



# Get involved...

**Pulmonary Rehabilitation – Experience, Expectations and Attitudes in Newcastle upon Tyne**

**August 2012**





# Contents

<b>Section 1: Introduction</b>	<b>1</b>
1.1 Involve North East	1
1.2 Context	1
1.3 The project	2
<b>Section 2: Methodology</b>	<b>3</b>
2.1 Interviews	3
2.2 Participants	3
<b>Section 3: Findings</b>	<b>5</b>
3.1 Course awareness	5
3.2 Pre-course information	5
3.3 Attendance and completion	7
3.4 Experience of 'course completers'	8
3.5 Expectations of non-participants	10
3.6 Willingness to attend	10
3.7 Barriers to attending	11
3.8 Provisional attendance	14
3.9 Summary	15
<b>Section 4: Recommendations</b>	<b>17</b>
4.1 Course awareness	17
4.2 Referral to courses	17
4.3 Course content and length	18
4.4 Course location	18
<b>Appendices</b>	<b>21</b>



# Section 1- Introduction

## 1.0 Introduction

### 1.1 Involve North East

Involve North East (formerly Community Action on Health) is an independent charity working across the North East. We are experts in innovative and practical involvement, working with patients, communities and harder to reach groups to gain the insight needed to design the best, most responsive and cost-effective health and social care services.

Newcastle North and East Clinical Commissioning group ('the CCG') has asked Involve North East to investigate uptake of, and attitudes towards, pulmonary rehabilitation courses by CCG patients with Chronic Obstructive Pulmonary Disease (COPD) in Newcastle upon Tyne.

### 1.2 Context

#### 1.2.1 Pulmonary rehabilitation

The CCG would like to improve participation in pulmonary rehabilitation courses by patients with COPD and other related conditions. The courses take place within the Royal Victoria Infirmary (RVI) and Freeman hospitals and include exercise programmes; relaxation and breathing techniques; and information to help patients manage their condition better.

Anyone with COPD can be referred to pulmonary rehabilitation, but currently most referees are patients whose breathlessness is so severe that it affects their quality of life. The Department of Health Outcomes Strategy for COPD and Asthma<sup>1</sup> recommends the provision of pulmonary rehabilitation for all people with COPD and a Medical Research Council (MRC) breathlessness score of three<sup>2</sup> or above.

The recently published NHS Medical Directorate Pulmonary Rehabilitation Service Specification also recommends provision for patients with an MRC score of two who are disabled by their condition to the extent of needing professional assessment and supervision of exercise training rather than simply advice on lifestyle changes; or who have confirmed diagnoses of COPD alongside other progressive lung conditions.

The NICE Clinical Guideline for COPD also identifies pulmonary rehabilitation as a priority:

---

<sup>1</sup> An outcomes strategy for people with chronic obstructive pulmonary disease (COPD) and asthma in England, Department of Health July 2011

<sup>2</sup> Walks slower than contemporaries on the level because of breathlessness, or has to stop for breath when walking at own pace  
[http://www.nice.org.uk/usingguidance/commissioningguides/pulmonaryrehabilitationserviceforpatientswithcopd/mrc\\_dyspnoea\\_scale.jsp](http://www.nice.org.uk/usingguidance/commissioningguides/pulmonaryrehabilitationserviceforpatientswithcopd/mrc_dyspnoea_scale.jsp)

“Pulmonary rehabilitation should be made available to all appropriate people with COPD including those who have had a recent hospitalisation for an acute exacerbation.”

### 1.2.2 Benefits of pulmonary rehabilitation

The NHS Medical Directorate Service Specification describes pulmonary rehabilitation as an essential element within a wider respiratory pathway; and refers to a growing body of evidence suggesting that it can be a highly cost-effective way to reduce mortality, hospital admissions, inpatient hospital days, readmissions and home visits as well as improving health-related quality of life for COPD patients.

### 1.2.3 Referral

Referral to pulmonary rehabilitation for patients in Newcastle currently comes from secondary care staff rather than from GPs or other practice staff. This means that GPs have little influence over their patients’ decisions to attend – or not attend – a course. However, there is an awareness that participation by CCG patients with COPD currently appears to be low.

