Breathlessness IMPRESS Tips for Researchers

These Breathlessness IMPRESS Tips (BITs) are one of a set of four BITs based on an IMPRESS programme to develop guidance for clinicians including an assessment and treatment interactive algorithm, commissioners, patients and researchers about how to improve services for the breathless population. See the Introduction and Methodology, Scope and Definitions for background information and references and the Prevalence Modelling that describes the size of the problem of long term breathlessness in adults.

All material can be freely accessed from here.

These BITs highlight areas of uncertainty or lack of knowledge we found when researching this work. We encourage the Academic Health Science Networks in England, and other research networks to address them.

1. **Consistency of terminology**

Ensure that your terms are clearly defined in any breathlessness studies, describe the breathlessness assessments used in detail, including how any questionnaires such as Medical Research Council dyspnoea scale or the New York Heart Association (NYHA) functional classification system are used and the cut-offs you are using.

**Rationale**

In our reviews of the literature we found considerable confusion about:

- a. The variety of terms used such as shortness of breath, dyspnoea, dyspnea
- b. The definitions of acute and chronic
- c. The variety of possible measures for breathlessness and what they were for.

For example, the MRC scale was originally published by Fletcher in 1959 but has been adapted on several occasions and appears to have lost some of its precision in the process of adaptation. For example, Fletcher’s Grade 3 asks: “Is the patient unable to keep up with normal men [later adaptations say “contemporaries”] on the level, but able to walk about a mile or more at his [sic] own speed?”. The adaptation is:

Grade 3: Walks slower than contemporaries on level ground because of breathlessness, or has to stop for breath when walking at own pace

Grade 4: Stops for breath after walking about 100m or after a few minutes on level ground

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The modified versions suggest a much lower, but unspecified, level of exercise tolerance compared to “a mile or more” and is not clearly distinguishable from grade 4. In addition, grade 5 “Too breathless to leave the house, or breathless when dressing or undressing” is subjective and can be due to many factors, including the underlying condition. Other scales used in other countries or guidelines have different scoring systems. There is no consistency in how these are completed: for example, patient-completion, practitioner assistance to patient, practitioner-completion. Therefore there is unwarranted variation in both completion and therefore in interpretation.

A consistent use of terminology and measures would also improve the quality of epidemiological studies on breathlessness.

One study that looked at the use of the NYHA functional classification system in heart failure found it subjective and poorly reproducible. “There is no widespread agreement on how to assign a patient to an NYHA class in clinical practice, with much interoperator variation, and clinical trials rarely reference the criteria used. We have suggested some alternative questions for use in assessment….. We observed that most cardiologists routinely ask patients with heart failure how far they can walk before they become breathless. However, our data suggest that there may be little value in asking patients how far they can walk, apart from being a simple opening gambit for conversation. We also showed that this self-reported walking distance had no predictive value for patients' actual exercise capacity, even when corrected for patients' poor perception of distance.”

2. Standardise breathlessness scores and measurements

Evaluate the potential to reduce the numbers of breathlessness scores and measurements used in a local health system so that local standards, coding and communication can be agreed and treatment decisions are consistent between patients eg referral to Pulmonary Rehabilitation.

Rationale

During our research there was considerable confusion also about the variety of possible measures for breathlessness. A recent systematic review identified 32 assessment tools available to measure breathlessness for patients with advanced disease. Of these, 29 were multidimensional of which 11 were breathlessness-specific and 18 disease-specific. Four tools were uni-dimensional, measuring the severity of breathlessness. The majority of disease-specific scales were validated for chronic obstructive pulmonary disease (COPD); few were applicable in other conditions. No one tool assessed all the dimensions of breathlessness, which affects the psychology and social functioning of the affected individual and their family - most focused on physical activity.

3. Psychological interventions

Evaluate which psychological interventions to support patient behaviour change work best in what sub-groups of a breathless population to improve outcomes. This could be done by behaviour, degree of breathlessness, or level of empowerment/activation.

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3 http://www.nice.org.uk/usingguidance/commissioningguides/pulmonaryrehabilitationserviceforpatientswithcopd/mrc_dyspnoea_scale.jsp
4 Raphael C. Limitations of the New York Heart Association functional classification system and self-reported walking distances in chronic heart failure Heart. 2007 April; 93(4): 476–482. Published online 2006 September 27. doi: 10.1136/hrt.2006.089656
6 Bausewein, C; Farquhar, M; Booth, S; Gysels, M; Higginson, I.J, Measurement of breathlessness in advanced disease: A systematic review, Respiratory Medicine, 2007, Volume 101, Issue 3, pp. 399–410
Rationale

There is good evidence for the effectiveness of psychological interventions in stop smoking, weight management, medicines management, exercise and dysfunctional breathing, but we lack evidence as to which particular type of psychological intervention is most effective in which patients with which behaviour.\(^7\)\(^8\)\(^9\)

4. Programmed rehabilitation

Evaluate the cost-effectiveness of combined pulmonary and cardiac rehabilitation for people with COPD and/or heart failure and other conditions such as interstitial lung disease (ILD); research the cost-effectiveness of interventions to sustain the improvements achieved during PR, and identify the right population segmentation to achieve the best completion rates of rehabilitation programmes.

