







RESEARCH ARTICLE

# “My life is not going to be the same, my health is going to improve”: a cross-sectional qualitative study of patients’ experiences of living with chronic respiratory symptoms and their views on a proposed pulmonary rehabilitation program at Queen Elizabeth Central Hospital, Blantyre, Malawi [version 1; peer review: awaiting peer review]

FANUEL MECKSON BICKTON <sup>1</sup>, Talumba Mankhokwe<sup>2</sup>, Martha Mitengo<sup>2</sup>, Felix Limbani <sup>1</sup>, Harriet Shannon<sup>3</sup>, Jamie Rylance <sup>1,4</sup>, Enock Chisati <sup>5</sup>

<sup>1</sup>Lung Health Group, Malawi-Liverpool-Wellcome Trust Clinical Research Programme, Blantyre 3, Post Office Box 30096, Malawi

<sup>2</sup>Physiotherapy Department, Queen Elizabeth Central Hospital, Blantyre, P.O. Box 95, Malawi

<sup>3</sup>UCL Great Ormond Street Institute of Child Health, University College London, London, WC1N 1EH, UK

<sup>4</sup>Department of Clinical Sciences, Liverpool School of Tropical Medicine, Liverpool, L3 5QA, UK

<sup>5</sup>Department of Rehabilitation Sciences, Kamuzu University of Health Sciences, Blantyre, P/Bag 360, Malawi

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## Abstract

**Background:** Malawi’s population has a substantial burden of chronic respiratory symptoms. Elsewhere, patients with these symptoms have benefited from pulmonary rehabilitation (PR), a program of exercise training, education, and behaviour management. Practically, PR in Malawi may not be delivered in the same format as elsewhere due to substantial contextual differences. These differences necessitate adaptation of the intervention to Malawi’s setting to be acceptable and effective. This study explored patients’ experiences of living with chronic respiratory symptoms and their views on a proposed PR program at Queen Elizabeth Central Hospital, Blantyre, Malawi, to inform the design of an individualized and culturally adapted PR program.

**Methods:** This was a cross-sectional qualitative study. Face-to-face, one-to-one semi-structured in-depth interviews were undertaken to data saturation. Interviews were audio-recorded, transcribed *verbatim*, and Chichewa transcripts were translated into English. The transcripts were anonymized and thematically analysed using an inductive approach.

**Results:** We recruited 10 patients (five males and five females) with

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functionally limiting chronic respiratory symptoms, with documented causes including chronic obstructive pulmonary disease, asthma, post-tuberculosis lung disease, and bronchiectasis. Symptoms most frequently included dyspnoea, with associated functional limitations including the reduced performance of activities of daily living. Participants' coping strategies most frequently included the use of inhalers. Participants were motivated to undertake the PR program owing to its anticipated benefits including improved health. They perceived transport costs and competing commitments as barriers to participation. The participant group gender mix and public nature of the program were considered socio-culturally sensitive by some participants.

**Conclusions:** The functionally limiting dyspnoea most frequently experienced by the study participants would be amenable to a PR program. To ensure participation by eligible patients, pre-program assessments should consider patient access to transport, suitability of the timing for the program's sessions, and patient views on organizational aspects of the program considered social-culturally sensitive.

### Keywords

Chronic respiratory symptoms, pulmonary rehabilitation, adaptation, qualitative research, Malawi



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**Corresponding author:** FANUEL MECKSON BICKTON ([fbickton@mlw.mw](mailto:fbickton@mlw.mw))

**Author roles:** **BICKTON FM:** Conceptualization, Data Curation, Formal Analysis, Funding Acquisition, Investigation, Methodology, Project Administration, Validation, Visualization, Writing – Original Draft Preparation, Writing – Review & Editing; **Mankhokwe T:** Formal Analysis, Investigation, Writing – Review & Editing; **Mitengo M:** Investigation, Writing – Review & Editing; **Limbani F:** Methodology, Supervision, Validation, Visualization, Writing – Review & Editing; **Shannon H:** Methodology, Supervision, Validation, Visualization, Writing – Review & Editing; **Rylance J:** Methodology, Supervision, Validation, Visualization, Writing – Review & Editing; **Chisati E:** Methodology, Supervision, Validation, Visualization, Writing – Review & Editing

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## Introduction

There is a high burden of chronic respiratory symptoms (including coughing, wheezing, dyspnoea, and phlegm production) in the Malawian population<sup>1</sup>. These symptoms interfere with individuals' activities of daily living and work productivity<sup>2,3</sup>, impair their health-related quality of life<sup>4</sup> and place an economic burden upon them and their families<sup>5</sup>. Evidence suggests an unmet health need<sup>6</sup>. Currently, available inhaled medications are associated with a modest reduction in exacerbation frequency and an even smaller effect on hospitalizations<sup>7-9</sup>. Moreover, poor availability and affordability of drugs for chronic respiratory symptoms is a big challenge for low-resource settings like Malawi<sup>10</sup>, which limits their impact. In such settings, a non-drug intervention called 'pulmonary rehabilitation' (PR) could help mitigate these deficits<sup>11</sup>.

PR is a program of exercise training, education, and behaviour management, designed to improve the physical and psychological condition of people with chronic respiratory diseases (CRDs) and to promote long-term adherence to health-enhancing behaviours<sup>12</sup>. In people with chronic obstructive pulmonary disease (COPD), PR is supported by high-quality evidence of improvement in symptoms (including dyspnoea, fatigue, anxiety, and depression), exercise tolerance, and overall health-related quality of life<sup>13</sup>. There is also evidence supporting PR for people with chronic respiratory symptoms of other CRDs including asthma<sup>14</sup>, post-TB lung disease (p-TBLD)<sup>15,16</sup>, and bronchiectasis<sup>17</sup>. In high-resource countries, PR has been shown to significantly reduce direct healthcare-related costs of COPD by decreasing hospital admissions<sup>18</sup>.

PR is recommended in international guidelines for the management of patients with COPD<sup>19</sup>, with some authors concluding that additional randomised controlled trials comparing PR and conventional care in COPD are not warranted<sup>20</sup>. However, such guidelines and conclusions are mainly based on research evidence produced in the global North, meaning that they cannot be robustly generalised to the global South<sup>21-23</sup>. This may be due to substantial differences in resources, healthcare configuration, and culture<sup>22,24,25</sup>. These differences necessitate adaptation<sup>26-30</sup> of PR to patients' local contexts to ensure that it is both acceptable and effective. In-line with the heuristic framework for the cultural adaptation of interventions<sup>31</sup>, the present study aimed to explore patients' experiences of living with chronic respiratory symptoms and their views on a proposed PR program at Queen Elizabeth Central Hospital (QECH), Blantyre, Malawi, to inform a culturally adapted and individualized PR program.

## Methods

### Ethics statement

Ethical approval was obtained from the University of Malawi, College of Medicine Research and Ethics Committee (approval number: P.07/19/2752). All participants provided written informed consent to participate in the study and to use their anonymized data for publication.

### Study design and setting

This was a cross-sectional qualitative study, using one-to-one face-to-face semi-structured in-depth interviews. This

method permitted an in-depth exploration and ever-widening explanation<sup>32-34</sup> of participants' experiences of living with chronic respiratory symptoms and their views on a proposed PR program. It was conducted in Blantyre at the Queen Elizabeth Central Hospital (QECH), Malawi's largest government referral hospital.

