise – they'd rather die. (white female #5)

Some people would rather sit in a chair and watch the telly... (white male #8)

Once you've committed to come here you're going to be here it's too easy to not do things on your own. (white male #7)

But there were some indications that people react in different ways to group dynamics when it comes to changing health behaviour.

Every one was egging everyone else on – we were having cycling matches - it was a competitive thing that might put off people – I found it supportive. (white male #6)

There was some evidence from people who were not 'joiners', or who were very embarrassed to struggle in front of people or who could not see the point.

My brother in law started this course [PR] but he couldn't stand it- he got all embarrassed with himself, he started on that line [bleep test] and now he does his exercise in the bedroom. (white male #2)

He was just embarrassed what people would think of him... he was frightened of what people would think about him. (white male #2)

Interestingly participants had heard of some 'non joiners' who had given entirely practical reasons for not attending or completing the course.

Fifty percent wouldn't come here [hospital] because the parking is so difficult. (white male #3)

Some people haven't got the money to travel. (white male #2)

You can get ill and get knocked back. (white male #6)

I can't get here some weeks; my wife is out to work so I have to take a taxi. (white male #4)

The ambulance doesn't turn up (white male #2)

We want to reiterate that we spoke to people who were engaged with managing their conditions. These comments are largely opinions about 'other people's' reasons for not attending.

In closing there was a call for PR to be 'marketed better'.

I know that if I keep committed I will hopefully be able to keep at bay the disease that I have got. These other people that are here have not had that good fortune to be spotted so early. That to me is the most important thing that the health service can do - to spot any form of this problem early and push people in to education as soon as possible. (white male #8)

9.6 Proactive follow-up post hospitalisation

Only two participants had been hospitalised with their COPD. Both experiences seemed to support the idea of intense, pro-active follow up to hospitalisation.

One participant who had been extremely anxious about going to hospital had been frightened to be released when they were:

The idea of going home – who is going to be there? who is going to look after me? ... it's really frightening, it is. It's the panic that is there when you are in hospital. (white female #1)

They were extremely grateful and surprised to have very intensive follow up from the COPD team once home.

The team followed me all the way from when I left – I had their number and phoned them up the one time I was bad before – I kept getting these infections they were contacting me – how do you feel? are you well enough? – I only have to phone up – the other girl there - I call her the mental nurse – they were brilliant the whole way through – they got a physio. out to see me – she was lovely. (white female #1)

They were sure their health improved more quickly as a direct result.

Another story was as negative as the first one was positive. The participant had had an extremely poor experience of being in hospital, then was unsatisfactorily released into the care of their GP and ultimately readmitted.

It's the only time I've been in hospital when I didn't want to go home - I was so frightened. (white female #4)

They told me to go back to my GP; I could phone the ward ... my consultant my GP never contacted me... I got a bit of depression and then I went to the GP... I would have appreciated a lot more contact (white female #4)

9.7 Self-management contracts between patients and their health professionals

There was a muted response to the idea of self-management contracts. People felt that if they were interested in self-management they would be engaged, and if not then any contract (real or implied) would not improve peoples' self-management.

If people don't want to do something they won't. (white female #1)

I can see the idea of it - as far as I'm concerned it wouldn't be different from now seeing the doctor or practice nurse. (white male #1)

A contract won't make a difference to me - I am the sort of person who doesn't need to be told to something more than once that is the way I am - If I think something is going to help me I will do it. (white male #6)

If it was more formalised it wouldn't make any difference to me. (white male #3)

But again, there was a sense that it might be a good idea for 'other people'.

I don't need to be bullied there are people who need to be bullied in to do it. (white male #1)

However, there was some interest in how such a thing might work.

If they ask you to do something it is up to you whether you do it or not isn't it I feel I owe my health to them so I will do whatever they ask. (white male #8)

I've had it before where other teams don't push you - if there wasn't some form of back up in the contract I wonder who would push you or motivate you to do it on your own. (white male #7)

There was also some sense whereby a contract might be more worthwhile were it with the COPD team rather than the GP.

