

NECLES HIEC

**Developing a Patient Reported Experience Measure
for Chronic Obstructive Pulmonary Disease
(PREM-COPD)**

Final Report

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NECLES HEIC

Developing a Patient Reported experience Measure (PREM) in COPD

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EXECUTIVE SUMMARY

The NECLES HIEC in collaboration with The Royal College of Physicians, British Thoracic Society, British Lung Foundation, Picker Institute, City University and Anglia Ruskin University collaborated in the development of a Patient Reported Experience Measure (PREM) for use in all Chronic Obstructive Pulmonary Disease patients (COPD).¹ The PREM-COPD is a move away from traditional medical model questionnaires, to look at the patient journey with COPD and identify the principle moments of quality care and affective experiences which will then make it possible to benchmark future service provision.

Our aim is to create a valid and reliable Patient Reported Experience Measure for patients with COPD and in doing so, provide a response to the Government's White Paper "Equity and Excellence, Liberating the NHS"² which puts the patient experience and patient outcomes as the metrics for quality improvements in healthcare.

The experiences of a 64 patients with COPD across the community of North East London, North Central London and Essex (NECLES) region, with a range of severity and presentation and 19 patients with recent hospitalisation due to COPD related conditions were captured. The experiences for both groups were grouped and coded separately leading to the development of items pertaining to both patient groups.

Twenty Affective (emotive or felt) responses were identified from patient responses. Negative Affective responses described by both the community and hospital patient groups included: scared; anxiety; worry; fear / frightened; frustration; annoyance / anger; confusion; embarrassment; surprise / shock. The negative Affective response "feeling depressed", was only identified in the community group responses and guilt was only in the hospital group.

Positive Affective responses identified for both groups were: gratitude; reassured and happy / enjoyment. Altruism, hope and acceptance were also mentioned in the community group.

Self-motivation, control and respect were either Negative or Positive Affective responses according to their context with the first two only identified in the community group.

The community patient group experience centred around 5 categories:

- **“Journey to diagnosis”**
 - This journey left patients frightened, frustrated, surprised and shocked
- **“Smoking”**
 - Self-motivation and being scared by their diagnosis or the symptoms associated with COPD led some patients to give up smoking
- **“Usual care (communication, staff and managing routine care)”**
 - Lack of, or poor communication, or the manner of communication with health professionals, left patients feeling frustrated, annoyed, confused and angry
- **“Exacerbation”**
 - This can frighten, scare, confuse, frustrate and depress patients
- **“My everyday life”**
 - The limitations of living with COPD are described as frustrating, annoying, worrying, depressing and embarrassing

The **“Hospital”** patient experience pivoted around 5 categories:

- Going to hospital
- On arrival to hospital
- On the ward
- Discharge from hospital
- Follow-up care

Preliminary items from the Affective responses for both patient groups have been developed and will undergo pilot testing with the aim of establishing reliability and validity of the PREM-COPD.

Completion of this testing will result in a sensitive and reliable PREM that can be used to measure self- defined important experiences of patients when using healthcare services.

Chapter 1. Developing a patient reported experience measure (PREM) for COPD

1.1 Introduction

Chronic Obstructive Pulmonary Disease (COPD) is a major cause of emergency hospitalisation, and death in the UK.^{3,4} Further, it is estimated that 2 million persons in England have undiagnosed COPD.^{1,3} National audits of COPD, however, identified variability in the management of this respiratory condition.^{1,4} Hospitalisation, quality of life and other clinical outcomes may be improved with effective management of exacerbations of this condition.^{1,3,4}

The development of a patient reported experience measure for COPD is a move away from traditional medical model and patient satisfaction questionnaires, to look at the patient journey with COPD. The aim is to identify the principle moments of quality care and experience which will then make it possible to benchmark future service provision. This report is about the identification of items for preliminary testing towards the development of a reliable and valid PREMS-COPD measure.

1.2 Project Design

Mixed methodological approaches are increasingly being used to research health care issues due to their complexity.⁵ A sequential exploratory research design is one that is particularly employed in the development and testing of a research instrument. This project used a mixed method sequential exploratory design to develop a patient reported experience measure for patients with COPD.