### Participants and data collection

Patients (both males and females) were purposively recruited. Inclusion criteria were: patients experiencing one or more functionally limiting chronic respiratory symptom as reported by the patient and recorded in their medical files; aged 18 years or older; and with their consent to participate. They were identified by two physiotherapists (TM and MM) at an outpatient chest clinic and in the medical wards at QECH. At the point of identification, each eligible patient was briefly informed of the study and their contact phone numbers taken by the physiotherapists. Later, they were individually invited via a phone call to a formal information and interview session conducted in a private room in the Physiotherapy Department at QECH. They were reimbursed for their transport expenses at rates mandated by the local research ethics committee<sup>35</sup>. The information session was guided by a participant information sheet<sup>36</sup> while the interview session was guided by a semi-structured topic guide<sup>36</sup> which had been informed by a literature review and received expert input from a Malawian social scientist (FL). The topic guide included open-ended questions and prompts were used where necessary. It was not pilot-tested and no significant areas for its quality or content improvement were identified as the interviews progressed. Interviews were conducted by three physiotherapists (FMB, MM, and TM) in 2021 from August to December. The principal investigator (FMB) is a cardiorespiratory physiotherapy specialist with qualitative research experience<sup>37</sup>; he guided MM and TM on conducting interviews. We had pragmatically proposed to interview 10 patients as evidence<sup>38</sup> suggests that a sample of six to twelve interviews may have been sufficient to enable development of meaningful themes and useful interpretations. We did reach both code and thematic saturation by the sixth interview, that is, a point at which no new codes or themes, respectively, were observed in the interview data<sup>39</sup>. Therefore, interviews seven to ten confirmed that the analysis of these additional interviews did not yield any new codes or themes or ideas (i.e., as a stopping criterion)<sup>39</sup>. Participants' sex, age, residential address, ethnic group, and documented CRDs were also collected.

### Data management and analysis

Audio-recorded interviews were transcribed *verbatim*, and Chichewa transcripts were translated into English by FMB<sup>40</sup>. Transcripts were anonymized and compared with the interview audio recordings to ensure completeness and accuracy. Subsequently, the transcripts were imported into QSR International's NVivo 12 qualitative data analysis software ([https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home?\\_ga=2.250773510.1649358996.1644678287-1855041936.1630525245](https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home?_ga=2.250773510.1649358996.1644678287-1855041936.1630525245)) for iterative line-by-line coding and inductive thematic analysis<sup>41</sup> across all interview data, independently by FMB and TM. This involved each researcher's familiarisation with the entire interview data set, by reading and re-reading the transcripts while making reflective notes on the literal

content, interpreting what the data meant by assigning initial codes or classifications to segments of text, exploring relationships between these classifications, and developing core general themes. Codes generated by the two researchers were then compared and themes merged. Merged themes were refined for referential adequacy by returning to the raw data. Participants' quotations from the transcripts were extracted to provide supporting examples for each final theme. We drew on consolidated criteria for reporting qualitative research (COREQ) guidelines<sup>42</sup> when narrating our findings<sup>43</sup>.

## Results

10 adult participants (five males and five females) were interviewed. They had a mean age of 54.7 years (range, 39 to 83 years). All lived in communities within Blantyre. Diagnoses documented in their medical files included COPD, asthma, p-TBLD, and bronchiectasis. The indigenous ethnic groups of nine participants included Lomwe, Yao, Chewa, Ngoni, Mang'anja, Sena, and Nyanja. One participant was mixed Scottish, Portuguese, and Malawian. On average, each interview lasted for 28 minutes (range, 15 to 40 minutes). Eight interviews were conducted in Chichewa while two were conducted in English. All interviews were conducted in private rooms, with eight of them conducted in the Physiotherapy Department at QECH and two at participants' homes.

Themes emerged under two sections, namely 'experiences of living with chronic respiratory symptoms' and 'views on the proposed PR program' and are described below. Additional participants' quotes are shown in [Table 1](#) (see underlying data)<sup>40</sup>.

### Section 1: Experiences of living with chronic respiratory symptoms

**Theme 1: Chronic respiratory symptoms.** Breathlessness was the commonly reported chronic respiratory symptom among participants. Other symptoms were cough, chest tightness, pain, dizziness, anxiety, and phlegm production:

*"Like I also feel pain. Sometimes dizziness. But what I am most anxious about is the breathlessness. Because even after taking medication for the breathlessness, it doesn't end. So, what causes me anxiety is the breathlessness. These other symptoms can improve but the breathlessness seems to not resolve."* ID 6, male, aged 39 years

**Theme 2: Functional limitations.** Participants reported that their chronic respiratory symptoms interfered with their work and various activities of daily living including walking, lifting objects, and sexual activity:

*"My times were going well for me. A weight which I could lift on head, I could lift alone. and putting it down alone, without people. But the change of my times: there are 20-litre buckets, when I lift on head, I make sure somebody comes to help me put it down. Or when lifting it, somebody has to help me do it. It's the same when I go home; when I don't find anyone, I lack peace of mind, almost reaching a point of hurling the thing to the ground because there is nothing I can do."* ID 3, female, aged 39 years

**Theme 3: Coping strategies.** To relieve themselves from their chronic respiratory symptoms, participants described various ways including resting, drinking water, and taking inhaler or drugs:

*"When I see that breathlessness persists, I take inhalers, beginning with those I was prescribed to take in the morning, so that it can subside. In addition, if I have an appointment and am late and I need to hurry up, I can start off well, but the breathlessness attacks me on the way before I reach the destination. So, in that case of breathlessness, I slow down the walking. Sometimes, I can also take the inhalers, and then continue the journey but slowly until the body accepts when I can feel comfortable to resume walking."* ID 4, female, aged 58 years

### Section 2: Views on the proposed PR program

**Theme 4: Enablers to PR program participation and completion.** When asked about factors that would enable them to participate in and complete a proposed six-week, twice-weekly PR program, participants commonly expressed the desire for positive change or improved health and improved knowledge of their condition and exercising:

*"The realisations that the program is aiming at improving health status, so that alone is a motivating factor. Because at the end of the day, one must have learnt or benefit something from the whole program."* ID 1, male, aged 42 years

Some participants, depending on their responses to interview questions, were probed on what would encourage them to attend the next PR session if they felt tired on the previous PR session. These attributed their resilience to the same desire for positive change or improved health:

*"I will just be courageous so that I can perhaps see a potential to get well."* ID 9, female, aged 72 years

**Theme 5: Barriers to PR program participation and completion.** Generally, participants said nothing would bar them from participating in and completing the program. However, illness, lack of transport access and competing commitments were implied as potential barriers:

*"I will be becoming, as long as there will be hospital provision of transport."* ID 9, female, aged 72 years

**Theme 6: Views on some organizational PR program aspects.** Participants were also asked for their views on some organizational features of the proposed PR program including travel to the PR program centre, venue (i.e., in gym room in the Physiotherapy Department at QECH and at home), day and time (either morning or afternoon hours), exercise component (individualised), education component (including smoking cessation), group delivery format, mixture of male and female participants in the group, sex (male or female) of the program leaders, and public nature of the program. Generally, participants' views on these aspects were positive provided there would be no barriers. For example, regarding travel to PR program centre, one participant said:

**Table 1. Additional anonymised participants' quotes in each section and theme outlined in the results section above<sup>40</sup>.**