My doctor said that they'd had a meeting and decided people like you know more about your condition than we do they are admitting that they don't know enough

*about it they are only **general** practitioners after all [their emphasis]. (white female #4)*

9.8 At what point/by who should discussions around end of life care be raised?

End of life care was a very difficult issue to tackle. We spent a good deal of time discussing this very sensitive subject and it was challenging to keep the discussion relevant to the question. In regard to end of life care, people mostly wanted discussions left as late as possible.

Leave it to the every last minute. (white male #8)

Only a handful wanted to think about the issue before things got much worse (remember many were finishing PR and were actually more positive about the future than they had been for some time).

I'm still young; I don't see myself as ill. (white female #4)

I really don't want to think about it. (white female #7)

I firmly believe in not pushing people to thinking about what will happen eventually... (white male #5)

I certainly haven't thought about it, I want to live each day as it comes. (white female #1)

People were worried about the sort of care that might be available.

They promised my next door neighbour all the help she needed but you've got to be joking – only there twenty minutes and she [home-carer] is away to the next one (white male #2)

There was very little agreement as to when is the best time to start planning for end of life care, it largely being seen as a personal decision.

Sooner rather than later. (white male #8)

Depends on circumstances – later rather than earlier. (white female #5)

if they ask six years before it will almost certainly be a different person at that time. (white male #7)

It is something you need to make your mind up about in advance but things change. (white male #8)

A fairly strong theme emerged about the appropriateness of somebody with a medical background bringing up the subject.

I wouldn't be uncomfortable talking to my doctor about this. (white female #4)

Speak with whatever medical advisor you have – the medical team around you. (white male #1)

In general participants felt that they had a more relevant and comfortable relationship with nurses in the COPD team rather than GPs or consultants.

I don't spend much time with doctors in here [hospital] Doctors haven't got time for that... I'd rather talk to one of the girls [the respiratory team] I'd feel more comfortable talking to them – I know they are hard pushed but they have more time than a doctor who's time is like gold dust so I'd rather speak to them (white female #1)

I am in awe of the doctor he is up there... the nurse is here... I could say anything to a nurse... (white female #2)

I wouldn't think that I'd want to talk to my GP. (white male #1)

Most people assumed “the hospital would bring it up when it's time”

It needs to be asked much, much later – these are questions that will be asked by people in hospital at that moment in time. (white male #8)

The other theme that emerged strongly was the need to involve carers in any of these discussions

It's a thing for the family isn't it not the person that it is happening to. (white male #8)

At this stage I'm not thinking about it – when someone reaches that stage – I think the most important person is the carer. (white female #3)

9.9 How acceptable is remote/innovative technology to patients?

The concept of remote or new technology was quite difficult area for patients to engage with since, in general, people don't know what is available or possible. Patients found it very difficult to imagine or dream of technological developments that would help.

The way things are progressing I'm quite happy – if things get worse I hope the technology will catch up. (white female #5)

They seem to have sorted the oxygen out. (white male #9)

As expected people's aspirations were modest.

If they could make that [portable oxygen] last twenty four hours a day that would be nice. (white male #1)

Liquid oxygen and the concentrators are very good. (white male #9)

The idea of *a new pair of lungs (white male #1)* came up more than once although usually as throwaway line.

Grow me a new set of lungs please? It's on its way... (white female #1)

[Have you thought about a transplant?] *Oh it's pie in the sky... (white female #1)*

Most people have the perception that there is a very strict age barrier for transplants.

Even if they were available they won't give them to you if you are over 55... that's it. (white female #6)

There was some interest in tele-monitoring, especially if it could avoid hospital admissions.

I'm lying in hospital and I'm saying why can't you give my bed to someone who needs it? All that's wrong with me is that I can't breathe.... (white female #5)

I never ever want to go in to hospital if I can be monitored at home - anything to avoid going to hospital especially these days with MRSA and so on. (white female #4)

9.10 Anything else healthcare planners might want to know?

There was, throughout this piece of research continual praise for the specialist teams that looked after patients with respiratory conditions.

