STUDY PROTOCOL

An evidence synthesis of holistic services for refractory breathlessness in advanced malignant and non-malignant disease

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Contents

Plain English Summary 3
Scientific Abstract 4
Background and rationale 5
Research aim and objectives 6
Systematic Review 7
Pooled secondary analysis of individual patient data 11
Stakeholder consultation 12
Project team expertise 15
Patient and Public Involvement 16
Outputs and Dissemination 16
Project timetable and milestones 18
References 19
Appendix 1: Example Invitation to TEC workshop 24
Appendix 2: TEC information sheet (v2, 21st July 2017) 25
Appendix 3: TEC consent form (v2, 21st July 2017) 28
Appendix 4: Invitation to online consensus survey 30
Appendix 5: Consultation survey participant information sheet (v2, 21st July 2017) 31
Appendix 6: Consensus Survey Introduction 34
Appendix 7: TEC Workshop schedule 35

Full Title: An evidence synthesis of holistic services for refractory breathlessness in advanced malignant and non-malignant disease

Plain English Summary

What is the background to this research?

Breathlessness affects over 2 million people in the UK every year. People with advanced stages of disease often experience shortness of breath, or breathlessness, which is present even when they are resting or performing very light everyday activities such as moving around the home. It is frightening for patients and families, causing a lot of anxiety and panic. Severe breathlessness that does not settle, or comes on unexpectedly, is often the reason for people calling an ambulance or coming to the emergency department.

Breathlessness is hard to treat. There are few effective drug treatments, and non-drug treatments are preferred. These include finding comfortable positions, using fans to cool down, or pacing activities. Some people find exercise programmes helpful, but for many others these are too difficult to get to, or are too much of a commitment to take on. Breathlessness services that offer a range of treatments to manage the symptom in each person in an individual manner are known as “holistic” services. These can involve staff from palliative care, physiotherapy, occupational therapy, and respiratory medicine. They encourage people and their family members to self-manage by teaching them ways to cope with breathlessness, to feel less distressed, and to be more in control.

What will we do?

In this project we will provide a detailed review of holistic breathlessness services. We aim to find out firstly, how acceptable they are to the people accessing them and other health professionals, secondly, how effective they are at improving the burden of breathlessness and other symptoms to improve quality of life, and thirdly, if they offer good value for money. We will also find out which people are most likely to benefit from these services and if certain types of service are more effective, e.g. those offered at home as compared to in a community practice. We will invite NHS patients, managers, and health care professionals involved in caring for people who are breathless to review the findings. Together, we will make recommendations to help policy makers, commissioners, and health care professionals make informed decisions about the value and use of holistic breathlessness services in the NHS.

Why is this research important?

These services may reduce distress and suffering among the large and growing number of people with advanced disease who are breathless. By helping people manage their breathlessness better at home, they may also help avoid visits to the emergency department

Scientific Abstract

Background: Breathlessness is a common, distressing symptom which affects over 2 million people in the UK every year. It increases as disease progresses and often becomes refractory, i.e. not responsive to treatment aimed at the underlying disease. It is frightening for patients and families, and results in reduced life expectancy and high NHS costs. There are few effective treatments for refractory breathlessness so services that combine treatments are required. Cardiac and pulmonary rehabilitation provide exercise-based approaches to help manage breathlessness, but their reach is limited, particularly to those with the most advanced disease who become socially isolated and 'invisible'. Holistic breathlessness services provide pharmacological and non-pharmacological treatments to patients and caregivers, across settings, using multidisciplinary approaches. They emphasise self-management, and target improvements in quality of life by reducing the impact of breathlessness and related symptoms on everyday living. Literature scoping has identified a body of primary research related to these services, including RCTs, but this evidence must be synthesised and understood as a whole to inform NHS policy and practice.

Aim and objectives: We aim to provide a comprehensive evidence synthesis of holistic breathlessness services for people with advanced malignant and non-malignant conditions. Our objectives are to describe the structure, organisation and delivery of services; determine their effectiveness for improving symptom burden and quality of life, cost effectiveness from a patient, societal and NHS perspective, and acceptability to health care professions and patients. Further objectives are to identify predictors of treatment response, and produce clinical recommendations for policy, commissioning, and practice related to holistic breathlessness services, including their role in relation existing rehabilitation services.

Methods: A systematic review, individual patient data analysis, and expert consultation. The systematic review will adopt an extensive search strategy, pool data using meta-analysis where possible, and appraise individual studies and overall quality of evidence. Individual patient data pooled from three RCTs with comparable outcome measures will be used to investigate predictors of treatment response. A transparent expert consultation will identify clinical recommendations and priorities via a workshop, nominal group technique and consensus survey involving key stakeholders.

Impact: We will produce a range of outputs of value to the NHS, the public and the research community including (1) a published synthesis of evidence on breathlessness services; (2) knowledge of which patients are most likely to benefit, and which types of services are most effective, and (3) clinical practice and research recommendations for refractory breathlessness as judged by key stakeholders. This work will help patients with refractory breathlessness and the NHS by enabling commissioners and clinicians to make evidence based decisions on holistic breathlessness services. If effective, breathlessness services could benefit the large and growing number of people with chronic breathlessness, and their families, by reducing distress and suffering. This may subsequently reduce demand on NHS services, especially unplanned hospital admission via emergency department presentation.

Background and rationale

The problem: refractory breathlessness and its impact on the NHS

Breathlessness is a common symptom that can have a devastating impact on people's lives, [1-3] causing anxiety, fear and social isolation for patients and their caregivers.[4-6] In the UK over 2 million people experience breathlessness each year. This includes up to 98% of the 1 million people diagnosed with moderate-to-severe chronic lung disease, [7,8] >50% of the 200,000+ people with incurable cancer and 50% of the 2 million with chronic heart failure. [9-12] In addition, breathlessness is found in people affected by advanced renal and liver failure, neurological conditions, HIV/AIDS and many autoimmune diseases.[10,13-15] Breathlessness increases as disease progresses and often becomes refractory, i.e. is not responsive to treatment aimed at the disease.[4,16] Refractory breathlessness is associated with shortened life expectancy, [17-19] is very frightening for patients and families [5,6,11,12,20] resulting in high health care usage, frequent emergency visits, and prolonged hospitalisation. COPD alone accounts for over £800 million of direct health care cost to the UK. The indirect costs of COPD are substantial [13] (24 million lost working days per annum) though data to quantify other indirect costs, e.g. informal care, are not available. People with refractory breathlessness have multiple symptoms, on average 12-14 [3,4], including cough, pain, anxiety and depression. [11,21,22] These too increase as diseases progress, therefore, a more holistic approach often involving palliative care is proposed as beneficial.