<b>SECTION 1: EXPERIENCES OF LIVING WITH CHRONIC RESPIRATORY SYMPTOMS</b>	
<b>Themes</b>	<b>Participants' quotes</b>
Chronic respiratory symptoms	"My breathing problem is difficult because I experience breathlessness. I can't walk a long distance or run. When I have worked hard, I experience breathlessness." ID 2, female, aged 39 years
	"Eh, my breathing, there is times when I'm able to breathe although there's two slight problems: I feel slight tightness. But sometimes my breathing difficulty is so tight." ID 5, female, aged 83 years
	"Also, when I am cooking, and when I am blowing to quench the fire, when I am blowing rapidly, I start breathlessness as well. Also digging (for gardening). I can start digging, then breathlessness just comes suddenly." ID 4, female, aged 58 years
	"After the end of TB, the cough never stopped. I was coughing until breathlessness, until now." ID 9, female, aged 72 years
	"Sometimes it's like I am having short breaths. Sometimes, it's alright. But it's not perfect as it used to be before". ID 1, male, aged 42 years
	"The breathing problem... because of the job I was initially doing... I once suffered from pulmonary TB. I was diagnosed with TB due to the job I was doing... I involved use of fire. So, it was found that my lungs were scarred due to smoke. So, the scars blocked the blood vessels of the lungs. So, it causes me breathlessness; since 2013 until now." ID 8, male, aged 53 years
	"Reduction in breathlessness and I can walk some distance without breathlessness; I become breathless after some time has passed." ID 7, male, aged 80 years
	"One, I am anxious about the cough I have told you about. I once suffered from TB but why is it that when people suffer from TB, their cough improves with TB treatment completion. It does show that it's over for that person (referring to end of cough). But me, this cough still troubles me. Is it the problem with the lungs as they told me that my lungs are not very well? I can ask myself: I don't find an answer." ID 3, female, aged 39 years
	"Me my breathing: when I am walking, I become short of breath. Cough, I also cough. Perhaps also vomiting." ID 10, male, aged 42 years "... the sputum is coming out and my breathing now is good." ID 10, male, aged 42 years
	"Body pains and the breathlessness is what troubles me very much." ID 10, male, aged 42 years "What causes me anxiety is one thing: that I married. But since after taking medication for epilepsy as well as started experiencing breathlessness, I no longer sleep with my wife." ID 10, male, aged 42 years

<b>SECTION 1: EXPERIENCES OF LIVING WITH CHRONIC RESPIRATORY SYMPTOMS</b>	
<b>Themes</b>	<b>Participants' quotes</b>
Functional limitations	<p>"When walking, I stop walking to catch my breath. Or when working, I stop working until my condition becomes better." ID 7, male, aged 80 years</p> <p>"... when I am just sitting, I am okay. But to do anything or walk or climb a step or get out of bed to get dressed or go outside the house, I first stop so that the breathlessness can reduce. Yes, so, it robs me of peace very much." ID 8, male, aged 53 years</p> <p>"But it often happens when I am waking fast. When I walk abruptly. Or when I wake up and want to go to relieve myself. when I wake up abruptly, it can also happen. Or sometimes it also happens on its own when I am sleeping. But it often happens when I shake myself. Or when I am bathing, I sometimes don't finish. Sometimes failing to wipe myself (in the toilet) because I have to bend..." ID 6, male, aged 39 years</p> <p>"I cannot exercise the way I used to do before." ID 1, male, aged 42 years</p> <p>"Well, the comment is that she is lacking the help (referring to lack of food and money problem) because whenever she is about to work, she experiences the breathlessness, she experiences the cough. So, she can't do work a long time, that's why she seems to be inactive. That's why she lacks the help (referring to lack of food and money)." Guardian for participant ID 9</p> <p>"... if I have an appointment and am late and I need to hurry up, I can start (walking/the journey) well, but the breathlessness attacks me on the way before I reach the destination. So, in that case of breathlessness, I slow down the walking." ID 4, female, aged 58 years</p> <p>"There's been times when I have to mop... I have a small little house. Sometimes when I mop, sometimes even before I finish, I have to lie down because of my breathing it's so... it's... I feel uncomfortable, I can't carry on with the job, I have to lie down and rest. Sometimes even the walking, I walk, by the time I reach the house, back inside my house, I am breathless, I have to rest." ID 5, female, aged 83 years</p> <p>"I can't walk a long distance or run. When I have worked hard, I experience breathlessness." ID 2, female, aged 39 years</p> <p>"Firstly, it is working, because working I fail to do anything. I just stay." ID 10, male, aged 42 years</p> <p>"What causes me anxiety is one thing: that I married. But since after taking medication for epilepsy as well as started experiencing breathlessness, I no longer sleep with my wife." ID 10, male, aged 42 years</p>
Coping strategies	<p>"When I use inhaler, it can temporarily change." ID 8, male, aged 53 years</p> <p>"What I do is taking and using the medicine. Then, afterwards, I feel my health becomes better." ID 7, male, aged 80 years</p> <p>"I use asthma drugs and inhaler." ID 1, male, aged 42 years</p> <p>"I can wake up and drink water. Then, the cough can subside. So, I breathe better... Uhm, for breathlessness, there is nothing I do. I just live and leave it the way it is... You know what happens on the communities. Sometimes one can come to disturb your thoughts. Sometimes you can be in a conflict. During the conflict, when you have high BP the BP can increase in the process of exchanging words. So, to avoid this, I see it wise to isolate myself and go somewhere quiet. Or when this happens while at the garden, I leave my hoe, and sit down and rest. When I see that my heart is rested, I can just take my hoe and go home, I shouldn't force myself (to dig)." ID 3, female, aged 39 years</p> <p>"I sometimes drink water... When there are drugs, I also take them." ID 9, female, aged 72 years</p> <p>"There, I must sit down. I should rest first or stop walking. Even standing still doesn't help. I must find a certain place to sit down. Or sometimes when I sit like this, the breathlessness can somehow stop. After calming myself, then I can walk. And if I walked a long distance going down the slope, upon walking up the slope, I take frequent rests... walking a short distance, then resting. Walking a short distance, then resting. I do reach the destination where I came from, but I will have taken a lot of rests before arriving. Let's say I am coming from the stage (minibus station) and it (breathlessness) has started there (at the stage), to go back to the stage I must rest about five to six times; walking a little then resting, walking a little then resting." ID 6, male, aged 39 years</p> <p>"But sometimes my breathing difficulty is so tight, where I have to use my pump or there is times where... what really helps me sometimes is have a hot bath, uhm sometimes I have to inhale blue gum leaves, boiling leaves, take uhm inhale leaves sometimes take pump – all these things help me." ID 5, female, aged 83 years</p> <p>"I would be taking inhaler until morning to find sleep... Using the inhaler. But even sometimes when I use inhaler, it's like it (breathlessness) still increases... When it's at night, I can wake up and go outside for a walk around. That's what I do oftentimes." ID 2, female, aged 39 years</p> <p>"That time, I was just staying, coughing, and sometimes vomiting. But after being told by the physios, they told me that when I am breathless while walking on the road, be under a tree and position yourself like this. If you are at home, be on a highchair, rest your back and lean. If you are right inside the house on the table, lean forward onto the table. If you are on the mat or bed, rush onto the bed and lie there in a stretched-out position." ID 10, male, aged 42 years</p>

<b>SECTION 2: VIEWS ON THE PROPOSED PR PROGRAM</b>	
<b>Themes</b>	<b>Participants' quotes</b>
Enablers to PR program participation and completion	<p>"There is a lot, according to the way I see it, because I want my health... also helping others... education like this can enable me to participate. I don't see any difficulty." ID 7, male, aged 80 years</p> <p>"As for exercises, we can't deny. We need to do as it also gets rid of other diseases, we already know that.... at this time, we can commit ourselves to see what happens." ID 6, male, aged 39 years</p> <p>"I can answer this way that what can enable me to participate in and complete this program: the main reason is the issue of the problem I am experiencing; I should see how it is going to give up or end. So, that's what can enable me to complete this program. Then I also heard from that first sheet, words were read that this if you enter in this research, many of your chronic lung problems would be seen and helped. So that's what can enable me to start through to completion of this program. Because I didn't understand when I was being x-rayed about my lungs, I didn't understand. They told me there was a mistake with my lungs. So, I want to see from that time I was told that to this day when we will start this program... I want them to tell me again, I should hear the results again and see what next about these lungs." ID 3, female, aged 39 years</p> <p>"I want to enter in the physical exercise research (kafukufuku wa ma fizo) to see how it's going to help my life, how it's going to change. But I long for a change in my life." ID 8, male, aged 53 years</p> <p>"The sickness, so that it will perhaps change." ID 9, male, aged 72 years</p> <p>"(laughs). I think those are good things as when we do them, we can see how life becomes. Perhaps they can also change our life, unlike other things we do once in a while. But when we do such exercises and see what is happening, there can be a habit of doing something that can help." ID 4, female, aged 58 years</p> <p>"I know it's getting worse. And I need relief. So, I really want your help. to teach me what to do, so that I can feel relief when I am really bad. Because sometimes it's not too bad, but sometimes I feel I am going, like I am fast asleep, then I have to get up because I can't breathe - there's been times like that. So, what I really want for your help is to be able to get relief with my breathing." ID 5, female, aged 83 years</p> <p>"What would encourage me to come back is because I know that by getting tired, there is something that has changed inside the body that has caused the tiredness. So, one still works hard so that the change that has happened can continue, so that things should continue to change." ID 8, male, aged 53 years</p> <p>"I think that I participate in this research, I will benefit because I have been suffering from this asthma for a long time, but I just live with it at home. So, if I enter in this research, you will be telling us some new things which we will be doing which can improve our life than just staying here at home." ID 2, female, aged 39 years</p> <p>"Me, my life, I cannot fail to participate in this programme because I am buying myself life. The way I used/was able to work, I would like to return to it, so that I can comfortably work." ID 10, male, aged 42 years</p> <p>"Yes, it encourages me because there come many people here at the hospital. But I was chosen when I just came, meaning that God is with me, He is looking after me, that's why He joined me into this small group to participate." ID 10, male, aged 42 years</p> <p>"No, it can't disturb because the hospital personnel also enlightened me that just lying is self-damaging to the body even while you are sick. But it requires you, even in this state, to be active. So, when am doing so, I am free so that I cannot be usually at home." ID 10, male, aged 42 years</p> <p>"No, I don't have doubts because I have said I am buying myself a life. Because if the hospital says, "We have arranged this. We want to buy you a life", then I too need to accept with the help of God. When it's time, it's time - that which must happen does happen." ID 10, male, aged 42 years</p> <p>"My expectation is just to wait for you, programme leaders, to communicate when we will start the programme and I am ready to come on that day. And I am happy that we will be reimbursed for transport money. Because if there were to be challenges, it would be that. Because I don't work. So, I am happy with that - I will be reimbursed for transport money." ID 10, male, aged 42 years</p>

SECTION 2: VIEWS ON THE PROPOSED PR PROGRAM	
Themes	Participants' quotes
Barriers to PR program participation and completion	<p>"There is no problem. Like you have said you will be giving transport?" ID 6, male, aged 39 years</p> <p>"Uhm, there isn't a thing that can bar me." ID 8, male, aged 53 years</p> <p>"Because I can be escorting him... (a few words missed) coming here if I find transport. But if I can't find transport, he can come alone." guardian for participant ID 8</p> <p>"As of now, I don't see any barrier, unless I suddenly become ill, or something has suddenly happened that can bar me from participating. But without anything, I don't see a barrier... I don't have any thoughts (reservations), I can accept that, unless if those two days include our Sabbath (Saturday); I can fail. But for the other six days, I am ready any day." ID 7, male, aged 80 years</p> <p>"My thoughts are I can come at any given time, either in the morning or afternoon. But if there is a barrier I have encountered – because anything can happen – maybe there is funeral, or it's (...) in our family, I will say my excuse. But if I am free, I should come, either in the morning or afternoon." ID 3, female, aged 39 years</p> <p>"When I have transport for traveling here. Right now, I have. When I don't have, I will be telling you that I don't have, according to the way financial issues are going these days. Sure." ID 3, female, aged 39 years</p> <p>"No, there isn't. If you send the transport, there is not any problem." Guardian for participant ID 9</p> <p>"Uhm, I don't see anything that can fail me. Because if there is any health problem while I am here, there is a possibility of reaching out to medical personnel for help. But if there isn't a problem, we can continue it to completion." ID 4, female, aged 58 years</p> <p>"I don't see anything that can fail me from starting and completing. I don't have any barrier. Perhaps sickness. That on the set day I am supposed to come here, I am sick whether headache or malaria, I already know. Then maybe I can be absent. But without any barrier, I am free to start through to completion." ID 3, female, aged 39 years</p> <p>"There's times I do catch public transport. But from the road to go to the house, it's quite a distance. So, when I get down, if it's public transport, I have to walk to go to the house." ID 5, female, aged 83 years</p> <p>"Probably busy schedules at work. But as much as possible, I should try to have permission from my superiors to attend the program wherever possible." ID 1, male, aged 42 years</p> <p>"Uhm, I don't see a problem that can prevent me from entering in this research." ID 2, female, aged 39 years</p> <p>Perhaps unless there is a funnel at home, it would indeed be difficult to leave because they would be saying, "What about him?" Because I was advised here at the hospital to stop attending funnels because of the epilepsy problem but if it's a home funnel, be there but when it's the casket time, don't be there. So, I cannot indeed come because of that." ID 10, male, aged 42 years</p> <p>"And I am happy that we will be reimbursed for transport money. Because if there were to be challenges, it would be that. Because I don't work." ID 10, male, aged 42 years</p>
Views on some organizational aspects of the PR program	



SECTION 2: VIEWS ON THE PROPOSED PR PROGRAM	
Themes	Participants' quotes
Regarding travel to PR program centre	<p>"There is not a problem." ID 2, female, aged 39 years</p> <p>"I will come because wherever there is help and you have been invited, one needs to go to receive the help that's there to see how it helps. So, if don't come but you need help, there is no benefit. You need to come to see how you will benefit... As already said, what we really need is help. So, I can't think of any barrier to fail me from coming. I still need to follow through. Because if I say I can't come, there is a good reason, but I see that there is a big burden/barrier in my life (referring to her lung condition) that fail from me doing soft activities that I can do by myself, for example lifting (on the head). I can't lift and walking up the terrain to reach the destination, I can't do." ID 4, female, aged 58 years</p> <p>"We will be arriving to the PR centre... When I have transport for traveling here. Right now, I have. When I don't have, I will be telling you that I don't have, according to the way financial issues are going these days. Sure." ID 3, female, aged 39 years</p> <p>"There is no difficulty, I can come." ID 8, male, aged 53 years</p> <p>"No, there won't be a problem. Like you have explained that the intervention is for a few weeks... So, there can't be a problem. We can try our best." ID 6, male, aged 39 years</p> <p>"There is not any problem. I will be setting off in accordance with the appointed time." ID 10, male, aged 42 years            Researcher: "What if there are rains?"            "We will just enter the rains (Tiyilowa mvulayo basi)." ID 10, male, aged 42 years</p> <p>"I don't mind coming any day you tell me; I will try coming." ID 5, female, aged 83 years</p> <p>"The time that I think would be convenient for me is afternoon. Because this season is for farming, so people are busy with the farming that so that it can help us later. So, the good time is indeed in the afternoon. Because in the morning you can go to the garden to dig a ridge, come back, cook, prepare, and go." ID 3, female, aged 39 years</p> <p>"... any day that you can give is agreeable/acceptable." ID 8, male, aged 53 years</p> <p>"... and time, I see that there is no problem. Because Bangwe is not really far, there are transport means all the time. So, I don't see a problem... I can manage the time if I know the start time so that I can try to be punctual, so that it should not fail." ID 7, male, aged 80 years</p> <p>"My thoughts are I can come at any given time, either in the morning or afternoon. But if there is a barrier I have encountered – because anything can happen – maybe there is funeral, or it's (...) in our family, I will say my excuse. But if I am free, I should come, either in the morning or afternoon." ID 3, female, aged 39 years</p> <p>"I will be coming early in the morning because our home is a bit far." ID 9, female, aged 72 years</p> <p>"But probably I would talk on the time, that maybe afternoon hours would do better, in as much as I know that exercises are better done in the morning but probably afternoon, so that if there are some constraints at work, one would concentrate on those first and later on in the afternoon, maybe from around 2 to 4, would come and then take part in the exercises." ID 1, male, aged 42 years</p> <p>"... if there are problems on the other days, we can be telephoning... like you said there can also be pictures (PR leaflets), then we can be doing it at home. But at this time, we can commit ourselves to see what happens." ID 6, male, aged 39 years</p> <p>"But it should be morning there." ID 6, male, aged 39 years</p> <p>"Perhaps in the afternoon. Afternoon because in the morning I could be doing household chores and other activities, unlike just waking up and coming here, while keeping in mind of the time to come here later." ID 4, female, aged 58 years</p> <p>"Any day, I am ready to come here." ID 10, male, aged 42 years            "I can't have a problem with either [morning or afternoon] because I have already said that I just stay because I don't do any work. So, anytime, I will agree to come here." ID 10, male, aged 42 years</p>
Regarding day and time	

SECTION 2: VIEWS ON THE PROPOSED PR PROGRAM	
Themes	Participants' quotes
Regarding PR program venue	<p>"At home, I will be doing. To see how I am benefiting in my life from what I am doing at here and at home. I am capable to do at home and here." ID 3, female, aged 39 years</p> <p>"The location has no problem." ID 3, female, aged 39 years</p> <p>"... if we can start with the location and the venue, it's obvious that its Queen Elizabeth, there is no any other venue." ID 1, male, aged 42 years</p>
Regarding the (individualised) exercise component	<p>"I have been exercising... it's just now that I haven't been well, so I haven't been exercising. But I have to exercise for my back. So, I have been doing exercise, walking. So, if I come and do the same thing, it will be good for me." ID 5, female, aged 83 years</p> <p>"I think those are good things as when we do them, we can see how life becomes. Perhaps they can also change our life, unlike other things we do once in a while. But when we do such exercises and see what is happening, there can be a habit of doing something that can help." ID 4, female, aged 58 years</p> <p>"Perhaps trying to run? Lifting weights to see if there is energy in the body. We will." ID 9, female, aged 72 years</p> <p>"My thoughts... as I have explained, I don't have any other thoughts (reservations) if the leader sees that I can manage, I can do. But if they see that I can't manage, I can fail. But if they see that I am well (fit), I don't see a problem." ID 7, male, aged 80 years</p> <p>"My thoughts are that I am ready to do any given exercise." ID 3, female, aged 39 years</p> <p>"My thoughts there are that it is good because I perhaps experience breathlessness because of inactivity. So, at least if we can do exercises, some problems in the body can go away." ID 2, female, aged 39 years</p> <p>"Those are exercises. We can manage. We can be doing but if there are things that need not be done, we also cancel them. Like the hospital staff will be seeing what need not be done. As for exercises, we can't deny. We need to do as it also gets rid of other diseases, we already know that." ID 6, male, aged 39 years</p> <p>"It's possible. I can do it without difficulty." ID 8, male, aged 53 years</p> <p>"The issue is everyone is given their exercises, yes... Ah there is no problem." ID 6, male, aged 39 years</p> <p>"My thoughts are that everything that happen in this program, I should follow it to completion." ID 4, female, aged 58 years</p> <p>"It's good because as you've put it that it's a tailored exercise which means it's well designed to fit this purpose for this exercise. So, it's a good thing and as you repeatedly do it, you get accustomed to it and the end of the day, it yields the results." ID 1, male, aged 42 years</p>

<b>SECTION 2: VIEWS ON THE PROPOSED PR PROGRAM</b>	
<b>Themes</b>	<b>Participants' quotes</b>
Regarding the education component (including smoking cessation)	<p>"If I smoke, I must accept to stop. If I also drink mowa (beer/alcohol) and this program says I should cease, I must accept. Because I wasn't born that way; I found it. So, if I want peace, these things which seem useless for me, I must leave them." ID 3, female, aged 39 years</p> <p>"I want to know what makes breathless, what is happening inside the lungs – those are what I want to know about." ID 8, male, aged 53 years</p> <p>"It's true because smoking can't go well with this disease. So, it will take the smoker to see what to do after receiving such advice, individually because I can't decide for them to cease smoking while they don't have the desire to do it. So, they will see themselves. Because smoking somewhat causes coughing. You can smoke but things can't go well, you start coughing, the problem comes there." ID 4, female, aged 58 years</p> <p>I don't see any other thoughts (reservations?) because I already stopped smoking... just patting myself on the back (kumangowombera mimanja) and encouraging others that... on this issue of smoking and drinking, I encourage others that 'your body is God's temple, don't damage it. That God depends on me. If I damage myself, then I have damaged God's temple.' You can be sharing with others some knowledge, and you can also be learning from others." ID 7, male, aged 80 years</p> <p>"I am really looking forward to that. Because to tell you the truth, I think it will help me with my breathing, yeah." ID 5, female, aged 83 years</p> <p>"We will learn. There is no problem. I want to know about the exercises we will be doing. To know how you do it." ID 9, female, aged 72 years</p> <p>"If they can stop smoking, it can be good." ID 9, female, aged 72 years</p> <p>"It's (smoking cessation education) also good. We can accept." ID 6, male, aged 39 years</p> <p>"Uhm, fortunately, I don't smoke, I have never smoked before. Neither do I drink. But we'd still want to know if there are other lifestyles that one would have to check, some other things that people do that they have to stop... uhm, so that they are in line with program. And for those who smoke, I would say there is need to find a better way of helping them so they can stop. First of all, they can understand why they have to stop smoking and then they should be assisted. Uhm, people have been assisted to quit smoking and they have... so you just have to design a good program that should really help them." ID 1, male, aged 42 years</p> <p>"They are good things. The ones who can hate it are the ones who smoke or drink. But I don't smoke. Because if a health personnel tells you to stop something, but you still do it, then you are doing it wrong. But for me, there is any possibility... I have approved of this programme." ID 10, male, aged 42 years</p> <p>Researcher: "So, if there will be found a thing that you do but will be told to stop, you will be comfortable to change?" "Very well, surely, without a problem because they are making my health." ID 10, male, aged 42 years</p> <p>"I think it will be alright. I don't mind." ID 5, female, aged 83 years</p> <p>"It is good. It is good because we will be meeting other people." ID 5, female, aged 83 years</p> <p>"If there is one group and another, I can join the morning one... there is no problem." ID 9, female, aged 72 years</p> <p>"I accept. Something you do with others is better than doing it alone. Because when you are doing it with others, you can take some lesson when you are lagging behind...." ID 7, male, aged 80 years</p> <p>"It's okay doing it in a group. We can do it together. We should be helped." ID 4, female, aged 58 years</p> <p>"There is not any problem... There is not any difference that I see can be an issue... Some are Muslims some are Christians, all those are people, so there is not any difference." ID 3, female, aged 39 years</p> <p>"Because you cannot do a thing alone. Because it is your friend who encourages, say 'My friend is doing something, let me also work hard, I should be as my friend has changed ('changed' as in 'improved'). But a person just doing alone, you can get lazy etc. That's why even at school, 'Oh my friend is passing great (akukhoza kwambiri), I should also work hard to be like them.' That's what happens." ID 8, male, aged 53 years</p> <p>"It's also good because you encourage each other on the exercise... it's possible to be together." ID 6, male, aged 39 years</p> <p>"There is not any difference because I am a proud choir leader in the church, and I sing as a choir master. So, what is 10 participants to a whole church group?" ID 10, male, aged 42 years</p>
Regarding group delivery format	

SECTION 2: VIEWS ON THE PROPOSED PR PROGRAM	
Themes	Participants' quotes
Regarding mixture of male and female participants in the participants' group	"It's not difficult there because everyone, male of female, have to receive treatment according to their problem... That is not difficult." ID 2, female, aged 39 years
	"I don't mind." ID 5, female, aged 83 years
	"It's also a good thing. Because it means we are meeting people of different abilities there, yes, both physically and socially; so, one group benefits from the other, so it's a good thing." ID 1, male, aged 42 years
	"Yes, there is no problem. We will be together." ID 9, female, aged 72 years
	"It's agreeable. There is no other answer can say, I agree with it. Because everything requires to be together, not alone, so there is nothing strange." ID 7, male, aged 80 years
	"There is no difficulty (palibe chovuta)." ID 8, male, aged 53 years
	"Same, as long as we get healthy (bola tapeza umoyo). There isn't (a problem)." ID 9, female, aged 72 years
	"There isn't a problem in a mixture of men and women; we should all receive the treatment as we have been instructed... Nothing. They are just people. It's like the we are in the minibus [public transport] or in even in the church, you can close to all sorts of people. So, there is nothing strange... According to our culture, I don't see any problem. Because that's our way of life here. I don't see any difference... there is no separation between men and women; oftentimes, there is a mixture. Where there are women, there are men. Where there are men, women can also be there. So, there is nothing strange." ID 3, female, aged 39 years
	"There can't be a problem, isn't it exercises?" ID 6, male, aged 39 years
	"There is not any problem. Because doing a play alone, or men only, it is not okay. But if there are also women, all goes well. I am comfortable to join the group and properly participate in the exercises." ID 10, male, aged 42
Researcher: "There won't be feeling of shyness doing them together with women, you will be comfortable?" "I will be comfortable." ID 10, male, aged 42 years	
Regarding sex (male or female) of the PR program leaders	"That's not difficult. Male or female helps one. What we are lacking is help (treatment). We want to be helped so that our health can progress well; the problem we have should decrease. So, there is no reason for us to look at whether one is male or female; anyone can help us." ID 2, female, aged 39 years
	"There is not any difference. It's the same with teachers in class, we have both female and male." ID 4, female, aged 58 years
	"I feel it's a good thing. Uhm because you still learn something; if it's a female, you still learn something on maybe how they are doing things... uhm maybe how they are demonstrating things and or a man would encourage to say if a woman can do that, I can also manage to exercise like that. So, I think it's a good thing." ID 1, male, aged 42 years
	"There isn't any concern. That's the way it is. We have to receive them; they should train/educate us. What we want is good health. We have to receive them; they should train/educate us the needful (atiphunzitse zofunkirazo). They should lead us. Whether it's a male, we will receive them. They should lead us what to do. Whether it's a female, likewise." ID 3, female, aged 39 years
	"Maybe if I was younger, I could say no that yes that. But I don't mind as long as I know I'm coming here for help. Either it's you [male interviewer] or the women, I don't mind." ID 5, female, aged 83 years
	"It's same being with male or female. There is no difference, it's same. I am not differentiating. No." ID 9, female, aged 72 years
	"It should be the way it should... There is not any problem." ID 8, male, aged 53 years
	"It's also good. There needs to be a leader." ID 6, male, aged 39 years
	"The helper is a helper. I will accept anyone to help me according to the life they want to buy for me through God." ID 10, male, aged 42 years

<b>SECTION 2: VIEWS ON THE PROPOSED PR PROGRAM</b>	
<b>Themes</b>	<b>Participants' quotes</b>
Regarding public nature of the PR program	<p>"No, that's no reason (ayi, si chijukwa chimenecho... as in that's not a problem/an issue). Because we are on our work." ID 9, female, aged 72 years</p> <p>"There is no difficulty, they can watch... they can also actually motivate me... Even football needs watching." ID 8, male</p> <p>"My thoughts are that we can't stop because people are passing by. We can continue it, since they (the non-participants) have their own stuff (akuyendera zawo), as we are also doing ours (ifeso tikupanga zathu) ... Embarrassing to be seen by others would be when we be exercising while naked. But in this case, I don't think it's embarrassing. Because that is hospital help." ID 4, female, aged 58 years</p> <p>"It's not embarrassing because you are not naked. It's embarrassing when you are naked, but if you are dressed, what's embarrassing? Or if they say you should remove your shirt, you remove the shirt and remain with a short. That's it." ID 7, male, aged 80 years</p> <p>"There is no problem with that, provided, in the first place, one is drilled on what they have do, so that when it gets to the public, they know exactly what they are doing, so they don't make mistakes and get embarrassed at the end of the day. But doing it even in public, that's also a motivating factor to show that you are able to showcase what you have mastered, and some people can also learn from you." ID 1, male, aged 42 years</p> <p>"There is no problem if the non-participants watch us. Those watchers are also good because they can give you feedback. On our won as trainees to do these exercises, if you are failing, there can't be anyone who can give you feedback to correct you – "you would have done it this way" – because there is no one... we are all like at school. But when there are watchers, those ones can correct you. You can follow their instructions until you do it. Where you are doing it wrong, they tell you what to do to get it right. Where you are doing it right, they tell you to continue – encouraging you." ID 3, female, aged 39 years</p> <p>"There is also no problem... Aren't we going to be doing what have we have come for? And we will be timing ourselves ... to finish and go. So, we can't pay attention to another person." ID 6, male, aged 39 years</p> <p>"There is no reason for us to feel shy or stop because others are seeing us, because what we are doing is for our own benefit, for the benefit of our health. So, we can't fail doing because other are seeing us. No, we need to continue." ID 2, female, aged 39 years</p> <p>"No, there isn't anything strange because I am buying myself life. I can't be afraid of a person who is passing by and is healthy, while I am struggling and looking for peace in my body, should I feel shy of breathlessness because of that person? Surely no." ID 10, male, aged 42 years</p>

<b>SECTION 2: VIEWS ON THE PROPOSED PR PROGRAM</b>	
<b>Themes</b>	<b>Participants' quotes</b>
Anticipated benefits of PR program participation	"I think that if I enter in this research, I will be helped. Because I have been living with this problem for a long time and I have seen the badness of this problem, the way I suffer. So, the advantage of entering in this group, I see that it will be of help to me. I will benefit from it." ID 2, female, aged 39 years
	"I would like the problem I have in my life to end and being able to do everything done by others, easily. That's why I am interested, so that maybe things that are impossible for me this time around can be possible. Yes." ID 4, female, aged 58 years
	"My comment is that I am proud and very glad about the coming of this research because, for me, I was just living with ignorance; because my asthma is old, but I was just living without knowing how I am going to be helped. I only knew of going to hospital to take medications and come back, going to hospital to take medications, and come back. But with this coming of you, researchers, I feel that I am going to benefit. My life is not going to be the same, my health is going to improve." ID 2, female, aged 39 years
	"I want the cough to go away from me (chifuwa chindichoke). The breathlessness should also end (kubanikaso kuthe)." ID 9, female, aged 72 years
	"My anxieties... I feel that if I enter in this program, I will not have anxieties ("nkhawa njee ndithu"). Because when I am doing this program, I will be forgetting about the problems I have been thinking/concerned about, and see how it is going to help me, what's going to be next for me ("zindithera bwanji"). I will be leaving such anxieties aside and focus on that one thing (referring to PR) I am doing so that it can help me. Because sometimes when you are anxious, the thing you are doing can't help you. It can't happen. Similarly, when you are taking drugs while also having a lot of concerns ("maganizo"), you can die despite available drugs because you have taken them but are not working well because of anxieties. But if I throw away these anxieties, which I ponder night and day, when I leave them aside, I have hope that all my problems are going to end through this program, sure." ID 3, female, aged 39 years
	"I would like it to change these times I am in (ndingakonde itasintha nyengo zomwe ndiri inezi) to the former times (pre-morbidity): that's when I can be happy. Even if they can take/improve me to half of the former (pre-morbid) times – better times – from the current times, wow I can be very happy. Not these bad times I am experiencing." ID 3, female, aged 39 years
	"I would really love to see that my respiratory condition has improved at the end of the whole exercise." ID 1, male, aged 42 years
	"I don't have anxieties, but my hope is the life I have, because it will continue, because I would sleep (meaning "die") soon, but because of this, I can have some more days – yes, prolonging my lifespan." ID 7, male, aged 80 years
	"Restoring my health... The breathlessness and my body to return to normal." ID 6, male, aged 39 years
	"My health... I want to return to my health as I was, doing work like used to before. The breathlessness should end, and I should be able to continue do things at home. Yeah." ID 8, male, aged 53 years
"I long to return to work in my life, which I used to do. Because I used to do brick laying (kuwumba zidina) and garden piece works, which used to bring me money at my home, but now everything stopped." ID 10, male, aged 42 years	

SECTION 2: VIEWS ON THE PROPOSED PR PROGRAM	
Themes	Participants' quotes
Advice for PR program success	<p>"All is good." ID 6, male, aged 39 years</p> <p>"So, I just have to be informed in good time, so I can inform my managers to allow me on the designated dates, so I can travel to Zomba and I can come... On the doubts, I don't have any doubt, in as long as you do your planning very well and re-inform all stakeholders in good time." ID 1, male, aged 42 years</p> <p>"I just train us so that we it can go well with us (ayi basi mungotiphunzitsa kuti zizatikhaliire bwino)." ID 9, female</p> <p>"My advice is that don't go backwards (osabwerera mimbuyo) and also us, the participants, we should be encouraging you; because if we become lazy, it will discourage you. But my advice is that what you are doing/have started should continue because it can help the lives of other people... I can have strength. Others who smoke or drink alcohol... can change." ID 7, male, aged 80 years</p> <p>"Our success will be your success; encouraging us." ID 8, male, aged 53 years</p> <p>"My advice is I need to understand and follow the program. I need to follow and do it in the way it should be done. I should see what becomes of my future. Because they say, 'fumbi ndiwe mwini' (self-confidence is success). So, if I don't follow the instructions, there is nothing that can benefit me. But I must follow what must be followed." ID 3, female, aged 39 years</p> <p>"For me to come regularly as... for me not to be absent, I must try to come regularly, do the exercises, trying to follow all the instructions that you are giving me, I think that would help." ID 5, female, aged 83 years</p> <p>"My advice is just a plea that when we start the research, when we go to the hospital, we shouldn't be sent back and being told that the doctors are not present, go back, come this day... going there and there is no clinic, returning... then they give us a far date that doesn't tally with your problem that has to be seen by a doctor... so what are you going to do there since you went to the hospital to be helped? So, here is my plea that we go to hospital, help us. Because if we go to hospital, it's because we have a problem that is preventing us from a living a normal day-to-day life. So, that's my please, that should be able to help us properly. We shouldn't be returning from the clinic ('tisamabwerere ku clinic'), no." ID 2, female, aged 39 years</p> <p>"I can't say in advance since the programme has not started yet. I mean, how can I point out the wrong if the wrong has not yet started? But if the wrong happens, and you will allow us to point it out, I will explain what will have gone wrong in our life where we, the trainees, will not have been helped. But people hear words differently, even in the church. Someone takes home something, someone else something else, especially the sermon. So, which means everyone knowledge is unique. So, I will perhaps say about my concerns only, while it may be all peace for others on that day. But I will surely be free." ID 10, male, aged 42 years</p>

*"I agree, as I have already said, I will do travel, Bangwe is not too far. If it were far than this, with my mind longing to be educated and helped, I can't be lazy."* ID 7, male, aged 80 years

Regarding day and time, some participants did not have preferences. For example, one participant said:

*"There is no problem with that. I am free to be there."* ID 2, female, aged 39 years

However, some participants had day and time preferences based on various factors some of which related to their health status, length of distance to travel to the PR centre, and competing commitments including work, household chores, and funeral attendance. For example, regarding day, one participant said:

*"I can accept that, unless if those two days include our Sabbath [Saturday]; I can fail. But for the other six days, I am ready any day."* ID 7, male, aged 80 years

Regarding time, one participant said:

*"Uhm, I think it should be around afternoon... Because perhaps to wake up early in the morning, I become very breathless. To do anything, to bathe etc... to get dressed after coming from the bathroom takes me 30 minutes or 1 hour of sitting down first. Breathlessness... Because around if it's around 1 O'clock, I can bathe early in the morning. I can... Yes, so, perhaps around 9... let me just say perhaps I can arrive here around 10 O'clock. Yeah, 9/10, I can be arriving here."* ID 8, male, aged 53 years

Regarding the PR program venue, one participant said:

*"Like isn't it right here where we have come? Ah, it's not difficult."* ID 6, male, aged 39 years

Regarding the (individualised) exercise component, one participant said:

*"I am proud of it. Because when I came for chest physiotherapy here, they told me that they would also come with the physical one aimed at being able to do some activities. In the process of my visits here, I have found an opportunity from God together with the Queens staff to join the physical exercise programme. So, while coming here for sputum excretion, God has also helped me to simultaneously do physical exercises."* ID 10, male, aged 42 years

Regarding the education component (including smoking cessation), one participant said:

*"Those are good ideas because for a person with such a chronic condition, it is not good to smoke because that smoke is not good, it can bring other problems in the body."* ID 2, female, aged 39 years

Regarding the group delivery format, one participant said:

*"It's a good thing because in the groups you learn a lot from each other. And in the groups, you also encourage each other..."* ID 1, male, aged 42 years

The program's public nature and participant group gender mix were considered socio-culturally sensitive by some participants. For example, regarding the program's public nature, one participant said:

*"Not seating and staring?... You don't have a curtain, where you...? ... [after interviewer said they have curtains] Ah then it's okay."* ID 5, female, aged 83 years

Regarding participant group gender mix, one participant said:

*"I can maybe say women can be in their own group and men in their own too, but we are together... As you said we would be doing exercises, right? So, I think this group of men, when they want to do their exercises, they should be men only. Women too should be in their own sub-group in this group. They can come in phases; men do their part and women do theirs too. It's possible... On reasons, I really can't say as I don't know what will be happening that will require us to separate."* ID 4, female, aged 58 years

None of the participants had concerns over the sex (male or female) of the PR program leaders. For example, one participant said:

*"It's the same; male or female, they are just a teacher you need to listen to."* ID 7, male, aged 80 years

#### **Theme 7: Anticipated benefits of PR program participation.**

When asked about aspects of their life they would like to see an improvement in after completing the proposed PR program, participants expressed various positive hopes and expectations including improved health, return to active lifestyle, and longer life:

*"I will be more active – yeah, it's that I really look forward to."* ID 5, female, aged 83 years

#### **Theme 8: Advice for PR program success.**

Finally, participants were asked to suggest ways of ensuring the success of the proposed PR program. Participants suggested aspects that both the program leaders and participants would need to do, including persistence/resilience and adherence to instructions, respectively:

*"My advice is resilience for the program leaders, they should be able to explain... we can sometimes do things wrong, but they should correct us to it the right way. Then we can be following their instructions. Because we will be doing some things we didn't know, we will be seeing for first time here. So, the encouragement/resilience from the program leaders will encourage us much. So that everything we want to do can progress."* ID 4, female, aged 58 years

## **Discussion**

### **Main findings**

Dyspnoea was the most reported chronic respiratory symptom by participants in this study. This finding is consistent with a global survey of PR professionals representing 430 PR programs, which identified dyspnoea as one of the seven most important outcomes for assessment in PR, although only one PR



program from Africa was represented<sup>44</sup>. In the present study, dyspnoea was accompanied by reduced physical activity tolerance which interfered with activities of daily living, another most important outcome for assessment in PR<sup>44</sup>. This necessitates inclusion of endurance training in the proposed PR program to improve participants' physical activity or exercise tolerance<sup>45</sup>.

