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## Diagnostic delays for breathlessness: a qualitative study in primary care to understand current care and inform future pathways

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**Title:**

Diagnostic delays for breathlessness: a qualitative study in primary care to understand current care and inform future pathways.

**Key words:** breathlessness, primary care, diagnosis, qualitative research.

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## Abstract

**Background:** Evidence to understand the delays to diagnosis for patients presenting with breathlessness is lacking.

**Aim:** To explore current care through the experiences of adults presenting with chronic breathlessness awaiting a diagnosis and primary care clinicians.

**Design and Setting:** Qualitative study with adults presenting with chronic breathlessness, and clinicians in primary care.

**Methods:** Semi-structured interviews were conducted with patients and clinicians. Participants were recruited from a feasibility cluster randomised controlled trial investigating a structured diagnostic pathway for breathlessness. The interview guide explored experiences of help-seeking for breathlessness, the diagnostic process, and associated healthcare. The transcripts were analysed using thematic analysis supported by NVivo software.

**Results:** 34 patients (mean [SD] age 68 [10.8] years, 20 [59%] female), and 10 clinicians (mean [SD] 17 [6.3] years of experience, 5 (50%) female) were interviewed. Five themes were identified:

1) Recognising and validating symptoms of breathlessness is an important first step; 2) Clinical decision-making for breathlessness is complex; 3) Difficult conversations arise when a disease-related diagnosis is not confirmed; 4) Disease management rather than symptom management is prioritised by clinicians; 5) Patient experience is influenced by clinician communication style.

### Conclusion

Our findings indicate potential explanations for delays to diagnosis for patients with chronic breathlessness. Interventions are needed to enhance symptom recognition, include alternative approaches to incremental investigation, expand the concept of diagnosis beyond a 'disease label' to improve communication, with the ultimate aim of earlier diagnosis and management to improve patient outcomes.

**How this fits in:** Delays to diagnosis for patients presenting with chronic breathlessness are well described. This study aims to understand current care for patients awaiting a diagnosis to inform future diagnostic pathways. Our data highlights the challenges of symptom recognition, timely investigations, making a positive diagnosis, and difficult consultations. To achieve earlier diagnosis

for chronic breathlessness, we need to ASK - validating the symptom, ACT - avoiding an incremental approach to investigation, ADVISE - rethinking 'what is a diagnosis' whilst offering contemporaneous breathlessness relief strategies.

## Introduction

Chronic breathlessness is a common, distressing symptom with a prevalence of 9-11% in the general population(1, 2) increasing to 25% in older age.(3) Chronic breathlessness syndrome is described as breathlessness persisting despite optimal treatment of the underlying cause, and which causes disability.(4) This complex symptom negatively affects physical function, quality of life, and survival,(5, 6) frequently leading to primary and emergency care consultations.(7, 8) Patients presenting with chronic breathlessness may receive a diagnosis for conditions including cardiorespiratory disease, anxiety, depression and obesity.(9, 10) Multi-morbidity is common in patients with breathlessness and cross-sectional population studies have shown considerable overlap in the causes of breathlessness.(11) One study showed that 66% of people reporting breathlessness had two or more contributing causes to their breathlessness, with respiratory disease and anxiety or depression as the most common combination.(10) The Australian national breathlessness survey found that obesity accounted for a quarter of breathlessness symptoms in adults.(12) Deconditioning is a likely important contributing factor that is currently less well quantified.(13)

Despite the impact breathlessness has on quality of life(14), sufferers may delay seeking help, normalising their symptoms, (15, 16) and frequently experience significant delays in diagnosis and treatment after seeking help.(17, 18)

Evidence about patients' experiences whilst awaiting diagnosis and about clinicians' experiences of managing the diagnostic challenges of chronic breathlessness in primary care is lacking. Previous

literature has described the experiences of patients living with breathlessness in specific disease conditions; commonly cancer or cardiorespiratory disease.(15, 19-22) Patients have reported the 'invisibility' of breathlessness, difficult to describe and associated with stigma, leading to embarrassment about its effects.(23) Patient help-seeking behaviour and clinician responsiveness to the patient and their breathlessness have been described as important factors in being able to live well with breathlessness.(22)

Challenges for clinicians around achieving a diagnosis include the complex multi-morbidity of breathlessness,(16, 24) accessibility of investigations,(25) and variable adherence to disease-specific diagnostic pathways.(18) Surveys of respiratory clinicians indicate a greater focus on clinical features (cough, sputum) than quality of life domains when assessing breathlessness.(26) Interviews with respiratory medical trainees highlighted concerns about discussing breathlessness with patients and with symptom management.(27) Overall there is limited literature to provide insight into the reasons for delays to diagnosis for chronic breathlessness and possible solutions.

