Breathlessness IMPRESS Tips (BITs) for commissioners:
discuss locally, and adapt to your local context

Introduction
These Breathlessness IMPRESS Tips (BITs) are one of a set of four BITs based on an
IMPRESS programme to develop guidance for clinicians, commissioners, patients and
researchers about how to improve services for the adult population disabled by long term
breathlessness. The BITs for clinicians include a new algorithm to assess and manage
breathlessness. There is also an introduction that describes the methods and scope we have
used and prevalence modelling for the main causes of long-term breathlessness: COPD, heart
failure, anxiety, obesity and anaemia. These can be found here.

The BITs build on previous IMPRESS work also undertaken with the London School of
Economics on the relative value of different interventions for chronic obstructive
pulmonary disease (COPD)¹ and previous IMPRESS work on More for Less.²

These BITs provide some guidance to commissioners about how to support and
incentivise the local healthcare system to take a symptom-based rather than a disease-
based approach to assessment and care of adults who have long-term breathlessness.
Taking a symptom-based approach has advantages because it

- Can harmonise potentially different approaches advised by different specialties to
  assessment and treatment of breathlessness and therefore reduce variation
- Guides the system to start at the point where people present to primary care - with
  symptoms not diagnoses - and suggests how to support the system to increase
diagnosis rates in at least three under-diagnosed conditions: COPD, heart failure and
  anxiety, which, if left untreated cause significant morbidity and high use of acute
  services
- Has the potential to address multi-morbidity. For example, only 14-18% of people
  with COPD only have COPD and when actively assessed for co-morbidities it may
  be as low as 3%. If not all of the morbidities are diagnosed and managed, this will
  also worsen health outcomes and may lead to higher use of unscheduled care
- Can also address the complex interaction between mental and physical health and
  address parity of esteem
- Requires the healthcare system to be alert to patients' capabilities, opportunities and
  motivation for healthy or unhealthy behaviours that contribute to their symptom, and
  to one or more underlying condition and to “make every contact count.”

¹ IMPRESS Guide to the relative value of interventions for people with COPD
A population-based approach to improving outcomes for people with chronic obstructive pulmonary disease
available at www.impressresp.com

Whilst there are clinical guidelines for a number of aspects of breathlessness assessment and care, these tend to be disease-specific, for an individual and often do not have cost-effectiveness data. Therefore there remains much uncertainty about how to commission for a population that takes account of multi-morbidity, outcomes and cost. These BITs for commissioners aim to fill in some of those gaps. They are not meant to ignore the local context and the services currently provided, but rather they should be adapted and interpreted on the basis of what local services are already in place.

When possible each BIT is complemented with one or more examples of good practices that we have found around the country.

**Why breathlessness: opportunities to improve value**

Prioritising breathlessness presents many opportunities to improve outcomes. The main diagnoses associated with breathlessness, COPD, heart failure and anxiety, are all under-diagnosed in primary care. Therefore it is not surprising that not all breathless patients receive right care at the right times, by the right people. As a consequence, there is unwarranted variation in diagnosis rates and overuse, misuse, underuse and under-coordination of care.

In COPD care, there is scope to increase investment in stop smoking provision as a treatment as well as prevention, in pulmonary rehabilitation services and in programmes to increase physical activity. Similarly the use of medications such as of inhaled corticosteroids and oxygen should be reviewed in order to ensure their rational and safe prescription. See Appendix 1.

According to NICE, seventy percent of all the expenditure on heart failure in England is spent on hospitalisations. Yet you need to treat just two patients with heart failure for 6 months with the right treatment including ACE inhibitors to prevent one death. A McKinsey value analysis of heart failure interventions ranked flu vaccination of patients with heart failure as the number one intervention in terms of cost-benefit. So there is a considerable need to shift the balance of care towards the community and towards a more preventative approach.

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8 http://vimeo.com/67787435  
10 NICE heart failure commissioning guide http://publications.nice.org.uk/services-for-people-with-chronic-heart-failure-cmg39  
Public health advice exists on cost-effective population approaches but is not implemented consistently. For example influenza and pneumococcal vaccination protect breathless patients from increased mortality and hospitalisation but variation in vaccination rates remain. A 2012 paper in the BMJ argues that vaccinating against influenza healthcare professionals who are in direct contact with patients should be mandatory. The 2013 NHS England campaign gives further evidence of the benefits, yet there is substantial variation.