GPs in Newcastle are keen to address this issue, and to find ways of ensuring that the right patients receive the right level of pulmonary rehabilitation in the right settings.

They are considering the introduction of direct referral by GPs rather than, or in addition to, secondary care practitioners. They would also like to explore the case for delivering pulmonary rehabilitation in the community rather than in hospitals.

## 1.3 The project

Practitioners within the CCG want to learn more about the reasons behind the low uptake of courses, in order to encourage better participation and completion rates in future.

This project aims to help practitioners within the CCG to:

- Gauge patients’ knowledge of pulmonary rehabilitation
- Identify barriers to uptake and completion of courses
- Identify ways to overcome barriers
- Explore patients’ feelings, beliefs and attitudes towards pulmonary rehabilitation

# Section 2 - Methodology

## 2.0 Methodology

In order to meet the objectives of this project, we conducted telephone interviews with 100 patients identified by GP practices across the city.

## 2.1 Telephone interviews

The information required by the CCG called for a largely qualitative approach to this project; and the timescale within which the research was conducted indicated that telephone interviews were the best way to elicit both factual and anecdotal information quickly.

## 2.2 Participants

The initial project brief identified two cohorts of COPD patients to contact:

- Primary care patients who have not been admitted to hospital in the last 12 months, who meet the eligibility criteria for pulmonary rehabilitation courses
- Patients with COPD who have been admitted to hospital but have not attended the course

Staff from 13 Newcastle practices identified 105 patients in the first category, and obtained each patient's consent to being contacted by Involve North East. In the event, however, five people were unable to take part because of illness or unavailability when the interviews were being conducted.

The practices were unable to identify people in the second category, as hospitals can only provide numbers and not the names of patients. The research therefore focused only on the first group of patients.

### 2.2.1 Interviewees

Of the 100 people whom we interviewed, 45 were male and 55 were female. All participants except one were over 46, with 33 people in the 66-75 age group and 27 over 75s.

All patients were white; 96 were white British, two white Irish and two others white European.

More detailed participant profiles are set out in Appendix 1.





# Section 3 - Findings

## 3.0 Findings

This section documents the findings of our research into users' and non-users' experience, expectations and perceptions of pulmonary rehabilitation services in Newcastle.

### 3.1 Course awareness

Only 18 of the 100 interviewees had heard of Newcastle's pulmonary rehabilitation courses. In 11 cases this was because the respondents had themselves been invited to attend a course. Of the seven people who knew about them but had not been invited, most had heard about friends and relatives who had taken part:

"One of my friends' mam's has COPD and was telling me about it."

"My wife did the course a few years ago."

"I know people who have been on them."

One person had been assessed for suitability:

"At the COPD clinic at the RVI about 10 years ago – the nurse had me walking up and down the corridor, and she decided I didn't need to go on a course because at the time I wasn't bad enough."

Others mentioned seeing British Lung Foundation or Asthma Society leaflets, hearing other people talking at the surgery, or simply 'assuming' the courses would exist.

#### 3.1.1 Awareness according to GP practice

Of the 18 people who were aware of pulmonary rehabilitation courses, five were patients of Benfield Park. Three others were from Denton Park, three from Throckley, and two each from Gosforth, Holly and Prospect. One person from The Grove was aware of the courses.

The five Benfield Park patients had all been invited to take part in a course. Two further invitees were with the Throckley practice, while one each of the respondents from Denton Park, Gosforth Memorial, Holly and Prospect had been invited.

### 3.2 Pre-course information

We asked the 11 people who had been invited to attend pulmonary rehabilitation to tell us what information they had had about it.

Everyone had received some information in at least one form:

	<b>No. of responses*</b>	<b>% of responses</b>	<b>% of patients**</b>
A letter explaining what it was	3	20.0	27.3
A letter telling me where and when I had to attend	2	13.3	18.2
A leaflet	1	6.7	9.1
I spoke with my GP	2	13.3	18.2
I spoke with a nurse	1	6.7	9.1
No information at all	0	0.0	0.0
Told by my consultant	4	26.7	36.4
Other	2	13.3	18.2
<b>Total</b>	<b>15</b>	<b>100.0</b>	

\* Patients could give more than one answer

\*\* No. of patients answering this question - 11

The two people who said they had received 'other' information could not in fact remember what this had been.