In order to develop diagnostic pathways to reduce delays to diagnosis and treatment, and to improve outcomes for patients, we aimed to understand current usual care from the experiences of patients living with breathlessness seeking healthcare, and of primary care clinicians involved in the diagnostic process.

## Methods

This research is reported in line with the standards for reporting qualitative research.(28)

### *Participants*

Semi-structured interviews were conducted with participants enrolled within a mixed-method feasibility cluster randomised controlled trial (cRCT) in England: Breathlessness DiagnosE Early in

Primary care (Breathe-DEEP , ISRCTN14483247).(29) The Breathe DEEP trial involved 10 General Practitioner (GP) practices across Leicester and Leicestershire, which were cluster randomised to either a structured diagnostic pathway (intervention) or usual care. The structured diagnostic pathway included a panel of investigations, completed within two months of consultation with the GP for breathlessness. Usual care involved clinician's normal practice with national guidance highlighted.(30) Eligible patients were: over forty years old, breathless for longer than two months, presenting for the first time, with no prior diagnoses for their breathlessness.(29) Semi-structured interviews were conducted with clinicians from ten practices enrolled in the cRCT, who were not necessarily directly involved in the care of the patients interviewed.

### *Interviews*

The patient interview guide (Supplementary Box 1) included questions on their experiences of help-seeking for breathlessness and related healthcare, and the conduct of the cRCT. The clinician interview guide (Supplementary Box 2) explored diagnosis and breathlessness management, associated challenges, impact of the COVID-19 pandemic during this timeframe, and the conduct of the cRCT. Interview data relating to patient experience during lockdown at the start of the pandemic is published elsewhere.(31) Data on the conduct of the cRCT are reported elsewhere.

Interview guides were developed collaboratively with members of the local patient and public involvement (PPI) group. The PPI group helped with phrasing the questions about how/when patients sought help for their breathlessness and their expectations. An iterative approach was taken throughout the interview and analysis process including reviewing and amending the guide to explore issues arising in earlier interviews. Interviews with patients continued until perceived theoretical saturation; the topic guide was no longer evolving and data was of sufficient depth and

complexity around the topic.(32, 33) Interviews with clinicians were completed until representation until each participating GP practice was achieved to maximise variation in responses.

Interviews were conducted face-to-face or via telephone by two interviewers, both trained in qualitative methods. Interviews were recorded and transcribed verbatim. One interviewer is a physiotherapist and the other has a non-clinical psychology background. Consistency of interview practice, communication style and quality of data obtained by the interviewers was independently verified by another researcher.

### *Analysis*

The transcripts were analysed using reflexive thematic analysis(34) with analysis grounded in the interview data, supported by NVivo software (Version 12). Analysis included familiarisation with data, generating initial codes, generating initial themes, for themes, reviewing and developing themes, refining and naming the themes and producing the report.(34) Initial coding was carried out independently by two researchers (GD and SC) to develop a coding tree. The first author (GD) completed full coding of all transcripts, maintaining a reflexive diary and discussions with the study team about the influences of previous experiences as a clinician working with patients with breathlessness. The wider research team discussed and reviewed the codes and patterns of shared meaning across the transcripts, drawing on experience and insight of the whole team which included clinicians and researchers. The team collaboratively identified themes, using quotes from the transcripts to check data interpretation. The data were presented to the PPI group to check interpretation and description of the themes remained in line with the original data. The first interviewer (GD) had not previously performed semi-structured interviews but was experienced in clinical consultations with patients presenting with breathlessness. This was balanced with a second interviewer (SC) who was not a clinician and had significant previous experience in qualitative research methods.

## Results

34/48 patients and 10 clinicians were interviewed between November 2019 and October 2021. All patients consented to an interview as part of the wider Breathe DEEP study. Clinicians from each participating GP practice were asked to express interest in an interview with the aim of gaining representation from each practice. Patients: 20 (59%) female, mean (SD, range) age 68 (10.8, 48-89) years, 32 (94%) White British, median (IQR) indices of multiple deprivation quintile 3 (2-5). Clinicians: mean (SD, range) of 17 (6.3, 6-30) years' experience, five (50%) female, seven (70%) White British. Clinicians were from ten GP practices with mean (SD, range) population per 10,000 of 15.3 (7.6, 10-40); nine were GPs and one was a Respiratory Nurse. There were five themes: 1) Recognising and validating symptoms of breathlessness is an important first step; 2) Clinical decision-making for breathlessness is complex; 3) Difficult conversations arise when a disease-related diagnosis is not confirmed; 4) Disease management rather than symptom management is prioritised by clinicians; 5) Patient experience is influenced by clinician communication style. The first four themes describe the patient and clinician journey, while theme five around communication was evident throughout the first four themes.

### **1) Recognising and validating symptoms of breathlessness is an important first step**

Patients delayed presenting with breathlessness, often normalising symptoms. Patients described either the impact of exertional breathlessness on daily activities prompting them to seek help, or situations where they had sought help for another problem when their breathlessness was identified.

*"I was getting out of breath, didn't really do anything about it until people started commenting at work about it." (Patient30)*

*“But then I found that I was getting breathless if I just walked upstairs at home or if I walked from the lounge to the kitchen, and that’s when I thought I better go and see my GP.”*  
(Patient 26)

*“I went to see my GP about another problem...and then you say a throwaway thing, you know...and I have problems with breathlessness.”* (Patient33)

*“It’s because I was getting these symptoms which I didn’t understand and I wanted somebody to go through it with me and just confirm whether I was ill or not.”* (Patient1)

Once patients sought help, they described being referred for investigation and how this helped to validate their symptom.

*“I did find it really good because I was just thinking... ‘Well I’m only breathless’ and I wasn’t really thinking it was anything bad, and then all of a sudden I was going for all these tests.”* (Patient7)

*“I’d sooner have it tested and know than not have it tested and don’t know.”*  
(Patient16)

At the point of presentation to the general practitioner (GP), patient and clinician priorities were closely aligned in finding a cause for the breathlessness.

*“I would like an answer... I think if you have an answer, you know where you’re going.”* (Patient7)

*“Again because breathlessness is just a symptom, it’s not a diagnosis, so you need to look for a cause.”* (Clinician7)

Clinicians interpreted the validity of breathlessness in light of a diagnostic plan to identify a disease label.

*“... when a patient has genuine pathology, the barriers are not so difficult. So if you’ve got somebody who has got genuine COPD, genuine ischemic heart beat, heart failure, or someone’s got asthma, we can test for that ...”* (Clinician3)

*“You may have a suspicion for example that it could be perhaps just down to some physical deconditioning but several differentials need to be excluded in order to confidently arrive at that diagnosis.”* (Clinician6)

## **2) Clinical decision-making for breathlessness is complex**

Clinicians described balancing the need to investigate appropriately with avoiding unnecessary investigations due to concerns over patient burden and increased costs.

*“In general practice we tend to try and be fairly focused. So you would try and do the investigations that you think are likely to show you what’s going on.” (Clinician8)*

*“I think with every investigation you need to have a specific question in mind. You don’t want to investigate everyone because then that will have a massive strain... on the whole of the NHS” (Clinician4)*

Clinicians described taking an incremental approach to diagnosis, as per their medical training.

*“You are taught to say well what’s the most likely diagnosis, so investigate for that and then revise your hypothesis in light of new information. So as a GP you’re taught that OK, so clinically I think this is COPD...Let’s arrange some spirometry and if that’s normal we’ll then revisit our hypothesis and revise our differential diagnosis.” (Clinician10)*

Clinicians described feeling less confident with a diagnosis of exclusion, when investigations returned with no abnormality, possibly finding it a trigger for onward referral.

*“Because even if those investigations were normal, if you are looking at something like dysfunctional breathing, I can’t access any help for that in general practice... And I also I kind of want that reassurance from the consultant that I’m not missing anything as well.” (Clinician10)*

*“Sometimes having been to a specialist clinic does reassure them more than I can, because they feel they’ve seen the expert in lungs, rather than a generalist GP.” (Clinician8)*

Patients expected to be sent for investigation or be told the cause of their breathlessness. Patients described different levels of investigation.

*“And it feels like I’ve not had any answers anywhere really, well answers to rule out. Now I’d have liked more done to check the heart, especially as there’s three things there that is wrong.” (Patient5)*

*“I think the best part of it, once you got the tests done, is getting a clear explanation of what is likely to be the problem, and equally what isn’t the problem.” (Patient40)*

### **3) Difficult conversations arise when a disease-related diagnosis is not confirmed**

All clinicians referred to difficult conversations with patients, often centred around causes of breathlessness without a disease label or where lifestyle advice and/or psychological support was required.

