

<b>Section A</b>		
<b>Institution:</b> Durham University		
<b>Unit of Assessment:</b> 27 - English Language and Literature		
<b>Title of case study:</b> Changing approaches to breathing and breathlessness		
<b>Period when the underpinning research was undertaken:</b> Between October 2014 and December 2019		
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:
Corinne Saunders	Professor of English Studies	1997-present
Jane Macnaughton	Professor of Medical Humanities (Associate Researcher, English Studies)	2000-present
David Fuller	Professor of English Studies	1989-present
Arthur Rose	Postdoctoral Research Fellow, English Studies	2015-2019
<b>Period when the claimed impact occurred:</b> Between October 2014 and December 2020		
<b>Is this case study continued from a case study submitted in 2014?</b> No		
<b>Section B</b>		
<b>1. Summary of the impact</b>		
<p>Interdisciplinary medical humanities research undertaken at Durham University as part of the Wellcome-funded <i>Life of Breath</i> project has changed approaches to breath and breathlessness, transforming understandings, offering new possibilities for management and therapy, and reducing stigma. Literary and cultural research has uncovered the history of ideas about breath and breathlessness. It has extended biomedical perspectives and challenged perceptions by illuminating the role of cultural contexts and individual emotions in experiences of breathlessness, and by revealing the paucity of language for breathlessness. Researchers have brought together and worked with communities including individuals with lived experience, support groups, carers, therapists, clinicians and creative artists to elucidate the nature of breath and breathlessness, understand their cultural constructions, open out ways of articulating experience, and implement new approaches to management of breathlessness. The exhibition <i>Catch Your Breath</i> and the related engagement programme have changed individual perceptions, extended understanding, and influenced creative and curatorial practice. The broad range of beneficiaries, including respiratory patients, clinicians and health practitioners, support groups and carers, creative artists, curators and the wider public, demonstrates the vital roles of language, culture and context in the understanding, treatment and representation of those experiencing breathlessness.</p>		
<b>2. Underpinning research</b>		
<p>Studies that inform knowledge of breathlessness are of profound importance. Chronic obstructive pulmonary disease (COPD), the central clinical focus of the Wellcome-funded <i>Life of Breath</i> project (2014 - 2020), will soon be the third leading cause of death worldwide, but respiratory health research has received considerably less public investment than heart disease or cancer. Those suffering from breathlessness are often invisible in society because the condition largely affects older people in socially deprived areas; stigma is heightened by its association with smoking and obesity. Many clinical questions remain concerning breathlessness, in particular, the problem of 'symptom discordance' (when clinically measured lung function does not equate directly to the breathless person's experience), making the articulation of breathlessness crucial in clinical and therapeutic contexts. Research undertaken through the project has demonstrated that breathing and breathlessness can only be understood fully by drawing on cultural, literary, historical and phenomenological sources in addition to physiological and pathological information, and that a nuanced and variegated language of breath, rooted in a long literary and cultural history, has a vital role to play in treatment and representation of those experiencing breathlessness.</p> <p>The research is based on the work of Professor Jane Macnaughton (PI, <i>Life of Breath</i>; a professional clinician and Professor of Medical Humanities who is Associate Researcher in English) and Professor Corinne Saunders (a specialist in medieval literature and history of ideas), on embodied experience and clinical generalism (the need for practitioners to</p>		

understand patients holistically). Macnaughton's approach combines clinical, social scientific and literary expertise to challenge the divergence between scientific and experiential approaches to clinical symptoms. Saunders offers a long cultural perspective, demonstrating the potential of pre-modern studies to offer new frameworks for understanding connections between mind, body and affect. Their research was supported by that of Dr Arthur Rose, a specialist in modern literary and cultural studies, and Professor David Fuller, a specialist in poetry, performance and aesthetics. Rose's research on the legacies of asbestos mining in South Africa and coal mining in North East England illuminated connections between breath, breathlessness, politics, materiality and cultural and individual memory (R1, R6). Fuller's research explored the aesthetics of breath in the creative arts, including music and dance.