### 3.2.1 Adequacy of information

Nine of the 11 invitees were very satisfied with the information they received. The three people who had received a letter telling them what the course was about and what it would contain were very happy with the information:

"I felt totally prepared for the course; they told me everything I needed to know."

"I knew exactly what to expect and where to go."

"It told me all I needed to know before I went."

Others felt that their conversations with their consultant, GP or nurse gave them the information they needed.

One of the people who received a letter explaining when and where to attend was perfectly happy with this; but the other participant who had had this letter was less impressed:

"There was no information about what the course would entail. I wasn't aware of the level of exercise involved."

The only other respondent who did not find the information useful was unable to attend because of home commitments, and did not in fact have any criticism of the letter's contents.

### 3.3 Attendance and completion

One of the concerns behind the decision to investigate awareness of, and attitudes to, pulmonary rehabilitation was a perception that take-up and completion of the course were not high among patients to whom it was recommended.

We asked the 11 people who had at some point been invited to participate in a course to tell us what their response had been:

	No. of patients	% of patients
Completed the full course	7	63.6
Completed some of the course	2	18.2
Decided not to go at all	2	18.2
Total	11	100.0

#### 3.3.1 Reasons for not attending

The two people (both women over 66) who decided not to attend at all had different reasons for declining the invitation. One simply said she didn't think it would help her, and was not interested.

The other person was coping with considerable, unrelated, pressures at home and did not feel able to commit to the course:

“I spoke to the nurse, and I was supposed to ring them back – but at the time I had just lost my brother, and was nursing one of my sisters and to be honest I was depressed. I was very weepy, and I felt I had too much to cope with.”

We asked both participants what would encourage them to attend a future course. In the case of the person with significant caring responsibilities, her family circumstances were the major obstacle:

“If I wasn't trying to look after my sister and other people, I might.”

However, the person who was simply not interested did not think anything would persuade her to attend:

“Nothing – I'm quite stubborn! . . . at my age, I don't think anything is going to help.”

Clearly, deciding not to attend a pulmonary rehabilitation course does not always constitute a rejection of the course or the concept of self-management: while one of the two respondents who declined an invitation was very clearly not interested, the other's external circumstances were a more influential factor than any reservations about the course itself.

### 3.3.2 Reasons for dropping out

The two people who started to attend a pulmonary rehabilitation course and dropped out were also women aged over 66. One found the course too taxing and felt that it made her feel worse:

“It was a friendly atmosphere and everyone was really nice and the relaxation bit was okay, but the physical side of it was too hard.”

The other partial attendee had a different reason:

“I enjoyed the exercises but I only went for one day . . . then I got a bad chest infection.”

This person also had problems accessing her course:

“The Freeman is not good for parking, even with a blue badge.”

However, since then she has received additional help which appears to be working well:

“I am now having home visits which is helping and I am getting more and more active. I don't think carrying on with the course would be of any additional help – the home visits are enough.”

Although this participant was happy with the benefits of home visits, the findings outlined in the next section indicate that people who completed the whole course benefited from the social, as well as the physical, aspects of the course.

## 3.4 Experience of course ‘completers’

The six people who completed the full course, and the one who has two more sessions to go and intends to complete, were generally very positive in their assessment of its impact.

### 3.4.1 Positive feedback

Among a number of very positive comments, one person highlighted clear and measurable physical improvements:

“Before I started, I could only walk twice up the hospital corridor. When I finished, I could do it five times.”

Other people identified less physical benefits:

“I just liked the assurance from the staff that I was doing the right thing.”

“First of all it got me out of the house and meeting people with similar experiences. Also being alongside other people who were worse than me pushed me on to do as much as I could while I was there because I didn’t want to end up like them.”

“The main thing was motivation, from the staff on the course and all the other people doing it at the same time.”

“I hadn’t done much [exercise] before and I enjoyed going on the bikes and treadmills. And the staff are all there to help you so they were great. I met a lot of other people too.”

Two people highlighted the educational aspect of the courses:

“I enjoyed the exercises, and the education sessions were good.”

“Breathing – what to do in an emergency, how to deal with build-up of fluid in the lungs; preventing infection.”