*“It’s a challenge where you’ve got somebody who is symptomatic with breathlessness and you’ve investigated them for everything that you can think of and there is nothing positive coming back on their tests. And you believe that it’s probably due to deconditioning, weight gain, so where there’s not a specific pathology and patients are challenging you on that.” (Clinician5)*

*“I think one thing I struggle with would be, if someone has got chronic breathlessness, diagnosing it due to their body habitus, or due to anxiety.” (Clinician2)*

*“If you tell that it might be because of their weight, they know that they’re going to be told off. So I think they probably don’t want to believe that is the reason for the breathlessness...” (Clinician1)*

Some clinicians indicated they would engage in conversations that they recognised might be hard for patients to hear.

*“For some patients I would diagnose the fact that they’re just unfit. They say they’re feeling breathless and you go well you’re fat and you do no exercise. I wouldn’t say it quite like that, but there’s a reality check of the fact that you’re totally deconditioned.” (Clinician7)*

Patients also described difficult discussions, either in relation to the reason offered for their medically unexplained breathlessness, or when no explanation was forthcoming. One patient also reported not knowing he had a respiratory diagnosis.

*“Told me that it was probably I wasn’t fit, they’ve done all the tests that they could, there was nothing wrong with me.” (Patient28)*

*“And then when I went to see the nurse for my second breathing test she said how long have you had COPD? I said what is COPD? And he’d not told me that that’s what I’ve got. So I was in the dark, you know, I didn’t know I had anything wrong with me at all apart from infection.” (Patient1)*

*“Everything gets put down to menopause or anxiety, I have anxiety problems, I did have menopause, I’m passed that.” (Patient40)*

Clinicians and patients also referred to time pressures within a consultation, both in relation to discussions with patients and to investigating in a timely manner.

*“The disadvantage is we are time pressured and you generally have 10 minutes for an appointment. Which isn’t a long time to do a thorough examination, history, explanations and all the things that go with it.” (Clinician8)*

*“And I guess in that time the patient and the doctor can get a bit frustrated, well we’re not finding anything, we’ve not found the cause of this yet, if you’re not getting your tests done in a timely way.” (Clinician10)*

*“...don’t think it was thorough, well they can’t be thorough can they because at the end of the day they’ve got next one in.” (Patient6)*

#### **4) Disease management rather than symptom management is prioritised by clinicians**

Although the need to find a cause for breathlessness was a clear and appropriate priority for both clinicians and patients, the data also highlighted a lack of advice for immediate symptom management during the diagnostic journey.

*“They’ve not given me any treatment to help it because it’s not diagnosed, which is what I found a bit odd. I mean they could have given me something to just tide me through a bit.” (Patient5)*

*“Just help to know, to be a bit more aware of what I can do to live with this.” (Patient31)*

Some clinicians acknowledged the importance of symptom management.

*“Because our primary concern would be the patient’s wellbeing and trying to make the patient feel better and give them some symptomatic relief.” (Clinician4)*

*“...advice would be around lifestyle, so BMI, smoking and just trying to exercise regularly would be a general advice; but also safety netting advice as well.”*  
(Clinician6)

*“I suspect that I would have a trial of treatment and see if that made a difference, think about trying an inhaler with their symptoms.”* (Clinician7)

However, many expressed lower confidence in suggesting non-pharmacological approaches to help with breathlessness.

*“In terms of breathing exercises and mindfulness and that side of things, I think I’m probably not in a particularly good position to advise patients very well.”*  
(Clinician3)

*“For me personally I don’t know that I necessarily give breathlessness management advice in terms of breathing techniques and things like that. I don’t know that I give that initially. It probably ends up happening once you get the actual formal diagnosis of COPD and then we maybe get into the disease management side of things.”* (Clinician10)

##### **5) Patient experience is influenced by clinician communication style**

A variety of clinician communication styles were described by patients and this theme ran throughout the patient journey. Several patients described the benefits of clear explanations and where they had positive experiences.