Treatment options and current service provision

There are few effective treatments for refractory breathlessness. Systematic reviews have found opioids to be effective,[23] benzodiazepines not, [24] and oxygen only when patients are at least mildly hypoxic.[25,26] Non-pharmacological treatments including breathing retraining, exercise, and self-management strategies can be effective.[27] In early disease, non-pharmacological treatments are offered in the form of pulmonary or cardiac rehabilitation programmes, involving multiple (>12) sessions of supervised exercise training plus education over 6-8 weeks. These improve symptom burden, physical fitness and health-related quality of life, and are recommended first-line disease management strategies.[28,29] However problems with uptake, travel, or social isolation restrict their reach to those with the most advanced disease, who are often 'invisible'[5] to these services due to refractory breathlessness limiting engagement.

In response to this unmet need, services specifically designed to support patients with advanced disease have been trialled using refractory breathlessness as a marker of high symptom burden and deterioration. These provide component treatments in an individually tailored manner, and typically over fewer sessions than exercise-based approaches of pulmonary and cardiac rehabilitation.

Defining holistic breathlessness services

No agreement has been reached on the definition of holistic breathlessness services, but as complex interventions they can be described in terms of their setting, structure and content. Holistic breathlessness services can be offered in outpatient, community or day hospice settings. Core features include; (1) drawing on multiple specialties, typically with input from palliative care and physiotherapy with or without respiratory medicine, cardiology or oncology; (2) generally include multidisciplinary team members e.g. physicians, nurses and allied health professionals; (3) use both pharmacological and non-pharmacological therapies, selected on the basis of a holistic needs assessment to identify individual patient and caregiver needs; (4) emphasising self-management,

through use of education and behaviour change techniques; and (5) targeting improvements in patient and caregiver quality of life, by reducing the impact of breathlessness and related symptoms on everyday living. The extent to which families and caregivers are supported directly varies.

Literature scoping and the need for this evidence synthesis

Following a positive report from a randomised trial (n=119) of nurse led service published in 1999,[30] evidence relating to holistic breathlessness services in the subsequent decade was minimal and generally low in quality; arising from uncontrolled service evaluations. In recent years, more robust evidence has emerged including two trials from the applicant team.[31-33] A Breathlessness Intervention Service (BIS) was evaluated in a mixed-method RCT of patients with advanced cancer (n=67). The service reduced patient distress due to breathlessness significantly more than standard care in patients with cancers, and 94% of respondents reported positive impact in interview and survey data. The service was associated with reduced healthcare contacts and need for informal care.[32] In patients with non-malignant disease (n=87) BIS had a non-significant effect on the outcome of distress, but a positive qualitative impact consistent with findings for advanced cancer.[33] A separate Breathlessness Support Service (BSS) integrated palliative medicine and respiratory medicine, comprising two outpatient clinic visits, home visits from AHPs, and a 'toolkit' including information and crisis plans. A RCT (n=105) found that BBS improved the primary outcome breathlessness mastery, a composite component of quality of life, without increase in overall costs to the NHS. Survival also improved.[31] Survey and qualitative data found that patients and their families felt the BSS helped them be more self-sufficient despite breathlessness.[34,35]

In addition to these RCTs, a scoping search for this proposal, limited to 2005 onwards, identified two further controlled trials,[36,37] two prospective cohort studies,[38,39] and five qualitative studies [34,35,40-42] relating to potentially relevant services. Eighteen narrative reviews or opinion pieces [43-60] and four consensus statements[1,61-63] concerning holistic breathlessness services were identified, underscoring the interest and relevance of this topic to health and social care. No systematic reviews have assessed the clinical or cost effectiveness of these services. A 'title withdrawn' notice was identified for a 2008 Cochrane review of non-pharmacological interventions for breathlessness, which noted the nurse led service.[64] Planned updates of this review will first focus on component treatments to inform the content, but not delivery of holistic services (personal communication). The scoping search will likely underestimate available evidence, but highlights a current need and demand for an evidence synthesis of holistic breathlessness services to inform NHS decision making and policy.

Research aim and objectives

This project will apply rigorous evidence synthesis techniques with the aim to provide a comprehensive and objective summary of current available evidence for the clinical and cost effectiveness of holistic breathlessness services for people with advanced malignant and non-malignant conditions. Our research objectives are to:

- Describe the available evidence for holistic breathlessness services in terms of the intervention format, content, organization and context, patient characteristics, study design and quality, and outcomes measured.
- Determine the clinical effectiveness of holistic breathlessness services on symptom burden, health status, and quality of life.

- Determine the cost effectiveness of holistic breathlessness services from a patient/caregiver, societal and NHS perspective.
- Using individual patient data, examine predictors of treatment response, including characteristics of participants (level of impairment, symptom burden, multi-morbidity) and interventions (setting, duration, professional input, delivery).
- Examine the acceptability of holistic breathlessness services from the perspective of health care professions and patients, considering rates of referral, uptake, adherence, as well as patient experience and satisfaction.
- Using stakeholder consultation, identify clinical recommendations for policy, commissioning, and future implementation of holistic breathlessness services, including their role and delivery in relation to cardiac and pulmonary rehabilitation services.

This study will comprise an evidence synthesis of published and unpublished data through a systematic review and pooled secondary data analysis, undertaken in conjunction with key stakeholder consultation.

Systematic Review

A systematic review will consider the clinical and cost effectiveness, and acceptability of holistic breathlessness services, to improve quality of life of patients and their caregivers. In line with our broad objectives, a range of study designs (quantitative, qualitative, and economic) will be synthesised. We will register the review on the PROSPERO database and adhere to guidelines from the Centre for Reviews and Dissemination and Methodological Expectations of Cochrane Intervention Reviews. Pooled individual patient data will be used to identify moderators of treatment response. Following data synthesis, clinical recommendations and priorities will be determined using a Transparent Expert Consultation. A Project Advisory Panel will assist throughout offering views on relevant clinical outcomes, awareness of breathlessness services, and key evidence to NHS stakeholders.

Eligibility criteria

Inclusion criteria will be as follows:

- ***Participants:*** adults described as suffering from breathlessness, dyspnoea, shortness of breath, difficulty breathing, laboured breathing and with advanced stages of diseases with a high prevalence of breathlessness, including but not limited to cancer, chronic respiratory disease, chronic heart failure, or neurological disease. The criteria for advanced disease are as follows; cancer should be advanced local or metastatic; chronic respiratory disease should be GOLD stage III-IV / grade C-D; heart failure should be New York Heart Association stage III or IV; neurological disease should be progressive. The cut-off point for including participant groups will be 50%, i.e. at least half of individual study populations should fall within the above definitions.
- ***Interventions:*** holistic breathlessness services, as defined in the background text, which are offered in outpatient, community or day hospice settings; draw on multiple specialties and/or include multidisciplinary team members; utilise pharmacological and non-pharmacological

interventions, selected on the basis of a holistic needs assessment; emphasize self-management; and target improvements by reducing the perception and impact of breathlessness and related symptoms.