The first phase of the study involved qualitative interviews with a sample of patients requiring long term community health care for COPD and with recent acute hospital care for a COPD related illness / exacerbation. The PREM-COPD items were developed from the interview data.

In the second phase of the project the survey will be piloted with a sample group of patients to establish the validity and reliability of the newly developed instrument scale.

The methodology and findings presented in this version of the report pertain to those for Phase One of the project.

1.3 Aim and Research Questions

Aim

The study aimed to explore patients' experience about their long term community health care for COPD and a recent acute hospital care for a COPD related illness / exacerbation.

Research questions

What is patients' everyday life experience of living with COPD?

What is the experience of being hospitalised with COPD?

1.4 Ethics

Ethics approval for the project was obtained from the relevant NHS trust to survey both sample groups. Patients were given an information sheet about the study and gave written consent for their participation including audio-taping of the interview.

1.5 Project Setting and Participants

The study was conducted in the East London and the City, Outer North East London and Essex regions of the UK. There were two groups of patients recruited to the study. Group 1 were those patients who were interviewed about their experiences of their long term community health care for COPD. Group 2 were patients who had recent acute hospital care for a COPD related illness / exacerbation.

1.6 Collecting the information

Patient Group 1 (Community Patients)

This group comprised community patients, who have COPD. The interviews for patients in group 1 were conducted in the selected regions and were undertaken by pre-registration graduate nursing students from a local university who were trained by the Picker Institute. Patients were asked about their experiences of living with COPD.

Patient Group 2 (Recent Hospitalisation)

This group comprised patients who had recent hospital experience due to a COPD related illness / or exacerbation and were asked about that experience. The interviews were conducted by clinical nurse consultants and other members of the HIEC team and were conducted in patients' homes.

1.7 Analysing the information

Introduction

Interviews were audiotaped and analysis of the interview data was undertaken directly from these tapes. The analysis was guided by Coffey and Atkinson⁶ and Mathieson and Barrie.⁷

The analysis of the data for both groups had two overall stages. The first stage involved developing codes by grouping similar content and then applying these codes in data analysis. This coding was primarily related to the *Content* discussed by patients in their interviews. In stage 2 the already coded data was analysed and coded again, structured by the stage 1 categories, to code the *Affective* responses in patient interviews. The resulting analysis has two layers. The first layer relates to content and the second layer relates to the Affective responses attached to the experiences. The emphasis in this report is on the latter layer.

While it is unusual to focus on “*Affect*” in the medical literature, we believe it adds an additional dimension to our understanding of patients’ experiences around COPD and their interactions with the health care system and health care personnel. We have used the concept “*Affect*” broadly in our coding to include emotions and feelings expressed by patients in their interviews.

Stage 1

Data analysis was shared by two researchers experienced in qualitative data analysis. Rigour in qualitative research includes consistency in the analysis of the data. To establish consistency in the coding between the researchers the following steps were undertaken:

- Audiotapes from two patients were coded individually by both researchers. The codes generated by the researchers were compared and contrasted. Following discussion, from this initial coding a standardised list of codes, including definitions and applications of codes to data, was developed.
- The standardised list of codes was again used individually by both researchers to code the same three patient audio-tapes. Once again the researchers met to compare the interview coding. With only a few minor differences, the coding was very consistent between the researchers. A few additions were made to the codes.
- The remaining patient audio-tapes were divided between the researchers for coding.

- Mid-way during the period of data analysis the researchers met again to compare results and discuss any potential revisions.

Stage 2

- Using the existing codes from stage 1, the interview findings were recoded according to the Affective responses underlying the interview data.

Table 1 indicates the Affective responses identified from the data for both groups. Affective responses can be considered negative, positive or as either positive or negative depending on the contextual response given. Some patients (in group 1 only) indicated they had been treated for clinical depression while others in this group made statements that indicated they were using the word “depressed” to indicate a negative feeling of being “down” and hence the coding “feeling depressed” in this project (Table 1).

