Breathlessness research
Evaluations

The Breathlessness Intervention Service (BIS) is being evaluated in collaboration with University of Cambridge and King’s College London. We are carrying out a randomised controlled trial (RCT) of BIS to find out if BIS is helpful to patients and their carers, their experience and views on the service, the views of those who refer them to the service and whether it is value for money.

This evaluation follows a series of development studies for and with the service including:

1. a qualitative study of patients with breathlessness who had a diagnosis of lung cancer or COPD - this study informed the design of the pilot service;
2. a qualitative study of service users - the results of which were fed back into BIS’s redevelopment;
3. a pilot randomised controlled trial (RCT) of BIS for chronic obstructive pulmonary disease (COPD) patients – the results of which were used to help us design the current RCT.

Funders of these studies have included: The Gatsby Foundation, Cicely Saunders International, NIHR Research for Patient Benefit and the Addenbrooke’s Charitable Trust.
Conferences

Phase I:

Farquhar M, Booth S, Fagan P, Higginson IJ. “Patients’ and carers’ perceptions of a Breathlessness Intervention Service for intractable breathlessness” (poster) Palliative Care Congress, University of Sheffield, 5th-7th April 2006.

Farquhar M, Booth S, Fagan P, Gysels M, Higginson IJ. “Patients’ and carers’ perceptions of a Breathlessness Intervention Service for intractable breathlessness” (poster/oral) Society for Academic Primary Care, University of Keele, 12th-14th July 2006.


Phase II:


Fagan P, Farquhar M, Booth S. “The Addenbrooke’s Breathlessness Intervention Service (BIS)” (invited speakers), Innovations in Dyspnea Workshop, 4th Advanced Learning in
Palliative Medicine, Conference of the Canadian Society of Palliative Care Physicians, Halifax, Nova Scotia, Canada, 31st May-2nd June 2007.


Farquhar M, Booth S, Fagan P, Higginson IJ. "Developing, evaluating and remodelling a breathlessness intervention service using the MRC framework" (oral paper) COMPASS Collaborative Annual Scientific Meeting, Leeds, 28th -29th June 2007.


Farquhar M, Booth, S, Higginson IJ. “Referring to a complex intervention for breathlessness, the ‘Breathlessness Intervention Service’ (BIS): expectations and experiences of referrers of COPD patients” (poster). Royal College of Nursing (RCN) Eastern Region Research Society Poster Forum, Addenbrooke’s NHS Trust, 28th-29th January 2009.

Farquhar M, Booth S, Fagan P, Higginson IJ. "Developing, evaluating and remodelling a breathlessness intervention service using the MRC framework" (oral paper) COMPASS Collaborative Annual Scientific Meeting, Leeds, 28th -29th June 2007.


Farquhar M, Booth, S, Higginson IJ. “Referring to a complex intervention for breathlessness, the ‘Breathlessness Intervention Service’ (BIS): expectations and experiences of referrers of COPD patients” (poster). EAPC, Trondheim, 28th -31st May 2008.


Farquhar M, Booth, S, Higginson IJ. “Referring to a complex intervention for breathlessness, the ‘Breathlessness Intervention Service’ (BIS): expectations and experiences of referrers of COPD patients” (poster). Royal College of Nursing (RCN) Eastern Region Research Society Poster Forum, Addenbrooke’s NHS Trust, 28th-29th January 2009.

Farquhar M, Higginson IJ, Booth S. Diversity of experiences and impacts of caring for a patient with breathlessness in advanced COPD (oral paper). Palliative Care Congress, Bournemouth, 10th-12th March 2010.

Farquhar M, Higginson IJ, Booth S. “Modelling the carer support component of a complex intervention for breathlessness in advanced disease” (poster). EAPC 2010, Glasgow.

**Phase III**

Farquhar M. “Using qualitative data to design, evaluate and re-model services: the example of a breathlessness intervention service for advanced disease” (invited speaker). Qualitative Research in the NHS – annual meeting, The Moller Centre, Cambridge, 16th October 2009.


Booth S “Management of Breathlessness in Palliative Care” (invited speaker) Annual Conference of Swedish Association of Palliative Medicine, Umeå, Sweden. 16-17 March 2010


Farquhar M, Higginson IJ, Booth S. Using qualitative data to design, evaluate and remodel complex interventions: the example of a Breathlessness Intervention Service for advanced disease (oral). Society for Academic Primary Care (SAPC) Annual Scientific Meeting, University of East Anglia, Norwich, 7-9th July 2010.


Farquhar M, Higginson IJ, Booth S. Value of qualitative data in the design and evaluation of complex interventions in advanced disease (oral). Palliative Care Research Forum (PCRS), Belfast, 11th May 2011.


Publications

Pre-clinical phase:


Phase I:


Phase II:


Phase III:


Study Protocol: Phase III single-blinded fast-track pragmatic
randomised controlled trial of a complex intervention for breathlessness in advanced

Related papers by members of research team:

Booth S (2006). Improving research methodology in breathlessness: a meeting convened by
the MRC Clinical Trials Unit and the Cicely Saunders Foundation. Palliative Medicine 20
(3):219-220.

breathlessness: International researchers' meeting on Breathlessness in London, November

breathlessness in advanced disease: a systematic review. Respiratory Medicine 101 (3): 399-
410.

breathlessness in advanced stages of malignant and non-malignant diseases (review).
Cochrane Database of Systematic Reviews 2008, Issue 2.

Farquhar M, Higginson IJ, Booth S. Repeated measurement of quality of life in palliative care
research: the experience of using the SEIQoL-DW in a pilot phase II RCT of a complex
intervention for breathlessness (PCC conference abstract) Palliative Medicine 2008; 22 (4):
596.

Farquhar M, Higginson IJ, Booth S (2009). Fast-Track Trials in Palliative Care: An
Alternative Randomized Controlled Trial Design. Journal of Palliative Medicine 12 (3): 213

Dorman S, Jolley C, Abernethy A, Currow D, Johnson M, Farquhar M, Griffiths G, Peel T,
Researching breathlessness in palliative care: consensus statement of the National Cancer
Research Institute Palliative Care Breathlessness Subgroup. Palliative Medicine 2009; 23:
213-227.


Abstracts

Phase I:


Phase II:


Farquhar M, Higginson IJ, Booth S. Referring to a complex intervention for breathlessness, the 'Breathlessness Intervention Service' (BIS): expectations and experiences of referrers of COPD patients (EAPC conference abstract) Palliative Medicine 2008; 22 (4): 459-60.

Phase III: