

# Experience-based co-design for improving and integrating mental health pathways within pulmonary rehabilitation services in south east London

Health Innovation Network South London

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# 1. Acknowledgements

This project was conducted by the Health Innovation Network South London on behalf of King's Health Partners and South East London ICS Population Health & Equity programme. We would like to take this opportunity to say thank you to the people with lived experience and staff working for pulmonary rehabilitation and mental health services across south east London who took part in the interviews, feedback events and co-design workshops - without your valuable input, this work would not have been possible.

# 2. Introduction

## 2.1. Project Background

South East London's Integrated Care System (SEL ICS) and King's Health Partners (KHP) have established South East London Coalition for Better Health and Equity, a joint a 5-year transformation programme focused on population health and equity. Part of this programme is the [Vital 5](#), which are the five risk factors that have a major impact on health at an individual and population level: blood pressure, obesity, mental health, smoking status, and alcohol intake.

A SEL-wide workshop was held in May 2023 to identify the mental health prevention priorities that are most important to system partners and service users facing the greatest health inequities. Following this workshop, an overall ambition to deliver better mental health outcomes for people with Long Term Conditions (LTCs) was agreed.

The Health Innovation Network for South London (HIN) has been commissioned as a co-design partner to work with KHP to plan, deliver, and report on a co-design project focusing on improving access to mental health and wellbeing support for patients with Long Term Conditions (LTC). This project specifically focuses on patients who are eligible to attend pulmonary rehabilitation (PR), which is an exercise and education programme designed for people with lung disease or respiratory conditions, who experience symptoms of breathlessness.

PR was selected as the focus of this project because it serves as an access point to services for people with LTCs. Evidence suggests that at least 30% of all individuals with an LTC also have a mental health problem (1) and therefore focusing on PR provides a tangible and effective way to reach people who are likely to need mental health services. One key mental health service is Talking Therapies, which offers psychological treatments for common mental and emotional problems like stress, anxiety and depression. There are lots of different types of talking therapy, but they all involve working with a trained therapist and offer self-referral.

The aims of this project are to facilitate the co-design of care pathways that enable personalised support to people who may require both PR and mental health services, through involving people with lived experience, and as a result produce recommendations for a clear and actionable implementation roadmap for pathway improvements.

## 2.2. Context

More than 15 million people in the UK (30% of the population) live with one or more LTCs, and over 4 million of these individuals also experience mental health problems (2). People with long-term physical conditions tend to have lower well-being scores than those without such conditions, and those with conditions like cancer, diabetes, asthma, and high blood pressure face a higher risk of mental health problems such as depression and anxiety (3). Conversely, individuals with severe mental health symptoms are more likely to have long-term physical conditions (3).

Poor respiratory health, such as asthma and chronic obstructive pulmonary disease

(COPD), is a significant concern, particularly in SEL, where 5% of people registered with GPs are diagnosed with asthma, and 1.3% are diagnosed with COPD, as indicated by 2021/22 Quality and Outcomes Framework (QOF) data. Comorbid anxiety and/or depression in COPD patients is associated with increased mortality, exacerbation rates, length of hospital stay, and decreased quality of life and functional status (4). Data on need and prevalence varies, with local integrating mental and physical healthcare (IMPARTS) data from 2021-2023 revealing that roughly 22% of respiratory patients experience clinically significant anxiety or depression, impacting healthcare utilisation and treatment adherence, and the recent Tandem trial highlighting that 42% of screened individuals experienced these symptoms (5).

A large proportion of eligible people are not referred to PR, although having comorbid depression increases the odds of referral (6). Patients referred to PR do not always have clear pathways to access mental health support, and depression and psychological distress can be a significant factor in non-completion of PR (7,8). However, accessing PR in itself can improve mental health outcomes (9).

There are different perspectives on other interventions that can support, with a recent randomised controlled trial (RCT) finding that a low intensity psychological intervention based on cognitive behavioural therapy (CBT) did not improve anxiety or depression in people with advanced COPD and mild to moderate anxiety or depression (5). Stress management, mood and anxiety are key topics included in PR programmes (10) but mode of delivery, signposting and referral is inconsistent (11).

In this context, the project aims to enhance access to and engagement with PR for individuals with mental health conditions, recognising the interconnectedness of physical and mental health and the need for integrated care approaches.

### 2.3. Involvement and experience-based co-design

Involvement is core to the HIN's approach to work, as we believe that by sharing their insights and knowledge, people with lived experience of health and social care services can help us to improve and innovate health and social care. The HIN have a co-produced Involvement Strategy and employ two Lived Experience Partners (LEPs) who advise on involvement approaches and build connections and trust with local communities and people who work with us.

A methodology called [experience-based co-design](#) (EBCD) has been followed for this project. EBCD is an established evidence-based approach developed by The Point of Care Foundation. It was designed for, and within, the NHS to develop solutions that offer patients a better experience of treatment and care. EBCD was agreed as an appropriate methodology for this project as it provides a structured approach to involvement and supports collaboration and trust among stakeholders, which is vital when co-designing in complex environments around sensitive topics such as mental health.

The EBCD process involves collecting and sharing insights from patients and staff in a way that builds understanding, mutual respect, and consensus. Experiences are gathered through in-depth interviews, observations and group discussions with both patients and staff. Emotionally significant points are identified and a short, edited impact film is created from the patient interviews to highlight these. Separate feedback events are held with both patients and staff, with patients viewing and discussing the impact film whilst staff

discuss findings and observations from interviews. Patients and staff are then brought together for a final joint feedback event where the impact film is shown to the combined group. A series of co-design workshops follow, to explore the findings and to work in small groups to identify and discuss activities that could improve the service or care pathway. The approach uses storytelling, focusing on experience and emotions rather than attitudes and opinions, to identify the opportunities for improvement.

This qualitative approach provides rich insights into the experience of patients as well as staff. Through the bringing together of staff and patients to prioritise areas for improvement and define actionable recommendations, the process is outcome-focused and leads to relevant and feasible results. The methodology is also adaptable and can be tailored to different situations.

