

Macarthur Breathless Clinic - working together to defeat breathlessness in COPD: Protocol

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Abstract

Background: Breathlessness is a distressing symptom for people with chronic obstructive pulmonary disease (COPD), impacting independence and community participation, resulting in reduced quality of life. With optimised treatment, non-pharmaceutical interventions deployed in a home-based breathlessness intervention service may provide additional benefits, reducing breathlessness to a manageable level.

Objective: The study investigates whether the Macarthur Breathless Clinic (MBC) reduces the burden of chronic breathlessness and healthcare utilisation in COPD patients. Participant and carer experiences will also be explored.

Methods: The proposed research is a single-site, mixed-methods, single-arm cohort study evaluating MBC. Eligible participants will have COPD confirmed by spirometry and chronic breathlessness as defined by modified Medical Research Council (mMRC) score at least two. Initially, participants will undergo a holistic medical assessment to understand factors contributing to breathlessness and to optimise therapy. The MBC intervention will be a nine-week multi-disciplinary program (with contributions from medical, nursing, physiotherapy and occupational therapy); most clinical interactions will occur within participants' homes. Central to this program will be coaching for breathlessness self-management utilising individualised, multicomponent strategies. Breathlessness impact will be assessed using questionnaire instruments measuring breathlessness mastery, symptom burden, quality of life and psychological distress, with the Chronic Respiratory Questionnaire's mastery subscale, as primary outcome. Assessments will be undertaken at baseline, nine weeks and 12 months. Participant and carer experiences will be evaluated using qualitative methods to inform development of the service. Twelve-month exacerbation rates, healthcare and rescue medication use will be monitored and measured against participants' historical data.

Results: We hypothesize that the Macarthur Breathless Clinic (MBC) will reduce the impact of COPD-related chronic breathlessness (in terms of coping ability, symptom burden, quality of life and psychological distress), reduce COPD-related healthcare utilisation and provide a positive consumer experience.

Conclusions: The proposed study will be an important addition to the growing body of evidence about the use of non-pharmacological interventions for chronic refractory breathlessness in patients with non-malignant disease. If positive, our research has the potential to improve the burden conferred by chronic breathlessness for patients living with COPD, to decrease the weight of responsibility for their carers and to reduce potentially unnecessary hospitalisation, thereby contributing to

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Original Manuscript

Macarthur Breathless Clinic – working together to defeat breathlessness in COPD: Protocol

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Running Head: Macarthur Breathless Clinic Study Protocol

Abbreviations:

Chronic obstructive pulmonary disease, **COPD**; heart failure, **HF**; modified Medical Research Council, **mMRC**; forced expiratory volume in one second, **FEV₁**; forced expiratory volume in one second divided by forced vital capacity, **FEV₁/FVC**; Macarthur Breathless Clinic, **MBC**; digital versatile disc, **DVD**; compact disc, **CD**; pulmonary rehabilitation, **PR**; participant information sheet and consent form, **PISCF**; Chronic Respiratory Disease Questionnaire, **CRQ**; numerical rating scale, **NRS**; COPD Assessment Test, **CAT**; Hospital Anxiety and Depression Scale, **HADS**; European Quality of Life Five dimensions, **EQ5D5L**; Dalhousie Dyspnoea and Perceived Exertion Scale, **DDPES**; diagnostic related group, **DRG**

Keywords: COPD, breathlessness, multi-disciplinary, chronic disease management,

breathlessness intervention service

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ABSTRACT

Introduction: Breathlessness is a distressing symptom for people with chronic obstructive pulmonary disease (COPD), impacting independence and community participation, resulting in reduced quality of life. With optimised treatment, non-pharmaceutical interventions deployed in a home-based breathlessness intervention service may provide additional benefits, reducing breathlessness to a manageable level. The study investigates whether the Macarthur Breathless Clinic (MBC) reduces the burden of chronic breathlessness and healthcare utilisation in COPD patients. Participant and carer experiences will also be explored.

