

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.

Farquhar M, Fagan P, Booth S, Higginson IJ. "Evaluation of the Breathlessness Intervention Service at Addenbrooke's Hospital (Cambridge)". (invited speaker) Novartis Foundation/Cicely Saunders Foundation Discussion Meeting on Breathlessness, Novartis London, 23rd November 2006.

Farquhar M, Fagan P, Booth S, Higginson IJ. "The Addenbrooke's Breathlessness Service". (invited speaker) Recent Developments in Managing Breathlessness, King's College London, London 24th November 2006.

Farquhar M, Booth S, Fagan P, Higginson IJ. "Patients' and carers' perceptions of a Breathlessness Intervention Service for intractable breathlessness" (poster) Royal College of Nursing (RCN) Eastern Region Research Society Poster Forum, Addenbrooke's NHS Trust, 26th January 2007.

Phase II:

Fagan P, Farquhar M, Booth S. "The Addenbrooke's Breathlessness Intervention Service (BIS)" (invited speakers) Medical Grand Rounds, Halifax Infirmary, Nova Scotia, Canada, 29th May 2007.

Fagan P, Farquhar M, Booth S. "The Addenbrooke's Breathlessness Intervention Service (BIS)" (invited speakers) School of Physiotherapy, Dalhousie University, Halifax, Nova Scotia, Canada, 29th May 2007.

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 a breathlessness intervention service using the MRC framework for the development and evaluation of complex interventions?" (poster – shortlisted for prize) EAPC, Budapest, 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 & Traue D. "Using MRC framework for complex interventions to build services" (invited workshop) 2nd Addenbrooke's Conference on Palliative Care in the Acute Hospital – Research into Practice, Moller Centre, Cambridge, 29th November 2007.

Farquhar M, Booth S, Fagan P, Higginson IJ. "Developing a breathlessness intervention service using the MRC framework for the development and evaluation of complex interventions?" (poster – shortlisted for prize) Royal College of Nursing (RCN) Eastern Region Research Society Poster Forum, Addenbrooke's NHS Trust, 24th January 2008.

Booth S, Farquhar M, Fagan P, Higginson IJ. "Developing a breathlessness intervention service using the MRC framework for the development and evaluation of complex interventions" (invited poster) Research Professionals Workshop, William Harvey Lecture Theatre, Addenbrooke's NHS Trust, 20th March 2008.

Fagan P, Farquhar M, Booth S. "Managing chronic breathlessness and the Addenbrooke's Breathlessness Intervention Service" (invited speakers). 19th Norfolk Palliative Care Conference. Norwich, 15th April 2008.

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" (oral paper) Palliative Care Congress, Glasgow, 29th April – 1st 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). EAPC, Trondheim, 28th -31st May 2008.

Fagan P, Farquhar M, Booth S. "Addenbrooke's Breathlessness Intervention Service" (invited speakers). The Chartered Society of Physiotherapy Annual Congress, Manchester Central Convention Centre, 17th – 18th October 2008.

Farquhar M, Fagan P, Higginson IJ, Booth S “Evaluating a complex intervention for patients with advanced disease: the Addenbrooke's Breathlessness Intervention Service” (invited speaker). Royal College of Nursing (RCN) Eastern Region Research Society Meeting, 14th January 2009.

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 & Traue D. “Using MRC framework for complex interventions to build services” (invited workshop) 2nd Addenbrooke’s Conference on Palliative Care in the Acute Hospital – Research into Practice, Moller Centre, Cambridge, 29th November 2007.

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Fagan P, Farquhar M, Booth S. “Addenbrooke’s Breathlessness Intervention Service” (invited speakers). The Chartered Society of Physiotherapy Annual Congress, Manchester

Central Convention Centre, 17th – 18th October 2008.

Farquhar M, Fagan P, Higginson IJ, Booth S “Evaluating a complex intervention for patients with advanced disease: the Addenbrooke's Breathlessness Intervention Service” (invited speaker). Royal College of Nursing (RCN) Eastern Region Research Society Meeting, 14th January 2009.

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

Farquhar M, Higginson IJ, Todd C & Booth S “Evaluating a complex intervention for patients with advanced disease using the MRC framework: the Breathlessness Intervention Service” (invited speaker). External Research Seminar Series in the School of Nursing, Midwifery and Social Work, University of Manchester, 18th November 2009.

Moffat C. “Breathlessness Intervention Service evaluation” (invited speaker). Addenbrooke’s Research Professionals’ Workshop, Cambridge, 27th November 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

Booth S [title tbc - breathlessness in advanced disease] (invited speaker). Scottish British Thoracic Society, April 2010

Booth S. Pharmacological palliation of breathlessness in the context of a Breathlessness Intervention Service (invited speaker). British Thoracic Society, Manchester, 25th June 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, Brafman-Kennedy B, Higginson IJ, Booth S. Recruiting malignant & non-malignant disease patients: lessons from a palliative care RCT (poster). COMPASS 2011 ASM, Edinburgh, 14th-15th April 2011.

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.

Farquhar M, Higginson IJ, Booth S. The value of qualitative data in the design, evaluation and remodelling of a complex intervention: the Breathlessness Intervention Service (poster). HSRN/SDO annual conference, Liverpool, 7-8th June 2011.