However, the male aged over 75 who has not yet completed the course did encounter problems:

“I developed a bad hip as a result of the exercises. The physiotherapist saw me during the session and said I had to have two weeks off and then she’ll assess me again to see if I’m fit to continue.”

#### 3.4.2 Reservations and suggested improvements

Apart from the participant who developed a bad hip, nobody expressed any serious reservations about the course and five people said they could not think of any potential improvements.

Of the two people who suggested improvements, one person was in effect asking for more of the same alongside one requested addition:

“I didn’t get any relaxation techniques. Also you can only do it once every two years so it would be good if you could do it every year. And, it lasts for eight weeks and it would be good if it could be longer.”

The other person who made a suggestion said they would have welcomed an introductory session:

“Even though I could probably make an educated guess, it would be good to have an explanatory session so you know what in theory the exercises are doing for you.”

### 3.4.3 Long term impact

Two people said the course had had long term benefits:

“I’m still keeping active now – I like to get out and about in the fresh air.”

“I have since joined Gosforth baths but have had a few infections so I haven’t felt able to go yet. But I will!”

However, one participant felt the benefits had not lasted:

“I finished the course with flying colours, but I have gone backwards now and my breathing is very bad.”

### 3.5 Expectations of non-participants

Given that 89 of our 100 respondents were either unaware of pulmonary rehabilitation courses or knew about them but had not been invited to participate, we asked people if they thought they would attend if invited in future:

	<b>No. of patients</b>	<b>% of patients</b>
Yes	33	37.0
No	32	36.0
Possibly	24	27.0
Total	89	100.0

### 3.6 Willingness to attend

People who said they would participate in pulmonary rehabilitation if invited came from all age groups, including four people who were over 75. They all tended to be very clear about its potential benefits:

“I’d definitely give it a go – anything that would help me to feel better and breathe better.

“Anything that would help, I’d be up for . . . I do get very stressed, so anything that helped me to relax and breathe better – I’d be there!”

“I would be happy to try a course, so that I could breathe more easily. I breathe heavily when I exert myself and I’d hope a course would help me with that.”

### 3.6.1 Taking control

Some respondents saw pulmonary rehabilitation as a chance to take greater control of their own health:

“I’m sick of taking tablets, I’d like to get better by exercising and managing it myself.”

“If it’s going to help, and make me learn about living with this, I’d go. It would be good to learn how to help myself.”

### 3.6.2 Overcoming fears

Others acknowledged that exercises might be daunting, but felt the challenge might be worthwhile:

“I’d certainly give the exercises a go, and then if I couldn’t manage them I’d stop.”

“I would try anything that might help with my breathing. I might not be able to manage exercises, but I would try at first and stop if I couldn’t do them.”

“I’d be nervous, but I think it would be worth it.”

### 3.6.3 Location and accessibility

People who said they would like to attend pulmonary rehabilitation tended to be less concerned about location and accessibility than unwilling participants. Two people expressed a preference for non-hospital locations:

“I think I might prefer it if the course was somewhere local rather than at the hospital.”

“It would be important that it was somewhere easy to get to . . . somewhere close to me would be good.”

However, most people felt that the RVI and/or the Freeman would be reasonably convenient.

## 3.7 Barriers to attending

The 32 people who said they would not accept a pulmonary rehabilitation referral were all aged over 46.

	No. of patients	% of patients
46-55	7	21.9
56-65	5	15.6
66-75	6	18.8
Over 75	14	43.8
Total	32	100.0

Generally speaking, this group was divided between people who felt they were coping well with their condition and did not need extra help; and those who felt that their age or disability had taken them beyond the point of being able to benefit.

### 3.7.1 Feeling too well to take part

Four of the people in the 46-55 age group who said 'No' felt that their condition was not bad enough to warrant pulmonary rehabilitation, while two said they still had work commitments and would not have time.

Among the older people who said they would not attend, several felt they were still coping well without pulmonary rehabilitation:

"I wouldn't go at the moment because I'm really fit and healthy; I cycle everywhere." (male aged 66-75)

"I go to the gym so I don't have any problems with my breathing at the moment." (male aged 66-75)

"I'm managing quite well so far. I've only got a small patch of emphysema and I gave up smoking 50 years ago, so I'm fit and well really." (female aged over 75)

Nine people who still felt well said they might consider rehabilitation in future if their health deteriorated.