- ***Comparators:*** for controlled studies, all comparators will be considered including no treatment, usual care, an attention control, e.g. a patient support group without a specific focus on breathlessness, or an active control, e.g. alternative rehabilitation service.
- ***Outcomes:*** effectiveness outcomes will include parameters of breathlessness intensity (e.g. numerical rating scale), affect (e.g. distress due to breathlessness), and impact (e.g. MRC dyspnoea scale for breathlessness related disability). Cost and cost effectiveness outcomes will include inpatient hospital costs, including inpatient length of stay, consultations and investigations; treatments, equipment and medications; unpaid caregiver costs from a societal perspective, including caregivers' time off work; condition specific outcome measures, quality-adjusted life years (QALYS) or equivalent generic health-related quality of life measures (e.g. EQ5D), formal and informal service use, including caregiver dependency. Acceptability outcomes will include patient flow data (uptake, adherence, completion), as well as patient and caregiver acceptability, satisfaction and/or experience.
- ***Study design:*** randomised controlled trials (RCTs) with a parallel, single-stage or cross-over design, including studies using minimisation; non-randomised studies including prospective and retrospective designs; quantitative and qualitative designs to elicit patient and caregiver satisfaction and experience.

Exclusion criteria will include studies of patients without any evidence of breathlessness, interventions that target breathlessness but which only use physical exercise, or are disease specific (including cardiac or pulmonary rehabilitation), opinion pieces, case studies and case series with fewer than five participants.

Search strategy

The following electronic databases, accessed via Ovid, will be search from their respective inceptions up to February 2017: Cochrane Database of Systematic Reviews (CDSR), Cochrane Central Register of Controlled Trials (CENTRAL) and Database of Abstracts of Reviews of Effectiveness (DARE) (*The Cochrane Library,* 1996); MEDLINE (1966); EMBASE (1980); CINAHL (1980); British Nursing Index (1985); PsycINFO (1985) and Science Citation Index Expanded (1985). The search terms and strategy will be developed and piloted with information specialists to ensure broad inclusivity. They will be informed by the scoping literature, MEDLINE MeSH terms, and subject filters within specific databases.

Additional studies will be identified by searching ***r***eference lists of identified articles, articles citing all retrieved studies, and relevant editorials and reviews. Websites, textbooks, and voluntary sector materials will be searched. We will also contact corresponding authors of retrieved studies and researchers known to be active in this field to learn of any unpublished data or grey literature arising from meetings or conference proceedings. There will be no language restriction in the selection of evidence reports.

Selection of studies

Potentially eligible reports will be imported into bibliographic software (Endnote X7 onwards), any duplicates removed, and two researchers will assess titles and abstracts for relevance

independently. Abstracts of potentially eligible studies will be reviewed and where any reference was made to breathlessness services full texts will be obtained. In cases where abstracts are not available, or the study could not be excluded on the basis of its title full texts will be obtained. Two review authors will assess identifiable full texts of potentially relevant studies independently for compliance with the review eligibility criteria. Any disagreements will be resolved by discussion between co-applicants and collaborators. Where required we will submit requests to study authors for further information until a consensus regarding study eligibility is reached.

Appraisal of studies

Two applicants will independently assess study and reporting quality using standardised checklists, outlined below. Rather than relying on a total score, these checklists will enable the teams to make a standardised, structured assessment about methodological aspects of each study and how they are reported. Information to aid these assessments may be obtained from primary or secondary reports, protocols, published comments and personal contact with corresponding authors.

Methodological Quality:

All studies will be assessed using the Standard Quality Assessment Criteria for Evaluating Primary Research Papers (QualSyst)[65]. This tool contains two checklists with accompanying manuals, designed to guide systematic quality assessment of quantitative and qualitative studies. For mixed methods studies, the both the quantitative and qualitative checklists will be used for each component of the study, and supplemented with three items specific to this design from the Mixed Methods Appraisal Tool[66].

Randomised controlled trials will also be assessed for bias using the Cochrane Collaboration's tool[67]. This considers six domains; sequence generation, allocation concealment, blinding of study participants and personnel, completeness of outcome data, selective reporting and other potential sources of bias, for example carry-over or blocking, where bias may be introduced. A judgement will be made about the level of risk of bias for each domain: low, high or unclear.

Reporting Quality

Established checklists will also be used to assess quality of reporting (please see Table 1).

Table 1: Tools for assessing reporting quality

Study Design	**Tool/s to assess reporting quality**
Randomised controlled trials	CONSORT statement[68]
Pilot / Feasibility trials	CONSORT extension for pilot and feasibility studies[69]
Quasi-experimental	Adaptation of CONSORT statement using applicable items
Observational	STROBE statement[70]
Qualitative	COREQ checklist[71]

Mixed methods	COREQ plus the most appropriate quantitative checklist

Quality of the evidence

Two of the project team will independently rate the quality of evidence for each clinical outcome using the GRADE (Grades of Recommendation, Assessment, Development and Evaluation) approach. GRADE considers study limitations, consistency of effect, imprecision, indirectness and publication bias, to assess the quality of the body of evidence for each outcome. Grades of evidence will be assigned for each outcome to rank the quality of the evidence using the GRADEprofiler software:

- High = further research is very unlikely to change our confidence in the estimate of effect;
- Moderate = further research is likely to have an important impact on our confidence in the estimate of effect and may change the estimate;
- Low = further research is very likely to have an important impact on our confidence in the estimate of effect and is likely to change the estimate;
- Very low = any estimate of effect is very uncertain.

Data synthesis

All data will be extracted by two independent reviewers using a pre-designed and piloted electronic data capture form to avoid error and permit data checking. The form will clearly record and report all relevant aspects of the studies.

Structure, organisation and delivery

To date, neither the content nor the organizational aspects of holistic breathlessness services have been studied. As differences between services may limit comparisons and benchmarking,[72] we will describe the overall content and organizational aspects to appraise the degree of consistency or heterogeneity. Data on the intervention setting (home, community, hospital), funding (NHS, non-NHS), team members by profession, referral sources, patient case mix (diagnosis, comorbidity), duration and frequency, target outcomes, and component interventions will be summarised.