- Stop smoking treatments are effective but underused in primary and secondary care for all sick smokers.
- Smokers who exercise at a moderate or high level reduce their risk of developing COPD and their decline in lung function.
- COPD patients who undertake an activity equivalent to walking 60 minutes a day halve their risk of being admitted as an emergency admission irrespective of their severity, nutritional status or respiratory rehabilitation.
- Obesity is an increasing and costly public health problem that is not being addressed by current services or policy and often leads to breathlessness and deconditioning.
- Physical inactivity has not yet been addressed systematically although new NICE guidance offers an evidence-based approach to increasing activity.
- There is insufficient use of the evidence base for behaviour change.
- Trained healthcare professionals offering brief advice is underused for the breathless population, yet is cost-effective in helping people reduce their breathlessness by being more physically active, managing their weight, stopping smoking and taking the right

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16 Influenza vaccination in healthcare professionals BMJ 2012;344:e2217
22 NICE, Physical activity: brief advice for adults in primary care, Issued: May 2013, NICE public health guidance 44, guidance.nice.org.uk/ph44
23 NICE, Behaviour change, Issued: October 2007, NICE public health guidance 6, guidance.nice.org.uk/ph6
Breathlessness IMPRESS Tips for commissioners

If we want to stimulate improvement in the care of people with long term breathlessness, where should we start?

It may not be necessary to set up new discrete breathlessness services, and it was not our remit to design services. Instead, these Breathlessness IMPRESS Tips for commissioners outline what we think commissioners should take into consideration when commissioning services for their breathless population.

1. **Be guided by a right care framework**
   In all discussions and decisions be guided by a value or “right care” framework. That is, at population and individual patient level allocate resources to the interventions that provide most population value and use incentives and levers to encourage providers to offer those “right”/high-value interventions consistently in the right way.

2. **Involve many stakeholders**
   Consensus about areas of investment and disinvestment will ultimately depend not only on a shared understanding of the evidence, but will also need to grow from what already exists provided by health and local authorities, and the voluntary sector, and will depend on the local populations’ needs and health status. Any planning process needs to build on and inform your joint strategic needs assessments and mapping of local services. Aim to develop symptom-based pathways over time working with the evidence and relevant local experts from practice teams, respiratory, cardiology, mental health services and obesity. You might want to run a local “decision conference”, as developed by the London School of Economics and Health Foundation, where professional colleagues bring and review the cost-effectiveness evidence and prioritise interventions, before commissioning logical but possibly unproven or undoable services.

3. **Foster integration across specialties**
   The service will need to integrate mental and physical health pathways and services to achieve parity of esteem, and a common and consistent approach to behaviour change across a number of health specialties and public health.

4. **Check how local provision matches the IMPRESS algorithm**
   The IMPRESS algorithm provides clinicians with an evidence-based integrated approach to assessment and treatment for breathlessness. We advise using the commissioning process to put in place the levers and support to make it easy for clinicians to apply this for every patient.

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24 NICE, Physical activity: brief advice for adults in primary care, Issued: May 2013, NICE public health guidance 44, guidance.nice.org.uk/ph44
25 Gray M. Optimising the value of interventions for populations BMJ 2012;345:e6192 doi: http://dx.doi.org/10.1136/bmj.e6192 (Published 17 September 2012)
It might be helpful to work with local clinicians from primary care, community services and hospitals to answer these five questions:

**a. What do you have in place already for the ongoing management of your breathless population in**

- Primary care
- Specialist primary care eg PwSI
- Community respiratory team
- Community heart failure team
- Combined primary and secondary care service
- Outpatients
- Inpatients
- Other

**b. How might you streamline this to ensure that the IMPRESS assessment algorithm can be implemented for every adult with long term breathlessness?**

**c. How does the current system identify and support the population at risk of poor health outcomes and use of unscheduled care:**

- Patients who continue to be breathless despite appropriate treatment i.e. MRC 3 and above?
- Patients who remain breathless post pulmonary rehabilitation?
- Patients who remain breathless post cardiac rehabilitation (for heart failure)?
- Patients who present in primary care with recurrent breathlessness that seems difficult to treat or manage?
- Patients who are admitted to hospital with acute breathlessness, with or without respiratory failure, and who do not improve with immediate treatment?

**d. Does your analysis highlight gaps that require change? If so, does it require:**

- Review of inclusion criteria for a service to harmonise approaches between diseases?
- Improved communication between sectors such as primary and hospital care?
- Pathway redesign?
- Commissioning of new services?