*“To be honest with you, it’s all been very good. Very clear, concise of just exactly what’s happening. This is what we’re going to do. I quite like doctors being very straightforward.”* (Patient50)

*“The follow-up side of it, they were very good...especially the doctor, she didn’t hang about... it all fell into place.”* (Patient29)

*“And I think it was taking that time to say OK yes...these are other things that need to be checked, these are tests that should have been done, so I’m going to get them done, and just taking that time to listen.”* (Patient40)

However, there were examples of patients feeling dismissed or embarrassed. These contrasting styles of delivering information and responding to patients' concerns also occurred at the point of diagnosis.

*"[GP] said 'Well you are overweight', just like that and that was it." (Patient47)*

*"[GP] said 'I think you're just getting anxious' and... that I need to just relax. And they [GP] said when the heart scan's done we'll then discuss it." (Patient44)*

*"I feel my next breath is going to be my last one. And his comments were 'Well that's a bit extreme'... he was very professional, but it was very short." (Patient24)*

*"Nothing the matter with you, it's just because you're not fit... I feel a fraud going, you know, I just don't want to go and be spoke to like that." (Patient28)*

Clinicians revealed their challenges in responding to patients' concerns and they described ways to discuss breathlessness with patients, particularly where a diagnosis is not straightforward.

*"By explaining why you've taken it seriously, you've excluded other causes, you're allowing them to come on that journey with you... And usually they come along with you, I think partly because they feel listened to..." (Clinician8)*

*"But I've got COPD and you say yeah but unfortunately you are quite overweight and... with obese patients you will get short of breath and especially if your levels of fitness are not very good. And it's hard to engage them to take some sort of responsibility for improving their overall health, they just want to be given an inhaler that's going to sort everything out." (Clinician9)*

## Discussion

### Summary

We report the experiences of current care in 2020-2021 for patients and primary care clinicians navigating the journey from presentation with breathlessness to possible diagnosis. Our data provide novel insights to possible reasons for the delays to diagnosis for patients presenting with breathlessness. The combination of poor symptom recognition and delayed help-seeking by patients, alongside an incremental approach to investigations could lengthen the diagnostic process. Clinicians described challenges in explaining breathlessness associated with deconditioning when specific disease states had been investigated and excluded. This frequently led to difficulty in progressing to effective breathlessness management. Throughout the diagnostic journey, communication was key and there was clear indication that time pressures in primary care and lack of specialist support were an issue.

### Strengths and limitations

To our knowledge, this is the first study to report usual care through the experiences of patients with chronic breathlessness awaiting a diagnosis, alongside the experiences of clinicians managing the diagnostic process. Thirty-four patients were interviewed, providing a sufficient sample size for data analysis.

The ethnicity of the majority of patients was White British, which is not representative of the diverse local population. Opportunistic recruitment at the point of consultation with the GP was used for the study and either adults from other ethnic backgrounds declined to have their details passed on to the study team or were not invited by their GP. Of the participants identified, two were excluded due to insufficient understanding of English, therefore interpretation should be offered for future studies. The number of clinician interviews was limited due to pressures in

primary care during the COVID pandemic. One clinician was interviewed from each of the GP practices in the study, but their views may not be representative. The sampling for clinician interviews was mostly opportunistic, possibly introducing positive responder bias. We can't exclude that being involved in the wider Breathe DEEP trial may have influenced patient and clinician experiences.

### Comparison with existing literature

We, like others, found that breathlessness is likely to be identified by clinicians when patients are seeking help for a different problem, thus increasing the complexity of patient assessment in an already time-limited appointment. (35) Some patients recalled being prompted by others to seek help, supporting existing literature around help-seeking behaviour by patients with breathlessness.(15, 19)

The incremental approach to investigation to rule out individual diagnoses described by clinicians may be due to disease-specific guidelines which promote excluding a particular diagnosis, rather than a holistic approach to find all causes of a symptom.(36, 37) An incremental approach could be appropriate if timely investigations and multiple reviews were possible, but this is commonly not the case and has been further exacerbated by the COVID-19 pandemic causing delays in healthcare.(38)

There are multiple causes of, and contributing factors to, breathlessness which may be missed when a single disease diagnostic algorithm is used. Our data highlights the tension between performing extensive investigations in every patient to find a diagnosis rapidly versus patient burden and over-use, cost; some investigations may also have a level of harm involved.(39, 40)

Clinicians described challenges when a disease label was not identified, feeling ill-prepared to offer advice or be definitive about weight, deconditioning and anxiety as causes for breathlessness.