Clinical effectiveness

Outcomes will be analysed as continuous data where possible. Mean difference (MD) or standardised mean difference (SMD) between the intervention and comparator groups with 95% confidence intervals will be estimated. Where there were sufficient data and consistent or comparable outcomes, we will perform meta-analysis to estimate the overall direction, size and consistency of effects. We will assess clinical heterogeneity using the I^2 statistic to quantify inconsistency across studies and impact on the meta-analysis; the percentage of the variability in effect estimates which is due to the condition rather than sampling error.[73] In case of minimal clinical heterogeneity an inverse variable fixed-effect model will be used. If considerable (I^2 > 50-75%) heterogeneity is confirmed a random-effects model will be preferred. Sensitivity analysis will restrict the analysis according to study population and risk of bias. In cases where there were missing data or insufficient data to perform meta-analysis, we will attempt to contact the study authors. Where

meta-analysis is not considered appropriate we describe and tabulate findings from individual studies.

Cost effectiveness

We will present pertinent characteristics of included health economics studies including data sources; jurisdiction and setting; analytic perspective and time horizon. We will present point estimates of measures of items of resource use and cost with associated measures of uncertainty for interventions and comparators, as well as point estimates of incremental costs and/or cost effectiveness, again with associated measures of uncertainty. US dollars (USD) costs where reported will be converted to Great British Pounds (GBP) (current year) based on Purchasing Power Parities (PPP) and gross domestic product (GDP) deflators. If there are sufficient data, we will identify and report incremental cost per QALY (or equivalent) and cost-benefit ratios where relevant. Further cost-effectiveness analysis will be depending on the level of data retrieved.

Patient acceptability and experience

We will record rates of referral, uptake and adherence to interventions, and the occurrence of any adverse events relating to acceptability. For patient or caregiver experience and satisfaction data, all text, including quotations reported in the article under the headings of 'results' or 'findings', will be imported verbatim into qualitative data software (Nvivo). A thematic synthesis, using three consecutive phases will be performed: (1) line by line coding of the results of included studies; (2) development of descriptive themes encompassing the themes or codes of the primary studies, with particular attention to similarities and differences across and between studies; and (3) development of analytical themes, going beyond presentation of the original data.[74] Findings from the quantitative surveys will be summarised descriptively and incorporated into the synthesis and thematic framework.

Pooled secondary analysis of individual patient data

To investigate the associations between clinical effectiveness, and characteristics of the different interventions and study participants, we will pool individual patient data from three randomised controlled trials conducted among the applicants for a meta-analysis.[31-33] All participants had chronic refractory breathlessness due to advanced disease, and in both designs the primary outcome measure related to the effect of breathlessness on patient distress and/or feeling of mastery. Combined, the trials provide a total of 259 sets of outcome data.

Anonymised individual patient data will be obtained from the data custodians, then datasets will be cleaned and harmonised. 'Treatment response' will be defined using known minimally important differences for the respective outcomes (0.5 points for CRQ Mastery domain, 1 point on a NRS for distress due to breathlessness). We will use regression models for binary variables to investigate baseline predictors of response. Univariate regression will be used to assess the relationships between response and candidate explanatory variables concerning intervention (setting, duration, professional input, delivery) and participants (level of impairment, symptom burden, multi-morbidity) characteristics. Variables associated with response ($p<0.15$) will be considered in a multivariate model, adopting a backwards conditional approach to retain variables in the model

(p<0.10). 'Study' will be included as variable to account for differences between designs. Using a dichotomous independent variable in the regression models (responder: yes/no) there is also sufficient power to reliably examine up to 25 independent variables,[75] permitting study of all candidate moderators of treatment response.

Stakeholder consultation

Following the data synthesis, a Transparent Expert Consultation (TEC) technique [76] will be used with service providers, commissioners, voluntary sector representatives. This will identify clinical and policy priorities to inform commissioning and implementation of holistic breathlessness services into practice. TEC uses consensus techniques of nominal group and survey consensus. It has been successfully used by our group among palliative care clinicians, academics and other key stakeholders, and enables a rapid wide consultation on the data synthesis.[77-79] We will use a workshop format; presenting data from the systematic review, and using small groups to generate recommendations on the salient findings from the data, implications for clinical policy, practice and commissioning, and evidence gaps. The recommendations generated in the TEC workshop will be combined, duplicates removed, and then presented in an online/postal consensus survey to all workshop participants, plus members of the Project Advisory Group.

Participants:

Workshop participants (n=40-60) will be purposively selected to represent different professionals, service providers and service commissioners involved in caring for people with refractory breathlessness, including specialists in palliative or respiratory care, and voluntary sector organisations, plus service user representatives. These individuals will be identified through contact lists of people and organisations we have previously worked with on research around breathlessness and palliative care, online searches, and recommendations from these individuals. This will include patient and public involvement (PPI) members at the Cicely Saunders Institute who represent people living with breathlessness and their informal carers.

Professional participants will include a range of the following:

- Health and social care practitioners providing care to patients with breathlessness, from a range of disciplines including (but not limited to) palliative care, respiratory medicine, physiotherapy, and occupational therapy.
- Commissioners who are leads for end of life care services
- Voluntary sector representatives (from local and national organisations supporting/advocating for people living with breathlessness; for example: British Lung Foundation, Breathing Matters, Alpha-1, Mesothelioma.org)
- Leaders in breathlessness research (e.g. Life of Breath project, Breathlessness Intervention Service project)

Service user representatives will include:

- People living with breathlessness
- People with current or prior experience as an informal carer for someone living with breathlessness

All participants must be adults with capacity to give informed consent and communicate in English.

Participants will be reimbursed reasonable travel costs for attending the workshop.

Survey participants will include:

- All those attending the workshop
- People who were eligible for but unable to attend the workshop
- Additional participants meeting the above criteria (in order to include professional/service user groups that were under-represented in the workshop)

Recruitment & Informed Consent

Purposively selected stakeholders will be contacted via email. They will receive a personal invitation to the workshop and be asked to reply to indicate their attendance/decline. Please see Appendix 1 for an example email. Those indicating attendance will then receive the information sheet for participation in the workshop, a copy of the consent form, and the schedule for the day. Informed consent to participate in the TEC workshop will be asked for when participants arrive at the workshop. Please see Appendix 2 and 3 for the TEC workshop information sheet and consent form.

All workshop participants, members of the project advisory group, and those who expressed and interested in the workshop but were unable to attend will be sent email invitations to the online consensus survey. We will also invite additional participants who did not take part in the workshop to complete the consensus survey, in order to ensure representation of all relevant stakeholders. These additional participants will be identified as above, via people and organisations we have worked with in the past.