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**Example**

Lambeth and Southwark Clinical Commissioning Groups (CCGs) have taken the IMPRESS BITs for clinicians and started to debate how they might be adapted for local use, including converting the IMPRESS algorithm into an EMIS Web decision tool. Southwark CCG is also discussing a neighbourhood model of primary care, and thinking through what assessment services would be provided by all practices, and which by those with a special interest, and have identified that training of practice teams, including practice nurses, will be critical to success.

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**Appendix 3** has some draft aims, objectives and criteria for services for a breathless population for discussion.

**5. Check that primary care has the right:**

**a. Equipment.** Ensure that primary care is equipped to deliver the assessment described in the IMPRESS algorithm and the BITs for clinicians. Check whether the equipment and training for GPs and practice nurses is sufficient. See **Appendix 2**

**b. Training.** Quantify current investment in behavioural change training and decide if
there is sufficient and also if there is sufficient guidance from qualified psychologists.

c. **Specialist behavioural change services to refer to.** Quantify what evidence-based services for weight management, physical activity, stop smoking, alcohol reduction and medicines concordance are available and how much is paid in total.

d. **Time.** Because of its complexity, a proper assessment of chronic breathlessness requires a planned and structured 20-30 minute first appointment. Therefore commissioners will need to find ways to accommodate this. There are some examples, often based on the Year of Care model.

e. **Coding templates** so that data on prevalence, incidence and outcomes can be collected, analysed and compared. We recommend that if primary care teams are using electronic records they should consider using a high level breathlessness symptom code (eg the Read parent code 173) until a diagnosis is confirmed, and maintain the symptom code as “active” and “significant” to encourage future review of breathlessness status and revisiting of the cause.

**Example**
The Outer North West London Integrated Care Pilot in COPD, diabetes and older people’s care has reorganised care to reduce emergency admissions. For an annual fee of £37.50 per patient with COPD, primary care provides a 40 minute care planning session and quality-assured spirometry, followed by discussion at a multi-disciplinary MDT if necessary. The pilot is being evaluated and tested so figures may change. 29 30 31 32

6. **Provide sufficient programmed rehabilitation**
We encourage you to review your current provision of programmed rehabilitation and your support to referrers. Check seasonality in its provision because adults with long-term breathlessness are a population whose health and use of services varies across a year. 33 34

NICE guidance recommends programmed rehabilitation for COPD and for heart failure. 35 36 37 38 IMPRESS has strongly recommended the value of pulmonary rehabilitation based on the evidence available. Compared to community care without pulmonary rehabilitation, pulmonary rehabilitation reduced hospital admissions for people with COPD over 34 weeks (number needed to treat (NNT)= 3) and mortality over 107 weeks (NNT=6). 39 There is a need to optimise, not maximise, prescribing before referral.

29 [http://www.northwestlondon.nhs.uk/publications/?category=1671-Integrated+Care+Pilot+%28ICP%29-d]
31 [http://www1.imperial.ac.uk/publichealth/departments/pcph/research/hrsu/northwestlondonicpevaluation/]
32 Personal communication with Clinical Director of ONWL. Feb 2014.
35 NICE. Chronic heart failure. National clinical guideline for diagnosis and management in primary and secondary care, Full version of NICE Clinical Guideline No 108, August 2010
37 NICE. Chronic obstructive pulmonary disease (COPD) Quality Standards, QS10 - Issued: July 2011
38 NICE, Chronic heart failure Quality Standards, QS9 - Issued: June 2011
There are insufficient pulmonary rehabilitation (PR) programmes in England\textsuperscript{40} but an even greater lack of cardiac rehabilitation (CR) programmes accessible to people with heart failure. Heart failure patients can be incorporated into existing CR programmes, but according to the 2010 national audit of CR, only 1\% of patients recorded in the audit had a diagnosis of heart failure.\textsuperscript{41} In a national survey published in 2012, only 35/224 (16\%) of CR centres provided a separate rehabilitation programme for people with heart failure,\textsuperscript{42} and in the 2013 audit of acute heart failure only 11\% of patients admitted with acute heart failure were referred to CR compared to an Outcomes Strategy target of one third.\textsuperscript{43}

The shortage could be addressed by increasing the places available in cardiac rehabilitation programmes, and/or inviting people with heart failure to PR clinics. Programmes for people with COPD, heart failure or both have been shown to be effective; and there are no safety reasons to exclude patients with heart failure except those with arrhythmias.\textsuperscript{44 45}

**Example**
In a current scheme in Mansfield based on this study, referrals to PR are received from heart failure nurses, as well as GPs and respiratory teams.\textsuperscript{46} We can supply more information and contacts. In the published studies, the enrolled patients had similar exercise needs. Any increase in capacity needs to be accompanied by support for referrers to build their confidence in promoting programmed rehabilitation to their breathless patients.

**Example**
The University of Hospitals of Leicester NHS Trust has developed a self-management manual for COPD, called SPACE: Self-management Programme of Activity Coping and Education. Its use in primary care is under evaluation. There is also an online version.

**Example**
A number of COPD services have introduced cognitive behavioural therapy through the expert guidance of a psychologist, following the work initiated at Hillingdon Hospital which produced a COPD breathlessness manual. This is to be used together with pulmonary rehabilitation. The Whittington Hospital, London has used psychologist input to increase completion rates for PR, to educate the multi-disciplinary team in psychological interventions and to offer support to the team.

\textsuperscript{40} Commissioning toolkit from Department of Health England (respiratory)
https://www.gov.uk/government/publications/commissioning-toolkit-for-respiratory-services
\textsuperscript{41} The national audit of cardiac rehabilitation. York: British Heart Foundation. 2010.
\textsuperscript{42} Dalal, Hasnain M; Wingham, Jennifer; Palmer, Joanne; Taylor, Rod; Petre, Corinna; Lewin, Robert. Why do so few patients with heart failure participate in cardiac rehabilitation? A cross-sectional survey from England, Wales and Northern Ireland, BMJ Open 2012;2:e000787
\textsuperscript{44} Evans RA, Singh SJ, Collier R, Loke I, Steiner MC, Morgan MD., Generic, symptom based, exercise rehabilitation; integrating patients with COPD and heart failure, Respir Med. 2010 Oct;104(10):1473-81
\textsuperscript{45} Evans RA, Developing the model of pulmonary rehabilitation for chronic heart failure, Chronic Respiratory Disease 8(4) 259–269
\textsuperscript{46} Personal communication. More information available on request.
7. **Ensure equal access by patients with breathlessness, no matter the underlying condition, to high quality end of life care that provides advance care planning and active management of symptoms**

Neither COPD nor heart failure are curable, and so towards the end of the person’s life they should expect that they have no needless suffering or pain: every symptom should be actively managed by the healthcare professional, carer and patient, and their choice of place to die should be discussed sensitively, without a bias in favour of one location; sick frightened and breathless people may choose hospital.47 48 Review local provision of palliative care for people with COPD and heart failure, and ensure that they meet the gold standard of palliative care and in particular the gold standard for managing breathlessness.

**Example**

There are several specialist breathlessness services for people with advanced and progressive disease that provide role models for care: [Breathlessness Intervention Service in Cambridge](https://www.breathlessnessintervention.org.uk) and the [Kings College Hospital Breathlessness Support Service](https://www.kclhospital.nhs.uk/services/breathlessness-support-service). These are being evaluated by a team at the [Dame Cicely Saunders Institute](https://www.damicelysaundersinstitute.org).

9. **Look for opportunities to integrate existing teams and services**

Consider whether more integration between heart failure and COPD services would provide more value for your population. Discuss when a single disease team or specialist might be necessary and differentiate between an unwarranted handoff and a right specialist-to-specialist referral. Recognise when hospital admission is right care.

10. **Consider the best allocation of resources to improve your population’s health outcomes**

In order to maximise the health outcomes of the population, aim for a system that allocates resources to populations and individuals based not just on disease severity, but consider also levels of empowerment and engagement in self-management. Keep an eye on research by the [Kings Fund and Oregon](https://www.kingsfund.org.uk) about moving to commissioning by population segmentation based on [patient activation levels].

11. **When specifying breathlessness services, talk to providers about the organisational model and new or extended professional roles and their feasibility and sustainability**

Some CCGs might choose to develop a federated model, with each general practice providing a core service, and then referring to a triage or primary care practitioner with a special interest. Elsewhere, CCGs may commission a breathlessness assessment service from the local hospital, that has diagnostic equipment such as echocardiography and chest X-ray on site. Understand whether in your area there is a shortage of specific roles and share the responsibility with your providers for creating services where people

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47 Lynn, J, Goldstein, NE (2003), Advance care planning for fatal chronic illness: Avoiding commonplace errors and unwarranted suffering, Annals Of Internal Medicine, 138(10): 812-818.
51 Entwistle, V.A. and Cribb, A. (2013), Enabling people to live well: Fresh thinking about collaborative approaches to care for people with long-term conditions, the Health Foundation, May 2013
want to learn and work. Take note of novel schemes such as integrated care consultant posts and registrar schemes. The BTS is currently reviewing a number of integrated care consultant roles.

**Example**
The University Hospital of North Staffordshire NHS Trust has set up an outpatient breathlessness clinic run jointly by a cardiologist with a special interest in heart failure and a respiratory consultant. It was designed by the consultants and then tested with CCGs and continues to be adapted. It provides new assessments and also follow-up appointments for unexplained breathlessness; patients with a previous diagnosis of COPD and heart failure are excluded because there are other community respiratory and cardiology services available. Referrals are made by GPs on a specific referral form, accompanied by diagnostic test results gained within the last month for BNP, ECG, spirometry and chest X-ray. Details available on request from IMPRESS.

**Example**
Health First ALW Community Interest Company in Atherleigh provides a Respiratory Practitioner-led Breathlessness Service offering assessment following GP-requested tests, in line with the IMPRESS algorithm. At the end of the referral form the referrer is asked:

**If the patient is given a diagnosis of COPD or asthma do you prefer: (please circle)**

a. The lead nurse to commence the patient on treatment according to NICE guidance

b. The lead nurse to send you a treatment management plan

**If the patient has a positive echo do you wish them to be followed up by a cardiologist? Yes or No?**

It also offers enhanced management reviews of medication, inhaler technique, treatment optimisation, personalised care plans, stop smoking support, vaccination, education, and referrals to PR, warm home schemes and other services such as weight management. Further details available on request from IMPRESS.

12. Enhance the use of IAPT services
Adults who are breathless will be anxious to some extent; the question is why and to what extent. Therefore some patients will benefit from referral to the IAPT service. There may also be scope for the IAPT service to include breathing training and stop smoking support. The Hillingdon Service is now liaising with its local IAPT service.

13. Apply lateral thinking when activating local resources for breathless people
Consider what else local authority or voluntary sector services such as swimming, yoga, pilates, tai-chi, choirs, walks and exercise classes might offer in addition to their core activity in terms of education: specify that there should be a “make every contact count” approach to behavioural change. Encourage the leaders of these activities who are

53 http://www.makingeverycontactcount.co.uk/
in contact with people who smoke to attend have stop smoking training such as the Very Brief Advice module. Personalisation, including the use of personal budgets and personal health budgets may offer opportunities for individuals with long term conditions to commission “hybrid” support workers who can offer a range of skills.

IMPRESS Breathlessness Working Party
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For a full list of materials and Working Party members go to www.impressresp.com

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The other IMPRESS documents can be found at http://www.impressresp.com/ in IMPRESS publications and feature:

IMPRESS Breathlessness Tips (BITs) Introduction: Responding to people with long-term breathlessness -

IMPRESS guide to breathlessness methodology definitions scope prevalence

IMPRESS breathlessness epidemiology literature review summary tables FINAL

IMPRESS breathlessness algorithm final

Breathlessness IMPRESS Tips for clinicians FINAL 2014-01-09

Breathlessness IMPRESS Tips for patients

Breathlessness IMPRESS Tips for Researchers FINAL 2014-02-04

APPENDIX 1 Relative value of interventions for people with COPD
APPENDIX 2 BITs for clinicians: essential equipment for assessment of breathlessness
APPENDIX 3 DRAFT objectives, aims and criteria for a population breathlessness service for local discussion

54 http://www.nice.org.uk/usingguidance/sharedlearningimplementingniceguidance/examplesofimplementatio n/eximpresults.jsp?o=516
Appendix 1


1. Before the application of any value model, ensure it is applied to the right population. Ensure the basics are right every time: first think prevention. Then ensure accurate diagnosis, using quality assured spirometry of existing patients; and careful removal of medicines which are being misused including inhaled corticosteroids and oxygen. This is likely to need investment in capability and capacity. The costs of training, education and support are not included in this document, but are fundamental to it and we would strongly support investment, as argued in the Kings Fund document on integrated care.

2. Refer to our More for Less document that gives examples of ways to save money doing things more efficiently.

3. We advise commissioners to specify that people admitted with a respiratory problem are seen by a specialist team within 24 hours as this will pick up any misdiagnosis or misuse of treatment. Patients should also be reviewed prior to discharge. We advise the use of an evidence-based care bundle.

4. Check if you commission stop smoking services in all settings including social care, and where you know significant numbers of people smoke locally. Ensure practitioners are trained in stop smoking counselling and using evidence-based formulary in all the services supporting sick smokers. Offer stop smoking counselling and using evidence-based formulary in all the services supporting sick smokers. Offer stop smoking professionals guidance on COPD and encourage case-finding by linking them into COPD pathways. Consider engaging teams in mental health services and acute services such as ambulance services. Link up stop smoking and oxygen services.

5. Do you commission pulmonary rehabilitation and in sufficient quantity to meet the need, where need is defined as ability to benefit from an intervention? Do you have a robust strategy for increasing appropriate referrals to it, as it is a skilled job to encourage breathless people to take exercise rather than to take more medicine? This should include early post-admission rehabilitation.13

6. How are you ensuring that prescribing of inhaled medicine and oxygen is responsible? Do all prescribers know about the costs and the cost-effectiveness of the drugs they prescribe? The full NICE guideline and appendices would be useful to medicines management advisers, as are NICE Medicines and Prescribing Centre bulletins. Are they making sufficient effort to ensure patients also understand their value and how best to use them?

7. Waste is apparent in overprescribing and/or inappropriate prescribing that could be saved and reinvested in commissioning high value services such as pulmonary rehabilitation. NICE recommendations need to be read in full, as there are contradictions between the full document and the Executive Summary, which is often used in isolation. The full document agrees with other national appraisals. Taken with actual primary care prescribing figures there is likely to be a clear cost saving by reviewing pharmacotherapy in those patients with an FEV1 >50% predicted.

8. Be even-handed with the evidence. Apply what is known about cost per QALY; do not use lack of evidence as an excuse for not considering their value and finding ways to know it. We have provided our analysis. Consider plugging the evidence gap with your own studies if you are in a position to invest in improvement projects or research.

Appendix 2
IMPRESS BITs for clinicians

Essential equipment

- Oximeter
- Watch/clock/computer/smartphone
- Stethoscope
- Blood pressure measure
- Calibrated weighing scales
- Height measure
- Thermometer
- Peak Expiratory Flow Meter/microspirometer
- Expired carbon monoxide monitor

Additional equipment required or local access to:

- Chest X-ray
- Spirometer
- Tape measure
- ECG machine
- BNP testing with hospital analysis
- Echocardiography: Note NICE does not recommend echocardiography in primary care.
APPENDIX 3

DRAFT objectives, aims and criteria for a population breathlessness service for local discussion

Definition of breathlessness (from IMPRESS Guide to Breathlessness Methodology Definitions Scope and Prevalence)

Breathlessness is the sensation of not getting enough air, and may be the result of anything that interferes with the extraction of oxygen from air and its delivery to the tissues. Therefore any of: altitude, asthma, rib fracture, COPD, heart failure, exercise or anaemia may be the cause. It can also be caused, or contributed to, by anxiety. Long-term or chronic breathlessness is experienced by an individual over a period of months and may develop without them noticing and seeking help.

Aim of service

Use a value framework to improve the health and quality of life of adults at risk of being, or already disabled, by their long-term breathlessness.

The sorts of problems it should address:
- Growth in the at risk population which is creating a long term and costly problem for the NHS, social care and employers
- Underdiagnosis of COPD, heart failure and anxiety in primary care leading to overuse of unscheduled care and poorer outcomes
- Underuse of proven primary prevention interventions for at risk populations including stop smoking, physical activity, weight management
- Underuse of simple measurements, examinations and tests that would timely support accurate diagnosis such as pulse oximetry, pulse rate and rhythm, BNP, spirometry, waist and neck circumference and echocardiography
- Underuse of effective interventions for heart failure and COPD including stop smoking as treatment and rehabilitation programmes as well as medicines
- Misdiagnosis of the root cause of breathlessness due to deconditioning
- Misuse of medicines such as misuse of doses of inhaled medicines in COPD and ACE inhibitors in heart failure and underuse of beta blockers in people with heart disease and COPD
- Overuse of oxygen for breathlessness without hypoxia
- Under-coordination of disease-specific pathways and teams given prevalence of multi-morbidities
- Underuse of evidence-based psychological interventions to support behaviour change
- Underuse of bariatric surgery for obese people

This will need shared leadership and a coordinated approach from colleagues with public health, commissioning and clinical roles.

