

Impact case study (REF3)

Institution: King's College London		
Unit of Assessment: 3 Allied Health Professions, Dentistry, Nursing and Pharmacy		
Title of case study: Better care and quality of life for people affected by severe breathlessness in multiple advanced diseases, including at the end of life		
Period when the underpinning research was undertaken: 2004 – 2020		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Irene Higginson	Professor Palliative Care & Policy	1996 –
Sara Booth	Hon Lecturer/ Research Fellow	2004 –
Claudia Bausewein	Clinical Fellow	2005 – 2012
Marjolein Gysels	Research Associate	2009 – 2012
Steffen Simon	Research Associate/Hon Fellow	2011 – 2012
Farida Malik	Clinical Fellow	2006 – 2011
Sabrina Bajwah	Clinical Senior Lecturer	2010 –
Matthew Maddocks	Reader	2011 –
Charles Reilly	Research Associate/Hon Fellow	2010 –
Mendwas Dzingina	Lecturer in Economics	2012 – 2019
Period when the claimed impact occurred: August 2013 – December 2020		
Is this case study continued from a case study submitted in 2014? N		

1. Summary of the impact

Every year breathlessness directly affects over 75 million people worldwide and over two million in the UK, as well as their families and carers, causing disability and poor quality of life. King's research created a paradigm shift for this previously neglected and poorly treated symptom, leading to better recognition, assessment, care and management of breathlessness for people, irrespective of their underlying diseases. King's researchers developed and evaluated treatments and combined them into a self-management toolkit and new services. These connected previously siloed clinical specialties and equipped health professionals, policy makers, commissioners and hospices to provide timely, proactive and multiprofessional care. These innovations are now recommended in guidance and implemented locally, nationally and across four continents. They have improved the lives, self-management and care of patients affected by breathlessness, including for those shielding during the COVID-19 pandemic, and those important to them.

2. Underpinning research

Since 2004, King's has spearheaded research to understand the effects of breathlessness on people affected by advanced diseases, and to develop and trial affordable, timely treatments, integrated care models and self-management tools that can be widely implemented.

King's research found that breathlessness is common across many diseases, increasing towards the end of life, and evaluated ways to assess it. King's academics revealed that breathlessness is common across many diseases, affecting over 95% of people with lung diseases, around 80-90% with heart failure, 50-80% with cancer; totalling >75 million people worldwide, > 2 million in the UK. King's researchers evaluated tools to measure breathlessness, aiding assessment in research and clinical care **(1)**. They discovered that people with breathlessness and advanced diseases experienced ~13-14 symptoms, alongside very severe, often fluctuating, breathlessness, which habitually caused longstanding suffering that worsened towards the end of life **(2,3)**.

King's work raised the visibility of breathlessness as a distressing and isolating symptom, of high cost to health and social care services, and to families. Researchers showed that

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breathlessness is frightening for patients and caregivers (2), with fluctuating severe episodes (3). People most affected became too breathless to go out or even speak (2). The nature and insidious onset of breathlessness often rendered it invisible to healthcare teams (2). The research found that traditional siloed models of health care did not work for patients with advanced disease and breathlessness, resulting in hospital admissions and high formal and informal care costs.

King's researchers fostered new multi-disciplinary collaborations to connect silos, improve treatment and create a paradigm shift. They set out to create a novel collaborative network, supported through workshops, reports, training fellowships and research. The network connected patients, families, palliative care clinicians, respiratory teams, therapists, physiologists and neurologists. It spanned teams across the UK, Ireland, Germany, Poland, Australia and Italy, Canada, the USA and Australia, including the UK National Cancer Research Institute. This interdisciplinary collaboration kindled fresh perspectives on the multidimensional nature of breathlessness, led to research that extended beyond the lungs to include muscle strength and the brain's response (4) and improved outcome measurement (1).

King's research improved responsible prescribing. King's academics discovered that, although benzodiazepines were commonly recommended and used to manage breathlessness, there was no evidence that they relieved breathlessness in advanced cancer or lung disease and they could have adverse effects (5).

King's provided evidence for non-pharmacological therapies as a first step in management. King's landmark Cochrane review revealed that inexpensive non-pharmacological interventions that could be used at home were effective, or showed promise, in improving mobility, self-care and reducing the impact of breathlessness in advanced diseases (4). These included: walking aids; breathing retraining; hand-held fans and neuromuscular electrical stimulation (NMES).

King's researchers developed and trialled novel toolkits and breathlessness services. They amalgamated their findings of effective therapies into novel self-management toolkits and integrated short-term Breathlessness Services (BSs). These built on earlier studies and collaborations, especially between Higginson and Booth, who together developed and trialled BSs in London and Cambridge. The BSs incorporated respiratory medicine, palliative care, physiotherapy, occupational therapy and social work. Patient home toolkits were provided at the first BSs assessment. BSs healthcare workers usually provided around three follow-up contacts, locally adapted to urban/mixed environments, to review patient and family concerns and care. The Breathlessness Services (BSs) randomised trial led by Higginson found that BSs improved quality of life and survival for people with lung diseases and cancer at no additional costs to the NHS (6). Similar cost-effectiveness was found in Cambridge (Booth senior author, co-authors Higginson, McCrone, King's), and in interstitial lung disease (Bajwah). These were developed and tested using the MRC guidance on evaluating complex interventions, with fast-track mixed-method randomised trial and outcome measures pioneered by King's researchers.

King's collated definitive evidence on breathlessness services (BSs) (7). King's led an NIHR evidence synthesis with meta-analysis and research consultation, combining all studies of BSs to determine the extent of international evidence of effectiveness and key service ingredients. The effectiveness of a BS (usually fewer than six contacts, face to face or phone) on psychological symptoms in advanced disease was similar to an 11-week programme of psychological therapy.

3. References to the research

- 1) Bausewein, C., Farquhar, M., Booth, S., Gysels, M., & Higginson, I. J. (2007). Measurement of breathlessness in advanced disease: A systematic review. *Respiratory Medicine*, 101(3), 399 - 410. DOI:10.1016/j.rmed.2006.07.003
- 2) Gysels, M., & Higginson, I. J. (2008). Access to Services for Patients with Chronic Obstructive Pulmonary Disease: The Invisibility of Breathlessness. *Journal of Pain and Symptom Management*, 36(5), 451 - 460. DOI:10.1016/j.jpainsymman.2007.11.008
- 3) Bausewein, C., Booth, S., Gysels, M., Kuehnbach, R., Haberland, B., & Higginson, I. J. (2010). Understanding Breathlessness: Cross-Sectional Comparison of Symptom Burden and Palliative Care Needs in Chronic Obstructive Pulmonary Disease and Cancer. *Journal of Palliative Medicine*, 13(9), 1109 - 1118. DOI:10.1089/jpm.2010.0068

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- 4) Bausewein, C., Booth, S., Gysels, M., & Higginson, I. (2009). Non-pharmacological interventions for breathlessness in advanced stages of malignant and non-malignant diseases. *Cochrane Database of Systematic Reviews*, 2009(2), [CD005623]. DOI:10.1002/14651858.CD005623.pub2 (update underway, protocols registered)
- 5) Simon, S., Bausewein, C., Booth, S., Harding, R., & Higginson, I. J. (2008). Benzodiazepines for the relief of breathlessness in malignant and advanced non-malignant diseases in adults. *Cochrane Database of Systematic Reviews*, (4), [CD007354]. DOI:10.1002/14651858.CD007354 (updated 2016)
- 6) Higginson, I. J., Bausewein, C., Reilly, C. C., Gao, W., Gysels, M., Dzingina, M., McCrone, P., Booth, S., Jolley, C. J., & Moxham, J. (2014). An integrated palliative and respiratory care service for patients with advanced disease and refractory breathlessness: a randomised controlled trial. *The Lancet Respiratory Medicine*, 2(12), 979-987. DOI:10.1016/S2213-2600(14)70226-7
- 7) Maddocks, M. T., Brighton, L. J., Farquhar, M., Booth, S., Miller, S., Klass, L., Tunnard, I., Yi, D. H., Gao, W., Bajwah, S., Man, W., & Higginson, I. J. (2019). Holistic services for people with advanced disease and chronic or refractory breathlessness: a mixed-methods evidence synthesis. Southampton (UK): NIHR Journals Library. PubMed PMID: 31241880

4. Details of the impact

Prior to King's research, breathlessness was poorly understood or quantified, with a lack of effective therapies once efforts to manage the underlying diseases were exhausted. Health professionals, patients, and those important to them, struggled with few evidence-based treatments, interventions or targeted services. This resulted in high distress, poor quality of life and invisibility for those affected, as well as strains on health and social care. King's-led and collaborative research has:

Generated a paradigm shift from breathlessness considered as a neglected and often invisible symptom, to a widely recognised symptom and syndrome. Breathlessness is now widely recognised in multiple advanced diseases and is better detected, assessed and treated. King's research is described in independent appraisal as 'catalysing a whole movement of taking breathlessness seriously and looking at it systematically' [A]. The field moved so much that by 2017 some clinicians argued that failure to manage breathlessness in advanced diseases was a 'breach of human rights', and an international Delphi exercise proposed 'chronic breathlessness' become a clinical syndrome. A major collaborative European Project (Better B) was launched in 2019 to connect respiratory, palliative and rehabilitative care with patient led groups and to disseminate and advance better breathlessness practice [B].