Information regarding the purpose of the survey and how their data will be used will be included in an attachment to their invitation email, and summarised at the start of the survey. In both cases the contact details of the researcher will also be provided in case the participant has any questions. Informed consent for the consensus survey is presumed through participation. A hard copy of the consensus survey will be sent to participants preferring this format, with a free post return envelope.

Please see appendix 4 for an example invitation email for the consensus survey, appendix 5 for the consensus survey participant information sheet, and appendix 6 for the introduction text to the consensus survey.

Procedure:

Transparent Expert Consultation Workshop:

The workshop format will begin with whole-group presentations and discussion on the data synthesis findings. This will be followed by 3-4 structured group sessions (n=10-15 per group) using the data to focus on critical questions in this field, for example:

- **How do we define and deliver 'holistic breathlessness services'?**
- **How and where can holistic breathlessness services be integrated into current practice?**
- **How should success of holistic breathlessness services be measured / monitored?**
- **What are future research priorities around holistic breathlessness services?**

These sessions will use a modified nominal group technique, facilitated and scribed by members of the research team. The facilitators will guide participants through a structured process of: brief discussion; individual writing of recommendations and ranking from highest to lowest (on structured sheets stating the group question, the ranking scale, and space for recommendations and rationale); and individuals in turn reading out their highest ranked recommendation including their rationale until individual lists are exhausted (or time is exceeded).[78] Scribes will record recommendations and each small group will discuss and agree the final priority order, to be presented and discussed with the whole group.[77] The small group discussions will be digitally recorded to provide a record.

Participants will then return to a whole-group forum to share and discuss the recommendations generated by each group in turn. These discussions will also be recorded for incorporation into the analysis. The workshop will be closed with a summary of the day, and information about the next step of the consultation: the online consensus survey.

Please see Appendix 7 for workshop schedule.

Online Consensus Survey

The recommendations generated in the TEC workshop will be combined, duplicates removed, and then presented in an online/postal consensus survey to all workshop participants, members of the Project Advisory Group, and additional participants needed to represent a broad range of stakeholders. Participants will receive a personalised email invitation to participate and two reminders: one after two weeks, and one after three weeks. In the survey, participants will be asked to indicate the level of agreement with the recommendations from (1, strongly disagree, to 9, strongly agree) and given an opportunity for free-text comments.[76,80,81]

Analysis:

Individual recommendations and ranks from the small group sessions of the workshop will be entered into Excel spreadsheets with assigned participant identification numbers. Flipchart records, scribes' notes, and verbatim quotes from the recorded workshop discussions will be typed and collated. Qualitative analysis will then be used to identify themes. These themes will be used to re-arrange and group the recommendations and relevant workshop notes/quotations. Duplicates will be combined and recommendations arranged by their priority rankings. Recommendations considered a high priority by participants and/or forming a prominent theme will be presented in the online survey. The where possible recommendations will retain participants' original language, with amendments to enhance clarity[82,83].

The online survey data will be analysed using descriptive statistics (frequencies, medians, inter-quartile ranges) to determine levels of agreement and consensus. Classification of agreement and consensus will be as follows[84]:

Agreement (median score):

- Strong agreement: ≥ 8
- Moderate agreement: < 8 – > 6
- No agreement: ≥ 4 - ≤ 6
- Moderate disagreement: < 4 - > 2
- Strong disagreement: ≥ 2

Consensus (inter-quartile range):

- High consensus: < 2
- Low consensus: ≥

Narrative comments will be collated by recommendation and thematically analysed to aid understanding and provide illustrative examples of the issues raised by the proposed recommendations[85].

Project team expertise

The project team comprises a consortium of international leaders and clinical-academics in palliative care, respiratory and rehabilitation research. They share strong links with the Pain, Palliative & Supportive Care Cochrane Collaboration Group, the National Institute of Health Research, and Department of Health. Most are trained and have experience in systematic review procedures to inform health and social care policy, and have an international reputation for work in palliative care and rehabilitation with specific reference to breathlessness.

- Dr Matt Maddocks (Lecturer in Health Services Research and Specialist Physiotherapist, KCL)
- Prof Irene Higginson (Professor of Palliative Care and Policy, Scientific Director of Cicely Saunders International and NIHR Senior Investigator, KCL)
- Ms Lisa Brighton (Research assistant, KCL)
- Dr Wei Gao (Senior Lecturer in statistics and epidemiology, KCL)
- Dr Deokhee Yi (Health Economist, KCL)
- Dr Sabrina Bajwah (Consultant and honorary senior lecturer, KCL)
- Dr Sara Booth (Honorary consultant & Associate Lecturer, University of Cambridge)

- Dr Morag Farquhar (Senior Research Associate and NIHR Career Development Fellow, University of East Anglia)
- Dr William Man (Senior Lecturer / Consultant Chest Physician, Imperial College London)
- Daniel Marion (Patient representative)
- Dr Charles Reilly (Consultant Physiotherapist, King's Health Partners)
- Ms Lucy Fettes (Specialist Physiotherapist, St Joseph's Hospice and KCL)
- Dr Nicholas Hart (Clinical & Academic Director Lane Fox Respiratory Service, Guy's & St Thomas' NHS Foundation Trust / Reader in Respiratory & Critical Care Medicine)

Patient and Public Involvement

Mr Daniel Marion is a named collaborator and part of the research team for this project. With his guidance we will plan and run PPI effectively throughout the project. He has agreed to participate in the project advisory group and help with interpretation and dissemination of findings. We plan to have two additional lay members in the Project Advisory Group, to be identified through the Cicely Saunders Institute PPI group, our website and local Breathe Easy and cancer support meetings. These individuals will comment on the overall plans, including recruiting PPI members for the transparent expert consultations. They will be involved in refining the project protocol; commenting on the acceptability outcomes and data; considering the meaning of the results; plans for workshops; and developing lay summaries, dissemination materials and reports. We will reimburse PPI member expenses and pay an hourly fee, in accordance with NIHR Involve guidance. We plan three meetings where patients and their families/caregivers, commissioners and health professionals will engage with the findings. PPI members will be encouraged to identify training needs and preferences, and given support via co-applicants and national resources, e.g. NIHR CLAHRC.

Outputs and Dissemination

The proposed work will produce a range of outputs of value to the NHS, the public and the research community: (1) a report of research evidence relating to symptom-led services for people suffering with refractory breathlessness, including how existing service are structured and delivered; (2) a published review on the evidence for the effectiveness and cost-effectiveness of symptom-led breathlessness services; (3) shared knowledge on patient and/or service characteristics that moderate a treatment response from symptom-led breathlessness services, to inform policy and service provision; (4) a list of practice recommendations and future research priorities for refractory breathlessness and it management, from an NHS perspective as judged by key stakeholders.

We will utilise a broad strategy to maximise dissemination, which will include; (1) sharing of scientific findings via open-access publication in high impact journals and presentation at international meetings; (2) plain English summaries of findings for public bodies and web-sites (e.g. Macmilllan, Marie Curie) to communicate evidence through a user-friendly interface; (3) use of social media (e.g. Twitter, YouTube) recognising its role in public education and potential to influence stakeholders and service providers; (4) public engagement via talks with service user groups and open public events at the Cicely Saunders Institute so patients and their caregivers can learn about the research; (5) direct sharing of findings with public bodies (e.g. National horizon scanning centre) and policy

makers with whom the applicants have direct access (e.g. NCRI Supportive and Palliative care CSG, European Association for Palliative Care) to facilitate uptake of findings into policy; and (6) education of professional bodies and lead service managers via our stakeholder workshop where we will leverage our co-applicant and collaborator links to ensure attendees have an influence over service delivery and policy.

Project timetable and milestones

The overall project duration is 14 months. Specific milestones, linked to the GAANT chart below, are (milestone 1) project set up and development of final protocol for the systematic review by month 3; (milestone 2) completion of initial literature searches and data extraction by month 4; (milestone 3) completion of data synthesis and interpretation (structure, clinical and cost effectiveness, acceptability) by month 8; (milestone 4) complete the predictors of response analysis by month 10; (milestone 5) undertake the stakeholder consultation event and consensus survey by month 11; (milestone 6) complete the final report and dissemination plan by month 14. Regular activities to review progress against these milestones and ensure proactive management include weekly meetings between the project lead, researcher, and available co-applicants as required; 3-monthly Project Advisory Group meetings; and three PPI meetings to be scheduled / held in parallel with project events.

CALENDAR MONTH	Mar-17	Apr-17	May-17	Jun-17	Jul-17	Aug-17	Sep-17	Oct-17	Nov-17	Dec-17	Jan-18	Feb-18	Mar-18	Apr-18
PROJECT MONTH	1	2	3	4	5	6	7	8	9	10	11	12	13	14
Set up and protocol development														
Searches and data extraction														
Data synthesis and interpretation														
Predictors of response analysis														
Stakeholder consultations														
Consensus survey														
Preparation of final report														
Dissemination activities														
PPI meetings/consultations														
Project advisory group meetings														
Milestones			**1**	**2**				**3**		**4**	**5**			**6**

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Appendix 1: Example Invitation to TEC workshop

Dear [INSERT NAME]

Re: Stakeholder consultation on holistic services for severe breathlessness in advanced disease

We would like to invite you to participate in a stakeholder consultation workshop on October 4th 2017 to help generate recommendations around the design, delivery, and evaluation of holistic services for people living with advanced disease with severe (i.e. refractory) breathlessness.

Your involvement would be invaluable because of your [INSERT clinical / research / commissioning / personal] experience around breathlessness. The workshop involves: presentations summarising relevant evidence about holistic breathlessness services; small group work to generate recommendations for future clinical practice and research; and after the workshop an online consensus survey to prioritise and explore the recommendations made. For full details, please see the participant information sheet attached [enclosed or link to PDF if email].

This stakeholder consultation workshop has been approved by the King's College London research ethics committee [INSERT REF], and is part of a larger project on holistic breathlessness services for people with advanced disease. The study is led by Dr Matthew Maddocks, and funded by the National Institute for Health Research.

We hope you are able to support this important and innovative research study. Please reply to this email or telephone the research team on 020 7848 5041 to indicate your interest in participating in the workshop. We will send detailed information about the workshop format, timing and venue. If you are unable to attend the workshop on the proposed date but would like to be included in the online consensus survey, please let us know. Thank you for considering this request, and we look forward to hearing from you.

Yours sincerely

Appendix 2: TEC information sheet (v2, 21st July 2017)

PARTICIPANT INFORMATION SHEET

REC Reference Number: LRS-16/17-4692

Title of study: Stakeholder consultation on holistic services for severe breathlessness in advanced disease

Background: Breathlessness and holistic services

People with advanced stages of disease often experience shortness of breath, or breathlessness, which is present even when they are resting or performing very light everyday activities such as moving around the home. Breathlessness services that offer a range of treatments to manage the symptom in each person in an individual manner are known as "holistic" services. These can involve staff from palliative care, physiotherapy, occupational therapy, and respiratory medicine. They encourage people and their family members to self-manage by teaching them ways to cope with breathlessness, to feel less distressed, and to be more in control.

What is the purpose of the study?

The purpose of this study is to generate evidence-based recommendations around clinical, policy, and research priorities to help policy makers, commissioners, and health care professionals make informed decisions about the value and use of holistic breathlessness services in the NHS. To do this we are inviting you to take part in a stakeholder consultation workshop, and a follow-up online consensus survey.

Why have I been invited to take part?

You have been invited to take part because you have clinical, research, commissioning and/or personal experience relent to severe breathlessness and/or holistic services.

Do I have to take part?

No, your participation is entirely voluntary. Deciding not to take part will not affect you in any way. If you do decide to take part and change your mind, you can withdraw at any time prior to November 1st 2017 without giving a reason.

What will happen to me if I take part?

If you decide to take part in the study you will be contacted by a Research Assistant from King's College London, who will provide the full details about our stakeholder workshop. The workshop will take place at the Cicely Saunders Institute, Denmark Hill, London (SE5 9PJ), as part of the 'Breathlessness: Current Innovations and Priority Setting' event. On the day of the workshop, we will ask you to sign a consent form for your participation. Please see the end of this information sheet for a copy of this consent form. All participants will be presented with evidence around holistic breathlessness services, before being split up to work in small groups to generate recommendations for future clinical practice in research. The recommendations generated in each group will be fed back to all participants and discussed. These priority setting discussions will be digitally recorded. We

anticipate the presentations and priority setting discussions to last approximately 5 hours in total, including breaks for lunch / tea and coffee.
Following the workshop, the research team will listen to the recordings of the discussions and collate the top recommendations. These recommendations will be circulated to workshop participants, and those who expressed an interest but could not attend. Participants will be asked to rate how much they agree / disagree with each of the recommendations, with opportunities for free text feedback. Results from this survey will inform a final list of recommendations. The survey will be circulated within 1-2 months following the workshop, and we anticipate it will take approximately 20 minutes to complete.

All information you provide will be linked-anonymised: meaning an ID number will be assigned to the information (one ID number per participant) and identifiable information will be removed and stored separately. Identifiable information will not be included in analysis or publications, unless you consent to your name being included in a list of workshop participants in the acknowledgements. All quotes from participants will be anonymised. The workshop recording will be destroyed after the study is completed.