These causes were considered less acceptable as a positive or confirmed diagnosis to both clinicians and patients. However, consideration of the definition of a diagnosis: *'the process of determining the nature of a disorder by considering the patient's signs and symptoms, medical background, and – when necessary – results of laboratory tests'*(41) highlights that the *nature* of the disorder can be a multitude of things and is not solely a disease label.

Several quotes in the data showed clinicians and patients recognised deconditioning and obesity were important factors contributing to breathlessness. Opportunistic behaviour change interventions (e.g. smoking cessation, increased physical activity, weight loss) are advocated in healthcare settings, however a lack of time and perceived lack of clinician skills and patient motivation, are known barriers.(42) Time was a factor identified by participants in this study. Successful supervised exercise programmes, such as pulmonary and cardiac rehabilitation, are designed for adults with respiratory or cardiac conditions with exertional breathlessness (36, 43); deconditioning is frequently the dominant cause of breathlessness, rather than the specific pulmonary or cardiac impairment and the mechanism of benefit of rehabilitation is through the effect on skeletal muscle. Research is ongoing to broaden these programmes for adults with exertional breathlessness regardless of underlying disease.(44) Recognising and describing deconditioning as a 'positive diagnosis' with a targeted therapy, e.g. exercise training, may aid communication between clinician and patient.

### Implications for practice and future research

These data indicate that there are challenges associated with reaching a meaningful diagnosis for patients with breathlessness, but that recognition and validation of the symptom of breathlessness is an important first step. Time is a constant pressure in GP consultations, however time spent

early on listening to the concerns of patients about how breathlessness affects them may improve the overall patient experience.(45, 46)

Clinicians' communication styles have a profound effect on patients and training around advanced communication skills, opportunistic behaviour change and motivational interviewing have been shown to have some benefit.(47, 48) Explanations to patients of the investigation process and about what has been excluded may be of therapeutic benefit in reducing anxiety about serious underlying pathology. However, this needs to be balanced with the receipt of a 'positive diagnosis'.

It is important for clinicians to consider breathlessness as a therapeutic target, as well as an important indicator of underlying illness.(49) There are models to support this approach which facilitate clinicians in enabling their patients to develop coping strategies and manage their symptoms.(16, 22) A symptom-based approach is commonly used with chronic pain,(50) which like breathlessness is a complex symptom with affective and sensory components.(51) Previous comparisons of clinicians' approaches to chronic pain and breathlessness suggest that breathlessness was less likely to be objectively assessed, followed up and perceived as requiring additional treatment than chronic pain.(52) Healthcare approaches to chronic pain serve as a good example of a symptom-based approach to a holistic assessment, diagnosis and management.

The data indicates that clinicians value specialist support in instances where a diagnosis is less straightforward. Understanding the most effective way to communicate the key messages to patients when the diagnosis for breathlessness is deconditioning, obesity or anxiety, or where other conditions have been excluded, alongside a personalised symptom-based management plan could also be of benefit.

A complex intervention is needed to support patient and clinician recognition of breathlessness, early symptom-based investigation which allows for the detection of multiple causes, and support

for clinicians to be confident with delivering less disease-specific diagnostic labels such as deconditioning.

## Conclusion

The data presented highlight several reasons for delays to diagnosis for patients presenting with breathlessness including: an unclear start to the process, an incremental approach to investigation, variable communication styles and an unclear end to the diagnostic journey. While waiting investigative results, provision of advice or information about low risk, evidence-based strategies for relief of breathlessness appeared to be an unmet need for patients. Overall, measures are needed to address these reasons for delays to diagnosis, to improve early accurate diagnosis and achieve better outcomes for patients.

**Take home message: To achieve earlier diagnosis for chronic breathlessness, we need to ASK - validating the symptom, ACT - avoiding an incremental approach to investigation, ADVISE - rethinking 'what is a diagnosis' whilst offering contemporaneous breathlessness relief strategies.**

**Ethical Approval:** Research Ethics Committee Nottingham 1 provided ethical approval for the mixed methods Breathe DEEP trial which is the wider basis of this qualitative work. REC Reference: 19/EM/0201.

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**Author Contributions:** RAE conceived the research idea, and developed the theory and plan for this study alongside her co-authors. GD and SC independently performed the interviews with participants. AH, MW, NA, GD, RAE and SC analysed the data and developed the themes alongside the other co-authors. GD drafted the initial manuscript and all co-authors (RAE, NA, MS, AH, MW, SC) reviewed, commented and approved the manuscript.

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**Data Availability statement:** The data sets generated and analysed during the current study are available from the corresponding author on reasonable request.

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