Population (taken from the IMPRESS guide to breathlessness methodology definitions scope prevalence FINAL)

The few epidemiological studies available seem to point in the direction that chronic breathlessness affects about 10% of the general population, but the magnitude of the problem is greater in specific groups of the population, such as the elderly with about
30% of them being breathless. Despite these significant prevalence rates, breathlessness is mentioned as a reason for encounter in primary care in about 1% of the recorded consultations in general practice. Whether this figures is affected by coding behaviour in primary care or under-reporting of the symptom by patients is for discussion.

**Draft objectives**

1. To prevent the development of long term breathlessness using a value framework (this will require support of the Health and Wellbeing Board and Public Health action)

**Draft criteria/metrics:**
- Decelerating trend in incidence of COPD, heart failure and misdiagnosed asthma in obese adults
- Increased long term quit rates of smokers
- Increased physical activity rates in smokers
- Reduction in adult obesity rates

2. To assess breathlessness accurately, sufficiently and in a timely way to achieve an accurate diagnosis

**Draft criteria/metrics:**
- Improved recording of breathlessness using an agreed and validated measure and code
- Proxies: Increase in echocardiograms, BNP tests, spirometry
- Increase in number of new cases of COPD, heart failure, COPD and heart failure

3. To treat breathlessness and its underlying causes effectively and safely within a value framework

**Draft criteria/metrics:**
- Decreasing percentage of COPD and heart failure patients who smoke
- Increasing numbers of patients reaching moderate or higher levels of physical activity
- Increase in numbers of people with breathlessness scores of MRC2 and above or equivalent New York Heart Scale completing pulmonary/cardiac rehabilitation
- Improved QoL, improved exercise tolerance and involvement in physical activity
- Increasing referral to bariatric surgery in line with NICE commissioning guidance
- Right use of medicines in line with NICE
- Reduction in misuse of oxygen for breathlessness

4. To support breathless people who are dying to die in their preferred place of care with no needless suffering

**Draft criteria/metrics:**
- Numerator: People who die from COPD or heart failure
- Denominator: people on end of life registers who have expressed preferred place of death

5. To engage people with long term breathlessness and their carers as equal partners

**Draft criteria/metrics:**
• Mutually agreed plans developed from regular care planning meetings for all patients recorded in a place accessible to the patient, carer and professionals

6. To develop multi-skilled long term condition clinicians with an interest and competence in managing breathlessness

**Draft criteria/metrics:**
- One programmed rehabilitation service
- One pathway
- Appropriate use of consultant-to-consultant referral

7. To evaluate the effectiveness of new pathways and interventions

**Draft criteria/metrics:**
- Evaluation metrics to be determined depending on the intervention. Coding consensus is essential.

8. To produce an annual report for the population to which the service is accountable

**Draft criteria/metrics:**
- An annual report is published

In order to meet some or all of these objectives, you may want to specify some additional elements after discussions with local clinicians, patients and public health colleagues:

**Purpose:** are you all agreed on the purpose of a breathlessness service?
What is its scope? Does this match what patients are expecting? Is there a common understanding of the different life-course trajectories of people with breathlessness, depending on the root cause of their problem?

**Identity:** do the people working in the service understand and describe themselves as long term condition clinicians working in partnership with their patients? How does the patient describe himself/herself? What language do they use?

**Beliefs:** what do the clinicians believe "works" in terms of behavioural change; what do patients believe is the cause of their condition, and what can be done about it and what their role is?

**Know-how:** do all the GPs in your locality know what the data from pulse and respiratory rate, oximetry, spirometry, BNP testing, breathlessness score and neck and BMI measurement mean for intervention? Can they explain this to patients so they know what to do and what to think about the results?

**Kit/environment:** are all the things listed in the BITs for clinicians routinely available (see Appendix 2)?

**Training:** is this provided routinely and consistently across the service following agreed protocols and sharing learning between trainees and experienced professionals, between different disciplines and between different specialities. For example, is there a common understanding and use of the MRC breathlessness score? (note our discussion in BITs for researchers).