### 3.7.2 Age and perceptions of disability

Other people who said 'No' were less positive about their own health and the potential benefits of pulmonary rehabilitation. This was particularly the case among some older respondents, especially those who had said 'Yes' when asked if they considered themselves to have a disability:

"It just wouldn't help at my age." (male aged over 75)

"At my time of life, I'm not sure it would be worth it." (female aged over 75)

"I'm too old for this." (two females, both aged 66-75)



“I find it hard to get out and about, and I don't think the course would help.”  
(male aged over 75)

### 3.7.3 Concerns about exercise

Several men and one woman were concerned about the prospect of being 'made' to do exercises:

“I would be embarrassed - even if it was a one to one in my own home.”  
(male aged 46-55)

“I couldn't do the exercises; I worry about being out of breath.” (female aged 46-55)

“I find it very hard to get air into my lungs, so I think it would be too much for me.” (male aged 66-75)

“Not sure about the exercises, I get breathless just bending down and doing light weeding. I would worry about breathlessness if I was exercising.” (male aged 56-65)

“I could get to the Freeman but I wouldn't feel confident doing anything physical.” (male, 66-75)

### 3.7.4 Anxiety or inhibition

In addition to the respondent who said he would be too embarrassed to try pulmonary rehabilitation, two people mentioned social or emotional difficulties:

“I get myself in a bit of a rut where I can't really be bothered. I don't think it would help.”

“I get nervous around strangers, I don't mix very well with people. I wish I could go on it but my nerves would stop me.”

### 3.7.5 Location and accessibility

While the respondents who said they would like to attend a course were generally willing to travel to one or both hospitals, reluctant participants regarded themselves as less mobile:

“I wouldn't be able to get to any of the hospitals.”

“I don't drive and I no longer feel safe on public transport so I would have to rely on my family to take me there and I don't want to have to ask them.”

“It costs me £6 by taxi to get to the Freeman, so that's a big consideration.”

“I don’t like getting on buses and don’t have anyone to ask to accompany me.”

“I’d be interested if they would come to my house and tell me what to do.”

“If there was transport put on or it was closer to where I lived.”

### **3.8 Provisional attendance**

Twenty-four people said they might ‘possibly’ accept pulmonary rehabilitation if they were invited to attend in future.

In some cases, this depended on feeling either worse (and therefore needing the course) or better (and therefore being physically able to attend):

“I’d have to be feeling worse than I do now.”

“I’d go if my back gets better.”

Other considerations focused mainly on location and transport, and the length of the course.

#### **3.8.1 Location and transport**

Some people had reservations about participating in a hospital-based course:

“If anything, I would prefer it if the courses were held in a local gym or pool, because I don’t like hospitals and I don’t like to think of myself as ‘ill.’”

“I wouldn’t want to go to hospital to attend a course.”

“To be quite honest I lost my wife in February and she was treated at the Freeman and I don’t have fond memories of hospitals!”

Other people who had reservations about the location were more concerned about travelling and accessibility:

“It would depend where it was, and how easy to get to.”

“If the course was in a local community centre I could get to easily, I think I might go.”

“I would need to have someone to take me there.”

“If I could get there I would definitely go.”

### 3.8.2 Length of the course

Although people who had attended the course had enjoyed participating over a period of time, some people who were ambivalent about attending expressed anxieties about committing to a long course:

“I’d go if the course was not too long.”

“If it was just a one-off, rather than a whole long course. I already do cardiovascular exercises three times a week and keep as fit as I can so I wouldn’t need a whole course.”

## 3.9 Summary

### 3.9.1 Course awareness

Clearly, awareness of pulmonary rehabilitation courses is very low among Newcastle’s COPD patients. The overwhelming majority of our respondents had no idea of their existence.

### 3.9.2 Course experience

Although some people who had attended pulmonary rehabilitation had reservations about length, content and location of the courses, overall feedback was very positive, and most people felt they had gained significantly in a number of ways. Some people felt that they would have benefited from either longer courses or follow-up.

### 3.9.3 Willingness to attend in future

Although some people were adamant that they would not be interested in attending pulmonary rehabilitation for a variety of reasons, the majority of those who had not previously been aware of its existence were either very willing or provisionally willing to consider attending if they were invited.