Equipped health professionals to better recognise, assess and manage breathlessness with person-centred approaches and treatments, irrespective of underlying pathology.

King's approaches, treatments and services are now recommended in multiple generalist and specialist textbooks, including in nursing, palliative care, geriatric, respiratory, primary care, physiotherapy and pharmacy. This transformation is evidenced by the growth in references to King's research and by the expanded content in textbooks on breathlessness assessment and management, especially non-pharmacological. For example, the Oxford Textbook of Palliative Medicine tripled its content on breathlessness between the 2011 (2nd) and 2015 (3rd) editions. In 2011, breathlessness (dyspnoea) had 18 pages with scant mention of non-pharmacological therapies and recommending benzodiazepines in acute severe breathlessness. In 2015 it devoted >55 pages to breathlessness management, recommending non-pharmacological treatments as first line, plus new sections on assessment, highlighting >15 King's research outputs. The 2014 edition of the Palliative Care Formulary, the unrivalled international source of guidance on medicines for pharmacists and clinicians caring for patients facing progressive life-limiting diseases, concluded that benzodiazepines do not relieve breathlessness per se, quoting King's research [B]. Now that healthcare staff have interventions to offer, they have become less anxious and strained at being unable to help patients suffering severe breathlessness. This nurtures staff wellbeing and job satisfaction [A].

In 2016, the European Research Society's monograph on Palliative Care in Respiratory Disease had six chapters dedicated to breathlessness, and multiple others, referencing King's research. This monograph placed non-pharmacological treatment before pharmacological treatment, quoted

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King's research, advocated that benzodiazepines should not be first line treatment and recommended Breathlessness Services (BSs) [B]. The independent report on the impact of King's research on breathlessness [A] identified additional opportunities to reach respiratory and primary care clinicians. In response, King's researchers hosted exhibition stands on breathlessness management, gave talks at the European Respiratory Society Conference, and engaged with the Primary Care Respiratory Society and the European Lung Foundation (2019). In 2019, King's Health Partners developed a new clinical e-learning programme, called 'E-Breathe', on breathlessness management and BSs with > 3000 logged users by mid-2020 globally [B].

Transformed public perceptions of breathlessness. King's research has featured in multiple media, TV, radio, and newspapers, often co-featuring patients alongside nurses, allied health professionals and doctors. They created a breathlessness specific public and patient involvement and engagement group, supported by the NIHR Applied Research Collaborative and charitable donors, to inform research and spearheaded local and national engagement. King's hosted public events, e.g. in King's Science Gallery London in 2019 with >260 visitors, exploring how people were affected by listening to different types of breathlessness. These provided a crucial step change in overcoming the invisibility associated with breathlessness, and the nihilism that nothing could be done [C].

Helped policy makers and the commissioning of quality services for better care. The introduction of King's research into clinical guidelines and policy documents was an important step to improve equity, access, efficiency and clinical practice in breathlessness support; alerting commissioners and clinicians to cost-effective therapies and models of care. King's breathlessness research underpins recommendations across international, national (UK and beyond), and local guidelines, including the Global Initiative for Chronic Obstructive Lung Disease (GOLD, 2018 and 2020), European Society for Medical Oncology (ESMO 2015 and 2020), National Institute for Clinical Excellence (NICE, 2018), and American Society for Clinical Oncology (ASCO, 2016) guidelines [D].

Better care through widened access to relevant non-pharmacological therapies. King's research widened access to therapeutic approaches tailored to advanced diseases. It integrated Allied Health Professionals into BSs with non-pharmacological treatments, such as mobility aids and breathing retraining, as a first step [A, E]. Patients highly valued these components: *"giving you tips on how to do things (referring to home visit from physiotherapist), you know...they're logged in the memory bank, but I remember them as I do them, it's become automatic"* [H]. They are especially useful for patients whose breathlessness restricts them to the home and who cannot reach outpatient rehabilitation services.

Benefited voluntary hospices, palliative care services and their leaders. A 2015 Hospice UK report highlighted King's research. This, and wider King's evidence on therapeutic approaches and BSs, has led voluntary hospices and other palliative care services in the UK and internationally to change from traditional day-care services, without physical therapies, to proactive rehabilitative approaches with outpatient services targeting symptom self-management and physical function, especially symptom-based BSs [F]. For example, St Christopher's Hospice teams have adopted and adapted King's research and BSs for their users over the last 5-10 years. Their 2019 survey revealed that over two thirds of their patients found breathlessness improved with these interventions [F]. In addition, the European Association for Palliative Care highlights multiple benefits of King's breathlessness research at conferences and via their social media to inform and guide their national member associations from Australia, New Zealand, 33 European countries, and individual members from over 50 countries [F].