That is the advantage of specific specialist team who knows you... (white male #5)

More specialist teams ...more [PR] courses. (white male #8)

There was a desire to raise the profile of COPD and pulmonary rehabilitation in the community and in to primary care settings.

Get information about PR in to the GP surgeries. (white male #8)

What I would like to see is something sent to GPs saying that anybody with a breathing problem should be referred to PR. (white female #6)

I put a notice up in the reception saying if you have breathing condition enquire about PR. (white female #4)

There was a feeling that COPD had an unfair low profile when compared to other conditions.

They put too much down to asthma. So many people with a breathing condition they just give them a pump... (white female #5)

These GPs get paid extra money for certain things, not COPD mind, it's all money, money, money isn't it? (white male #7)

There was a desire for more uniformity in the provision of services for COPD.

one nurse was not interested about it; the other was very proactive. (white male #8)

People had not heard about NSFs but when they became aware of them they wanted the framework to be based around real improvements for patients.

It's got to come down to reality – they have to think about the practical reasons for it - these guys in suits don't get out of their offices and see the problems. (white male #7)

10 Conclusions testing NSF themes

The research was by necessity a pragmatic attempt to get patient feedback to some emerging NSF themes. The areas of discussion that provoked a passionate response are indicative of those areas that are priorities for patients.

Given the nature of their recruitment the participants to whom we spoke may not be representative of the whole of the COPD patient population. However we are reasonably confident that patients will welcome the idea of:

- a screening programme
- more proactive pulmonary rehabilitation
- proactive follow up to hospitalisation and more specialist COPD teams.

They are not unhappy with the equipment that they have – we sensed that there may be some latent interest in **lung transplants** but expectations would need to be managed.

They are less sure that:

- contracts will make a difference
- employers have a role in prevention beyond their statutory responsibilities for health and safety (now including the smoking ban)

There appears to be little commonality of views about end of life care. However there is a feeling that people would want to discuss it with somebody “medical” who had time to give to the discussion. In their experience this would probably mean a nurse. Finally:

- They wish that more people, **including those within the health service**, knew more about COPD.

Appendix 1: Participants

1.1 Participants from minority ethnic communities affected by COPD

<i>Identifier</i>	<i>Age</i>	<i>Gender</i>	<i>Ethnicity*</i>	<i>Diagnosis*</i>
Asian female #1	70-80	Female	Indian (Kenya)	COPD
Black male #1	60-70	Male	Black UK	COPD (Emphysema)
White Male #10	70-80	Male	White UK	COPD
White male #11	60-70	Male	White UK	Asthma
Asian male #1	70-80	Male	Asian (Kenya)	COPD
Asian male #2	70-80	Male	Indian (Uganda)	IPF
Asian male #3	60-70	Male	Indian	COPD
Asian female #2	60-70	Female	Indian	Carer
Asian male #4	70-80	Male	Pakistani (Middle east)	COPD
Black male #2	50-60	Male	African Caribbean	COPD
White female #8	40-50	Female	White UK	COPD (complex)

**As defined by the participant*

1.2 Participants affected by COPD considering possible NSF proposals

<i>Identifier</i>	<i>Age</i>	<i>Gender</i>	<i>Ethnicity</i>	<i>Diagnosis</i>
White male #1	60-70	Male	White UK	COPD
White male #2	70-80	Male	White UK	Chronic Bronchitis
White male #3	70-80	Male	White UK	COPD
White male #4	70-80	Male	White UK	COPD
White male #5	70-80	Male	White UK	Chronic Bronchitis
White female #1	50-60	Female	White UK	COPD
White female #2	50-60	Female	White UK	(Carer)
White female #3	70-80	Female	White UK	(Carer)
White female #4	50-60	Female	White UK	COPD (complex)
White male #6	50-60	Male	White UK	COPD
White female #5	70-80	Female	White UK	IPF
White female #6	60-70	Female	White UK	COPD
White female #7	60-70	Female	White UK	COPD
White male#7	30-40	Male	White UK	COPD
White male #8	60-70	Male	White UK	COPD
White male #9	70-80	Male	White UK	COPD

Appendix 2: Question topic guide

Themed Discussion (60 mins)

Not all topics will be covered in any one discussion group: topics to be selected from the following list in light of priorities for NSF development and relevance to patients and carers involved in the discussion group. Facilitators will use additional prompts where necessary to clarify responses.