### 3.9.4 Course location

People who had attended pulmonary rehabilitation, or who declared themselves to be interested in future participation, were generally unconcerned about location. However, people who were negative or anxious about attending were more likely to say they would prefer a non-hospital setting closer to their own homes.



## **4.0 Recommendations**

The recommendations in this section are based on the findings of our research, and on the feelings, beliefs and attitudes to pulmonary rehabilitation that we uncovered in our conversations with 100 people across Newcastle upon Tyne.

### **4.1 Course awareness**

Given the very low levels of awareness among our interviewees, there is clearly a need to raise the profile of pulmonary rehabilitation so that people know of its existence, understand its potential benefits and – crucially – are given much more opportunity to participate than is currently the case. This could be achieved by:

- Greater awareness by primary care health professionals of the nature, availability and benefits of pulmonary rehabilitation – so that patients who might benefit from the courses are given the right information at the right time by the right people
- Local ‘ambassadors’, drawn from patients who have benefited from pulmonary rehabilitation and can provide written and in-person endorsements to encourage reticent or anxious patients to participate. This could be particularly useful for patients who feel that they are too old, or that their condition is too severe, to warrant pulmonary rehabilitation
- Clear, accessible posters and information in surgeries, to raise awareness and arouse the curiosity of patients for whom pulmonary rehabilitation might be appropriate

### **4.2 Referral to courses**

Given the low awareness by patients of pulmonary rehabilitation in Newcastle, it would appear that most patients are not being invited to take part in courses by the secondary care practitioners who are currently responsible for referral.

However, the positive response from our respondents once pulmonary rehabilitation had been explained to them, suggests that many would welcome the chance to take part and in particular to learn how to manage their own condition, maintain their independence and reduce hospital admissions.

- This could be more easily achieved through the introduction of a wider range of referral paths, so that patients could be identified and invited to participate by GPs and other primary care health professionals as well as secondary care consultants

- It might also be helpful to adopt a broader range of eligibility criteria for participation, combined with varying levels of rehabilitation to accommodate different levels of severity. This would mean that people whose symptoms do not yet match the Department of Health recommended eligibility criteria could be given the opportunity to understand and adopt positive lifestyle practices, potentially preventing or delaying the onset of more severe symptoms.

### **4.3 Course content and length**

Given the generally positive response of people who had experienced pulmonary rehabilitation, the course would appear to be helpful and well received. However, participants did suggest a number of improvements; and non-participants also made suggestions that might help to overcome the reservations of potential participants in future:

#### **4.3.1 Course content**

- An introductory session to explain the approach of the course and answer questions about its content might help to engage people more fully, and encourage course completion. In particular, an engaging introductory session or conversation might help to overcome people's anxieties about exercise classes
- Not everyone who had taken part had been helped to develop relaxation techniques, which participants and non-participants alike felt would be useful. Relaxation and other self-management techniques could be made available to all pulmonary rehabilitation participants.

#### **4.3.2 Course length and frequency**

- While one participant felt that eight weeks was not enough, some potential participants were wary of committing themselves to 'long' courses. It is impossible to please everyone, but it might be advisable to consider developing courses of varying lengths to meet varying levels of need
- One former participant suggested that it would be helpful to be able to undertake pulmonary rehabilitation annually, to help maintain the benefits of the original course. This might also accommodate people like the participant who had finished the course with 'flying colours', but whose condition had since deteriorated.

### **4.4 Course location**

Although people who had already completed pulmonary rehabilitation were happy to attend courses at the Freeman or the RVI, some people who had reservations about taking part were less comfortable about a hospital location.