Rationale

NICE clinical guideline 101 on COPD published in 2010 recommends pulmonary rehabilitation (PR).\(^10\) The value of PR is laid out in the IMPRESS guide to PR.\(^11\) NICE clinical guideline 108 on chronic heart failure published in 2010 made a new recommendation supporting cardiac rehabilitation for people with chronic heart failure.\(^12\) The NICE quality standards for heart failure and COPD recommend CR and PR respectively given the benefit in terms of mortality and morbidity.\(^13\)\(^14\)

However, there is insufficient programmed rehabilitation for either COPD or heart failure patients. The 2010 national audit of cardiac rehabilitation indicated that only 1% of patients recorded in the audit had a diagnosis of heart failure.\(^15\) 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.\(^16\)\(^17\)

The extent, nature and cost of provision varies around the country, with some services developing in a haphazard way with no core funding and relying on charitable donations and time 'borrowed' from various hospital departments. A generic approach is likely to find favour with patients and commissioners, and its availability and use might be improved with better cost-effectiveness data building on the research undertaken in Leicester.\(^18\)\(^19\)\(^20\)

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\(^7\) Michie S et al. A refined taxonomy of behaviour change techniques to help people change their physical activity and healthy eating behaviours: The CALO-RE taxonomy. Psychology & Health, 26:11, 1479-1498 (2010).


\(^12\) 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

\(^13\) NICE, Chronic obstructive pulmonary disease (COPD) Quality Standards, QS10. July 2011

\(^14\) NICE, Chronic heart failure Quality Standards, QS9. June 2011

\(^15\) The national audit of cardiac rehabilitation. York: British Heart Foundation. 2010.


\(^19\) Evans R et al. Developing the model of pulmonary rehabilitation for chronic heart failure. Chronic Respiratory Disease 8(4) 259–269
5. **Physical activity and breathlessness**

Evaluate the cost-effectiveness of individual and population-based physical activity in early breathlessness and physical activity in comparison to drug interventions.

**Rationale**

From the IMPRESS BI Ted for clinicians and patients there are many recommendations about physical activity. These are fully referenced in the documents. However, IMPRESS discussions have also raised the issue of the value of earlier intervention, before someone is sufficiently disabled by their breathlessness to be classified as MRC 3 and eligible for PR. Another dimension to this is raised by a recent BMJ paper on the value of physical activity which did not include people with respiratory problems, but did include those with heart failure.\(^{21}\) This study of 16 meta-analyses including 305 randomised controlled trials with 339,274 participants highlights the near absence of evidence on the comparative effectiveness of exercise and drug interventions on mortality outcomes. It concludes that “the relative dearth of evidence leaves substantial uncertainty on which patients would benefit more from what type of exercise, and which forms of exercise may not be effective in different settings.” It also recommends “Given the scarcity of financial resources to fund future trials of exercise interventions, one option would be to require such evidence from pharmaceutical companies that are under increasing pressure to perform active-comparator trials for market entry. For example, regulators should consider requiring pharmaceutical sponsors of new drugs to include exercise interventions as an active comparator arm in drug trials.” This would seem to make sense for people with long term respiratory problems too.

6. **Obesity**

We encourage researchers to consider the impact of obesity on breathlessness, to quantify it, including the proportion who do not have a physical illness, and to test appropriate interventions that offer value.

**Rationale**

There is an emerging research field connecting researchers in obesity, metabolism, inflammation, the immune system and lung disease which is exploring the interactions between them.

However, this has not yet reached practical guidance. For example, breathlessness is only mentioned once in the Action on obesity report from the Royal College of Physicians.\(^{22}\)\(^{23}\)

7. **Support respiratory physiotherapists to evaluate their interventions**

A 2013 Cochrane review found that there is currently no evidence that breathing exercises are effective for dysfunctional breathing/hyperventilation syndrome.\(^{24}\) More research is required into interventions that might work including psychological and physical interventions.

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\(^{22}\) Academy of Medical Royal Colleges (2013) Measuring up the medical profession's prescription for the nation's obesity crisis?


Rationale
The 2013 Cochrane study asked how effective are breathing exercises for dysfunctional breathing/hyperventilation syndrome (DB/HVS) in adults and concluded that the results of this systematic review are unable to inform clinical practice based on the inclusion of only one small, poorly-reported trial which compared relaxation therapy (RT) versus RT and breathing exercises and a no therapy control group. There was no credible evidence regarding the effectiveness of breathing exercises for the clinical symptoms of DB/HVS.

It is currently unknown whether these interventions offer any added value in this patient group or whether specific types of breathing exercise demonstrated superiority over others, although empirical data show that it helps patients and is offered by respiratory physiotherapists. On this basis, the BITs for clinicians does suggest that people who have dysfunctional breathing/hyperventilation syndrome are referred to respiratory physiotherapists. Amongst the techniques they offer is breathing re-education.

8. IMPRESS algorithm and BITs
Evaluate the uptake and impact of the IMPRESS breathlessness algorithm and guidance.

Rationale
The IMPRESS algorithm and BITs provide new guidance on the assessment and management of long term breathlessness, the implementation of which should be evaluated.

IMPRESS Breathlessness Working Party
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For a full list of participants see Impressions 31 at http://www.impressresp.com

Also available: Introduction, IMPRESS breathlessness algorithm, IMPRESS BITs for clinicians, IMPRESS BITs for patients, IMPRESS BITs for commissioners, prevalence modelling for breathlessness and COPD, obesity, anxiety and heart failure from http://www.impressresp.com