Service user representatives will be reimbursed reasonable travel costs for attending the workshop.

What are the possible risks of taking part?
There is a very small risk that the nature of the workshop (which relates to severe breathlessness and advanced disease) might be distressing for some people. If you do become distressed, a researcher will be present to talk with you in private. If you or the researcher feels you may need further support as a result of taking part in this study, we will work directly with our clinical colleagues to identify appropriate help.

What are the possible benefits of taking part?
You will have the opportunity to share your views and experiences around breathlessness and holistic services, which will help us inform future clinical practice and research. We hope that this will be of interest to you. You may also receive a summary of the findings from the research study at the end of the project if you wish.

Will my taking part be kept confidential?
Yes, all the data you provide will be confidential. As detailed above, all information will be link-anonymised, so you cannot be identified during analysis and reports/publications. Only the research team and individuals supervised by members of the research team will have access to your personal information. This may include review by responsible individuals from the Sponsor for monitoring and audit purposes.

We will only list your name in our acknowledgement of workshop participants if you specifically provide consent for this when completing the consent form. In all cases, quotes from the workshop discussion and free text comments will remain anonymous.

Anonymous research data will be kept securely at King's College London in line with departmental guidelines for a period of 7 years. Anonymised data may be shared with other researchers in the department for the purposes of additional data analysis.

How is the project being funded?

The research project is being funded by a grant from the National Institute of Health Research.

Who is running the study?

The study is run by King's College London, led by Dr Matthew Maddocks, and will take place within the 'Breathlessness: Current Innovations and Priority Setting' event run by the Collaboration for Leadership in Applied Health Research in South and North West London.

What will happen to the results of the study?

The findings from the consultation will be written up and presented at conferences, in a report to the funder and in journal publications. We may also share our findings on our website, blogs, and on social media. If anything you say in the workshop or free-text survey comments is quoted, we will do everything we can to ensure it is anonymous and not traceable to you.

Who should I contact for further information?

If you have any questions or require more information about this study, please contact Lisa Brighton (Research Assistant) or Dr Matt Maddocks (Principal Investigator) using the following contact details:

Lisa Brighton: lisa.brighton@kcl.ac.uk, 020 7848 5041
Dr Matt Maddocks: matthew.maddocks@kcl.ac.uk, 020 7848 5242

What if I have further questions, or if something goes wrong?

If this study has harmed you in any way or if you wish to make a complaint about the conduct of the study you can contact King's College London using the details below for further advice and information:

The Chair, Biomedical Sciences, Medicine, Dentistry and Natural & Mathematical Sciences Research Ethics Panel, rec@kcl.ac.uk, 020 7848 4070

Thank you for reading this information sheet and for considering taking part in this research.

Appendix 3: TEC consent form (v2, 21st July 2017)

CONSENT FORM FOR PARTICIPANTS IN RESEARCH STUDIES

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of Study: Stakeholder consultation on holistic services for severe breathlessness in advanced disease

King's College Research Ethics Committee Ref: LRS-16/17-4692

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

	Please tick or initial
I confirm that I understand that by ticking/initialling each box I am consenting to this element of the study. I understand that it will be assumed that unticked /un-initialled boxes mean that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element I may be deemed ineligible for the study.	☐

		Please tick or initial
1.	*I confirm that I have read and understood the information sheet dated 21st July 2017 (v2) for the above study. I have had the opportunity to consider the information and asked questions which have been answered satisfactorily.	☐
2.	*I understand that I will be able to withdraw my data up November 1st 2017	☐
3.	*I consent to the processing of my personal information for the purposes explained to me. I understand that such information will be handled in accordance with the terms of the UK Data Protection Act 1998.	☐
4.	*I understand that my information may be subject to review by responsible individuals from the College for monitoring and audit purposes.	☐
5.	Anonymity is optional for this research. Please select from the following two options:	
	a. I agree to be fully identified	☐
	b. I wish to remain anonymous	☐

6. I agree to be contacted in the future by King's College London researchers who would like to invite me to participate in follow up studies to this project, or in future studies of a similar nature. ☐

7. I agree that the research team may use my anonymised data for future research ☐

8. I understand that the information I have submitted will be public as a report. ☐

9. I consent to my participation in the workshop being audio recorded. ☐

10. I consent for the research team to contact me to invite me to participate in the online /postal survey on the recommendations generated at the workshop ☐

_____	_____	_____
Name of Participant	**Date**	**Signature**

To be completed by the researcher:

_____	_____	_____
Name of Researcher	**Date**	**Signature**

Appendix 4: Invitation to online consensus survey

Dear [INSERT NAME]

Re: Online consensus survey about holistic services for severe breathlessness in advanced disease

[VERSION 1 (New participant)] We would like to invite you to participate in an online consensus survey, to provide feedback on our draft recommendations around the design, delivery, and evaluation of holistic services for people living with advanced disease with severe (i.e. refractory) breathlessness.

Your involvement would be invaluable because of your [INSERT clinical / research / commissioning / personal] experience around breathlessness. This survey includes a list of recommendations generated at a recent stakeholder event: you will be asked to rate how much they agree / disagree with each of the recommendations, and provide free text feedback. Results from this survey will inform a final list of recommendations. For full details, please see the participant information sheet attached [enclosed or link to PDF if email].

OR

[VERSION 2 (Workshop attendee)] Thank you for your participation in our recent stakeholder consultation workshop. We would now like to invite you to participate in the follow-up online consensus survey. This will give you the opportunity to feed back on the recommendations generated in the workshop.

Your involvement would be invaluable because of your [INSERT clinical / research / commissioning / personal] experience around breathlessness. This survey includes the most prominent recommendations generated the recent stakeholder workshop: you will now be asked to rate how much they agree / disagree with each of the recommendations, and provide free text feedback. Results from this survey will inform a final list of recommendations. For full details, please see the participant information sheet attached [enclosed or link to PDF if email].