Participants described various coping strategies for their chronic respiratory symptoms and associated functional limitations, including the use of an inhaler/bronchodilator. However, the use of an inhaler/bronchodilator only provided temporary relief and sometimes did not help such that some participants required hospital admissions. This is not surprising because, while inhalers/bronchodilators are the mainstay of pharmacological treatment for people with CRDs such as COPD, none reduce the progressive decline in lung function<sup>46,47</sup>. Conversely, evidence suggests that PR confers both short-term and long-term benefits to patients with COPD, including reduced anxiety, reduced hospital admissions, and improved quality of life<sup>48,49</sup>.

Participants' motivations for, or enablers to, participating in the proposed PR program included anticipated benefits of the program. However, this was after the researchers had explained the benefits of PR during the information sessions, which might have influenced their expectations. This finding resonates with a systematic review using the Theoretical Domains Framework that identified expectations of anticipated PR program outcomes as one of the factors influencing uptake<sup>50</sup>. Conversely, a lack of perceived benefit from PR was expressed regularly across the included studies as one of the factors that may impede uptake of PR. This highlights the need for regular updates during PR that include benefits of PR in relation to the outcomes patients would like to achieve<sup>51</sup>.

Participants' perceived barriers to participating in the proposed PR program included lack of access to transport, illness and competing commitments. Similar barriers have been reported elsewhere<sup>52,53</sup>. For example, many are unable to attend due to work commitments and social activities including caring for other family members<sup>52</sup>.

Finally, participants provided generally positive views on some organizational aspects of the proposed PR program, including

group delivery format, participant group gender mix, and its public nature. Participants' anticipated benefits of the group delivery format included providing an opportunity to meet new people and encourage or motivate each other. These are well-documented social benefits of group PR for people with COPD who are reportedly prone to feeling socially isolated<sup>54,55</sup>. It offers participants a social opportunity to interact, receive and provide emotional support, and encourage and motivate one another<sup>53,56</sup>.

Participant group gender mix and public nature of the proposed PR program are socio-culturally sensitive considerations in Malawi and other culturally proximal indigenous African communities. For example, in a study of healthcare professionals exploring barriers and enablers to PR in low- and middle-income countries, a participant from Malawi said: "... the first day we started the exercise therapy, there were people watching us or observing us. So, one person had observed this woman exercising amongst the team of men as well, a mixture of men and women and had reported to the husband. So, she said "Oh, it was an issue actually when I went home. You know, my husband wasn't happy about this and that and he asked me not to come back." So, luckily... when we explained to the husband, it was okay. And actually, the husband was asking if he could join..."<sup>21</sup>. Mohammed<sup>57</sup> found a similar gendered element in the Dagbamba community, Northern Ghana, in her research: "... when I was planning to go to a rural community in the Northern Region to conduct research with men and women about their media consumption habits, I shared my plans with the older people in my family and in the wider community. Some of them asked if men and women would be grouped together for these conversations. When I said yes, they told me that they believed the women would defer to the men if they were put together and asked me to reconsider this choice. Sensorially listening to the larger community about my methodological strategies enabled me to create space for women participants to comfortably share their perspectives without pressure to defer to the men.

### Implications for the proposed PR program and future research

There is a strong rationale for enhancing patient participation in PR through strategies tailored to the key barriers that are relevant to the setting<sup>58</sup>. By exploring the barriers to participating in the proposed PR program, potential patient-tailored and

**Table 2. Potential strategies to overcome participants' barriers to PR participation.**

Barriers	Potential strategies
Transport costs	<ul style="list-style-type: none"> <li>• Provide financial support to participants to cover their transport costs (short-term).</li> <li>• Provide tele-PR (long-term).</li> <li>• Provide home- and/or community-based PR (short- or long-term).</li> </ul>
Public nature	<ul style="list-style-type: none"> <li>• Use curtains to protect participants' privacy during PR sessions/classes (short-term).</li> <li>• Provide participants with a dedicated PR room/gym (long-term).</li> </ul>
Participant group gender mix	<ul style="list-style-type: none"> <li>• Split participant group into "male" and "female" sub-groups during PR sessions/classes.</li> </ul>
Timing and competing commitments	<ul style="list-style-type: none"> <li>• Provide both morning and afternoon PR sessions/classes and allocate participants to either of these according to their individual time convenience or preference.</li> </ul>

culturally adapted strategies were suggested for this participant group (Table 2).

The efficacy of these strategies in improving PR participation warrants further research. Globally, a major knowledge gap exists on strategies to improve patient uptake and completion of PR<sup>58</sup>, despite the increasing awareness of patient barriers to PR<sup>21,50,59</sup>.

### Study strengths and weaknesses

This study provides locally driven data that inform the design of an individualized and culturally sensitive PR program for people with chronic respiratory symptoms in Malawi. The use of in-depth interviews enabled the researchers to collect open-ended data on participants' experiences<sup>60</sup>. However, participants' views on the proposed PR program came from a hypothetical standpoint, which might not reflect similar elements of reality and lives of participants with lived PR experiences as reported elsewhere<sup>61</sup>. In addition, although data saturation was reached, the theoretical transferability<sup>62</sup> of our findings is limited since our study was conducted at a single site. Furthermore, unlike a similar study conducted elsewhere<sup>63</sup>, we did not perform spirometry to confirm the respiratory diagnoses documented in our participants' medical files, as we were interested in functional impairment based on symptoms.

### Conclusion

Participants with chronic respiratory symptoms commonly experienced dyspnoea which interfered with their work and activities of daily living. They were motivated to participate in a proposed PR program owing to its benefits. However, this was on the provision that perceived barriers such as transport costs, competing commitments, and concerns over the program's organizational aspects that were considered socio-culturally sensitive, were addressed. To ensure participation in the proposed PR program, pre-program assessments should consider patient access to transport, suitability of the timing for the program's sessions to participants, and patient views on the organizational aspects, including the program's public nature and participant group gender mix. The efficacy of these considerations in improving PR uptake in Malawi warrants further research.

### Data availability

#### Underlying data

Figshare: "My life is not going to be the same, my health is going to improve": a cross-sectional qualitative study of patients' experiences of living with chronic respiratory symptoms and their views on a proposed pulmonary rehabilitation program at

Queen Elizabeth Central Hospital, Blantyre, Malawi. <https://doi.org/10.6084/m9.figshare.19165667><sup>40</sup>.

This project contains the following underlying data:

- Anonymised transcripts for in-depth interviews with patients who participated in this study.

Data are available under the terms of the Creative Commons Zero "No rights reserved" data waiver (CC0 1.0 Public domain dedication).

#### Extended data

Figshare: "My life is not going to be the same, my health is going to improve": a cross-sectional qualitative study of patients' experiences of living with chronic respiratory symptoms and their views on a proposed pulmonary rehabilitation program at Queen Elizabeth Central Hospital, Blantyre, Malawi. <https://doi.org/10.6084/m9.figshare.19165682><sup>36</sup>.

This project contains the following extended data:

- Participant Information Sheet.
- Interview Topic Guide.

Data are available under the terms of the Creative Commons Zero "No rights reserved" data waiver (CC0 1.0 Public domain dedication).

#### Reporting guidelines

Figshare: COREQ checklist for "My life is not going to be the same, my health is going to improve": a cross-sectional qualitative study of patients' experiences of living with chronic respiratory symptoms and their views on a proposed pulmonary rehabilitation program at Queen Elizabeth Central Hospital, Blantyre, Malawi. <https://doi.org/10.6084/m9.figshare.19165685><sup>43</sup>.

Data are available under the terms of the Creative Commons Zero "No rights reserved" data waiver (CC0 1.0 Public domain dedication).

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