The research followed three interconnected strands: i) the historical and cultural study of breath and breathlessness; ii) the exploration of breath in the creative arts; and iii) the study of how language and culture shape embodied experience. The historical, cultural and creative arts research was developed at an international conference (2018) and lecture series (Arts of Breath, 2017/18), and led to two co-authored volumes (R1 and forthcoming 2021) as well as individual publications. The forthcoming co-authored volume is a major collection of 24 essays with contributions by poet Michael Symmonds Roberts and artist Jayne Wilton. This interdisciplinary research underpinned a pilot dance project (R4) addressing three central findings concerning 'pulmonary rehabilitation' (PR), the standard clinical intervention to manage COPD: that the language of PR was alienating to patients; that PR took place in culturally unfamiliar gym-like spaces; and that it did not support participants' interoceptive awareness, which is associated with symptom discordance. Dance addressed these problems through its cultural and linguistic familiarity, enabling participants to engage with their bodies in positive and collaborative ways. The approach is the subject of a publication in a key clinical respiratory journal and a National Institute for Health Research (NIHR) Research for Patient Benefit application.

Research findings offer insights into: the power of pre-modern models to illuminate the interdependence of physical and psychological experience and breath's centrality in emotional experience (R1); the long history, cultural continuities and shifts in ideas and assumptions connecting breath and being, breathlessness and death (R1); the place of breath in the creative arts (R1); the role of language and culture in conceptions of breath and breathlessness, and the possibilities for change (R3, R6); the political and social valences of breath and the marginalisation of breathlessness sufferers (R2, R4, R5); therapeutic possibilities and new opportunities for management offered by better understanding of the intimate interconnection of embodied experience and interoceptive awareness (R2, R4, R5).

### 3. References to the research

- R1. Rose A, Heine S, Tsentourou N, Saunders C, Garratt P. (2018). *Reading Breath in Literature*. Palgrave Pivot Series. Palgrave Macmillan. doi:10.1007/978-3-319-99948-7
- R2. Macnaughton, J. (2020). Making Breath Visible: Reflections on Relations between Bodies, Breath and World in the Critical Medical Humanities. *Body & Society*. doi: 10.1177/1357034X20902526
- R3. Oxley R, Harrison SL, Rose A, Macnaughton J. (2019). The meaning of the name of 'pulmonary rehabilitation' and its influence on engagement with individuals with chronic lung disease. *Chronic Respiratory Disease*. 16:1479973119847659. doi:10.1177/1479973119847659
- R4. Harrison S, Bierski K, Burn N, McLusky S, McFaul V, Russell A, Williams G, Williams S, Macnaughton J. (2020). Dance for people with chronic breathlessness: a transdisciplinary approach to intervention development. *BMJ Open Respiratory Research*. 7:e000696. doi: 10.1136/bmjresp-2020-000696
- R5. Macnaughton J, Carel H, Dodds J. (2015). Invisible suffering: breathlessness in and beyond the clinic. *The Lancet Respiratory Medicine*. 3.4:278-279. doi: 10.1016/S2213-2600(15)00115-0.
- R6. Rose A. (2016). Breath in the Technoscientific Imaginary. *BMJ Medical Humanities* 42.4:E31-E35. doi: 10.1136/medhum-2016-010908

**Evidence of quality:** The research was conducted as part of the *Life of Breath* project, funded by a Wellcome Senior Investigator Award, 103339/Z/13/Z, GBP852,508 (PIs: Macnaughton and Havi Carel (Bristol); Named Collaborator: Saunders, 2015-19). R2, R3, R4,

R5, R6 appear in peer-reviewed internationally leading journals; R1, downloaded 24,000 times, is published by a leading publisher in the discipline. R1 and R2 are submitted in REF2.