We hope you are able to support this important and innovative research study. If you would like to take part, please click this link to complete the survey:

[INSERT LINK]

This online consensus survey has been approved by the King's College London research ethics committee [INSERT REF], and is part of a larger project on holistic breathlessness services for people with advanced disease. The study is led by Dr Matthew Maddocks, and funded by the National Institute for Health Research. Thank you for considering this request, and we look forward to hearing from you. If you have any questions, please contact Lisa Brighton (lisa.brighton@kcl.ac.uk / 020 7848 5041),

Yours sincerely

Appendix 5: Consultation survey participant information sheet (v2, 21st July 2017)

PARTICIPANT INFORMATION SHEET

REC Reference Number: LRS-16/17-4692

Title of study: Stakeholder consultation on holistic services for severe breathlessness in advanced disease

Background: Breathlessness and holistic services

People with advanced stages of disease often experience shortness of breath, or breathlessness, which is present even when they are resting or performing very light everyday activities such as moving around the home. Breathlessness services that offer a range of treatments to manage the symptom in each person in an individual manner are known as "holistic" services. These can involve staff from palliative care, physiotherapy, occupational therapy, and respiratory medicine. They encourage people and their family members to self-manage by teaching them ways to cope with breathlessness, to feel less distressed, and to be more in control.

What is the purpose of the study?

The purpose of this study is to generate evidence-based recommendations around clinical, policy, and research priorities to help policy makers, commissioners, and health care professionals make informed decisions about the value and use of holistic breathlessness services in the NHS. To do this we are inviting you to participate in an online consensus survey. In this survey, you will be able to share your views on recommendations generated at a recent stakeholder workshop.

Why have I been invited to take part?

You have been invited to take part because you have clinical, research, commissioning and/or personal experience relent to severe breathlessness and/or holistic services.

Do I have to take part?

No, your participation is entirely voluntary. Deciding not to take part will not affect you in any way. If you do decide to take part and change your mind, you can withdraw at any time within 2 weeks of the survey close date without giving a reason.

What will happen to me if I take part?

If you decide to take part in the study we ask that you please complete the online consensus survey, following the link provided in the invitation email. The survey will include a list of recommendations generated at a recent stakeholder event. You will be asked to rate how much they agree / disagree with each of the recommendations, and given opportunities for free text feedback. Results from this survey will inform a final list of recommendations. We anticipate the survey will take approximately 20 minutes to complete. Please note that submission of the survey implies consent for us to use your data as specified in this information sheet.

All information you provide will be linked-anonymised: meaning an ID number will be assigned to the information (one ID number per participant) and identifiable information will be removed and

stored separately. Identifiable information will not be included in analysis or publications. All quotes from participants will be anonymised.

What are the possible risks of taking part?

We do not anticipate any risks of taking part in this study.

What are the possible benefits of taking part?

You will have the opportunity to share your views and experiences around breathlessness and holistic services, which will help us inform future clinical practice and research. We hope that this will be of interest to you. You may also receive a summary of the findings from the research study at the end of the project if you wish.

Will my taking part be kept confidential?

Yes, all the data you provide will be confidential. As detailed above, all information will be link-anonymised, so you cannot be identified during analysis and reports/publications. Only the research team and individuals supervised by members of the research team will have access to your personal information. This may include review by responsible individuals from the Sponsor for monitoring and audit purposes.

Anonymous research data will be kept securely at King's College London in line with departmental guidelines for a period of 7 years. Anonymised data may be shared with other researchers in the department for the purposes of additional data analysis.

How is the project being funded?

The project is being funded by a grant from the National Institute of Health Research.

Who is running the study?

The study is run by King's College London, led by Dr Matthew Maddocks.

What will happen to the results of the study?

The findings from the online survey will be written up and presented at conferences, in a report to the funder and in journal publications. We may also share our findings on our website, blogs, and on social media. If anything you say in the free-text survey comments is quoted, we will do everything we can to ensure it is anonymous and not traceable to you.

Who should I contact for further information?

If you have any questions or require more information about this study, please contact Lisa Brighton (Research Assistant) or Dr Matt Maddocks (Principal Investigator) using the following contact details:

Ms Lisa Brighton: lisa.brighton@kcl.ac.uk, 020 7848 5041
Dr Matthew Maddocks: matthew.maddocks@kcl.ac.uk, 020 7848 5242

What if I have further questions, or if something goes wrong?

If this study has harmed you in any way or if you wish to make a complaint about the conduct of the study you can contact King's College London using the details below for further advice and information:

The Chair, Biomedical Sciences, Medicine, Dentistry and Natural & Mathematical Sciences Research Ethics Panel, rec@kcl.ac.uk, 020 7848 4070

Thank you for reading this information sheet and for considering taking part in this research.

Appendix 6: Consensus Survey Introduction

Welcome to the Holistic Breathlessness Services Consultation Survey:

All responses to this online survey will be CONFIDENTIAL. Although we ask that you please enter your email address at the beginning of the form, this will only be used to match this survey with any previous responses, and will be replaced with an anonymous ID code prior to data analysis and reporting.

Your responses will be stored on a secure UK-based server and handled in accordance with the UK Data Protection Act (1998).

If you have any questions, please contact our research assistant Lisa Brighton on 020 7848 5041 or lisa.brighton@kcl.ac.uk

For a reminder about the full study information, please see the participant information sheet: [INSERT LINK].

Please begin by entering your email address.

This must be the email address we sent this questionnaire link to:

…….

Appendix 7: TEC Workshop schedule

Breathlessness: Current Innovations & Priority Setting

Collaboration between CLAHRC South London, CLAHRC North West London, and the Holistic Breathlessness Services Research Project

Wednesday 4th October 2017

At the Cicely Saunders Institute, Dinwoodie Suite, Bessemer Road, London SE5 9PJ

Time	Title	Speaker/Facilitator
09:00-09:45	**Registration**	
09.45–10.00	Welcome and Introduction	tbc
10:00 -10.15	Patient and Carer Story	tbc
10.15-10:40	A systematic review of holistic breathlessness services	Matt Maddocks
10.40 –11.05	Who benefits most from holistic breathlessness services?	Lisa Brighton
11.05 - 11.30	Rehabilitation for Breathlessness	William Man
11.30 - 11.55	Care Bundles and Breathlessness	tbc
11.55-12.15	Introduction to afternoon group work	Matt Maddocks
12.15 -13:15	**Lunch**	
13.15-15.00	**Priority setting: group discussion**	
	Group 1: Defining service structure	Sabrina Bajwah & Charlie Reilly
	Group 2: Implementing	Vimal Sriram
	Group 3: Metrics	Lisa Brighton
	Group 4: Future research	Irene Higginson
15.00 -15.15	Next steps & closing	Irene Higginson
15.15 - 16.30	**Networking**	

Cicely Saunders International
Better care at the end of life

Collaboration for Leadership in Applied Health Research and Care South London (CLAHRC South London)

NIHR CLAHRC Northwest London

NHS National Institute for Health Research

Contacts:

Lisa Brighton: lisa.brighton@kcl.ac.uk Tel: 020 7848 5041

Lelia Oniri: lelia.oniri@kcl.ac.uk Tel: 0207 848 0096