Farquhar M, Brafman-Kennedy B, Higginson IJ, Booth S. Recruiting patients with advanced malignant and non-malignant disease: lessons learned from a palliative care RCT (poster). MRC Clinical Trials Methodology conference, Bristol (4th-5th October 2011).

Publications

Pre-clinical phase:

Booth S, Silvester S, Todd C (2003). Breathlessness in cancer and chronic obstructive pulmonary disease: using a qualitative approach to describe the experience of patients and carers. *Palliative and Supportive Care* 1 (4):337-344.

Phase I:

Booth S, Farquhar M, Gysels M, Bausewein C, Higginson IJ (2006) The impact of a breathlessness intervention service (BIS) on the lives of patients with intractable dyspnoea: a qualitative Phase I study. *Journal of Palliative and Supportive Care* 4: 287-293.

Phase II:

Farquhar M, Higginson IJ, Fagan P, Booth S. The feasibility of a single-blinded fast-track pragmatic randomised controlled trial of a complex intervention for breathlessness in advanced disease. *BMC Palliative Care* 2009; 8:9.

Farquhar MC, Higginson IJ, Fagan P, Booth S. Results of a pilot investigation into a complex intervention for breathlessness in advanced chronic obstructive pulmonary disease (COPD): brief report. *Palliative and Supportive Care* 2009; 8 (2) (in press).

Farquhar M, Ewing G, Higginson IJ, Booth S. The experience of using the SEIQoL-DW with patients with advanced chronic obstructive pulmonary disease (COPD): issues of process and outcome. *Quality of Life Research* 2010 (in press).

Phase III:

Booth S, Moffat C, Farquhar M, Higginson IJ, Bausewein C, Burkin J. Developing a breathlessness service for patients with palliative and supportive care needs, irrespective of diagnosis. *Journal of Palliative Care* 2011;27(1): 28-36.

Farquhar M, Prevost AT, McCrone P, Higginson IJ, Gray J, Brafman-Kennedy B, Booth S. Study Protocol: Phase III single-blinded fast-track pragmatic randomised controlled trial of a complex intervention for breathlessness in advanced disease. *Trials* 2011, 12:130.

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.

Bausewein C, Malik F, Booth S, Higginson IJ (2007). Recent developments in managing breathlessness: International researchers' meeting on Breathlessness in London, November 2006. *Progress in Palliative Care* 15:279-284.

Bausewein C, Farquhar M, Booth S, Gysels M, Higginson IJ (2007) Measurement of breathlessness in advanced disease: a systematic review. *Respiratory Medicine* 101 (3): 399-410.

Bausewein C, Booth S, Gysels M, Higginson IJ (2008) Non-pharmacological interventions for 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, Moosavi S, Byrne A, Wilcock A, Alloway L, Bausewein C, Higginson I, Booth S. Researching breathlessness in palliative care: consensus statement of the National Cancer Research Institute Palliative Care Breathlessness Subgroup. *Palliative Medicine* 2009; 23: 213-227.

Rocker G, Horton R, Currow D, Goodridge D, Young J, Booth S. Palliation of dyspnoea in advanced COPD: revisiting a role for opioids. *Thorax* 2009;64;910-5.

Gray J. E. A., Booth S., Brage S., Yorke J., Moosavi S., Bausewein C., Molasiotis A., Johnson M., and Farquhar M., (2010) BRIG *Progress in Palliative Care*, 18 (12); 95-98

Booth S, Moosavi SH, Higginson IJ. The etiology and management of intractable breathlessness in patients with advanced cancer: a systematic review of pharmacological therapy. *Nature Clinical Practice Oncology* 2008; 5(2): 90-100.

Galbraith S, Fagan P, Perkins P, Lynch A, Booth S. Does the use of a handheld fan improve chronic dyspnea? A randomized, controlled, crossover trial. *Journal of Pain & Symptom Management* 2010; 39 (5):831-838.

Bausewein C, Booth S, Gysels M, Ku"hnbach R, Haberland B, Higginson IJ. Understanding Breathlessness: Cross-Sectional Comparison of Symptom Burden and Palliative Care Needs in Chronic Obstructive Pulmonary Disease and Cancer. *Journal of Palliative Medicine* 2010; 13 (9): 1109-1118.

Abstracts

Phase I:

Farquhar M, Booth S, Fagan P, Higginson IJ (2006). Patients' and carers' perceptions of a Breathlessness Intervention Service for intractable breathlessness (PCC conference abstract). *Palliative Medicine* 20 (2): 144.

Farquhar M, Booth S, Gysels M, Fagan P, Higginson IJ (2006). Patients' and their carers' perceptions of a breathlessness intervention service for intractable breathlessness (SAPC conference abstract). *Family Practice* 23 (Suppl 1):105.

Phase II:

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. 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:

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. *SAPC Annual Conference 2010 Abstracts*, 7–9 July 2010, University of East Anglia, UK. *Primary Health Care Research & Development* 2010; 11: 46-47.

Farquhar M, Brafman-Kennedy B, Higginson IJ, Booth S. Recruiting malignant & non-malignant disease patients: lessons from a palliative care RCT. Abstracts for the COMPASS ASM, 14-15th April 2011, Edinburgh. *BMJ Supportive & Palliative Care* 2011; 1 (Supp 1): A19.