#### **4. Details of the impact**

Research conducted as part of the *Life of Breath* project has changed the way that a range of communities, including health practitioners, respiratory patients, creative artists and the general public, approach and understand the personal experience and meaning of breathing and breathlessness, and its relationship to both illness and wellbeing.

#### **Creating the project community and working with support groups to develop resources for people with breathlessness:**

Through co-produced and engaged research activities, externally focussed communications, an exhibition and public events, researchers have constructed a diverse and unprecedented community dedicated to exploring breathing and breathlessness, including experts-by-experience, healthcare professionals, artists and academics of other disciplines. Since 2014 *Life of Breath* has assembled 1,623 Twitter followers, a podcast series with approximately 3,000 listens, a blog with 166 posts and approximately 85,000 visitors, and a mailing list of 580 people [E1]. The blog audience is predominantly in the UK (51%) and USA (21%), with India, Australia and Canada (collectively 9%) completing the Top 5 countries [E1]. This community represents not just reach, but also significance, including tangible outcomes (described in more detail below) such as mutually beneficial relationships, new resources to support those living with breathlessness and a platform to share these resources with those who may benefit from them.

The key research partnership has been with two British Lung Foundation Breathe Easy support groups for people with respiratory illness in Darlington and elsewhere in County Durham. While collaboration with these experts-by-experience was initially focussed on informing the research [R2, R3], findings led directly into the development of creative writing [E4] and dance programmes [R4, E8] exploring the potential of the arts to help people live well with breathlessness. Work with Breathe Easy groups and research on the power of language and culture [R1, R3] underpinned the pilot project assessing the potential of dance to offer an enjoyable and effective form of exercise for people with respiratory illness. Undertaken in collaboration with the Darlington Breathe Easy group, the pilot comprised a 10-week dance movement programme, which resulted in improvements in physical measures, including exercise capacity, strength and balance, reduced anxiety and breathlessness perception, and improved wellbeing [R4]. The dance group has continued to meet online during the COVID-19 pandemic with the support of their instructor. Gaynor Williams, Chair of Breathe Easy Darlington and member of the Dance Easy working group, said *'the resulting dance sessions became the lynchpin of our group activities [...] What will stay with me especially is the sheer joy of dancing. Seeing our little group of purple panting puffers grow and blossom as they relaxed, became less inhibited and more active was a sight to lift the lowest of spirits. I wish more people had access to it'* [E5]. Dance project collaborator and respiratory physiotherapist, Dr Samantha Harrison (Teesside University) described the resulting shift in her practice: *'I have stepped away from a medicalised approach to pulmonary rehabilitation... I now believe that offering a choice which is consistent with peoples' values and culture is the best approach to encourage engagement in sustainable physical activity'* [E7]. Work to assess the effectiveness of dance is ongoing and has already led to an invited NHS Improvement Case Study [E8]. A series of free follow-along videos (led by Dance Easy creator Sian Williams) produced by the project [E8] became even more valuable when the COVID-19 lockdown left many individuals with respiratory illness shielding without access to their usual forms of exercise. The Dance Easy videos were added to lists of patient resources created by the British Thoracic Society, Isle of Wight NHS Trust and Lung Foundation Australia [E8]. To date the Dance Easy webpage has been visited 1,558 times (rank 14 of 166 posts, peaking during lockdown) and the videos collectively viewed 2,145 times with the Warm Up the 3<sup>rd</sup> most popular video on the *Life of Breath* YouTube channel [E8]. The pandemic also led to a dramatic increase in public awareness of breathlessness. In response, the project website hosted video and audio breathing exercises, created by research collaborator Kate Binnie (Bristol). Her post *'Breathing in Isolation: support with anxiety & breathlessness during lockdown'* has been viewed 2,512 times (rank 6 of 166 posts) and elicited this comment from a COVID-19 sufferer: *'I want to thank you for the*

*relaxing breathing video. It is amazing and helped me twice last night through coughing fits. It's my best friend at mo'* [E9]. The *Life of Breath* website is also cited in the NIHR resource '*Managing breathlessness at home during the COVID-19 outbreak*' [E9].

**Curating the first interpretive exhibition about breath:** *Catch Your Breath*, the first exhibition ever to focus on breathing and breathlessness, drew directly on the research, especially R1, R5 and R6, incorporating quotations and other research findings. The exhibition was hosted at Palace Green Library, Durham (between November 2018 and March 2019), the Royal College of Physicians, London (Between April and September 2019), Bristol Southmead Hospital (Between October and December 2019) and Bristol Central Library (Between January and February 2020), with a pop-up version touring North East libraries and scientific/medical conferences (from Autumn 2019). It was one of four past exhibitions chosen by Palace Green Library for digitisation during the COVID-19 pandemic, is currently the most visited of these (receiving 20% more visitors than the next most popular) and will now be available online indefinitely [E2].

Combined visitor numbers are approximately 10,000 people, with a further 22,000 visits to the online exhibition and exhibition website (76% UK, 24% elsewhere worldwide). *Catch Your Breath* in Durham welcomed 3,592 visitors, comparing favourably with previous exhibitions at this venue (average visitor number for previous 6 winter exhibitions: 2,554), a particularly impressive number given the potentially challenging subject matter. Surveys indicate that up to 84% of visitors were day visitors or tourists. The comprehensive engagement programme increased visitor numbers to 5,183. The London exhibition attracted more than 1,993 visitors and event participants. It was also used as a breakout space and was therefore visited by an incalculable number of predominantly medical conference attendees. While in London the exhibition was featured on London Live TV and reviewed in *The Lancet*, *The Lancet Respiratory* and *The British Medical Journal* (BMJ). The Bristol exhibition reached approximately 1,400 visitors with a further 500 attending events. The pop-up exhibition, specifically designed for libraries, included further literary content and an accompanying reading list. It was shown in 5 libraries (Newton Aycliffe, Durham, Stockton-on-Tees, Darlington and Middlesbrough) in Autumn 2019, reaching approximately 1,000 people. With the exception of Durham City these towns include some of the 10% most deprived postcodes in England, significantly increasing the social reach of the research. The team was invited to bring the pop-up exhibition to the World Health Organization (WHO) International Air Quality Summit (October 2019) and the Dyspnoea20 medical conference (rescheduled for July 2021 due to COVID-19) [E2].

As well as influencing visitors, the unusual and challenging project of preparing the exhibition profoundly influenced curators, museum staff and artists [E2, E6, E7]. Curator David Wright said '*I thought visitors might reject the idea of an exhibition about breathing. It sounded really challenging. But now I have a lot more confidence that there's no subject, no matter how intangible, that can't be explored in an interesting way to make it exciting and engaging for visitors*' [E6]. The exhibition was a first for the Royal College of Physicians, whose displays typically focus on medical history. RCP Exhibition Officer Matthew Wood commented on '*getting that patient voice in there rather than just hearing about doctors*': '*That's not something we've ever done before [...] I don't think it's something we could have done if we hadn't had that support from Life of Breath as that was their research, their focus... I think it will change our practice, to be a bit braver*' [E2, E6]. Two RCP clinical fellows were so inspired by the exhibition that they created their own booklet [E3] to accompany it.

**Changing the ways people think about and articulate breathlessness:** A key goal of research and engagement was to explore and challenge ways of speaking about breathlessness. The poet Christy Ducker was appointed as writer-in-residence, to work alongside visitors to the exhibition and to encourage Breathe Easy Durham & Derwentside, one of three support groups in County Durham for people with respiratory illness, to engage deeply with the research and exhibition content. The evaluation [E4] found that this engagement helped people with breathlessness feel heard, validated and empowered; and that members of the general public were challenged to address their relationships with their breath, increasing empathy with breathlessness sufferers. The poems fed back into *Life of*

Breath project research, informing R2, and were also featured in the pop-up exhibition. Christy Ducker emphasised the empowering effect of self-expression: *'Because you can lose your words so easily, especially breath patients. Words get taken from you, literally because you can't speak and you only have clinical terms to express what you are feeling, so to be able to mobilise a whole other vocabulary is a kind of linguistic and social musculature'* [E4].