- Where reservations centred on an aversion to hospitals, moving pulmonary rehabilitation to community venues might help to overcome resistance and encourage people to participate
- Given that many of our respondents either had no transport or were dependent on other family members for their transport, community venues might make the courses more easy to access
- Providing some form of transport to and from classes might also help to overcome resistance

# Appendices





## Appendix 1 – Participant Profile

### Gender

	No. of patients	% of patients
Male	45	45.0
Female	55	55.0
Total	100	100.0

### Age

	No. of patients	% of patients
18-25	0	0
26-35	0	0
36-45	1	1.0
46-55	17	17.0
56-65	22	22.0
66-75	33	33.0
Over 75	27	27.0
Total	100	100.0

### Location

	No. of patients	% of patients
Arthur's Hill	4	4.0
Benton	1	1.0
Byker	8	8.0
Chapel House	1	1.0
City Centre	2	2.0
Cochrane Park	1	1.0
Coxlodge	1	1.0
Dumpling Hall	1	1.0
Etal Park	1	1.0
Fenham	2	2.0
Gosforth	21	21.0
Hazelrigg	1	1.0
Heaton	6	6.0
High Heaton	4	4.0
Jesmond	5	5.0
Kenton	3	3.0
Killingworth	2	2.0
Kingston Park	1	1.0
Longbenton	2	2.0
North Kenton	1	1.0
Sandyford	1	1.0
Seaton Burn	1	1.0
Shieldfield	1	1.0
Throckley	10	10.0

Walker	15	15.0
Walkerdene	1	1.0
Wallsend	1	1.0
Westerhope	2	2.0
Total	100	100.0

### Ethnicity

	No. of patients	% of patients
White British	96	96.0
White Irish	2	2.0
Any other White background – Czech	1	1.0
Any other White background – Italian	1	1.0
Mixed White and Black Caribbean	0	0.0
Mixed White and Black African	0	0.0
Mixed White and Asian	0	0.0
Any other Mixed background	0	0.0
Asian or Asian British - Indian	0	0.0
Asian or Asian British - Pakistani	0	0.0
Asian or Asian British - Bangladeshi	0	0.0
Any other Asian background	0	0.0
Black or Black British – Caribbean	0	0.0
Black or Black British - African	0	0.0
Any other Black background	0	0.0
Chinese	0	0.0
Any other ethnic group	0	0.0
Total	100	100.0

### Do you consider yourself to have a disability?

	No. of patients	% of patients
Yes	53	53.0
No	47	47.0
Total	100	100.0

### Type of disability

	No. of responses*	% of responses	% of patients**
Physical impairment	26	38.8	49.1
Mental health problem	1	1.5	1.9
Long-standing illness	31	46.3	58.5
Sensory impairment	2	3.0	3.8
Learning disability/difficulty	0	0.0	0.0
Other	7	10.4	13.2
Total	67	100.0	

\* Patients could give more than one answer. \*\* No. of Patients answering this question - 53

## Other disabilities

- COPD
- One lung
- Memory problems
- COPD
- Heart and chest problems
- Heart problems, COPD
- Heart problems and diabetes

## GP practice

	No. of patients	% of patients
Benfield Park Medical Group	11	11.0
Biddlestone Health Group	9	9.0
Denton Park Medical Group	6	6.0
Falcon Medical Group	9	9.0
Gateway Medical Practice	6	6.0
Gosforth Memorial Medical Centre	9	9.0
Holly Medical Group	10	10.0
Prospect House Medical Group	6	6.0
Regent Centre Medical Group	9	9.0
The Grove Medical Group	8	8.0
Throckley Primary Care	9	9.0
Walker Medical Group	8	8.0
Total	100	100.0

## Appendix 2 – Questionnaire

### Section 1 – About you

**1a What is your gender?**

Male  Female

**1b Are you aged...?**

18 – 25  56 – 65   
26 – 35  66 – 75   
36 – 45  Over 75   
46 – 55

**1c Where do you live?**

.....

**1d What is your ethnic background?**

a. WHITE

British

Irish

Any other White background (Please write in ) .....

b. MIXED

White and Black Caribbean

White and Black African

White and Asian

Any other Mixed background (Please write in) .....

c. ASIAN OR ASIAN BRITISH

Indian

Pakistani

Bangladeshi

Any other Asian background (Please write in) .....

d. BLACK OR BLACK BRITISH

Caribbean

African

Any other Black background (Please write in) .....

e. CHINESE OR OTHER ETHNIC GROUP

Chinese

Any other ethnic group (Please write in) .....

**1e Do you consider yourself to have a disability?**

Yes

No

**1f If yes, please state the types of impairment which apply. (Tick all that apply)**

- Physical Impairment
- Mental Health Problem
- Long-standing illness
- Sensory Impairment
- Learning Disability/ Difficulty
- Other (Please write in) .....
- .....