Methods: The proposed research is a single-site, mixed-methods, single-arm cohort study evaluating MBC. Eligible participants will have COPD confirmed by spirometry and chronic breathlessness as defined by modified Medical Research Council (mMRC) score at least two. Initially, participants will undergo a holistic medical assessment to understand factors contributing to breathlessness and to optimise therapy. The MBC intervention will be a nine-week multi-disciplinary program (with contributions from medical, nursing, physiotherapy and occupational therapy); most clinical interactions will occur within participants' homes. Central to this program will be coaching for breathlessness self-management utilising individualised, multicomponent strategies. Breathlessness impact will be assessed using questionnaire instruments measuring breathlessness mastery, symptom burden, quality of life and psychological distress, with the Chronic Respiratory Questionnaire's mastery subscale, as primary outcome. Assessments will be undertaken at baseline, nine weeks and 12 months. Participant and carer experiences will be evaluated using qualitative methods to inform development of the service. Twelve-month exacerbation rates, healthcare and rescue medication use will

be monitored and measured against participants' historical data.



INTRODUCTION

COPD is a multisystem disease, primarily affecting the lungs and characterised by incompletely reversible airflow obstruction ¹. COPD is common, affecting 10% of adults worldwide and 14% of Australians aged above 40 years ². Despite treatment according to guidelines, people with COPD experience a range of symptoms. Breathlessness is often prominent among these and may contribute to physical and psychological distress, reduced functional status and community participation¹. Breathlessness is responsible for a high proportion of ambulance presentations, medical admissions and healthcare costs^{3,4}. Yet patients suffering from refractory breathlessness and their caregivers feel that there is a lack of awareness of the symptom burden amongst healthcare providers and insufficient provision to address this burden within healthcare services^{2,5,6}.

Breathlessness intervention services have been clearly shown effective in reducing the burden of breathlessness for populations with malignant and mixed aetiology disease⁷. Existing breathlessness intervention service research primarily targets participants with malignant disease, in Europe, over a four to six week period, led by clinicians whose expertise is in palliative care ⁷. An Australian protocol for a single-blind, randomized, parallel-group study investigating the impact of a breathlessness intervention service on people with COPD has been published, however the study outcomes are not yet fully reported⁸.

The primary aim of this study is to assess whether a bespoke nine week “Breathless Clinic” focused on non-pharmacological interventions such as breathing retraining, energy conservation, physical activity and use of the hand-held electric fan, will improve the impact of breathlessness for participants living with COPD. A secondary aim is to monitor participants’ exacerbations, healthcare and rescue medication use

after the intervention for comparison with past patterns of disease activity. Further, we will use qualitative methods to assess patient and caregiver experiences.

Hypothesis

The hypothesis is that the Macarthur Breathless Clinic (MBC) will reduce the impact of COPD-related chronic breathlessness (in terms of coping ability, symptom burden, quality of life and psychological distress), reduce COPD-related healthcare utilisation and provide a positive consumer experience.

METHODS

Study Design

This research is a prospective, single-arm implementation study of MBC, a breathlessness intervention service, assessed using mixed methods. The intervention is designed to adapt to incorporate components found to work well and to discard or revise those found to be less effective during implementation, informed by the experience of conducting the program.

The service will be evaluated with subjects acting as their own controls, before and after the clinic intervention. Twelve months' follow up with sequential cross-sectional assessments will provide opportunity to assess breathlessness impact, exacerbations, healthcare utilisation and sustainability of outcomes.

Ethics and registration

This study protocol has been approved by the South Western Sydney Local Health District's Human Research Ethics Committee and is listed on the Australian and New Zealand Clinical Trial Registry (ANZCTR) ACTRN12620001330932. Written informed consent will be obtained from each participant before any intervention or data collection related to the study.

Setting

The study will be conducted predominantly within participants' homes across the Campbelltown, Camden and Wollondilly local government areas in Sydney, Australia. This is an area on the fringe of metropolitan Sydney, which accommodates a population with ethnic and linguistic diversity, social disadvantage and a comparatively higher proportion of Aboriginal Australians. In addition to home visits, a maximum of two scheduled healthcare interactions will occur in selected outpatient sites within the Macarthur Health Service.

Recruitment

Clinician referrals will be sought via outpatient services or after stabilisation following hospital admission for COPD-related illness. Referrals will be screened by research personnel to ensure eligibility. Previous piloting of this mode of referral and recruitment has demonstrated feasibility for achieving the recruitment target over 12 months.

Where applicable and with patient agreement, carers will be invited to participate in the trial to contribute qualitative data to reflect on their support person role and perceptions of the service.

Sample size

Recruitment target estimation is constrained by limited precedent data, most of which originate from research undertaken in the United Kingdom, studying subject populations, interventions and outcomes that differ to ours^{7,8}. However, pilot data from Westmead Hospital's Breathlessness Clinic for COPD patients (similar target population to that proposed in this study) demonstrated statistically significant and clinically relevant outcome improvements in preliminary analysis of only ten

subjects⁹. The currently proposed model has been informed by their prior experience. To allow for the substantial losses to follow up commonly seen in clinical trials in moderate to severe COPD patients, we have set our recruitment goal at 92 subjects, in anticipation of 30% discontinuation or dropout.

Data collection methods

All participant outcome data will be collected by non-clinician Macarthur Breathless Clinic (MBC) staff to minimise social acceptance bias. To ensure consistency in data evaluation, the same staff members will, where possible, collect outcome data for individual patients throughout the study.

A combination of outcomes has been chosen to comprehensively assess the effect of implementing the intervention. Breathlessness impact will be measured using standardised questionnaires. These questionnaires will be administered in a pen-and-paper format in the home setting by interviewers without detailed knowledge of the intervention to further reduce bias. Participants will attempt questionnaire responses uninformed about their previous results but can be prompted with this information, if needed, in the event that the participant is otherwise unable to respond.

Healthcare utilisation and exacerbation data will be gathered through structured interviews with participants. These interviews will be designed to capture detailed information about healthcare visits, hospitalisations, and other relevant healthcare interactions over the study period. The self-reported data from these interviews will be cross-referenced with participants' health records to improve accuracy.

Qualitative data will be collected through in-depth interviews using a predefined semi structured interview with participants (See appendix 1). These interviews will aim to

capture participants' experiences and perceptions of the intervention, providing valuable insights into its impact on their daily lives. The qualitative data will be analysed using thematic analysis to identify common themes and patterns, which will complement the quantitative findings and offer a more complete understanding of the intervention's effects. Analysis will be undertaken both by staff involved in the clinic as well as researchers with knowledge of similar clinical interventions to ensure holistic analysis.

Inclusion and exclusion criteria:

Proposed inclusion and exclusion criteria are shown in Table 1.

Description of intervention - Macarthur Breathlessness Clinic:

The proposed intervention, the Macarthur Breathless Clinic (MBC), is a nine-week program to manage chronic refractory breathlessness. The MBC team will include respiratory physician, occupational therapist, specialist respiratory nurse and physiotherapist with referrals as needed to dietetic and speech pathology services. The MBC itself will comprise nine healthcare interactions of 60-90 minutes, with most visits occurring within the patient's home as outlined in **Table 2**.

Following initial assessment, medical review and optimisation of medications, non-pharmacological therapies will commence. Through the MBC, patients and carers will receive coaching for breathlessness management and daily coping strategies to enhance independence and productivity. The clinical team will coach participants through individualised strategies to improve management of breathlessness in daily activities (**Table 3**) based on Cambridge Breathlessness Intervention Service's "Breathing, Thinking, Functioning" clinical model¹⁰. A broad repertoire of standard interventions will be tailored to individual patients' needs, goals and preferences.

The role of each clinician and coaching topics covered is illustrated in **Figure 2** noting that any cross-over of topics between clinicians will serve as reinforcement of strategies provided or will allow colleague cross-cover. There will be fortnightly multidisciplinary team case conferencing of all participants during their nine week intervention. Case conference discussion will aim to optimise, co-ordinate, troubleshoot and plan intervention activities.

Outcome Measures:

Breathlessness outcomes

The proposed primary outcome is mastery of breathlessness, as measured by the Chronic Respiratory Disease Questionnaire (CRQ) subscale of mastery¹¹.

The proposed secondary outcomes will measure the impact of the intervention using several scales to provide a full understanding of change across a number of dimensions and are listed below.

- CRQ total and other CRQ subscale scores
 - a. The CRQ is a validated measure of breathlessness and breathlessness-related quality of life. It consists of four subscales – dyspnoea, fatigue, emotion and mastery. In each scale, higher scores reflect better health. The minimal clinically important difference (MCID) for each subscale individually is an increase of 0.5 on a seven-point scale, with a change of one representing a moderate change and 1.5 a large change¹¹.
- Breathlessness intensity, unpleasantness and confidence numerical rating scales (NRS). International guidelines recommend assessing both intensity and unpleasantness of breathlessness¹² The MCID for these measures is a

change of one unit¹³.

- COPD Assessment Test (CAT) is a validated 8 item tool which provides a reliable measure of the impact of COPD on a patient's health status. Higher scores reflect worse health with an MCID of two¹⁴.
- Hospital Anxiety Depression Scale (HADS) is a 14 item self-reported measure with anxiety and depression subscales each with seven items. A MCID of 1.5 points for HADS in COPD populations has been suggested¹⁵.
- European Quality of life scale five dimensions, five levels (EQ5D5L) is a standardised measure of health status which provides a simple, generic measure of health for clinical and economic appraisal. The scale explores the degree of difficulty across five domains: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. The score is between -0.59 to 1, with higher scores reflecting better health and the mean MID is 0.051. It also includes a visual analogue scale 0-100, rating overall health from worst to best with a mean MID of 6.9¹⁶.
- Pedometer readings of average number of steps per day over the past seven days. There is no consensus regarding the MCID for this measure.
- Dalhousie Dyspnoea and Perceived Exertion Scale (DDPES) tracks dyspnoea and perceived exertion. The scale consists of seven pictures representing breathing effort, chest tightness, throat closure and leg effort, with increasing severity depicted in the pictures, traversing from left to right ¹⁷

Healthcare resource utilisation

Self-reported exacerbations, emergency department visits and hospitalisations will be collected and verified using patient electronic medical records where possible. Data will be updated at six and 12 months from MBC enrolment and will include the

annual number of:

- Emergency department (ED) presentations (all presentations), lasting less than 24 hours, which do not result in hospitalisation
 - o Breathlessness-related ED presentations, lasting less than 24 hours, which do not result in hospitalisation
- Unplanned hospitalisations
 - o Unplanned hospitalisations due to breathlessness
- Hospital length of stay in bed days (all unplanned hospitalisations)
 - o Breathlessness-related hospital bed days
- Exacerbations of COPD counted by patient-reported activation of COPD action plan, along with occasions of prescription of antibiotics and/or corticosteroid for the treatment of symptoms of respiratory exacerbation during hospitalised events.

Comparison will be made with patients' baseline data from the year prior to enrolment in the breathless clinic and benchmarked against non-participant comparator hospital patients with 1) ED presentations for reasons of breathlessness, triaged as "shortness of breath (SOB) – respiratory" or 2) hospitalised with exacerbations of COPD or heart failure as per diagnostic related group (DRG) assignment, with these benchmarking comparisons contributing to exploratory analyses.

Qualitative Outcomes

Patients and carers (where relevant) will undertake semi-structured, audio-recorded interviews up to nine weeks after completion of MBC. These interviews will explore participant perceptions of the MBC, any particularly helpful components and seek

recommendations for future versions of the service (appendix 1). To identify key concepts and themes, interviews will be analysed using thematic analysis¹⁸. Interviews will be coded by two researchers, one of whom has been involved in the conduct of the MBC and a researcher from the Westmead Breathlessness Service to provide comprehensive assessment of the data. Input from additional researchers, experienced in qualitative methods, will provide triangulation of the results to enhance trustworthiness of the analysis.

Discussion

Strengths and limitations

The study's focus on a homogeneous disease population of patients with moderate to severe COPD will ensure that the results are highly relevant to this specific group. This targeted approach will allow for more precise conclusions regarding the efficacy and safety of the intervention being tested. That said, we will recruit a wide range of patients with COPD in terms of severity and exacerbation susceptibility ensuring broad applicability to this important, and large, patient group. Thus, our results will add to the evidence base, as most previously published data include more heterogenous participant populations; patients with malignant disease and/or patients with a variety of restrictive and obstructive non-malignant respiratory disease.

The extended duration of the study protocol is another notable strength. By spanning a longer period, an entire year, the study will mitigate the potential confounding effects of seasonal variations in COPD symptoms and exacerbations. This will ensure that the observed outcomes are more likely attributable to the intervention rather than external seasonal factors. Additionally, the proposed intervention requires

behaviour change which can take time to implement. By having a longer duration than previous interventions we hope to enable patients to embed into their routine the suggested non-pharmacological strategies and to thus realise a durable effect beyond the nine weeks of the program.

Finally, the use of the COPD Assessment Test (CAT) as a key assessment tool will underscore the study's relevance to clinical practice. The CAT is a validated, disease-specific instrument that will provide a comprehensive evaluation of COPD symptoms and their impact on patients' quality of life. This may allow for the MBC to be ranked against other treatment interventions used in COPD, so that any positive study findings can be integrated into existing treatment paradigms, thereby facilitating the translation of research into practice.

This study has several limitations that must be acknowledged. Firstly, the lack of randomisation means that all recruited participants will receive the intervention and act as their own controls. This design could introduce both time and attrition bias and is a clear limitation on the level of evidence produced. However, given that COPD is a chronic and progressive disease, evaluating the impact of breathlessness over time may still yield valuable insights, provided the results are interpreted carefully. Whilst potential mortality among participants with more severe disease may skew study results, on the other hand, worsening COPD symptoms over time may mask benefits when determining results over 12-months. Considering this, even if patients appear to be 'stable' with respect to outcome measures at 12 months, this may actually represent improvement compared to the expected trajectory in COPD which is one of deterioration. In fact, clinically-significant breathlessness is a known marker of poor prognosis for patients with COPD¹⁹, and so our target population will be expected to deteriorate more rapidly than the COPD group as a whole. The 12-

month follow-up period is designed to account for the impact of seasonal variations on COPD symptoms as well as giving insight into the durability of the intervention over a prolonged period. Moreover, to date, the scientific literature contains few reports of outcomes for this type of intervention extending beyond two or three months, when showing sustained symptomatic benefits for this type of population with non-malignant, chronic disease is perhaps much more important than demonstrating a short-term response. Regarding COPD exacerbations, patient recall is notoriously poor. Where possible we will seek to confirm hospitalised exacerbations using local hospital records, however acknowledge the limitations in this methodology.

Language proficiency requirements also present a limitation. Although it is not ideal for English comprehension to exclude patients from accessing therapy, the decision to include only English-speaking participants was made due to significant ethnic and cultural differences in the expression and description of breathlessness. Additionally, some of the outcome measures are only validated in English. The exclusion of people who do not speak English will limit the generalisability of our results to the English-speaking population. To mitigate this and perhaps to provide an alternative means to express breathlessness in future iterations of the program, the Dalhousie pictorial scales, which help bypass literacy and language barriers, have been included as an outcome measure.

The study's development for a single metropolitan centre situated within a large semi-rural area may limit its applicability to other settings. However, it is encouraging that concurrent research on this topic is being conducted at other centres in Australia, which may help validate and extend the findings of this study.

The proposed study will be an important addition to the growing body of evidence

about the use of non-pharmacological interventions for chronic refractory breathlessness in patients with non-malignant disease. If positive, our research has the potential to improve the burden conferred by chronic breathlessness for patients living with COPD, to decrease the weight of responsibility for their carers and to reduce potentially unnecessary hospitalisation, thereby contributing to improved health and economic outcomes.

Author contributions

All listed authors meet the criteria for authorship per the International Committee of Journal Editors Guidelines. BC and TS have contributed to the study design. JL, TK, BC and TS drafted the paper. SS, SF, LG have made substantial contributions to the critical review of the paper. All authors read and approved the submitted version of the article.

Declaration of Interest

Belinda Cochrane received an investigator-sponsored study grant from GSK to conduct the research conducted for this manuscript, personal advisor/consultancy fees from GSK and Sanofi, speaker fees from Chiesi, Moderna, Astra Zeneca (AZ), Inside Practice and RX Global, and is a member of Lung Foundation Australia's COPD Coordinating Committee, none of which represent direct COI with the work presented here. This is relevant to the current manuscript but does not represent a COI. Sheree Smith declares membership of the TSANZ Conference Committee but has no specific conflicts related to this work. Soo Wei Foo has received speaker fees from AZ, travel and accommodation support from GSK, Chiesi, AZ and Boehringer Ingelheim, none of which represent direct COI with the work presented here. Teresa Kemp declares membership of the Respiratory Nurses Special Interest Group but has no specific conflicts related to this work. Jonathan Lee, Tracy Smith and Luisa Garcia have no potential COIs to declare.

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Tables

Table 1. Inclusion and exclusion criteria

Inclusion criteria:

1. Clinical and spirometric diagnosis of moderate to severe COPD with FEV1 <80% predicted and FEV1/FVC ratio <70%
2. Severe breathlessness with modified Medical Research Council (mMRC) score $\geq$ two
3. Age $\geq$ 40 years

Exclusion criteria:

1. Bed-bound or moribund
2. Cognitive impairment that precludes ability to engage and participate in education strategies;
3. Current active diagnosis of cancer, substance abuse (other than nicotine dependence) or other uncontrolled medical or psychiatric disorder;
4. Moderate or severe exacerbation of COPD^a within four weeks;
5. Insufficient command of the English language to comprehend and engage with interventions;
6. Current enrolment in pulmonary rehabilitation program (may participate if still eligible upon program completion or if involved in a long-term maintenance program)

^a Moderate to severe exacerbation of COPD is defined as an escalation of treatment to include systemic corticosteroids and/or antibiotics²⁰.

Table 2: Macarthur Breathless Clinic nine-week program

Schedule	Location	Activity
Week 1	Patient's home	• Initial assessment, Respiratory Nurse
Week 2	Outpatient clinic	• Medical assessment by respiratory physician • Multidisciplinary Team assessment of breathlessness, contributing factors and impacts to develop recommendations and management plan • Introduction to non-pharmacologic strategies, including provision and use of a battery operated handheld fan • Fact sheets on managing breathlessness
Week 3	Patient's home	• Physiotherapist
Week 4	Patient's home	• Occupational Therapist
Week 5	Patient's home	• Respiratory Nurse
Week 6	Patient's home	• Physiotherapist
Week 7	Patient's home	• Respiratory Nurse

Week 8	Patient's home	• Final assessments, Research Assistant
Week 9	Outpatient clinic	• Closure and follow up arrangements, Multidisciplinary Team

Table 3: Non-pharmacologic breathlessness interventions

Theme	Examples
Beliefs	• Validation of breathlessness • Clarifying mistaken beliefs - for example, breathlessness is not always due to low oxygen levels and breathlessness itself is not dangerous • Motivational interviewing
Strategies	• Use of a hand-held battery-operated fan • Breathing techniques such as “breathing around a rectangle”, “pursed lip breathing”, “flickering the candle”, “paced breathing” or “diaphragmatic breathing” explained with an accompanying fact sheet • Positions to relieve breathlessness • Sputum clearance techniques
Exercise	• Walking program with use of a pedometer • Strengthening exercises
Aids/efficiency	• Shower chair • Four-wheel walker • Energy conservation • Home modifications • Referral to dietitian if underweight or malnourished
Education and Self-management	• Inhaler technique • Disease education (including medications and other Therapies) • Written breathlessness action plans • Written COPD exacerbation action plan • Breathlessness DVD to reinforce key interventions • Relaxation CD • Fact sheets on managing breathlessness
Miscellaneous	• Carer support • Assessment and management of incontinence

Appendices

Appendix 1: Qualitative Outcomes - Interview Questions

Consumer Interview – Patient

Breathlessness

1. How (if at all) did BC affect the severity of your breathlessness?
2. How (if at all) did BC affect the unpleasantness of your breathlessness?
3. After completing BC does your breathlessness bother you less or do you think that you manage it better?
4. Has your confidence to manage breathlessness in public changed? How? Please give examples.
5. Prior to BC, were you anxious about your breathing or did you feel down in the dumps about it? Since completing BC has this changed in any way?
6. If you have a partner/carer - during an attack of breathlessness, do you find that they are more able to support you? How?

Activity

1. How (if at all) did BC affect your ability to get around the house or venture out?
2. How has BC affected your ability to cope at home or undertake daily household chores?
3. Since completing BC, have your social activities changed? e.g., shopping, coffee with friends, outings (How?)
4. Starting BC, did you set goals? (If yes, please explain how you went?)
5. After completing BC, has your life changed in any way? How?

Clinic

To remind you and assist you responding to the following questions, BC components

and activities include: breathing techniques, posture, hand-held electric fan, self-talk, exercise goals, home modifications, gait aids, other devices to assist function, breathlessness plan, relaxation CD, breathlessness DVD.

1. Did participating in BC provide any unexpected experiences, effects or surprises for you?
2. Thinking of the clinic activities, which, if any, were helpful? Why or why not?
3. Do you think that the number of appointments were enough, too many, not enough?
4. Were the number of BC appointments difficult to include in your schedule?
5. What worked well in BC?
6. Is there anything that you would change about the BC to make it more helpful?

Conclusion

1. In retrospect, is there anything you would like to add or is there anything that you feel that the BC team should know about your experience with the BC?
2. What advice would you give other people with COPD and breathlessness about whether to enrol in the clinic and how to get the most out of it?
3. Which, if any, components of BC will you use in future or incorporate into your daily routine

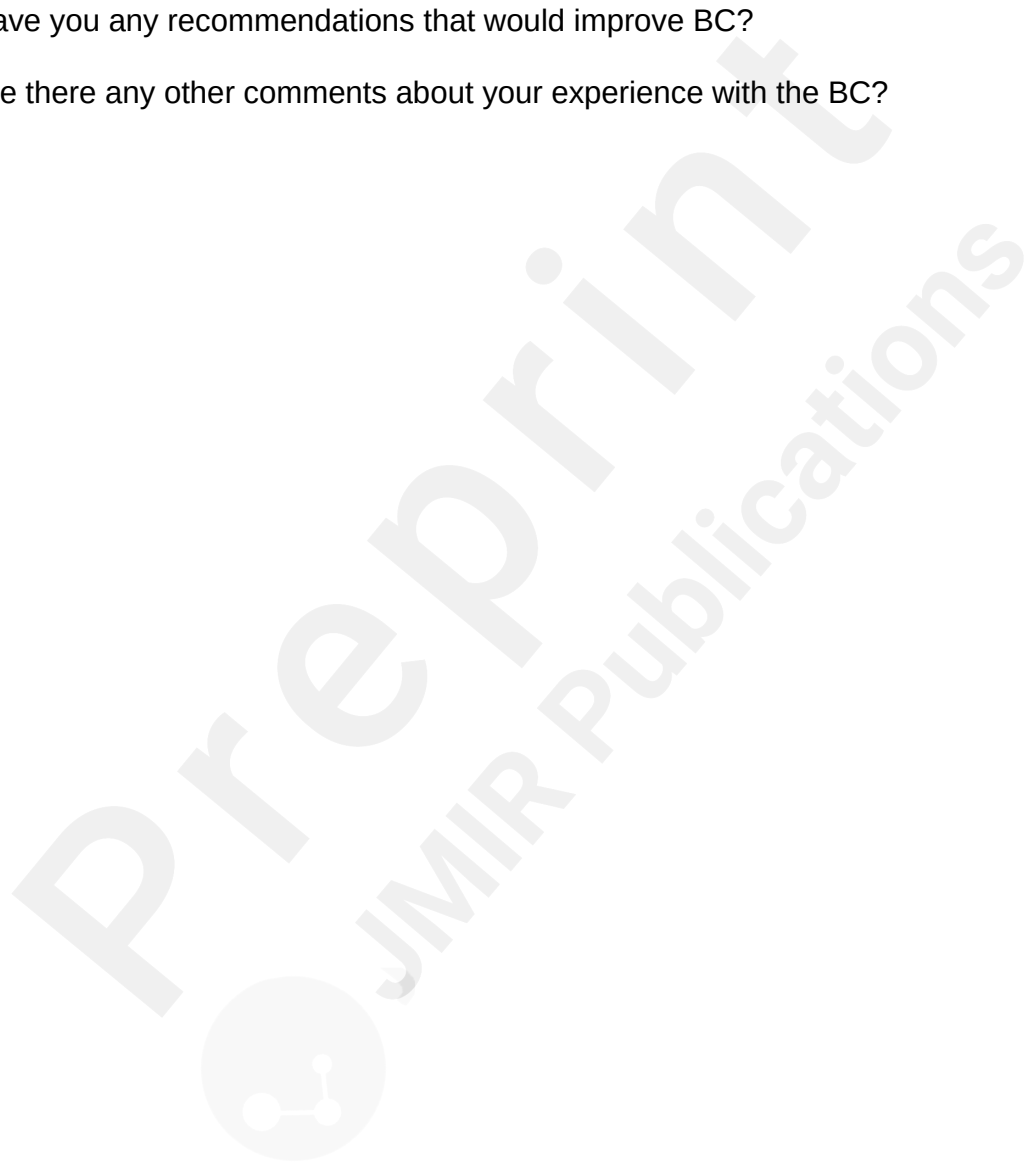
Consumer Interview – Partner/Carer

You care for someone who suffers with severe breathlessness.