The artist Jayne Wilton, whose work focusses on visualising the breath, participated in research group meetings and the Arts of Breath programme, and credits the *Life of Breath* project with inspiring many works, including a blown glass sculpture entitled *'Breath which turns back on itself'* and a series of 12 covers for *The Lancet Respiratory* in 2016. She describes the influence of the research on her creative process: *'I was able to think laterally as a result of this wonderful insightful anthropological paper to create something so visually different, rather than just trying to medically illustrate what cystic fibrosis could look like'* [E7]. Neuroscientist and anaesthetist Dr Kyle Pattinson (Institute of Neuroscience, University of Oxford) emphasises insights gained concerning the influence of language and culture: *'I think the Life of Breath has helped me contextualise the patient's experience, particularly the way that words are used, which [...] helps you not get distracted or misinterpreted [...] both the patient's language and the language we use as academics to express ourselves'* [E7]. His collaborations with the research team led to new hypotheses on the cultural contexts that shape the experience of breathlessness and the problem of symptom discordance. On hearing of the Dance Easy project, an international group of respiratory clinicians were moved to write to The Lancet Respiratory letters page hailing *'...the Life of Breath funding period is complete. Its seeds of humanistic evaluation and exploration of breathlessness as a lived experience are now sown and shared [...] We join with others to keep this fathomless garden tended, flourishing, and unfurling'* [E7].

Exhibition feedback repeatedly emphasised the effect of making people think intensely about their breath, often for the first time, clearly achieving the aim of making individuals more aware of this invisible, often overlooked bodily function, and of the cultural underpinnings of their assumptions. Perceptions of those with respiratory illness (and their carers, families and friends) were challenged, extending understandings of breath and breathlessness, including of its causes and treatment, and reducing stigma [E2]. Typical comments included *'Breathlessness is not something to be ashamed of and should be discussed more openly'; 'I am a healthcare professional with COPD patients. It made me consider the daily struggles of simple things like eating'* [E2]. On working with school groups on the Arts Award, learning officer Emily Dowler observed, *'At first they (children) just didn't understand how to describe that feeling [being out of breath] because it's really difficult to describe. By the end they had a lot more vocabulary to explain how it felt [...] They started to think of more ideas like making art, making music or the things that they hadn't realized you could use your breath for. It's not just for staying alive'* [E6]. The project's impact is summed up in this poem 'A Chance', written by Jill Gladstone, chair of the Breathe Easy Durham & Derwentside Group, during the creative writing workshops: *'Grab, grasp with gratitude/ this chance to speak./ To say what?/ Can I do it?/ Do we have the courage?/ Do we have the language?/ We have the thoughts,/ mostly hidden./ But words?/ Denied, or rather not asked for/ over the millennia./ Thoughts fly./ Words flood./ Whose language/ do we use?/ Who can share?'* [E4]. This poem encapsulates what the research has uncovered: that language, culture and context are critical to articulating breath and its lack and thus to understanding, management and treatment of breathlessness.

##### **5. Sources to corroborate the impact**

- E1 Life of Breath communications statistics including website hits, podcast and Twitter
- E2 Catch Your Breath exhibition evaluation reports
- E3 RCP Fellows 'Breath and Breathing' booklet
- E4 Writer-in-residence evaluation report
- E5 Breathe Easy Group testimonials
- E6 Exhibition-related practitioner testimonials (artists, curators and learning team)
- E7 Practitioner testimonials and The Lancet Respiratory letter
- E8 Dance Easy videos, statistics, and evidence of inclusion in websites/guidance
- E9 Breathing exercises statistics, breathlessness resource and testimonial