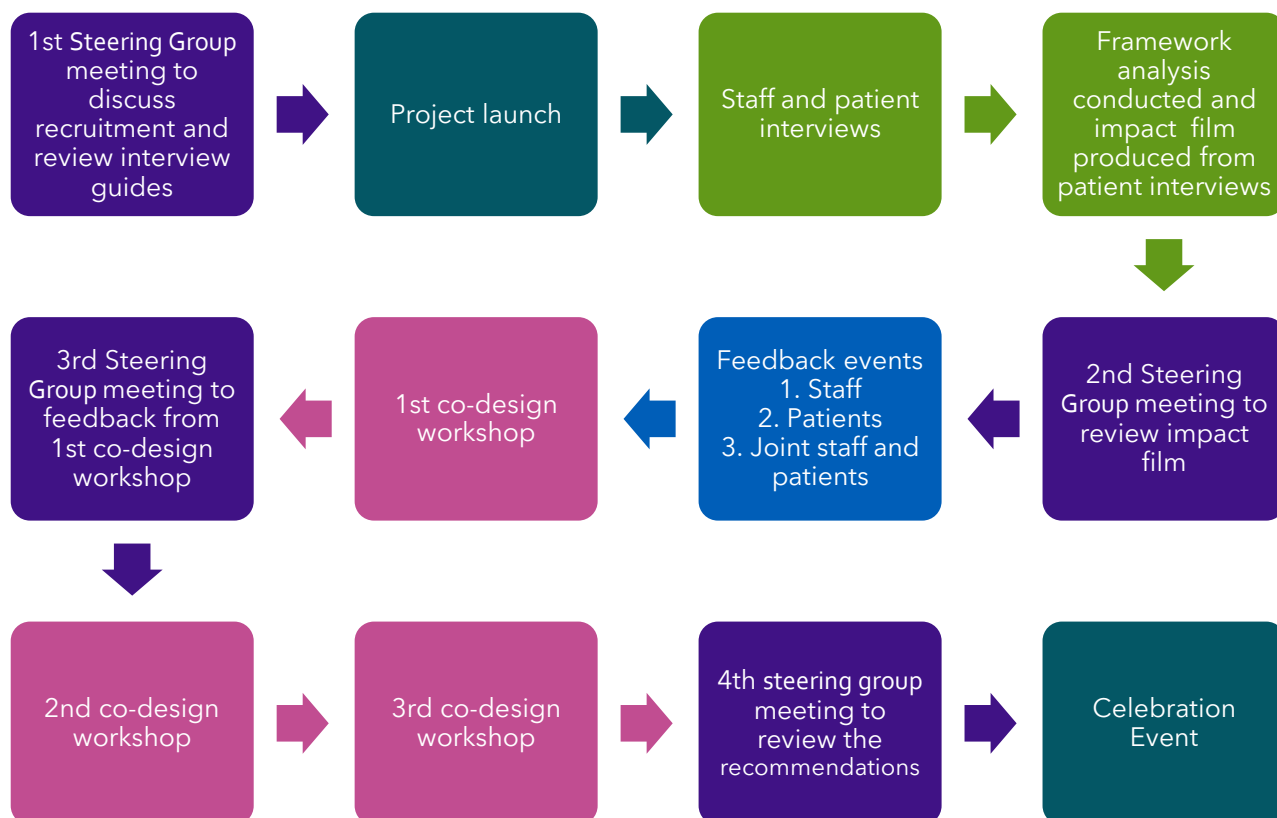
## 3. Methodology

### 3.1. EBCD process

A number of adaptations to the standard EBCD process were made for this project, the main one being the timeline; the standard time, recommended by The Point of Care Foundation, is nine to twelve months. To meet the wider programme requirements, a pragmatic and adapted approach was adopted to fit within the given timeframe of five months, whilst maintaining the principles and ethos of EBCD. To enable delivery against the shortened timeline, the project only ran one co-design workstream focusing on all priorities identified in the feedback events whereas usually several workstreams run in parallel. Additionally, online sessions were held rather than in person, and therefore feedback events and co-design workshops were shorter in length to support effective engagement and minimise fatigue. To allow these shorter sessions, breakout rooms were used to ensure all participants could contribute and some elements (such as emotional mapping) were not completed.

The adapted EBCD model used for this project is depicted in Figure 1. A project steering group (including clinical leads from PR and Talking Therapies and a LEP) was set up to meet at critical points throughout the project and provide oversight. Further information about each stage is detailed in the following sections of this report.

**Figure 1 Adapted EBCD process**



## 3.2. Recruitment

### 3.2.1. Patients

EBCD is a resource-intensive methodology which focuses on the value of in-depth, qualitative insights and this, coupled with the co-design nature of the approach, relies on building trusted relationships with participants (staff and patients). Therefore the Point of Care Foundation suggest recruiting a relatively small numbers of participants (5-15 patients) to ensure people are appropriately involved, have a positive experience and are able to provide detailed insights into their personal experiences. For this project we anticipated recruiting 10 patients (or carers).

To recruit patients, promotional materials to advertise the opportunity to participate were developed (flyers, emails) with the input of one of the HIN Lived Experience Partners (LEP). Invitations and participant information packs were produced, outlining the purpose, process, payment, and time commitment required and shared with existing patient and carer's networks. Patients were also directly recruited through healthcare professionals working in PR in SEL, the project team attending a PR class to recruit attendees, and the opportunity to participate was advertised in the HIN involvement newsletter.

Following review by the steering group of the recruitment material by the 22 January 2024, a 4 week patient recruitment period commenced with interviews then taking place between 25 January 2024 and 15 February 2024.

### **3.2.2. Staff**

To recruit staff, invitations and participant information packs were produced, outlining the purpose, process and time commitment required. The project team and steering group members reached out to existing networks, and the project team attended a PR class to recruit facilitators. Care was taken to recruit staff working at different levels of the system including south east London PR service and respiratory clinical network leads, physiotherapists and health care assistants working in PR, GPs and practice nurses, psychologists and psychological therapy leads, and Voluntary and Community and Social Enterprise (VCSE) partners.

Interviews took place between 23 January 2024 and 6 February 2024.

## **3.3. Interviews**

The interviews aimed to garner the views and experience of patients and staff. Whilst the focus of this project was on access to mental health support for people living with long term conditions, it was important for interviews to be as open ended as possible to capture the real experience, and accompanying emotions, that this entails.

Staff and patient interview questions (appendices A and B) were reviewed by one of the HIN's LEPs, mental healthcare professionals and PR staff at the first steering group meeting to check the terminology used was appropriate and ensure questions were not leading. All interviews were conducted via MS teams or telephone and lasted 30-60 minutes.

### **3.3.1. Patients**

In total, nine patients who had attended PR were interviewed (eight on MS Teams, and one via phone call). Interviews were recorded with consent and the patients were offered payment for their time in line with the HIN's payment guidance for participants with lived experience. Once the interviews were completed, all recordings were reviewed. An analysis framework was developed to capture information from the raw interview data and aid the development of themes and sub-themes.

### **3.3.2. Staff**

Seven members of staff were interviewed including clinicians from primary care, Talking Therapies, and PR, and one housing navigator who worked with people with both breathlessness and mental health needs. Interviews were recorded and thematically analysed to aid the identification of key issues and priorities.

## **3.4. Impact film**

The impact film is an essential element of the EBCD process and 'involves creating a comfortable environment for patients to share their stories of services, and capturing those stories effectively, to provide rich information that will guide improvement' (12). The purpose of the impact film is to capture the patient experience and amplify this to allow staff to see the service and their experiences through their eyes. It also 'provides a



platform for direct, honest conversation between the staff and [patients] to raise areas of concern or missed opportunities and celebrate and replicate areas of success' (13). The film is designed to be shown solely as part of the EBCD process to act as a discussion prompt, rather than as an output which is shared more widely. This serves to build trust with patients, and a psychologically safe space for them to speak freely rather than being concerned about who may potentially view the film.

To produce the impact film, a framework analysis approach was undertaken. Project members reviewed the patient interview recordings and transcripts to identify key quotes to be assigned within the framework. Two members of the HIN project team independently reviewed the framework quotes and determined which would be most valuable to include in the impact film.

A simple structure for the impact film was then developed based on these selected quotes, organised under subheadings for the overarching themes (diagnosis/condition, PR, and mental health). This structure along with the video clips were shared with the HIN communications team for review and the development of a draft film. The draft was subsequently shared with the steering group and both HIN LEPs for feedback, leading to adaptations based on their input.

Simultaneously, and ahead of the patient feedback event, each patient was informed which of their quotes were to be included in the impact film, to provide opportunity to exclude elements they did not wish to have viewed. The draft film was 20 minutes in length and was presented at the patient feedback event for approval and sign off prior to being shared at a joint event. This is a further element of the EBCD methodology designed to create a psychologically safe space for patients to share their thoughts openly.

## 3.5. Feedback events

Three online feedback events were held to view and discuss reflections on interviews and the impact film, and to determine the areas of focus for the co-design workshops.

### 3.5.1. Staff feedback event

This purpose of the staff feedback event was to enable staff to highlight their priorities for improvements within their service. Key findings from the staff interviews were presented in the meeting, and the facilitator asked for feedback and discussion on these points.

### 3.5.2. Patient feedback event

The aim of the patient feedback event was to allow patients to have a first view of the impact film reflecting their experience of living with a LTC and participating in a PR service. Within the workshop patients were asked again if they were happy with the materials used and offered the opportunity to share comments via email or a separate conversation if preferred; this approach gave patients control of the material in a way that built trust between the facilitators (HIN) and the patient group.

After watching the impact film, patients were asked about their initial thoughts and reflections, and a discussion around the key areas for improvement was facilitated using a 'round' technique, ensuring all participants had the opportunity to contribute.

### 3.5.3. Joint feedback event

The joint workshop was an opportunity to bring staff and patients together to start building consensus and to develop trust and rapport in advance of the co-design workshops, with the HIN acting as a consistent trusted partner. An overview of the process so far was provided. The combined group watched the impact film together and discussed the footage. The staff and patient priorities that were agreed at the earlier (separate) feedback events were shared so that all participants could see the priorities discussed and comment on these to help refine them further.

## 3.6. Co-design workshops

Following the feedback events, a co-design group was formed and a series of three online co-design workshops were designed (Figure 2). The aim was for patients and staff to work together to identify and design solutions to the eight priority issues highlighted in the feedback workshops:

1. Patients understand the link between a long term condition and mental health and where to seek support.
2. At point of referral, patients have a full understanding of the education/rehabilitation programme they will be participating in.
3. Patients have an opportunity to ask questions about what to expect from PR.
4. Any education/rehabilitation programme aimed at people with long term conditions should contain education\* about mental health.
5. Any education/rehabilitation programme aimed at people with long term conditions should contain an opportunity for group peer support.
6. Clinicians are aware of the different mental health and wellbeing services available to signpost patients to if further help is needed.
7. MH specialists embedded within LTC teams to provide expertise.
8. Patients are offered ongoing wellbeing support after PR.

\*note: 'education' in this context encompasses information sharing, signposting and awareness raising.

During each co-design workshop, participants were split into small break-out groups (4-5 participants, including both staff and patients - wherever possible both mental health and PR staff were included in each break-out group) before feeding back to the wider group. At the first workshop each priority was discussed focusing on what good practice already exists, and then at the second workshop the conversation was built on by focusing on what does not currently exist but could be considered.

At the final workshop, five of the eight priorities were identified for further discussion (the three which were not discussed were deemed as out of scope due to lack of feasibility, or lack of focus on mental health). For these five priorities, the work completed in the first two sessions was then further tested against what was feasible within the scope of this project, culminating in the recommendations in section 5.

As not all participants could attend each workshop, all were given the chance to input in between sessions via email.

**Figure 2 Structure for co-design workshops**



### 3.7. Celebration event

To conclude the project, all participants were invited to attend an online celebration event. The event provided the opportunity to thank all participants for their time and valuable contributions, share the project outputs, and to reflect on what had been achieved as well as to provide feedback on the EBCD process.

## 4. Findings

EBCD methodology is an evolving, iterative process, with each stage informing the next as well as building on preceding events. The findings, therefore, are grouped sequentially to support the narrative, and represent the context for the recommendations.

### 4.1. Approach to conversations about mental health

Throughout the EBCD process, discussions surrounding mental health were occasionally explicit, but were more often addressed indirectly through topics like wellbeing, self-care, loneliness, feeling overwhelmed, uncertainty, and social interaction. These themes emerged from patient conversations and are reflected in various quotes within this report.

The patient interviews and feedback event revealed that while some patients responded well and related to the term 'mental health', others did not. When discussing language, some staff raised the importance of addressing stigma by using the term 'mental health', yet acknowledged the need for alternative terms if patients didn't resonate with it. As a result, the project team opted to use the phrase 'mental health and wellbeing' to ensure these discussions were more inclusive.

## 4.2. Participant characteristics

Please note: not all participants attended all feedback events and co-design workshops.

### 4.2.1. Patients

We recruited a small number of patients (n=9), in line with the EBCD methodology, for the interview stage. This included people from five of the six SEL boroughs and people with various respiratory conditions (COPD, asthma, bronchiectasis and pulmonary fibrosis), as well as one individual who had been identified as high risk of not completing PR. Following the interviews, 8 patients agreed to continue and attend the feedback events and co-design workshops.

### 4.2.2. Staff

Seven staff were enlisted to participate in the interview process, encompassing representation from six organisations and various roles spanning PR services, talking therapies, primary care, and health inclusion. Whilst twelve staff members from PR services, talking therapies, and the VCSE attended the feedback events and co-design workshops, representing eight organisations.

Note: one interview was conducted with a staff member from outside SEL, and one different individual from outside SEL attended the co-design workshops. Their input was sought based on recommendations from other staff partaking in the project, as they shared similar experiences despite working outside of the region.

## 4.3. Feedback events overall attendance

	Number of patients attended	Number of staff attended
Patient	6	N/A
Staff	N/A	4
Joint	6	6

## 4.4. Patient feedback event

Six patients attended the patient feedback event. Patients' reflections on the impact film gave fairly equal weighting to both positive elements and barriers faced by people with LTCs in making the most of available support including the challenges posed by living with a lifelong chronic condition.

### Social support

Patients felt the film accurately reflected the importance of the social aspect of PR, including informal opportunities for conversation, hearing the experiences of peers, and the more structured support from PR ambassadors.

*You meet new people, get to talk to other people, you get to realise that other people have got these problems. You're not the only one cause you do tend to with the illnesses I think a lot of people spend their time indoors, and with that they're locked away basically from other people that have these issues. And when you realise that other people have got these issues, doesn't make it easier. But it's just, you know, you could talk to people. They understand what you're going through.* - Patient interview 005

*The social side of it, you meet other people with your condition. We have coffee after, we talk and that's quite refreshing. You know you don't feel quite so isolated because it's very scary when you, when you, when you have an attack and you just can't get that air in and you know you think that's your last breath.* - Patient interview 006

### **Education**

PR education sessions were greatly valued, and were informative, helpful and reassuring. A session delivered by a psychologist was highlighted as a particularly helpful.

*There's a combination of [exercise] and the education class, what it's like living with COPD. We covered dieting, exercising at home, chest clearance, clearing the mucus etc., all the various aspects of living with COPD. That got me over the panic stage when I couldn't breathe. I was learning a lot about how my body worked as well what's going on inside the lungs and how the exercises are clearing it.* - Patient interview 003

### **Lack of information**

During the interviews and the feedback event, several patients highlighted that they received limited information about the PR programme at the point of referral and did not know what to expect. It was noted that this could contribute to non-attendance.

*Apprehensive, nervous, could I do it? What is it? What have I gotta do? For starters, I've got no clue on what I had to do in the beginning. There's no information about it out there. Basically you get a call saying... 'you've been selected to do the pulmonary rehab class, are you ready to do it, yes or no? Yes, great starting this time that day and yeah, go to Plumstead leisure centre.' And with that, you're turning up blind. And yeah, there's a lot of apprehension.* - Patient interview 005

Supporting this, whilst it was clear that some patients had been made aware of helpful educational material and literature about PR, long term conditions and mental health as well as health and wellbeing more generally, this was not a universal experience amongst the cohort. It was also noted that this material should be provided at different touchpoints - diagnosis, PR referral, during PR and afterwards where possible to support understanding and reiterate key messages.

*They've given me... lots of information about how to control your breathing. You know that they gave me leaflets on how to, if you've got a problem with your breathlessness, how to address the problem. How to, you know, regain your breath.* - Patient interview 002

### **Physical access to venues**

A number of patients mentioned the difficulty they face in travelling to venues that were far from home, particularly for people living with the threat of exacerbations and other conditions.

*I had a referral for PR again which led to an email exchange with the PR team but they've subsequently stopped doing the online, the virtual PR. And so I said, because of me immunity and I didn't wanna go over there so that that was the end of that. - Patient interview 001*

## 4.5. Staff feedback event

Four staff attended the staff feedback event. Broadly, feedback to interviews with colleagues fell into three categories: staff education; operational challenges; and a recognition of the barriers faced by patients who need mental health support.

### **Staff education**

A strong steer from staff interviews, and further underscored in the feedback event, was that healthcare staff working with people with LTCs need ongoing and regular training on how to have conversations about mental health; and should have up-to-date knowledge on resources and services that can be accessed by patients struggling with low mood. It was recognised that within the wider healthcare landscape, there is limited awareness of the impact of LTCs on patients' psychological wellbeing.

*There's a lot of drop out in completion, and PR teams aren't necessarily that well-resourced to address the factors that are contributing to the dropout. So they don't necessarily have the skills in addressing issues of motivation. They might not have had the training, they might not have the time and the skills to kind of assess and signpost for mental health because you know, there's these group classes, they're focused on the group, it's difficult to sort of follow up with people. - Staff interview 006*

### **Operational challenges**

An identified area for improvement was closer working between Talking Therapies and PR services, supporting quality referrals, joint working and communication.

### **Barriers to access**

It is recognised that rehabilitation services for LTCs, like PR, are in themselves an intervention that supports mental wellbeing (14). Viewed through this lens, staff recognised that barriers to access needed to be addressed. Notably, better information at the point of referral about what PR is, as well as being informed that they are being referred to PR in the first place, could support uptake of PR by helping patients understand why it can benefit them and reducing anxiety about what to expect. This aligned strongly with insights gained from patients.

*"90% don't know and a lot, I'd say like half of them, haven't even been told by their GP that they've been referred for the program and then half of them have been told that they're referred to the programme, but they have no idea what it is that they've been told that they'd be referred to." - Staff interview 007*

*"Based on who referred them, their sort of expectations of what they're coming to can be quite different. Some clinicians explain really well what pulmonary rehab is, have a really good understanding. But some clinicians... it's really hard for them to have a really good idea of what PR is and be able to explain that to the patients. I think sometimes that sort of unknown can be quite anxiety inducing in patients." - Staff interview 004*

Long waiting times between referral to services, assessment and attendance were also highlighted as barriers to access, with some multiple appointments required before the first PR session and limited service capacity which can delay appointments and availability of PR.

*We refer in and then there is a bit of a delay time in patients getting the appointment, and then they are assessed by somebody from the COPD team and then... So it's quite a long process where sometimes you want someone to be seen sooner rather than later when you've tried to encourage them to go, because otherwise things change in their lives. - Staff interview 003*

## 4.6. Joint Feedback Event

Six patients and six staff attended the joint feedback event. It was clear from staff feedback that the film not only had a significant emotional impact, but also provided new insight into the lived experience of patients away from their contact with the healthcare system. One area that stood out was the period before people reach PR services:

*In the beginning, I initially locked myself in a room and went to bed. Not just for a few days, for years. - Patient interview 007*

Patients too, were profoundly affected by the experiences of their peers, relating to descriptions of years of low mood, being “locked in at home” and being “nearly destroyed” after being signed off work due to their condition. It is notable how universal the experience of long periods of low mood was, often persisting for many years. In their experiences of care, patients did not think that mental health was a priority and did not, in most cases, perceive this low mood to fall into the category of ‘mental health’ and did not relate it to their physical health condition.

*I just wish that it [mental health needs] had been picked up. I was in the system for 40 years and nobody ever asks. I was always given medication but nobody took the extra step to ask how I was. - Patient workshop quote*

*This is again with this kind of thing, this kind of program that you realise that there are times when you have been perhaps in a lower state that you have and I hadn't really connected it. So I've talked about those moods and depression and stuff many, many times, but I haven't connected it with my condition and I think through my life I probably played down my condition for one reason or another. Didn't want to be defined by having a problem. I feel more open about it today, much more. - Patient interview 008*

Operational considerations aside, there was a remarkable degree of alignment between staff and patient groups in the identified areas for improvement to support better mental health. This was evident from both groups independently mentioning the need for consistent provision of educational material and information to patients, and staff confidence (and need for ongoing education) to support conversations about mental health. The latter would go some way towards addressing the lack of attention given to people living with LTCs, with its associated increased prevalence of mental illness (1).

## 4.7. Co-design workshops

	Number of patients attended	Number of staff attended
<b>Workshop 1</b>	5	6
<b>Workshop 2</b>	6	5
<b>Workshop 3</b>	6	6

Three co-design workshops built on the themes that emerged from feedback events to develop recommendations that were realistic and could be implemented within a 12 - 18 month timeframe. The value of having staff and patient groups working in tandem to develop these recommendations (see section 5) was made clear in the third and final session, as staff provided context and insight into what was within the gift of the current healthcare system.

Note: whilst the workshops identified both gaps and areas of good practice, this was not intended as a detailed mapping exercise or gap analysis and instead was designed to generate ideas and discussions to contribute to the recommendations.

See Appendix C for a summary of the workshops, with feedback organised according to the priority areas that were identified in feedback events.

# 5. Recommendations

The recommendations presented here are a result of the co-design process and have been derived from the patient perspective moderated by staff experience and contributions. They have been kept deliberately solution-agnostic to allow systems and services to respond to them in a way that is feasible and suitable locally.

<p><b>Theme 1: Strengthening the link between pulmonary rehabilitation and mental health</b></p>	<p><b>1. Integration of care</b></p> <p>Specialist roles and services (e.g., Talking Therapies, social prescribing, respiratory nurses and charitable services) should be integrated into the PR pathway from referral, where appropriate, through delivery and after completion.</p> <p><b>2. Patient information</b></p> <p>PR services should take a consistent and comprehensive approach to patient information, ensuring signposting to appropriate services, the sharing of educational materials and clear routes for patients to seek further support.</p> <p><b>3. Screening and assessment</b></p> <p>Validated mental health screening tools should be used consistently at appropriate points throughout the PR pathway so that patients can</p>
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	<p>be referred or signposted to appropriate support services (where available) if required.</p> <p><b>4. Language</b></p> <p>Across the pathway, the terms 'mental health', 'mental illness' and 'wellbeing' should be adopted and used in tandem, highlighting how the three are interlinked and how there are different levels of support available for individual needs.</p> <p><b>5. Staff education RE wellbeing</b></p> <p>PR services should ensure clinicians and ambassadors are supported to have the appropriate skills, knowledge, confidence and awareness relating to using assessment tools, having wellbeing conversations, wellbeing check-ins, managing peer groups and signposting to support.</p>
<b>Theme 2: Peer support</b>	<p><b>6. Peer support</b></p> <p>PR services should incorporate an element of peer support into their service model as a way to facilitate informal conversations about mental health and wellbeing.</p>
<b>Theme 3: Operational improvements</b>	<p><b>7. Post-PR</b></p> <p>Patients should complete the PR course having been given the knowledge of where and how to access future support for both physical and mental wellbeing including social prescribing and the VCSE.</p> <p><b>8. Addressing drop-outs</b></p> <p>PR services should take a quality improvement approach to understanding and addressing drop-out 'moments', such as between referral and pre-assessment, ensuring that the drivers (health equity) are fully understood.</p>

Note: for each recommendation, some possible solutions are presented in Appendix D; these were identified during the co-design workshops and are included here as helpful suggestions rather than as a prescriptive or comprehensive list of responses to achieve the recommendations.

## 6. Limitations

There were a number of limitations that are inherent to the compressed timeframe of the project delivery phase. These are listed below, including steps taken to mitigate their impact during this project:

### 1. Limitations to the EBCD methodology and adapted approach taken

The EBCD approach is a qualitative methodology which relies on in-depth insights from a relatively small number of participants. This means that the sample is often unlikely to be representative of the wider population and may have limited generalisability. Additionally

the adapted approach that was taken during this project, namely the reduced timeframe, impacted upon the ability to recruit a diverse group of patients and staff (see limitations 2 and 3). The project has therefore added validity to existing assumptions but further work is required to ensure generalisability of findings.

## **2. Patient cohort limited diversity**

Whilst it was possible to recruit individuals from different boroughs and with different conditions, there were some characteristics (e.g. gender and ethnicity) where it was not possible to obtain the diversity desired within the timeframe. We know, for example, that women are under-represented in PR (15) and that the ethnicity of the patient cohort does not represent the demographics of people in SEL. Additionally, all participants in the project had completed the PR course and therefore could provide limited insight into why people drop out, although ill-health, finding the course too hard and difficulty getting to the classes were all highlighted as possible reasons for non-attendance.

Building trust with groups e.g. those without housing or those with dependence issues, to obtain a diverse cohort takes time and requires in person contact to build trust. The four-week recruitment window did not support this approach. The HIN's LEP (whose role in the project was to amplify and advocate for the patient voice using their lived and learnt experience from working closely with a range of people in the local community) was therefore a pivotal part of the project and provided some mitigation, offering a perspective closer to those who have limited engagement with the healthcare system.

## **3. Diversity of staff representation**

A key consideration of the project was to ensure all staff groups involved in the pathway contributed not just to the workshops, but also to the recommendations. Whilst balanced representation was achieved across the project timeline, not every staff group was represented at each workshop. The project team mitigated the impact of this by ensuring summaries of key points were circulated following each event, allowing for comment offline although limited responses were received via this method.

Additionally, there was minimal input from primary care, with only one practice nurse interview and one GP represented in the steering group. Existing contacts were used to try to maximise engagement, however obtaining greater representation was challenging due to existing pressures within the system.

## **4. Virtual meetings**

Convening meetings in person was not possible given the timeframe of the project. The EBCD process emphasises building of relationships and trust fostered by human connection that is far easier in person. Virtual meetings do change the dynamic between people but the HIN project team placed emphasis on personal contact with each patient in the cohort, providing a consistent point of contact. Furthermore, given the challenges faced by patients with breathing difficulties, virtual meeting offered improved access for many who would have otherwise been excluded if workshops were hosted in person.

## **5. Time allocation**

Online meetings tax human attention in a different way to in person interactions and therefore are recommended to be shorter. However, this means that duration of time for comment is more limited i.e. each participant will not have the opportunity to contribute to each area of work, particularly where recommendations are concerned. Mitigation was put in place in two ways: 1) by creating breakout groups with smaller groups of people,

creating 'space' for conversation and 2) by circulating recommendations and supporting material following each workshop to allow people to comment offline.

## **6. Gap analysis**

Whilst this project did not seek to produce a gap analysis, insights were gained into some of the different services available in SEL (see Appendix C). This is not exhaustive, and a further dedicated mapping exercise would be required to obtain detailed insights into individual services across SEL.

# 7. Glossary

**CBT:** Cognitive behavioural therapy

**COPD:** Chronic Obstructive Pulmonary Disease

**EBCD:** Experience based co-design

**HIN:** Health Innovation Network South London

**ICS:** Integrated Care System

**IMPARTS:** Integrating mental and physical healthcare

**KHP:** King's Health Partners

**LEP:** Lived Experience Partner

**LTC:** Long term condition

**QOF:** Quality and Outcomes Framework

**PR:** Pulmonary rehabilitation

**RCT:** Randomised controlled trial

**SEL:** South East London

**VCSE:** Voluntary and Community and Social Enterprise

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# 9. Appendices

## Appendix A – Staff interview topic guide

### Warm up

- 1. To start, can you tell me about your background with providing care to people who require pulmonary rehabilitation and how you came into your role.**
  - What is your role and where do you work?
  - Can you tell me about the referral process to PR, and what your role is in this?

### Main questions

- 2. What do you think it is like being a patient requiring pulmonary rehab in your service / the PR services in this area?**
  - Why?
- 3. In your opinion, what are the major 'touch points' or critical moments in the patient journey (the things or events that really shape patient's overall experience)?**
  - What impact do these points have?
  - Are there any barriers which patients face at these points?
- 4. What are the different roles of the staff involved in managing the care of a person who requires pulmonary rehab?**
  - GP, consultant, wellbeing services, pain specialist, physiotherapy, social services, social prescribers
- 5. Other than pulmonary rehab, what other services are you aware of which could benefit people who require pulmonary rehab?**
  - Mental health, wellbeing, exercise, social prescribing/app, peer support group/website, charities: info and signposting
- 6. Can you tell me about any mental health or wellbeing services which can support patients alongside pulmonary rehab?**
  - How do patients get referred to these services?
  - Are there any challenges associated with these?

**7. What works well about pulmonary rehab services currently?**

- Why?

**8. What is not working so well about pulmonary rehab services currently?**

- Why and how could this be improved?

**9. In your opinion, where might we begin to improve the patient experience around pulmonary rehab services locally?**

- What would be the impact on patients and their carers?
- Examples could include addressing: reasons DNA appointment, ways services are communicating with patients/carers e.g. deaf patient and receiving phone calls / accessible info standard

**10. What do you see are the main priorities for improving the service from the staff point of view?**

- What additional support/resource would be helpful to achieve these / overcome the challenges you've identified?
- What would this enable? How?

**11. How to you share best practice / spread and adoption of current successful models?**

- Where do you learn about best practice, and where would you take learning to?

## Closing the interview

That's all the questions that I had planned to ask.

**12. Is there anything else that you would like to add or any other comments that you would like to make before we finish the interview?**



## Appendix B – Patient interview topic guide

### Warm up

- 1. Can you tell me about your lung condition, and what a usual day looks like for you?**

### Your journey

- 2. Can you tell me about when you first were diagnosed with your lung condition?**

- When was this and how long did the diagnosis process take?
- How did this come about? What was your first reaction?

- 3. How have breathing difficulties affected your life?**

- Does living with this condition impact your day-to-day life?
- What is the impact on your well-being, mood?
- What support do you have (friends / family etc.)?

- 4. Can you describe your experience of getting help for your condition / breathlessness?**

- Have you seen any of the following: GP, consultant, pain specialist, physiotherapy, social services, wellbeing services

- 5. Can you tell me about when you were referred to pulmonary rehab?**

- When was this and how long did the referral take? What was your first reaction?
- What information were you given? Is there anything you weren't told which you would have liked?

- 6. Did you attend any pulmonary rehab sessions?**

- If yes, why? What encouraged you to keep attending? Did you attend them all?
- If no, why? What would have enabled you to attend?
- Consider: transport, health, finance, timing, carer support.
- Note: there are three options for people: 1) referred and completed PR, 2) referred, started and dropped out, or 3) referred but didn't start

- 7. Has anyone been in touch since you've been to your pulmonary rehab sessions?**

- Do you have regular contact with any healthcare professionals (physical health or mental health)?

**8. Living with breathing problems can be tough. Do you have low moods, or have you been diagnosed with anxiety, depression or another MH condition?**

- Does this impact on your ability to manage your condition?
- Did this affect your attendance to pulmonary rehab?
- If not,
  - Would you know where to go for support if you needed it?
  - Do you think anyone on your cohort was accessing other services, or would have benefitted from them to support their mental health / wellbeing

**9. Have you had other support to help you with your wellbeing, for example, mental health services, social care, community groups?**

- If yes, was this before / after you were referred to pulmonary rehabilitation? What was it like getting hold of these services? How did you know where to find them? Can you explain more about this and how you have found it?
- If no, do you think you would have benefited from mental health or wellbeing support and why?

**10. Thinking generally, what has worked well in regards to managing your condition?**

- Any particular medication, support, healthcare professionals? Why?

**11. What has not worked so well in regards to managing your condition?**

- Any particular medication, support, healthcare professionals? Why?

**12. At any time during your condition management journey would you have liked more information?**

- Is there any information about mental health or wellbeing services you would have liked specifically? When would you have liked this information?
- What difference do you think it would have made?

## Closing the interview

That's all the questions that I had planned to ask.

**13. Is there anything else that you would like to add or any other comments that you would like to make before we finish the interview?**

## Appendix C – Summary of findings from co-design workshops 1 and 2

Priority	Session 1: what already exists	Session 2: what could be considered
<p><b>Patients understand the link between a long term condition and mental health and where to seek support</b></p>	<ul style="list-style-type: none"> <li>Greenwich have GAD and PHQ-9 – dependent on score patients may be referred to clinical psychologist or Talking Therapies.</li> <li>Expert patient programme – work with other patients to talk about mental health – unsure whether these still exist.</li> <li>QI project in Greenwich to fast-track patients who have been assessed and not attended or dropped out.</li> <li>Standardised mental health screening for physical health clinics at GSTT</li> <li>Greenwich have educational classes with Time to Talk</li> </ul>	<ul style="list-style-type: none"> <li>An educational piece for any staff who work with patients with long term conditions</li> <li>Start using the term mental health early on in the diagnosis</li> <li>Further training for ambassadors – they are the ones who work with the patients throughout the entire process</li> <li>MH check in should happen at every opportunity i.e. during annual COPD review or when being referred to PR. Integrate questionnaires into routine care.</li> <li>A respiratory nurse or social prescriber at the GP surgery could meet with patients when they are diagnosed to discuss MH</li> <li>Promote singing for lung health – naturally supports MH</li> </ul>
<p><b>At point of referral, patients have a full understanding of the education/rehabilitation programme they will be participating in.</b></p>	<ul style="list-style-type: none"> <li>SEL videos explaining PR</li> </ul>	<ul style="list-style-type: none"> <li>Have an ambassador or peer support worker at check in with patient.</li> <li>Share the existing videos – a 5/10 min presentation.</li> <li>Workshops for new starters – play the video/have ambassadors present to answer questions.</li> <li>Having one place where patients can go for information, and having it available in</li> </ul>

		<p>different formats and signpost to this at the point of referral.</p> <ul style="list-style-type: none"> <li>• Materials should be co-produced with people who have been through the whole process.</li> </ul>
<p><b>Patients have an opportunity to ask questions about what to expect from PR.</b></p>	<ul style="list-style-type: none"> <li>• GSTT informal group discussions on zoom</li> </ul>	<ul style="list-style-type: none"> <li>• Patients should be provided with contact details so that they can voice questions/concerns in the initial materials.</li> <li>• Give opportunity to observe a PR class without taking part.</li> </ul>
<p><b>Any education/rehabilitation programme aimed at people with long term conditions should contain education about mental health.</b></p>	<ul style="list-style-type: none"> <li>• Lewisham PR workshop sessions on stress/anxiety and sleep delivered by TT staff</li> <li>• Greenwich PR have a session with Time to Talk (people can self-refer)</li> </ul>	<ul style="list-style-type: none"> <li>• Make this part of the social element - have MH specialist there to take part in chat.</li> <li>• Goal setting as part of PR classes - achievements can be boosting. Seeing small steps is significant for improving physical health and has good MH effects.</li> <li>• Integrate resources into PR courses, such as Living well with long-term conditions booklets</li> </ul>
<p><b>Any education/rehabilitation programme aimed at people with long term conditions should contain an opportunity for group peer support.</b></p>	<ul style="list-style-type: none"> <li>• Improve study on PR-Buddies will be completed soon</li> <li>• Bromley ran a LTC group for a while with peer support element.</li> </ul>	<ul style="list-style-type: none"> <li>• There could be training during the induction of staff/ have a period of shadowing on how to run a group.</li> <li>• Set up a WhatsApp group for the cohort.</li> <li>• Should always have time for socialising after with tea and biscuits.</li> <li>• Have ambassadors present at all sessions.</li> </ul>

		<ul style="list-style-type: none"> <li>Group work is a skill - is this in the newly developed pan-London PR staff competency framework? Should it be?</li> </ul>
<p><b>Clinicians are aware of the different mental health and wellbeing services available to signpost patients to if further help is needed.</b></p>	<ul style="list-style-type: none"> <li>Every mind matters (online education and support)</li> </ul>	<ul style="list-style-type: none"> <li>Keep things like MECC Link and host nationally instead of each area having their own information systems</li> </ul>
<p><b>MH specialists embedded within LTC teams to provide expertise.</b></p>	<ul style="list-style-type: none"> <li>Mental health specialist, in both cardio and PR teams, means staff are more confident knowing they have a mental health specialist to ask.</li> <li>King's College London run a 5 day course IMPARTs mental health skills for for non-MH clinicians. Staff who complete the course say they are now able to have meaningful conversations with patients who require it.</li> <li>Kings College Hospital - embedded psychologist and psychiatrist</li> </ul>	
<p><b>Patients are offered ongoing wellbeing support after PR.</b></p>	<ul style="list-style-type: none"> <li>Greenwich offer ongoing management plan for physical and mental health, can refer to a gym programme, active walking, singing for health.</li> </ul>	<ul style="list-style-type: none"> <li>Invite patients back after a year to do a follow up course.</li> <li>Continue to facilitate online peer support groups.</li> </ul>

## Appendix D – Recommendations

Theme	Recommendation	Possible solutions
<b>Strengthening the link between pulmonary rehabilitation and mental health</b>	<p><b>1. Integration of care</b> Specialist roles and services (e.g., Talking Therapies, Social Prescribing, Respiratory nurses and charitable services such as 'Time to Talk') should be integrated into the PR pathway from referral, where appropriate, through delivery and after completion.</p>	<ul style="list-style-type: none"> <li>• PR to include mental health educational sessions delivered by specialists such as Talking therapies and/or Time to Talk (e.g., stress/anxiety and sleep).</li> <li>• 121 specialist support provided to those who need it / meet a threshold.</li> <li>• At key points in the pathway (e.g. diagnosis / referral to PR), have an automatic link to social prescriber / respiratory nurse to discuss mental health - including check-ins with patients between referral and starting PR.</li> <li>• Integration of PR and mental health services - named contacts / shared training opportunities / drop in slots to discuss patients that may need support from the other.</li> </ul>
	<p><b>2. Patient information</b> PR services should take a consistent and comprehensive approach to patient information, ensuring signposting to appropriate services, the sharing of educational materials and clear routes for patients to seek further support.</p>	<p>Collate / raise awareness of and link to existing materials and resources, including:</p> <ul style="list-style-type: none"> <li>- <a href="#">South east London PR videos</a></li> <li>- <a href="#">IMPARTs resources</a> on living well with a long-term condition</li> <li>- <a href="#">Every mind matters resources</a></li> <li>- Written material for COPD</li> <li>- <a href="#">Living well with long-term conditions</a> booklet</li> <li>- Breathlessness support groups</li> <li>- <a href="#">MECC Link - online signposting tool</a></li> <li>- Promotion of self-referral to mental health services such as '<a href="#">Greenwich Time to Talk</a>'</li> <li>- '<a href="#">Men's Sheds</a>' initiative</li> <li>- <a href="#">The Breathe Easy Programme</a></li> </ul>
	<p><b>3. Screening and assessment</b> Validated mental health screening tools should be</p>	<ul style="list-style-type: none"> <li>• GAD and PHQ-9 (anxiety and depression screening) completed as part of PR.</li> </ul>

Theme	Recommendation	Possible solutions
	used consistently at appropriate points throughout the PR pathway so that patients can be referred or signposted to appropriate support services (where available) if required.	<ul style="list-style-type: none"> <li>Standardised mental health screening during physical health clinics.</li> <li>Patients should understand the purpose, rationale and benefits of these screening tools.</li> </ul>
	<p><b>4. Language</b> Across the pathway, the terms 'Mental Health', 'Mental Illness' and 'Wellbeing' should be adopted and used in tandem, highlighting how the three are interlinked and how there are different levels of support available for individual needs.</p>	<ul style="list-style-type: none"> <li>Ensure existing materials, resources and training incorporate the full spectrum of ways in which different groups (e.g. patients and staff) refer to mental health, for example, low mood, wellbeing, mental health, and mental illness.</li> </ul>
	<p><b>5. Staff education RE wellbeing</b> PR services should ensure clinicians and ambassadors are supported to have the appropriate skills, knowledge and awareness relating to having wellbeing conversations, wellbeing check-ins and managing peer groups.</p>	<ul style="list-style-type: none"> <li>Annual mental health education should be included as part of PR staff mandatory training.</li> <li>Staff aware that wellbeing check-ins scheduled at regular time points in PR sessions is an informal way to incorporate wellbeing support.</li> <li>Upskilling of PR ambassadors to have skills to support mental health conversations.</li> <li>PR staff can use goal setting as part of pulmonary rehabilitation classes as achievements can be boosting for mental health.</li> </ul>
<b>Peer support</b>	<p><b>6. Peer support</b> PR services should incorporate an element of peer support into their service model as a way to facilitate informal conversations about MH/wellbeing.</p>	<ul style="list-style-type: none"> <li>Structured time for socialising (e.g., tea and biscuits and actively encouraged to go for a coffee afterwards).</li> <li>Appropriate venues (space for people to talk and socialise).</li> <li>PR ambassadors supported to be present at every session.</li> <li>Incorporate a group wellbeing check in at the start of each PR session.</li> <li>Embed <a href="#">pulmonary rehabilitation buddies</a> (current research trial).</li> </ul>

Theme	Recommendation	Possible solutions
		<ul style="list-style-type: none"> <li>• Optional WhatsApp group (for discussions/queries but also for facilitator to check in which would encourage attendance and motivation).</li> <li>• Encourage visit from social prescribers to raise awareness of other peer support groups available in the community to support patients pre and post-PR.</li> </ul>
Operational improvements	<p><b>7. Post-PR</b> Patients should complete the PR course having been given the knowledge of where and how to access future support for both physical and mental wellbeing.</p>	<ul style="list-style-type: none"> <li>• Embed 'What Next?' conversations towards the end of a PR course which feed into an ongoing physical activity plan and an ongoing mental health plan.</li> <li>• Known contact for clinical advice e.g., respiratory nurse either at borough or practice level.</li> <li>• Ongoing access to physical activity sessions, at a cost.</li> <li>• Promotion of activities that support lung health and wellbeing (e.g. singing) - a PR directory of services could be compiled to support this.</li> <li>• Develop links with social prescribers, breathe easy groups and other relevant community organisations.</li> </ul>
	<p><b>8. Addressing drop-outs</b> PR services should take a quality improvement approach to understanding and addressing drop-out 'moments', such as between referral and pre-assessment, ensuring that the drivers (health equity) are fully understood.</p>	<ul style="list-style-type: none"> <li>• Proactive follow up and fast-track reintroduction for those assessed but not attended.</li> <li>• Offer taster sessions for people to meet facilitators, start building group rapport and address concerns and barriers to attending to pro-actively address reasons for non-attendance.</li> <li>• Alignment with <a href="#">Pan-London Pulmonary Rehabilitation Competency Framework</a> competency: "Assess the individual's readiness, confidence, and motivation to participate in pulmonary rehabilitation. Identify those at potential risk of drop out and respond to any questions or concerns raised clearly and honestly".</li> </ul>