Timely access to breathlessness services (BSs) becoming the care standard. The 2015 independent NIHR dissemination report 'Better Endings' highlighted King's BSs as a means to improve timely access to better multiprofessional care [G]. There is expanding implementation of BSs internationally, following dissemination from early adopters and King's trained clinicians and collaborators [A, G]. Health professionals say: *"It's now hard not to do this"* [A]. Underpinned by King's collaborative research, BSs have developed internationally including: Early Integrated Palliative Home Care for end-stage Chronic Obstructive Pulmonary Disease patients in Belgium; The Munich Breathlessness Service in Germany; The Advanced Lung Disease Service in Australia, and others in Singapore and Africa [A]. A 2020 national mapping exercise among Australian and New Zealand palliative care services found that 22% of respondents had integrated

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respiratory and palliative care BSs. Of those without BSs, 78% expressed interest in their establishment [G].

Improved the quality of life, dignity and empowerment of people living with severe breathlessness. The person-centred approaches to breathlessness management, including self-management toolkits and BSs, trialled in King's research, have improved the lives, dignity and care of patients across the globe. Patients have verified this in interviews, surveys, letters, audits and videos, explaining how they felt transformed; from feeling “worthless” and that they “*might as well die*”, to being able to cope, and “*having a new perspective on myself*” (video, 2015) [H]. They have been able to resume social activities, with one patient stating: “*I've gone back to my choir last Friday, first time in six months... and it was fantastic*” [H].

Patients value the individually tailored information that BSs has provided, empowering them to understand and manage their own breathlessness: “*I was thrilled to bits to be able to be getting some knowledge of what my complaint was all about... that they're doing something. The knowledge gained is described as having 'greatly improved the symptom, and in so doing been transformative in my life'*” (patient testimonials and surveys) [H].

They commented on staff expertise in person-centred care, improving respect and dignity and new-found self-management skills: “*I would get into a panic when I was breathless, but now I can sit down, use my fan, wet my face, read my laminate (breathlessness poem, part of the toolkit) and I calm down*” and “*I was in a very bad state before I came (to the service). I was thinking that I was about to be dying. .. but now I know...can handle this*” [H]. Audits and surveys have found similar positive accounts by patients about BSs [A, H]. For example, in an audit of the BS launched in Australia, based on King's research, patients said it increased their confidence (87/88, 99%) and helped them to self-manage their breathlessness (84/88, 96%) [H].

Improved the lives of families, carers and others close to them. Breathlessness is distressing for those close to patients. Family and carers were often uncertain what to do in a crisis and had been neglected previously by care services. King's incorporated into BSs family/carer views to ensure they were heard, supported, and could use the toolkit. Family members describe feeling more confident supporting patients with their breathlessness with less fear about the future: “*...that certainly helped me...you know, I can probably help him to calm down*” [I]. These benefits are evinced in service audits, reports and surveys from services in several countries [A, I].

Rapid impact during the COVID-19 pandemic, local to multinational. The consequences of the COVID-19 pandemic meant that people with advanced diseases and breathlessness lost access to their usual services and needed to self-manage at home. King's researchers responded rapidly by co-producing with patients, families, clinicians and best evidence from their breathlessness research, practical home guidance that could be implemented remotely. This was rapidly disseminated and then spread around the world with >80,000 Twitter impressions in less than a month, and adopted by Hospice UK [F], the European Association for Palliative Care [F], the International Association of Gerontology and Geriatrics, and the patient led European Lung Foundation (who report >275,000 views) [J].

5. Sources to corroborate the impact

[A] Independent Report on Impact of the Breathlessness Research Programme

[B] Evidence bundle on a paradigm shift and equipping health professionals

[C] Evidence bundle on transforming public perception, overcoming stigma

[D] Evidence bundle on helping policy makers; commissioning of better services for better care

[E] Evidence bundle on widened access to non-pharmacological therapies

[F] Evidence bundle on benefiting voluntary hospices, palliative care services and leaders

[G] Evidence bundle on timely access to breathlessness services (BSs) as the care standard

[H] Evidence bundle on quality of life, dignity and empowerment

[I] Evidence bundle on the improved the lives of families, carers and others close to them

[J] Evidence bundle on rapid impact during the COVID-19 pandemic, local to multinational