Table 1 Affective Responses Identified

Negative Affective Responses	Positive Affective Responses	Negative or Positive Affective Responses
Scared	Gratitude	Self-motivation ¹
Anxiety	Reassured	“Feeling in control” or “Feeling that it is out of your control” ¹
Worry	Happy / Enjoyment	Respect / Lack of Respect
Fear / frightened	Altruism ¹	
Frustration	Hope ¹	
Annoyance / Anger	Acceptance ¹	
Confusion		
Feeling depressed ¹		
Embarrassment		
Surprise / Shock		
Guilt ²		

All Experiences identified in both groups except: ¹Identified in Group 1 only; ²Group 2 only

Chapter 2. The experience living with COPD

2.1 Introduction

The findings for patient group 1 are grouped into 5 categories: 1) “*Journey to diagnosis*”; 2) “*Smoking*”; 3) “*Usual care*” (communication, staff and managing routine care); 4) “*Exacerbation*”; and 5) “*My everyday life*”. The content in each of these categories has been grouped into subcategories with a summary of the main content (*General Findings*) discussed briefly. The *Affective Responses* linked to the *General Findings* are then presented.

2.2 About the patients

Sixty four patients, were interviewed in this phase of the study. The sample comprised 62.5% (40) males with a mean age of 71 years and 37.5% (24) females with a mean age of 73 years.

2.3 Journey to Diagnosis

General Findings

The journey to diagnosis was varied among patients. For some patients it was a gradual onset of repeated chest infections over a number of years that finally resulted in being diagnosed with COPD, whereas others had a significant infection that resulted in hospitalisation leading to their diagnosis. Some patients reported having been diagnosed with respiratory conditions such as asthma, bronchiectasis, and emphysema leading up to the diagnosis of COPD. A few had tuberculosis in the past, and others mentioned pneumonia. Physical limitations on exertion were symptoms that resulted in some patients seeking medical attention leading to their diagnosis of COPD.

Affective Response

The Affective responses for journey to diagnosis are given in Table 2.

Table 2 Journey to Diagnosis: Affective Responses with Explanation and Examples

Affective response	Explanation and Example
Frightened	This primarily related to patients’ experiencing physical limitations and uncertainty of what they were caused by <i>“On a couple of occasions I had to run for the bus and I thought I was having a heart attack.... It frightened me.</i> And recognition of what the diagnosis meant: <i>“I was afraid I would end up like....”</i>
Frustration	This was primarily around getting a definitive diagnosis for their symptoms: <i>“I kept seeing the GP- and was getting frustrated.... Eventually I saw a Dr who said go for a Chest X-Ray (which led to diagnosis)...”</i>
Surprise / Shock	The diagnosis was a surprise/shock to some patients who considered they were fit or without any symptoms <i>“For someone who was always physically fit...”</i>

2.4 Smoking

General Findings

Many patients indicated that they had smoked for much of their life with many starting at a very young age. Patients recognised *“We always knew it was bad for us.”* While many patients have given up smoking there are those who continued to smoke yet indicated a desire, but being unable to give up.

Affective Response

The Affective responses for “Smoking” are given in Table 3.

Table 3 Smoking: Affective Responses with Explanation and Examples

Affective response	Explanation and Example
Self-motivation	Many patients had given up smoking but some continued: <i>“I have stopped many times...the slightest bit of stress and I go back. I know I should pack it up.”</i>
Scared	Being diagnosed or having symptoms associated with COPD made some scared and they stopped smoking <i>“I stopped smoking after first COPD attack as (I) was scared.”</i>

2.5 Usual Care

Usual care was concerned with the community care given to patients and comprised three categories “Communication”; “Staff” and “Managing Routine Care”.

Communication

General Findings

Communication general findings were categorised into:

- Knowledge / understanding of treatment / medications - this was about patients; knowledge and understanding about their treatment or medications their experiences with obtaining, or not, of this information generally from health professionals:

“I had never heard of COPD before but the consultant gave me lots of information.”

“I haven’t quite got to the bottom of it (understanding of condition).”

- Style of, and inconsistencies, in communication (by health professionals):

“The hospital nurses advised I get a rescue pack but the GP doesn’t agree with it so won’t prescribe it.”

Affective Response

The Affective responses are given in Table 4.

Staff

General Findings

COPD patients interact with many health practitioners. Health Professionals mentioned were GP; Practice Nurse; pulmonary rehabilitation nurses, other nurses. Some patients did not distinguish between the nurses in different roles and simply referred them as “nurse”.

Affective Responses

Affective responses are given in Table 4.

Managing Care

General Findings

This was about the experiences related to pulmonary rehabilitation, medications/inhalers; physical symptoms; regular reviews, vaccinations. Patients had varying opinions about pulmonary rehabilitation and while overall many indicated being very satisfied with the program there were those who did not know about it, chose not to go or found that it not suitable for their requirements.

Affective Responses

Responses are given in Table 4.

Table 4 Usual Care: Affective Responses with Explanation and Examples

Affective response	Explanation and Example
Communication: Lack of information (doctor; other health professionals; system; programs) about condition; medications; treatments leads to:	
Frustration/ Annoyance	Lack of information (doctor; system) about a patient's condition; medications or treatments leads to patient frustration / and annoyance: <i>"Nobody tells you anything."</i> ; <i>"Feels like my experience is ignored."</i> ; <i>"Inhalers not explained."</i>
Confusion	Conflicting information/ lack of consistency between professionals (GP/Consultant; GP/Nurse) results in confusion for the patient: <i>"I don't really know how the medication- how I would be if I just didn't take it. Would I be the same or would I worse? I am a bit in the dark as to where I am really."</i>
Control	Patients seek information so they feel in control of their health: <i>"I don't think the staff went out of the way to tell me anything. I found it all out for myself, by trial and error."</i>
Communication: Sufficient information elicits these responses:	
Reduces anxiety / fear	<i>"Understanding my condition stops me from being frightened."</i>
Feeling in Control / Reassured	<i>"Knowledge helps me to handle my COPD (panic attacks)."</i> <i>"Finding out as much as I can (about COPD) makes me feel better."</i>
Communication: the manner of communication leads to:	
Frustration / Annoyance	<i>"I've feel I've been 'kissed off' (by health professionals)... Most people with COPD are elderly. We need advice. We need to be spoken to, not like children... We are responsible people. When you reach a certain age they treat you as if you are infirm."</i>
Communication: Inconsistent information/ Conflicting information/ lack of consistency between professionals (GP/Consultant; GP/Nurse) results in:	
Frustration / Annoyance / Confusion	<i>"I've been told I shouldn't take steroids, but I went to the GP and he gave me hundreds."</i>

Table 4 Usual Care (continued)

Affective response	Explanation and Example
Staff: The care and responses from various health care staff result elicit these responses:	
Respect	Being listened to by their Health Professionals (GP; Consultant; Nurses) makes patients feel respected: <i>“The GP says ‘You know better than we do...’”</i>
Gratitude	Patients are grateful for the care given: <i>“COPD nurses have all the information. If you’ve got a problem they can always answer it for you.”</i>
Frustration	Lack of understanding by health professional about patient’s condition, treatment, individual needs leads to frustration: <i>“I don’t think (the GP) understands that when you are phoning for a home visit or an appointment it’s because you can’t breathe.”</i>
Managing Care: Responses regarding pulmonary rehabilitation programmes	
Enjoyment / gratitude	Patients expressed enjoyment at going to rehabilitation and gratitude for the programme: <i>“The COPD clinic is very good... Meet some nice people. Have a good laugh.”</i>
Self-motivation	Rehabilitation is motivating: <i>“Gives you a reason to get up.”</i>
Frustration	Frustration with participants in rehabilitation group: <i>“Rehab. Frustrating... ‘older participants.’”</i>
Managing Care: General	
Self- motivation	About motivating self to manage or prevent any deterioration in their health status: <i>“I know I will end up on Oxygen but I’ll fight it.”</i>
Confusion	Confusion about symptoms; how to use inhalers: <i>“Never been explained how to take medications.”</i>
Frustration	Frustration with appointments at a hospital out-patients clinic: <i>“I had an appointed (at clinic) but when I attended they told me the appointment had been brought forward one day. I was supposed to get another appointment but they never contact me again.”</i>

2.6 Exacerbation

General Findings

This is about the experiences related to preventing or managing an exacerbation of patient’s COPD and included rescue drugs (antibiotics, steroids), access to staff in an emergency, home visits and staff response

Affective Response

Affective responses are given in Table 5.

Table 5 Exacerbations: Affective Responses with Explanation and Examples

Affective response	Explanation and Example
Frightened	The physical symptoms in an exacerbation are described as frightening: <i>“Like having a plastic bag over your head... so frightening.”</i> <i>“A bit frightening (exacerbation). Especially if you let it get too bad.”</i>
Scared / Anxiety	Patients are anxious about the anticipation of having an exacerbation and what to do: <i>“Last winter was scary- would I have such a bad chest infection that I would not wake up?”</i> <i>“...worry about what to do.”</i>
Frustration / Annoyance / Anger	Some patients have difficulty getting access to the doctor when they have an exacerbation and this is frustrating and annoying: <i>“Difficulty getting appointments.”</i> <i>“Fight to get an appointment.”</i>
Reassured / Frustration Annoyance / Anger	Access to health professionals is reassuring: <i>“The COPD team will come round if I’m too unwell to go to them”</i> <i>“Reassured by tele-health.”</i> Sometimes however it can be a: <i>“Fight to get an antibiotic.”</i>
Confusion	Trying to decide what the symptoms mean can be confusing: <i>“I don’t know when I’ve got a chest infection or when it’s just a flare-up.”</i>
Feeling Depressed	Having frequent exacerbations can make patients feel depressed: <i>“Frequent infections can pull you down a bit.”</i>

2.7 My Everyday Life

This is about the experience of living with COPD and included the following themes:

- Limitations – (to life) Acceptance *“Over the years I’ve learnt to live with it.”*
- Hygiene / ADL Activities of daily living)
- Good days Bad Days
- Physical symptoms: Coughing; Mucous; Breathlessness
- Diagnosis and Labelling
- Responsibilities (family; job)
- Side effects (drugs/steroids, fractures)- Co-morbidities
- Identity/ comparison
- Life expectancy/ prognosis
- Compliance

Affective Response

Affective responses are given in Table 6.

Table 6 My everyday life: Affective Responses with Explanation and Examples

Affective response	Explanation and Example
Frustration /Annoyance	This concerned the limitations due to COPD <i>"I can snap at people due to frustration"</i> <i>"I get annoyed with myself. I can't do what I want to."</i>
Anxiety / Worry	Physical symptoms can cause worry / anxiety for the patient: <i>"I can panic when I'm breathless."</i> <i>"Try not to let it worry me too much."</i>
Feeling Depressed	Patients may feel symptoms of feeling depressed: <i>"I get depressed because of going up and down, up and down (with COPD)."</i> <i>"If you can't do something you like doing, you do get depressed."</i> <i>"Talking about the future can be depressing."</i>
Embarrassment	The limitations and symptoms of COPD can be embarrassing to some patients: <i>"It's embarrassing to tell others (about having COPD). I just say I have another infection."</i>
Acceptance / Self-Motivation / Gratitude Hope	Some patients have learnt to accept the limitations and symptoms of COPD and try to motivate themselves and hope that their condition will improve or not lead to further limitations: <i>"You settle down and... you make your life as good as its going to be";</i> <i>"I can't give up. If I do I will go backwards. So keep alive"</i> <i>"I saw other carrying bottles at rehab...I'm glad I don't have to do that."</i> <i>"Over the years I've learned to live with it."</i> <i>"I hope I never have to rely on a carer."</i> <i>"I'm not too bad... I'm not in bed every day so I've got a lot to be grateful for."</i>
Gratitude	Patients expressed gratitude for the assistance they receive from family, friends and carers: <i>"...grateful for having a good wife.../ help of partner..."</i>
Altruism	Some patients go on research trials to help the others who will develop COPD in the future: <i>"I go on (research) trials to help other people."</i>
Feeling in Control	Patients want to feel: <i>"In control of it (COPD) most of the time. Self help is vital."</i> <i>"I learned how to control COPD. It can control your life- if you let it."</i>

Chapter 3 My recent hospital experience

3.1 Introduction

This section related to patients with recent experience of being admitted to hospital for an exacerbation related to their COPD. Recent was defined as within the last three months although most had been admitted to hospital in the previous 6 weeks. All had been admitted to hospital at least once before with the majority having had multiple admissions. The findings for this group of patients was categorised into four areas: “Going to hospital”; “On arrival to hospital”; ‘On the ward’; and “Discharge from hospital and “Follow-up care”.

3.2 About the patients

Nineteen patients were interviewed in this phase of the study, with the sample comprised of 63% (12) males and 37% (7) females. The mean age was 70 years for both groups.

3.3 Going to hospital

General Findings

A COPD patient may have a significant change in health status, recognise the seriousness of it and that it may require specialist review and treatment that can only be provided in hospital. Some patients may have used the medications in the rescue pack but realise that they have not resolved the problem:

“So when I know I am getting real bad I start antibiotics. After 10 days if hasn’t cleared I ring X hospital and ask if there is a bed.”

While some patients make the decisions to go to hospital based on their self – recognition, for others someone else has made that decision for them. They may be referred by the doctor or COPD nurse, or made contact with them by phone to get confirmation about whether to go to hospital. Others rely on a partner or spouse or family member to make the decision to call an ambulance or transport the patient to hospital. Some are reluctant to go which may in part be based on previous experiences of being in hospital.

Once the decision was made to go to hospital, there was little comment about the actual journey. Where the transport to hospital was by ambulance patients felt that the

ambulance response was quick and they were happy with the assessment and care given.

Affective Response

The Affective responses are given in Table 7.

Table 7 Affective responses for “Going to hospital”

Affective response	Explanation and Example
Anxiety / Fear	<p>This was about patients’ trepidation of being making the decision to go to hospital: <i>“It is difficult if it is yourself- to decide how bad or good you are. To make a decision which is a big decision to go into hospital. I feel that it is a big, big decision that you can’t take lightly.....It is difficult making the decision for yourself...”</i></p> <p><i>“I think there is a fear of going to A & E (Accident and Emergency).”</i></p> <p>For some, the trepidation stemmed from their first ever experience with hospital: <i>“I didn’t want to get like the first time I had ever been admitted (to hospital).”</i></p> <p><i>“When I went in the first time the put this contraption on me to help me breath. It is the most horrendous thing you can come up against.... I was dreading they were going to do it to me again this time. It was my overall fear.”</i></p>

3.4 On arrival to hospital

General Findings

On arrival at hospital, depending on circumstances, patients were assessed by the triage nurse, admitted straight into a cubicle or observation ward or taken into “Resus” (Resuscitation bay). Overall patients felt the preliminary assessment was quick, but also recognised that it might take time to do a complete assessment, for example taking blood gases, X-Rays. Views about communication from staff varied slightly but generally they felt they were kept informed of about what was happening although there was some tension whether they were to be admitted to hospital or discharged. A patient mentioned that:

“Couple of doctors were brusque but they were busy...They can be short at times.”

Affective Response

The primary Affective responses are given in Table 8.

Table 8 Affective responses for “On arrival to hospital”

Affective response	Explanation and Example
Gratitude / Reassured	There was a degree of reassurance obtained when a patient arriving at hospital: <i>“They look after me. I feel safe.”</i> And thankfulness for the care given: <i>“They saved me... I am sitting here talking to you.”</i> And reassured by the communication from staff: <i>“They kept me informed of what they were doing... It was very, very reassuring.”</i>
Frustration / Annoyance	This was primarily about inconsistency about whether patients were going to be admitted and transferred to a ward or they were going home: <i>“I was just getting dressed to go home and he came back and said we are keeping you in.”</i>
Worry / Respect	A few question how they will be treated: <i>“Will they respect my need for care? You think -does it go through their mind ‘Why worry about him?’”</i>
Embarrassment ¹	The asking of personal questions and lack of privacy in the Accident and Emergency department can cause embarrassment: <i>“When down in the assessment ward they was asking personal questions with visitors still around you. I don’t mind the wife being there but my daughter-in – law was there. That sort to thing was a bit off and a bit embarrassing...”</i>

¹ Embarrassment about the COPD symptoms was also mentioned in this group of patients but in relation to everyday care and not hospitalisation per se

3.5 On the ward

General Findings

Patients were may spend time in the assessment ward or have been transferred directly to a ward. The ward they were transferred to was important for satisfaction and eliciting Affective responses. The specialist skills of all staff on a respiratory ward was respected

“Because they know what is happening. And the nurses know it (respiratory conditions/ treatments) inside out. They are brilliant. All have knowledge of COPD. That makes you feel safer.”

Generally the patients felt included satisfied by the communication from doctors and consultants, with whom many were very familiar due to the long-term contacts with them, but sometimes they couldn’t understand *“all the jargon”*.

Patients made comments about the lack of communication at times about their symptoms or answers to questions, the frequency of getting responses to requests for assistance, the difficulty with toileting and the importance of getting medications prescribed correctly. Access to the toilet, and staff response to call bell caused patients some concern. There was an acceptance by patients about hospital food which they liked, disliked or were ambivalence about. Similarly there was ambivalence / acceptance about access to television or radio although the lack of access for some meant that it could be “*boring*” in hospital.

Affective Response

The primary Affective responses are given in Table 9.

3.6 Discharge from hospital

General Findings

While patients generally felt consulted in the decision to go home at times the decision could be unexpected, mainly they were pleased to be going home but some were concerned that it was “*too early*” and most were of the opinion that discharge process was slow and not streamlined. Waiting for medications was seen as the primary reason for the delay although waiting for a wheelchair could also be a reason for delay. Delays made it difficult to arrange transport with family and were seen as “*wasting time*”. Delays also made some patients feel uncomfortable that they were occupying a bed that could be used for other patients. Discharge medications were usually explained to patients although they were very familiar already with most, if not all of them already. Some patients who had multiple admissions to hospital had devised strategies to make the process more streamlined. There was a general relief about going home:

“I wanted to get home. I started to feel better. I seemed to stabilise and I wanted to get home I wanted to walk in my house, sit down and have a nice cup of tea.”

Affective Response

The primary Affective responses are given in Table 10.

Table 9 Affective Responses for “On the ward”

Affective response	Explanation and Example
Fear / Worry / Anxiety / Reassured	<p>The ward patients were admitted to, staff expertise, access to toilet facilities, dying in hospital, prompt response to calls for assistance and medications were all areas that may make patients frightened, worried anxious or reassured.</p> <p>Ward Where patients were admitted could either worry / cause anxiety or be reassuring to patients: <i>“Not all wards are the same.’ ‘They did find a space on another ward which was not designated to take people with chest problems which was not nice. They were ok but it was quite clear they hadn’t had training in that field...”</i> Being admitted to a specialist respiratory ward made patients feel reassured because of the staff expertise or because the staff were familiar: <i>When you go to X you have hit the jackpot- the staff are very friendly. The doctors are expert in what they are doing and you feel more confident than anywhere else.”</i> <i>“I was glad to see a friendly face.”</i></p> <ul style="list-style-type: none"> • Toilet facilities The access to toilet facilities including distance from their bed and availability to portable oxygen cause COPD patients concern: <i>“I have to walk down corridor to use toilet. I say I can’t walk all that way...”</i> This may give particular concern at night when there was less assistance available. It was reassuring however if <i>“At night they left me a commode I could get in in and out of the bed but there was no way I could walk the ward. They didn’t have the trolleys with the Oxygen on that I could walk with.”</i> • Getting attention from nurses The response to either using the call bell or other means of getting attention was frightening to some patients: <i>“...Answer bell... (You need) more attention from nurses - it frightens you sometimes.”</i> <i>“You live in fear (response to call bell)... if unable to go to the toilet yourself.”</i> • Staffing numbers at night <i>“It was a bit worrying. At night, staff were reduced, particularly at weekends.”</i> • Medications COPD patient generally have a great deal of medications that need to be prescribed and given while in hospital. Omissions of usual medications, non-administration of medications or changes to expected times lead to feelings of anxiety: <i>“I am on 26 tablets a</i>

	<p>day.... Sometimes when in hospital they miss medications off the list.”</p> <p>Dying in hospital: <i>“I have seen too many die of this (COPD). I have seen them (other patients) speaking like this and then they have died. I don’t want to die in hospital and everyone knows it...”</i></p>
Affective response	Explanation and Example
Frustration / Annoyance / Respect (lack of)	<p>Patients were frustrated by the response to requests to staff; information given or lack of respect for their opinion about their care:</p> <p><i>“..(Things are) done at their pace rather than the pace you want. And if you want 3 things one of them might be forgotten and you might have to ask them again.”</i></p> <p><i>“Still didn’t explain what steroids and antibiotics were for.”</i></p> <p><i>“Somethings you regard as really important they don’t... Some occasions I sweated very heavily, like at night- soaking the bed. No reason was given. I don’t think it particularly mattered (to them) but to me I wanted to know ‘why is it like that?’”</i></p> <p><i>“If I get aggravated it starts (COPD) off. If I am in hospital they try to keep you on oxygen but I won’t take because eventually I will be on it 15 hours a day and until that happens I won’t take it that often...”</i></p>
Scared / Reassured	<p>Exacerbations in breathing could lead to patients being scared but on the other hand being in hospital was reassuring: <i>“(I am) scared, very scared when (my) breathing is worse than usual... It is reassuring that ‘I know everybody is there’.”</i></p>
Happy / Enjoyment / Frightened	<p>The manner of staff on the ward could evoke positive and affective responses in patients:</p> <p><i>“They (nursing staff) was funny – you could have a joke with them.”</i></p> <p><i>They (some staff) just can’t be bothered. When you don’t feel well it frightens you sometimes.”</i></p>

Table 10 Affective Responses for “Discharge from hospital”

Affective response	Explanation and Example
Frustration / Annoyance	The process of waiting/ arranging discharge is frustrating and annoying to patients who have to make arrangements with family: <i>“You can be told that you are going home but you could wait until 4pm.”</i> <i>“That is a bone of contention... awkward when you are arranging transport (to go home). The main problem is they have to arrange the drugs you are going to be given and it takes a while... you couldn’t get a porter for love nor money. Getting out is difficult.”</i>
Surprise / Confusion	Patients may feel surprised and confused about the conflicting information given about the possibility of discharge: <i>“It was surprising. Seeing as two doctors said I was staying until X and another group of doctors came around and said you’re being discharged today.”</i>
Happy	Patients may have feelings of happiness about being discharged from hospital: <i>“It made me cheerful as I don’t like staying in hospital.”</i>
Respect	Patients may feel respected if their opinion about discharge is recognised. <i>“The doctor would have preferred me to stay in. On the other hand he saw the benefits to me- of going home and he could see it wouldn’t be such a dreadful thing.”</i>
Guilt	The delay in discharge can make patients feel guilty: <i>“(I) Feel that the day could have been used better.... I just feel guilty taking a place (in hospital).”</i>

3.7 Follow-up care

General Findings

Follow-up care was appreciated patients indicated satisfaction with visits or care by doctors, and nurses (including COPD and district nurses).

“COPD nurses- they quite good and they come in (to your house) and they are very reliable.”

Affective Response

The Affective responses are given in Table 11.

Table 11 Affective responses for “Follow-up Care”

Affective response	Explanation and Example
Anxiety	If the follow-up care was not seen as planned it could cause anxiety to the patient. Also if there was concern that the discharge was too early patients may be: <i>“You are on edge as you know you are going to have to come in again.”</i>
Gratitude	There was gratitude for the care from doctors and nurses <i>“The aftercare from XX and the others was excellent.”</i>
Annoyance / Respect (lack of)	There may be an expectation about the after-care treatment: <i>“The GP didn’t want to give me more antibiotics. Then he phones you and treats you like a baby but it is better than ignoring you.”</i>

Chapter 4. Conclusion

The interviews uncovered rich and detailed information from patients with COPD with recent hospital experience and those from the community. Gratitude for assistance and care given, by health care professionals, was a strong Affective response by many patients. However, there are areas where the experience for patients could be improved, or streamlined. Living with COPD is a challenge for patients who may have daily limitations, on what they can do, have symptoms that can leave them anxious, and the fear of having an exacerbation is something they live with constantly.

The 50 PREMS-COPD Affective items that have been generated from patient experiences captured in this study are being piloted to determine their reliability and validity. It is anticipated that when this testing is completed it will result in a sensitive and reliable PREM for COPD that can be used to help measure and respond to the self-defined important experiences of patients when using healthcare services.

For more information about the study the PREM items or the development of the PREMS-COPD scale please contact the team leader Professor Michael Roberts.

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