**Section 2 - Course awareness**

**2a Are you aware of the Pulmonary Rehabilitation courses in Newcastle?**

- Yes
- No  [\(Go to Section 6\)](#)

**2b Have you been invited to attend a Pulmonary Rehabilitation course?**

- Yes  [\(Go to Section 3\)](#)
- No
- Can't remember

**2c How did you hear about the Pulmonary Rehabilitation course?**

.....

.....

.....

.....

[Go to Section 6](#)

**Section 3 – Information about the Pulmonary Rehabilitation course**

**3 What information did you receive about the pulmonary rehabilitation course? (tick all that apply)**

- A letter explaining what it was
- A letter telling me when and where I had to attend
- A leaflet
- I spoke with my GP
- I spoke with a nurse
- No information at all
- Other (please state).....
- .....

**3a Was the information you received useful?**

- Yes
- No

**3b Why is this?**

.....  
.....  
.....  
.....

**3c What, if anything, would have improved the information you received?**

.....  
.....  
.....

**Section 4 Experience of the Pulmonary Rehabilitation course**

**4 When you were invited, did you:**

- Complete the full course  **(Go to Q4c)**
- Complete some of the course  **(Go to Q4a)**
- Decide not to go at all  **(Go to Q4b)**

**4a Why did you only complete some of the course? (Tick all that apply)**

- It was too far to travel
- It was at the wrong time of day
- I didn't enjoy it
- It made me feel worse
- Other (please state).....  
.....

**Go to Q4c**

**4b Why did you decide not to go at all? (Tick all that apply)**

- It was too far to travel
- It was at the wrong time of day
- I didn't understand what it was about
- I was afraid in case I might have to do exercises
- I didn't think it would help me
- Other (please state).....  
.....

**Go to Section 5**

**If you attended all or part of the course, please tell us what you thought:**

**4c What worked well for you on the course?**

.....  
.....  
.....

.....  
**4d What did not work well for you on the course?**  
.....  
.....  
.....

**4e Are there any improvements you would like to see made to the course?**  
.....  
.....  
.....

**4f What other comments would you like to make about the Pulmonary Rehabilitation course?**  
.....  
.....  
.....

**Thank you for taking part!**

**END FOR THOSE THAT ATTENDED SOME CLASSES**

**Section 5 - Information about our courses**

**5 If you did not attend, what do you think would encourage you to attend a future course? (Tick all that apply)**

- A different time of day
- A more convenient location
- More information about the course, so I would know what to expect
- A chance to meet the course leader beforehand, so I would know a friendly face
- Comments from people who had done the course and found it useful
- Reassurance that I wouldn't have to do anything I didn't want to
- Other (please state).....  
.....

**5a Are there any improvements you would like to see made to the pulmonary rehabilitation course?**  
.....  
.....

**5b What other comments would you like to make about the pulmonary rehabilitation course?**  
.....  
.....  
.....



Thank you for taking part!

**END FOR THOSE THAT DID NOT ATTEND ANY OF THE COURSE**

**Section 6 - Have not heard/were not invited to a Pulmonary Rehabilitation course**

**Tell patients what the course is...**

- Patients get referred by hospital staff - either during an inpatient admission or an outpatients appointment.
  - (Anyone with COPD can be referred but it tends to be those who are so breathless that it impacts on their quality of life. There is a breathlessness score an MRC score of 3 or more are supposed to be referred as per NICE guidelines).
- The classes take place in hospital (either the RVI or Freeman) and consist of:
  - A series of education classes regarding aspects of COPD
  - An exercise programme
  - Teaching re. breathing/relaxation exercises
- People will often be given no info pre referral or may be given a British Lung Foundation material leaflet about pulmonary rehabilitation

**6 Do you think that you would attend a course if you were invited in the future?**

- Yes                    **(go to Q6c)**  
No                     **(go to Q6a)**  
Possibly              **(go to Q6b)**

**6a What are your reasons for deciding not to attend the course in the future?**

.....  
.....  
.....  
.....

**6b What might encourage you to attend the course in the future?**

.....  
.....  
.....

**6c What other comments would you like to make about the pulmonary rehabilitation course?**

.....  
.....  
.....

Thank you for taking part!