Since attending BC in your view:

1. Do you think that they cope better with their breathlessness? In what ways?
2. Have they increased their social activities? Please expand?
3. Has their overall level of activity changed? In what way?

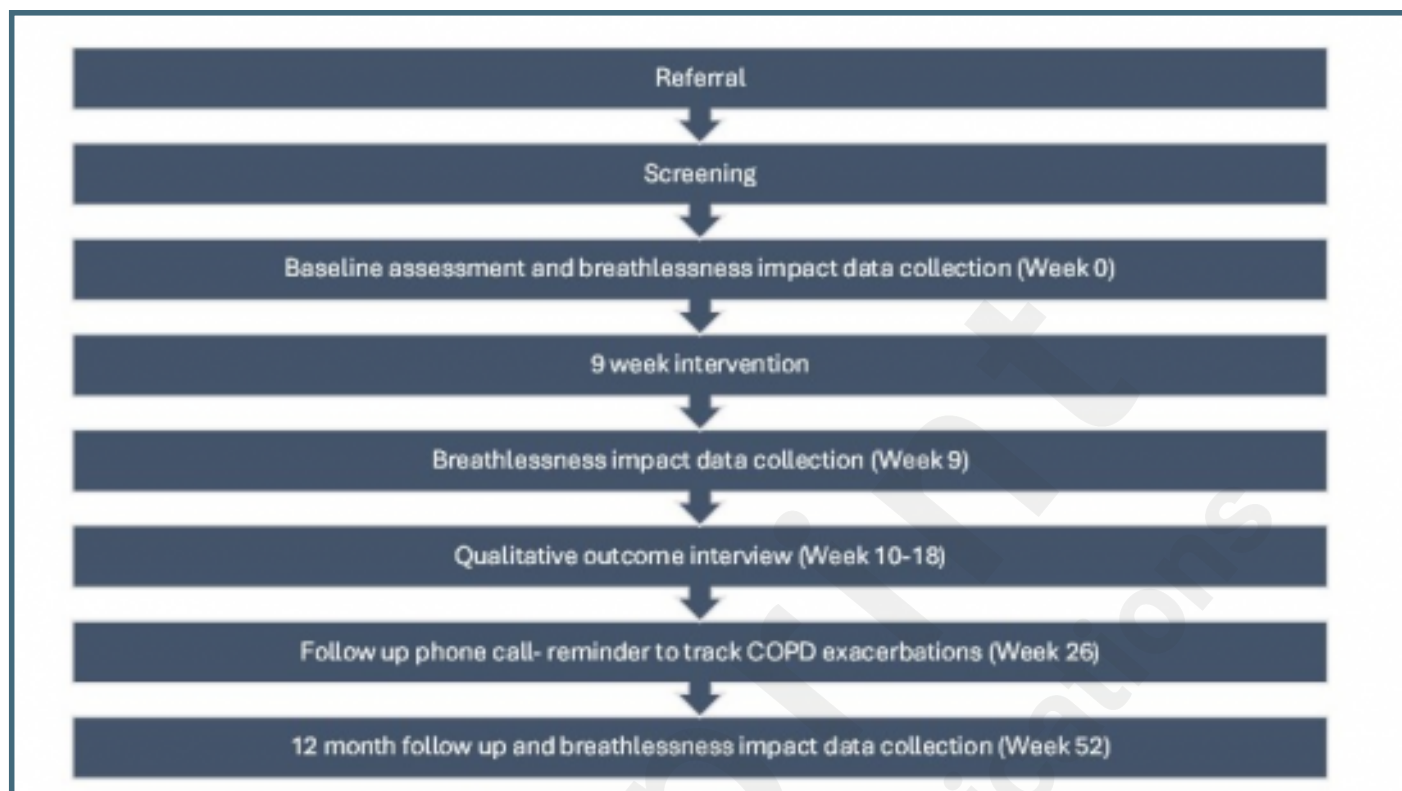
4. Have they changed in terms of their stress levels or mood? In what way?
5. Do you feel more confident to support them?
6. Was managing the number of BC appointments difficult to manage?
7. Were any aspects of BC particularly helpful to you? Which?
8. Have you any recommendations that would improve BC?
9. Are there any other comments about your experience with the BC?



Supplementary Files

Figures

Schedule of activities.



Clinician roles and coaching topics.