Introduction

- What happened to make you think that something might be wrong?
- What made you first go to the doctors? (*Did anything make you delay going?*)

Obtaining a diagnosis

- Who made the initial diagnosis?
- Can you remember what tests did you have to obtain a diagnosis? (Where and by whom?)
- How long did you have to wait to obtain a diagnosis?
- Was the diagnosis explained to you in a way you could understand?

Information

- Did you get enough information about your condition? (then and since)
- Could you understand the information that you were given?

Day to day care

- How could the care you receive from health professionals be improved?
- How could you and your carers be helped better manage your condition on a day-to-day basis?
- Do you ever get depressed by your condition?
- Where do you get support from?
- What support and information do you expect to help you manage your condition?

Devices

- What devices and equipment have been useful to you? Can you imagine any device that would help you manage your condition?
- *Have you had issues with home oxygen therapy? (is this a red herring?)*

Medicines

- Have you started to take any new medicines for your COPD?
- Were you as involved as much as you wanted to be in deciding about the best medicine for you?
- Were you given enough information about why you should take the medicine(s) and what the effects might be?
- *Do carers think they know enough about the patients' medicines?*

Hospital

- Have you been admitted to hospital for treatment for your COPD?
-

- What could you have had that would have stopped your needing to go to hospital?

Hospital treatment

- How would you describe the treatment you received once admitted to hospital?
How could it have been improved?
- How were you supported emotionally and physically during your hospital stay?
- Were you treated with dignity and respect?

Pulmonary rehab

- Have you been a place on a rehabilitation (rehab) programme (*describe*)
- Did you take it up? - *if not why not?*
- How useful was it?
- Would you have been interested in a home based option?

Healthy living

- Has your doctor, nurse or other health professional ever given you information or advice about things that might help prevent your COPD getting worse, such as: stopping smoking, physical activity diet healthy weight?
- How useful was the information and/or advice?
- Since being diagnosed with COPD have you done anything to help prevent your condition getting worse?
- What would help you to make more changes?

Awareness raising

- What more could be done to raise people's awareness of COPD?
- What more could be done to raise people's awareness of the causes of COPD?
- Who else should we be trying to reach with information about COPD?
- What message would you like to give about your overall experience of care and treatment for your condition?

Appendix 3: Topic guide for NSF initiative “testing” with mainstream patients

COPD NSF Focus Groups Bristol/Chertsey/Woking December 2007

Themed Discussion (90 mins)

The following list contains some broad themes likely to feature in the priorities for NSF development. They all need to be covered in a natural conversational manner ie the order is unimportant.

Facilitators will use additional prompts where necessary to clarify responses.

- Introductions
- Beliefs
- The concept of a lung health check for all people starting at the age of seven
- The role of employers, in prevention
- Exercise or pulmonary rehab - which is the preference?
- Proactive follow-up post hospitalisation
- Self management plans as a contract between patients and their NHS partners
- Would free NRT act as an incentive for people to give up smoking?
- How acceptable is remote/innovative technology to patients?
- At what point/by who should discussions around end of life care be raised?
- Anything else people would like to add?

Picker Institute Europe

King's Mead House

Oxpens Road

Oxford OX1 1RX

Tel: +44 (0)1865 208100

Fax: +44 (0)1865 208101

Email: info@pickereurope.ac.uk

Website: www.pickereurope.org

Charity Registration no: 1081688



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